Culture and the Care of Children With Chronic Conditions

Their Physicians’ Views

Julia Joseph-Di Caprio, MD, MPH; Ann W. Garwick, PhD; Claire Kohrman, PhD; Robert W. Blum, MD, PhD

Background: Little is known about physicians’ perceptions of the influence of culture on the health care of children with chronic and disabling conditions.

Objective: To identify physicians’ perceptions of the impact of the family’s ethnocultural background on the health care of school-aged children with chronic conditions and recommendations for improving care.

Design: Qualitative study in 2 midwestern metropolitan areas.

Setting: General community.

Participants: Convenience sample of 52 physicians nominated by 60 African American, Hispanic, and European American families of school-aged children with chronic conditions.

Methods: In-depth interviews were conducted with the physicians. Content analytic techniques were used to analyze the data.

Results: In 44% of the responses, the physicians reported that ethnocultural background did not influence the care the child received, noting that comparable care was provided to all of their patients. In 14% of the responses, the effect was unknown. The overall effect was negative in 26% of the responses and positive in 16%. Physicians’ recommendations focused on 4 topics: improving the training and education of health care professionals and families; ensuring good communication between the child, family, and health care professionals; supporting families; and improving the access and provision of services for children from diverse cultural backgrounds.

Conclusion: Although the majority of participants reported that ethnocultural background did not affect the care the child received from the health care system, physicians’ recommendations reflected awareness of the influence of culture on the care of children with chronic conditions and the need for further training on this issue.


Much has been written about the need for health care providers to address issues of culture in clinical practice.1-5 For example, one of the published guidelines for providing care for children with special needs specifically recommends that clinicians honor the racial, ethnic, cultural, and socioeconomic diversity of families.6 Yet, little is known about physicians’ views regarding the impact of culture on the care of children with chronic conditions. This study addresses this gap in the literature by investigating physicians’ perceptions of the influence of the family’s ethnocultural background on the health care of African American, Hispanic, and European American school-aged children with chronic conditions and their recommendations for improving care for children from diverse cultural backgrounds.

Understanding the role of culture in pediatric care is important for several reasons. First, the United States is an increasingly diverse nation, and children of culture have disproportionately high rates of various types of chronic and disabling conditions.7 Racial and ethnic minorities are the fastest-growing segments of the US population, composing almost 20% of the total population in 1990 and increasing to 25% by the turn of the century.8 Among those younger than 19 years, nonwhite children will account for one third of the pediatric population by the year 2000.8

Culture also affects how chronic and disabling conditions are defined and
PARTICIPANTS AND METHODS

RECRUITMENT

Data for this project were drawn from the second phase of the Cross-Cultural Meanings of Chronic Illness and Disability project. In the first phase of this community-based project, families who care for school-aged children with a variety of chronic illnesses and disabilities (eg, asthma, cerebral palsy, diabetes, Turner syndrome) were interviewed about how they view and manage these chronic conditions. The goal of the second phase was to determine physicians' perspectives on the impact that chronic conditions have on families from 3 ethnocultural groups—African American, Hispanic, and European America—as well as the impact that culture has on the child's care. Institutional review board approval was obtained before the project was initiated.

Sixty-one families from phase 1 provided written permission for us to invite the physician who knew their child best to participate in phase 2 of the project. Fifty-three physicians were identified, and 52 agreed to participate. The physician participants provided care for children in families who identified themselves as African American (n = 24), Hispanic (n = 17), or European American (n = 19). Approximately half of the families (n = 28) were recruited from the Minneapolis–St Paul, Minn, metropolitan area, and the rest (n = 32) were from Chicago, Ill. The families were recruited through community leaders who themselves were identified by community organizations that serve school-aged children (eg, YMCA, YWCA, community parks and recreation centers, coordinators of community health programs, religious organizations, and parent advocacy groups).

Community leaders identified and contacted families in their communities who had school-aged children with chronic conditions. A chronic condition was defined as an ongoing physical health condition with the following characteristics: (1) it has a biological, anatomical, or physiological basis; (2) it has lasted, or is expected to last, a determined period of time; and (3) it either produces or is very likely to produce 1 or more of the following long-term sequelae: shortened life expectancy, disability, disfigurement, limitation of function or activities compared with healthy peers, requirement of medical care or related services over and above the usual for the child's age, necessity for surgical intervention, requirement of special ongoing treatments at home or in school, dependency on medication or special diet for normal functioning, and dependency on technology for normal functioning.

