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SI DIOS QUIERE: HISPANIC FAMILIES' EXPERIENCES OF CARING FOR A SERIOUSLY MENTALLY ILL FAMILY MEMBER

ABSTRACT. Among Hispanics, the family is viewed as the primary care giver for seriously mentally ill family members. This paper reports on a study of minority families' conceptions of serious mental illness, of their interaction with mental health resources, and on the burdens experienced by families in caring for a seriously mentally ill family member. The focus of this paper is on Hispanic families in New Jersey, with some comparative data from other ethnic group families. Families' conceptions of serious mental illness are explored and analyzed to demonstrate the importance of concepts of *nervios* and *fallo mental* in shaping families' responses to their ill family member. Social support systems for families are also explored with particular attention to the role of religious institutions and religious healing as a major source of solace.

INTRODUCTION

The family plays a central role as care giver for the seriously mentally ill. It is estimated that 65% of patients discharged from mental hospitals return to live with their families (Goldman 1982, Lefley 1987b). In addition, families provide major care-giving to ill family members living in other settings than the family home. In this paper, we discuss the experiences of Hispanic families in caring for a seriously mentally ill family member. Among Hispanics, the family is viewed as the primary care-giver for seriously mentally ill family members (Casas & Keefe 1978, Garcia-Preto 1982, Jenkins 1988a). *Si Dios quiere* (If God wishes) or *Que dios nos bendiga* (May God bless us) are common refrains when talking to Hispanic families about their expectations for the long-term prospects of their seriously mentally ill family member. These expressions reflect Hispanic families' strong religious beliefs and, at the same time, the hopes and frustrations they experience in dealing with illnesses that are deeply troubling and that frequently defy explanation.

One of the earliest studies of families' experiences in caring for a mentally ill family member was that of Clausen, Yarrow, and colleagues (1955). This study focused on spouses of mentally ill individuals among middle class, European American families. One finding of this study was that families experienced a sense of marginality and stigma. The authors suggested that the families experienced many of the same feelings about their relationship to society as members of racial and ethnic minority groups (Hatfield 1987a:15, see also Lefley 1989). Our study of minority families highlights the issue of the "double stigma" faced by minority families caring for a mentally ill family member – the stigmas of mental illness and of minority group status. In this paper we examine

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Hispanic families' understandings of serious mental illness and address how the interpretations of the illness serve to de-stigmatize both the person and the family.

While there have been a series of studies on the family as caretaker for seriously mentally ill family members following the studies of Clausen and colleagues (see Hatfield 1987a:15–26 for a review of this literature), the 1980's have seen a major increase in studies of the key role of the family as caretaker of the mentally ill and of others with chronic illness (Vine 1982, Hatfield 1987b, Hatfield & Lefley 1987, Tessler et al. 1987, Noh & Turner 1987, Jenkins 1988a,b, Gubrium 1988, Rubinstein 1989, Grella & Grusky 1989, Albert 1990). However, there has been limited research in the U.S. on the particular problems experienced by families of minority patients whose coping capacities may be strained to the limit by scarce financial resources and fragmented community structures. How such stressors affect the willingness and ability of families to provide support to their family members when they are patients in community treatment has been similarly neglected. Ethnicity and social class simultaneously affect levels of family support, the social adjustment of ill individuals in the community, and contact with the mental health care system. Family's cultural background and social class influence how the patient, the family, and mental health professionals perceive the illness and formulate the strategies required for managing it. Existing research indicates that pathways into treatment are affected by the interpretations the family members place upon the patient's symptoms (Rogler, Malgady & Rodriguez 1989). While considerable research exists on the cultural construction of mental illness (Marsella and White 1982, Kleinman and Good 1985), few studies have explored processes of symptom interpretation and illness definition among U.S. ethnic minority families of seriously mentally ill family members, whose cultural construction of mental illness often diverge quite radically from those of the majority and of professionals (Rogler and Hollingshead 1985, Jenkins 1988a,b). In this paper we expand on the work of Jenkins in extending similar analyses to east coast Hispanic communities and we build on the work of Rogler and Hollingshead in Puerto Rico to look at contemporary Puerto Rican populations on the mainland U.S.

One major impetus for an intense focus on the family as care giver of the seriously mentally ill has come from the rise of family advocacy groups, particularly the National Alliance for the Mentally Ill (NAMI) as a result of the deinstitutionalization movements of the 1970's and 1980's. Active in NAMI have been several researchers who have written extensively concerning the need to refocus research to look at the strengths of families of the mentally ill and to identify their needs for help in dealing with their family member's illness (Vine 1982, Hatfield 1987b, Hatfield and Lefley 1987, Lefley 1990). NAMI has had a major role in changing the research and treatment focus on families from identifying family members as the cause of illness to examining the challenges families face as the major caretakers of mentally ill individuals. NAMI has developed materials for family education (Lefley 1988). At the same time, NAMI has strongly advocated for a NIMH research agenda focused on the biological bases of schizophrenia and has led to a separation of clinical services from social/rehabilitation services (McLean 1989). It has only been recently that minorities have had a formal voice within NAMI with the creation of their Minority/Ethnic Concerns Network.

Within the social science literature, two major approaches have dominated research on the role of families in caring for the mentally ill. One focus has been on the emotional tone of families, the families' level of "expressed emotion" (EE), and its role in re-hospitalization of family members (see Jenkins 1988a,b, 1991 for a review of this literature). The "expressed emotion" literature has focused on family criticism and over-involvement with their schizophrenic family member. Jenkins (1991) has provided a thorough anthropological critique of the "expressed emotion" construct, showing that culture strongly shapes the emotional responses of families to their ill family member through the different ways that mental illness is understood and the ways that families relate to and support ill family members.

A second focus has been on measuring "family burden" – the kinds of problems and strains that having a mentally ill family member places on the family (Platt 1985, Lefley 1989). While the family burden literature has refocused attention on the needs of families as caretakers, it has done this by focusing attention on the problematic aspects of the caretaking role. Less attention has been paid to the values families and ethnic groups place on providing care and the effects of these attitudes on response to an ill family member. In this paper, we highlight the value Hispanic families place on taking care of ill family members and the strong sense of responsibility Hispanic families feel for keeping their ill family member at home.

A major outcome of research and of advocacy has been the development of treatment approaches for families, often referred to as "psychoeducation", which emphasize providing families with information about mental illness and its treatment, providing advice on how to deal with symptoms, and providing resources to aid families (Falloon et al. 1984, 1985, McFarlane 1983). The psychoeducation approach also emphasizes reducing the level of "expressed emotion" in families, that is, lowering the levels of criticism and over-involvement with the ill individual. The psychoeducation approach has focused on presenting the medical model of schizophrenia and its treatment to families with minimal attempts to assess families' knowledge, understandings, and attitudes towards aiding their mentally ill family member. Rivera (1988) suggests that many features of psychoeducation fit with Hispanic families' responses to a mentally ill family member, but points out that little work exists on how to adapt psychoeducation for Hispanic families and on what the results would be.

Jenkins (1991) provides an extended critique of the literature on family response to serious mental illness, focusing in detail on the cross-cultural validity of the construct of "expressed emotion." Jenkins argues that the focus on cricitism and emotional over-involvement is culturally bounded. In her own study of Mexican-American families with a schizophrenic family member, there were marked differences between ethnic groups in the number of "high" expressed emotion families. When comparing Mexican and Anglo-Americans, fewer Mexican-American families scored "high" on "expressed emotion." While criticism and emotional over-involvement characterized the Anglo-American families' responses well, the Mexican-American families' responses were better expressed by a range of feelings of sadness. These different emotional response styles in turn had different relationships to relapse. Jenkins ends her paper with a cogent argument for a range of studies of sociocultural response to mental disorder. Our paper furthers the anthropological study of families' responses to serious mental illness within a different Hispanic-American context.

