

## The Importance of Treatment-Seeking Stigma in Understanding the Experience of Families with Epilepsy in Africa

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### Abstract

*Epilepsy is the most frequent neurological disorder in children in developing countries and has dramatically higher prevalence rates in these countries than in the developed world. Rates on the African continent are among the highest among countries in the developing world. However, with high levels of patient adherence biomedical anti-epilepsy drugs are very effective at controlling seizures and eliminating symptoms.*

*The following paper presents several widely held African perceptions of epilepsy causation that demonstrate the complexity of community illness beliefs and adherence behaviors. Several unsuccessful health care interventions are discussed. The failure of these programs reinforces the fundamental role of careful research and the utility of employing "well-being" as a research model prior to intervention design and implementation. Preliminary findings from dissertation research are then presented. This research focuses on an epilepsy intervention program and demonstrates the complexities of epilepsy intervention design in Africa. An anthropological concept of well-being is reviewed. Well-being is a promising tool for studying disabilities such as epilepsy as it provides insight into the specific ways that illness affects daily life. The utilization of this concept in ethnographic research is promising as a means for designing intervention programs that improve the lives of targeted populations.*

## Introduction

Epilepsy has dramatically higher prevalence rates in developing countries than in the developed world (Shorvon 1990). This discrepancy may be related to higher incidences of alcoholism or more frequent childhood trauma, both factors that have been shown to increase the likelihood that an individual will develop epilepsy (*ibid*). Other research has suggested that higher rates may be due to birth or marriage practices (Jilek-Aall 1993). Poor sanitation and high degrees of cysticercosis contamination, a parasite that affects the brain, also have been suggested as explanations for high epilepsy rates (Diop, de Boer et al. 2003).

Epilepsy rates in Kenya have been measured at approximately 9 percent, 10 times that seen in the developed world (*ibid*). Striking gaps between prevalence statistics and the number of individuals receiving biomedical treatment (*i.e.*, the treatment gap) make these statistics even more dramatic. In Kilifi, Kenya only 4-10 percent of children with epilepsy receive biomedical treatment (Carter 2002). However, biomedical anti-epilepsy drugs are effective at controlling seizures and eliminating symptoms. When epilepsy is treated with these drugs, 75 percent of patients achieve full and immediate remission of symptoms (Coleman, Lopyy et al. 2002). It is therefore paramount for the control of seizures that biomedical treatment be available to children with epilepsy. Unfortunately, the availability of appropriate health care for children with epilepsy does not ensure treatment adherence. Adherence requires that barriers to treatment be identified and lowered and that health care be provided in a manner that is culturally acceptable to the family and community.

Intervention programs must not only focus on eliminating symptoms. These programs are more effective at improving the lives of the targeted populations if they focus on the well-being of families of children with epilepsy. In this paper I will address several widely held African perceptions of epilepsy causation. These causes underscore the complexity of community illness beliefs and stress the need for careful ethnographic work as a component of health care interventions. I then will discuss several unsuccessful interventions as they further reinforce the fundamental role of careful research prior to intervention design and implementation. Next, I will present a component of my preliminary research as a means of providing a more detailed example of the complexities of epilepsy intervention design in Africa. Finally, I will review an anthropological concept of well-being. The significance of this concept for studying epilepsy also will be discussed. Well-being is a promising tool for studying disabilities such as epilepsy. The way that such disabilities impact the lives of both the person affected and his or her family is complex and multifaceted. However, such an understanding is promising as a means to design intervention programs that improve the lives of target populations and efficiently employ limited funds.

### **Perceptions of Causation**

Social science research to date has shown that cultural beliefs in Africa about epilepsy causation and appropriate treatment are wide ranging. Most individuals living in the United States believe that epilepsy is caused by misfiring neurons or chemical imbalances in the brain (Bishop and Allen 2003). However, people in other cultures have very different epilepsy etiologies. In many cultures, epilepsy is

believed to be the result of curses or witchcraft. Amadou Diop and his co-authors (2003) cite such beliefs in many African cultures. Henry Rwiza and his colleagues (1993) find that a significant percentage of the population of a large rural section of Tanzania believes that epilepsy is caused by witchcraft. George Onchev (2001) cites similar beliefs on the Tanzanian island of Pemba as does Julia Segar (1994) in the East Cape region of South Africa. Many cultures also hold the belief that epilepsy is caused by angry ancestral spirits avenging past ritual indiscretions (Conrad 1992; Diop, de Boer et al. 2003).

