The Impact of Thalassemia on Southeast Asian and Asian Indian Families in the United States: A Qualitative Study

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Objective: To describe the challenges, including sociocultural and socioeconomic barriers, faced by an urban immigrant population in the United States affected by thalassemia major.

Design: Ethnographic, semi-structured, 1-on-1 interviews using an interview guide developed for this study. Digital recordings were transcribed and data analyzed using constant comparative method.

Setting: University-based, Comprehensive Thalassemia Program at Children's Memorial Hospital, Chicago, IL, USA.

Participants: Fourteen Southeast Asian and Asian Indian parents of children with transfusion dependent thalassemia.

Main Outcome Measure: Qualitative descriptions of parental experiences, frequency of codes applied to interviews and emergent themes.

Results: Thalassemia has its greatest impact on the emotional and social well-being of affected children and their parents. Current and future concerns were related to disease-specific complications and challenges with management such as transfusions and chelation therapy. These perceptions were tied to parental hope for a cure, a frequently coded coping mechanism. Despite their availability, few parents relied on support systems beyond immediate family members due to perceived public knowledge gaps about thalassemia. Culturally based past experiences and barriers did not emerge as dominant themes in our analysis.

Conclusion: The impact of thalassemia is tremendous for affected children and their parents and is due more to factors that were either disease-specific or common to other chronic disease models rather than those influenced by culture. The unmet needs of these families require additional investigation to facilitate the development of initiatives aimed at improving quality of life and lessening overall impact of thalassemia. (*Ethn Dis.* 2011;21(3):361–369)

Key Words: Thalassemia, Qualitative Research, Southeast Asian, Asian Indian

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Introduction

The thalassemia syndromes comprise a heterogeneous group of disorders in which mutations in the α globin or β globin genes cause decreases in the amount of globin chains that make up hemoglobin. Chain imbalances associated with the reduced production of either α globin or β globin components of hemoglobin result in poor red blood cell production and hemolysis. Consequently, individuals affected by thalassemia may experience varying degrees of anemia, poor growth, iron overload and bony abnormalities as well as may require lifelong transfusions. The clinical and psychosocial impact of thalassemia on affected individuals is tremendous[1,2] and, left untreated, the condition may lead to early morbidity and mortality.

In North America, thalassemia was initially described in individuals of Mediterranean descent, the majority of whom had β thalassemia. Worldwide, however, Asia, the Indian subcontinent and parts of the Middle East account for almost 95% of live births affected by thalassemia.[3] Recent changes in immigration patterns have resulted in an influx into North America of these populations disproportionately affected by thalassemia.[4–7] Despite the increase in individuals with thalassemia from Asia and the Indian subcontinent in the United States, few studies have systematically examined the challenges associated with health care access faced by this emerging group. Barriers to health care in this population include language difficulties, unfamiliarity with Western medical practices or socioeconomic hardships.[8,9] Mistrust of health care providers, who may not understand thalassemia and its management, may lead these individuals to underutilize the health care system.[10] These barriers contribute to disparities in health-related outcomes and may be especially salient in the immigrant thalassemia population.

Special efforts are required to understand the factors, including sociocultural and socioeconomic, that affect the health care of the US immigrant population affected by thalassemia. It is also imperative that we gain a better understanding of the struggles these parents and their affected children face given the little data that exist in the literature about the psychological im-

It is also imperative that we gain a better understanding of the struggles these parents and their affected children face given the little data that exist in the literature about the psychological impact of thalassemia during childhood.[11,12]