To be included in this study, the child had to (1) have a chronic illness or disability with a physical health impairment of at least 1 year's duration, (2) be between 5 and 12 years old, and (3) live at home.

PROCEDURES

Members of the research team contacted the identified physicians to inform them about the study. Written permission was obtained from the physicians before their participation in the study. They were informed that their participation was voluntary and that they could withdraw at any time. Face-to-face, semistructured interviews were conducted with the physicians in their offices by means of an interview guide that assessed the physician's perception of the impact of the child's chronic condition on the family and the influence of culture on the child's care. The interviews were conducted by 1 of us (J.J.-D.) in Minneapolis–St Paul, who is a physician, and by 3 members of the research team in Chicago (C.K. and 2 research assistants), who are social scientists. The interviews were tape recorded and then transcribed verbatim.

Sixty interviews were completed. The discrepancy between the number of interviews (n = 60) and the number of physician participants (n = 32) is because several families nominated the same physician. Since the interview guide was designed to assess the physician's perspective on a particular case, separate interviews were conducted for each child.

This report focuses on the analysis of physician's responses to 2 specific open-ended questions in the interview guide: (1) How has the family's ethnocultural background affected the care the child receives from the health care system? (2) What recommendations do you have for improving the care of children with chronic conditions from different cultural backgrounds?

ANALYSIS

Content analytic methods were used to analyze the open-ended interview data gathered from the participants. The principal investigator (J.J.-D.) first carefully read the transcripts in their entirety and identified major themes. Next, responses to the 2 research questions were reviewed on a line-by-line basis and coding categories were identified. Then a code book was constructed that included instructions, operational definitions for coding categories, and lists of coding categories for each research question. Using the code book, 2 independent raters (the principal investigator [J.J.-D.] and a research assistant) coded each transcript. The interrater agreement for codable incidents was 95%. Reliability was calculated by dividing the total number of exact agreements by the total number of incidents coded by both raters. Discrepancies between the raters were resolved by having a third person code the disputed segments.

treated. For example, European Americans typically emphasize physical survival and functional capacity and therefore tend to battle against chronic conditions and disabilities that they see inflicted on them. In contrast, many Asian cultures emphasize living in harmony with nature; thus, a chronic condition is seen as part of the normal cycle of life. A person's culturally based health beliefs and practices determine what problems are recognized as needing traditional Western medical care and whether someone will follow through with prescribed treatment. Conversely, because of historic inequalities and racism in the health care system, persons from minority groups may delay seeking health care. Beliefs about health and illness also influence clinician-patient communication.
tals, since placing the child in the translator role could violate traditional parent-child boundaries.8

Understanding the family’s cultural background is particularly important for physicians who work with children with chronic or disabling conditions, as the majority of daily care for these children is provided by families, who are the mediators of cultural beliefs and practices for their children.13 Health care professionals need to understand the cultural context in which care is provided, since culture influences how families view and manage the child’s chronic condition.6,14 For example, many Native Americans live in extended family and social support networks where the emphasis is on community acceptance and integration of people with chronic conditions, rather than private, individualized care.13 This study focuses on aspects of culture related to the family’s ethnicity, which refers to the family’s identification with a group with shared cultural traditions and a heritage that spans generations. A family’s ethnocultural background is reflected in its customs, rituals, values, attitudes, and beliefs.15

### RESULTS

#### PARTICIPANTS

Participants included 15 pediatricians, 6 family practice physicians, and 31 pediatric specialists. Most practiced primary care (n = 29 [56%]), and their practice locations ranged from a specialty hospital to an urban community clinic. The majority of the participants (n = 30 [58%]) had been in practice 20 years or less (range, 1-35 years; modal category, 11-15 years). Approximately half of the physicians were from Minneapolis–St Paul, and the other half were from Chicago.

The majority of physicians (72%) who responded to a question about how they described their own ethnocultural background mentioned race or ethnicity. For example, many of the physicians (n = 24) described themselves as white or of European origin. Four of the physicians said that they were African American, and 13 mentioned other ethnicities.

#### EFFECT OF CULTURE ON CARE

The physicians’ responses to the question about the effect of the family’s ethnocultural background on the care the child receives from the health care system were divided into 4 major categories: (1) positive effect, (2) negative effect, (3) no effect, and (4) effect unknown. Table 1 summarizes the findings by the family’s ethnicity and type of effect on care. Note the range of types of effects reported for each ethnocultural group.

