

Culture, Ethnicity, and the Family: Critical Factors in Childhood Chronic Illnesses and Disabilities

Hamilton I. McCubbin, PhD*; Elizabeth A. Thompson, MA*; Anne I. Thompson, MS*;
Marilyn A. McCubbin, RN, PhD†; and Andrea J. Kaston*

The family has always been implicitly and explicitly recognized as a critical social unit mediating cultural beliefs and traditions from one generation to another. This includes the mediation of beliefs and practices regarding health, illness, and chronic conditions.¹ There is, however, a dearth of research linking cultural and ethnic factors to the ways in which families respond to and cope with childhood illnesses and disabilities, despite the recognition that effective health care practice involves an awareness of the strong, often covert, influence of culture in shaping family reactions and responses to health problems. In fact, cultural and ethnic sensitivity alone is no longer adequate; health care professionals must also be ethnically and culturally competent, that is, be able to recognize, respect, and engage ethnic diversity in a way that leads to mutually desirable outcomes. This expectation for cultural competence is directly related to the ever-growing percentage of ethnic minorities in the United States, particularly the increase in the number of persons of Southeast Asian and Hispanic origin, the increased risk minority status places on child development, and the emerging emphasis on, if not renaissance of, cultural and ethnic identity.

The effectiveness of interactions with families of different cultural backgrounds may well be shaped by pediatricians' and other health care professionals' awareness of and sensitivity to the influence of culture and ethnicity on children's psychosocial development as well as on the family's response to the long-term care of a child with chronic conditions or disabilities. This article attempts to encourage this line of inquiry, first, by identifying the family processes of appraisal focusing on schema and paradigms which are influenced by culture and ethnicity and which appear to come into play in shaping the family's response to the illness or disability; and, second, by focusing on two Native American cultures, aboriginal American Indians and Hawaiians, their cultures' influence on the family system and the family's response to children with chronic illness and disabilities mediated by culture. Thus these two processes, schema and paradigms, become critical targets for intervention and fall within pediatricians' realm of sensitivity and, to some degree, their influence.

From the *Center for Excellence in Family Studies and the Family Stress Coping and Health Project, School of Family Resources and Consumer Sciences; and †School of Nursing, University of Wisconsin-Madison.

CULTURE AND FAMILY FUNCTIONING

The impact of culture on family life has been documented in the literature of family studies. The comprehensive review by Tseng and Hsu¹ reveals that over time culture has influenced family functioning in a great variety of ways: marriage forms, choice of mates, postmarital residence, the family kinship system and descent groups, household and family structures, the primary axis of family obligations, family-community dynamics, and alternative family formations.²⁻¹⁶ Historically, the family has been the conduit for cultural transmission, providing a natural atmosphere for traditions to be passed from generation to generation, as well as updated throughout the ages to keep culture and ethnic heritages alive. In turn, the traditions themselves have given families a sense of stability and support from which they draw comfort, guidance, and a means of coping with the problems of daily life.

A cursory review of the literature of chronic childhood illness across ethnic groups reveals a meaningful but rather stereotypic list of descriptions of family values and patterns of functioning, such as having "strong ties with extended families," and the "practice of tribal customs and traditions."¹⁷ Although they have not rendered clarity to the interacting influences of culture and the family, these stereotypes have served a useful function of pointing to the importance of cultural differences and revealing the profound variability that exists even within cultural groups. Efforts to homogenize ethnic groups, both in research and descriptive accounts, contribute to stereotyping and reinforce the current practice of oversimplification and using broad descriptive categories to encompass, and thereby mask, the variability within ethnic groups. Dependence upon stereotypes is strengthened by the absence of research that attempts to understand within-group diversity, such as the difference between the experiences and values of *immigrant* ethnic groups and those of *aboriginal* ethnic groups. A case in point: national studies of ethnic families continue to group Asian and Pacific Islanders as a major demographic category even though Asian-Americans are largely immigrants and Pacific Islanders are primarily aboriginal, Native Americans. Another example is the Asian-American category, which includes Japanese, Chinese, and Koreans and is too broad to render clarity to cultural differences and uniqueness.

