

Evaluating the Effects of Refugee Experiences on Cognitive and Social-Emotional Development in Refugee Children in the Primary Care Setting

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Background

Of the 10.7 million world refugees in 2013, 50% were children.¹ The prevalence of developmental disability among refugee children is unknown. However, the disruption of families and education, in addition to the witnessed traumatic events, that often accompany the refugee and resettlement experience are known to impact cognitive, social, emotional, and physical child development.² Meanwhile, an estimated 16% of children around the world have developmental-behavioral disabilities, but less than one-third that total number are thought to be detected and directed to the appropriate intervention, likely in part due to inadequate screening.³ Difficulty with adequate screening is compounded within refugee populations, for whom differences in culture and language often present barriers to the use of commonly used screening tools. This paper aims to explore the ways in which the refugee experience affects cognitive and social-emotional development of refugee children resettled in high-income countries; it will then consider refugee perspectives of developmental screening and culturally/linguistically-appropriate methods of developmental screening of refugee children in a primary care setting in order to most effectively and accurately identify children at risk for developmental delay to ensure timely referral for early intervention.

Trauma and Stressors Within the Refugee Experience

Exposure to Trauma

Though the refugee experience should not be assumed or generalized when working with any one patient, it may be useful for healthcare providers to acknowledge and assess the wide range of traumatic events that, by definition, a

refugee child may have experienced before resettlement. A recent study characterized the trauma exposure of heterogeneous refugee youth referred for assessment and treatment by providers in the National Child Traumatic Stress Network across the U.S. In comparison to U.S.-origin youth and immigrant youth, individual refugee youth had been exposed to a significantly higher total number of trauma types (on average, 5.43 compared to 3.79 and 3.63, respectively).⁴ The profile of trauma experienced along refugees' often perilous journeys differed significantly, as well; compared to U.S.-origin youth and immigrant youth, refugee youth had higher rates of exposure to forced displacement, community violence (e.g., the destruction of homes and schools, witnessing death), traumatic loss and bereavement of family and friends, and separation from parents.^{1,4} In addition, the refugee youth had higher rates of exposure to an impaired caregiver compared to immigrant youth. Notably, refugee youth had lower rates of exposure to sexual maltreatment/abuse compared to both U.S.-origin youth and immigrant youth; however, the study did acknowledge that underreporting due to particularly strong stigmas among refugee populations against discussing sexual violence may lead to underestimation of this traumatic exposure.⁴

Exposure to Stressors

Exposures to stress, however, are not limited to the traumatic settings of war and persecution escaped by refugees. Perhaps unexpectedly, resettlement location— i.e. whether a child spent time in a refugee camp before arrival to a host country— is notably not established as a source of stress associated with poor mental health outcomes.⁵ Instead, most of the stressors that constitute risk factors for poor health outcomes in refugees relate to post-migration experiences.

Refugee families face many post-migration adversities such as discrimination, lack of continuity of cultural experience, lack of safety, low social connectedness in fragmented refugee communities, post-migration violence exposure, repeated changes of residence in the host country, low socioeconomic status, and poor financial support.⁵ The daily hardships of resettlement and challenges of acculturation often faced by refugee families resettled in high-income nations are powerful stressors that exert formative influences on refugee children's mental health. Other stressors emerge from the refugee experience which more uniquely affect children and threaten their development, including the loss of role models either through separation from parents or through the loss of parents' normal livelihood/parental distress, altered child roles and the assumption of early responsibility, and alienation between children and parents following resettlement.⁶ Sources of the damaging experiences inflicted upon refugee children once already arrived in their new host country are particularly salient as potential subjects of intervention in order to improve outcomes for the children.⁴ Therefore, the care coordination and environments for these vulnerable children ought to be thoughtfully arranged with preventive interventions in place to minimize post-migration trauma and stressors.⁷

Effect of Refugee Experience on Cognitive Development and Mental Health

The refugee experience and associated traumas and stressors are known to affect children uniquely, because children are still developing throughout the experience; their personalities, abilities, and coping skills are therefore particularly vulnerable to the unstable environment that they and their families often face in the midst of the refugee experience. Forcibly subjected to extreme stressors and struggling in resource-limited environments or with resettlement issues, refugee families are less equipped to provide the sense of self-esteem, identity, and security necessary for flourishing child development. The UNHCR 1994 publication,

