

15. Transcultural epilepsy services

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This paper describes one of the earliest adaptations of the RAP guidelines, their use for determining the cultural values that influence the perception of health and reactions to epilepsy among different ethnic groups in the United States. The study made evident the need for both services and education campaigns for persons with epilepsy to address the issues specific to ethnic and underserved groups. - Eds.

INCREASING NUMBERS OF anthropological studies of various ethnic groups in the United States show that cultural identification and values are retained for many generations and play a significant role in the individual's behaviour in relation to health and illness. Ethnic and cultural values are known to influence people in their perceptions of health, reactions to illness, levels of information about and trust in treatment sources, and attitudes toward health care and social service providers. Four studies report estimates of the incidence and prevalence of epilepsy among whites and non-whites in the United States. Each study reveals an increased rate among blacks compared with the white population, consistent across males and females [1-3]. Hauser [3] found the prevalence of epilepsy in the United States to be 6 to 7 per 1,000 for whites, 9 to 10 per 1,000 for Hispanics, and 10 to 12 per 1,000 for blacks; with the risk of seizures during a lifetime at 10% for whites and 25% for blacks (no figures are available for Hispanics). Hauser observes however, that whether this difference is real or whether it is due to such factors as increased risk of head injury or poorer perinatal care in lower socio-economic status populations, it remains an unanswered question.

In recognition of these concerns, the Epilepsy Foundation of America's National Board of Directors called for a national transcultural programme initiative, which culminated in the launching of a national transcultural demonstration project in 1986 targeting American Black, Haitian, and Hispanic communities in Dade County, Florida, an ethnically and culturally diverse area of the country.

The transcultural epilepsy demonstration project

Implemented in collaboration with the Epilepsy Foundation of South Florida and the University of California at Los Angeles, the project had as its goal to develop a better understanding of epilepsy among ethnic and culturally diverse groups, to find more effective ways to reach these groups, and to make services and epilepsy education more accessible and relevant. The first phase of the project consisted of an ethnographic field study among American Black, Haitian, and Cuban communities in Dade County, Florida, designed to elicit answers to the following questions: (a) How do individuals and families in these groups recognize epilepsy and what do

they consider to be its nature and treatment? (b) Who are the key figures who influence individual and family health care practices? (c) What are some of the special needs of individuals with epilepsy and their families in these communities? (d) What are some of the unique strengths and resources of these groups, and how can they be marshalled to address the needs of people with epilepsy?

An ethnographic survey tool Rapid Assessment Procedures (RAP) [4] originally developed by Dr. Susan Scrimshaw of the School of Public Health, UCLA, and Elena Hurtado, was adapted specifically for this project by Dr. Scrimshaw and Anna Long, a doctoral student at UCLA, resulting in the "Epilepsy Rapid Assessment Procedure (ERAP): Rapid Assessment Procedure for the Evaluation of Epilepsy Specific Beliefs, Attitudes and Behaviors" [5].

Interviewers from the communities who were culturally congruent with the three target populations were selected for training about epilepsy and anthropological field survey techniques using a specially developed field guide and training manual.

A total of 81 individuals, comprising four types of households in the three communities, were interviewed. Types of households included those from the general population and the target families, the latter consisting of households in which at least one individual had either exhibited seizure symptoms or had been diagnosed as having epilepsy. These target families comprised those with family members with epilepsy in the general health care system, those with family members with epilepsy currently not in the health care system, and those with epilepsy using the Cuban clinical health care system.

General findings

Seizure recognition is the first step in seeking treatment for epilepsy. We found seizure recognition to be a major problem, not only in the Cuban, Black and Haitian communities in general, but also in epilepsy target households in these communities. The data indicate that concepts and indicators used in determining health and illness, general perceptions of common illnesses in adults and children, and perceptions of epilepsy are important factors contributing to lack of recognition, particularly of non-convulsive seizure types.