Within the medical community, the importance of culture, ethnicity, and the family has long been rec-

ognized in the diagnosis of specific illnesses and conditions.^{18,19} Medical professionals are aware of the genetic and sociological connections between certain ethnic groups and higher incidence of certain illnesses; sickle cell anemia is more prevalent among African-Americans, and fetal alcohol syndrome is higher among Native Americans.²⁰ Yet, while culture and ethnicity have been used by medical professionals to make predictions about the distribution of illnesses, the impact of ethnicity and culture on the family's response to illness has not received the attention it deserves.

In assessing the adaptation of the family system to a chronic illness or a disability, the medical community has tended to apply Anglo-American perceptions of disability to all families, including those of ethnic minorities. The unspoken assumption has been that the existence of common symptoms would lead to similar family reactions regardless of the ethnic or cultural associations of the patient's family.²¹ When ethnicity has been considered, the tendency among practitioners has been to accept global assumptions of all ethnic groups without exploring the diverse aspects of culture that shape family problem-solving and adaptation.

We have attempted to address these issues here, by drawing from the limited literature on two aboriginal groups: Native American Indians, particularly the Navajo, and Native Hawaiians. In focusing on these two groups, we can begin to shed light upon which culturally relevant values and behaviors appear to shape the family's responses to children with chronic illness and disability. In turn, we can begin to understand the mediating influence of the family system's appraisal processes involving family schema and paradigms in adapting to the stress of childhood chronic conditions.

In an effort to minimize stereotypic global assumptions about ethnicity and culture, we chose these two groups of Native Americans, not only to illustrate cultural variation, but also to highlight their basic similarities, including aboriginal status, being colonized by nonnative groups, and the apparent resiliency of their native cultures to adversity. Additionally, many Native Hawaiians and Native American Indians, referred to together in this article as the *Aboriginal Cluster*, are striving for greater political recognition of sovereignty and a rejuvenation of their cultural heritages through major cultural renaissance initiatives. In examining the relationships between ethnicity and family coping with chronic illness and disability, the Native Hawaiians and Native American Indians are also similar in that each has a high risk for certain diseases. Native Hawaiians have higher death rates for heart disease, cancer, stroke, and diabetes than nonnatives.²² Likewise, the increased incidence of alcohol-related illnesses, diabetes, gallbladder disease and obesity among Native American Indians has been acknowledged by the medical community.^{23,24} For this article, it is also significant that both of these aboriginal populations place central cultural emphasis on the family as a mediator of culture and as a critical social agent

through which medical treatment and long-term care are provided.²⁵⁻²⁷

APPRAISAL PROCESSES OF FAMILY ADAPTATION: INFLUENCE OF ETHNICITY AND CULTURE

Both ethnicity and culture, used similarly in this article, are defined as the customary beliefs, integrated patterns of human behavior (eg, thought, speech, action), social forms, and traits of a racial group. They are nurtured, cultivated, and transferred across generations and among family members through traditions and celebrations, as well as through family problem-solving efforts.²⁸ In solving problems and managing family life when a child has a chronic illness or disability, the family's culture fundamentally influences two critical levels of family appraisal involved in the process of adaptation: the family's schema and paradigms.^{29,30} These processes of family life are the way in which families give "meaning" to having a chronically ill child, and they appear to play a fundamental role in shaping the family's responses and strategies for initial and follow-up medical care and treatment.