"Refugee Children: Guidelines on Protection and Care," describes the breadth of the effects that such extreme situational stress has on child development: "The uprooting, disruption and insecurity inherent in refugee situations can harm children's physical, intellectual, psychological, cultural and social development. These factors are severely compounded when, in addition, children suffer or witness the torture or murder of family members or other forms of abuse or violence."⁶

Cognitive Development

The prevalence of cognitive delay among refugee children is unknown, as data are limited due to inadequate screening in an already vulnerable population. However, it is known that many aspects of the refugee experience challenge children's cognitive development. In a structural sense, refugee children may be deprived of play and school opportunities to varying degrees depending on the safety and resources available in their refugee camp.⁶ Even after resettlement, stressors associated with discrimination, acculturation, and chronic poverty may limit a child's full participation in school and cognitive performance.¹ School and play opportunities are essential to successful cognitive development, and prolonged interruption of these activities may contribute to the development of cognitive delay.⁶

Impairments of executive functioning, memory, attention, and abstract reasoning – i.e., impairments of the elements of effective cognition— are associated with childhood experiences of neglect or traumatic events. Moreover, the cognitive development of refugee children is closely intertwined with the mental health of these children. Research suggests that the relationship between traumatic event exposure and a detriment to cognitive functioning is particularly strong for children with PTSD symptoms. Many PTSD symptoms, including poor concentration, forgetfulness, and intrusive memories, may interfere with learning and performance in school; other symptoms, such as hypervigilance and dissociation may directly impede cognitive processes such as problem

solving, shifting between concrete and abstract thinking, and understanding instructions. Other psychiatric responses to trauma such as anxiety and depression may interfere with learning and cognitive performance as well, as they inhibit creative play, anticipation of success or failure, the capacity for emotional self-regulation, reflection, self-confidence, and the ability to benefit from adult guidance. Thus, poor emotional regulation following traumatic experiences inhibits cognitive processes and maturation.¹

A neurobiological basis for the effects of trauma and stress on the developing brain has been elucidated. Childhood adversity is associated with hypothalamic-pituitary-adrenal axis dysfunction, which manifests as impaired development of various vulnerable areas of the brain.¹ Observational studies in child victims of sexual abuse have related impairment localization to the age at which the trauma occurred; the brains of children abused between ages 3 and 5 and 11 and 13 years exhibited hippocampal impairment, while the corpus callosum was impaired in those abused between ages 9 and 10 and the frontal cortex was affected in those abused between ages 14 and 16.⁸ Functional impairment in these various areas leads to varying presentations in cognitive deficit, including difficulties with memory, visuospatial functioning, or attention and impulse control.¹ In addition, a positive correlation exists between the duration of the trauma exposure and the degree of impairment.¹ Based on this information, the age at which refugee children are exposed to the traumas and stressors of conflict and migration, as well as the length of time for which they are exposed, may shape their eventual cognitive status.

A longitudinal study of refugee children in Australia offers a unique perspective on developmental disabilities occurring after resettlement, as Australia's refugee policy at the time of the study excluded children with significant developmental disabilities from entering the country. Refugee children completed the Australian Developmental Screening Test (ADST) at 2 years and 3 years after resettlement; of interest, the 27% of children who tested as

having mildly abnormal development (particularly in language and cognitive domains) at 2 years post-resettlement all scored within normal ranges at the 3-year post-resettlement follow-up, following no intervention. By the 3-year post-resettlement mark, in fact, a different set of the children— another 23% among those studied— was scoring in the mildly abnormal range.⁹ Reassuringly, the effects of post-resettlement stressors on cognitive development, at least, seem to be fluid and likely to resolve with watchful waiting if cognitive delay is observed to be only mild upon screening.