Among Black, Cuban, and Haitian study participants, general perceptions of health and illness were clearly associated with seizure recognition. In all groups, health was defined as a state of emotional and physical wellbeing, with indicators such as good appearance, good mood and social behaviour, and normal functioning. On the other hand, informants used indicators such as inability to function normally, poor appearance, and the presence of symptoms to determine when an individual was ill. Tonic clonic seizures, by virtue of their obvious symptoms, were usually recognized as "epilepsy" and were generally considered chronic conditions to be dealt with by a physician.

Non-convulsive seizure types, such as complex partial and absence seizures, were usually not recognized as epilepsy. Often these conditions were considered temporary emotional upset or inattentiveness rather than seizures. Lower levels of recognition of these seizure types are due in

part to the lack of dramatic symptomology and the ability of the individual with these seizures to function normally in the absence of seizures.

When examining informants' perceptions of common illnesses, informants in all three ethnic groups named less serious acute illnesses for children, and more serious, chronic conditions for adults. The perception that children's common illnesses are acute and less serious may contribute to lack of recognition of absence and complex partial seizures in children. Among Cuban informants, "nervous conditions" were named as adult common illnesses. The symptoms described by Cuban informants included many that were consistent with complex partial seizure symptoms, suggesting a high probability that complex partial seizures are often labelled as "nervous conditions" among some Cubans.

Complex partial seizures, because of low levels of recognition among all three groups, are an important case for discussion in this context. Complex partial seizures were least frequently recognized as epilepsy by all three ethnic groups. Absence seizures were also difficult to recognize by all families. Consequently, they were often defined and treated in culturally specific manners. Haitian general population informants only recognized tonic clonic seizure symptoms as a form of epilepsy. Complex partial seizure symptoms in this group were believed to be caused by emotional and mental disorders. Among Cubans, complex partial seizure symptoms were labelled "nervous conditions" or emotional problems. Among Black informants, these symptoms were labelled nervous breakdowns, emotional stress, and insanity.

The problem of seizure recognition in these communities requires extensive health education efforts campaigns. The design and approach taken in the implementation of health education in these communities will be the major factor in determining their success. First, health education materials focusing on recognition must present images of seizure symptoms that closely correspond to their actual appearance. Seizure recognition will increase by first drawing attention to these symptoms and then alerting individuals to the fact that these may be symptoms of epilepsy.

Second, any educational health campaign materials must utilize culturally-specific labels for the various seizure disorders in order to facilitate recognition. For example, "spells," "attacks," "mal cadie," "fits," "crises," "nervous conditions," and "ataques" or "convulsiones" among Hispanics are common labels in these communities for symptoms consistent with various seizure types. In order to facilitate seizure recognition, materials must utilize culturally-specific names for seizure symptoms, thereby linking the culturally recognized condition to "epilepsy." Finally, educational materials must present images of the community members themselves. The need to utilize locally-recognized figures in depicting information in culturally appropriate manners cannot be over-emphasized. In the Haitian community, for example, epilepsy is a severely stigmatized condition. Health education materials with "EPILEPSY" printed boldly across the top will most likely be received poorly.

Utilization of epilepsy specific health services

Examination of perceptions of appropriate treatment for common illnesses and seizure symptoms

among Cuban, Black, and Haitian informants indicated that illness was also treated in culturally appropriate modes. Black informants tended to seek biomedical modes of treatment more frequently than Cuban and Haitian informants. Among both Cubans and Haitians, utilization of biomedical modes of treatment was often associated with the degree of acculturation.

Black informants utilized biomedical approaches in the treatment of common illnesses more exclusively than did Cuban and Haitian informants. The illnesses of children were most often treated with over-the-counter medication, consultation with physicians, and prescribed medications. Adult illnesses were generally treated by physicians with prescribed medications. Cubans and Haitians, on the other hand, used a combination of biomedical modes of treatment and culturally specific home remedies to treat the illnesses of adults and children. This has important implications for the manner in which epilepsy is perceived and treated in these communities.