DESCRIPTION OF THE STUDY AND THE SAMPLE

The data and interpretations which we report in this paper come from our larger study, which was a comparative investigation of Hispanic (primarily Puerto Rican and Cuban), Black (both African-American and West Indian), and European (primarily from Southern and Eastern Europe) families who were primary caretakers of a seriously mentally ill family member.[1] The study investigated families' conceptions of mental illness; their interaction with mental health care resources; and the problems they experienced in caring for an ill family member. The general aims of the study were:

1. To document systematic cultural differences in *interpretations of mental illness*, exploring, in particular, the processes by which family members come to recognize and label deviant behavior in the mentally ill member;
2. To examine the impact of different socio-cultural interpretations of mental illness by family members on the *utilization of mental health services*;
3. To identify the *family coping strategies* and *family support systems* of patients in the community.

The case material and data are from interviews with the main family care giver of seriously mentally ill individuals. The total sample for the study consisted of 90 families, of which 45 were Hispanic families, 29 African-American families and 16 European-American families. The families were identified through family groups and client populations of public community mental health centers and state psychiatric hospitals in the state of New Jersey. The sample consisted of individuals who had family members whose course of mental illness was prolonged and who required significant functional and emotional support from their families over an extended period. For the most part, the psychiatric diagnoses of the ill individuals, as reported by the families and the clinical staff, were either schizophrenia or bipolar disorder.

The study consisted of in-depth interviews with the family member who identified her/himself as being most involved in caring for the ill individual. The objective of these interviews was to determine how the family members responded to and coped with the patient's illness. The interview lasted approximately 1–1/2 hours and covered the family's experience with the mental health care system; conception of the problem; social support systems; and problems experienced as a result of having a seriously mentally ill family member. Interviews were tape-recorded, transcribed and then coded for computer analysis. The interviews contained considerable case material which we use to illustrate key points in the paper.

The focus of this paper is on the Hispanic families. In the Hispanic subsample of 45 families, 30 families were Puerto Rican (67%), 6 families identified themselves as Cuban (13%), and the remaining 9 families came from other Caribbean, Central or South American countries (20%). Most of the ill family members (39 of the 45 patients) were born outside of the U.S., and the majority came to this country in their teens or at a younger age. The average age of the ill member was 40 years, with the youngest being 14 years old and the oldest 70. Eighty percent (36) of the main care givers were women; including mothers, wives, daughters and sisters of the ill family member. The mean age of care givers was 48 years: younger than the mean age of either African-American or European-American care givers. The youngest care giver was a daughter of 15 years, and the oldest, a mother of 82 years (see Table I).

In comparison to the other families in the study, the Hispanic families experienced considerable social disadvantage. This disadvantage of the Hispanic families is particularly striking since the majority of the families in the study were low or middle income and had always been dependent on the public mental health care system. A large proportion of the care givers had only attended elementary school. Over three-quarters of the Hispanic families reported family incomes of less than $20,000 per year, in spite of two-thirds of the families having a member working full-time. Hispanics, to some extent, moderated their economic disadvantage with access to social resources. Most Hispanic families were either dual parent or extended family households. Hispanics were also actively involved in religious groups – both Hispanic Catholic Churches and the newer Pentecostal Churches – which provided significant support.

The Hispanic families in this study maintained strong ties to Hispanic culture in spite of many years of residence in the United States. Although the average

TABLE I
Socio-demographic characteristics of care-giver families with a seriously mental by ill member

Socio-demographic Characteristics	Hispanic	Afro-American	Euro-American
N	45 (50%)	29 (32%)	16 (18%)
Sex of Care Giver			
Female	80%	90%	81%
Male	20	10	19
Mean Age of Care giver	47.8	53.8	54.7
Relationship to Patient			
Mother	38%	62%	62%
Father	5	14	13
Sibling	11	21	19
Spouse	24	0	6
Daughter/son	20	3	0
Other relative	2	0	0
Family Structure			
Dual Parent	60%	38%	56%
Female Headed	31	62	25
Extended Family	9	0	0
Living Alone	0	0	19
Family Income			
Less than $9,999	41%	18%	7%
$10 – 19,999	36	18	13
$20 – 39,999	21	32	40
More than $40,000	2	32	40
Religion			
Catholic	62%	3%	69%
Protestant	4	59	25
New Protestant	29	17	0
Muslim	0	7	0
No answer	4	14	6

number of years of the families living in the United States was 22, seventy-one percent of the families reported that the language most often spoken at home was Spanish. Eighty percent of the families reported that all of their friends were Hispanic. These data indicate that in terms of traditional measures of acculturation, these Hispanic families are strongly tied to Hispanic language and culture.

FAMILIES' CONCEPTIONS OF ILLNESS: SOMA, PSYCHE AND SOCIETY

Both Puerto Rican and Cuban families' conceptions of their family member's illness were shaped by the concepts of *nervios* (nerves) and *fallo mental* (a mental failure). *Nervios* is a rich idiom for expressing emotional upset, somatic distress, and social dislocation. There is a growing anthropological literature on *nervios* which provides detailed discussions of this idiom (Guarnaccia and Farias 1988, Davis & Low 1989, Jenkins 1988a,b, Koss-Chioino 1989, 1990, Low 1981, 1985, 1989, see also the papers by Swerdlow and Weiss in this volume). There has been little discussion of *fallo mental* as a specific illness label in the Hispanic mental health literature, although studies of Mexican-Americans (Newton 1978, Jenkins 1988a,b) and Puerto Ricans (Rogler and Hollingshead 1985) have distinguished between emotional illness and mental disorder. In these studies, *nervios* is seen as less serious and more transient than mental illness. In addition, there is a developmental sequence imbedded in these conceptualizations where untreated *nervios* can become mental disorder as the person's symptoms and behavior worsen.

In discussing the problem as one of *nervios*, families focused on the agitated behavior, the inability to sit still, and the rapid talking that people experience when the illness "acts up." While *nervios* translates in English as "nerves," *nervios* means more than the fibers that conduct sensation through our bodies. People who suffered from *nervios* were described as having a weaker constitution; as being susceptible to many health problems.

> *El problema es que ella no es lo suficientemente fuerte para enfrentar cosas cotidianas. Cualquier cosa la pone muy nerviosa.* [The problem is that she is not sufficiently strong enough to deal with everyday things. Any little thing makes her nervous.] Comments of an aunt about her 43 year old niece.[2]

Often, this lack of emotional strength was attributed either to serious physical problems in childhood or early emotional stresses, often related to parent-child conflicts.

> *Como le dije, ella padecía de anemia desde que era pequeña. Ella se puso bien delgada. Ella dió a luz esos tres muchachos y parece que fisicamente no estaba en constitución suficiente.* [As I told you, she suffered from anemia from the time she was a little girl. She became very skinny. She gave birth to those three boys and it seems that her constitution was not strong enough.] Comments of a husband about his 38 year old wife.

In this case, the woman's *nervios* followed from a series of physical illnesses and problems in pregnancy. The physical weakness that resulted left her vulnerable to developing nervous problems.

One sister commented on what she thought caused her mentally ill brother's problem.

> *El papa de nosotros tomaba. Cuando éramos chiquitos, le hacía miedo a uno y parece que cuando a uno le dan miedo desde chiquito le dañan los nervios. Cuando mi papá tomaba, llamaba a los muertos y uno se moría de los nervios.* [Our father drank a lot.