#### POSITIVE EFFECTS

In 6 cases, physicians discussed the positive effects that the family’s ethnocultural background had on the child’s care. Five factors were associated with these positive effects: (1) positive caregiver characteristics (eg, an involved parent or family who demands that their child receives necessary care, or a personable parent who communicates well with staff); (2) religiosity of the family; (3) parental acceptance of the child’s chronic condition; (4) increased attention related to a language difference between provider and family; and (5) availability of family resources. In reference to the influence of a family’s religiosity and caregiver characteristics on patient care, one physician said, “When you have a family like this, you know, you just really want to do everything you can. I mean, it tends to energize you.” In another case, a physician said that the family’s cultural background made the family more accepting of the condition, and, thus, the child received better care. Another physician explained that a Spanish-speaking family’s inability to speak much English had a positive effect on the care the child received. He said he gave the family more attention because, “I know that they have handicaps with communicating with other staff.”

#### NEGATIVE EFFECTS

Physicians identified language barriers, lack of understanding of a family’s culturally based health beliefs, and factors that may be perceived by physicians as either cultural traits or individual characteristics (eg, negative caregiver characteristics, family problems, and fragmented care) as reasons why the family’s background negatively affected the child’s care. In 8 cases. Language barriers were the most commonly cited problems that affected the care of children in Spanish-speaking families. In reference to interpreters, one physician said,

Quite often they use people who are not trained medical professionals. You’d go to an emergency room, even at some of our best children’s hospitals, and get a cleaning woman who will serve as an interpreter because it’s 12 o’clock at night and nobody’s around that speaks Spanish.

Another physician reported that language barriers made it difficult to establish a good relationship with the child and to find resources for the family.

#### NO EFFECT

In the majority of cases (44% of the responses), the physicians said that ethnocultural background had no effect on the care the child received because of 2 predominant reasons: (1) standard care is provided to all children with a given condition regardless of their ethnocultural background.
background and (2) certain families surmount obstacles to health care and are able to ensure that their child receives needed health care services. For example, the physician of a Hispanic child noted that the child's mother was able to overcome problems with care: “Of course language was a barrier, but she could handle the situation. She has her ways to handle the situation.” The physician noted that other family members spoke English, therefore enabling the mother’s “looking for the place for her to go in order to get better things.” The physician did not indicate whether the mother found her ways satisfactory, nor was it clear whether he was making assumptions about her or her ethnic group.

EFFECT UNKNOWN

In 10 cases, physicians responded that they did not know about any effect of ethnocultural background on the care the child received from the health care system. Some physicians noted that they did not know how other health care providers interacted with the child or their family. For example, one physician said, “I don’t know how they are treated outside of my office.” Some physicians added that they could not comment about other influences on the family, such as social supports.

PHYSICIANS’ RECOMMENDATIONS FOR IMPROVING CARE

Physicians provided a variety of recommendations for improving the care of children with chronic conditions from diverse ethnocultural backgrounds. Recommendations are summarized in Table 2.

COMMUNICATION RECOMMENDATIONS

The most frequently mentioned recommendations were related to communication between the physician and the family. According to many physicians, health care professionals need to ensure good communication between the child, family, and themselves by gaining the family’s trust. They suggested that respecting the family’s culture, identifying family strengths, learning about the family’s cultural background and functioning in the community, and communicating medical alternatives clearly to the family do this. One participant said,

I have people here from all over the world. Whether they are from Asia, Africa, Latin America, Europe, they all care about their children. They want their children to be healthy. If they have some chronic problem, they want somebody who can explain it in clear language.

Some physicians made language-related recommendations. For example, they recommended providing information in the family’s language and assigning an interpreter to the family to accompany them to appointments and help them coordinate care.

TRAINING RECOMMENDATIONS

Participants made specific recommendations for the training and education of physicians to improve the care of children with chronic conditions from different cultural groups. Specifically, some physicians recommended recruiting minorities into health care and training a diverse group of providers. Other participants said that providers need to learn about the patient’s culture by listening to families, as well as by learning about the values, beliefs, and practices of different cultural groups. For example, one physician noted the benefits of continuing education and said, “I have actually done some additional reading to understand some of the different cultural values.” Finally, one physician recommended that providers work collaboratively with healers from different ethnocultural backgrounds, saying, “At what point do you realize that there is something going on that you don’t know how to deal with and you need to seek a consultation from a health care provider, some kind of medicine man, a shaman, or Western physician, or the pharmacist down the street?”