Family Appraisal Process: Family Schema and Paradigms

The concept of family schema, so important in processes of appraisal, may be traced to the general literature on the psychology of stigma, which underscores the critical importance of ethnicity and culture.³¹⁻³³ A family schema may be defined as a structure of fundamental convictions and values shaped and adopted by the family system over time, which creates the family's *unique character* and serves as an overriding shared informational framework against and through which family experiences are processed and evaluated. A family schema, which is expressed through the family's "world view," encompasses cultural and ethnic beliefs and values and evolves into an encapsulation of experience that serves as a framework for evaluating incoming stimuli and experiences.^{34,35} A family schema, which is highly resistant to change, could include values such as respecting and maintaining one's ethnic heritage and honoring and respecting one's elders; it might include convictions such as making a commitment to the education of one's children even if it means a personal sacrifice for family members, fostering independence for all members, having and maintaining open family communication, and sharing an unwavering commitment to the care of children and commitment to the preservation of the family unit. Not only does a family's schema give some order and stability to family life and is shaped by the influence of culture and ethnicity through the mediating process of family paradigms, it plays an influential role in shaping the family's responses to chronic illness or disability. Through this second-level family process of creating, maintaining, and changing paradigms, families also determine the specific problem-solving and coping strategies that are part of adaptation to the crisis of childhood chronic illness and disabilities.³⁶

The concept of family paradigms,³⁷ defined as the family's *specific* set of beliefs and expectations (eg, the use of tribal methods of treatment; the expectation that they work as a family unit to solve problems) is used to guide the family's patterns of functioning affecting *specific* domains of family life (eg, the domains of the marital relationship, child rearing, intergenerational relationships, health care and treatment, sibling relationships, work roles, education, definition and treatment of chronically ill and disabled members). In the context of a family's schema, family paradigms develop to guide the day-to-day care and management of family life. Paradigms serve as a family framework intended to create, guide, change, affirm, and legitimate family behaviors and patterns of functioning.³⁸ Family paradigms concerning the care of a chronically ill or disabled member may include a belief in an unconditional acceptance of the child accompanied by the expectation that all members will contribute to providing care, the belief in the importance of tribal methods for treating illnesses and the expectation that the health care system will allow and respect their "methods," and the belief in their definition of the family, which includes relatives and close friends and which is accompanied by their expectation that health care professionals will respect and affirm their "being part of the family." Within this family paradigm, grandparents' involvement in care and decision-making may be as important as the use of medical specialists and highly specialized medical centers or institutions.

The meaningful relationship between family schema and paradigms may be described by using the metaphor of a simple umbrella intended to provide protection, in this case to help a family unit cope with stress. At the top, the center of the umbrella is the hub, the family schema consisting of its shared and fundamental values and convictions. Emanating from the hub are a series of ribs, or spokes, each with a specific purpose designed to define and bring breadth, balance, and stability to the umbrella. These spokes may be viewed as family paradigms designed to guide different aspects of family life—the marital relationship, parenting, work and family, intergenerational relationships, and health care. Each is linked to the hub, but each has a unique purpose in guiding and supporting family coping and functioning. To complete the metaphor, the umbrella, characterized as the family's appraisal process, is designed to provide protection to the family system, particularly during periods of adversity and inclement conditions.

Once a paradigm is shaped and adopted by the family system, family behaviors will then be guided, if not governed, by that paradigm or successive paradigms. Once a paradigm is used to interpret phenomena and to guide family behavior (eg, a traditional family paradigm with mother working "full time" in the child caretaking role), the family will never function in the absence of some paradigm. Concomitantly, for a family unit to reject a paradigm that has served to shape a domain of family life without simultaneously substituting another (eg, an egalitarian family paradigm with shared roles and

responsibilities in child care) is to reject the nature of family functioning itself. Once shaped, adopted, and employed to guide family behavior, family paradigms will be maintained and upheld as long as they are successful for the family unit. Family paradigms are not likely to be doubted until the family faces a crisis that places the family's paradigm in question, whereupon alternative paradigms are considered and tested for congruency with the family's schema and for efficacy in shaping patterns of functioning that would be helpful in achieving a satisfactory level of family adaptation in the face of the crisis.

It is our perspective that family paradigms are influenced by the ethnic and cultural heritage and teaching of family members, which have already been incorporated into a family's schema. Ultimately, culture and ethnicity shape paradigms for family functioning, particularly in the crisis situations in which the family's stability and continuity may be threatened. To further this reasoning, we can begin to describe the integration of culture into the family schema and paradigms by drawing from the literature on Native American Indians and Native Hawaiians, the Aboriginal Cluster.

