

# Translation of the Parents' Evaluation of Developmental Status (PEDS) Developmental Screening Tool for Identification of Developmental Delay in Children from Birth to Five Years of Age in the Karagwe District of Northwestern Tanzania, East Africa: A Pilot Study

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## Abstract

**Objectives:** The purpose of this pilot study was to trial the translation of the Parents' Evaluation of Developmental Status (PEDS) developmental screening tool to determine usefulness in identifying developmental delay in children from birth to five years of age (U5s) in the Karagwe district of Northwestern Tanzania.

**Methods:** A random sample of convenience was utilized for this study. Twenty children's caregivers interviewed using the PEDS questionnaire at the Maternal-Child clinic at the Nyakahanga District Hospital.

**Results:** The results of this study placed children in pathways indicative of potential disability at a higher than expected frequency.

**Conclusions:** Based on the outcome of this pilot study, further research is needed to determine if the PEDS is an appropriate screening tool for developmental delay in U5s in Karagwe, Tanzania, East Africa.

## IRB APPROVAL

IRB approval was granted as "exempt" by the University of Pittsburgh's IRB board on January 5, 2005. The IRB number is 0412105.

This project was conducted at the Nyakahanga District Hospital, Karagwe, Tanzania, East Africa.

## INTRODUCTION

Early intervention programs provide rehabilitative services (physical therapy, occupational therapy, speech-language pathology, etc.) to infants and children with identified disabilities. In many western countries, these programs have existed for 30 years. "The earlier a disability is detected, the more a child can benefit from both rehabilitation as well as simple interventions that help maximize abilities and potential" (Kolucki, 1999). Nearly 80% of the majority of infants and children in the world that have disabilities,

however, live in developing countries (Kolucki, 1999; Sherer, 2002).

"The Convention of the Rights of the Child (CRC) includes the right of children who are disabled to equal opportunity as well as to have their disability detected and treated as early as possible... This a moral and ethical imperative that will, as the research tells us, positively or negatively affect the lives of millions of children in the world" (Kolucki, 1999). The United Nations International Children's Emergency Fund (UNICEF)'s mission includes a commitment to ensure protection for children who are disabled.

Karen Edwards states, "In many developing countries, children with moderate or mild disabilities are not identified until they reach school age. This delay in identifying disabled children means that intervention has less impact because it happens at a later stage in a child's development. This, in turn, means that disabled children participate less in

their communities” (2002).

The Government of Tanzania has developed a National Health Policy to improve the health of its citizens.

Objectives that are most applicable to children include:

-”To upgrade the health status of the population by increasing life expectancy through reduction of disease burden and improvement of maternal and child-care services and disease prevention of common illnesses.”

-”To ensure a sufficient number of adequately trained health personnel are at the different levels in the health care infrastructure.”

-”To ensure that individuals, families and communities take a larger share of responsibility for their own health” (National Website, retrieved 10/17/2004).

Despite the commitment of the government to upgrade the health of children, Tanzania has limited resources. The 2000 World Health Report indicated that U.S.\$36 was spent per capita in Tanzania versus U.S.\$3724 spent per capita in the United States (Boland, 2004).

The Nyakahanga Hospital in the Karagwe district of Northwestern Tanzania is jointly supported by the Tanzanian government and the Evangelical Lutheran Church of Tanzania. It serves as the government district hospital for 400,000 people. According to the Nyakahanga Hospital website, the facility provides care to 230 inpatients patients and 200 outpatients on a daily basis.

A Maternal-Child clinic (MCH) is part of the Nyakahanga Hospital. It serves the pediatric healthcare needs of children from birth and their mothers. It is estimated that 500 – 800 children are seen per month (Dr. Linda Winkler, personal communication). “Preventative medicine is a special concern in public health, and developmental screening for the early detection of disability in children is part of this concern” (Anastasiow, 1982).

The importance of screening for identification of developmental delay/disability has been established above. Vigorous review of literature yielded only one established program for surveillance of children under 5 (U5s) in all of Tanzania. This program is the Integrated Management of Childhood Illness (IMCI). It was developed by the World Health Organization (WHO) and UNICEF. Although it is in the early phases of implementation/expansion in 82

developing countries, including Tanzania, the Karagwe district is not involved at this time (Tanzania IMCI Multi-Country Evaluation Health Facility Survey Study Group, 2004).

