

Multiculturalism, Chronic Illness, and Disability

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The past two decades have brought significant improvements to the lives of children and adults with chronic illness and disability. Medical, technological, social, and legal advances have shifted the focus from the hospital and the institution out into the community, where all but a small percentage of Americans with chronic illnesses and disabilities will now spend their lives. Moving the frame of reference into "the community;" however, raises another set of issues that have yet to be adequately addressed.

Too often, the "community" under discussion in the literature is an abstraction, with the services and networks which are assumed to exist reflecting stereotypical white, middle-class values and concerns. It is now widely acknowledged that these stereotypes do not hold true even for the family structures, support networks, and community resources found within the white middle-class America of the 1990s. We believe that such assumptions are even less helpful in defining the community-based needs of individuals with chronic illness or disability from ethnic and minority communities found throughout our country.

Many ethnic and minority populations, reflecting their own unique and long-standing cultural beliefs, practices, and support systems, do not define or address disability and chronic illness in the same manner as "mainstream" American culture. Their concerns are not necessarily identical, their solutions are not always the same, and the strengths shown in many ethnic and minority groups may present alternative ways of addressing needs that merit our careful attention.¹ We strongly argue that to better service children and adults who have a chronic illness or disability within our multicultural society, it is imperative that we understand the cultural beliefs and attitudes that determine behaviors, guide decisions, and effect interactions with the broader society. This should include the fact that our own traditional "American" way of addressing issues of chronic illness and disability is, in itself, not culture-free, but a unique product of our nation's history, legal system, and social structure.

The concept of cultural sensitivity and compromise is a recent one. Previous waves of immigrants have been called upon to become part of a "melting pot." The popular belief was that whatever beliefs and traditions were brought to the United States by immigrants would quickly disappear, replaced by solidly "all-American" values, attitudes, and behaviors. Social scientists now recognize that each ethnic and minority group that has come or been brought to the United States, from the Pilgrims on, while incorporating much from the broader society, has also tended to retain parts of its traditional beliefs and practices.

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The result is that each ethnic and minority group develops a unique mix of cultural roles, expectations, and conceptual frameworks that, in part, determines how its members view its social networks, support systems, and communities. These culturally based belief systems are not simply of scholarly interest, but are real social *facts* which help to shape the decisions made by individuals with a disability or chronic illness and their families. (Note 4)

In response to this growing awareness of diversity, health care professionals, educators, employers, and politicians have begun to use the term "multiculturalism" or "cultural diversity" when designing policies, programs, and services intended to meet the needs and expectations of dozens of distinct ethnic and minority groups. However, for a program or a policy to be truly multicultural, there must be a real understanding of the differences within and between cultures.

Too often differing cultural belief systems are approached by the dominant society and by professionals in an oversimplified manner. As members of the dominant American society, they are drawn to what they perceive to be the strange or the exotic way in which people respond to different physical or mental conditions. Understanding differing cultural belief systems can often provide an important conceptual tool when working with children and families in a culturally diverse society.

Note 4: It is imperative to note that caution must be used in the broad categories currently employed in popular culture (and unfortunately, all too frequently in research as well), when current American ethnic and minority populations are discussed. All but the smallest of cultural groups are themselves further divided into a number of subgroups that are significant in their differences. For example, although African-Americans are often discussed as members of a single group (and all certainly have confronted similar issues of racism), in fact the socioeconomic, educational, and medical needs of the suburban, professional black couple with a disabled child may be significantly different from those of a single, teenage mother and *her* disabled infant living in an inner-city housing project. "Hispanic" is used both by researchers and in the dominant culture to refer to individuals from any one of over 20 different countries. The social service needs of a disabled child whose parents are college professors from Venezuela may be markedly different from those of Indian parents, speaking a native Indian dialect, here as illegal immigrants from the highlands of Guatemala (parents for whom even Spanish is a second language) "Asian" as it is currently used in the literature too often refers to anyone whose ancestors come *from* the Orient—a region that includes several dozen major countries and over a third of the world's population. That we can lump together non-European ethnic groups in such a manner speaks to a lack of understanding of these cultures, not to their lack of internal diversity.

