Assessing Developmental Delay in Refugee Children

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Tamara Saint-Surin

Childhood is typically seen as a time of innocence, playfulness, and growth, but unfortunately this is not the case for a large proportion of the world's young population. Those living in countries plagued by war and unsafe environments for those of different religions have to deal with harsh realities that seem almost unfathomable to citizens of developed countries. In 2009 there were over 16 million refugees in the world, with over 45% of this group being under the age of 18[4]. Having to be uprooted from your place of origin or being born into an unstable environment such as a refugee camp places children at risk for a number of issues including early neglect, exposure to trauma, poor health, lack of education, behavioral disturbances, mental health issues, and developmental delay. Developmental disabilities can involve sensory or cognitive difficulty, social or communications problems, motor impairment, and/or adaptive delay[1]. In addition to the standard risk factors, refugee children often have a different culture than that of the country they are displaced to, thus they face unique challenges that must be taken into account when performing a full and accurate developmental assessment. Timely diagnosis and a treatment plan may make a monumental difference for a child and their family that have already endured more than the standard household, therefore it is important to be able to identify the relationship between birth history, education, language, family, culture, and religion on a refugee child's growth and development.

Prior to gaining entry into the United States, all refugees undergo an initial medical screening examination. Despite physical and cognitive development being an essential topic to investigate for all children, this is normally not addressed until the child sees a health care provider when settled into their new country. Most refugee placement sites in the U.S. do not have anything similar to the International Family Medicine Clinic where refugees can be automatically connected to a Primary Care provider. Therefore, there may be even further delays in addressing any developmental concerns, which regardless are seldom the focus of an initial visit. The Ages & Stages Questionnaires (ASQ-3) is a commonly used method of screening children between the ages of one month and 5.5 years for developmental delays, but since it is to be completed by the parents there are risks of inaccuracies due to language and cultural barriers even with the use of an interpreter. While the shortage in reliable and validated tools may continue to persist for some time, health care professionals should do their best to approach the assessment during the child's initial visit or a timely follow-up visit in an objective, holistic, and thorough manner that minimizes the impact of language and cultural barriers on the results.

Taking an extensive medical and social history is the most important segment of any child's visit to a healthcare provider, as it can provide clues to the etiology of any suspected cognitive or physical delay. With refugee patients, it is imperative to begin with inquiries about the family's refugee experience. Listed below are some examples of comprehensive questions to ask the parents[7].

Refugee Experience	Under what circumstances did you leave your home country? Did you spend time in a refugee camp, and for how long? Have you been separated from close family and friends? Did you witness any violence or experience any physical or emotional trauma?
Birth History	What was the gestational age and birth weight of the child? Where was he/she born – at a home, clinic, hospital, or elsewhere? Were there any complications with the pregnancy such as infections, bleeding, hypertension, or hyperglycemia? Was the mother able to obtain a regular diet while pregnant? Was the mother under any significant stress during the pregnancy? Was there any exposure to drugs, alcohol, medications, or toxins before, during, or after the pregnancy? Did the baby experience any jaundice, respiratory distress, or other issues shortly after birth? Has the child ever had any issues with sleeping, feeding, or growing?
Medical History	Has the child ever been hospitalized? Have there been any injuries or accidents? Have they ever had surgery or had to take medications? Have they had dental care? Have they ever had any serious infectious such as encephalitis or malaria? Have they had any ear infections, and how many? Are there any concerns with their hearing or vision? What type of foods does he/she eat – any concerns for nutritional deficiencies? Were they breastfed, and if not what type of milk did they drink? Any issues with persistent constipation or diarrhea?

Family History	Ask about medical illnesses, mental health, trauma experience, parents' education, and parents' occupation. Ask about consanguinity.
Development	Ask about age-specific gross motor, fine motor, language, and social/adaptive milestones. What language does he/she speak, and at what age did they start talking? Have they progressed similarly to their siblings?
Social History	What type of environment did they grow up in? With whom does he/she interact on a daily basis? How often do they get to play with other children their age? What educational opportunities have they had, and was their schooling ever interrupted? Were they ever held back a grade?
Mental Health	Have there been any signs or reasons to worry about posttraumatic stress, depression, grief, or anxiety? Has the child seemed more angry and/or aggressive?

