Developmental Screening of Refugees: A Qualitative Study

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abstract

BACKGROUND AND OBJECTIVES: Refugee children are at high developmental risk due to dislocation and deprivation. Standardized developmental screening in this diverse population is challenging. We used the Health Belief Model to guide key-informant interviews and focus groups with medical interpreters, health care providers, community collaborators, and refugee parents to explore key elements needed for developmental screening. Cultural and community-specific values and practices related to child development and barriers and facilitators to screening were examined.

METHODS: We conducted 19 interviews and 2 focus groups involving 16 Bhutanese-Nepali, Burmese, Iraqi, and Somali participants, 7 community collaborators, and 6 providers from the Center for Refugee Health in Rochester, New York. Subjects were identified through purposive sampling until data saturation. Interviews were recorded, coded, and analyzed using a qualitative framework technique.

RESULTS: Twenty-one themes in 4 domains were identified: values/beliefs about development/disability, practices around development/disability, the refugee experience, and feedback specific to the Parents' Evaluation of Developmental Status screen. Most participants denied a word for "development" in their primary language and reported limited awareness of developmental milestones. Concern was unlikely unless speech or behavior problems were present. Physical disabilities were recognized but not seen as problematic. Perceived barriers to identification of delays included limited education, poor healthcare knowledge, language, and traditional healing practices. Facilitators included community navigators, trust in health care providers, in-person interpretation, visual supports, and education about child development.

CONCLUSIONS: Refugee perspectives on child development may influence a parent's recognition of and response to developmental concerns. Despite challenges, standardized screening was supported.

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Dr Kroening conceptualized and designed the study, supervised the study, collected data, analyzed and interpreted data, and drafted the initial manuscript; Drs Moore and Welch contributed to the study design and analyzed and interpreted the data; Drs Halterman and Hyman contributed to the study design and supervised the study; and all authors critically reviewed and revised the manuscript and approved the final manuscript as submitted.

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WHAT'S KNOWN ON THIS SUBJECT: Research has examined developmental and behavioral screening in immigrant children, but limited literature exists addressing effective developmental and behavioral screening approaches for refugee children. Refugee and resettlement experiences increase developmental–behavioral risk and may impact critical stages of child development.

WHAT THIS STUDY ADDS: This qualitative study provides foundational information on beliefs and practices of refugee parents related to child development and disability. The Health Belief Model serves as a framework for understanding how parents of refugee status identify and respond to developmental concerns.

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By 2014, 59.5 million people worldwide were forcibly displaced from their homes and living as refugees or stateless people. Over 50% of these individuals were children.[1] Of the nearly 70 000 refugees annually resettled to the United States, ~30% are children.[2] The United Nations High Commissioner for Refugees reports that refugee and resettlement experiences may impact critical stages of intellectual, social, emotional, and physical child development.[3] Disruption to families and education and witnessed traumatic events impact the presentation of developmental concerns.

Globally, rates of pediatric developmental disability range from 5% to 20%.[4–6] The prevalence of developmental delays and disability in the pediatric refugee population is unknown. Developmental screening and surveillance is recommended by the American Academy of Pediatrics for all children in the context of well-child care.[7] However, standardized assessment instruments validated for use in non-Western cultures and languages are limited, and little is known about the cultural beliefs, perceptions, and practices around identification of developmental delays in refugee communities.[8–13]

Although developmental and behavioral screening of immigrant children has been studied, voluntary immigrants who enter the United States differ from refugees in their exposure to dislocation, deprivation, and loss (experiences common to refugees).[3,14–17] Developmental delays in refugee children may not be appreciated by families and, once identified, cultural barriers may interfere with intervention.[18,19] Delay or absence of services may negatively impact outcome.[20] Given the evidence for the positive effects of early intervention, it is important to identify the most appropriate approach to effectively screen refugee children.[21–24]

This qualitative study explores cultural and community-specific values and practices related to child development, as well as barriers and facilitators to developmental screening and interventions if delays are identified. We use the Health Belief Model (HBM) as a framework for understanding how parents of refugee status identify and respond to developmental concerns. The HBM explains how health-related behaviors are impacted by belief and is used to guide interventions that promote the continuum, from identification to treatment of disease.[25] The model assumes that the likelihood of action around a specific health behavior depends on an individual's sociocultural background (modifying factors), their beliefs (about self-efficacy, susceptibility to/seriousness of the problem, and barriers to taking action), and their exposure to cues that prompt action.