THREE KEY ISSUES

An individual's culture is not a diagnostic category; no cultural heritage will wholly explain how any given individual will think and act, but it can help health care professionals anticipate and understand how and why families make certain decisions. The understanding and clinical application of cultural difference is a new task for health care professionals. While disability studies is a discipline barely a decade old, our current state of knowledge allows us now to begin to identify key issues concerning the social implications of chronic illness and disability. Among these, the following three issues seem to be almost universal, appearing prominently and consistently in cross-cultural studies:

1. The culturally perceived cause of a chronic illness or disability is significant in all cultures studied to date. The reason why an illness or disability is believed to have occurred in a particular individual and/or family will play a significant role in determining family and community attitudes toward the individual.
2. The expectations for survival (usually conceptualized in terms of actual physical survival) for the infant or child with a chronic illness or disability will affect both the immediate care the child receives and the amount of effort expended in planning for future care and education.
3. The social role(s) deemed appropriate for disabled or chronically ill children and adults (often based on a consensus about their productive potential and beliefs about how the disability is transmitted) will help determine the amount of resources a family and community invest in an individual. This includes issues of education and training, participation in family and community social life, the latitude permitted for individual autonomy, and the long-range planning done by, or undertaken for, the individual over the course of a lifetime.

Culturally Perceived Causes of Disability

The first of these issues, the culturally perceived cause of a chronic illness or disability, is of particular importance because it tends to color all other aspects of the family's and the community's attitudes toward the affected child.

Chronic illness and disability is seen by many cultures as a form of punishment. The individual with a disability, his or her family, or an ancestor, according to the particular belief system, has been either cursed by God or the Gods, sinned, or violated a taboo. Support for the individual or the immediate family in such cases might be half-hearted or lacking. Others may seek to distance themselves from those who have incurred such "evil." This is more than the simple distancing of former friends and relatives frequently reported in the literature by parents of children with disabilities. In some ethnic groups, the child is seen as tangible evidence of divine displeasure, and its arrival is accompanied throughout the community by prolonged public and private discussions about what wrongs the family may have committed.

Nor is divine punishment by any means the only explanation. In a number of African, Caribbean, and Pacific Basin societies, as well as among many Native American tribes, witchcraft is strongly linked to ill health and disability. An individual who has been bewitched is presumed to be a victim, but is not necessarily seen as innocent. The reason for the witch's curse again is subject to public discussion. Close association with such a person, it is believed, may place others at risk for witchcraft. (A version of this is commonly found throughout the Mediterranean basin and Latin America, where a child's serious illness, particularly if it is of rapid onset, is often said to be caused by the "evil eye".)

Inherited disorders and illness are frequently envisioned as being caused by a family curse or as "running in the blood." Within such families, a clinician's desire to determine who is the carrier for a particular gene may be interpreted as an attempt to discover who is at fault, and such an endeavor may be met with great resistance by family members.' Bad blood, a widely held European folk belief, was strengthened by the late 19th century eugenics movement, which emphasized the concept of inheritability of tainted and defective genes. Folk ideas mingled with eugenics particularly throughout Western and Southern Europe, giving birth to the widely held belief that many conditions, particularly mental retardation, are the products of intermarriage among close relatives. This traditional belief that a weak or disabled child may be the product of an incestuous relation may further complicate attempts on the part of professionals and advocates to encourage parents and families to come forward for assistance. (Note 5)

In societies where belief in reincarnation is strong, such as among Southeast Asian groups or in Indian society, a disability is frequently seen as direct evidence of a transgression in a previous life, either on the part of the parents or the child. Those who are disabled are frequently avoided or discounted because of their past lives, while they are simultaneously urged to lead particularly virtuous lives this time around. Answerable both to the past and the future, too little time and energy are often devoted to improving life in the present.

Not all belief systems emphasize punishment or witchcraft. For example, the belief that chronic illness and disability are caused by an imbalance of elements humors in the body is found in various forms throughout Latin America and Southeast Asia. This belief system places the burden of responsibility for disability with the affected individual. The cause and the potential cure lie within the individual. He or she must try to reestablish his or her own equilibrium, and by extension good health. An individual with a chronic illness or permanent disability who cannot be fully healed within this conceptual system may be considered to exist in a continually impure or diseased state.