A discussion of the sources of cognitive impairment in refugee children would not be complete without brief mention of the deficiencies and toxicities that affect cognitive development. Poor nutrition due to food shortages and restricted diets based on availability within refugee camps can lead to iodine deficiency, iron deficiency, and deficiencies of other micronutrients important for cognitive development.¹⁰ Exposures to lead in refugee camps and native countries can also affect cognitive development, even at blood levels less than 10 micrograms per dL.¹¹

Social-Emotional Development

Social-emotional development is also deeply influenced and challenged by the pre-migration trauma and post-migration stressors inherent in the refugee experience. Delay in social-emotional development may lead to the development of mental disorders or psychiatric symptoms in refugee youth. A recent examination of National Child Traumatic Stress Network data compared the clinical mental health problems of refugee youth exposed to trauma to those of U.S.-origin and immigrant youth exposed to trauma; trauma exposure in refugees manifested as significantly higher clinical evaluation ratings for phobic disorders, traumatic grief, dissociation, and somatization in refugee youth compared to the other groups.⁴ Unlike the dearth of information related to the cognitive development of refugee children, epidemiological evidence for the clinical

effect of trauma on the social-emotional development of refugee children is available. The prevalence of PTSD among refugee children is estimated at 19-54%, whereas the prevalence is only 2-9% in the general pediatric population.¹ The prevalence of anxiety and depression has been found to be elevated amongst refugee children in comparison to the general pediatric population, too.¹ Refugee children exhibit increased rates of both externalizing behavior problems— problems involving delinquent or aggressive behavior— and internalizing behavior problems— problems of withdrawal, somatic complaints, anxiety or depression— than the general pediatric population. Uniquely, though, refugee children may demonstrate “a predominance of internalizing symptoms that differs from other traumatized groups,” manifesting as fear, somatization, social withdrawal, and depressive symptoms.¹²

In general, children’s emotional well-being is heavily influenced by the support and care received from families and communities. In the refugees’ setting of forced migration due to war and persecution, families’ abilities to provide this support for children are challenged by parental distress. Child abuse, abandonment, familial strife, or familial disintegration often occur in the setting of extreme stress on adults.⁶ In the absence of nurturing caregivers, a child’s attachment is threatened; poor attachment can have dire consequences on emotional regulation. A poorly attached child lives in a state that is distressed, anxious, or angry, with little expectation of being comforted. A sense of inner agency often fails to develop in these children, and a dissociation between emotion and cognition can occur that may persist into adulthood; therefore children who do not form secure attachments due to separation from caregivers or due to care from distressed caregivers may struggle to integrate emotional and cognitive information and therefore find themselves maladapted to both sorts of information processing.¹ This serves as yet another example of the complex ways cognitive and emotional forms of development are

intertwined. Lacking secure attachment, children are anxious rather than curious, and so they will not benefit and learn from a natural childlike curiosity.¹

Much more broadly than the quality of a child’s familial nurturing environment, a child’s environment in total also heavily impacts emotional well-being. A dimensional approach may be utilized to understand how environments of threats and deprivation constitute stressors that lead to psychopathology. In terms of threats, children may spend long periods of time living in constant fear or anxiety related to traumatic war exposures.⁶ Such states of chronic emotional distress may direct future emotional tendencies and inhibit development of appropriate coping skills. Further, severe deprivation— e.g., lack of food, lack of shelter, neglect— also places a patient at risk for mental illness. The degrees to which a patient suffers on the dimensions of threats and deprivation, it has been posited, direct the development of specific forms of psychopathology.¹² Baseline risk factors may affect a child’s vulnerability to these environmental factors negatively affecting their mental health; for example, delayed cognitive development or poor physical health are strong determinants of poor emotional well-being.¹³

The longitudinal study of refugee children in Australia also offered a glimpse into the progression expected of social-emotional difficulties. Social-emotional screening was conducted using the Strengths and Difficulties Questionnaire (SDQ) at 2 years and 3 years after resettlement. Results of the study demonstrated that, for most school age children, their social-emotional well-being improved with time, even without psychological intervention. Despite this improvement, social-emotional difficulties did not completely resolve with time. The SDQ component of most persistent emotional difficulty for refugee children over the resettlement period relates to peer problems, despite evidence of pro-social behavior and fewer conduct and hyperactivity problems on the part of the refugee children.⁹ These peer related issues might be related to discrimination, isolation, language barriers, and difficulties with acculturation.