A final common misperception of epilepsy in Africa is that this disorder is contagious (Gerrits 1983, Birbeck and Kalichi 2004). In a Nigerian study, researchers found that 100 percent of lay participants and over 40 percent of a sample of medical students believed that epilepsy was highly contagious and contact with persons with epilepsy was to be avoided at all costs (Awaritefe 1989). In some areas of Africa there is the belief that epilepsy is spread by coming into contact with the bodily fluids of a person with epilepsy. In other areas there is the belief that *any* contact with an individual who is in the process of having a seizure can spread the disorder. Finally, in some areas, epilepsy is believed to be caused by improper contact with certain animals (Millogo et al. 2004).

Consideration of causation beliefs discussed above is necessary in analyzing health care choices, adherence and illness experience. Spiritual and supernatural notions of causation are dissonant with biomedical treatment options and affect decisions not to access these options. Conversely, these beliefs also may be important in understanding why individuals select "traditional" treatment modalities in response to certain symptoms. Perceptions of contagion

are vital to understanding the generation and enactment of stigma and how these processes may shape illness experience.

### **Health Care Interventions**

The provision of health care in developing nations that lack funds and infrastructure is a formidable task. Many programs fail to consider local, cultural and ecological contexts and thus have limited success. Each failed program underscores the cost effectiveness of investing time and money on research prior to the design of an intervention. Howard and Millard (1997) provide a vivid example of the importance of cultural appropriateness for the success of an intervention in their account of a failed program among the Chagga in the Tanzania. Their work illustrates the importance of understanding the cultural conceptions of fear and shame associated with some disorders. If barriers had been identified through an initial survey and ethnographic study of parental attitudes toward child malnutrition, many of the project's problems could have been avoided.

Mcqueen and Swartz (1995) propose an intervention plan. They focus is on educating the population about biomedical treatment of epilepsy. The intervention program's primary tool is an educational pamphlet, which would be distributed at area hospitals and clinics as well as in prominent community locations. Education is a difficult goal in intervention programs. Ideas of illness causation are deeply seated in a cultural system and often rely on fundamental tenets that structure and guide the goals and values of a given system. In this way, merely publishing and

distributing pamphlets is highly problematic as a means of increasing the well-being of the targeted population.

Ball (2000) formulated an intervention plan aimed at decreasing the treatment gap in a rural population of Zimbabwe. The program's primary component was providing education to community leaders. The education program focused on emphasizing the importance of receiving biomedical care for the treatment of epilepsy. Researchers measured the number of cases of diagnosed epilepsy and the number of cases of treated epilepsy in the district before the implementation of their education program. They then measured these figures six months after the start of their program and found that there were no new cases of epilepsy being treated and no new cases diagnosed. These examples emphasize the need for careful ethnographic study of a population prior to the formulation and implementation of intervention measures. Program designers must have an understanding of what significant barriers to treatment are and factors that the targeted population feels are important in increasing well-being.

As part of my preliminary research, I analyzed transcripts of interviews conducted as a part of an intervention program on the Kenyan coast. Field workers employed by a district hospital conducted the interviews. Individuals interviewed included the following: individuals with epilepsy, family members of individuals with epilepsy, village chiefs, community health workers and traditional healers. I summarize the results of the preliminary analysis of these transcripts below. These results emphasize the need for carefully formulated ethnographic work and interview methodologies in designing successful intervention programs.

## Major Findings

Symptoms of seizure disorders recognized by patients or families of patients were consistent across focus groups and individual interviews. However, information from the interviews did not clarify what types of seizure disorder individuals were discussing. Because symptoms classification affects the way that treatment is sought (in terms of both where and when treatment is sought), confusion with regard to disease categorization may contribute to the treatment gap, or at least to a better appreciation of the reasons for this gap. For example, if parents misconstrue a seizure disorder as febrile convulsions, they falsely may believe it appropriate to leave seizures untreated. There was also considerable confusion among patients and their families in the conception of epilepsy as an acute rather than chronic disorder. Many individuals believed that epilepsy could simply be cured and therefore had difficulty rationalizing the need for ongoing and long-term daily medication. It is thus important not only to stress the effectiveness of epilepsy medication but also to provide appropriate symptom education.