Cultural Factors and the Family Schema

To illustrate the role of ethnicity and culture in shaping a family's schema, we describe the Aboriginal Cluster, and contrast them with Anglo-Americans on five components of family schema.^{39,40} The family's schema includes shared values and convictions regarding family structure, self or group concept, spiritual beliefs, nature and the land, and time orientation (see Table 1). Specifically, the Aboriginal Cluster emphasizes the extended family structure, or tribal structure in the case of the Native American Indians. They have a common concern for the social and economic well-being of all and have a family network of support that encompasses both immediate and extended family. Generally, the opposite is true of the Anglo-American system, which emphasizes the closed, mutually supportive, nuclear family support system of parents and children. Predictably, the Aboriginal Cluster has developed a "we" group orientation where the needs of the whole rise above the needs of the individual.⁴¹ In the case of Native Hawaiians, the concept of *malama*, or caring, is the dominant theme that places the family group as a whole above the individual. Such a view is in sharp contrast to the Anglo-American schema, which underscores the individual or the "I" orientation.

Spiritual-religious underpinnings also play an important role in shaping the family's response to the challenge of long-term care of the child who is chronically ill or disabled. The Aboriginal Cluster views the world in terms of a "Great Spirit"; spirituality is part of the entire world. From the Native Hawaiian perspective, spirits appear in many forms, and the individual strives for unity with the cosmos as the way to achieve spirituality. This is unlike the Anglo-American schema, in which religion and spirituality are compartmentalized and individualized aspects of life, and spirituality is formalized through well-structured and well-delineated religious groups and be-

TABLE 1. Ethnic and Cultural Dimensions of Family Schema or Family World View

Family Values and Convictions	Anglo-American	Aboriginal Cluster	
		Native American Indian	Native American Hawaiian
Family structure	Nuclear family: parents and children	Extended family tribal structure: concern for social and economic well-being for all	Extended family: social support networks
Self/group orientation	"I": individual orientation	"We": group orientation with emphasis on the needs of the group above that of the individual	"We": group orientation with mutual <i>malama</i> (caring) more important than the individual
Spiritual beliefs	Individualized, compartmentalized: God is other-worldly	The Great Spirit is in all: spirituality is part of the world	Spirits appear in many forms in the world: individual should strive for spiritual unity with the cosmos
Land/nature	Land is inanimate: environment should be owned, controlled, and used by humans	The environment is living: land should be respected and preserved; what we do to the land we do to ourselves	Land is the basis for <i>aloha aina</i> or <i>aloha malama</i> (love and care for the land); resources must be nurtured and preserved for future generations
Time orientation	Future-oriented: time must be structured	Present-oriented: time is relative, life is cyclical	Present-oriented: time is relative

liefs. Religion then becomes a source of support to give meaning to life. Conversely, the Aboriginal Cluster sees spirituality as a natural outgrowth of *all* aspects of life. This spiritual orientation to life facilitates the Aboriginal Cluster's ability to create a family paradigm that cultivates the belief that a "disabled" child is "normal" and a "valued" member of the community, despite any physical or developmental handicaps.

The two additional components of family schema which shape family paradigms are nature and land, and time orientation. The Aboriginal Cluster views the environment as living. Land cannot be owned and should be respected and preserved. From their point of view, what we do to the land we do to ourselves. The Native Hawaiian view is that land is the basis for life. *Aloha aina* or *aloha malama* reflects their belief in loving and caring for the land. Resources must be nurtured and preserved for future generations. The Aboriginal Cluster extends the philosophy of harmony with the land to other aspects of life, with emphasis on achieving balance with nature and a sense of wholeness and harmony. By contrast, the Anglo-American schema regarding the land emphasizes that land is inanimate and that the environment should be owned, controlled, and used for productivity and development.