In this study, we examined themes regarding sociocultural modifiers and individual beliefs related to child development and disability that may impact a refugee parent's acceptance of developmental screening, as well as factors that might prompt recognition and response to identified developmental concerns.

METHODS

Setting and Participants

The study was conducted between March 2014 and February 2015 in Rochester, New York. Rochester is a refugee resettlement city, identified by the United Nations High Commissioner for Refugees to receive and provide services and education/employment opportunities to 700 new refugees annually, including nearly 300 (40%) children (personal communication with Jim Morris, Director of the Department of Resettlement, Immigration, and Language Services, Catholic Family Center). Refugees are predominantly from Bhutan, Myanmar (Burma), Iraq, and Somalia.

We used a purposive sampling strategy to recruit representatives from 4 target groups: parents of refugee status (n = 7), medical interpreters serving refugee families who were themselves refugees (n = 9), clinicians caring for pediatric refugee patients (n = 6), and community collaborators (n = 7) involved in refugee resettlement (Table 1).[26] Parents and clinicians were recruited from the Center for Refugee Health, a primary care clinic for newly resettled families. Medical interpreters were recruited from the Office of Community Medicine within the Rochester Regional Health System. Community collaborators were recruited from the Rochester Committee on Refugee Resettlement. Participants received a $25 gift card in compensation.

Interviews and Focus Groups

Key-informant interviews and focus groups were conducted by the physician-investigator trained in qualitative techniques (A.K.). Information was gathered in English or with in-person interpretation as needed. An open-ended interview guide was used (Supplemental Information). Member checking for understanding and clarification of participants' contributions was integrated into the interview process.[27] Questions explored roles, beliefs, and practices regarding child development and disability within refugee communities. The Parents' Evaluation of Developmental Status (PEDS) was provided and participants were asked to comment on how the screening tool might be received and understood by refugee parents.[28]

TABLE 1 Study Participants by Target Group, Ethnicity, and Community Role

Target Group	Ethnic Group	Community Role
Medical interpreters	*n* = 9	Community members
	Bhutanese-Nepali (*n* = 4)	Health care liaisons/navigators
	Chin (*n* = 1)	interpreters
	Karen (*n* = 2)	
	Karenni (*n* = 1)	
	Somali (*n* = 1)	
Refugee parents	*n* = 7	Community members
	Bhutanese-Nepali (*n* = 6)	Mothers (*n* = 6)
	Iraqi (*n* = 1)	Fathers (*n* = 1)
Community collaborators	*n* = 7	Community outreach program directors
		English as a second language teacher
		Health case manager
		Public school psychologist
		Public school social worker
		Refugee community leader
Medical providers/staff	*n* = 6	Nurses
		Clinic social worker
		Family nurse practitioner
		Administrative staff
Total	*N* = 29	

Study participants included refugee parents, medical interpreters, refugee-focused healthcare providers, and community collaborators providing post-resettlement support. Selected participants represent general perspectives from Rochester, New York's predominant refugee communities. In addition, 3 parents identified their own children with developmental disabilities, including Down syndrome (Bhutanese-Nepali), attention-deficit/hyperactivity disorder and language disorder (Iraqi), and autism (Afghan).

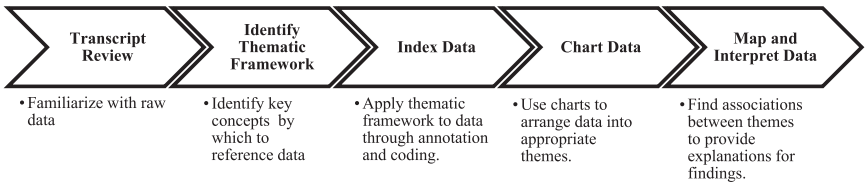

FIGURE 1
Data analysis using a qualitative framework technique. A qualitative framework technique is one approach to qualitative data analysis that involves initial familiarization with transcript data, followed by development of a thematic framework used to organize data. Data are coded, indexed, and charted into annotated themes within the framework. Themes are then mapped and associated into overarching constructs.