While doctors' theories of causation were consistent, patient perceptions of causation were highly variable. Although many patients offered ideas of inheritance, these ideas are rarely in accord with a biomedical gene model and often were framed in terms of inheritance of past indiscretions or personality types. In the following quote this folk conception of inheritance is illustrated: "If you listen well to it, they should look for a sheep to amend issues of the home (beliefs). This signifies that in the past there are things that went wrong in the home." Many patients also expressed, albeit reluctantly, supernatural theories of

causation. "I am praying for him so that the devil can go and the child stop fitting." As I discuss below, patients did not go into sufficient depth as to these folk theories of causation. Given that beliefs inform and guide practice, understanding patient theories of causation is critical to efforts to understand health behavior in practice.

With the exception of traditional healers, stakeholders' reports were consistent both within and between categories. Patients professed their faith — and often blind trust — in biomedical care and its practitioners. They discussed traditional healers in a negative manner and focused on disadvantages of this treatment option. One respondent said, "You take him there (the traditional healer), get the herbal bath and he still remains sick until you can take him to the hospital where they get treatment and get cured." In contrast, informants spoke positively about doctors and medical health care options. Frequently stakeholders failed to cite negative aspects of this option or to make suggestions for improving hospital treatment. When asked about negative aspects of hospital care one participant simply responded, "There is nothing that is bad." This response is characteristic of the patient group more generally. Assuming the patients' reports are unbiased, this positive attitude toward biomedical care implies that patient beliefs have little to do with the treatment gap, and that other barriers, such as cost and distance, are more primary reasons for the low percentage of people with epilepsy who seek long-term care for their disorder (see below for caution on this point).

Discussions of barriers to effective/optimal treatment revealed two noteworthy trends. First, both medical doctors and community health workers frequently cited lack of patient education as a major barrier to health care: "There are some of our people who believe that this epilepsy is

caused by curses and demons, so why come to (the) hospital when these are not hospital-related conditions." Both of these groups also overwhelmingly endorsed improved education of patients as a means to improve health care and service delivery. Second, patients did not express this view, but instead cited the cost of transportation and cost of drugs as the primary impediments to optimal treatment for epilepsy. These two trends do not immediately suggest a method of intervention, rather they point to the need for further investigation in order to appreciate the significance of this discrepancy and its relation to the existing treatment gap.

Interviews with traditional healers revealed beliefs that differed from those of patients and community health care workers. Nevertheless, statements made by the traditional healers suggested that they are not opposed to referring patients to biomedical clinics. They frequently recognized the value of biomedical care. When asked about the effectiveness of hospital treatment one traditional healer responded, "They (persons with epilepsy) are given drugs and they get healed." The openness of healers to the possibility of referral suggests that it may be feasible to incorporate them into the clinic structure, and that providing them with education about disease symptoms may thus result in increased patient referrals.

### **Methodological Considerations and Study Limitations**

The fact that the interviewer was affiliated with the project may have biased the patients' responses. Given that the interviewer was clearly connected to the hospital at which patients sought care, interviewees may have been reluctant to discuss supernatural beliefs of causation for fear of being

considered old fashioned or ill-informed. The interviewees also may have been reluctant to describe positive aspects of traditional healers or the negative attributes of biomedical care. In addition, the hospital affiliation of the interviewer may have had a dampening effect on patient suggestions for improving the hospital treatment option.

The structure of these interviews may also have affected patient responses. Asking for positive and negative aspects of treatment options forces patients to consider treatment in polar terms (bad and good) and discourages patient narratives and accounts of past treatment experiences. Having only one interview with each stakeholder may further constrain their responses, as the interviewee may be reluctant to discuss personal issues related to illness experiences and health beliefs.

The above-noted methodological limitations may be responsible for the tendency for patients to dichotomize their sentiments regarding treatment effectiveness (hospitals = good and traditional medicine = bad). Information about the order in which treatment options are sought, though sparse, revealed that patient beliefs may be more complex than is suggested by this dichotomy, and the patients may not, in fact, wholeheartedly endorse hospital care while shunning traditional options. Several patients from the present study repeatedly accessed relatively expensive traditional options despite their ineffectiveness.

Patient interview data was comprised exclusively of interviews with individuals who had sought care in hospital settings. This leaves a large and integral subset of individuals with epilepsy left unstudied: those with the disorder who do *not* choose to access care. Sampling of a broader cohort of patients would likely lead to a better understanding of the illness beliefs that contribute to the treatment gap.

Information on traditional healers remains relatively incomplete. There is little information about how traditional healers treat epilepsy, how much they charge for their service, and the extent and conditions under which they refer patients with symptoms of epilepsy to hospitals or community health stations.