Table 1. Interview questions and domains of inquiry

Domain	Questions
Impact of thalassemia on the parent, affected child and family	What is it like for you, as a parent, to have a child with thalassemia? How has having a child with thalassemia changed your life? What is it like for the rest of your family to have a child with thalassemia? How has thalassemia affected your child? Affected how your child is doing in school? Affected how active your child is (probes: taking part in sports, playing with friends, taking gym class at school)? Affected how your child feels about himself or herself (probes: how happy or sad your child is day to day)? What are some concerns you have for your child's future (probes: living independently, holding a job, paying for healthcare)?
Sociocultural and socioeconomic barriers to health care access	What do you do, as a parent, to make sure that your child gets good medical care for his/her thalassemia? Please give me some examples of things that get in the way of your child's thalassemia care (probes: problems with insurance, transportation, language or other reasons). What is it like for you when your child's thalassemia doctors or nurses talk to you about your child and your child's medical care? Please give me some examples of things that are hard for you to understand when your child's thalassemia doctor or nurse talks to you. How can doctors or nurses help you understand these things better (probes: written information in your own language or through an interpreter)? What are some things your family does to help your child with thalassemia? Where did you learn about these things? How comfortable are you talking with your child's thalassemia doctor or nurse about these things?
Family and social support network and coping mechanisms	Who are some of the people you talk to about your child's thalassemia? Tell me what you talk about with them. Who are some of the people you would not be comfortable talking to about your child's thalassemia? Tell me why you feel uncomfortable talking to them about your child's thalassemia. Where else do you turn to for support in dealing with your child's thalassemia? What beliefs do you have that help you deal with your child's thalassemia? How comfortable are you talking with your child's thalassemia doctor or nurse about these beliefs?

pact of thalassemia during childhood.[11,12] To our knowledge, this study is the first to systematically examine the unique aspects of thalassemia among emerging North American population by using interviews with parents of affected children. Our broad objectives were: 1) to describe the challenges, including sociocultural and socioeconomic risk factors, faced by an urban immigrant population affected by thalassemia; and 2) to generate hypotheses and conceptual model that may lead to the development of a set of initiatives aimed at improving health care for this population.

METHODS

Target Population and Sampling Frame

The unit of analysis was a cross-sectional cohort of parents of children with thalassemia followed in the Comprehensive Thalassemia Program at Children's Memorial Hospital in Chicago, Ill. The Chicago-area population is culturally diverse and contains sizable Asian and Asian Indian communities. Asian and Asian Indian children comprise almost 90% of patients requiring chronic transfusion support in our program. We relied on purposive, homogenous sampling of key informants who met these criteria: 1) parent of a child with thalassemia requiring transfusion support; and 2) parent is of Asian, Southeast Asian or Asian Indian descent. Parents rather than their affected children were interviewed for two reasons. More than half of the children in this study were < 12 years old, and as such, we believed their parents would better articulate the impact of thalassemia on both their children and the family. Also, these parents could offer more insight into the relationship between culture and thalassemia given the majority of their children were born in the United States. We conducted 14 interviews divided equally into two groups: 1) Asian and Southeast Asian (Chinese, Lao, Vietnamese, Cambodian) and 2) Asian Indian (Indian, Pakistani). Informants were categorized by ethnicity rather than by their child's genotype since all children were transfusion dependent and therefore, clinically similar in disease severity and intensity of management required. This non-probabilistic sample size was derived from the principle of theoretical saturation, in which it is assumed that further interviews and data collection no longer yield new information or novel themes due in part to the homogeneity of one's sampling population. It has been shown that 12 to 14 interviews derived from a relatively homogeneous sampling population are sufficient in qualitative studies similar to ours.[13]

Interview Guide and Data Collection

Interviews were conducted using a moderator's guide (Table 1) consisting of 13 direct, open-ended main questions and probes for when a respondent's initial answer did not cover key areas of interest. All respondents were

Table 2. Final codes and subcodes from parent interviews

Domain	Final Codes and Subcodes
Impact of thalassemia on the parent, affected child and family	Parental impact (PI)
	PI – Financial and lifestyle
	PI – Emotional
	Child Impact (CI)
	CI – School performance
	CI – Disease management
	CI – Social and emotional
	Family impact
	Disease management
	Future concerns
Sociocultural and socioeconomic barriers to health care access	Barriers to care (BC)
	BC – Provider deficits
	BC – Parental deficits
	BC – Disease management
	Knowledge Gaps (KG)
	KG – Parental knowledge
	KG – Provider knowledge
	KG – Family and friends
	Communication with team
	Cultural practices
	Past experiences
Family and social support network and coping mechanisms	Support network
	Coping mechanism (CM)
	CM – Educate self
	CM – Educate others
	CM – Hope for cure
	Faith and religion

asked identical questions in the same sequence divided into three primary domains of inquiry: 1) impact of thalassemia on the parent, affected child and other family members; 2) sociocultural and socioeconomic barriers to health care access; and 3) family and social support network and coping mechanisms. Parents were recruited from the clinic setting during either their child's regular clinic visit or transfusion appointment. A single trained research assistant conducted all interviews in the clinic or home setting. The interviewer was not involved in the care of any of the patients whose parents were interviewed to maintain openness between the subject and interviewer. Participants completed a brief, self-administered questionnaire to collect demographic data. Although interpreting services were offered to each parent, all parents preferred to be interviewed in English. Interviews were digitally recorded for later verbatim transcription using a standard protocol. The Children's Memorial Hospital institutional review board approved this study.