Further, according to Non-governmental Tanzanian society (NGO) Comprehensive Community Based Rehabilitation Tanzania (CCBRT), “a large number of physically impaired children in Tanzania have treatable disabilities or suffer impairments that can be considerably reduced” (retrieved from website 1/11/2005). The most commonly named pediatric disabilities are Cerebral Palsy (CP) and Spina Bifida (SB)/hydrocephalus. Treatment can occur only if/when these children are identified.

Developmental screening (as cited in Al-Ansari, 1998) aims to detect potential disability. Utilization of Physical Therapy (Physiotherapy) examination and intervention is expanding in Tanzania. In order for children in need of Physical Therapy and other rehabilitative interventions to be identified, a screening mechanism needs to be put into place. “Using the reports of parents on their child's developmental status has been found to be appropriate and reliable” (Al-Ansari, 1998).

The PEDS (Parents' Evaluations of Developmental Status) is a developmental screening test with many advantages for use in this population. The following information was retrieved electronically on December 4, 2004 from <http://www.pedstest.com>:

The PEDS takes about 2 minutes to administer if conducted as an interview. It may be used longitudinally for summarizing surveillance of a child. It is highly reliable and can be easily administered by a range of professionals after minimal training. It is inexpensive to administer. The PEDS has been shown to be effective regardless of parental/caregiver education, income, race, marital status, or child's age or birth order. The PEDS was initially standardized in English and Spanish in 1997. The tool has been translated into Somali, Vietnamese, Hmung and Chinese. It is currently undergoing standardization in Canada, Slovenia, Australia and Malaysia. The sensitivity is 74% – 79% across age levels while specificity is 70% – 80% across age levels. These qualities make the PEDS a quick and easy method to screen for disability in a busy Maternal-Child Clinic.

It is the purpose of this pilot study to trial the translation of

the Parents' Evaluation of Developmental Status (PEDS) developmental screening tool to determine usefulness in identifying developmental delay in children from birth to five years of age (U5s) in the Karagwe district of Northwestern Tanzania, East Africa.

## **METHODS**

Prior to implementation, this study was approved and classified as exempt by the Institution Review Board at the University of Pittsburgh. A random sample of convenience was utilized for this study. Parents/caregivers of children from birth to age five who were seen at the Maternal and Child Health Clinic on the grounds of the Nyakahanga District Hospital in Karagwe, Tanzania on August 2, 3, and 5, 2005 were interviewed in a private office for this study. A student physical therapist who works at the hospital served as an English/Swahili translator.

The translator assisted in collecting the following data: child's gender and age, birth order of the child, age of mother at time of child's birth, mother's level of education, person who is the child's primary caregiver, and any known medical diagnoses of the child.

After collecting demographic information, the translator read the written 10 question PEDS questionnaire to the caregiver and responses were recorded. Data was analyzed to determine the frequency in which the children were categorized into the various PEDS paths.

## **RESULTS**

A total of 20 caregivers were interviewed regarding their children. The sample included 10 male and 10 female children with the following age ranges represented:

< one month (N = 3), 1 month – 11 months (N = 4), 1 – 2 years-old (N = 4), 2 – 3 years-old (N = 3), 3 – 4 years-old (N = 5), 4 – 5 years-old (N = 1). Birth order was: 1<sup>st</sup> born (N = 7), 2<sup>nd</sup> born (N = 0), 3<sup>rd</sup> born (N = 4), 4<sup>th</sup> born (N = 1), 5<sup>th</sup> born (N = 4), 6<sup>th</sup> born (N = 2) 7<sup>th</sup> born (N = 0), and 8<sup>th</sup> born (N = 2).

Primary caregivers were reported as follows: mother (N = 15), housegirl (N = 2), mother and housegirl (N = 2), mother and father (N = 1), grandmother (N = 1). Of the 18 women who knew their age, the average age of the mother at the child's birth was 28.9 years-old. Educational level of the mother was: none (N = 3), Standard 7 (N = 14), Form 2 (N = 2), and Form 4 (N = 1).

Based on the answers to the PEDS interview questions, the children were placed into the following PEDS pathways: A (N = 7), B (N = 0), C (N = 12), D (N = 0), and E (N = 1).