Data Analysis

Interviews and focus groups were audio recorded and transcribed verbatim. A qualitative framework technique was used for analysis (Fig 1).[29,30] Quotes from interviews were analyzed within a thematic framework developed by the researchers to focus on 4 HBM-related domains: (1) beliefs, values, and perceptions about child development and disability; (2) cultural and community practices related to development and disability; (3) additional observations about refugee community experiences; and (4) specific feedback on using the PEDS in a primary care setting.

Three investigators (A.K., J.M., and T.W.) reviewed and coded each transcript independently (triangulation).[27] A consensus process followed, in which investigators categorized data into common themes emerging from within each of the 4 domains noted. Themes were subsequently charted and mapped into overarching constructs within and across cultural groups.[29]

Participant enrollment continued until data saturation was achieved and additional interviews failed to yield new themes. All study procedures were approved by the University of Rochester Research Subjects Review Board.

RESULTS

Twenty-nine individuals participated in 19 key-informant interviews and 2 focus groups, with representation from Afghan, Bhutanese-Nepali, Burmese, Chin, Iraqi, Karen, Karenni, and Somali cultural communities. Within the 4 domains of the thematic framework, investigators identified and mapped 21 themes and 11 subthemes (Fig 2, Table 2).

Domains 1 and 2: Beliefs, Values, and Perceptions and Practices Related to Child Development and Disability

Noting a consistent pattern of refugee community beliefs influencing practices, the first 2 domains were combined.

Themes of Communal Mentality, Family Structure, Parenting, and Schooling Practices

Study participants described a communal mentality, with little emphasis on privacy or autonomy (Table 3, Quotation 1). Healthcare, in particular, is traditionally not viewed as private or individual. Decisions are often made in consultation with elders in the family or community with deference to societal hierarchies (Table 3, Quotation 2).

Family structure is nonchild focused; children exist as units of the family or community. Compliance with gender-specific responsibilities is expected of children as they age (Table 3, Quotations 3 and 4).

Teachers command respect (Table 3, Quotation 5) and have a role in discipline. Parents are not expected to participate in their children's education (Table 3, Quotation 6).

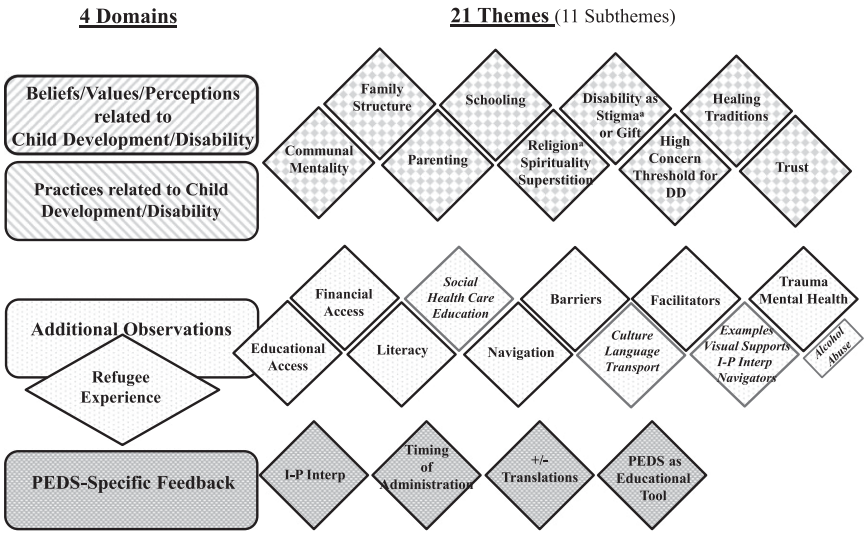

FIGURE 2
Themes from data analysis organized by thematic framework domains. Themes were grouped into 4 domains. Themes 1 and 2 were merged because of content overlap: beliefs/values/perceptions influenced practices related to development and disability. Subthemes are in italics. [a]Notes where content within themes differed across cultural groups. DD, developmental delay; I-P Interp, in-person interpretation.

Themes of Religion and Spirituality, and Stigma versus Blessing

Beliefs and practices around child development and disability are strongly influenced by religious and spiritual traditions that vary between cultural groups. For those communities that practice a multideity religion, stigma exists for disability that is thought to be a curse, with generational/karma implications (Table 3, Quotations 7–9). This stigma isolates a family from relatives, community members, and potential sources of support (Table 3, Quotation 10). For those communities that practice Islam or Christianity, a child with a disability is described as being given by God (Table 3, Quotation 11). Although parents still describe experiences of isolation, traditional Islamic or Christian refugee communities report more inclusive practices.