Data Reduction and Analysis

All interview transcripts were analyzed using the constant comparative method, in which data are coded for underlying themes and the coding repeated until no further themes emerge. The codebook was developed using a standard iterative process, starting with a pre-determined set of codes and subcodes based on our interview questions (Table 2). The codebook was revised as needed with each round of application to the data (ie, in vivo coding) and included the following components to ensure consistent coding: 1) brief definition for each code; and 2) explanation of when to apply the code, with examples from the primary data. Each transcript was analyzed by a trained coder and reviewed by the principal investigator (RL) and co-investigator (MM) for coding appropriateness and consistency. Coded transcripts were subsequently analyzed using NVivo 7.0 (QSR International Inc, Cambridge, MA) to generate coding summaries and hierarchal ordering, which were then used to categorize coded segments with common elements into primary and secondary themes for hypothesis building. Using SPSS version 12.0 (SPSS Inc, Chicago, IL), we performed descriptive analysis to evaluate the frequency of applied codes contributing to our thematic analysis. For each code, we calculated the percent true agreement between 2 coders (BG and SP), who each coded a subset of seven interviews. Direct quotes in this paper were ascribed using pseudonym initials to protect the identities of the parents interviewed.

RESULTS

Target Population

We conducted 1-on-1, semi-structured interviews with 14 parents, 7 of Asian (Lao, Hmong, Vietnamese and Cambodian) descent and 7 of Asian Indian (Indian and Pakistani) descent, who had a total of 16 children (mean age 12.3 years old) with transfusion dependent thalassemia in our program. Fathers comprised 50% of the total target population, although separately, they comprised 43% and 57% of informants in the Asian and Asian Indian groups, respectively. All of the parents and 25% of their children were born outside of the United States. These children, 44% of whom were male, had the following thalassemia genotypes: 8/16 (50%) with β thalassemia major, 6/16 (38%) with hemoglobin E-β thalassemia, and 2/16 (12%) with hemoglobin H/Constant Spring (Table 3).

Applied Codes and Coder Agreement

The 20 codes most frequently applied to our transcripts are listed by

Table 3. Characteristics of parent key Informants and Their Children

Interview	Informant Sex	Child Sex	Child Age (years)	Child Ethnicity	Child Diagnosis
1	Father	F	9	Pakistani	β Thalassemia Major
2	Mother	F	15	Pakistani	β Thalassemia Major
3	Father	F	11	Vietnamese	E-β Thalassemia
4	Father	M	13	Pakistani	β Thalassemia Major
5	Father	M, M	11, 9	Pakistani	β Thalassemia Major
6	Mother	F	9	Cambodian	H/Constant Spring
7	Mother	M	9	Hmong	E-β Thalassemia
8	Father	M	12	Lao	E-β Thalassemia
9	Father	F	8	Lao	H/Constant Spring
10	Mother	F, F	5	Cambodian	E-β Thalassemia
11	Mother	F	16	Indian	β Thalassemia Major
12	Mother	M	23	Vietnamese	E-β Thalassemia
13	Mother	M	19	Pakistani	β Thalassemia Major
14	Father	F	19	Indian	β Thalassemia Major

primary theme in decreasing order of frequency in Table 4. There was no significant difference in the frequency of codes applied to transcripts of Asian versus Asian Indian informants. To evaluate the reliability of our codebook and the coding process, we examined the percent of true agreement in coding between 2 coders (BG and SP) who each analyzed a subset of 7 transcripts. Percent of true agreement in coding ranged from 25 to 100% (mean 70.7%) but was less than 50% for only 4/20 (20%) of the following codes: Child Impact – Social & Emotional; Child Impact – Disease Management; Coping Mechanisms – Educate Others; and Barriers to Care.