### Future Directions

Anthropological methods of participant observation offer a promising approach to obtain further insights into reasons for the present epilepsy treatment gap. While interviews are useful in identifying important themes, this method is based only on verbal report and may thus be insensitive to actual health care practices, or to behavioral manifestations of health beliefs. A participant observation study with individuals afflicted with epilepsy would be an effective method for determining what *actually* is happening in terms of health seeking behaviors and would provide a better understanding of patient perceptions of epilepsy.

A person-centered interview methodology relies on a series of interviews in which the interviewer builds rapport with the informant. The informant is free to address issues that he or she finds relevant instead of responding to a set of structured questions posed by an individual who represents hospital services. The procedure would address many of the problems related to informant bias and would be fruitful in understanding folk theories of causation and how patients make health care decisions.

Future studies of the existing treatment gap should focus on obtaining data from a more complete sample of the population of individuals suffering from epilepsy. Specifically, efforts need to be made to obtain information

from those individuals who do not choose to access hospital treatment. Future work with traditional healers also is recommended to enhance understanding of their methods of treatment, cost of service and the extent and conditions under which they make referrals for biomedical care for epilepsy.

### Well-being

*Walking up to the crudely constructed lean-to that the family is presently using as shelter, the force and gravity of being excluded from village life hits home. This family has been ostracized and stigmatized, forced to leave the village through the exertion of tremendous social pressure. They now live approximately a mile and half from their former homestead. Because of fears of the family's involvement with witchcraft and the contagious nature of frequent seizures they have been forced to live on their own, without the social or material support formerly offered by their home village. They are experiencing a low level of well-being (Excerpt from field notes from September 2005).*

The concept of "well-being" is a theoretically useful tool for understanding the effects of disability. Well-being can be thought of as how *well* an individual feels in life and their overall attitude about life in general. The concept is influenced by many contributing factors. I propose that conceptualizing well-being from a family perspective provides unique insights on how specific disabilities affect the family and its members.

A brief review of any social science article database reveals that well-being appears to be an important and well-studied concept. However, well-being is researched, measured and defined very differently across the disciplines of the social sciences. In the field of economics and political science, well-being and the more frequently used term "quality of life" are concepts used to make cross national or regional comparisons. Well-being in these disciplines is a quantifiable measure, based on a long list of factors that together are meant to capture how well or happy the people of a given area are (Antonucci 2003, Furstenberg 2003, Meyers 2003, Miringoff 2003, United States Office of the President 2003).

In psychology, well-being is employed in the study of pathology to analyze the negative affects of specific disorders (Birbeck 2002, Bishop and Allen 2003, Panayides 2004, Rodenburg 2005, Stevanovic 2005). For example, psychological studies of well-being utilize surveys often employing numerical values in which respondents are asked to rate their internal states of happiness or satisfaction while engaged in certain activities (Trimble 1985, Jacoby 1992, Austin 2004, Panayides 2004, Baker 2005). While such studies reveal important aspects of well-being, there is a fundamental flaw stemming from the fact that *internal* states of happiness are measured using *external* numerically based surveys often administered in laboratory settings or over the telephone.

Research in public health also has dealt with the concept of well-being. Such studies are similar to those conducted in economics or political science in that they focus primarily on external material factors as the determinants of well-being (Devinsky 1993, Hentinen and Kyngas 1996, Mielke 2000, Bishop and Allen 2003, Brim 2004). Public health

studies of well-being and quality of life occasionally employ survey work aimed at obtaining individuals' subjective assessments of their health. This research tends to use the terms and concepts of "health" and "well-being" interchangeably and, in so doing, excludes many factors that may contribute to well-being (Snowden 2005).

Anthropologists are concerned with two important aspects of well-being. Well-being can be divided into internal/felt and external/comparative aspects. The internal/felt dimension includes things that make an individual *feel* well, such as the absence of sickness or sensory pleasures. On the other hand, the external/comparative aspect includes components that the person uses to assess or evaluate whether or not they are living a "good" life. This includes such things as cultural goals, values and social interactions. These dimensions are not distinct in practice and there are almost always aspects or factors affecting well-being that are both felt and comparative in nature. Thinking through both the felt and comparative elements of each of the constituent factors facilitates a better understanding of the various ways that these factors affect and shape well-being.

The idea of pleasure is an important dimension of well-being. Falling into the internal/felt dimension, sensory pleasure is central to any understanding of how well an individual or group is. However, the way pleasure is experienced, the activities that create it and its meanings are determined by cultural context. Pleasurable experiences can contribute to an individual's wellness experience and, conversely, the lack of pleasure or presence of pain in a person's life can contribute to feelings of being un-well. The pleasure factor also can have a comparative dimension. Comparing levels of pleasure with the perception of the

pleasure experiences of others may lead to a comparative evaluation of well-being.