> When we were small, he scared us and it seems that when one is frightened from the time one is small it damages the "nerves." When my father drank, he called the dead and one almost died of "nerves."]

A common theme is that young children's "nerves" are not fully developed and that stressful experiences in childhood can leave a person's nerves permanently debilitated, putting one at lifelong risk for developing nervous illness. Particularly frightening was the father's "calling the dead" – within Puerto Rican culture, the role of spirits of the dead in causing problems in the world of the living is quite prominent. While this relationship is encoded in *Espiritismo*, a formal religious and healing practice which involves communication with the spirits of the dead (Garrison 1977, Harwood 1977, Weiss in this volume), contact with the dead through visions and dreams is not uncommonly reported by Puerto Ricans. What was particularly frightening according to the sister's account in this case was the active calling of the dead which can leave one vulnerable to the negative influences of spirits.

In discussing the illness as *nervios*, many of the psychotic symptoms are bracketed out and the label of *locura*, of enduring madness, is avoided (Newton 1978, Rogler and Hollingshead 1985, Jenkins 1988a,b).

> *...yo diría que mi hijo lo que es, un nervioso más en la vida, una persona enferma de sus nervios ... el enfermo mental, completamente loco, lo primero que pierde es la memoria. No sabe quien es la madre, la hija, el padre. ... No tiene concepto del tiempo. No le interesa bañarse, ni vivir la vida.* [I would say that my son is a nervous person, someone sick from his nerves. The mentally ill, those completely crazy, the first thing they lose is their memory. They don't know who their mother, daughter, or father is. They have no concept of time. They have no interest in bathing, nor in living life.] Comments of a mother about her 25 year old son.

By labelling her son as sick from *nervios*, his mother draws an explicit distinction between her son and those who are truly crazy. This distinction between emotional problems and mental disorder continues as a recurrent theme in the literature on Hispanic ethnopsychiatry (Rogler and Hollingshead 1985, Newton 1978, Jenkins 1988a,b).

The largest group of Hispanic families identified their family members' problem as an emotional problem related to *nervios* (see Table II). European-American families saw the problem as a medical one most frequently and had been most influenced by the medical model of schizophrenia. Identifying the problem as an emotional problem was an equally common answer, but not as frequent as the Hispanic families. African-American families also most frequently saw the problem in medical terms. Both African-American and European-American families displayed considerable diversity in conceptions of the problem, with significant numbers of families reporting each of the major conceptions of the problem.

In contrast to the concept of *nervios*, the more serious labelling of the problem as *fallo mental* – a failure of the brain to function properly – drew attention to

TABLE II
Families' conceptions of mental illness

Conceptions of Mental illness	Hispanic	Afro-American	Euro-American
N	45 (50%)	29 (32%)	16 (18%)
Care givers' Conception of Illness			
Medical Problem	20%	31%	31%
Emotional Problem	40	24	31
Personality Deficit	4	14	19
Social Interaction	9	14	6
Other	27	17	13
Care giver's Report of Professional's Label			
Schizophrenia	33%	48%	69%
Bipolar Disorder	4	8	6
Depression/Anxiety	7	8	6
General Emotional Problem	19	4	6
Mental Retardation	2	0	0
Don't know	35	32	13
Care giver's Agreement with Professional's Label			
Agreed	27%	39%	71%
Most Important Factor Contributing to the Illness			
Heredity	13%	10%	44%
Alcohol/Drugs	16	7	6
External Stressor	20	28	19
Interpersonal Relationships	29	24	12
Don't Know	22	31	19
Care givers' Expectation of Cure			
Think it will be cured	65%	52%	19%
Don't think it will be cured	31	34	81
Don't know	4	14	0

the confusion, loss of rationality, and troubling ideas which ill family members experienced and expressed. As one mother described her 33 year old son, "*El tiene un fallo que no lo deja llegar a un conocimiento normal como toda persona.*" [He has a failure that does not allow him to have a normal understanding of things like other people.]

Problems were often viewed as coming on suddenly with the beginning of the illness, often in adolescence or early adulthood. In some cases, it highlighted the stark contrast between the period when the family member showed great promise in school and/or career and the current time when the person experienced significant problems in everyday living.

Bueno, él tenía 15 años de edad cuando él comenzó. El estaba yendo a la escuela y entonces yo veía que él llegaba de la escuela bien cabizbajo. Era una persona que hablaba mucho, le gustaba hacer amistades. Era una persona alegre, y de la noche a la mañana, él fué como cortando eso. Todo se le fué yendo y yo lo fuí notando raro, que llegaba con la cabeza baja y no hablaba – bien callado. Yo le preguntaba que le pasaba y me decía que nada. Pero ve, como yo sabía como él era, a lo que estaba pasando, yo si noté que algo le estaba pasando a él. Cada día estaba peor, y llegaba a su cuarto y se encerraba, no hablaba con nadie. [Well, he was 15 years old when he began to become sick. He was going to school and I noticed that he would come home looking sad. He had been a very talkative person who liked to make friends. He had been a happy person, and then almost overnight he changed. Everything was going wrong and I noticed that he was acting strangely, that he would arrive home from school with his head hanging down and would not speak – very silent. I asked him what was the matter and he would say nothing. But as I knew how he had been, I could see that something was happening to him. Each day he got worse and he would come home and lock himself in his room, he would not talk to anyone.] Mother's description of her 23 year old son who later began to have fits of rage, when he would break things and strike out at his mother, even threatening her life.

This notion of "mental failure" focused on the apparent sudden breakdown in basic cognitive processes which marked the onset of illness and a total change in behavior from the way the person was before. This sudden breakdown often occurred after a particularly stressful experience, such as the sudden and unexpected death of a family member.

A mi mamá, se le murió una hija cuando yo tenía 8 o 9 años. Ella murió baby de 6 meses. Cuando la fueron a enterrar, mi mama empezó a reirse. Despues no volvió a ser normal. Si le hubieran hecho algo a tiempo a los problemas que ella tenía, pues yo creo que ella tendría cura. Pero ya después de tantos años, ya se le ha pasado. [When I was 8 or 9 years old, my mother lost a daughter. The baby died when it was 6 months old. During the funeral, my mother began to laugh. After that, she was never normal again. If they had gotten her help at the time the problems began, she might have been cured. But now after so many years, the time has passed.] Comments of a daughter about her 60 year old mother.

This example emphasizes the conception that serious life events can cause major changes in a person's mental state. These events are strong enough to provoke mental disorder and if help is not received can lead to a worsening state eventually leading to madness (*locura*). The move towards more serious disorder is a result of both the seriousness of the life event and the timeliness of seeking help.[3]

In other cases, the use of *fallo mental* referred to a long history of learning problems in school which culminated in a crisis at adolescence.

Yo comenzé a saber que mi hijo teniá problemas desde la edad de cuatro a cinco años. Lo puse en la escuela y entonces en la escuela hacía travesuras, cosas malas entonces. Pues me lo llevaron para un sitio a evaluarlo. El hacía cosas que no estaba supuesto a hacer en la escuela ... fue creciendo un poco más y le daba una locura que se me arramaba. Entonces yo fuí a un sitio a ver si me lo podían poner en un hospital a ver si podía estar mejor. [I knew that my son had problems from the time he was 4 or 5 years old. I sent him to school and in school he got into trouble and did bad things. They took us to a place where they evaluated my son. He did things he was not supposed to do in

> school. ... As he got a little older, he got so crazy that I felt I could not control him. So, I went to a place to see if they could hospitalize him to see if he would improve.] Mother's description of the beginning of her 34 year old son's illness. She recounted a long history of psychiatric hospitalizations. She now describes him as if he were a child who needs to be told and shown how to do everything.