Table 4. Most frequently applied codes and percent true agreement by theme

Code or Subcode	[†]Number Applied	[††]True Agreement (%)
Impact of thalassemia on the parent, affected child and family		
Parental impact – emotional	153	62
Disease management	100	50
Future concerns	89	59
Child impact – social and emotional	86	30
Parental impact – financial and lifestyle	58	88
Family impact – general	54	60
Child impact – general	40	57
Child impact – school performance	35	100
Child impact – disease management	39	33
Sociocultural and socioeconomic barriers to health care access		
Communication with team	124	80
Past experiences	67	91
Cultural practices	42	100
Barriers to care	36	44
Knowledge gap – parental knowledge	35	100
Knowledge gap – family and friends	33	75
Family and social support network and coping mechanisms		
Support network	115	87
Coping mechanism – hope for cure	71	91
Coping mechanism – educate self	52	78
Coping mechanism – Educate others	41	25
Faith and religion	34	100

[†] Total number of times code was applied to all 14 interviews.
[††] Percent agreement between subset of 2 coders (BG and SP).

Theme 1: Impact of Thalassemia on Parent, Affected Child and Family

Data elements related to this theme were identified using questions that asked parents to discuss what it is like to have a child with thalassemia and how it has affected their lives as well as the lives of other family members. Separate codes for parental and child impact were used to identify specific areas of impact, including financial state, emotional health, school performance and disease management.

Our interviews found a considerable impact of thalassemia on parents of affected children. Specifically, the impact of thalassemia on parental emotional well-being was the most commonly applied code to our transcripts and emerged as a dominant theme. Parents expressed feelings of worry, frustration and helplessness regarding their affected children.

> *"Seeing them like that makes me hurt inside. They're just kids. They were born like that and it hurts me because I would rather it be me. Why can't it happen to me? Why did it have to be my kids?" (C.H., mother, Cambodian)*

Parental concerns were tied to the impact of treatment, especially transfusion and chelation therapy, as well as disease progression and transfusional iron overload in their children.

"We are a little more worried than before about her because we know these things. The blood transfusions attack the organs, slowly, slowly…the liver and heart and everything. So we're always worried about her." (R.U., father, Pakistani)

The impact of thalassemia on their affected children also emerged as a dominant theme in our interviews with parents. For these children, the rigorous schedule associated with transfusion support and chelation contributed much to the social and emotional impact of thalassemia. The need for transfusions and nightly chelation kept children from activities such as sleepovers, school trips or extended vacations.

For children without permanent venous access devices, enduring frequent ''sticks'' for IV placements during transfusions or nightly subcutaneous chelation was especially painful and represented a major struggle that strained the parent-child relationship.

Significant fatigue, lack of energy and irritability frequently affected children between transfusions and impacted their emotional well-being. Disease management also had a major impact on school performance since transfusions and hospital appointments led to school absenteeism.

As expected for most chronic medical conditions, the impact of thalassemia on parental finances and employment emerged as an important secondary theme. Having an affected child posed a financial strain for parents and impacted their lifestyle. Parents cited ongoing struggles to maintain health insurance coverage for their children. Loss of private insurance, which required them to apply for public assistance, was common. The amount of time parents took off work for their child's medical care, including transfusions, clinic visits and acute care (ie, trips to the emergency department), was significant and led to loss of employment for some.

"And when it came to chelating my child when she was 2 years old, I couldn't give attention to my house, to my [work] and to my child, so I had to stop working to pay more attention to my child and so I had to do all that for her." (M.I., mother, Pakistani)

Parents also voiced concerns about the impact of thalassemia on their children in these other areas (in decreasing order of frequency): social and emotional, disease management and school performance. Parents spoke of their children wanting to be ''normal'' and asking that their thalassemia not be disclosed to others.

"This is a very sensitive age, the adolescent age, and they get inferiority complexes. When she was a little child, M used to have these complexes that you know, 'don't tell her about it…why do you tell everybody that I have thalassemia? Nobody should know.'" (M.I., mother, Pakistani)

Physical changes related to thalassemia, including jaundice and facial bony abnormalities, represented a major source of distress in some children that affected their social well-being and interactions.

"Before when we didn't know that he had thalassemia, his face, his bone structure, it was expanding and just the face was different so he got picked on at school about it." (B.R., mother, Hmong)

Theme 2: Sociocultural and Socioeconomic Barriers to Health Care Access

To examine barriers specific to this theme, parents were asked to give examples of specific factors that prevented them from accessing health care for their affected children, such as challenges with transportation or insurance. Other barriers were identified indirectly through questions that probed parents' communication with the health care team and past experiences of hardships. Distinct codes were used for differentiating among various barriers discussed by informants.