Particular attention should be given to the birth history, as the mother's circumstances around the time of the pregnancy and childbirth may have been less than ideal and could have contributed to any abnormalities. They may have not had access to quality prenatal care, during which they would have been screened for serious infections that can cause significant damage to the fetus such as HIV, cytomegalovirus, toxoplasmosis, rubella, syphilis, and group B streptococcus[1]. In addition to the aforementioned infections, it is crucial to investigate a history of parasitic infections, as one study in Turkey indicated that children under the age of six with parasitic infections had growth delay, general developmental delay, language-cognitive developmental delay, and fine motor development delay more than twice as often as children without parasites[9]. Similarly, a study of a cohort of children in an urban Brazil town found that cognitive function was significantly lower in children with a history of persistent diarrhea in early childhood[10]. As one goes through the process of obtaining this extensive history for a child with suspected delay, however, healthcare providers can soon recognize the sizable influence of non-medical factors.

Knowing and celebrating one's birthday is something that many U.S. citizens take for granted. A number of refugees do not have an accurate date of birth on any of their documents upon arrival to a new country. Inaccurate dating can be due to a number of things including the banning of calendars in their home country, a child being adopted or spending time separated from their parents, administrative errors, visa authorities making an inappropriate estimate, or simply not knowing the specific day or month[3]. Accurate age determination is key for vaccinations, evaluation of developmental milestones, and ensuring that the child starts at a suitable educational level. Questions that may be useful in helping the parents determine the accurate age include asking where the family was at the time of the birth, the season during which the child was born, how long ago the child started walking, how long ago the child was toilet trained, and the child's age in relationship to other children in the family[3]. The level of education does not always correlate with the child's age, however. Children often have interrupted education during the process of displacement and living in a refugee camp, or may have never had the opportunity to receive a formal education due to other responsibilities. Teachers may express concern about a child's cognitive abilities when instead it may be a case of a child having to adjust to a new school system at a higher grade level as well as not having immediate fluency in English[8]. While there are programs such as ESL that are designed to help children learn English and better integrate within the school system, it has been suggested that the language at home also affects the child's development and progress.

Poverty is an important risk factor for child development overall, and children living in linguistically isolated homes are at greater risk for living in poverty[5]. When comparing children of foreign-born mothers who live in households that are linguistically isolated, children of foreign-born mothers living in non-linguistically isolated households, and children of U.S. born mothers the lowest cognitive scores were in the children living in linguistically isolated homes[5]. Parents with limited English proficiency aren't able to assist their children with schoolwork or with practicing English, and may have limited access to resources overall. It is imperative to take a family-centered approach when managing a child with possible cognitive delay, as the potential progress of the child is also dependent on the progress of the parents and other members of the household.

Family dynamics and cultural beliefs influence views on developmental delay and approaches to treatment. What may be seen as obvious warning signs to others may be thought of as normal behavior to the parents, and consequently would make them less likely to voice concerns to their healthcare provider. Some may attribute decreased intellectual capacity to a "weak memory," or label a child that is unable to follow instructions as "stubborn"[2]. In some south Asian cultures, such as those from Pakistan, a girl is expected to be like her mother and a boy like his father – if this doesn't occur there may have been a disturbance in the natural order or the child may have been taken over by a

spirit[2]. In these cases, the parents may feel isolated due to stigma and may turn to a non-traditional healer in an attempt to remedy the situation. Some cultures emphasize the importance of social relationships over intellectual abilities, so they may not be too concerned whether or not their child has cognitive delay if they are still able to interact well with others[2]. In countries where girls are expected to be more shy, such as Saudi Arabia, it has been shown that autism spectrum disorder has a later age of diagnosis in girls than in boys[2]. Religion also often plays a part for refugee patients, as some may consider their child's condition to be an "act of God." Understanding each family's views on developmental disabilities is essential so that an open conversation can be held about the child's prognosis and a treatment plan can be agreed upon.

Barriers to developmental screening in refugee populations include language, childcare, low socioeconomic status, family education level, cultural beliefs, and trust of their medical provider[6]. While some of these may seem difficult to overcome, a patient and holistic approach to management that involves the child's family and those in their immediate environment can lead to a successful outcome. Once a potential developmental or cognitive issue is identified, the primary care provider should refer the child to a Developmental Pediatrician and/or a behavioral health specialist, and should also utilize other resources in the community that would benefit both the child and their family. The challenging situations that these children have had to endure in their short lifetime alone does increase their risk of having some abnormalities, but with timely diagnosis, close medical follow up, close partnership with the school, and social support, the future can be promising.

Resources:

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