

ETHNIC DIFFERENCES IN THE INTERPRETATION OF MENTAL ILLNESS: PERSPECTIVES OF CAREGIVERS

Glen Milstein, Peter Guarnaccia,
and Elizabeth Midlarsky

This study seeks to understand differences among African-Americans, European-Americans, and Hispanic-Americans in their conceptions of mental illness and their attitudes toward mental health professionals and help-seeking. Primary caregivers of persons who have a long-term mental disorder were interviewed because it is usually the responsibility of the family to provide primary care for the person labeled mentally ill (Goldman 1982), and it is through the family that the family member often gains (or does not gain) access to mental health services (Rosenfield 1984).

Several recent studies have demonstrated different conceptions of mental illness and different beliefs about proper help-seeking

Research in Community and Mental Health, Volume 8, pages 155-178.

Copyright © 1995 by JAI Press Inc.

All rights of reproduction in any form reserved.

ISBN: 1-55938-139-6

behavior among African-Americans, European-Americans, and Hispanic-Americans. Although early studies showed a lack of psychiatric knowledge among European-Americans, more recent studies have demonstrated a greater familiarity with psychiatric nosology and a greater agreement with the current views of professional psychology among European-Americans than among either Hispanic-Americans or African-Americans.

Forty years ago, Yarrow, Schwartz, Murphy, and Deasy (1955) studied the factors which they believed kept European-American women from recognizing symptoms of mental illness in their husbands, and which made these women less inclined to encourage their husbands to seek mental health services. One finding was that the seemingly idiosyncratic strangeness of the husbands' behavior, and the women's lack of familiarity with psychiatric knowledge, made it more difficult for the women to identify the behaviors as representative of an illness which was in any way treatable. The women were not inclined, therefore, to seek professional help for their husbands.

Since 1955 several research projects have demonstrated that ethnicity influences the conception of mental illness. These studies indicate that today there is a much greater familiarity with psychiatric nosology, and an increased openness to using mental health services among European-Americans as compared to other ethnic groups. For example, Hall and Tucker (1985) studied the attitudes toward mental illness and treatment among African-American and European-American school teachers in Florida. Questionnaires were mailed to the teachers which looked at conceptions of mental illness (Nunnally 1960) and attitudes associated with seeking psychological help (Fischer and Turner 1970). The study also sought recommendations about persons with mental health problems who were described in written vignettes. Hall and Tucker found that African-Americans showed strongly culturally mediated conceptions of mental illness. African-Americans believed that mental problems could best be controlled by the avoidance of morbid thoughts, and that willpower could cure mental illness more than psychological treatment. This was the opposite of the view held by the European-Americans in the study.

Hall and Tucker suggested that one reason for this emphasis on willpower is derived from the cultural influence of African-American religious leaders who stress willpower and prayer as solutions to

problems in general. They also emphasized that these differences represent fundamental conceptualizations about mental illness that are rooted in the different historical and cultural experiences of African-Americans and European-Americans. Boyd-Franklin (1989) has suggested that African-Americans have a healthy suspicion of all systems, given their historical treatment in the United States. She additionally makes the point that African-Americans have evolved strong social support networks through both extended family structures and their own religious institutions. Adopting the role of the client, especially with someone outside of the family and community, could be seen as a sign of weakness, and an act of disloyalty to the family.

Differences have also been shown in studies with Hispanic-Americans. Edgerton and Karno (1971) studied the perceptions of mental illness of European-Americans and Mexican-Americans. Overall, they did not find significant differences between the perceptions of these two groups. They did, however, find differing perceptions among Mexican-Americans depending on the language in which the subjects chose to respond. For example, Spanish-speaking Mexican-Americans felt that recovery from mental illness would be facilitated best if a person remained exclusively within the family. They showed little desire for their family member ever to become involved with psychiatric services. English-speaking Mexican-Americans agreed with European-Americans that recovery would best be realized outside of the home with the help of professionals.

In responding to a vignette about a 17-year-old girl with symptoms of schizophrenia, all subjects agreed that the girl's problem was "serious." Most European-Americans referred to the problem as mental illness. Mexican-Americans, as a group, referred to it as a "nervous" condition. When Edgerton and Karno looked specifically at the Mexican-American subjects' responses, they found that those who were interviewed in English more often referred to the problem as "mental illness." Persons who took the interview in Spanish referred to it as *nervios* ("nerves").

Jenkins (1988) studied different conceptions of mental illness between Mexican-American and European-American caregivers of family members labeled mentally ill. In the study she found that 68 percent of the European-Americans considered their family member's illness a mental or psychiatric disorder, whereas 67 percent of the

Mexican-Americans considered it to be a problem of *nervios* ("nerves"). Jenkins also found that only 47 percent of the Mexican-American families who had received psychiatric diagnoses agreed with the physician's diagnosis, whereas 63 percent of European-American families agreed. In addition, Jenkins found that European-Americans used a medicalized description of the illness and that Mexican-Americans used terms from their own cultural knowledge.