Language acquisition in refugee children

Refugee children, upon resettlement in the U.S., are expected to learn English in order to thrive in their new school environment. As adult family members will often speak their traditional language in the home (as their opportunities to study English may be only as work schedules permit), children are immersed solely in the English language through schools, after-school programs, and media— often forced to make a rapid, complete transition to an unfamiliar language in educational contexts— and then are returned to environments where their first language is spoken only during the nighttime. In this form of bilingual environmental structure, language and literacy development of refugee children is altered (first language development is attenuated, second language learning may be impaired). Assessing whether children have learning difficulties, speech delay, difficulty learning English, or a combination of these is therefore complicated by more than simply the need for an interpreter.¹⁴ Instead, the appropriate developmental stage for expressive and receptive language for a refugee child may be unclear.

Research on second language acquisition in children offers some guidance for the expectations of providers attempting to assess for speech delay or learning disabilities in refugee children. Longitudinal studies have demonstrated that second language proficiency conducive to academic achievement is not acquired until at least 4-5 years following arrival; conversation proficiency requires 2-3 years. It is a common misconception that younger children are faster to acquire a second language than are older children. In fact, in successive bilingual children, the success and rate of second language acquisition are correlated with mastery of the first language, which sets the foundation and structure for learning a new language.¹⁴ Complex language skills in any language are not developed until between 6 and 12 years of age; before that, children are establishing and filling “domains” of language.¹⁵ Therefore, children ages 8-12 at arrival and at grade level in their first language skills tend to be fastest to learn the second

language (see Table 1)¹⁴; older adolescents may not have time to achieve academic proficiency while in school and their academic achievement will more likely suffer as they miss complex content instruction in English while attempting to master basic language skills.¹⁵

Time to Academic Language Proficiency in Non-English Speaking Children by Age	
Age upon arrival to U.S.	Time to proficiency
4-7 years	5-8 years
8-12 years	4-5 years
12-15 years	6-8 years

Table 1

Additional disadvantages posed by the refugee experience to second language acquisition can include interrupted or often limited prior schooling, low literacy in the first language, trauma exposure, complex medical or mental health issues, barriers (language and otherwise) to parental support in learning and involvement with schools, and stressors associated with resettlement.¹⁴ In contrast to the tendency of refugee children to adapt and conform to their new environment by focusing on only English language development,⁶ in order to best enhance a child’s ability to acquire second language skills, parents should maintain interaction with their child in the first language in increasing complex ways and encourage development of language skills and literacy in the first language concurrently with ESL learning at school.¹⁴ This approach helps foster the foundational structure children need to learn a second language, as well as helps to preserve family culture, traditionally defined parent-child roles, family identity, and self-confidence.¹⁴ This approach should be applied more loosely to children with established severe developmental delays or learning difficulties; in these children, focusing on developing the language that will afford maximum functionality may produce the best outcomes (personal communication Dr.

Rebecca Scharf, UVA Developmental Pediatrician, 2018 July 17).

Developmental Screening in Refugee Children

Early identification of developmental delays (cognitive, social-emotional, linguistic, or otherwise) is key; early intervention can alter the trajectory of a child's development and long-term health and well-being.⁹ Surveillance during well-child visits and standardized developmental screening tests at ages 9, 18, and 30 months are recommended to increase the frequency with which children with developmental delays are identified, tested formally, and treated with interventions in a timely manner.¹⁶

Refugees' Perspectives on Developmental Screening

A recent qualitative study published in *Pediatrics* on the developmental screening of refugees elicited the beliefs regarding developmental screening and corresponding therapies from a focus group of informants from Afghan, Bhutanese-Nepali, Burmese, Chin, Iraqi, Karen, Karenni, and Somali cultural communities in Rochester, New York. Their responses were examined using a Health Belief Model framework, in which health behaviors are related to: 1) sociocultural background; 2) beliefs regarding self-efficacy, susceptibility, and barriers; and 3) exposure to cues that prompt action.¹⁷