Theme of High Threshold for Developmental Concern

All refugee communities identified a high parental threshold for being concerned about developmental delays. Participants stated that parents of refugee status will not generally consider developmental delay until their child is at least 2 or 3 years old, believing that a child will follow his or her own "track" (Table 3, Quotation 12). Monitoring of developmental milestones is not a familiar concept, and most participants could not identify a specific word for development in their language of origin (Table 3, Quotation 13)

TABLE 2 Themes From Data Analysis Organized by Thematic Framework Domains

Domains 1 and 2: Beliefs, Values, Perceptions, and Practices Related to Child Development and Disability	
Theme	
Communal mentality	
Family structure	
Parenting	
Schooling	
Religion/spirituality[a]	
Disability as stigma versus gift[a]	
High concern threshold for developmental delays	
Trust (in the pediatric provider)	
Domain 3: Additional Observations From Data Related to the Refugee Experience	
Theme	Subtheme
Financial access (pre-resettlement to United States)	
Educational access (pre-resettlement to United States)	
Literacy and navigation	Social, healthcare, and education
Barriers to developmental care	Cultural differences, language, transportation
Facilitators to developmental Care	Visual supports, use of examples, in-person interpretation, cultural navigators
Mental health/trauma experiences	Alcohol abuse
Refugee experience	
Domain 4: Feedback Specific to the PEDS	
Theme	
Interpretation services (preference for in-person interpretation)	
Timing of administration	
Availability/use of translations	
PEDS as educational tool	

Themes were grouped into 4 domains. Themes 1 and 2 were merged because of content overlap: beliefs/values/perceptions influenced practices related to development and disability.
[a] Notes where content within themes differed across cultural groups.

TABLE 3 Qualitative Data Themes and Representative Quotations, Organized by Domains

Theme	Representative Quotations
Domains 1 and 2: Beliefs, Values, Practices Related to Child Development and Disability	
Communal mentality	(1) "…And they are now, let us say, a little bit conscious about privacy. But in our country that was not a big deal…If, for example, in our community when we were in Nepal, so if a particular person is having some peculiar type of diseases everybody used to know if a person is having like tuberculosis." (MI 1, Nepali)
	(2) "Some family have well educated – some society have well educated people in some cases…Low caste and high caste. That may affect the society's way it is, the traditional way. . . you know, it affects the child's health or the parents in some cases." (MI 2, Nepali)
Family structure	(3) "And after the children are like 5 or 6, 7 years old they ask them to take care of the other, the younger brother, siblings…" (MI 6, Karenni)
Parenting	(4) "Because our culture, we don't. . . treat the children in so much a good way or like a friend…I see some American moms talking to their child as if he's a friend or she's a friend…our way is a little more authoritative. Do this, do that. Don't do that. You know." (MI 3, Nepali)
Schooling	(5) "When I grew up, a teacher basically is your second father… You have to listen to your teacher, what he is telling you is right." (MI 9, Somali)
	(6) "The expectation is that the kid comes to school to learn, the teachers know best and it's kind of like a hands-off policy…I think that many of our cultures feel that school is the responsibility of people here…they are sending their children here to learn and that's it. And that's how it would be in their home country." (CC 6, school psychologist)
Religion and spirituality	(7) "So most of the Nepalese are based on Hinduism and Buddhism and they believe in some kind of superstition…people think that disability children is born because of the bad scene or bad karma…So, for example, my child is disabled now and people believe we did something wrong in our previous generation and we have child with disability because of that thing." (RP 3, Nepali)
	(8) "And the demon from the forest, it, you know, it was that cursed my baby and that's why he is not sitting. It is not their fault but they believe in that way." (MI 2, Nepali)
Disability as stigma versus gift	(9) "…It is kind of like—like a curse from God or something like that. Kind of something shameful happened to the family. And yeah, they try to keep it like in the family." (MI 5, Chin)
	(10) "Only the people who support is the family who are having child with disability." (RP 3, Nepali)
	(11) "But as in the house or outside they are respected. They believe in God and they feel that God gives and they will have to respect that." (RP 2, Iraqi)
High threshold for developmental concern	(12) "Like we don't have that culture of like tracking the development of a child. So it grows, the child grows by himself or herself, you know?" (Nepali, MI 3)
	(13) "No [specific word in Chin for "development"]…I kind of explain like it's kind of their growth process. Something like that." (MI 5, Chin)
	(14) "My elder brother's son who got finally diagnosed with autism, so he was like 2 years. And we expected him to speak and then behave nicely, you know. At least follow little things we say. You know, come here, go there or whatever. But he was totally disobedient. At least 2 years…everybody expects the child to speak a little bit. And smile or whatever." (MI 3, Nepali)
Traditional healing practices	(15) "…But you know, first and foremost child development when child had any problem, medical problem or any physical and mental problem they will go to the religious first." (MI 2, Nepali)
Trust	(16) "They will start to tell you everything, you know, if you ask them. But…this also depend on trust. If some people don't trust you they will never tell you anything…first before you bombard them with a question you kind of create a good relationship with them. Talk to them what is the problem." (MI 6, Karenni)
Domain 3: The Refugee Experience (Additional Observations From the Data)	
Financial and educational access literacy	(17) "We were confused because we didn't know about Down syndrome…we didn't know anything about chromosome…how this gonna affect our child. And our child looked very different at the time. It was a horrible experience…So my wife was crying a lot but I tried to understand because I know how to read and how to write." (RP 3, Nepali)
Navigation	(18) "They don't speak the language, they don't speak English and they are exposed to a new system here and they don't know how to teach their children…and how to help their children." (MI 6, Karenni)
Barriers to developmental care	(19) "One family…have one kid who is mentally handicapped. And they go through the system, you know, the doctor they see. The problem is when it comes to therapy most of the people don't speak the language and they don't understand what therapy is. They don't know." (MI 9, Somali)