The major barriers to care cited by parents were those common to most chronic medical conditions. These barriers were socioeconomic in nature rather than culturally based. They included loss of insurance and reliance on Medicaid, parental job loss and transportation issues related to distance from their thalassemia treatment center. Language barriers, however, were specific to this population. While most parents believed their English skills were adequate for everyday conversations, they expressed occasional difficulty with understanding medical terminology during conversations with health care team members.

Parents frequently discussed knowledge gaps about thalassemia as a source of frustration. Besides acknowledging their own knowledge deficits, they noted a general lack of understanding and experience in many medical providers they encountered. One child experienced a significant delay in diagnosis despite developing pathologic fractures and major bony changes in his face from bone marrow expansion.

"So they referred him to an oral surgeon and the oral surgeon was like, 'Oh, I've never seen anything like this'…and then he kept fracturing all these bones so then the orthopedic surgeon sent us to [kidney specialist] upstairs and he's like, 'Well, maybe he's just iron deficient and he just needs some calcium', whatever. So we were like, 'Okay, maybe that's what it is'. Then we just let it be." (B.R., mother, Hmong)

A related theme was lack of awareness and knowledge about thalassemia in friends and extended family members, which led to misconceptions that contributed to parental and child social isolation and a general feeling of lack of support from those outside their immediate family.

"My close family members, they know everything. But others, they think that something is wrong and that it is a very bad thing. They think that all our other children, that they might have this thing, too." (R.U., father, Pakistani)

Parental concerns about their children's future and access to health care, which affected their own emotional well-being, emerged as an important theme. Parents were worried about their children's ability to find happiness in marriage, have families of their own and achieve independence as adults, with adequate medical care and insurance coverage. Parents spoke frankly of worries about early mortality in their children due to disease progression and complications. For some parents, concerns about their children's future stemmed from culturally based experiences related to the perceived stigma attached to thalassemia; in one case, the parent knew of individuals whose marriage prospects were negatively affected by having thalassemia.

"They talk, especially when they grow up. We have an arranged marriage system…not here, but our culture is still there. Last week, I heard this girl got engaged and the guy didn't know she had thalassemia. When somebody told him, he no longer wanted to marry her. My wife told me last week, somebody told her, it's true." (R.U., father, Pakistani)

Theme 3: Family and Social Support Network and Coping Mechanisms

Data elements related to this theme were investigated using questions that asked parents to discuss the people in their lives with whom they felt comfortable or uncomfortable discussing their children's thalassemia or to whom they turn for support. A general code for support network and other codes related to specific coping mechanisms were applied to the interview transcripts.

Despite the obstacles and barriers they faced, parents of children with thalassemia depended on few resources for support. Parents relied on communication with thalassemia team members, including physicians and nurses with whom they had built longstanding relationships. Outside the hospital setting, however, parents rarely looked for support beyond immediate family members (i.e. their own spouses, siblings and parents), even though other support systems were available to them.

Parents' reluctance to extend their social support network emerged as a dominant theme. Parents cited the desire for privacy and perceived lack of knowledge in others as the most frequent reasons they did not seek support from or discuss their children's thalassemia with others.

"Sometimes it's kind of embarrassing because like, somebody who don't know us but they heard from rumors that my kids have that (thalassemia) and they think that I have disease. Asian and Cambodians, they would think like 'Oh, she has AIDS, HIV'…so I usually don't tell anyone about it besides our family." (C.H., mother, Vietnamese)

Another important theme that emerged from the interviews was the adoption of several mechanisms for coping with their children's thalassemia. Parents spoke of trying to instill a sense of normality in their affected children and treating them no differently than their siblings.

"It never affected her. I raised her as a normal child. I told my family that, 'you will never pity her'. Since she was a child, as she was growing up, I kept telling her about her disease, what was wrong with her, and she has taken it very well." (M.I., mother, Pakistani)

It was also common for parents to cope through self-education. They sought updates from their children's thalassemia care providers, referred to internet-based resources or consulted written information from the Cooley's Anemia Foundation (CAF) or Thalassemia Action Group (TAG). Some parents insisted on keeping up with information about new treatment options related to chelation and transplantation.