Note 5: The folk belief in inherited traits also provides an excellent example of how folk medical categories do not always correspond with modern genetic knowledge. A parent discussing his or her family's "bad blood" will not infrequently cite as proof a list of unrelated conditions in an extended family over the course of several generations—a blind great-aunt, a mentally retarded third cousin, and a nephew with cerebral palsy—as evidence of an inherited problem. For believers in the folk concept of bad blood, the specific type of disabling condition is of less importance than the belief in the presence of an underlying and unifying problem.

All these perceived causes are linked, for in all of them, the family or the individual who is disabled is held accountable for his or her own problems. As a consequence, the members of a particular community may hesitate to respond to requests to provide assistance or permit social integration. Indeed, in some cultures, it is believed that even mentioning the name of an individual who is ill or disabled puts the discussant at risk for a similar impairment. For example, the widely held European folk belief that a pregnant woman who sees or thinks of an individual with a disability "marks" her baby with the same impairment is still widely found among descendants of English and Irish settlers in the rural South and Yankee New England. In cultures where this belief is particularly strong, even a simple census or community needs assessment survey may miss a significant percentage of those they are trying to reach.

These traditional beliefs do not necessarily disappear simply because a genetics counselor, physician, or special educator explains the way genetic inheritance works or the physiological patterns of progression of a chronic illness. Often, new information is quickly integrated into the traditional system of folk beliefs. An explanation of how a genetic disease spreads through a family may be readily accepted, but does not guarantee that the older belief in a curse, or bad blood, will disappear. For the strong believer, the issue is not only how a disease spreads or a physical or intellectual impairment occurs, but why one particular person out of all those in a family or community is the one affected. Traditional beliefs systems have shown themselves to be particularly adaptable, often successfully integrating the most traditional of beliefs and the most modern of scientific research.

The consequences here are particularly of concern. Where disability is seen either as a divine punishment, an inherited evil, or the result of a personal state of impurity, the very presence of a child or adult with a disability may be something about which the family is deeply ashamed or with which they are unable to cope. Fortunately, even in such societies, abusive behavior toward infants and children, even those with the most severe of disability conditions, is relatively rare.¹ Of greater concern, however, is the issue of neglect—the failure of the parents to nurture and provide adequate ongoing care, education, and emotional support.

Neglect may be reflected in many forms. In some ethnic and minority groups, parents of young children may hesitate to come forward to request aid or advice. Keeping the child at home, unseen even by close family and neighbors, is, by some, considered preferable. This may be done for several reasons. Embarrassment about the child's condition may be only one factor. Equally as common is the practice of keeping a child isolated in an effort by caring parents to protect that child from the jeers and taunts (or feared jeers and taunts) of others.

In many countries, the very notion that a disabled child can be helped by early intervention or stimulation has not become a part of the standard knowledge base, even in the minds of medical and educational professionals. (Indeed, ideas such as early intervention date back only a few decades in our own country, and many parents of significantly impaired teenagers and young adults can still recall being told to "take the child home and love him until he dies.") Unfortunately, particularly in the case of pre-school-age children who may not receive needed interventions and services until they reach mandatory school-age, important developmental years are frequently lost in the process.

In addition to the particular beliefs and understandings of the immediate family, service providers and advocates must be aware that in those ethnic and minority groups where disability is regarded as unacceptable, there is often enormous social pressure placed not only on the disabled child and adult but also on his or her immediate and extended family. Even when families are aware of the need for special services, *they* may be reluctant to participate in programs, fearing that these will call attention to their members' physical or intellectual limitations. This is of particular concern for pre-school-age children with a chronic illness or disability who are yet to be enrolled in educational programs where their needs will be clearly identified and followed. Often, parents of these children may hesitate or refuse to participate in any programs if their child is not in need of immediate medical care. Where blame is attached to the individual with a disability, families who appear to be uncooperative or unenthusiastic about participating in programs may be basing their actions on a much broader set of social factors than outside program coordinators have considered. For example, when the traditional belief is that a disability runs in a family or is evidence of divine retribution, a family with siblings of

marriageable age may be more likely to hide its disabled member away so as not to lessen the chances of finding suitable mates for the other children. In many cases, parents and other family members may fear losing work, social status, or "face" should their child's condition become widely known.