Many physicians also recommended educating the families of children with chronic conditions from different ethnocultural groups by assessing the families’ understanding of the medical condition and how it impacts family life and providing education to all members

Table 2. Physicians’ Recommendations for Improving Care for Children With Chronic Conditions From Diverse Cultural Backgrounds

<table>
<thead>
<tr>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ensure good communication between child, family, and health care professional</td>
</tr>
<tr>
<td>Gain family's trust by respecting family's culture</td>
</tr>
<tr>
<td>Identify family strengths</td>
</tr>
<tr>
<td>Learn about family's cultural background and functioning in community</td>
</tr>
<tr>
<td>Communicate medical alternatives clearly to family</td>
</tr>
<tr>
<td>Language-related recommendations</td>
</tr>
<tr>
<td>Provide medical care and information in family's language</td>
</tr>
<tr>
<td>Assign an interpreter to family to accompany them to appointments and help them coordinate care</td>
</tr>
<tr>
<td>Educate providers</td>
</tr>
<tr>
<td>Recruit more minorities into health care</td>
</tr>
<tr>
<td>Train a diverse group of health care professionals</td>
</tr>
<tr>
<td>Learn about patient's culture by listening to families</td>
</tr>
<tr>
<td>Learn about values, beliefs, and practices of different cultural groups</td>
</tr>
<tr>
<td>Learn how different cultures define disability</td>
</tr>
<tr>
<td>Work collaboratively with healers from different cultural backgrounds</td>
</tr>
<tr>
<td>Educate families</td>
</tr>
<tr>
<td>Assess family's understanding of medical condition and how it impacts family life</td>
</tr>
<tr>
<td>Educate child and family about medical condition, health care system, and available resources</td>
</tr>
<tr>
<td>Link families with other families of similar ethnic backgrounds who have children with special health care needs</td>
</tr>
<tr>
<td>Provide videotapes and educational materials in family's own language about medical condition</td>
</tr>
<tr>
<td>Support families</td>
</tr>
<tr>
<td>Identify who is in family unit</td>
</tr>
<tr>
<td>Acknowledge positive role of extended family members</td>
</tr>
<tr>
<td>Advocate for child and family</td>
</tr>
<tr>
<td>Coordinate child's care with family and other providers</td>
</tr>
<tr>
<td>Facilitate appropriate referrals</td>
</tr>
<tr>
<td>Individualize treatment for each child and family</td>
</tr>
<tr>
<td>Involve providers from family's cultural background in child's care</td>
</tr>
<tr>
<td>Provide continuity of care</td>
</tr>
<tr>
<td>Improve access and delivery of services</td>
</tr>
<tr>
<td>Locate clinics in communities</td>
</tr>
</tbody>
</table>
of the child's family about the medical condition, the health care system, and available resources. Other recommendations for educating families included linking families of children with chronic conditions with other families of similar ethnic background who have children with special health care needs and providing videotapes and educational materials in the family's own language about the medical condition.

FAMILY SUPPORT RECOMMENDATIONS

Participants had a number of recommendations for supporting families of children with chronic conditions from diverse ethnocultural backgrounds. Some physicians said that providers need to understand who is in the family unit, acknowledge the positive role of extended family members, advocate for the family, coordinate services with the family and other providers, and facilitate appropriate referrals. The physicians also recommended individualizing the care of children with chronic conditions from different ethnocultural groups, involving providers from the family's cultural background in the child's care, and providing continuity of care.

Finally, some providers recommended improving access and delivery of health care services to children with chronic conditions, by locating clinics in communities and offering home visits. One physician said,

The nurses and the clerical staff and those folks, if they haven't worked at [this health center] they've been in the community for 10 or 15 or 20 years, so there's clearly a sense this is not a place where other people work. It's an “us” kind of place. And that, I think, is important for the patients, to feel like it's their health center, not someone else's foreign health center that they're going into.

