

Congenital Abnormalities: Using the Parent Evaluation of Developmental Status (PEDS) Screening Instrument in a Displaced Amazonian Community of Peru

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Abstract

Reducing developmental delay and congenital anomalies has become a primary focus for improving conditions for children and families in developing countries. With decreased infant and child mortality, the occurrence of developmental delays and disabilities has increased. Consequently, the prevalence of developmental issues is larger in developing countries. This study focused the rate of congenital abnormalities among young children in a displaced Amazonian community of Peru. Information was gathered on mothers' perceptions of their child's development using the Parents Evaluation of Developmental Status (PEDS) survey instrument.

1. Introduction

Congenital anomalies as defined by the World Health Organization (WHO) consist of birth defects, congenital malformations, metabolic disorders, hearing or vision problems, intellectual disabilities, or other abnormalities. WHO collects frequency data concerning children with congenital abnormalities in countries such as Africa, the Americas, South-East Asia, Europe, Eastern Mediterranean, and West Pacific. Throughout these regions there are many developing countries where people live in extremely low socio-economic communities and are at high risk of illness due to environmental and other health factors (WHO, 2019).

Reduction in the percentage of children with developmental delays is an initiative of the United Nations member states. However, research on congenital anomalies in small, rural cities of developing countries is lacking. The reduction of children who demonstrate developmental delay can only be achieved with increased research, and the assistance of health providers, community programs, and families working together (World Health Organization, 2019). This study seeks to build on that need by using the Parent Evaluation of Developmental Status (PEDS) screening instrument to gain knowledge about the frequency of congenital anomalies in developing areas of Peru.

Literature Review

2.1 Cognitive Abnormalities Among Young Children in Developing Countries

Ninety four percent of severe congenital anomalies appear in developing countries and are indirectly related to a lack of access to sufficient and nutritious foods, or lack of access to health care and screening (World Health Organization, 2019). Further, congenital anomalies accounted for 303,000 deaths at birth and 200 million children who experience cognitive abnormalities throughout their lifespan (Scherzer et al., 2012). Long term consequences for young children (B-8) identified as having a cognitive abnormality or disability includes poor academic outcomes, decreased job fulfillment, low wages, and increased poverty. Moreover, cognitive abnormalities that appear early in the child's life have been noted as risk factors for more extreme issues such as infant death, impaired cognitive performance, and immature social interactions (Walker et al., 2007).

3. Assessing Cognitive Abnormalities

The American Academy of Pediatrics (2006) has been successful at exploring and identifying early assessment strategies for identifying young children who are at risk for developing disabilities or cognitive abnormalities. When problems are detected early in the child's life and appropriate intervention strategies are used, significant reductions in the negative effects of the disability have been noted (American Academy of Pediatrics, 2006). Furthermore, early detection allows opportunities for parent education and support, which has shown to have a great influence on parent-child interaction. Parental awareness and education will lead to more appropriate daily childcare, such as carrying, holding, feeding, dressing, and bathing (McIntire, 2008). In locations with available resources and intervention services, early uses of therapy in the motor and speech areas, and the use of feeding and motor equipment has led to an improved quality of life and enhanced cognitive, motor, and social development (Guralnick, 1998).

The Center for Disease Control delineates three major stages of assessment when looking for delay among young children. These include (a) monitoring, (b) screening, and (c) formal evaluation (CDC, 2018). These stages are described in the succeeding paragraphs.

3.1 Developmental monitoring. Developmental monitoring occurs when a person close to the child observes how the child grows and changes over time and whether the child meets the typical developmental milestones in playing, learning, speaking, behaving, and moving (CDC, 2018). Doctors or nurses check children for these developmental milestones during well visits, and parents are informed of other milestones their child should be reaching in the near future. If milestones are not achieved, it could be a sign of a developmental problem, and the child can be checked out more thoroughly or tested by a specialist (CDC, 2022). This type of developmental monitoring has been used in developing countries such as Cambodia where mothers were provided informal developmental checklists to assess milestones of their own children (Brothers et al., 2008; Francis, 2011).