"I've heard there are new technologies coming like non-sibling transplantation. I'm waiting for that thing and every month, I will ask for something, but they don't have it still…So I am hoping they find a donor for my children and they transplant the bone marrow and after that, hopefully, they will be okay and they live a regular life." (D.E., father, Pakistani)

Additionally, parents actively sought to educate others about thalassemia and relied on this as a coping mechanism.

"We kind of told them that you know, 'Make sure you have your blood tests', because usually Pakistanis are arranged marriage, you know. If you and your wife both have [thalassemia] minor, you have to be really careful about that. (K.A., mother, Pakistani)

We found faith and religion to be a recurrent theme, especially among Asian Indian parents, when asked about coping mechanisms. Parents spoke about the "will of God" when discussing their children's future.

"But most of all, I put most of my trust in God because he can do miracles that no doctors out there can do. And so, I believe we go through life…most of our problems, most of the things we go through make us stronger spiritually and as a person." (B.R., mother, Hmong)

This theme was tied closely to parental hope for cure, which occurred frequently throughout interviews. Surprisingly, parents rarely mentioned coping with their children's thalassemia through culturally based remedies, even when they were probed directly. Such practices, including homeopathic therapy, were mentioned only within the context of discussing negative past

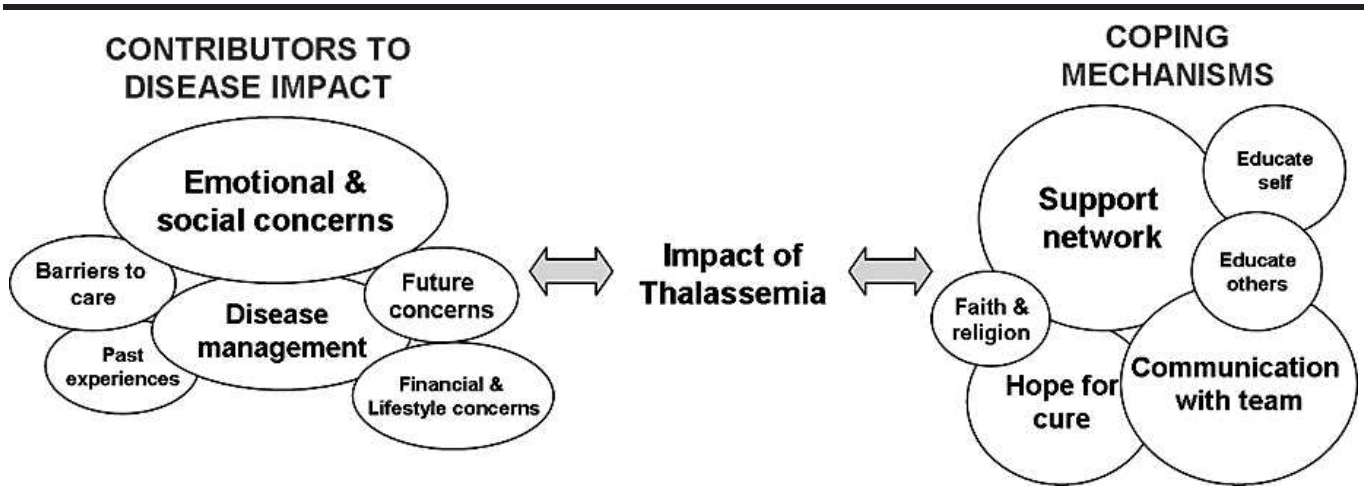

Fig 1. Model depicting relationship among disease impact, contributors to impact and coping mechanisms

experiences, when other medical resources were unavailable.

DISCUSSION

To our knowledge, this is the first study to explore in depth some of the barriers, challenges and sociocultural considerations relevant to immigrant parents of children affected by severe thalassemia in the United States. The primary themes that emerged from our analysis were: 1) the impact of thalassemia on parents, their affected children and the family; 2) the sociocultural and socioeconomic barriers to health care; and 3) the family and social support network and coping mechanisms of this study population. Our data allowed for the development of a conceptual model that demonstrates how the impact of thalassemia is associated with contributors to the effects of the disease and coping mechanisms that might influence each other (Figure 1).

The primary themes that emerged from our analysis were: 1) the impact of thalassemia on parents, their affected children and the family; 2) the sociocultural and socioeconomic barriers to health care; and 3) the family and social support network and coping mechanisms of this study population.