The study revealed several beliefs that might hinder the early diagnosis of developmental disabilities and referral for therapy. Cultural perspectives on disability of any sort depended on religion: those practicing multi-deity religions stigmatized disabilities as a curse implicating a family of wrong-doing, whereas those practicing Islam or Christianity viewed disabilities as ordained by God (though with a less negative connotation than multi-deity religions). Both of these viewpoints minimize motives to identify, diagnose, communicate about, or treat developmental delays.¹⁷ Such cultural perspectives were corroborated as applicable to the Charlottesville refugee community by anecdotes of Ms. Mirna Dickey, a family support

coordinator for the International Rescue Committee of Charlottesville. Many refugee parents, she recalled, would often be hesitant to screen for, accept, or seek treatment for disabilities such as autism or cognitive deficits of children for fear that public knowledge of a disability would ruin marriage prospects not only for the affected child, but for the entire family, too. Rather, parents would do everything in their power to hide that their child was different from others. Parents, in such cases, were all looking to do the best they could for their children, including the affected child, as marriage prospects constitute a significant measure of success for family members in many of the refugees' cultures. However, the family-based, less individualistic focus of many refugee families evidenced by this cultural perspective—especially when combined with the many stressors on the often large refugee families—certainly results in a lesser emphasis placed on each child's developmental health than is expected in U.S.-born families, sometimes inhibiting early intervention (personal communication Mirna Dickey, 2018 July 11).

The Rochester study exposed additional culturally based factors contributing to why many refugee parents may put less emphasis on spotlighting a child's developmental achievements or screening for delays. Most participants in their study reported that no simple word or phrase exists in their various languages to describe child development. This offers insight into different cultures' varying conceptions of childhood growth: either patterns of growth and maturing are paid so little attention in the participants' cultures that no word needs to be attributed in their languages, or their concepts of how a child grows and matures are simply different enough that no direct translation can be made (one participant said that they see children as growing on their "own track" until at least 2-3 years old, rather than in comparison to other children). In any case, monitoring of developmental milestones was qualitatively demonstrated to be an unfamiliar concept to the refugee participants. In fact, parents did not see themselves in a role related to education of their children; teachers filled this

role, in addition to the role of disciplinarian. Of the possible disabilities, however, the participants cited language and behavioral disabilities as the most concerning; the participants could apply no cultural context to help them understand the utility or process for accessing therapies or mental health interventions which could address these delays. The participants described physical disabilities, in contrast, as being more commonly known, accepted, and treated in their communities.¹⁷

Facilitation of Developmental Screening Among Refugees

Despite backgrounds and perspectives among refugee parents that do not prioritize developmental screening, refugee parents have suggested several recommendations for approaching refugees with the topic of child development and developmental screening and for promoting parental disclosure of concerns. These include:

- Establishment of trust with healthcare providers over time
- Screening administered by clinicians once trust is established (not at initial visit)
- Use of in-person interpreters, if possible
- Use of visual aids
- Use of healthcare or cultural navigators (e.g., refugee resettlement agencies) to link patients to community interventions.¹⁷

A transcultural child psychiatry clinic in Montreal proposes some additional steps to encourage receptiveness of refugee parents to developmental screening and intervention, including:

- Incorporation of multimodal therapies (e.g., Western psychotherapy and pharmacotherapy techniques, sand play therapy, traditional storytelling therapy, art and drama therapy, traditional or religious therapies)
- Extension of effort to include referring parties, cultural navigators/brokers, and/or extended family councils (as healthcare decisions often are made by convened family members) in clinic visits involving major treatment decisions, in order to enable

families to explore and conduct traditional family healing practices

- Inclusion of culturally diverse psychologists on the care team in order to help elicit refugee families' explanatory models for illness which may differ than those generally proposed by western medicine, and incorporating treatment which aligns with these explanatory models into treatment plans, if possible, in order to promote families' senses of self-efficacy in managing behavioral crises¹⁸