3.2 Developmental screening. Developmental screening occurs when parents, healthcare providers, early childhood teachers, or other trained providers look for developmental milestones using a formal validated screening tool. This could occur when a professional physically and orally assesses the child, or it may occur when a parent completes a validated questionnaire about their child (CDC, 2018). The examination or questionnaire provides the professional with more detailed information about the child's development than is gathered in an information observation or interview. Screening may include developmental domains such as language, movement, thinking, behavior, and emotions (CDC, 2018). The purpose of the developmental screening tool is to alert professionals and parents concerning further investigation that may be required. When a screening test reveals that a child may not be meeting developmental milestones, children are then referred for more formal evaluations.

3.3 Formal evaluation. A formal developmental evaluation is a more in-depth look at a child's growth trajectory. Evaluations are usually done by a trained specialist, such as a developmental pediatrician, child psychologist, speech-language pathologist, occupational therapist, or other specialist (CDC, 2018). Evaluations involve a multitude of tests including things such as observing the child, formally testing the child, asking the parent(s) questions, and having the parents fill out questionnaires about their child's behaviors, abilities, and other concerns that they may have (CDC, 2018).

4. The Importance of Early Intervention in Developmental Delay

Effective assessment of young children can lead to an intervention in the child's life that will change the trajectory of a delay from a negative outcome to a more positive one. When this intervention is systematic and planned it is characterized by manipulating a series of environmental or experimental factors and is most successful when initiated during the first five years of life (Guralnick, 1987; Heward, 2009). The United States has acknowledged the positive outcomes of early intervention through inclusion in the nation's premier special education law, the Individuals with Disabilities Education Act (IDEA). In IDEA, "Early childhood interventions consist of multidisciplinary services that are designed to enhance child development, minimize potential delays, and remediate existing problems to prevent further deterioration (Shonkoff & Marshall, 1992).

5. Developmental Delay in Peru

Children who reside in countries considered "developing" are particularly vulnerable to congenital abnormalities and/or delays. Peru is one such country. The largest group of people with disabilities in Peru are those with physical impairments (53%). Second, 50.9% of people with disabilities report being blind or visually impaired. Attendance rates at school are 40% lower for children with disabilities than children of the same age with no disabilities (Instituto Nacional de Estadística e Informática, 2022). In addition, children with mental health needs are excluded from school (Mental Disability Rights International, 2004). Less than one percent of children who experience any type of disability receives pre-primary or primary education (World Report on Disability, 2011).

6. Methodology

This study seeks to examine the incidence of perceived developmental disabilities by mothers of young children (B-8) within a displaced Amazonian people group who live in the village of Cashahuacra near the town of Chosica, Peru. The people of this village have been displaced from their indigenous Amazon community due to deforestation of their native homelands. This is an intact community that is only populated by those who have migrated from the same region on the Amazon. Moreover, this study seeks to determine if the Parents Evaluation of Developmental Status (PEDS) screening instruments can be used with this population to show how mothers might rate their children on questions of developmental delay. Specifically, the research question is listed below.

6. 1 Research Questions

Can the Parents Evaluation of Developmental Status (PEDS) survey instrument be used to measure mothers' perceived developmental delay among their young children within the Cashahuacra community of Peru?

Which behaviors of children pose the greatest risk of congenital abnormality as perceived by mothers in the Cashahuacra community of Peru as rated on the PEDS screening instrument?

6. 2 Subjects. The subjects of this study consisted of 35 women, who have children (birth- age 8). The mothers' ages ranged from 15 years old to 37 years old. These women came to pop-up clinics that were set up near their homes. They were most likely at the clinics because of an illness or injury for which the mother or child needed medical attention. The mothers were asked to complete the PEDS questionnaire regarding their child.