TABLE 3 Continued

Theme	Representative Quotations
Facilitators to developmental care	(20) "The patient, they always told me like they feel more comfortable with in-person [interpretation]…I start knowing them and they start like kind of trusting us. And then they like talking to you and seeing you…They also mention to me like the phone translators are not really efficient…they will say like we kind of ask some question but then like what we get back the answer is not exactly what we like expect." (MI 5, Chin)
	(21) "I've got a lot of people coming in my house. Some are having problems with the Medicare. Some are having problems with the food stamp. Even some people, if they have problem with a ticket…they will come with me. I will solve that problem…Even I don't know, I have to ask, call, make calls, do everything but I've got to help. I'll say I don't know but I'll try to help you….So I'm trying to be a middle man for the provider and the Nepali people." (MI 2, Nepali)
Mental health and trauma experiences	(22) "I just think that, you know, the culture, their background, what they saw affects them forever. They'll never forget it, what they saw. " (CC 4, Teacher of English as a Second Language)
Refugee experience	(23) "We are trying to fit in America." (RP Focus Group, Nepali)
Domain 4: Feedback Specific to the PEDS	
In-person interpretation services	(24) "So sometimes the interpreter should express the facial expression, right? And the mood of a people. So in a phone they will definitely not know what mood the patient is having. So by facial expression also we can say (()) is having something more problem." (MI 1, Nepali)
Timing of administration	(25) "I will say like not the first visit. Probably like the second or third visit you will ask these kind of questions. But for the first visit if you ask too much question they probably overwhelm and they probably won't tell you the truth, they might shy…" (MI 7, Karen)
Language translations	(26) "I think it's good to have somebody to interpret because in Karen we don't…we are lack of education so not all the Karen can read Karen. There are a lot of family that I work with, they never go to school so they don't even know how to read Karen." (MI 7, Karen)
Educational tool	(27) "Some parents don't know what not to expect…Not just telling them what is normal. Because sometimes some kids look normal but they're not…maybe 'If your child did not talk by that age even though he seems to understand you, let us know.'" (MI 5, Chin)

CC, community collaborator; MI, medical interpreter; RP, refugee parent.

Like other parents, refugee parents often use instinct and comparison with siblings or community peers to identify developmental differences. Delays may or may not be of concern, depending on the age of the child and the nature of the developmental difference.

Language delays and behavioral challenges were identified as most distressing for families, with absence of speech or noncompliant behavior as the first concerns parents identify (Table 3, Quotation 14). Timing of parental disclosure of developmental concerns to a clinician is influenced by the parents' culture of origin and educational background.