Culturally-Appropriate Assessment of Cognitive Status

Cognitive assessment tools normed and validated on English-speaking, U.S. born patients may not be normed or validated to screen for cognitive deficits in diverse, non-English speaking refugee populations. The implications and difficulties of applying cognitive assessments not designed for patients with diverse cultures, educational backgrounds, and languages are evidenced in a small qualitative study conducted at the Concord Hospital Family Health Center, which evaluated the cultural and linguistic appropriateness of cognitive assessment screenings for dementia or cognitive impairment in adults greater than age 55. In the study, Bhutanese refugee patients were screened with both the Montreal Cognitive Assessment (MoCA) and the Rowland Universal Dementia Assessment Scale (RUDAS).¹⁹ The RUDAS has been validated by multiple studies as uninfluenced or minimally influenced by education level or preferred language of patients, and it has been found to screen for dementia with 91.4% specificity across patients of diverse cultures and backgrounds, including immigrants.²⁰

Qualitative insights from assessment administrators compared the MoCA and the RUDAS to highlight key aspects of effective transcultural cognitive assessment. The differences in efficacy of the assessments, per the reports of the administrators, centered around the language used in questions, the level of literacy and wide cultural exposure required to complete the assessment, and the involvement of

the English, rather than the Nepali, alphabet in questions. For example, Bhutanese patients struggled to complete A-B visual sequencing or to list words starting with the letter “B” (as demanded in the MoCA), but identifying parts of the body (familiar across cultures) or listing animals (as patients could select animals with which they were familiar) as demanded by the RUDAS presented reasonable, linguistically appropriate screening challenges. In addition, the study revealed that the MoCA, which is not validated in diverse populations including those with low-education and non-English speakers, overestimated the severity of cognitive impairment.¹⁹

Developmental-Behavioral Screening Tools for Refugee Children in a Primary Care Setting

Similar transcultural issues as those observed with the MoCA plague assessment tools for child cognitive development, social-emotional development, and behavior; however, the successful RUDAS design is a testimony to the potential to use cultural competency to adapt cognitive assessment materials to be culturally and linguistically appropriate. Children should be screened for developmental delays according to the recommendations of the American Academy of Pediatrics algorithm for Developmental Surveillance.¹⁶ Many screening tests are approved for this purpose; two tests, the Ages and Stages Questionnaire (ASQ) and the Parents’ Evaluation of Developmental Status (PEDS), are commonly used, quickly administered (less than 15 minutes) screening tools for assessing children’s development.¹⁶

The PEDS is a 10-item standardized questionnaire of open-ended questions related to the development of children up to age 8 and designed to be completed by parents, either online or on paper.²¹ The questions are written at the 2-3rd grade reading level and cover expressive and receptive language, fine motor, gross motor, behavior, socialization, self-care, and learning, and parental concerns are scored in predictive and non-predictive categories of developmental concerns, based on the child’s age.²² The predictive concern total then correlates to a

“path” which offers referral or further screening recommendations, secondarily triaged by the types of concerns identified.²¹ A brief guide to administration and scoring available with PEDS provides prompts for test instructions and guides for scoring. The test is highly sensitive (86%) and specific (74%) in estimating developmental risk as high or moderate risk based on parental concerns expressed in the screening. A supplemental PEDS-Developmental Milestones (PEDS-DM) test is available to formally assess milestones related to each area of development, as well; this test is best used in conjunction with PEDS to determine whether referral, as opposed to parental education, is needed when the PEDS indicates moderate-risk.²¹

The PEDS is unique in its open-endedness combined with reliance on parental concerns and observations. It enables providers to quickly and specifically inquire about a full spectrum of aspects of development without relying on parents’ understanding of the concept of development. At the same time, the questionnaire pushes the provider to gauge the parent’s perspectives of their child and, if discrepancies between provider observations and parental observations arise or if free responses are blank or short, the provider may encourage parents to share their understandings of appropriate abilities at their child’s age, rather than proceeding with a long list of questions about milestones. The PEDS, therefore, facilitates discussion, particularly encouraging parents to vocalize their interpretation of their child’s development; in this opportunity, providers may learn about their refugee families and also screen parents for the need for education on developmental expectations.²¹