The goal of this qualitative study was to identify physicians' perspectives on cultural aspects of caring for children with chronic conditions from diverse cultural backgrounds. Although this exploratory study is limited in size and scope, the findings provide the groundwork for future research, and the recommendations for improving care have important clinical and training implications for clinicians. Regardless of the child's ethnicity, the majority of participants stated that the family's ethnocultural background had no effect on the care the child received from the health care system. There are several possible explanations for this finding. Physicians may have been reluctant to say that the family's ethnocultural background affected care, because to do so may suggest that patients receive differential treatment as a consequence of their background. Also, if a family's ethnocultural background was not perceived by the physician to be significantly different from their own, or to have interfered with the child's medical management, physicians may not have viewed culture as having an effect on care. This conclusion is supported by the fact that the majority of physicians who reported that the family's background had a negative effect on care did so primarily when discussing Spanish-speaking, Hispanic families who encountered language barriers in the health care system.

The fact that physicians in this study described relatively few positive influences of culture on the child's health care is an interesting finding in light of recommendations for providing family-centered care. The goal of family-centered care is to build on family strengths, not deficits. Our view is that family-centered care requires an acknowledgment and understanding of the positive influence of culture on the care of children with chronic conditions. There are at least 4 reasons. First, family functioning is strongly influenced by culture. Second, health care providers can facilitate healthy family functioning by building on family strengths and reducing risk factors, such as inadequate support networks, that contribute to poor outcomes. Third, the experience of illness is culturally shaped in that how chronic conditions are perceived, experienced, and withstood stems from patients', families', and providers' culturally specific explanatory models of sickness. Clinicians can provide culturally competent care by first listening to the meanings that chronic conditions have for families and identifying their beliefs about chronic illness and disability. Fourth, health care professionals can then more effectively plan care that fits the family by understanding how culture shapes views of chronic illness and disability. By treating the chronic condition within the cultural context of the family, the provider can influence clinical management, compliance, patient satisfaction, and treatment outcomes.

A limitation of the present study is that a select group of physicians were interviewed. Therefore, the extent to which these findings can be generalized is limited. Nevertheless, this study explored an area that has not previously been investigated, and key issues were identified for further investigation. The hypothesis generated from this work is that many physicians who provide medical care to children with chronic illnesses and disabilities have a limited understanding of the role of culture in health care. Whether this is because these physicians have limited knowledge of the importance of culture and ethnicity in the lives of children, especially children whose families identify themselves solely as European American, warrants further study. In addition, the perception of some physicians that acknowledgment of a child and family's ethnocultural background may portend inferior, biased care needs to be examined further. Many of the physicians perceived culture as factoring into care only when it interfered with medical management.

RECOMMENDATIONS

Overall, physicians' recommendations for improving the care of children with chronic conditions from diverse cultural backgrounds were similar to those reported by families in the first phase of the project. Physicians and families both emphasized the need to improve (1) the education that health care professionals and families receive; (2) communication between the child, family, and health care professionals; (3) family support resources; and (4) the access and provision of services for children with chronic conditions.

We recommend that physicians receive training, starting in medical school, to improve their understanding of the role of culture and ethnicity in their patients' lives and how they can use this understanding of the role
of culture in their clinical work with young people who have chronic conditions and their families. The American Academy of Pediatrics Committee on Pediatric Workforce recently published recommendations for medical school, residency, and continuing education training in culturally effective health care. Continuing education forums need to address how clinicians can implement culturally sensitive care in a busy practice. Clinicians must be aware of the diversity within ethnic and minority communities and avoid stereotyping the families they serve. Effective techniques that easily incorporate cultural issues into clinical practice need to be developed. For example, interview questions and brief questionnaires that address cultural beliefs and practices need to be developed and field-tested in clinical settings. Finally, the large number of physicians who perceived language as a barrier to the care of the Hispanic children indicates that training in the use of interpreter services should be included in the medical school curriculum. Clinicians should also be trained that culture is much more than language and affects all of their interactions with patients.

Accepted for publication February 15, 1999.

This study was part of the Cross-Cultural Meanings of Chronic Illness and Disability project and was funded in part through grant H133G30005 from the National Institute on Disability and Rehabilitation Research and through Adolescent Health Training Program grant BRHP05053 from the Maternal and Child Health Bureau and Minnesota Rehabilitation Research Training Grant H133P0004 from the National Institute on Disability and Rehabilitation Research, all in Washington, DC.

We acknowledge the contributions of research assistants Emma Fritz and Janet C. Titus.

Reprints: Julia Joseph-Di Caprio, MD, MPH, Department of Pediatrics, Hennepin County Medical Center, 701 Park Ave S, MC 867B, Minneapolis, MN 55415 (e-mail: julia.joseph@co.hennepin.mn.us).

REFERENCES