Physical disabilities are common and are generally more accepted within refugee communities than cognitive, language, or behavioral concerns. Pre-resettlement, children with physical disabilities are typically integrated into family life and traditional school settings without resources or supports. If disabilities are severe, children are isolated at home. Special schools were described in some Bhutanese-Nepali and Burmese communities for children with vision or hearing differences.

Theme of Traditional Healing Practices

Timing of parental reporting of developmental concerns may also depend on the use of traditional healing practices, which are often pursued before medical evaluation (Table 3, Quotation 15). At the advice of elders, parents are often referred to traditional healers, particularly among Bhutanese-Nepali, Karen, and Chin families.

Theme of Trust

Timing of reporting developmental concerns depends on trust, an important value in refugee communities (Table 3, Quotation 16). The greater the trust between a refugee parent and their clinician, the more likely a parent will disclose concerns. These cultural communities view medical providers as having high social status and, out of respect, may not spontaneously ask questions or offer additional information until a relationship has been established.

Domain 3: Additional Observations Related to Refugee Community Experiences

Data from this domain revealed themes rooted in the refugee experience, including the processes of displacement, resettlement, and acculturation.

Themes of Financial and Educational Access, Literacy, and Navigation

Previous education or financial status affects a parent's literacy and navigational skills after resettlement, including their ability to understand and navigate social, healthcare, and educational systems. (Table 3, Quotations 17 and 18). Parents who are more educated were often leaders or teachers in their camps and adjust more easily to resettlement. Parents with literacy in their language of origin and some knowledge/awareness of western

culture also resettle more easily. These foundational traits facilitate learning of basic American societal practices (ie, reading and responding to mail), healthcare processes (ie, scheduling a follow-up appointment), and educational expectations (ie, practicing therapy recommendations or attending a parent–teacher conference).

Theme of Barriers to Seeking or Accepting Developmental Care

Regardless of background wealth or education, all participants identified 3 common barriers to developmental screening, diagnosis, and intervention: culture, language, and transportation. Participants reported that cultural differences in recognizing developmental expectations may limit identification of delays. Language barriers may impede communication of concerns. In addition, many refugee parents have limited access to transportation to attend evaluations or meetings.

Additionally, participants described a lack of familiarity with community-based educational interventions in the United States (Table 3, Quotation 19). Many families have no cultural context for "therapy" (physical, speech/language, or occupational therapies). Participants stated that parents often express uncertainty regarding how their child may benefit from these services.

Theme of Facilitators to Seeking or Accepting Developmental Care

Despite the barriers, participants also cited several facilitators to developmental screening, including in-person interpretation services, access to a healthcare or cultural navigator, and provider use of visual supports.

All participants preferred in-person over telephone-based interpretation services, stating that in-person interpretation facilitates communication and rapport (Table 3, Quotation 20). They felt that providers could promote developmental care by using visual aids or specific examples to explain developmental skills.

Additionally, most participants felt that parents of refugee status benefit from a cultural or healthcare navigator; an identified leader within their respective communities capable of guiding families through the acculturation processes. Medical interpreters who were refugees themselves often assume this role, and some study participants self-identified as such a liaison (Table 3, Quotation 21).

Theme of Mental Health and Trauma Experiences

The roles of mental health and trauma experiences for both children and parents were highlighted by many (Table 3, Quotation 22). Behavioral challenges and sleep problems were connected to trauma experiences for children, whereas substance abuse (alcohol in particular) and anxiety or depression were cited as concerning for many refugee parents. Participants noted that most refugee communities do not have an understanding of "mental health," and may be reluctant to pursue interventions.

Theme of the Refugee Experience

Participants described refugee families as desiring to share in and contribute to American society (Table 3, Quotation 23). Many described challenges to this acculturation process, noting intergenerational differences and difficulties with self-efficacy after the regulated structure and provisions of the refugee camp.

Domain 4: Feedback Specific to the PEDS

Themes of In-Person Interpretation and Timing of Administration

Participants felt that the PEDS would be well-received for developmental screening within their cultural communities. All felt that in-person interpretation during screening is more likely to elicit parent concerns (Table 3, Quotation 24). Standardized screening tools should not be given at the initial patient visit but should be administered by the clinician in a later visit, once parent–provider trust has been established (Table 3, Quotation 25).