Jenkins (1988) has explained that the Spanish term *nervios* is used to describe an ailment believed to afflict vulnerable persons. It is seen as a condition which could befall anyone at some time in their life. Its etiology is believed to be in the environment, and it is not necessarily seen as a permanent ailment. The European-Americans' and English-speaking Mexican-Americans' use of "mental illness" refers to a physiological trait with non-specific biochemical etiology and probable permanence. One motivation for using the Spanish term, is that the label of *nervios* places less of a stigma upon the ill individual than "mental illness" and less stigma on Hispanic-American families who have a family member labeled mentally ill. Guarnaccia, Parra, Deschamps, Milstein, and Argiles (1992) have pointed out that the use of the term *nervios* provides a descriptor of behavioral symptoms of mental illness while excluding socially detrimental labeling. Thus, labeling of illness is critical in understanding the social consequences of mental illness.

Family researchers need to understand these cultural differences in the ways people label and understand mental disorders. All families, when faced with a dysfunctional family member, try to create an understanding for themselves of what this change in their relative is, and how to respond to it (Terkelsen 1987). Cultural factors are fundamentally salient to the way the family members conceptualize their relative's abnormal behavior (Lefley 1990; Jenkins 1991), and the outcome of this conceptual process will be integral to the subsequent care-seeking behavior of family members. Fabrega (1989) has argued that only by a comparative study of the effect of culture on a person suffering from a mental disorder can we achieve a genuine understanding of the dysfunctional behavior. For the professional to communicate effectively, the cultural assumptions of the persons being spoken to must be well understood.

The mental health professional has a number of models for understanding mental disorders as diagnostic labels derived from the

medical model of psychiatric disorders. This model has been developed extensively in the last ten years and is codified by the behavioral and biochemical descriptors of the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders—Fourth edition) (American Psychiatric Association 1994). This most recent edition also includes codes for religious (V62.89) and acculturation (V62.40) problems which should be understood as similar to marital problems or bereavement, and distinct from psychiatric disorder. In addition, the DSM-IV contains a glossary of “culture-bound syndromes” which is new to this edition. These syndromes are new categories that have not yet been widely used by mental health professionals. These additions represent a recognition that to work effectively, mental health professionals need to gain a more sophisticated awareness of the influences of religion, culture, and ethnicity on the experience and understanding of mental illness.

Wakefield (1992) has extensively discussed the medical model as one of the many ways that mental disorders are understood, all of which are mediated by social values. Recognizing this, Estroff (1989) has argued that a standardized nosology of mental illness does not take into account the unique cultural influences on the individual’s own experience of mental illness. This point elucidates a crucial inadequacy of the medical model: because the unique deficits caused by mental illness affect all parts of an individual’s functional and interpersonal life, families rarely experience these deficits as something confined within a discrete “illness.”

Nevertheless, the medical model has been used as the basis for psychoeducation curricula which have been developed as a method of treatment for serious mental illness (Torrey 1983; Taylor 1987; Pratt and Gill 1990; Halford and Hayes 1991). One goal of this method is to teach families a biochemical view of the etiology of the family member’s mental illness: the medical model teaches that mental illness is a disease of the brain and that it is a lifelong illness. A second is to help families develop specific measures necessary to aid a family member with mental illness. The principal recommendations to the family members who are the primary caregivers are for the relative to make contact with mental health professionals, and to assure that medication be maintained at therapeutic doses (Hatfield 1988; McFarlane 1990; Falloon, Boyd, and McGill 1984). Families are also encouraged to be active participants in their family members’ treatment (Grunebaum and Friedman 1988). Although the

curricula of the medical model of psychoeducation have evolved as research into the biological bases of mental dysfunction has increased, this has often occurred to the exclusion of other clinical models (Hunter, Ferholt, and Hoffnung 1991).

The biological model of mental disorder informs the research program of the National Institute of Mental Health (NIMH) and determines its funding priorities for research on the treatment of mental illness based on this model (McLean 1990). The medical model has also become the foundation of the education and advocacy programs of the National Alliance for the Mentally Ill (NAMI), an advocacy group for families of persons with mental illness. NAMI has made great efforts to educate the public about, and reduce the stigma of, serious mental illness. One example of this perspective is expressed by a publication of the State of California's Department of Mental Health. In an information pamphlet for families written by the California Alliance for the Mentally Ill (1989), severe mental illnesses are discussed as "biological diseases of the brain" (p. 9) and that therefore the family should learn to "hate the illness and love the person" (p. 17). This idea of an illness separate from, yet residing within a loved one is not a concept that is shared across ethnic groups in understanding mental illness.

Hall and Tucker's (1985), Jenkins' (1988), and Edgerton and Karno's (1971) studies show that the use of medical terminology and familiarity with the medical model of mental illness has increased among European-Americans since the study conducted by Yarrow, Schwartz, Murphy, and Deasy (1955). However, these three studies also show that different views of mental illness are common among non-European-American ethnic groups.

Because of the low utilization of mental health services by ethnic minorities (Sue, Fujino, Hu, Takeuchi, and Zane 1991), professionals need to understand and be sensitive to cultural variation in order to more appropriately serve these rapidly growing populations. Malgady, Rogler, and Constantino (1987) have pointed out that the responsibility for adaptation to cultural variation rests with the mental health professional. Lefley (1990) has further noted that an understanding of these differences could bring about more innovative and effective treatments that could benefit all persons with mental disorders.