The PEDS has now been translated into “complete cultural translations” in 50+ languages by bilingual healthcare providers who are required to test the translation with patients and staff. The questions are written to be open-ended and non-culturally dependent, but still provide a strong sense of the specific questions being asked of parents. The test may therefore be administered at home (written responses), by clinic-based interpreters, or even by phone-based interpreters (depending on the literacy of the

patient's parents in their language) using validated translations, rather than ad hoc translations. Because questions are open-ended rather than asking about specific milestones, the test does not rely on cultural assumptions of children's activities or exposures to the English alphabet, specific toys, specific settings, etc. The test has been standardized in many nations and languages independently.^{21, 23}

The ASQ is a 19-question parent-completed questionnaire screening communication, gross motor, fine motor, problem solving, and personal adaptive skills. The test is written at the 10th grade reading level.²¹ Pass/fail scores are offered in each domain, but specific referral algorithms are not provided. The test also does not address social-emotional or behavioral components of development, as has been discussed above as a key consideration in refugee children in particular. Though the ASQ is modifiable by excluding questions which are not culturally appropriate (those which rely on exposure to playground slides, interlocking puzzles, etc.), the questions are close-ended and based in milestones, many of which may not be transcultural as this test has not been validated transculturally and in translation as extensively as PEDS. Though a recent comparison found that the ASQ had higher sensitivity and specificity compared to the PEDS (sensitivity: 82 vs 74%, specificity: 78 vs 75%) for identifying patients of moderate risk for developmental delays, both were found to be reasonable for use in primary care settings, with the choice of which to use determined by practice setting, provider preferences, and the population served.²⁴ Therefore, the cultural-appropriateness and language-appropriateness may easily outweigh the increase in sensitivity gained from use of the ASQ; this increased sensitivity may be attributable to potential overestimations of delay on testing due to culturally-inappropriate administrations or changes in information arising from ad hoc translations.

The recent Rochester study with focus groups of refugees, after a demonstration of the PEDS, remarked the belief that the test would be well received by parents with in-person interpretation. They particularly envisioned the

screen as a useful educational tool to learn about developmental milestones and expectations, when paired with visual support.¹⁷ An example of a potential useful visual support document is the Pictorial Pediatric Symptom Checklist-17, which illustrates child behaviors that might be of concern to providers conducting developmental screening.²¹

Recommendations

- Encourage attendance at school taught in English language, but also provide support to the family for the maintenance of cultural integrity and positive family attitudes toward maintaining the child's first language. Encourage that the child continue to develop competency in their first language while learning ESL. However, with severe learning disability or developmental delay, focus on the language which will provide the most functional ability at child's level.
- Consider the implementation of PEDS, in replacement of the ASQ, for developmental screening in the primary care setting for children 8 and under. Primary care providers or primary care psychologists may administer initial PEDS at 2nd or 3rd follow-up visit with a live interpreter present if the parents are illiterate; prior review of the test by parents or home administration of the test paired with CyraCom phone interpretation in the clinic could be considered for parents literate in one of the 50+ languages available. Consider use of visual supports with administration.
- When concern for a possible cognitive developmental delay is identified, consider social-emotional delay or mental illness as a contributing factor to the cognitive delay, and vice versa, as these forms of development are deeply interconnected, particularly in refugee children who have experienced unstable environments and traumatic exposures during childhood. Conduct screening for both cognitive development and social-emotional development in order to identify overlap.
- When moderate or high risk for developmental concern is identified using

PEDS (+/- PEDS-DM), refer for appropriate developmental testing with Developmental Pediatrics. If there is concern for any mood or thought disorder that is not manageable in the primary care setting, refer to Child and Family Psychiatry. Behavioral concerns may be referred to Developmental Pediatrics or Family Stress Clinic.

- Avoid the use of children to serve as interpreters; children may demonstrate aspects of their development, but they may not report on their own behaviors for their parents.
- Promote post-migration environments that minimize stressful exposure for refugee children by carefully coordinating care in a patient-centered home and advocating for refugee patients.

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