The future-oriented and "timeless" structure of the Anglo-American schema may be contrasted with the Aboriginal Cluster's view of time. From the latter's perspective, time is relative, just as life is cyclical. Native Hawaiians as well as Native American Indians think of time in the present; families do well if they take advantage of the positives and the strengths of the moment. The Anglo-American paradigm, on the other hand, encompasses time with a future-oriented perspective: it must be managed and used effectively.

Culture and Family Paradigms

One's culture and ethnicity have a formative effect on schema-level appraisal, and, whether or not ethnicity is consciously and planfully incorporated into

the paradigmatic patterns of family functioning, their effects can be observed.^{42,43} In a recent study of Navajo children with autism and their families, it was shown that despite some families' conscious choice to follow a less traditional path and thus define themselves as modern (rejection of ethnically based traditional ways) or semitraditional (living in a nontraditional way, but incorporating some ethnically based traditional ways), the influence of cultural beliefs and definitions of disability had a wide-ranging and powerful effect on the family's paradigm and the family's adaptation to the long-term care of their disabled member.

As depicted in Table 2, the culturally shaped paradigms of childhood chronic illness or disability for Native American Indians and Native Hawaiians are distinct from those paradigms held by Anglo-American families. Although Native American Indian values vary between specific tribes, the overall Native American Indian definition of illness or disability focuses less on the inabilities of the children involved, and centers instead on the function the children, whatever their abilities, can serve within the family and the community.

The wider range of accepted behavior in Navajo culture and their family paradigm, for example, means an individual's function within society is valued regardless of how limited his or her contribution is. "Thus to be able to care for lambs with minimal supervision, to help with chores such as gathering wood or carrying water, to express a flicker of recognition towards a familiar person, and to attempt to communicate through wordless vocalizations or non-verbal gestures, is quite often seen as falling within the broad standards of becoming a socially competent Navajo."⁴⁴

Whereas the Anglo family paradigm may consider disability and illness as foreign and intrusive in the family system, the Native American Indian and Native Hawaiian paradigm stresses the wholeness and harmony of life, of which illness is a part. While an Aboriginal Cluster family faced with a serious dis-

TABLE 2. Ethnic and Cultural Dimensions of Family Paradigms: Specific Beliefs and Expectations

Specific Domains of Family Functioning	Anglo-American	Aboriginal Cluster	
		Native American Indian	Native American Hawaiian
Child rearing	Parent-focused responsibility	Community-focused child rearing: children are to be shared; discipline and nurturing responsibility of all	Community-focused child rearing: each child is a <i>pua</i> (flower) representing the future; extended family has major responsibility
Work roles	Work for the future: success demonstrated through wealth	Work for the present: accumulated wealth should be shared with extended family; legitimates and values work roles	Work for the present: work should provide a service or benefit to society; legitimates and values different work roles
Education	Formal education stressed: individual achievement is stressed	Education occurs in all facets of life: individuals should learn from one another	Education is part of the group orientation: learning from one another is more important than individual achievement
Meaning and treatment of chronically ill and disabled members			
Role of disabled	Limited: viewed as different and stigmatized	Viewed as valued, functioning member of the society	Absorbed as valued, functioning members of the society
Source of illness	Scientific cause, outside of family	Introspective: illness or disability may be due to misconduct for which family is being punished, family or kin is responsible	Introspective: illness or disability reflects an imbalance in the <i>mana</i> (energy) or <i>pono</i> (harmony); family or kin responsible
Definition of illness or disability	Foreign, intrusive	Part of the whole: view illness as part of a more general pattern of harmony disharmony	Illness is part of wellness; normal
Language of disability	Stigmatizing labels	No words in most Native languages to classify disabled: assimilated	No words in Hawaiian language to classify disabled: assimilated
Orientation to treatment	Private and professional with focus on cure	Public: medicine involves ritual and spirituality; aimed at restoration of wholeness and spiritual balance; community/family involvement	Family and community with medicine focused on restoring <i>pono</i> (harmony) and wholeness
Problem-solving and accommodation	Individualized and private, with emphasis on professional care	Community-oriented, with emphasis on community acceptance and integration: extended family and tribal social support; emphasis on care of family members	Community acceptance and integration: extended family form protective net around individual: <i>aloha 'ohana</i> (love of kin) and <i>ho oponopono</i> (ritualized family and kin problem-solving)

ability is forced to process the same information and many of the same reactions of sadness and sorrow experienced by an Anglo-American family, the former's assessment and accommodation of the disability also centers around the restoration of harmony rather than a singularly focused attempt to "cure" or "fix" the disabled child.