The degree to which informants in epilepsy target households relied on biomedical approaches to the treatment of epilepsy was related to three main factors: (1) seizure recognition; (2) whether or not the aetiology of the condition was known; and (3) the degree of seizure control achieved under medication.

As previously discussed, when seizures were not recognized as epilepsy, they were treated in culturally relevant manners, based on perceptions of the symptoms. In some cases, informants with epilepsy, while seeking treatment in the biomedical system for tonic clonic seizures, also sought care from mental health practitioners, spiritualists, and herbalists for symptoms of non-convulsive seizure disorders.

In cases where a specific cause for seizures could not be identified, epilepsy target informants more often utilized alternative sources of care. Among Haitian informants this was a frequent observation, with some families citing spiritual causation as the probable aetiology of the condition. Reliance on culturally appropriate explanations for symptoms in the absence of a medically identified aetiology was also common among Black and Cuban informants. Among Cubans, seizures were sometimes attributed to nervous and emotional problems, and occasionally to periodic spirit possession. Among Black informants, idiopathic non-convulsive seizures were attributed to stress and mental disorders. These patterns of beliefs were important in the choices of alternative care.

When non-medical sources and other support systems of treatment were sought, these included Blacks utilizing mental health professionals and occasionally, ministers and priests. Cubans and Haitians, on the other hand, used spiritual practitioners (santeros, voodooists) and a variety of traditional practitioners, such as homeopaths and herbalists in the treatment of *idiopathic*, poorly controlled seizure disorders. In addition, some Cuban informants had consulted mental health professionals for the treatment of nervous conditions and complex partial seizures.

When epilepsy had been diagnosed and treated in the medical system, poor seizure control, in spite of maintaining medication therapy was frequently associated with the use of alternative sources of care. Utilization of spiritual practitioners and herbal remedies among Cubans and Haitians, and mental health practitioners among Cubans and Blacks, were common in cases of

poorly controlled seizures. The logical deduction was that, if the medication did not work, then perhaps the condition was not entirely medical in nature.

All individuals with epilepsy in target families knew that medication worked on the brain, but did not know how. Most of the individuals took medication but showed consistent irregularity in complying with treatment. For example, they took medication only at the first sign of a seizure, whereas others took twice as much medication after forgetting a dosage.

Among Black and Cuban informants, non-convulsive seizures, poor seizure control, and levels of disruptiveness of the symptoms were associated with cessation of using epilepsy-specific health services. Among Haitian informants, documentation status was an additional factor in service utilization. While the group of informants studied did not include Cubans of undocumented immigration status, it is likely that a similar problem exists in the Cuban community.

The factors associated with use of services in the three communities examined have important implications for early intervention in the primary stages of treatment. First, health professionals need to be aware of alternate explanations for seizure symptoms in these communities. In providing services to individuals with idiopathic seizures (*seizures of unknown origin*), it is possible that beliefs regarding emotional, mental and spiritual causation will be strong. Understanding these beliefs, and the culturally appropriate modes of treatment often sought, may facilitate more open communication between the individual with epilepsy and those providing medical care.

Second, physicians, especially, should be aware of the potential for dropout when seizure control is not easily achieved with medication. The need to change medications or adjust dosages should be discussed thoroughly with the individual and his or her family shortly following diagnosis. Medication, while not generally perceived as a cure for epilepsy among those interviewed, was often viewed as an immediate control measure for seizures. It is important that individuals with epilepsy understand that the first medication prescribed may not completely control their seizures, but that other medications are available. By discussing the individual's perceptions of medication and his or her frustration with continued seizures while on medication, health professionals maintain open lines of communication, thereby reducing the probability of dropout.

Psychosocial concerns

The manner in which epilepsy is perceived is an important factor in the psychosocial adjustment of individuals with seizure disorders. When family, friends, and acquaintances relate with acceptance and understanding to the individual with epilepsy, good adjustment to the medical aspects of epilepsy is facilitated. On the other hand, when the individual is ostracized and feared, epilepsy can easily become a major psychosocial complication in the person's life.