Public disgrace is not the only possible issue involved. Among some immigrant groups, for example, those from parts of Eastern Europe, parents may have real fears that their children will be taken away and institutionalized should they be located by the authorities. This has been standard practice in the countries from which they have recently immigrated, and it represents a real fear on the part of caring parents.

Finally, it must be stressed that some cultural explanations of the cause of chronic disease or disability are quite positive. A recent study of Mexican-American parents of chronically ill children found that the informants believed a certain number of ill and disabled children would always be born in the world.^(Ref 6) They believed, furthermore, that they had been singled out by God for the role because of their past kindnesses to a relative or neighbor who was disabled. ^(Note 6)

Expectations for Survival

Not only is an understanding of the socially perceived cause of chronic illness and disability important, the accepted body of folk knowledge about the probability for survival by these disabled infants and young adults must also be noted.

An accurate understanding of the traditional expectations about the health and well-being of these children as they grow is imperative. The persistent belief in many societies that more severely disabled children will simply not survive makes the allocation of scarce resources such as medical care and parental attention to healthy children seem more reasonable to families. Even today, throughout much of the world, withholding of these necessities turns the cultural expectations into self-fulfilling prophecies. Although sophisticated medical technologies in the United States can now ensure the physical survival of many of these children, the parent's choice either to neglect such children or, conversely, to shower them with love and attention "because they're with us for so short a time" may reflect traditional expectations of survival. Such attitudes, unfortunately, may severely compromise attempts to encourage parents to plan realistically for their child's future. Either neglecting or overprotecting an ill or disabled child can certainly have grave implications for healthy psychological development.

Cultural expectations cannot be divided neatly into groups in which long-term survival is expected vs groups where it is not. How one is believed to be restored to health is also at times an important issue, and it has serious implications for long-term planning. For example, in some African-American households, particularly those that are strongly affiliated with the church, hope for even the most critically ill child is encouraged, with parents hearing from both family and friends that maybe a miracle will occur or that maybe the doctors are wrong. In at least one study this appears to have led to a far greater acceptance and improved quality-of-life for the child in question." On the other hand, such a belief, while comforting for those who believe, can also complicate long-term planning. Parents planning for a child's surgery, attempting to clarify an educational plan, or arranging for sophisticated adaptive equipment have all reported during interviews that friends and relatives, particularly older relatives, will dismiss long-term concerns by saying: "maybe God will make your baby all better on its own," and "don't worry so, wait for God's word, and all will be made whole."

Note 6: Interestingly, there was an unexpected addendum to this. Several of the same parents who welcomed the birth of a disabled child as God's will, voiced great annoyance not at their physicians, but at their clergy. Strong Catholics, they had fully accepted the Church's explanation that God Himself had assigned them their particular child, but were dismayed to learn their local priests knew little about disability. Many voiced great concern that some of their clergy carried the same misunderstandings and prejudices toward disability as the rest of society. Apparently, the parents feel that the clergy, whom they believe to be God's representatives here on earth, were failing in their role to provide a link to God and in passing along His further instructions and intentions for their children: "make your baby all better on its own," and "don't worry so, wait for God's word, and all will be made whole."

Expectations of Social Participation

Problems do not end when an individual who may be chronically ill or disabled survives childhood. Where society dictates limited occupational roles and few social roles for individuals with a chronic illness or disability, the time, energy, and expense invested in educating a child with a disability may be regarded by family members and their support system as unnecessary. (Indeed, the belief both in dominant US society and a number of ethnic groups still remains that many with chronic illnesses or disabilities will always be dependent and cannot be educated or live independently.) In many societies, the roles given to disabled individuals outside the home may be severely restricted; and parents may lose face or be severely criticized by family and friends from within the community if they were to be so heartless as to make their significantly disabled child work rather than caring for them at home.

Furthermore, certain cultural practices and value systems within ethnic or minority groups must be understood, even if the practices and values are not those with which the dominant culture feels comfortable. For example, a gender bias in favor of male children is found in many cultures. A Chinese

or Indian family may be willing to go to great lengths to obtain expert medical care or arrange for a solid education for a disabled son. Daughters, on the other hand, are often considered a poor financial risk, and disabled daughters, doubly so. Far fewer resources and much less attention may be given to girls and young women with chronic illness or a disability in traditional families. This does not mean that these children are not loved-it is simply perceived culturally as less justifiable to expend vast amounts of the family's resources on them.