Family Meaning of Disability. The Aboriginal Cluster appears to cultivate a family paradigm that gives no "special" meaning to having a child with a chronic illness or disability; the children and their medical conditions are not labeled. Illness and disability are seen as part of a more general world view of wellness and harmony; family members may differ in the degree to which they may be ill or well, but all members are accepted and valued regardless of their physical condition along the continuum. What the Aboriginal Cluster labels as the source or cause of illness appears to be an extension of their schema. They place responsibility for the child's medical situation upon themselves, as well as upon the natural cycle of life characterized by periods of harmony and disharmony. This paradigm places responsibility for care and treatment of the child upon

the family and kin system; harmony can best be achieved through shared family and community efforts. The extended family is emphasized as a source of long-term care. By contrast, for Anglo-Americans, illness and disability are foreign to the family unit, and thus become stigmatizing labels which, in turn, necessitate their receiving "special" treatment. Since the cause for the illness or disability is perceived to lie outside the Anglo-American family unit, the emphasis on medical treatment is likely to become a major strategy for providing ongoing care.

These paradigms about the meaning of disability are supported by two complementary paradigms in the realm of work roles and education. Parental roles in providing care for the children are supported by a paradigm which accentuates the value of providing a service or benefit to society. In contrast to the Anglo-American family system, in the Aboriginal family Cluster, education and learning are not only shared among family members, but experiential learning is highly valued and affirmed. Essentially, family development and functioning in the Aboriginal family Cluster is underscored in the family paradigms of sharing the responsibilities for long-term care among

members and kin, affirming the value of all members and their contributions to the family and its members.

Family Care and Treatment. Clearly, the family's paradigms which give meaning to illness and disability, and which shape the family's development and functioning, interact with the family's paradigm for providing care and treatment. The Aboriginal Cluster of families uses cultural methods to assist the family in restoring harmony and healing, and these methods often include the immediate family and the kin network of relatives and friends in problem solving. Acceptance and incorporation of the ill or disabled member is an underlying goal of the family's efforts to cope with the situation. The Anglo-American culture places a strong emphasis upon private and professional treatment of the chronically ill or disabled member. In this case the family functions as a closed unit, limiting information and care to select persons and professionals.

ETHNICITY, CULTURE, AND CLINICAL PRACTICE

With the added emphasis upon culture and ethnicity in understanding the plight of families caring for members who are chronically ill or disabled, there is a fundamental belief that the family system is a viable target for intervention.^{45,46} As Stanton⁴⁷ has emphasized, the family unit must be seen as people interacting within a context—both affecting it and being affected by it. Consequently, family-focused interventions assure that family members can change and family paradigms may be modified, thus allowing new behaviors and family patterns of functioning to emerge, if the overall family context is changed.

The ease with which health care professionals incorporate cultural or ethnic factors into their repertoire of interventions and strategies will depend upon several factors: (1) the cultural or ethnic background of the health care professional; (2) the sensitivity and competence of the health care professional to deal with cultural and ethnic factors; (3) the degree of conflict between the family's paradigm for care and treatment and the use of the services of health care professionals; (4) the residual and often asymptomatic influence of racism, poverty, and political powerlessness that accompanies cultural and ethnic consideration; and (5) the critical elements of language, and strength of cultural and ethnic identification.^{48,49}