Theme of Translation

Most participants felt that the PEDS should be offered in a parent's language of origin. However, low literacy rates among many refugees would require provider administration (Table 3, Quotation 26).

Theme of Educational Tool

When used with visual supports and examples of age-appropriate developmental expectations, participants felt the screening tool could teach parents more about child development (Table 3, Quotation 27).

Synthesizing the Data into the HBM

The 21 themes and 11 subthemes identified and analyzed in this study integrate within the HBM to provide a framework to approach developmental screening for refugee children (Fig 3).

DISCUSSION

This qualitative study explores diverse refugee community and collaborator perspectives of beliefs and practices around child development and disability. Integration of this rich, community-based data within the HBM offers pediatric providers a conceptual framework through which to engage with refugee parents to support standardized developmental screening and early identification of developmental delays.

Results from this study point to the value of the medical home. Our data suggest that parents of refugee

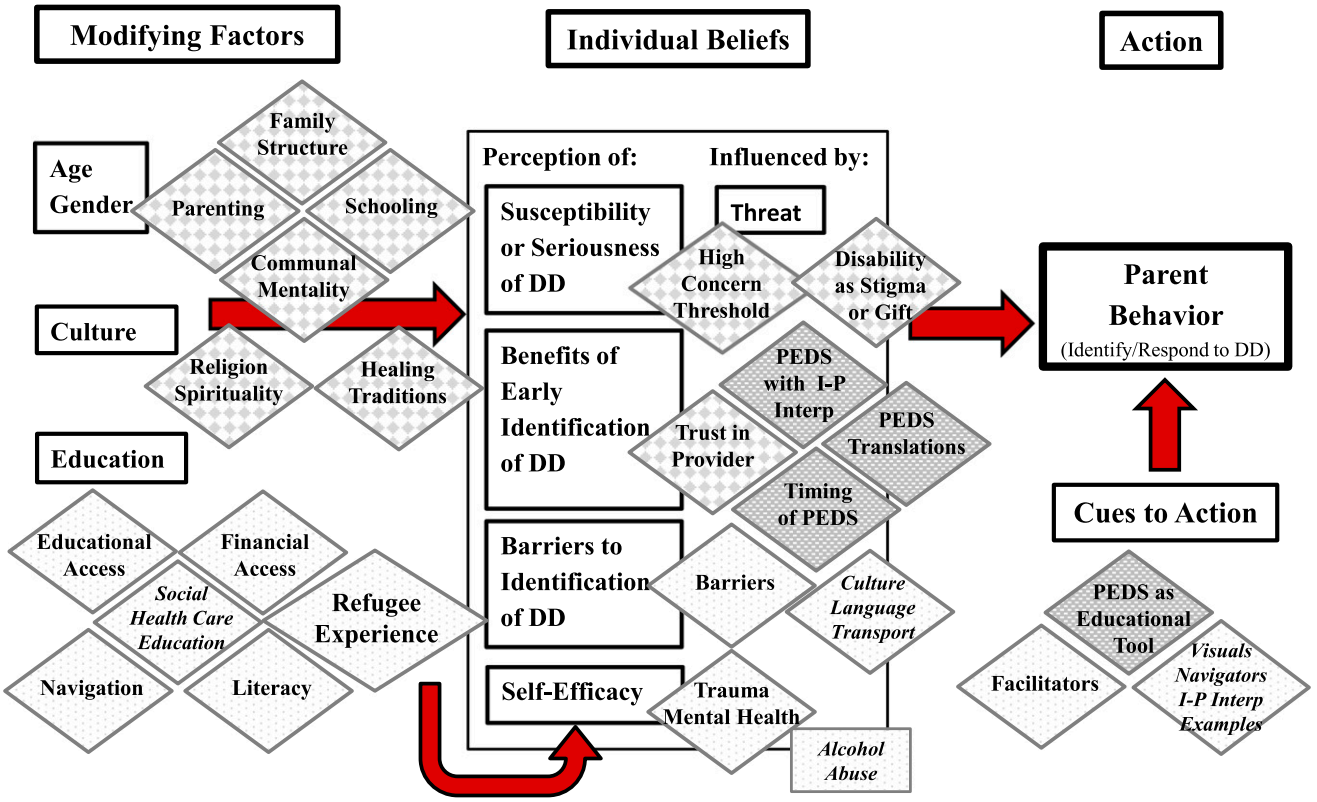

FIGURE 3

HBM as a framework to approach developmental screening for refugee children. Themes map onto HBM to explain parents' identification and response to developmental concerns. Modifying factors include sociocultural traditions, practices, and factors mediated by the refugee experience. Themes identify barriers to developmental care and facilitators enhancing parent–provider trust, PEDS screening effectiveness, and parental understanding of development. DD, developmental delay; I-P Interp, in-person interpretation.