Lack of formal education and occupational training should also not obscure the fact that disabled individuals master many skills and often contribute significantly to their households and family units. Indeed, there are probably few families which can afford to allow any but those with the most severe disability to remain idle. Child care, housekeeping, cooking, and cleaning done by disabled children and adults frequently make important contributions to the overall functioning of the family unit. Hence, a family's reluctance to educate or train a disabled child or encourage a disabled adult to work outside the home may have economic as well as social implications.

REDESIGNING US SYSTEMS TO BETTER SERVE A MULTICULTURAL POPULATION

At a broader level it is clearly impossible to understand chronic illness or disability in a multicultural society without more fully understanding some of the basic and long-identified issues in cross-cultural communication and the immigrant and minority experience. An extensive literature already documents many of the issues encountered when different ethnic and minority groups must be served by social, medical, and education systems that do not have some ability to be flexible in light of differing sociocultural needs. (Ref 1,2) A key issue in all of this is to remember that the standard US systems, laws, and approaches to serving children and adults with chronic illness and disability are not culture-free. They are unique products of the history and social fabric of the United States.

For example, both in law and in practice within US society, the father and mother of a chronically ill or disabled child will be asked to make the final decisions concerning that child's care and education. The nuclear family is the pattern we consider normal and upon which most of our programs are designed. However, cross-culturally, the nuclear family is a rarity; in fact, in only 6% of the world's societies are families as isolated and nuclear as they are in the United States today. The extended family is far more universally the norm.

In societies where the extended family is the norm, parents, particularly young parents, are considered far too inexperienced to make major decisions on behalf of their child and key decisions are made in consultation with older relatives, grandparents, uncles and aunts, and/or a more distant cousin if that individual is considered the head of the family. Not only are decisions made within a larger extended family unit, but much of the actual care, assistance, and emotional and financial support received will come from this extended family network as well.

While US law and custom without doubt will ensure that parents retain the right to make decisions on behalf of their child-and competent adults with a chronic illness or disability to make decisions on their own behalf-it would behoove service providers and advocacy groups to make allowances for extended as well as alternative family systems. Often, in an attempt to empower parents, clinicians, counselors, and educators have refused to include grandparents, cousins, or significant others who have accompanied parent(s) to conferences where a child's case is to be discussed. The assumption that such participation by "outsiders" is disruptive may not be valid. Indeed, parents may not be able to come to a final decision until others have been consulted, and parental requests for others to be included on such occasions should be respected.

Societies may differ not only in the central role played by families, but also in the way they are structured hierarchically. In many parts of the world distinct lines are drawn between members of society based on family connections, education, and wealth, and all members of the society are keenly aware of where they fit within this hierarchy. Professionals such as physicians and nurses, teachers, and social workers are often at the upper end of the hierarchy and their word carries great weight. In such environments a professional asking a patient whether a particular course of action is acceptable will be met with confusion. Such a question may be virtually meaningless within their frame of reference. In many cultures, professionals are presumed to know the answers, and asking for feedback indicates a lack of knowledge or training in the professional. Under such circumstances, when such parents are asked whether they approve of a particular course of action, their answer will almost invariably be a polite "yes." The patients and families who agree in such situations do not always intend to comply, and the frustration felt by professionals who struggle to set up services only to have patients and clients disappear or become lost to follow-up is significant *and* predictable from a cross-cultural perspective.

In societies that have strong social hierarchies, service providers' lives are also complicated by attempts to serve individuals who in the country of origin would be above them on the social ladder. Individuals who have grown up in families of wealth and power within some societies may be difficult to work with, for they may view all who must go out to work for their livelihoods, including professionals, as clearly below the top of the social ladder. In this case, the physician, nurse, or social worker may be treated as hired help. Many professionals can recount stories of individuals who have refused advice,

suggestions, or care while vociferously demanding to speak with the "top man" (rarely the top woman) and insisting that they be served first and best. This approach often comes as an eye-opener for professionals in the United States, who are usually treated with more respect, and has made for heated confrontations on many a hospital ward and in many a social service agency. In such situations, culture is, in large measure, to blame. The demanding, elite foreigner is often simply assuming that a hierarchical system of privilege similar to the one with which he or she is familiar also exists in the United States.