The quality of social relationships and interactions is another important dimension of well-being. This factor contributes centrally to how well or unwell a person *feels* and *evaluates* himself to be. Dimensions of social relationships influencing well-being would include how a person believes he is perceived by those around him and the sensory pleasure he experiences during interactions with others. Stigma is a significant aspect of this dimension of well-being and shapes how the individual feels others are perceiving him (Baker 2000).

Understanding culture is another essential dimension of an anthropological concept of well-being. Specific components of interest in a cultural system are goals, values and the manner in which significance is assigned to life events and activities. Examining these factors enables the researcher to evaluate how an individual perceives cultural goals and his or her ability to meet these standards.

Location is an additional component to consider in studying well-being. Understanding how a culture views its environment and changes to this environment can yield key insights into the way individuals think about being well (McGregor 2003, Izquierdo 2005). In many cultures, a group's relationship to and connection with the environment is central to both the sensory experience and evaluative aspects of well-being (Beverly and Whittemore 1993). This component of well-being may be an especially important consideration in refugee populations. In such cases low levels of well-being can be understood, in part, from having been removed from native lands and living without the continuous connection with ritually and symbolically important land and locations.

Daily activities and routines are essential components of well-being. Every day activities are, to a large degree, responsible for shaping the lives and experiences of individuals and families (Weisner 2002). While understanding broad cultural goals and values is important in examining what constitutes wellness or happiness, there can be no substitute for a detailed knowledge of how a group lives their daily lives and how seemingly minute routines and interactions shape general states of wellness.

"Environmental stress," or resource availability is also of central importance to the anthropological study of well-being (Edgerton 1970). This term refers to an individual's or group's material needs and the individual or group's ability to meet these needs. Resources determine both the way that an individual feels as well as how the individual compares or evaluates his or her life in relation to cultural ideals and other individuals. The resources available to an individual or family are integral aspects of well-being. For anthropologists, resources such as livestock, foodstuffs, money and time are best understood not only by the number and types available, but also in *how* resources are made available, used and dispensed.

Physical health is a final component that an anthropological concept of well-being must address. Physical health is integral to both felt and comparative dimensions of well-being. The presence or absence of sickness clearly affects how an individual feels. However, physical health also is used comparatively as individuals assess their own level of well-being in relation to the physical health of those around them.

To review, the following components constitute an anthropological concept of well-being: pleasure, social interaction, cultural goals and values, daily routines and

activities, resource availability and physical health. A comprehensive study of well-being should consider all of these components. Anthropology is uniquely qualified and outfitted to study these constituent factors due to the ethnographic method and person-centered approach. Together with survey and statistical research these methods provide a more complete and culturally relative understanding of what it means to be well.

Most studies of well-being have focused either on the individual, or conversely, on the well-being of a society or region as a whole. The preoccupation with studying individual well-being is, in part, due to the importance of the individual and autonomy in Western culture (Ingersoll-Dayton 2004). Large surveys and quantitative data have resulted in numerous regional studies of well-being. However, few studies have focused on the middle ground and evaluated well-being at the family level. The central importance of family and the family unit in the African context demonstrates the need for such analysis (Chavunduka 1978, Janzen 1978). Studying well-being at the family level provides information as to the well-being of multiple individuals. Examining the wellness of a family provides a useful lens through which to examine how each of the constituent members is living. Focusing on the family therefore provides a perspective on the well-being of a *group* of *individuals* and in this way is both an efficient and effective means of looking at the well-being of a community. Secondly, examining the well-being of children is often difficult methodologically. Focusing on the family provides a good perspective of the quality of the lives of children. A young child's family and the environment in which they live structure daily life and determine, to a large extent, the quality of the child's experiences.

## Treatment Seeking

Fabrega defines treatment-seeking behaviors as "...the sequence of treatment-related actions that an individual takes during the time that he considers himself ill" (Fabrega 1972: 189). Treatment-seeking behavior refers to the decisions that individuals make when confronted with illness symptoms. The first category in the treatment-seeking literature assumes that the most important determinants in decision making are *internal* such as mental models of culture. The second category focuses on *external* factors such as economic variables and contends that these variables are primary in an individual's decision making. Both theoretical positions acknowledge the roles of both internal and external factors, but differ in terms of which factor is of *primary* importance.