Our coding scheme led to the recognition of several important secondary themes. We demonstrate that affected children and their parents perceive thalassemia as most significant in terms of its impact on their emotional and social well-being. Most commonly, current and future concerns were related to disease-specific complications and ongoing challenges with chronic transfusions and chelation therapy. These perceptions were tied to parental hope for a cure, which represented one of the most frequently coded parental coping mechanisms. Few parents relied on support systems beyond immediate family members or their medical care providers due to perceived knowledge gaps about thalassemia in the general public. We also found no difference in the frequency of applied codes in our Asian vs Asian Indian parents.

Sociocultural and socioeconomic barriers to health care access have long been recognized in the Southeast Asian and Asian Indian adult immigrant and refugee populations.[14–17] Health care disparities and unmet needs in these populations may be attributed to language barriers, lack of insurance, mistrust of Western medicine and culturally held beliefs regarding illness. Fewer studies, however, have examined the challenges faced by parents of children affected by chronic medical illness in these communities or the role that culture plays in parental perceptions of inherited childhood disease.[18–22]

In their review, Choy et al describe outreach strategies and offer guidance for providing culturally sensitive education about thalassemia and trait testing in the Southeast Asian community.[23] The authors base their suggestions on their program's experiences and address issues extrapolated from the existing literature about culture, health models and perceptions of illness in this population. In contrast, we used qualitative methods to explore and gather information related to a broad range of domains, including disease impact, contributors to disease impact and characteristics of available support sys-

tems, as discussed by Southeast Asian and Asian Indian parents of children with transfusion dependent thalassemia. We were surprised at the relative lack of references to culturally based practices, barriers or attitudes given the demographics of our key informants, who were all born outside the United States. Reasons for this may include the duration of care received in the Comprehensive Thalassemia Program at the study location, parental perceptions of disease severity, the resources made available at the hospital, or parental initiative in thalassemia self-education, which was evident from our interviews. Similarly, Reece et al showed that, in a group of Southeast Asian parents, despite provider expectations, attitudes toward asthma, asthma care and adherence to therapy were not affected by cultural beliefs or practices.[20]

Some limitations in this study warrant discussion. Although the mean percent of true agreement between coders was acceptable, agreement related to the application of some codes was low. This may be due to poor coder understanding of specific responses because of language barriers in some parents or potentially, due to the complexity of our codebook. Codes narrow in scope, such as those related to specific areas of child impact, might be applied discordantly to responses containing overlapping themes. In contrast, a more general code, such as that related to barriers to care, might be used too broadly to capture specific but dissimilar references depending on coder interpretation of the context. Still, two investigators reviewed all coding summaries and determined in most instances, that similar albeit different codes were applied to the same response. Thus, the broad themes that emerged from our analysis were unaffected. Second, we did not interview both parents and thus, we may have missed the opportunity to garner parent responses that could have shed light on gender-specific challenges, barriers and perceptions. Finally, we cannot extrapolate our results to those parents of children with thalassemia outside of the Chicago-wide area or families without access to a comprehensive care program due to differences in available expertise, resources or support that may shape these families' experiences. Nonetheless, our data provide an initial, comprehensive look at the issues that face parents of children most severely affected by thalassemia. Although the socioeconomic and psychosocial burden of thalassemia voiced by our parents are similar to that described in other thalassemia populations worldwide,[24–31] including immigrant populations in the United Kingdom and United States, we believe ours is the first study to use an in-depth qualitative approach to examining these issues in immigrant families of Asian and Asian Indian descent in the United States.

In summary, our results hold important implications for the care of Southeast Asian and Asian Indian families affected by thalassemia. The impact of thalassemia is significant for this emerging US population but, contrary to our assumptions, stemmed more from factors either disease-specific or common to other chronic disease models rather than culturally influenced. Importantly, parents were unwilling to access extended support systems because of knowledge gaps related to thalassemia in others. From these data, we generated key hypotheses upon which changes to our program might be considered. First, improvements in care delivery may lessen the impact of thalassemia directly related to the burden of disease management. This is important given the emphasis parents placed on challenges associated with transfusions and chelation therapy as well as the overall impact disease management had on theirs and their children's well being. Second, paying closer attention to parent and child coping mechanisms may help alleviate feelings of social isolation and identify need for expanded support services. This represents a critical intervention given the limited support network that many of our parents discussed in their interviews. Further work is needed to test these hypotheses and to delineate other needs-based initiatives aimed at improving quality of life and lessening overall disease impact in these families.

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