Even some of the most fundamental of American beliefs and values, such as individual choice and independence, do not necessarily translate cross-culturally. For example, a family which had recently immigrated from southern Italy reacted strongly (and negatively) to the suggestion that their 22-year-old retarded daughter move into a nearby group home. No amount of discussion of the advantages and independence their child would enjoy could persuade them. Further discussion revealed the cause: traditionally, no proper Italian girl in their social circles lived alone until she was married. The daughter's retardation was thus regarded as irrelevant, a contention strongly supported by the presence of two older, college-educated daughters, also living under the same rules.

Some issues considered key to serving chronically ill and disabled individuals in this country may not be as relevant within some ethnic and minority groups. Education and issues of evaluation through testing provide relevant examples. A complex battery of tests have been developed over the past 50 years in this country by well-intentioned middle-class and upper middle-class professionals for whom education has been very important in their own lives and the lives of their children. Such formal academic accomplishments may be of far less concern to many parents (although the long-term benefits of encouraging any child, where possible, to receive a good education and to become self-supporting is, we believe, important). At a recently observed school conference called by teachers of a mildly retarded, mainstreamed 10-year-old girl, her Puerto Rican mother was solemnly told that the child would be unable to compete in regular high school and, of course, would be unable to go on to higher education. The mother looked blankly at the team of experts and said: "I never finished eighth grade and I've done alright." She then expanded on her first statement by explaining that she wanted her daughter to find a nice boy: "She's kind of pretty, and she likes babies; I think she'll make a good mom."

Issues are not confined simply to differing perceptions of medical, educational, and social supports. The very understanding and expectations of child development may vary. A cross-cultural knowledge is needed, even when one is called upon to assess a child's physical, mental, and psychological development, for even here, culture does make a difference and an awareness of the expectations and experiences of a child within its own cultural environment is crucial.

In children, the expectations for physical self-sufficiency may vary markedly. The age of many childhood phases is based, in part, on social as well as physiological issues. For example, cross-culturally, toileting skills may vary widely (some cultures beginning as early as 4 to 6 months, some as late as 4 years). Toddlers may not be as adept at crawling if they are regularly carried or in feeding themselves if they are always fed by an adult. In some societies infants and toddlers are rarely separated from their mothers and may cry and carry on "inappropriately" when separated, especially if a stranger is nearby. Physical autonomy is viewed very differently in such societies than in the United States, where middle-class norms dictate that even newborns are often kept in separate rooms, far down the hall from their parents. (In some cultures, "abandoning" a baby in such a manner is considered abusive.) Conversely, some cultures stress autonomy.

In many societies, children are supposed to be seen and not heard, and children are encouraged to be shy with all adults, or all adults outside their immediate families. Trying to treat or evaluate such children using standard white, middle-class norms, where behaviors such as speaking assertively in front of grown-ups and looking adults squarely in the eye are valued traits, can be very misleading. Indeed, in the majority of the world's cultures, assertive children who stare directly into an adult's eye while answering them are simply considered rude.

It is important to determine whether a child-rearing practice is unique (and possibly limiting) to a disabled child, or whether it is the cultural norm for all children. Whenever in doubt, a good rule is to compare the treatment a disabled or chronically ill child receives to that of a non-disabled child of the same age and sex, whose parents have similar social, economic, and sociocultural backgrounds. For example, the coordinator of a program for disabled children recently complained that a Puerto Rican mother of a toddler with cerebral palsy continued to spoon feed her child, despite repeated insistence on the part of the staff that the child learn to feed himself. The coordinator and the staff feared the mother was coddling a disabled child and fostering an inappropriate dependency. On further inquiry, however, it became clear that the issue was not the child's disability. Many 2-year-old Puerto Rican children continue to be spoon-fed by their mothers months after their white middle-class cohorts have stopped. Such care, in Puerto Rican eyes, is simply part of being a good parent.

No matter what the particular culture involved, it is important to underscore the fact that children from all societies master the full range of developmental skills needed by the time they finish their pre-school years. We live in a society where the medical and intellectual assessment of such children is

often based on finely graded differences in development. However, evaluating children from culturally distinct backgrounds must be done with added caution.