6.3 Setting. Data was collected at the Cashahuacra Community Medical Clinic, which is located in the village of Cashahuacra, Peru. Cashahuacra is a community one hour east of Lima, Peru in the Santa Eulalia district in the Huarochirí province. The village is habited by approximately 402 citizens of the Shipibo-Konibo indigenous people group who were displaced from their Amazonian lands due to climate change and deforestation.

In addition to experiencing deforestation in the native lands, a 2015 flooding and landslides caused over 90 homes, public transportation vehicles, the sewage system, and electrical poles and accessibility to be destroyed in their new community of Cashahuacra. (International Federation of Red Cross And Red Crescent Societies, 2015). Clean up and waste exposure caused cuts, severe wounds, diarrhea, dermatitis, severe insect bites and infestations, disease, dehydration from shortage of water supply, and even death in some cases (International Federation of Red Cross and Red Crescent Societies, 2015).

6. 4 Instrument. Data was collected using the Parents Evaluation of Developmental Status (PEDS) survey. The PEDS survey is a validated tool for use as developmental-behavioral screening instrument used during interviews with parents. This instrument is used in an interview type meeting with close acquaintances such as a parent or

family member. Ten questions are posed on the questionnaire, and the child is rated according to three choices (yes, no, a little). The PEDS instrument has been used within several international settings including Ghana, Korea, and South Africa. The PEDS survey can be completed in ten minutes and is used to determine whether further intervention services may be required. The PEDS instrument was translated into Spanish for the Cashahuacra village and Quechua for the Ancash communities. Table A provides the PEDS document.

Table A

PEDS questions used while interviewing mothers in Peru

Please list any concerns about your child's learning, development, and behavior?

No, Yes, a Little

Comments:

Do you have any concerns about how your child understand what you say?

No, Yes, a Little

Comments:

Do you have any concerns about how your child uses his or her hands and fingers to do things?

No, Yes, a Little

Comments:

Do you have any concerns about how your child uses his or her arms and legs?

No, Yes, a Little

Comments:

Do you have any concerns about how your child behaves?

No, Yes, a Little

Comments:

Do you have any concerns about how your child is learning to do things for himself/herself?

No, Yes, a Little

Comments:

Do you have any concerns about how your child is learning preschool or school skills

No, Yes, a Little

Comments:

Please list any other concerns:

Comments:

6.5 Data Collection. Families were invited to come to the Community Clinic through a flyer that was circulated throughout the community. The flyer announced the clinic hours and services that could be performed by the doctors. Two interviewers approached each mother and told them that we were seeking health information about their children. All interviews were conducted by two members of the community who speak the language of the community and have been trained via online training to use the PEDS instrument. Written informed consent was obtained from each participant following explicit information regarding the research procedure through the mother's signing their name.

6.8 Data Analysis. The frequencies of all variables were calculated. Simple percentage and frequency data was developed.

7. Results

Responses concerning the mother's perception of their child's achievement of developmental milestones revealed that mothers from the Cashahuacra community reported significant concerns about how their child behaves (N=23), how their child is learning in school (N=20) and how their child talks and makes speech sounds (N=18). Contrasting, the mothers rated the question concerning using the hands and fingers to do things as the lowest (N=2). In addition, only three mothers rated question concerning using arms and legs as a concern. Figure A provides the frequencies of positive responses on each question of the PEDS screening instrument.