Our study is an attempt to better understand these diverse ethnic interpretations of mental illness by the families of persons labeled

mentally ill. Improved understanding of these conceptualizations is important in increasing access to treatment, making interventions more appropriate, and sustaining the use of treatment by ethnic minorities. This improved understanding will also improve the diagnostic sophistication of mental health professionals. In determining which conceptual information to evaluate, we sought to examine four questions:

1. Are the ethnic differences in this study in primary caregivers' conceptions of their relatives' mental illness similar or different from that reported in other multi-ethnic studies?
2. Does the model used by European-Americans reflect the current medical model used in psychoeducation curricula?
3. Do differences in the understanding and labeling of mental illness among African-Americans and Hispanic-Americans reflect culturally based conceptions of mental illness and/or a rejection of the medical model of psychiatric disorder?
4. Do the conceptions of mental illness reported by Hispanic-Americans and African-Americans reflect a lack of communication by mental health professionals?

METHOD

The data reported in this paper come from a study of the role of families in caring for a mentally ill family member and the interaction of these families with mental health services. The data are from interviews with the primary caregivers of family members whose course of mental illness has been prolonged, and who have required significant functional and emotional support from their families over an extended period.

Sample

This study simultaneously analyzes interviews conducted with European-American, African-American, and Hispanic-American families. In this way we provide a more direct comparison of these ethnic groups than previous studies that have compared only African-Americans and European-Americans or Hispanic-Americans and European-Americans. We further expand the breadth of the research

in this area by analyzing the interviews with Hispanic-Americans of Caribbean (primarily Puerto Rican), rather than Mexican, descent.

The total sample for the study consisted of ninety families, of which twenty-nine were African-American, sixteen European-American, and forty-five Hispanic-American families. Among the Hispanic-American families, thirty families were Puerto Rican, six families were Cuban, and nine families were from Central and South America. Hispanic-Americans were further separated into those families in which Spanish was the primary language and those families in which English was the primary language. This resulted in four ethnic groupings:

1. Hispanic-Americans: Spanish-dominant (32 caregivers)
2. African-Americans (29 caregivers)
3. European-Americans (16 caregivers)
4. Hispanic-Americans: English-dominant (13 caregivers)

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 families were recruited through referrals by program staff and direct contacts with family programs at seven community mental health centers, one independent family group, and one state hospital in New Jersey. The overwhelming majority of these families had used only public mental health care services. Community mental health centers were the primary focus of family recruitment because they had significant contact with minority families and because they had made an active effort to establish family groups. In addition, ethical considerations required that we work through established agencies to legitimize our contact with families and to protect families' confidentiality. It is important to emphasize that this was an exploratory study and that the sample was an opportunistic one. In this report we highlight areas of commonality and large difference among the ethnic groups involved.

Table 1 shows the socio-demographic characteristics of the caretakers.

As shown in Table 1, the great majority of caregivers were female. Among African-Americans and European-Americans, mothers were the primary caregivers. Hispanic-American respondents included several spouses and children. Hispanic-Americans and European-

Table 1. Socio-demographic Characteristics of Caregiver Families with a Seriously Mentally Ill Member

<i>Socio-demographic Characteristics</i>	<i>Hispanic American</i>	<i>African American</i>	<i>European American</i>
Sex of Caregiver			
Female	80%	90%	81%
Male	20	10	19
Mean Age of Caregiver	48	54	55
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
N	45 (50%)	29 (32%)	16 (18%)

Americans came mostly from dual parent families and reported their religion as Catholic. Most Hispanic-Americans reported a family income of under \$20,000, whereas most African-Americans and European-Americans reported family incomes of above \$20,000.

Interview

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 overall objective of the interview was to determine how the family members responded to and coped with the patient's illness. The full interview lasted approximately one to one-and-one-

half hours and covered the family's experience with the mental health care system, conceptions of the problem, social support systems, and burdens experienced.

Interviews were tape-recorded, transcribed, and then coded for computer analysis. This provided a total of 163 quantitative measurements from the transcribed interviews. Seven specific questions were analyzed for this study. These deal with conceptions of mental illness, attitudes toward the mental health system, and hopes and desires for the family member. The interviews contain considerable narrative material which we will use to illustrate key points in this paper.

RESULTS

Ethnic differences in the interpretation of mental illness and attitudes toward the opinions of mental health professionals were found. Though specific patterns of response were varied, European-Americans most often expressed views that were closer to the medical model of mental illness and were different from the other ethnic groups in the study.

Conceptions of Mental Illness

Caregivers were asked what type of problem they felt their relative has now. Hispanic-Americans described their relative's current problem as "*Emotional*" (indicated by "nervousness or anxiety") twice as often as the other groups. African-Americans and European-Americans responded with a preference for the "*Medical*" (indicated by "mental failure or chemical imbalance") category, (Question #1).

Caregivers were also asked what they felt was the most important factor which contributed to their family member's problems (Question #2). Only European-Americans showed a clear preference for one of the nine factors listed as contributing to their family member's problems. They felt that "*Heredity or Family History*" was the most important factor, (Question #3).