Individuals on the internal side of this debate believe that culture and the mental organizational models that provide the structure of culture, dictate where and when an individual will seek care for a symptom. These culturally shaped constructs are known in the literature as *explanatory models* (Fabrega 1974, Kleinman 1980, Young 1980, Good and Delvecchio 1981). Kleinman (1980) theorizes that the basis of health decisions can be discerned by examining the way the individual assembles information and thinks about the factors causing the illness, the symptoms and process of symptom onset, the course that the sickness will take, and views as to the treatment of the illness. By examining these factors, researchers are able to understand why individuals make health care decisions.

According to this view, an individual's perception of causation may influence his treatment-seeking behaviors. For example, if an individual's cognitive cultural model

attributes a symptom to spiritual causation he or she would seek treatment that corresponds with the perceived agent of causation, from a witchdoctor or "spiritist." The role of cultural consonance<sup>1</sup> in treatment-seeking behavior remains contested in anthropology (Kroeger 1983, Wilce 1997, Dressler and Bindon 2000). In an ethnographic study of the Swahili on the Tanzanian island of Mafia, Caplan supports the view that consonance is significant in understanding treatment choice. She writes that long duration or sudden onset of symptoms lead individuals to one cultural interpretation of causation (witchcraft) while gradual symptom onset implies another causal agent (ancestor spirits). Caplan suggests that each of these interpretations of causation corresponds with an appropriate treatment modality and that these perceptions of causation are the primary factors in understanding treatment-seeking behaviors (Caplan 1997). While some researchers think consonance between perception and treatment is a significant factor in treatment seeking, others suggest that it has relatively little to do with treatment choice (Kroeger 1983, Rubel and Hass 1990).

A second issue with the internal approach to understanding treatment seeking is the tenuous connection between *self-report* and actual *behavior*. Research suggests that the reports or descriptions that individuals give of their behavior are often dramatically different from their *actual* behavior (Yoder 1997). Employing participant observation *and* interview methodologies allows for the consideration of these discrepancies. Finally, theories proposing the primacy of internal mental determinants make little effort to explain the pathways and mechanisms by which culture informs and shapes cognitive models — a problem of cultural models theory more generally (Shore 1996).

The proponents of theories that emphasize the role of external influence on health care decision making propose that factors such as the distance an individual lives from a clinic, the size of social network, disposable income, religion, age and education are more important in shaping decisions than etiological beliefs (Woods and Graves 1973, De Walt 1977, Lasker 1981). Many African populations have low levels of education, lack disposable income, or live a considerable distance from a health facility. These factors predict a lower likelihood of seeking care from biomedical options and need to be considered in an understanding of health seeking behaviors.

By focusing on correlations between actual treatment outcomes and a set of external variables, advocates of the external perspective avoid one of the weaknesses of the explanatory models theory; the disconnect between self-report and actual behavior. However, researchers holding this view often are criticized for merely demonstrating correlations among variables and for avoiding the *why* questions. The methods employed by many of these researchers fail to answer *why* a variable such as age or income is statistically related to treatment seeking. A second problem is that in testing these relationships, variables often are chosen relatively arbitrarily and potentially meaningful factors often are ignored (Garro 1986). This frequently leads to omitted-variable bias, which may overstate or inflate the effects of the variables that *are* included.

A limitation with both the internal and external positions is that no one factor is likely to be primary in shaping an individual's decision making process, as decisions in times of illness are complex and multi-factorial (Young 1980). Furthermore, even if we assume that there *is* a dominant factor influencing these decisions, this factor may vary across

illness episodes. Material factors such as distance from a clinic may be primary in an individual's decision at one point in time, while cultural explanatory models may be dominant on other occasions.

### **Treatment Seeking, Stigma and Illness Experience**

*To understand why patients and families decide to do what they do, it is essential to understand their experiences of illness and of treatment (Kleinman 1995: 1324).*

Treatment seeking and adherence are affected by many factors and are complex concepts to study and model. However, the connection between these concepts and the experience of an individual suffering from a given illness or disability is relatively straightforward. Decisions to seek and adhere to treatment affect health outcomes, as certain options may be more effective at dealing with certain illnesses than others. The options that are accessed and the experiences during treatment interactions also shape the patient's satisfaction with treatment, which also impacts the illness experience. When confronted with symptoms, individuals are forced to interpret meanings and synthesize cultural and material factors in making a decision. These decisions offer a unique view of the components that structure illness experience and shape well-being. Stigma is an important component in the illness experience. A review of this theory reveals important insights into treatment-seeking and adherence behavior.