In the Haitian community the stigma associated with epilepsy often resulted in severe isolation and ridicule. Epilepsy was indeed a "hidden condition" in the Haitian community and was not openly discussed among community members. Individuals with epilepsy were maligned and feared. Consequently, they did not disclose their condition to others and avoided contact with all but their closest friends and relatives. Much of the stigma associated with epilepsy in this

community was related to beliefs regarding spiritual causation. Beliefs that epilepsy was contagious also contributed to the isolation individuals experienced. However, even when informants believed that their condition was medical in nature, epilepsy was not generally discussed outside of the household. The hidden nature of the condition contributed to the perpetuation of the stigma within the community.

While the stigma of epilepsy was not as severe among Cuban and Black informants, there were distinct perceptions of epilepsy that impacted the manner in which individuals with the condition were treated within these communities. The majority of Black and Cuban informants with epilepsy stated that they were treated differently by the general community and often by family and friends. Among family members, overprotection and restriction of activities were the major problems cited. Among the general community, informants cited job discrimination and isolation as the major problems associated with their condition.

In all three ethnic groups, stigma was based on fear. Among Haitians, fear was associated with contracting the illness or being exposed to the seizure itself. (It is important to recall that only tonic clonic seizures were recognized as epilepsy among the Haitian general population informants.) Among Cubans and Blacks, fear was associated with witnessing a seizure. Informants with epilepsy stated that people were afraid primarily because they would not know what to do in the event of a seizure. Individuals with epilepsy were often viewed as less capable intellectually and socially.

The stigma associated with epilepsy in these communities can be combatted on several levels. First, public education is greatly needed in these communities, not only to facilitate seizure recognition, but also to provide information on first aid practices to reduce the fear associated with witnessing a seizure. Second, education and outreach for individuals with epilepsy and their families is needed to facilitate recognition of non-convulsive seizures, assist families in coping with frustration regarding poor seizure control, and reduce the likelihood of persons leaving the medical system.

Educational campaign

Once the critical information needs of the target populations were identified through the use of the ERAP, the Epilepsy Foundation of America designed a public education campaign that included the development of culturally relevant educational materials and a media campaign with public service announcements on radio and television. Primary goals of the campaign included outreach and epilepsy education of individuals, families, and the general public from these ethnic groups, and increased awareness by affiliates and other health care professionals of the unique strengths, resources, and needs of the communities.

The materials developed as a result of the transcultural study Epilepsy Demonstration Project have been produced in both English and in Spanish and include television and radio public service announcements, radio announcements, posters on recognition, medical advances and first aid, press kits with newspaper ads and special articles for the press. It also includes a set of five of the most frequently requested brochures on epilepsy and on living with epilepsy.

Principles followed in the development and production of the campaign materials were those elicited from the ethnographic study through the use of the ERAP. These included using terms and idioms familiar to the communities as occasional synonyms for seizures; approaching folk or religious beliefs with respect, but emphasizing the need for a medical approach; addressing practices and beliefs that might limit options for the individual; using photos and graphics representative of the ethnic communities; using recognized figures of authority for conveying messages; and developing bright, colourful, and attractive educational materials that could be easily read.

Further, the Epilepsy Foundation of America has followed these principles in the design of other programmes and materials to maintain the cultural relevance for these groups. Additionally, EFA recently received national recognition for its transcultural education materials to consumers by the U.S. Food and Drug Administration.

To further strengthen the transcultural initiative nationwide, in 1989 EFA awarded nine *Outreach to Underserved* grants to local affiliates. One of the grantees chose to work with the Hispanic community through the Catholic Church. Other grants were directed to American Indians, migrant families, prisoners, Hawaiians, the elderly, and rural populations.

Endnote

1. Address all inquiries to: Nyrma Hernandez, Deputy Executive Vice President of the Epilepsy Foundation of America, 4351 Garden City Drive, #400, Landover, MD 20785.

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