Caregivers' Responses to Information from Professionals

When caregivers were asked the label given to their family member by mental health professionals, a clear distinction emerged. While

Table 2. Caregiver's Conceptions of Mental Illness by Ethnicity

<i>Questions Asked</i>	<i>Hispanic- American/ English (Percent)</i>	<i>Hispanic- American/ Spanish (Percent)</i>	<i>African- American (Percent)</i>	<i>European- American (Percent)</i>
Question 1: What kind of problem do you think _____ has now?				
Medical: mental failure, chemical imbalance	15	22	33	38
Emotional: nervousness, anxiety, "lives in another world"	46	38	24	23
Personality: selfish, aggressive	15	0	14	15
Social: interaction with others	8	9	14	8
Other	15	31	14	15
N = 79	13	32	21	13
Question 2: Do you think any of the following things might have contributed to _____'s problem? (percent yes)				
Heredity/Family History	46	47	42	69
Frightening/Traumatic Event	62	59	68	58
Alcohol	38	17	26	33
Drugs	31	7	37	42
Witchcraft, Sorcery, Possession	15	17	11	8
Personal Pressures/Stresses	92	59	47	91
Family Relations	58	45	26	54
Personal Relationships or Experiences	38	48	47	82
Friendships with the Wrong Kind of People	31	14	47	36
N = 71	12	29	19	11
Question 3: What do you think is the most important factor that contributed to your family member's problem?				
Heredity/Family History	15	12	5	46
Frightening/Traumatic Event	0	12	19	15
Alcohol	23	9	0	0
Drugs	8	0	10	8
Witchcraft, Sorcery, Possession	0	0	0	0
Personal Pressures or Stresses	15	9	5	0
Family Relations	15	16	10	8
Personal Relationships or Experiences	0	16	10	8
Friendships with the Wrong Kind of People	0	3	5	0
Don't Know	23	22	38	15
N = 80	13	32	21	13

Table 3. Information from Professionals and Caregivers Responses

<i>Questions Asked</i>	<i>Hispanic-American/English (Percent)</i>	<i>Hispanic-American/Spanish (Percent)</i>	<i>African-American (Percent)</i>	<i>European-American (Percent)</i>
Question 4: What do the mental health professionals call the problem?				
Schizophrenia	38	31	48	69
Bipolar Disorder	0	6	8	8
Depression/Anxiety	15	3	8	0
General Emotional	8	22	4	8
Mental Retardation	8	0	0	0
General Medical	0	0	12	0
Other/Don't Know	31	37	20	15
N = 83	13	32	25	13
Question 5: Do you think they are right?				
YES	40	38	32	73
NO	10	14	32	0
Diagnosis Unknown	50	48	37	27
N = 61	10	21	19	11
Question 6: Do you think it will ever be cured?				
NO	38	30	40	77
YES	62	70	60	23
N = 74	13	30	18	13

"Schizophrenia" was the most common response given by all caregivers, a strong majority of European-Americans proffered this label of mental illness. Hispanic-Americans speaking English offered the medicalized label of *"Depression/Anxiety"*, while Hispanic-Americans speaking Spanish responded with *"General Emotional"* and African-Americans responded with *"General Medical"*. It is very important to notice the high percentage of people—one in three Hispanic-Americans and one in five African-Americans—who could not provide the diagnosis of their family member, (Question #4).

Families were then asked if they agreed with the professionals' label. No European-Americans disagreed. Hispanic-Americans as a group were mostly split between agreement with and lack of knowledge about the diagnosis. African-Americans were split

between agreement, disagreement, and no knowledge of the diagnosis (Question #5).

The most dramatic difference of response came when the caregivers were asked if they felt their family members' illness would ever be cured. African-Americans and Hispanic-Americans felt that there could someday be a cure, European-Americans overwhelmingly felt that a cure would not be found (Question #6).

Families' Preferences for Residence

Finally, an interesting difference emerged when caregivers were asked if they would prefer their family member to live someplace other than in the caregiver's home (Question #7).

The majority of European-American family members already lived away from the family. Only a small percentage of the remaining European-American families preferred that their family member live at home. Only a small percentage of Spanish-dominant mentally ill individuals lived outside their families' homes. This finding reflected both families' preferences and the lack of residential programs for Spanish-dominant individuals. As a group, the African-American and Hispanic-American families whose relative was still living with them, did not want their ill family member living somewhere other than the family home.

Table 4. Caregiver's Preference for Where Their Family Member Should Live

<i>Questions Asked</i>	<i>Hispanic-American/English (Percent)</i>	<i>Hispanic-American/Spanish (Percent)</i>	<i>African-American (Percent)</i>	<i>European-American (Percent)</i>
Question 7: If it were possible, would you prefer that _____ live somewhere else?				
NO	54	52	50	8
YES	8	28	15	25
Patient Currently Lives Apart	38	17	35	67
Other/Don't Know	0	3	0	0
N = 64	13	29	20	12

Overall, the ethnic differences found, broke into two groups: African-Americans and Hispanic-Americans in one group, European-Americans in the other. These differences are consistent with previous research.

DISCUSSION

Ethnic differences, shaped by culture, language, and religiosity, were found. This confirmation of culturally-mediated interpretations of mental illness is particularly demonstrated by the following comparison in the data: although socioeconomic indicators showed that Hispanic-American and African-American caregivers were most dissimilar, their conceptions of mental illness were most similar when compared to European-Americans. These differences point to at least two explanations.