## **DISCUSSION**

The results of this pilot study placed children in pathways indicative of potential disability at a higher than expected frequency. 35% of responses to the PEDS questionnaire lead to categorizing children into Pathway A, multiple significant concerns for disability and the need for referral. This is compared to 10% that was anticipated (Glascoe, 2002). It should be noted that one child diagnosed with Menigomyelocoele was appropriately categorized into PEDS Pathway A. 60% of children were categorized into Pathway C, nonsignificant concerns not predictive of disability. Anticipated placement into Pathway C was 20% (Glascoe, 2002). Lastly, 5% of responses lead to classification into Pathway E, the absence of concerns, while it was expected that 20% of respondents would be in this pathway (Glascoe, 2002).

There were several challenges that contributed to the results of this study, particularly the disproportionate number of children that were classified into Pathway A. One was the word “concern” in the PEDS questions. The majority of caregivers interviewed had concerns regarding their children in a context reflective of extrinsic environmental considerations evident in this third world country versus that of a potential developmental delay/disability for which the PEDS was screening.

Specific concerns expressed by the caregivers were keeping the baby away from insects, maintaining cleanliness of the child, breastfeeding issues, diet/nutrition, lack of paternal involvement in caregiving, and general health. In addition, concern was reflective of the fact the the region was in the midst of a malaria epidemic. The caregivers were, therefore, in an overall heightened state of concern about all aspects of their child's health. Many expressed concerns were related to fever, decreased appetite, and malaise. However, no concerns were expressed regarding developmental delay.

There may have been lack of standardization of the translation of the PEDS questionnaire by the translator despite education in the importance of administering the PEDS uniformly. The author is not able to qualify this due to lack understanding of the Swahili language.

## **FURTHER INVESTIGATION**

The PEDS has been translated into a written form in Swahili with special care used to accurately reflect the intention of the word “concern”. This could assist future researchers in completing a more uniform interview with caregivers. Caregivers who are able to read Swahili could complete the questionnaire independently whereas those who require translation would benefit from a consistent template from which the translator would read.

A larger sample size overall and in each age range are needed to further determine the usefulness of the PEDS in identifying disability in Karagwe, Tanzania. Further, longitudinal assessment would further establish the usefulness and accuracy of the PEDS.

It would be beneficial to trial the PEDS in a time absent from significant health concerns, such as a malaria epidemic. This may be challenging as some children are not seen for well-child visits at the Maternal-Child Clinic. It is also difficult to control for the environmental considerations evident in this third world country.

## **CONCLUSION**

Based on the Tanzanian government's objectives, screening for developmental delay is appropriate and warranted. Additional research is needed to determine if the PEDS is the appropriate screening tool for developmental delay in children from birth to the age of five in Karagwe, Tanzania, East Africa.

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## **APPENDIX 1**

### **DESCRIPTION OF PEDS PATHS (11)**

#### **PATH A: WHEN MULTIPLE SIGNIFICANT CONCERNS ARE PRESENT: REFER**

2 or more significant concerns are identified by the caregiver. These children should be referred to appropriate practitioners for examination.

“These children are 20 times more likely to have disabilities than children for whom there are no concerns. This means that about 50% have disabilities, while an additional 20% perform well below average in areas critical to school success.” (11)

#### **PATH B: WHEN THERE IS ONLY ONE SIGNIFICANT CONCERN: ADMINISTER A SECOND SCREEN OR REFER FOR SCREENING**

1 significant concern is identified by the caregiver.

When time is limited, referral for additional screening is recommended. If time is not a factor, a second, different developmental screening test should be administered. If the second screen is failed, referral to an appropriate practitioner is warranted. If the second screen is passed, the parents should be offered reassurance and follow recommended developmental surveillance.

#### **PATH C: RESPONDING TO PARENTS WITH NONSIGNIFICANT CONCERNS**

In this path, concerns raised are not predictive of disabilities. The concerns most often are about behavior.

The PEDS manual (11) suggests three approaches to address these issues: brief advice, in-office counseling and informational handouts; screen behavior and emotional well-being; and referring for parent training or behavior management training.

#### **PATH D: WHEN PARENTS HAVE DIFFICULTY COMMUNICATING: CONSIDER ALTERNATIVE DETECTION METHODS**

It is anticipated that about 3 out of 100 parents will have communication barriers such as illiteracy, language disorders, different primary language than the person administering the tool, or mental health problems. These

children are categorized in Path D.

Several recommendations to address these barriers are offered in the PEDS manual (11).

#### **PATH E: WHEN THERE ARE NO CONCERNS**

No parental concerns are identified while administering the PEDS.

Parents should be reassured that the child appears to be coming along well. Encouragement should be given to continue regular, repeat screenings.

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