Immigrant status adds to and may intensify some of these issues. Psychological stress, linguistic differences, changing personal and familial values, changing role expectations, and (often) lowered socioeconomic conditions all take their toll. For those immigrants who are here illegally, the fear of being sent back makes many reluctant-or extremely fearful-to come forward to request services for disabled family members. The fear of being sent back to chaotic economic or political situations can only be compounded by the fact that their native countries may well have no services available for their disabled family members.

Particularly among more recent immigrants, a long-standing fear of any government agency or hierarchy may make contact and assessment all but impossible. For such families, even the prospect of having a child separated from the parents for an overnight hospital stay may be refused by parents who have lost children in the past. Recently, a Southeast Asian mother became hysterical when her year-old daughter was taken out of the hospital room by a nurse to obtain urine samples. Unable to speak the language and fearing all authority, the mother believed her daughter would simply disappear. The staff, none of whom had any multicultural training, felt her reaction completely inappropriate. In fact, in light of her previous experiences, it was probably not. Three of her older children had been taken "briefly" from her for a work detail in Cambodia. None had returned.

The psychological and physical stress, and in some cases torture through which many of our new (as well as old) immigrants have passed before coming to this country, as well as stressful and often discriminatory experiences while in the United States, are unknown and unappreciated by all too many Americans, including many of those working in the medical and service delivery field. Immigrant parents need clear explanation, whenever possible in their native language, as to what will be done with their child and the reasoning behind it, thus allowing them to participate and make decisions on their child's behalf.

CHANGES IN TRADITIONAL BELIEF SYSTEMS

That a system of beliefs already exists does not imply that new information cannot be provided or that change will not occur. Traditional belief systems on disability have at times proved to be quite adaptive, shifting in response to social, economic, and educational experiences gained during the acculturation process.

When traditional beliefs are discussed, an issue that cannot be avoided is whether change should be fostered. With almost missionary zeal, some professionals and advocates insist that minority groups-particularly those new to the United States-be convinced of the scientific validity of current ideas and approaches. Such educational attempts are often frustrating and unproductive for all involved, for they beg the question of whether members of an ethnic or minority group would be willing to abandon their traditional belief systems.

This approach may also neglect to consider how functional and positive some traditional beliefs and practices are. In many ethnic and minority groups there is a tradition of strong community support for the child or adult with disability and his or her family. In such cases, it may be far wiser and more efficient to build on the strengths already demonstrated by these traditions.

Moreover, how each ethnic and minority group chooses to handle disability within its own ranks is, in part, its own decision. However, while traditional beliefs should be respected and community must always have a voice in the decisions made, we would strongly argue that in those instances where traditional beliefs about disability deny individuals their basic civil and human rights, changes can and should be advocated. Professionals can play a key role here by providing both individuals and families with the most accurate and timely information available, so that they can make informed decisions. However, the most productive on going change within ethnic and minority belief systems will, we suspect, come about internally, through the empowerment of individuals with chronic illness and disability who are members of these particular communities.

ASSESSING SOCIAL ATTITUDES TOWARD CHRONIC ILLNESS AND DISABILITY CROSS-CULTURALLY

Everyone has a cultural heritage that influences his or her health beliefs and practices. It is thus not practical to learn in detail the infinite details of specific cultures, but rather to assume that such variations occur and learn how they might affect one's health practices.' Rather than teaching every health practitioner to be a mini-medical anthropologist, it is more important for practitioners to be sensitive to the patient's heritage, to their own heritage, and to what happens when different heritages and belief systems come together.

US professionals are not only members of the dominant medical culture, but they also share the cultural identity of other racial, ethnic, religious, and gender groups." As such, they may also hold the prejudices and biases of their groups.

How then does one determine the attitudes toward chronic illness and disability, as well as attitudes toward medical care and other social services found within the particular ethnic or minority community with which one is working? When possible, discussion with individuals and families from these ethnic and minority groups who are already involved with issues of chronic illness and disability is a good place to start. The adult with a chronic illness or disability, not surprisingly, is often most aware of the strengths and limitations displayed by his or her own community's particular response to impairments and will be best able to identify how this may or may not articulate with attitudes in the broader society. Schoolteachers, religious leaders, elders, and traditional healers can provide further information on cultural and community attitudes and responses.