First, Hispanic-Americans and African-Americans only partially accept some of what they are being told by mental health professionals. One reason for this partial acceptance seems to be that the medical model does not coincide with strongly held religious beliefs. Secondly, there is evidence that mental health professionals are not communicating well to Hispanic-Americans and African-Americans. Our results indicate that they are receiving neither specific information about their own family members, nor current information about mental illness based on the medical model of psychoeducation. We will discuss these differences and suggest a more culturally integrative approach to the psychoeducation of families that could be of benefit to all caregivers of persons with mental disorders.

In this study European-Americans demonstrated strong agreement, in general, with the mental health professionals who provided services to their ill family member. They were most aware of their family member's diagnosis and knew it to be schizophrenia. They also saw heredity—a biological source of the illness—as a strong factor in the etiology of their family member's mental illness. All of these views are consonant with the medical model of psychoeducation.

Pinderhughes (1982) has noted that African-Americans have learned to cope with all adversity (including mental illness) in contradistinction to established authority. It is therefore not surprising that they most often disagreed with their mental health

professionals. Often they did not even know their relative's diagnosis. When asked for it, they were the only group to provide a "*General Medical*" descriptor as a professional diagnosis. This is consistent with the findings of Hall and Tucker (1985), who suggest that mental illness carries a greater stigma among African-Americans than physical illness.

Stigma may also be part of what differentiated the responses of Hispanic-Americans from other ethnic groups. They responded more frequently with emotional rather than medical attributions for their relatives' problems. In part, this response pattern may be because their relatives have more affective disorders. It may also be that they are motivated to give this emotional categorization because it carries less of a stigma (Guarnaccia et al. 1992), and because the category of *nervios* ("nerves") is a part of their cultural experience and vernacular (Guarnaccia 1993; Jenkins 1988). Although the results were not as dramatic as in the study conducted by Edgerton and Karno (1971), English-dominant Hispanic-Americans did offer more medicalized diagnoses while Spanish-dominant Hispanics proffered more general responses. As with African-Americans, many Hispanic-Americans did not know their relative's diagnosis.

One reason why European-Americans were more likely to respond in ways consistent with the medical model of mental illness may be because of the increased availability of psychoeducation programs in recent years. These programs have encouraged a greater sense of inclusion in the process of caring for one's ill family member. As one European-American mother recognized, the problems of a diagnosis become intertwined with the bureaucratic requirements for providing service:

The necessity of putting a label on it is for all kinds of reasons. Services from the mental health field and the government all require labels. I understand that, but it's too bad that it has to be a label that has such a negative connotation as schizophrenia does.

The National Alliance for the Mentally Ill (NAMI) has been a leader in organizing and promoting education and empowerment groups for family members of persons labeled mentally ill. Since 1979, NAMI has grown from some 284 members to over 80,000 (McLean 1990). The present membership of NAMI is primarily European-American and middle-class families (McLean 1990). The significant

growth of this organization is one factor in the shift in the understanding of mental illness by European-Americans to a more medical model. Recently NAMI has made significant efforts to recruit minorities and has established a Multicultural Concerns Network.

For now, while there may have been a shift among European-Americans, which leads them to greater involvement with the mental health system, ethnic minorities are not as likely to view mental illness from the perspective of the medical model nor are they as ready to involve their relatives with mental health services. Rivera (1988) has pointed out that although many features of psychoeducation may fit with Hispanic families' responses to a mentally ill family member, little work exists on how to adapt psychoeducation for Hispanic families. This adaptation is important because Hispanic-Americans use alternative explanatory models of mental illness from the model most often presented in standard psychoeducational programs. As one mother noted, people in her community encouraged her to seek alternative sources of help for her mentally ill son. When asked if she had sought help for her son from healers in the community she said:

No creo en eso, pero lo llevé una vez para probar porque la gente siempre me dice que tal vez es un trabajo que le han hecho. [I don't believe in this, but one time I took him to try the healers because people are always telling me that his illness may be the result of a spell someone put on him.]

Families often try multiple treatments based on competing hypotheses about the source of the illness. Given the difficulties of coping with serious mental illness, families often will "leave no stone unturned." Other families have strong alternative views of the sources of mental illness and religious healers are their preferred source of treatment. A husband commented:

Bueno, como nosotros somos Pentecostales, nosotros pensamos que era un ataque del Diablo-Satanas.... Yo confío en Dios en que ella un día pueda recuperar totalmente. [Well, since we are Pentecostals, we believe that it is an attack of the Devil—of Satan.... I have complete faith in God that one day she will completely recover.]

African-Americans also share ideas of demonic possession as a source of mental illness. One mother commented:

I feel like she is Demon possessed That means that you get to disliking people so much, you have so much hatred built up until the Devil comes in and takes over and you start doing strange things and acting strange and liking the things of the world so much.

In response to a follow-up question about whether she consulted her pastor about her concerns about demon possession, this same mother responded:

The Lord showed it to me through prayer and knowledge he revealed it to me. From praying and reading the Bible you could see. Years ago you didn't have all these institutions. I remember when I was a little girl we had one insane asylum and that's where they sent people to and it was far away. Now you have mental institutions all around. This is telling me that it is something going on other than mental. I believe her demon possession is getting better because she doesn't argue and she tries to control herself.