In the cases described above, the identification of the problem as one of *fallo mental* emphasized an inability to make rational judgements, a tendency to be fooled and exploited by others, and problems in managing everyday affairs. It then fell on the family to help their family member cope with everyday living.

Families' conceptions of the problem differed markedly from the understandings of medical professionals who labeled the problem as schizophrenia with its focus on psychotic symptoms and the implication (often explicitly stated by psychiatrists consulted by the families) that the disease was life-long and incurable (see Table II). In response to the questions: "What do mental health professionals call the problem? Do you think they are right?"; more than a third of the families (16) did not know what the professionals called the problem. Of those who knew, 15 identified schizophrenia as the medical diagnosis. However, family members' responses indicated that they often had not completely accepted this diagnosis.

> *Yo no sé, pero he oido decir que la enfermedad es algo que se llama esquizofrenia, algo así.* [I do not know, but I have heard that the illness is something that they call schizophrenia, something like that.]

> *Según lo que me dijo el doctor, que ella padece de esquizofrenia. Que esa enfermedad, segun me dijo el doctor, no se curaba nunca.* [According to what the doctor told me, she suffers from schizophrenia. This illness, according to what the doctor told me, never is cured.]

Almost a fifth of the families reported that mental health professionals labeled the problem as an emotional problem or *nervios*. Many of the families attended clinical programs with Hispanic professional staff who engaged the families using the cultural category of *nervios* (see Low 1988 for a detailed discussion of physician use of *nervios* in Costa Rica). Use of this cultural category by providers as well as patients increased rapport and decreased the stigmatization of using mental health services.

Education and ethnicity were key determinants of families' knowledge of the medical diagnosis and the degree to which they accepted it. The Cuban respondents tended to have higher levels of education and income than the Puerto Rican respondents. While many of the Cubans had completed post-high school education; many of the Puerto Ricans had less than a primary school education. Cuban families were more likely to know the medical diagnosis and to be able to report it to the interviewer. Even when families understood the medical diagnosis, their own conception of the illness reflected culturally mediated understandings of mental illness.

Gender of the ill family member also played a key role in how families conceptualized the illness (Jenkins 1988a). For women, emotional sources of illness were more frequently mentioned. Failures of romantic relationships and betrayals by men were often seen as major triggers of the onset of symptoms. The illness often began either after a break-up with a *novio*, a serious boyfriend, or after a divorce.

... cuando terminó la escuela superior, ella tuvo una relación con un novio, y después, esa relación no duró mucho tiempo. Después se terminó el noviazgo, y después de eso fue que siguió bien, pero tu sabes un poco asi, disgustada y no sé, distinta. No quería compartir mucho, no le gustaba salir, asi empezó ... Entonces, ella tambien tuvo su trauma, porque cuando ellos rompieron las relaciones, entonces él tenía ya otra novia. Y ella en persona fué a la iglesia a ver la pareja que se estaba casando. [When she finished high school, she had a relationship with a boyfriend, and this relationship did not last very long. After their relationship ended, she seemed O.K., but she seemed, you know, disgusted with life, and, I do not know, different or changed. She did not want to talk with us much; she did not want to go out; this is how it started. Then she had her trauma, because when they broke up, he already had another girlfriend. And she went to the church to watch them get married.] Parents' description of the beginnings of their 33 year old daughter's illness, diagnosed by professionals as paranoid schizophrenia.

The body, *cuerpo*, is the core symbol system for discussing one's place in the world. Disorders of the body reverberate with disorders in the social sphere. Serious mental illness disrupts a person's relationship to the self and to their social network in profound ways (Estroff 1989). This disruption is often reflected in bodily disturbance (Csordas 1990, Kleinman 1985, 1986). For some of the women, somatic problems such as problems in menstruation were linked with onset of the illness or exacerbation of symptoms. One mother highlighted both menstrual problems and chronic illness in talking about her mentally ill daughter.

Para mi que ella ha nacido con eso ... No sé si fué el dolor de la menstruación o fué que siempre tenía la enfermedad crónica en las 'tonsils'... [For me, she was born with this problem ... I do not know if it was the pain from menstruation or it was that she always suffered from a chronic infection of the tonsils...]

The mother went on to identify problems during the birth of her daughter as potential precursors of her mental illness. When the interviewer asked the mother which was the most important factor she responded:

Posiblemente el parto. Ella es gemela, nació en el campo, con ayuda de comadrona. Fué la segunda y nació de piernitas y envuelta en una mantilla... [Maybe it was her birth. She was a twin, born in the countryside with the help of a traditional midwife. She was the second to be born and was born breach and enveloped in a sack...]

A sister felt that difficulties during pregnancy and problems with the physical development of her children were the causes of her sister's illness. Up until her pregnancies began, her sister seemed fine. When the interviewer asked directly what caused her sister's problems she stated:

Los embarazos; antes ella era normal ... y que los niños le salieran con problemas. El *mas grande tiene problemas de aprendizaje.* [Her pregnancies; before she was normal ... And that the children were born with problems. The oldest child has a learning disability.]

Families were much more likely to see a male's mental illness as a result of either *fallo mental* or a chemical imbalance. For men, failures in the social world of school and work were also seen as underlying the onset of mental illness. In one case, failure to get a bank training job seemed to be the trigger of the illness. In another, the mother described her son's problems as preoccupation with the future and lack of meaningful work to do. She stated: "*el desarollo del hombre es mas fuerte que el de la mujer*" (the development of a man is more difficult than that of a woman).

These differences in understandings of the onset of illness reflected broader themes of gender roles in Hispanic society. For women, traditional social identity is tied to the roles of wife and mother. Traditionally, men are expected to find employment and to provide material support for the family. While these role patterns are clearly not unique to Hispanics, they have been maintained more strongly than in other ethnic groups. These discussions of the causes of illness and why the illness started when it did indicated that Hispanic families focused on strains in social roles as key issues in the development of mental illness.

This focus on social strains was also reflected in forced choice responses to a set of standardized causes of mental illness (Jenkins 1988b). These causes were presented to each interviewee in our study for their comments on whether they thought these problems contributed to their family members' illness. The most important factors listed by respondents included interpersonal relationships (29%), which included both family relationships and personal relationships (see Table II). Next in importance were external stressors (20%), including personal pressures or stresses and frightening or traumatic events. The conception of *nervios* focuses on the role of external stressors provoking illness, rather than illnesses coming from internal, intrapsychic sources. Sixteen percent of families identified alcohol or drugs as the major contributing factor, while 13% saw hereditary or biological factors as the primary source of their family member's illness. Strikingly, 22% of the families could not identify a major contributing factor. Thirty-two of the respondents (73%) identified other close family members with nervous or psychiatric problems and half (22) had other family members with drug or alcohol problems, indicating considerable family experience with various kinds of mental distress.

Spiritual and religious factors were also prominent in family members' discussions of the sources of mental illness. One mentally ill woman attributed her illness to the effects of spiritual works.

Yo tenía como 13 o 14 años. Cuando yo vivía en P.R., yo vivía en un callejón y había una casa que tenía dos señoras. Yo no creo en Espiritismo, pero Satanás existe, entonces *ellas eran espiritistas las dos. Yo iba cruzando así, y como yo soy débil, yo 'cache' algo en la mente. La biblia lo dice tambien que hay espíritus, y yo 'caché' eso en la mente. De eso es que me recuerdo y que estoy padeciendo ahora....* [I was only 13 or 14 at the time. When I lived in Puerto Rico, I lived down a side street and there was a house where two women lived. I do not believe in *Espiritismo*, but the Devil exists, and these two women were *espiritistas*. I was crossing the street, and as I was weak, I 'caught' something in my mind. The Bible also says there are spirits and I 'caught' them in my mind. This is what I remember about it and this is what I am suffering from now...]