### **Stigma Theory**

Stigma theory is based largely on the writings of Erving Goffman (1963). According to Goffman, stigma is "...the

situation of the individual who is disqualified from full social acceptance" (ibid: 1). He is concerned primarily with stigma created and experienced in social interactions. Much of his theory of stigma is based on his other theoretical works discussing the importance of interactional cues and minute conversational dynamics in shaping social interaction (Goffman 1963 and 1982). Stigmatization occurs when "routines" and "normative expectations" are violated in a way that "discredits" the perpetrator (Goffman 1963: 2).

An individual becomes stigmatized when a marking behavioral or physical characteristic presents others with information that conflicts with normal social categories or expected behavior. The person with such a characteristic is perceived to fall outside of normal status and occupies a "liminal" social position. The person being stigmatized is most often aware of the social process that is transpiring. This awareness affects the individual's identity and behavior in future interactions.

Stigma is shaped by *interactions* between individuals, *social* perceptions and categories. It is, therefore, a decidedly social process (Schur 1971, Ben-Yehuda and Farrell 1990). However stigma is also a cultural process and is shaped by the cultural context in which it is socially enacted. The individual becomes stigmatized when he deviates from the normal standard or the commonly held conception of being a complete person. Such ideas of normalcy and completeness are shaped by the culture in which the individual is situated and the set of values and system of ideals that this culture structures (Goffman 1963, Schur 1971).

The degree to which the individual is held responsible for his or her condition and the extent to which the disorder disrupts social situations have been found to be factors that

contribute to the stigma associated with a given condition (Albrecht 1982). Others maintain that stigma results from a violation of cultural values. Wiener (1988) and Crandall and Moriarty (1995) find that disorders become stigmatized because individuals are seen as out of control of their bodies and actions.<sup>2</sup> Temkin (1945), who has written one of the only historical accounts of social attitudes toward epilepsy and its treatment, finds that one of the main sources of stigma cross-culturally is the perception that the disorder is contagious. Preliminary research confirms Temkin's finding and supports the connection between contagion and stigmatization in an East African context. Others have found a similar connection between the perception of contagion and the stigmatization of a disorder (Jacoby 2005). Temkin (1945) also finds evidence that stigma associated with epilepsy is derived from the perception of supernatural causation and retribution for past social or cultural infractions.

### **Stigma and Treatment-Seeking Behaviors**

When a condition is stigmatized, individuals making treatment-seeking decisions are presented with a dilemma. Seeking treatment by going to a clinic, traditional healer or hospital, in most situations is a *public* activity and constitutes a public acknowledgement of the disorder. A decision to seek treatment forces the individual to endure the negative social and identity effects of stigmatization. If these costs are deemed too severe, the individual may choose to conceal the disorder and forgo treatment. Stigma theory is an important cultural dimension to examine when analyzing treatment-seeking behaviors because of its role in shaping concealment.<sup>3</sup>

Stigma also influences interactions between the affected individual and doctors, healers and health care professionals. If the individual perceives that the doctor does not or will not "...really 'accept' him and are not ready to make contact with him on 'equal grounds'" (Goffman 1963: 7) because of the stigmatized disorder, the individual may be unwilling to enter into the treatment interaction in the first place. In addition, the doctor or health worker *actually* may treat the individual poorly due to the condition. In this case the individual is not likely to receive optimal treatment. Awaritefe (1989) has shown that a large percentage of bio-medically trained health care professionals in Nigeria believe that epilepsy is highly contagious. Such attitudes likely influence the treatment of persons with epilepsy.

Stigma also may influence how non-health care professionals treat the affected individual. Stigmatization can lead to an unwillingness to provide assistance or a lack of response at specific times of symptom onset. In the case of epilepsy, this often is seen as community members, even those close to the affected individual, are unwilling to move a person suffering from a seizure out of danger (Rwiza 1993, Jallon 1997). This is often the result of fears of contagion. Frequently, individuals who have fallen into fires during seizures are not immediately pulled out. Stigma also may cause hesitance or resistance in helping the individual seek treatment. A lack of support and assistance effectively limits the treatment options that are available to the individual, shaping treatment-seeking behaviors, illness experience and well-being.