In addition to the cultural differences mentioned earlier, there are clear communication barriers between mental health professionals and minority caregivers. Some Hispanic-American and African-American caregivers pointed out that they were never directly spoken to by mental health professionals. This is reflected in their lack of knowledge of their family member's diagnosis. Several Hispanic families expressed the need for mental health professionals who are able to communicate with them in Spanish. When asked what services were needed for his ill relative, one brother said:

Personal hispano y un servicio de mantener a los familiares informados . . . que a veces hay una secretaria o personas que hacen limpieza. Como hasta nosotros mismos estamos dispuestos a dar dinero para que nos informen. Porque ahora mismo nosotros podemos decir lo que nosotros creemos pero en si no estamos bien conscientes de lo que está sucediendo y por eso tambien no tenemos esa seguridad de que esto es lo mejor o en esto está fallando. [Hispanic personnel and a service to keep families informed . . . at times there is a secretary or cleaning staff who speak Spanish. We are even willing to pay so that they will spend time with us to inform us. We are willing to share what we think but we are not really aware of what is happening, and for this reason, we are not sure if the services are the best for him or if there are things that are not working.]

This lack of information leaves the family with a deep sense of vulnerability to which mental health professionals need to be sensitive. As one daughter said when asked if she was satisfied with the services her mother received:

Yo quisiera que alguien me dejara saber como ven a mi mamá, que opinan de la recuperación de mi mamá, si ellos creen que mi mamá algún día va a volver a descontrolarse, a volver a ser internada. Bueno, son cosas que a mi me gustaría saber. [I would like someone to let me know how my mother is doing, what they think about the possibility of her recovery, if they believe that one day my mother will lose control again and have to be hospitalized. These are things I would like to know.]

As one mother said succinctly:

Sería mejor si hubiera más información. [It would be better if there were more information.]

This experience of lack of information is in contrast to one European-American mother who talked about how her being an activist mother resulted in a different response from mental health professionals:

The services from beginning to end have been good, but I wonder if it's because I'm standing right at the door waiting for the answers. I don't think they would have done the same thing if there wasn't a concerned parent. I don't think others get someone to come and push for them. I give. I sit on the board of directors of the mental health clinic.

This type of activism requires time, resources, an ability to be demanding of professionals, and open communication lines with professionals; these features are often lacking in the lives of minority families and in their interactions with professionals. For Hispanic families, language barriers further complicate these issues.

For African-Americans, the sense of having little interaction with many professionals is very frustrating. Even though there is not a language barrier, Jones (1991) has noted that a pervasive if subtle racism may also lead to a lack of communication by professionals. As one African-American caregiver said about a family-group therapy session:

It seemed like they just listened to the white people. I don't mean to sound prejudiced, but they didn't want to hear what the black person had to put into the conversation. They must have thought we were ignorant.

Finally, for many Hispanic-Americans and African-Americans the models of mental illness of the mental health professionals did not

agree with minority families' cultural views. This was demonstrated most strongly when asked if they felt the illness could ever be cured. For some this became a religious question. For one Hispanic-American mother, God is the ultimate source for a cure:

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

For the sister of another person, the power of God to heal was central. Yet she also struggled with what for her was the uncomfortable need to use medications:

Porque esas cosas las cura Dios. Esas cosas ni se pueden ir a los brujos esos porque eso lo que hace es que lo enferman más, ni se puede ir, y un doctor te da mucha pastilla y lo que te pone es más, como. Esas son unas drogas que con el tiempo dejan la persona, que yo no creo que quede muy bien la persona. Uno debe tener una fé muy grande en Dios para...Entonces yo no sé, yo tengo las medicinas, pero tu debes de buscar a Dios para que te mejores. Yo le dije que uno tiene que primero, nosotros tenemos un doctor invisible, que no lo vemos, verdad. Que es Dios. [Because these things God cures. You can't take these things to the 'witches' because they just make you sicker, and you can't go to doctors because they give you a lot of pills which make you worse. These medicines harm a person over time; they don't leave the person well. One needs to have great faith in God ~~to get better. I don't know~~, I have medicines, but one has to look to God to get well. I say that first we have an invisible doctor that we don't see. And that is God.]

Correction:

so that ... well. I don't know

An African-American mother was able to integrate her belief in God with her confidence in mental health professionals:

I know prayer is very strong, but you need counseling on the outside also. That's why God has these men down here to help you.

Religious belief was also important for some European-Americans as a way to cope with the strains of having a mentally ill family member. One mother expressed that prayer was a comfort for her—but not a way to cure her son:

I think the best thing I can have is prayer. I would be lost without my religion.

For many religious persons, the belief in the possibility of a cure is an expression of their belief in the healing power of God. This runs

counter to a fundamental conceptualization within the medical model: mental illness is a lifelong disease of the brain and does not have a cure. If not recognized, such conceptual differences may put caregivers and mental health professionals in conflict. It should further be noted that the information which states that serious mental illness is a life-long illness may be misleading. There is evidence from longitudinal studies (Bleuler 1978; Harding, Brooks, Ashikaga, Strauss, and Breier 1987) that many persons who were at one time diagnosed with schizophrenia do not remain debilitated throughout their lives, and that some recover completely. Nevertheless, all of the subjects in our study had prolonged difficulty with mental illness.