The role of spirits in causing illness is a prominent theme among Hispanics. The two women described in this quote would become possessed by spirits of deceased relatives of their clients as part of the healing rituals of *espiritismo*. This woman felt that she had been affected by an intranquil spirit called by the *espiritistas*, and that this had occurred by accident as she passed their house. The ambivalent attitude toward *Espiritismo*, towards people who have the power to communicate with the spirit world, is frequently expressed when discussing spiritual causes of illness with Puerto Ricans and other Hispanics (Garrison 1977, 1982, Harwood 1977). One husband reported that he felt his wife's illness resulted from both religious and physical causes.

Bueno, como nosotros somos pentecostales, nosotros pensamos que era un ataque del Diablo, Satanás. Pero tambien pensé que como ella sufrió de anemia pues podía ser que como ella tuvo 3 hijos uno tras otro, se debilitó fisicamente. [As we are Pentecostals, we thought that it was an attack of the Devil, of Satan. But then I also thought that it might be from anemia, as she had three children, one right after the other, and this weakened her physically.]

This quote provides a sense of the multiple concerns of Hispanics in seeking an explanation for mental illness: the role of the birth experience and the toll on women of this experience; the role of social pressures and the instability of social life for poor Hispanics living on the mainland; and the concerns about the spiritual world and its role in everyday affairs.

In spite of prolonged illness and difficulty helping their ill family member, Hispanic families expressed considerable optimism for the future of their family members. When asked if they felt the illness would ever be cured, two-thirds said they thought it would be (see Table II). This feeling was stronger than that expressed by African-American families and much stronger than the European-American families. Many of the families expressed strong religious beliefs in response to this question.

Si Dios hace la obra, él se va a sanar, aunque los doctores digan que él va a ser asi siempre. [If God performs the deed, he will get well, even though the doctors say he will always be like this.]

Esa es le fe que yo tengo. [This is the faith that I have.]

Si, yo creo mucho en Dios. [Yes, I believe strongly in God.]

Some families expanded on the beliefs expressed above in ways that provided insight into the "subjunctive" sense of the world built into both Spanish language and deeply felt religious belief. Families' responses to the question of cure focused much more on issues of being able to take care of oneself than on other areas of life.

> *Yo creo que si. Por lo menos si no se cura, que pueda funcionar, como otros casos que yo sé. Porque mire, él no es retardado mental, él es inteligente, afectuoso, oye bien, no tiene ningun defecto físico, no es mal parecido, en fin.* [I think so. At least if he cannot be cured, that he can function, like other cases I have known. Because, look, he is not mentally retarded, he is intelligent, affectionate, he hears well, he has no physical defect, he is not bad looking, that is it.]

What Latino families meant by cure was qualitatively and quantitatively different than what either medical professionals or the European-American families meant by cure. Hispanics were not focusing on a medical cure which would remove the disorder – though like all families of the mentally ill they would be thrilled if one were to be found. They were using cure not in the biomedical sense, but more as anthropologists have defined *healing* – as the processes of providing explanation for why the person has become ill and attending to the social consequences of the illness for the individual and the family. For many of the families, religious themes provided some way to understand this baffling problem of serious mental illness. At the same time, their faith left open the possibility that their family member would at least be able to participate as part of the family, to interact with key others and to re-enter the community again. Families' optimism was more based in this religious belief – *Si Dios quiere* (if God is willing) – than in reassurances from mental health professionals. These beliefs also contributed to strong support from family of the ill individual.

FAMILY SUPPORT SYSTEMS

Families' conceptions of the illness as a breakdown in social development and the strong sense of family loyalty among Hispanics led the people we interviewed to see the family home as the appropriate place to care for their ill family member (Casas and Keefe 1978, Jenkins 1988a, 1990, Rogler and Hollingshead 1985). More than other ethnic groups in the study, Hispanic families turned to other family members both when they just needed someone to talk to and when they needed specific advice on how to deal with their ill family member. For example, one mother commented on her support network.

> *Bueno, para ayuda para andar de aqui para allá, porque yo no sé ingles, le pediría al hijo, a los hijos mios casados, mis hijas ... amigos son mis hijos nada más, eso es lo único que yo tengo.* [For help in getting around, as I do not speak English, I ask my son, my married children, my daughters ... my only friends are my children, they are the only ones I have.]

This quote suggests the strong family support network that existed for many of the Hispanic families. It also reflects the deeply held feeling that families did not want to go outside the family network to reveal their problems with mental illness. Finally, it highlights the problem of social isolation faced by older Latina women who do not speak English and often do not move outside the circle of family and Church.

When families were asked, as part of the section on family burden: "If it were possible, would you prefer that [your family member] live somewhere else?" half of the families responded No (see Table III). As an example, a brother and sister-in-law spoke about their commitment to their mentally ill brother, who lived in the same house with them and their family.

> *Por las niñas, si hubiera el 'chance' de que viviera con otra familia. Pero él solo de dependiente dejarlo botado, no!* [For our daughters, if there was a chance he live with another family, we would prefer he live somewhere else. But him alone, dependent only on himself, to throw him out, no!]

TABLE III
Care taking roles of families with a seriously mentally ill member

Care taking roles	Hispanic	Afro-American	Euro-American
N	45 (50%)	29 (32%)	16 (18%)
Care giver Prefer Patient Live Somewhere Else			
No	53%	48%	12%
Yes	20	21	38
Currently living somewhere else	27	31	50
Types of Help Provided (% yes)			
Personal Care	43%	44%	27%
Meal Preparation	66	46	40
Medication & Appointments	64	36	8
Money Management	47	54	33
Social/Emotional Support	98	85	80
Major Areas of Problems (% yes)			
Financial Burden	50%	59%	60%
Effect on Health of Caregiver's Family	52	52	88
Disruption of Family Routine	74	59	87
Decrease in Social Life	40	18	43

A fifth of the families reported that they would prefer that the family members had their own apartments. In ten of the families, the family member either lived with his/her own family or lived alone. One of the differences between the Hispanic families and other families in our study was the number of Hispanic ill individuals of both sexes who were married and lived with their own families.

Another source of social support for Hispanic families is *compadrazgo*, the relationship among godparents. An 18 year old daughter, who is the main care giver of her mentally ill mother who lives separately from her, relies heavily on her *comadre* for help in taking care of her mother. Her *comadre*, the godmother of her child, is the person who takes care of the children when the daughter goes to take care of her mother. For a crisis in the middle of the night, she also calls her *comadre*. Social supports of this type allow a family to care for their mentally ill family member at the same time as they care for the other members of the family.

The majority of family members strongly felt that they understood the person better than anyone and that home was the best place for them to live.

> *Ay! no, si él es la vida mia ... él quiere, yo quisiera que se me quedara.* [Oh no, he is my own life ... he wants, I want that he should stay with me.] Mother, father and son live together.

> *Ay! no, yo no sé, ahí yo no. Yo quiero estar con el. El esta muy acostumbrado a mi y yo a el.* [Oh, no, I do not know, out there no. I want to be with him. He is very accustomed to me and I to him.] Mother and son who are the only ones in the house.