There is a need for practitioners to be conscious of cultural beliefs, values, and perspectives on illness and disability that have significant influence on the perceptions and reactions of families whose responsibility it is to care for a chronically ill or disabled child. Cultural sensitivity and competence to deal with ethnicity can prevent health care professionals from unintentionally alienating parents or families through miscommunication or what the family considers inappropriate and unacceptable suggestions or behavior. Since such misunderstandings could result in the child's receiving inadequate medical attention, particularly if the family feels hesitant about placing trust in someone who so clearly does not

understand their values, it is vital that practitioners remain aware of the cultural context within which the family is operating. For example, a direct style of addressing the family and confronting the issues would likely be viewed as noncondescending by Asian-Americans and African-Americans, and conversely may be perceived as rude by Native American Indian families, and threatening by Mexican-Americans.⁵⁰

Similarly, if a suggested treatment conflicts with family cultural or religious beliefs, it may be difficult to convince the family that the physician has the child's best interest in mind. Conflicts may range from a refusal to consent to surgery due to cultural taboos against cutting someone open, to the varying definition of "disabled" across cultures. In the case of disability, if a child's condition does not seem problematic to the family, it is unlikely that they will respond favorably to the notion of treatment; there is no reason to apply a repair process to something that is not broken. For example, a Native American Indian family may reject the removal of a "disabled" child to an institution for care or therapy since they consider that the child functions as perfectly and productively as his/her abilities allow.

It is also important for physicians to understand how their own cultural identity and their own family "paradigms" might affect the reactions of a family or patient, particularly with regard to issues of trust and shared confidences, openness in discussing problems, value placed on the practitioners' medical opinion, and willingness of the family to accept treatment or advice for their child. Reticence in any of these areas is often attributable to the family's paradigms of cultural values or biases and thus should not be taken for ignorance about the problem or lack of concern about the need for a solution.⁵¹

In *Ethnicity and Health*, Farley⁵² argued that because all health care providers are part of diverse and mixed society, it is imperative for all primary care providers to be aware of and responsive to society's diverse cultural heritage. Some have developed a personal insensitivity to patients and, for example, fail to recognize an ethnically based family's paradigm which includes and legitimizes "at home" treatment; a treatment belief system resulting in bruises on a Hmong child from "coining" or "cupping" may be erroneously reported as child abuse. A caring and ethnically sensitive provider who recognizes the family paradigm, and the same clinical symptoms as the result of a culturally related healing system, may respond differently and appropriately.⁵²

A practitioner who is aware of the impact of cultural beliefs on a family's schema and ultimately on its paradigms regarding a chronically ill or disabled child is better equipped to approach discussions and suggest treatments in a way that the family finds nonthreatening and acceptable. This, in turn, will foster a trust between the family and the practitioner, which should make the family more willing to implement the physician's suggestions and may even enable the latter to convince the family of the need for certain treatments which, in the beginning, they may have rigorously opposed, or refused.

There are many specific ethnic or cultural practices which practitioners should consider on a situation-by-situation basis, among them: the implications for the family of the suggested treatment, for example, the cultural ramifications of a long-term separation of the child from the parents; the possibility of topics that should not be discussed with a parent who is not of the same gender as the physician; and cultural curative practices that the family may have legitimated in their paradigm and thus prefer over "modern" or "scientific" ones.⁵³ In the end, however, physician and parent have a common bond: the child's well-being. Thus, for the sake of the child, it behooves practitioners to understand their own prejudices, beliefs, and behavior and how these "fit" or do not "fit" with the family's schema and paradigms. Ethnic sensitivity and competence and family-centered, community-based care require this kind of collaboration and congruency.

ACKNOWLEDGMENTS

This project was funded by the Agricultural Experiment Station and the Center for Excellence in Family Studies at the University of Wisconsin-Madison.

We thank Drs Anne M. Donnellan, Jennie R. Joe, and Jeanne L. Connors for their timely contribution to the manuscript. We also thank Dr Joan Patterson of the University of Minnesota for her editorial assistance and insightful critiques, which helped to strengthen the article. We also thank Peggy DaValt, secretary, for its preparation.

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