Another example of a way that the biologically-based medical model of mental illness might not be complete is exemplified by McFarlane (1990). He has demonstrated the efficacy of multiple-family treatment groups among European-Americans. McFarlane seeks to empower these families and to encourage them to work within and among themselves to ameliorate the effects of mental illness on their family members as well as themselves. An important and salient factor in this treatment is that the families seem to become interdependent, therapeutic communities.

Some of the goals which McFarlane has for his treatment groups are in fact already present within the cultural values and experience of the ethnic minority families we studied. This is shown in the commitment to family which is consistently present within Hispanic-American (Edgerton and Karno 1971) and African-American (Boyd-Franklin 1989) families. It is further demonstrated in our results by the reluctance of the Hispanic-American and African-American caregivers to have their family member live outside the home. Also, McFarlane's descriptions of the development of an interrelated group are very similar to what has been described as characteristic of the African-American community (Pinderhughes 1982; Jones 1991).

Therefore, the goal of the mental health professional should be not only to teach the medical model to African-Americans and Hispanic-Americans, but also to incorporate into the treatment model their confidence in the importance of the family and giving mutual support. Mental health professionals need to develop a culturally-integrative approach to working with families which both respects their salient cultural conceptions of mental illness at the same time as it provides additional treatment information. It is also important that Spanish-speaking mental health professionals be

made available for the many Hispanic clients who speak little or no English. These families, too, wish to be active participants in their family members' care.

Finally, this study has shown the importance of religion to the family caregivers of persons with mental illness. When using the medical model of psychoeducation, mental health professionals must be sensitive to the religious beliefs of persons for whom faith in the possibility of a cure is religious faith. The importance of understanding religious views has become increasingly important with the publication of DSM-IV (American Psychiatric Association 1994). In this edition, there is a code for Religious or Spiritual Problem (V62.89) which recognizes that some personal religious difficulties should not be viewed as psychiatric disorder (Lukoff, Lu, and Turner 1992; Larson, Thielman, Greenwold, Lyons, Post, Sherrill, Wood, and Larson 1993). The challenge to the clinician is to have sufficient cultural knowledge to make this distinction.

Our investigation of differing ethno-specific interpretations of mental illness by family members of persons labeled mentally ill should directly influence later research looking at the development of treatment interventions. An understanding of these differentiated beliefs are important because psychoeducation, in order to be effective, must integrate a family caregiver's own cultural knowledge as well as provide them with new information. Also, there may be some aspect of this knowledge which, although different from the medical model, may be helpful to the family member labeled mentally ill and their family. As Lefley (1990) has noted, we may in fact find that a multicultural view can improve the effectiveness of treatment and psychoeducation for all consumers.

ACKNOWLEDGMENTS

The research reported in this paper was supported by a grant from the Robert Wood Johnson Foundation (#13180) and the Center for Research on the Organization and Financing of Care to the Severely Mentally Ill at the Institute for Health, Health Care Policy, and Aging Research, Rutgers University. The center is funded by the National Institute of Mental Health (MH43450-04).

REFERENCES

- American Psychiatric Association. 1994. *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., revised). Washington, DC: American Psychiatric Association.
- Bleuler, M. 1978. *The Schizophrenic Disorders: Long-term Patient and Family Studies*, translated by S.M. Clemens. New Haven: Yale University Press.
- Boyd-Franklin, N. 1989. *Black Families in Therapy: A Multisystems Approach*. New York: The Guilford Press.
- California Alliance for the Mentally Ill. 1989. *Families Know*. Sacramento: California Department of Mental Health.
- Edgerton, R. and M. Karno. 1971. "Mexican-American Bilingualism and the Perception of Mental Illness." *Archives of General Psychiatry* 224: 286-290.
- Estroff, S.E. 1989. "Self, Identity, and Subjective Experiences of Schizophrenia: In Search of the Subject." *Schizophrenia Bulletin* 15: 189-196.
- Fabrega, H. 1989. "The Self and Schizophrenia: A Cultural Perspective." *Schizophrenia Bulletin* 15: 277-290.
- Falloon, I.R.H., J. Boyd, and C. McGill. 1984. *Family Care of Schizophrenia*. New York: Guilford.
- Fischer, E.H. and J.L. Turner. 1970. "Orientations to Seeking Professional Help: Development and Research Utility of an Attitude Scale." *Journal of Consulting and Clinical Psychology* 35: 79-90.
- Goldman, H. H. 1982. "Mental Illness and Family Burden: A Public Health Perspective." *Hospital and Community Psychiatry* 33: 557-560.
- Grunebaum, H. and H. Friedman. 1988. "Building Collaborative Relationships with Families of the Mentally Ill." *Hospital and Community Psychiatry* 39 (11): 1183-1187.
- Guarnaccia, P.J. 1993. "Ataques de nervios in Puerto Rico: Culture-bound Syndrome or Popular Illness?" *Medical Anthropology* 15: 157-170.
- Guarnaccia, P.J., P. Parra, A. Deschamps, G. Milstein, and N. Argiles. 1992. "Si Dios quiere: Hispanic Families' Experiences of Caring for a Seriously Mentally Ill Family Member." *Culture, Medicine and Psychiatry* 16 (2): 187-216.
- Halford, W.K. and R. Hayes. 1991. "Psychological Rehabilitation of Chronic Schizophrenic Patients: Recent Findings on Social Skills Training and Family Psychoeducation." *Clinical Psychology Review* 11 (1): 23-44.
- Hall, L. and C. Tucker. 1985. "Relationships Between Ethnicity, Conceptions of Mental Illness, and Attitudes Associated with Seeking Psychological Help." *Psychological Reports* 57: 907-916.
- Harding, C.M., G.W. Brooks, T. Ashikaga, J.S. Strauss, and A. Breier. 1987 "The Vermont Longitudinal Study of Persons with Severe Mental Illness: II. Long-term Outcome of Subjects who Retrospectively met DSM-III Criteria for Schizophrenia." *American Journal of Psychiatry* 144 (6): 727-735.
- Hatfield, A.B. 1988. "Issues in Psychoeducation for Families of the Mentally Ill." *International Journal of Mental Health* 17 (1): 46-64.