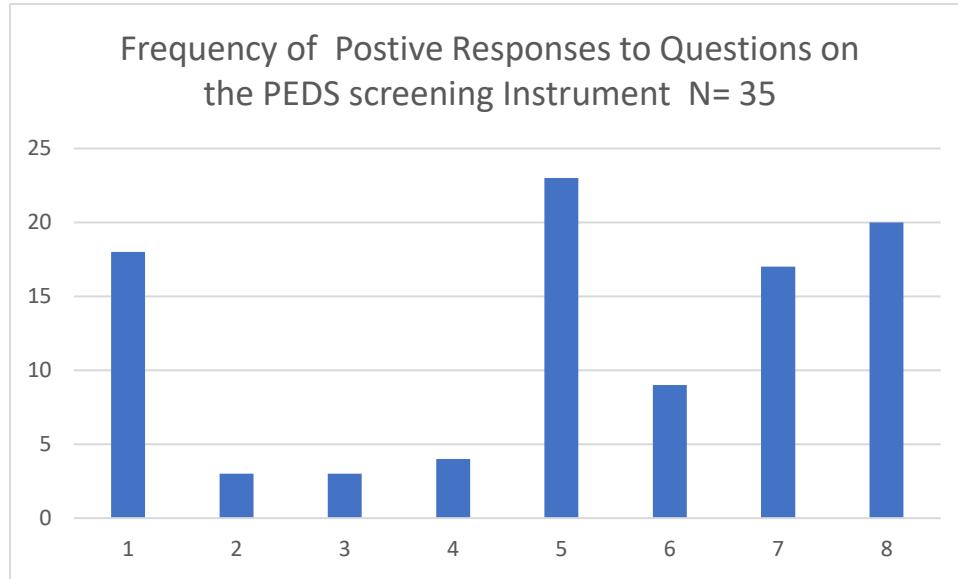


Figure 1: Q1= Do you have concerns about how your child talks and makes speech sounds? Q2= Do you have concerns about how your child understands what you say? Q3= Do you have any concerns about how your child uses his/her hands and fingers to do things? Q4=Do you have concerns about how your child uses his/her arms and legs? Q5= Do you have concerns about how your child behaves? Q6=Do you have concerns about how your child gets along with others? Q7=Do you have concerns about how your child is learning to do things for himself/herself? Q7= Do you have concerns about how your child is learning preschool or school skills?

8. Implications

The purpose of this study was to examine the research question: Can the PEDS screening instrument be used to capture a mother's perception of their child's developmental delay among families who have been displaced from Amazonian regions of Peru? The analysis revealed that mothers from Cashahuacra community revealed concerns over their child's lack of speech development and their child's behavior. Further the second research question, "Which behaviors of children pose the greatest risk of congenital abnormality as perceived by mothers in the Cashahuacra community of Peru as rated on the PEDS screening instrument?" The mother's rated behavior and learning school skills as their two major concerns.

9. Limitations

This study included several limitations concerning the demographic information and sample size. First, the demographic descriptors such as gender and age were not included in this research to protect the anonymity of the respondents in this village. The inclusion of this information would have helped the researcher understand better how the mother's responses might have been associated with specific variables such as age and gender. Second, the small sample size precludes generalization to the population and infers a positive skew that does not correspond to the general population. However, it is noted that in rare cases a small sample size may be appropriate for a rural setting such as the one in this village (<https://wordvice.com/how-to-present-study-limitations-and-alternatives/>). Therefore, the small sample size may be appropriate for this setting but cannot be applied to a larger population of families in this regional area.

10. Conclusion

The data gained from using the PEDS survey instrument with mothers whose families live in the displaced Amazonian Cashahuacra community of Peru revealed that the PEDS instrument could be used to identify concerns that a mother might have about their child's development. This is consistent with the use of the PEDS in other developing countries. However, the concerns of the mothers did not match the demographic data concerning high incidence disabilities in Peru. Physical disabilities and blindness are rated as having the highest incidence of disability in Peru. In this study, behavior and school performance were rated as the highest areas of concern.

11. Summary

Increased research in this area is needed. Both qualitative and quantitative research can lead to understanding the causes and indicators of developmental disabilities and cognitive anomalies more thoroughly in developing countries. Furthermore, heightened knowledge and understanding will allow health providers and parents to be more aware and informed. Instruments such as the PEDS assessment tool can be a valuable aid in helping families understand their child's development and integrate needed interventions early in children's' lives. Further, the need clearly exists for more emphasis among developing countries to identify young children who may have congenital abnormalities. By identifying these children early, appropriate resources can be designed and provided to the children and their families and increase the hope that all families have for their children.

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