> *Mientras yo exista, prefiero que no, porque yo soy la que comprende mejor que otra persona.* [While I am alive, I prefer not, because I am the one who understands her better than anyone else.] Mother, father, daughter and son live together.

Mothers expressed that the major strains of caring for their children were when their children displayed *una falta de respeto* (a lack of respect) and when they did not eat or sleep well. Another major concern for sons was violent behavior. Many families reported that they could tell when the illness was acting up when their family member was disrespectful of parents or other family members. Daughters yelling and swearing at their mothers appeared particularly stressful.

The final quote cited above raises a concern that was central to many families with a seriously mentally ill family member – what will happen when the parents die? One mother poignantly expressed the concerns of many families of all ethnic backgrounds in talking about her mentally ill son.

> *Yo le he enseñado mucho ... le enseñé a lavar. Que si yo muero pues él sepa y mi hija no tenga esa obligación, porque mi esposo murió hace tres años ... pero yo no voy a dejar a mi hijo, mientras yo este en vida, a mi hijo yo no lo voy a desamparar. Tengo una familia muy buena y grande, tengo una hija muy buena. Ellos viven aquí cerca. Cuando uno tiene familia buena, nunca estoy sola porque ellos vienen y mis problemas me ayudan a resolverlos ... Si, la familia es muy unida y por ahí pasamos los sufrimientos.* [I have taught my son a lot ... how to do his laundry. So that if I die he will know how to do it and my daughter will not have to do it for him, because my husband died three years ago. But I am not going to leave my son, as long as I am in this life I will not put my son out. I have a good and a large family, I have a good daughter. They all live close to here. When you have a good family, you are never alone, because they come and help me solve my problems. Our family is very united and that is how we get through our sufferings.]

This quote poignantly expresses the strong family loyalty and wide social network available to many of the Hispanic mentally ill family members. Many of the adult children live in close proximity to the parental home and share in the caretaking. The role of adult siblings of the mentally ill comes through strongly in the comments of a sister on her mentally ill sister:

> *Lo que pasa es que cuando ella está así me pone a mi mal. Pero a mi no me estorba porque es mi hermana. A mi esposo, mi mama muy grave le dijo, 'yo lo que quiero es que esté con Uds.' Y mi esposo le dijo, 'yo nunca la abandonaré'.* [What happens is that when she is sick I feel terrible. But it is not a burden because she is my sister. When my mother was dying, she said to my husband, 'What I want is that she be with you'. And my husband said, 'I will never abandon her'.]

Again, intra-ethnic and social class differences between Puerto Rican and Cuban families were highlighted. The Cuban families in our sample tended to have fewer children and fewer relatives in the local area. This put greater strain on these families, and particularly on adult siblings, in the continuing care of their ill family member. On the other hand, siblings in Puerto Rican families had more social problems which made them less able to respond as supporters to their ill family member. A key question for families and for mental health policy is, who will take over the care of the ill individual when the parental generation dies. It is less likely that siblings can take on all the care responsibilities carried out by parents. Yet their role as key supporters needs to be maintained and supported to the greatest extent possible.

Among Hispanic families, spouses of the mentally ill individual often played key support roles. In contrast to African-American and European-American families in this study, where there were no currently married ill individuals, several of the mentally ill Hispanics were married and had their own children. For both wives and husbands, the role of caretaker often became all encompassing. Several spouses, both husbands and wives, had to stop working to care for their partner, their children and the household. These arrangements, which were seen as expected behavior by the spouse, were often viewed skeptically by social service providers as the family often was supported by public assistance. Yet the kinds of dedicated care provided by these spouses could not be easily substituted for in other forms in ways that were either culturally acceptable or cost efficient. Often these spouses turned to a religious leader and to God for support.

RELIGION AS A MAJOR SOURCE OF SOLACE

Beliefs and practices concerning the spirit, *espiritu,* and God are often sources of support and solace in the face of crisis. Certainly, serious mental illness presents a crisis to families and challenges their notions of fairness and compassion in the world. It is not surprising then that many people turn to spiritual guidance as one form of help in dealing with serious mental illness. In Hispanic communities, sources of spiritual help are quite varied, including Catholic churches, Pentecostal congregations, *centros de espiritismo* (spiritist centers), and *santeros* [for discussions of *espiritismo* and *santerismo* see Garrison 1977, 1982, Harwood 1977, and the paper by Weiss in this volume].

In addition to support from family members, religious involvement was a major form of social support for families. Hispanic families were much more likely than either African-American or European-American families to turn to help from religious leaders both around the hospitalization of their family member and when they needed someone to talk to about their concerns for the ill person. Members of Pentecostal Churches received considerable help, both from ministers and from members of the congregation, often referred to as "sisters" and "brothers" in the Church. One woman frequently sought the help of her minister in dealing with her mentally ill husband.

> *Bueno, cuando nosotros lo necesitamos, él enseguida viene porque primero teniamos uno que siempre nos estaba ayudando, pero que él salió de esa iglesia. Ahora vino otro ministro y cualquier problema yo se lo digo a él y él me ayuda.* [Well, when we need help, he comes immediately because our first minister always helped us, but he left our church. Now another minister has come and whatever problem I tell him, he helps me with it.]

A husband sought considerable help from members of his church in coping with his mentally ill wife. "*El pastor se levantaría a cualquier hora a darme la mano*" [The pastor would get up at any hour to give me a hand]. When asked whom he talked to when he needed to tell someone about his concerns about his wife's problem, he responded: "*Con el hermano de ella y mi pastor, yo oro para que Dios me dé resignación...*" [With my wife's brother and my pastor, I pray to God so that He can help me be resigned to my problem]. The husband did all of the housework, cooking, child care, and took care of his wife. He had not worked in several years to be available for his family. In considering who would come to help him care for his family if he needed help, he replied: "*Ademas las hermanas de la iglesia estarían dispuestas, pero no ha habido la oportunidad*" [In addition, the "sisters" of the church are willing to help, but there has not been an opportunity for them].

Families reported that church was a setting where the ill individual was accepted. For most families, religion was one of the few sources of solace and hope for the deeply disturbing challenges presented by serious mental illness. This was particularly true in the face of the pessimistic assessments of the future offered by psychiatric professionals. The adult sister of a mentally ill man expressed the role of faith in God in helping her to cope with her brother's illness. This woman was actively involved in the Catholic Church.

> *Esas cosas las cura Dios. Esas cosas ni se pueden ir a los brujos esos, porque eso es lo que hace que lo enferman más, ni se puede ir a un doctor porque te da muchas pastillas. Uno debe tener una fe muy grande en Dios ... Le dije, tu debes de buscar a Dios para*

> *que te mejores ... Le dije que fuera a un grupo de oración que teníamos aquí, y que tuviera una conversación con el padre.* [These things God cures. These things you should not bring to "sorcerers" because they make you sicker nor should you go to doctors because they give you too many pills. One should have a great faith in God ... I told my brother, you should find God so that he can cure you ... I told him he should go to a prayer group that we have here and he should have a conversation with God.]

When this sister faced a crisis with her brother, she coped by seeking spiritual guidance: "*Yo siempre buscaría una dirección espiritual de un sacerdote, no de un doctor*" [I always look for spiritual direction from a priest, not from a doctor]. This sister's faith in God reflects the strong religious feelings of several of the Hispanic families we interviewed; at the same time her beliefs were more deeply religious than many families we interviewed. She believed that while doctors could help her ill brother, faith in God was necessary for the treatments to work.