### **Studies of Epilepsy that Give Primary Importance to Stigma Theory**

Stigma theory is a central component of the majority of the literature dealing with chronic disorders in general, and specifically in research focusing on epilepsy. In order to conceptualize the illness experience of persons with epilepsy, researchers applying this theory maintain that it is necessary to understand the process of stigmatization, the specific factors responsible for the generation of stigma and dimensions of life that are affected by stigma (McQueen and Swartz 1995, Baker 1997, Kyngas 2000, Austin 2004, Jacoby 2005). For these researchers epilepsy is a "stigmatizing condition par excellence" (Baker 1997: 353). However, such studies adopt a very narrow focus on stigma theory and the perception of unwanted distinction. Stigma frequently is depicted as the sole factor in accounting for compromised level of quality of life for individuals with epilepsy (*ibid.*).

### **Problems of the Stigma-Based Research on Epilepsy**

One general critique of this literature is that research has been conducted primarily in Western cultures. Therefore, results should be viewed with caution and must be limited to application in Western cultural contexts. Future studies are required to investigate stigma cross-culturally, paying specific attention to epilepsy and other neurological disorders that affect an individual's control over his body.

A second critique of this literature is the *narrowness* of its focus on stigma theory. An exclusive focus on stigma eliminates the possibility of uncovering other dimensions of the disorder, which may be key in structuring an

individual's experience. Preliminary research in Kilifi, Kenya suggests that stigma is important in understanding the experiences of persons with epilepsy. However, of equal if not greater importance in shaping the experience of individuals are the daily activities that those with epilepsy are excluded or restricted from participating. Cooking, or standing beside a cooking fire, and getting water are two fundamental tasks in the daily lives of individuals living in rural areas of the coast. These are also activities that are dangerous for individuals suffering from frequent grand-mal seizures. As such, they are frequently off-limits to individuals with epilepsy. These restrictions contribute significantly to the illness experiences of persons with epilepsy as they are not able to participate in fundamental daily activities. This important dimension might be excluded from consideration if attention were focused narrowly on social stigma. Whyte's (1995) work in Tanzania expresses similar concerns regarding epilepsy, illness experience and quality of life.

The majority of this literature also can be critiqued in its theoretical positioning of the individual with epilepsy. The literature presents the individual as a passive agent who is *subject* to stigma. There is little discussion of the importance or role of personal agency, negotiation or construction of narratives in shaping illness experiences.

### **Epilepsy Prevalence and Perceptions of Causation in Africa**

A review of prevalence data and perceptions of causation demonstrate the extent of the problem of epilepsy in Africa. Not only are prevalence rates higher than in the United States and other developed nations, but there are

common and wide ranging causation beliefs that lower the well-being of individuals and families with this disorder. The internal approach to treatment seeking laid out above emphasizes the importance of analyzing causation beliefs in order to understand the health care choices of affected individuals. These beliefs may shape treatment choice, cause poor adherence and a lack of satisfaction with treatment. Ideas of causation are also central to understanding stigma generation and enactment. Furthermore, by affecting treatment seeking and stigma, causation beliefs shape the overall illness experience of persons with epilepsy.

### **Conclusion**

Prior research reveals high rates of epilepsy in the developing countries of Africa and presents some general perceptions of causation held by various groups on the continent. Analyzing the cultural beliefs in the specific area of study is essential to understanding how individuals and families experience epilepsy and how this disorder shapes their lives.

This essay has demonstrated that employing the concept of well-being is a means of understanding the experiences of families with children with disabilities. Well-being offers an insightful perspective on how disability affects the lives of families and how they experience compromised or uncompromised wellness. This perspective is essential in designing effective intervention programs that use limited funds to target the most salient aspects affecting the happiness and functionality of families and their constituent members.

Well-being is shaped by many factors. Understanding treatment-seeking behaviors and stigma are two vital

components in analyzing factors that shape well-being. Anthropology, with its ethnographic methods, interest in lived experience and person-centered approach, offers a unique opportunity to uncover key components of what it means for an individual and a family to be well. Conclusions based solely on statistical analysis of material variables or survey methods must be avoided. A more complete understanding of well-being requires supplementing these methods with qualitative data. The importance of examining daily activities as they occur cannot be overstated.

### Endnotes

<sup>1</sup> Cultural consonance refers to continuity between perceived causation and treatment. In a culturally consonant treatment scenario the treatment addresses the perceived agent of causation.

<sup>2</sup> This conclusion is dependant on the presence of a cultural value of control. A disorder characterized by a difficulty in control would only be stigmatized in cultures in which there is a premium placed on ideas of self-command and control over bodies and actions.

<sup>3</sup> Concealment, as noted above, has clear implications in making treatment decisions.

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