Professionals in our society are trained to obtain information by reviewing the literature; however, a direct approach, particularly in the case where little has yet been written, is often far more profitable. For example, a pediatrician recently recounted the efforts she had made in searching Medline to find information on Mexican attitudes toward the mentally retarded child, and she admitted to being frustrated over the lack of critical literature on the subject. She had overlooked her Mexican-American nurse, her Mexican-American secretary, and five Mexican-American cafeteria workers whom she saw daily in the hospital, all of whom, when asked, had insightful things to say on the issue.

Consulting members of a particular ethnic or minority group may prove to be valuable when trying to determine whether a particular individual's choices and actions are the result of cultural differences or true pathology.^(Ref #10-13) It is possible to dismiss potentially serious social and psychological reactions of an individual from another ethnic or minority group as simply being the result of cultural differences, when in fact the individual may be in need of direct and immediate assistance. It is also quite possible that an individual may display evidence of both cultural differences *and* individual distress. All cultures have customary ways for individuals to display grief, fear, concern, and disagreement. When an individual's actions exceed the customary limits, all societies designate such actions as inappropriate. In such situations, consulting with others from the same cultural heritage can prove to be extremely helpful in clarifying the situation. As in the case of all other patients, even in such situations, the right of a patient or client to privacy must be respected. As ethnic and minority communities are often small and closely connected, protecting the privacy of an individual, even when others in their community are called upon for input, is essential.

It is also important to note that when very traditional beliefs are at issue, those who most directly participate in the local community are often the best informed. An ethnic or minority group's prominent citizens may be better educated and more acculturated than many others in their community, and hence be unaware of, or far more ready to dismiss, traditional folk belief systems. For example, a French-educated, professional Haitian recently spent a good part of a morning convincing the social service staff of his local hospital that voodoo is something that Hollywood has made up about his fellow islanders. The same afternoon, a Haitian mother arrived at the clinic with a toddler with cerebral palsy festooned with amulets.

Acculturation ranges across a broad continuum, and determining an individual's or a family's belief systems and social structure must be done on a case-by-case basis. No one can simply assume on the basis of a person's cultural heritage, dress, or language what his or her individual ideas or understandings may be.^(Ref #14, 15) Nonetheless, it is important to remember that traditional attitudes about disability may hang on long after other cultural beliefs are gone, although more acculturated individuals may be sophisticated enough to know that publicly expressing beliefs, such as the presence of witchcraft, is unacceptable.

SUMMARY

To gain at least an initial understanding of the underlying beliefs and attitudes in a cross-cultural situation, we believe that the three key points discussed in this paper should prove a significant point of departure:

1. Traditional beliefs about the cause of chronic illness or disability will play a significant role in determining family and community attitudes toward individuals with a disability and will influence when, how, and why medical input is sought.
2. The expectation of survival on the part of parents and community will have an effect on the amount of time, energy, and cooperation shown by family and community for the individual who has an impairment."
3. The expectations by family and community for the social role(s) an individual with a chronic illness or disability will hold will affect a broad range of issues, including education, social integration, and independence.

Furthermore, although chronic illness and disability are often considered as issues distinct from the full range of problems encountered in society for immigrant and minority groups, in fact, these issues could not be more closely tied. The frequently discussed concerns within the ethnic and minority community about the role of the family, integration and acculturation, social articulation with the

greater American society, stress, cross-cultural misunderstanding, and outright prejudice can all compound the problems encountered for the chronically ill or disabled individual in a multicultural society.

CONCLUSION

Ultimately, it will be the members of these ethnic communities themselves and the chronically ill and disabled members of their own communities who will have the final say in how the old and new concepts are integrated or redefined. Not only should up-to-date information on chronic illness and disability be provided to these families and communities, but it behooves program providers to continue to monitor how new information and ideas are integrated into the established community belief system. It is our obligation to provide them with as much information and insight as we can muster, and it is their right to interpret these ideas in light of their own beliefs and concerns. No one individual can anticipate all the problems that might arise in an attempt to understand chronic illness and disability in a multicultural society, but we can all have enough sensitivity to realize that there might be significant differences, and enough respect for others to ask questions and listen carefully to the replies.

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