> *Nosotros tenemos un doctor invisible, que no los vemos, verdad? Que es Dios. Siempre cuando nosotros vamos a buscar una medicina, vamos a un doctor, siempre tenemos que estar presentes que ese médico está inspirado por Dios y que nos va a dar algo que nos va a aliviar porque siempre tenemos que tener mas presentes que quien hace esa curación es el Señor, y que el Señor nos puede curar de cualquier cosa que nosotros tengamos, material y espiritual.* [We all have an invisible doctor, that we do not see, no? This doctor is God. Always when we go in search of a medicine, we go to a doctor, but we must keep in mind that this doctor is inspired by God and that he will give us something that will help us. We must also keep in mind that who really does the curing is God, and that God can cure us of anything that we have, material or spiritual.]

This notion of God being an invisible doctor is a powerful image. The doctor's power to heal comes through God and God imbues medicines with the strength to overcome illness. This quote provides another perspective on how some of the Hispanic families interpreted the meaning of "cure" and the role of religious belief in the healing of their family member. At the same time, it makes clear that strong religious belief is not an impediment to seeking medical care. Rather, it provides a strong incentive for and alternative rationale for help-seeking.

Families participated in various activities of both Catholic and Evangelical Protestant churches and involved their ill family member as well. Sixty-two percent (28) of the Hispanic families were Catholic, while a third belonged to various Protestant churches. For the Protestant families, the frequent services, prayer meetings, and meetings of church-based organizations provided social contact for both the family and the ill individual. Some of the Catholic families also participated in church organizations in addition to attending mass. Thirty-two percent (14) of the families attended church more than once a week and forty percent (18) attended weekly services. Prayer, at any time, was clearly central to many families' coping with serious mental illness.

In addition to involvement in Catholic and Pentecostal Churches, consultation with *Espiritistas* played an important role in some families' efforts to cope with the mental illness of their family member. Some families sought help both in

Espiritismo and the Catholic Church. A mother described her search for help for her mentally ill son in the following way:

> *Yo fuí a un espiritista en Puerto Rico, pero mi hijo no quizo ir, y ella me dijo unas cuantas cosas que eran verdad, que pasaron. Me dijo que había alguien que quería ver a mi hijo detras de una reja en la carcel. Y eso fué un trabajo que le echaron a una persona y lo cojió el ... Yo tambien lo he llevado a círculos de oración y se ha mejorado. El sacerdote me dice que oremos y pidamos mucho al Señor. El dice que es una enfermedad muy seria y hay que tener mucho cuidado porque la persona con esa enfermedad a veces reacciona de una manera violenta ... Yo tengo mucha fe en el Señor. Antes yo era cursillista y pertenecia al coro en Filadelfia.* [I went to an *Espiritista* in Puerto Rico, but my son did not want to go. She told me some things that were true, that had happened. She told me that there was someone who wanted to see my son behind bars in jail. This was a "work" that had been sent to someone else and my son "caught" it instead ... I have also taken him to prayer circles and he has improved. The priest told me that we should pray and ask much of the Lord. The priest said that this was a grave illness and that we had to be careful because a person with this kind of illness can sometimes act out violently ... I have a lot of faith in God. Before I used to be a teacher for retreats and a member of the choir in our Catholic Church in Philadelphia.]

This quote illustrates the multiple help-seeking of many families with a mentally ill family member. It also indicates that for many Catholic Hispanic families there is little incompatability in seeking help both from the Catholic Church and from *Espiritistas*.

For other families, the turn to *Espiritismo* and other forms of religius healing with Afro-Caribbean roots, is one made out of desperation and families can become frightened and withdraw. This is illustrated in the following case recounted by a mother about her mentally ill son.

> *Estuve una vez tan sufrida que un hombre vino aquí ... y me habló y me dijo, 'señora, usted tiene un enfermo y necesita ayuda' y me estuvo raro porque yo creo en Dios. Y cuando me dijo eso, usted sabe cuando una madre está con esa ansiedad que necesita ayuda, él me dijo, 'señora, yo pertenezco a un grupo en Newark' ... Y con miedo mi esposo y yo lo llevamos y cuando entré era en una factoria en la parte de atrás y estaban todos vestidos de blanco ... eran unos brazileños y el hombre era de Perth Amboy y noté que fuimos cuatro veces y para el muchacho fue una ayuda; que cuando empezó a hablar yo dije, el Diablo hace tantas cosas y condena a uno. Pero una noche fuimos y mi esposo mi dijo, 'no nos engañemos, por favor no volvamos más. Nuestro hijo es enfermo y puede ser que el Diablo esté buscando manera de confundirnos, vamos a la iglesia y no volvamos más.* [There was a time when we were suffering so much with our son's illness that a man came ... and he talked to me and said 'Señora, you have a family member who is very sick and you need help' and this was strange because I believe in God. And when he said this, you know a mother can be so anxious that she needs help. He said to us, 'I belong to a group in Newark' ... With a lot of fear, my husband and I took our son there and when we entered the building we found that it was a factory in the back part of the room and in front everyone was dressed in white ... they were mostly Brazilians and the man we spoke to was from Perth Amboy. We went four times and it helped him some; but when he began to speak, I said the Devil does many things and can condemn one. Then one night we went and my husband said to me, 'Please, let's not lie to ourselves anymore, let's not go back there. Our son is sick and it may be that the Devil is trying to find a way to confuse us. We will go back to the Church and not return.']

The ambivalence felt by many Hispanic families is reflected in this quote. The healer helped her son and yet the family was concerned that the healers might be working with the Devil rather than with good spirits. Later in the interview the mother reports that she tried to pay the healer and the healer would not accept payment. Her son was also involved during this period and up to the present with mental health services, again reflecting the multiple use of care to deal with the seriously troubling challenges posed by mental illness.

Two families consulted once with an *espiritista* at the urging of other family members. One of the ill individuals was told that she had *facultades*, that she could see things such as impending death. A diagnosis of *facultades* by an *espiritista* signifies the belief that the person should go into training to become a medium under the protection of an *espiritista*. The ability to see things that will happen signifies heightened sensitivity to the spirit world which can lead to problems if the person does not develop their spiritual faculties. However, the family never pursued further development of the person within *Espiritismo*. One family consulted an *espiritista* during acute episodes and reported considerable relief from the *limpiezas*, ritual cleansings, the son received. Interestingly, this *espiritista* encouraged the ill individual to always take his medicine and exhorted the mother: "*Traígalo aquí, pero no deje de ir al medico.*" [Bring him here, but do not stop going to the doctor.]

For Hispanic families, religious involvement filled a multiplicity of needs. Families sought both solace and hope from religious helpers; support which they frequently did not get from mental health professionals. Families also received various kinds of concrete support from members of their congregation. For some families, seeking help from the various religious healers was an important form of treatment, with at least temporary effect in relieving the problems caused by serious mental illness. Prayer provided an opportunity to relieve oneself of the troubles and frustrations of dealing with a chronically mentally ill family member. At the same time prayer was an active form of seeking help for the ill family member.

DISCUSSION: NERVIOS, CUERPO Y ESPIRITU

Nervios (nerves), *cuerpo* (body) and *espiritu* (spirit) are core themes that organize Hispanics' approach to mental health. *Nervios* is a multi-vocal symptom and syndrome for expressing psychological distress, somatic discomfort, and problems in the social sphere. The body, *cuerpo*, is the core physical and symbolic nexus of expressing one's experience in the world. Social stress is mirrored in somatic distress. Serious mental illness disrupts a person's relationship to self and to their social network in profound ways. Syndromes such as *nervios* express these multiple levels of personal and social dislocation.