status need a primary care setting that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective.[31] Models are emerging within refugee healthcare that provide bilingual staff, full-time social workers, and on-site mental health and interpretation services.[32] Parents of refugee status respect their child's healthcare provider and are more likely to understand and participate in the process of developmental screening once there is trust in both the provider–patient/parent relationship and in the interpretation service. All participants in this study found in-person interpretation most effective for communication, particularly for discussions around child development. This highlights the importance of taking time, perhaps over several visits, to establish rapport and cultivate relationships with families of refugee status.

This study supports the expanding role of cultural navigators who are trained to serve as leaders, mediators, and liaisons between their cultural communities and the new systems they must learn. Such cultural brokerage eases the process of resettlement and facilitates acculturation and self-efficacy.[33,34] Interpreters within refugee communities often serve as de facto cultural navigators, advocates, and care coordinators.

Our findings are consistent with a preliminary report of developmental screening of recent immigrant and refugee children, in which 6 bilingual/bicultural caseworker/cultural mediators were interviewed regarding beliefs and attitudes about developmental screening.[11] Four general attitudes/beliefs were identified among study participants: parental reactions of blame, shame, confusion, or acceptance; influence of cultural and religious beliefs; inheritance of disability; and denial. As in our study, educational outreach was identified as an important means of increasing awareness of child development and barriers to screening included language, transportation, parental education level, and trust in the clinician.[11] Our study confirmed and extended these findings from other refugee groups in a second location.

Our study also suggests that providers may have success using the PEDS as a developmental screening tool in refugee-focused pediatric primary care, particularly when linked with appropriate

interpretation services. Translations, explanations of developmental domains, and visual supports may aid in accuracy of screening. Standardized screening with these supports is especially important when surveillance may be limited because the language of origin does not include vocabulary or context to identify the symptoms of concern. Additionally, the PEDS may serve as a mechanism to promote trust and developmental–behavioral teaching. Many participants expressed interest in learning more about child development, American child-rearing practices, and how to integrate this information within their own cultural traditions.

This study had several potential limitations. Societal hierarchical roles may have influenced focus group dynamics. Most participants spoke openly to the interviewer (A.K.), but there were a few whose responses were brief and deferential. Methods were modified early on (from focus groups to key-informant interviews) to improve communication and promote trust. Member checking was incorporated into the interview process but was not done after data analysis. As qualitative data, these results may not be generalizable to other refugee communities; however, given the shared refugee resettlement experience and the confirmation and extension of data from another refugee resettlement community, findings may be transferable to other refugee clinics considering developmental screening implementation.[11]

This research lays a foundation for effective engagement with refugee families around developmental screening. It will be important to evaluate the processes involved in clinic-based implementation of standardized developmental screening with pediatric refugee patients, using the PEDS or other validated tools, and develop culturally appropriate screening protocols. Community-based participatory research can promote health literacy and health care navigation for children and families with developmental disabilities, as well as provide bidirectional, culturally sensitive education on parenting practices and child behavior and development. Collectively, this research can be used to develop policies around interpretation services and intervention delivery for children of refugee status in health and education settings.

CONCLUSIONS

This study informs implementation of developmental screening of refugee children through identification of their parents' beliefs and practices and the modifying factors that influence recognition of and response to developmental concerns. The HBM illustrates initial steps for clinicians to promote developmental screening of refugee children:

1. Recognize that many parents of refugee status view child development within their own cultural context. Clinicians need to understand child-rearing expectations of the cultural groups they serve.
2. Use of in-person interpretation during developmental screening is recommended for accuracy of narrative and cultural context.
3. Developmental screening is an opportunity for educating parents of refugee status about child development. Visual supports may facilitate understanding.
4. Establishment of clinician–parent trust before developmental screening is critical.

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ABBREVIATIONS

HBM: Health Belief Model
PEDS: Parents' Evaluation of Developmental Status

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