- Hunter, D.E., J.B. Ferholt, and R.J. Hoffnung. 1991. "Back to the Future: In Search of Psychodynamic Family Therapies in the Treatment of Families of Individuals with Prolonged Mental Illness." *Journal of Family Psychotherapy* 2 (3): 81-96.
- Jenkins, J. 1988. "Conceptions of Schizophrenia as a Problem of Nerves: A Cross-cultural Comparison of Mexican-Americans and Anglo-Americans." *Social Science and Medicine* 26: 1233-1243.
- _____. 1991. "Anthropology, Expressed Emotion and Schizophrenia." *Ethos* 19 (4): 387-431.
- Jones, J.M. 1991. "The Politics of Personality: Being Black in America." In *Black Psychology* (3rd edition), edited by R.L. Jones. Berkeley, California: Cobb and Henry.
- Larson, D.B., S.B. Thielman, M.A. Greenwold, J.S. Lyons, S.G. Post, K.A. Sherrill, G.G. Wood, and S.S. Larson. 1993. "Religious Content in the DSM-III-R Glossary of Technical Terms." *American Journal of Psychiatry* 150 (12): 1884-1885.
- Lefley, H. 1990. "Culture and Chronic Mental Illness." *Hospital and Community Psychiatry* 41: 277-286.
- Lukoff, D., F. Lu, and R. Turner. 1992. "Toward a More Culturally Sensitive DSM-IV: Psycho-religious and Psycho-spiritual Problems." *Journal of Nervous and Mental Disease* 180: 673-682.
- Malgady, R., L.H. Rogler, and G. Constantino. 1987. "Ethnocultural and Linguistic Bias in Mental Health Evaluation of Hispanics." *American Psychologist* 42: 228-234.
- McFarlane, W. 1990. "Multiple Family Groups and the Treatment of Schizophrenia." Pp. 167-189 in *Handbook of Schizophrenia* (volume 4) *Psychosocial Treatment of Schizophrenia*, edited by M.I. Herz, S.J. Keith and J.P. Docherty. New York: Elsevier Science Publishers B V Biomedical Division.
- McLean, A. 1990. "Contradictions in the Social Production of Clinical Knowledge: The Case of Schizophrenia." *Social Science and Medicine* 30 (9): 969-985.
- Nunnally, J.C. 1960. *Popular Conceptions of Mental Health: Their Development and Change*. New York: Holt, Rinehart and Winston.
- Pinderhughes, E. 1982. "Afro-American Families and the Victim System." In *Ethnicity and Family Therapy*, edited by M. McGoldrick, J.K. Pearce, and J. Giordano Eds. New York: The Guilford Press.
- Pratt, C.W. and K.J. Gill. 1990. "Sharing Research Knowledge to Empower People who are Chronically Mentally Ill." *Psychosocial Rehabilitation Journal* 13 (3): 75-79.
- Rivera, C.R. 1988. "Culturally Sensitive Aftercare Services for the Chronically Mentally Ill Hispanics: The Case of the Psychoeducational Treatment Model." *Research Bulletin of the Hispanic Research Center* 11 (1). New York: Fordham University.
- Rosenfield, S. 1984. "Race Differences in Involuntary Hospitalization: Psychiatric Versus Labeling Perspectives." *Journal of Health and Social Behavior* 25: 14-23.

- Sue, S., D.C. Fujino, L. Hu, D.T. Takeuchi, and N.W.S. Zane. 1991. "Community Mental Health Services for Ethnic Minority Groups: A Test of the Cultural Responsiveness Hypothesis." *Journal of Consulting and Clinical Psychology* 59 (4): 533-540.
- Taylor, E.H. 1987. "The Biological Basis of Schizophrenia." *Social Work* 32 (2): 115-121.
- Terkelsen, K. 1987. "The Meaning of Mental Illness to the Family." Pp. 151-166 in *Families of the Mentally Ill: Coping and Adaptation*, edited by A.B. Hatfield and H.P. Lefley. New York: The Guilford Press.
- Torrey, E.F. 1983. *Surviving Schizophrenia: A Family Manual*. New York: Harper and Row.
- Wakefield, J.C. 1992. "The Concept of Mental Disorder." *American Psychologist* 47 (3): 373-388.
- Yarrow, M., C.G. Schwartz, H.S. Murphy, and L.C. Deasy. 1955. "The Psychological Meaning of Mental Illness in the Family." *Journal of Social Issues* 11: 971-978.