In contrast to the categorical approach to mental illness as discrete entities now dominant in American psychiatry and codified in DSM-IIIR (American Psychiatric Association 1978), many Hispanics view mental illness on a continuum. This continuum ranges from *estar nerviosa* (to be nervous) related to situational distress, to *padecer de los nervios* (to suffer from nerves) due to both constitutional weakness and more enduring stress, to *fallo mental* (mental failure) related either to extreme social stressors or to some physiological dysfunction, to *locura* (craziness) which signifies loss of touch with reality and little hope for recovery (Rogler and Hollingshead 1985, Newton 1978, Jenkins 1988a, Koss-Chioino 1989). This notion of mental illness as a continuum provides, on the one hand, a model in which support and treatment can move people towards the less severe end of the continuum, and on the other, the ominous possibility that the family member can slip into madness.

By interpreting serious mental illness through these core cultural idioms, the ill individual is brought back into the family and community. *Nervios* serves as a broad idiom for emotional disturbance and encapsulates the more visible behavioral manifestations of schizophrenia, while bracketing out some of the less socially acceptable psychotic symptoms. The link between bodily distress and psychological distress permeates discussions of schizophrenia as well.

These conceptions of mental illness also protect the Hispanic families in our study to some extent from the guilt and self-blame for the illness which has become such a key issue for European-American families. While European-American families have been exposed to and affected by the various "family blaming" theories of several American approaches to mental illness (Lefley 1989), this experience has been much less common for the Hispanic families we interviewed. In part, this has been a result of limited communication with American psychiatrists and other mental health professionals who often do not speak Spanish. At the same time, Hispanic families much more frequently attribute the onset of mental illness to external stressors in the social environment or to intrinsic weakness over which the ill individual has little control. This does not mean that mental illness is not stigmatized among Hispanics, for there is considerable stigma associated with psychological disorder. But the stigma is more attached to the aberrant behavior than to the family and its role in the onset of illness.

A core insight of medical anthropology has been a focus on *illness* – on the personal meanings and social context of disorder (Kleinman, Eisenberg & Good 1978, Kleinman 1980). Serious mental illness is profoundly social and cultural in its impacts – it not only disorders the ill person, but also remakes that person's identity, changes his/her relationships to family and friends, and alters the person's ability to act in society. The illness categories of *nervios* and *fallo mental* help families to understand and come to terms with the transformations of their ill family member in quite different ways than the disease category of schizophrenia does. This is one of the reasons that even the families who knew their family member was diagnosed as schizophrenic, questioned and even resisted the label. It is also these notions of illness that opened the possibilities for *healing* – of moving back down the continuum towards health. In contrast, the disease label of schizophrenia offers little opportunity at this time for *cure*; that is for reversal of the disease process.

Beliefs and practices concerning the spirit, *espiritu*, and God are often sources of support and solace in the face of crisis. Certainly, serious mental illness presents a crisis to families and challenges their notions of fairness and compassion in the world. It was not surprising, then, that many family members turned to spiritual guidance as one form of help in dealing with serious mental illness. Religious involvement provided solace for some families deeply troubled by their experiences with caring for a seriously mentally ill family member and offered them support to continue to work with and for their family member in helping them to lead as full a life as possible.

In spite of the differences among different ethnic group families in their conceptions of illness and response to their ill family member, their needs for concrete supportive services for dealing with the social consequences of mental illness – what anthropologists have termed *sickness* (Young 1982) – were similar. All families in our study emphasized the need for vocational programs to provide their ill family member with activities that would enhance their social identities and to prepare them for entry into the world of work. Similarly, family members identified the need for social activities and programs where ill family members could interact with people who shared their problems. These programs were also seen as a respite for families from providing all of the social and emotional supports of their ill family member.

Families also saw supportive housing programs as a key need for their family member, although they differed in when they saw their ill family member leaving the family home. Hispanic families in our study expressed the strongest sense that they preferred that their ill family member live in the family home as long as possible. However, they also recognized that with the death of parents, the goal of having the ill family member live with other relatives would be quite difficult, in spite of considerable support provided by siblings.

A major form of help for families of the mentally ill has been the development of psychoeducation programs which focus on educating families about serious mental illness and its treatment, helping families develop methods for coping with problematic behaviors, and building support networks among families with a mentally ill family member (Falloon et al. 1984, 1985, McFarlane 1983, Rivera 1988). Rivera (1988) presented an assessment of the applicability of the psychoeducation model to Hispanic families, using her experience with a family support group in the Bronx. Rivera argued that the inclusion of families in treatment; the focus on providing concrete information on mental illness; the use of concrete treatments such as medications and explicit behavioral instructions; and the effort to alleviate families' sense of blame for the illness were all compatible with Hispanic culture and fit with the needs identified by Hispanic families in the Bronx. At the same time she aruged that the use of an egalitarian problem-solving paradigm within psychoeducation; the lack of attention to spiritual factors in illness and the misinterpretation of some spiritual beliefs as signs of psychosis; and the problematic assessment of what is over-involvement with an ill family member all suggest the need for modification of the psychoeducation approach in using it with Hispanic families.

Our research provides further insights into ways that family educational programs would need to be modified for Hispanic families. Many Hispanic families' conceptions of mental illness are rooted in cultural models which see mental illness as a continuum. These ideas about illness both allow families to be accepting of their family member and to maintain some hope for the future. Introducing information to families about the medical model of schizophrenia and other serious mental illness needs be done in a way that acknowledges and builds on the conceptions of these families. Minimally, educational programs need to start by assessing families' understandings of mental illness and working from those ideas. A more difficult task is to come to terms with the implications of the medical model for families' acceptance of and hope for their ill family member. We are not advocating that families not learn the most current medical information on the disorders of their family members. Rather, we are arguing that any model of illness carries with it value judgements about the person and expectations for his/her future. These issues need to be discussed openly with providers and among families. In order to achieve this goal, providers need to develop a deeper understanding of families' perspectives on mental illness and the implications of these conceptions for their role as caretakers.

A second assumption of family education models is that families are isolated by mental illness from their natural support networks, so that a new network of families with mentally ill family members needs to be created. This model has, in fact, worked quite well with middle class, European-American families. Many of the Hispanic families in our study had much broader social networks and did not experience the ruptures with relatives and friends that European-American families experienced. Many of the Hispanic families' social networks provided significant support. This suggests that family models can and need to build on these strengths of this social and cultural matrix within Hispanic communities in designing family intervention models. Psychoeducation groups, rather than being built on groups of unrelated individuals or couples who share a similar problem, might be built on larger family networks which share ties of kinship or membership in key community institutions such as churches. At the same time, some of the poorest Hispanic families in our study experienced ruptured family networks and broken ties with others. One approach to working with these families would be to integrate them with other family networks and with community institutions, such as churches, which have resources for providing support.

A deeper appreciation of the roles of cultural and social factors in shaping families' understandings of serious mental illness is critical to furthering research on families' responses to serious mental illness and to developing programs to support these families. We have provided detailed interpretations of a sample of Puerto Rican and Cuban-American families' perspectives on their family members' illnesses and on their roles as caretakers. This analysis furthers work on the cross-cultural study of social responses to serious mental illness. At the same time, it provides directions for developing programmatic interventions which build on the strenghts of Hispanic families to improve both their lives and those of their ill family members.

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NOTES

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[2] We have chosen to include the direct Spanish quotations from the transcript followed by the English translation for the following reasons: (1) it allows for verification of the accuracy of our translation and (2) it provides researchers with specific key idioms used by Hispanics for discussing mental illness which can be explored in further research on this subject.

[3] See Newton (1978) for a fuller discussion of this model of an emic system of mental illness for Mexican-Americans.

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