The Program for Global Paediatric Research
Outcomes Research for High Risk Newborns and Children in Developing Countries

Methods for Evaluating Cognitive/Intellectual Outcomes in Low and Middle Income Countries

Academic Societies Meeting
Toronto, Canada
May 9, 2009

Robert Armstrong, MD PhD FRCPC
Associate Professor, Department Pediatrics, UBC
Director, Centre for International Child Health
BC Children’s Hospital
barmstrong@cw.bc.ca
The Program for Global Paediatric Research

Outcomes Research for High Risk Newborns and Children In Developing Countries

Methods for Evaluating Cognitive/Intellectual Outcomes in Low and Middle Income Countries

Challenges In Evaluating the Domains of Developmental Outcomes in Low and Middle Income Countries
Outcomes Research for High Risk Newborns and Children In Developing Countries

Challenges In Evaluating the Domains of Developmental Outcomes in Low and Middle Income Countries

Objectives

1. Measuring development is important and we must do it even though it is difficult!
2. There are many measures being used and the field could be described as chaotic!
3. There are achievable solutions that can advance our knowledge much more rapidly than if we continue the way we are currently.
“...our conservative estimate is that more than 200 million children under 5 years of age in developing countries are not developing to their full potential.”

Critical Risk Factors Influencing Developmental Potential

- Inadequate Cognitive Stimulation
- Stunting
- Iron Deficiency
- Iodine Deficiency
Additional Risk Factors Influencing Developmental Potential

Iron Deficiency Anemia
Malaria
Maternal Depressive Symptoms
Violence
Low-birthweight infants with IUGR
Exposure to metals (lead, arsenic)
Kathmandu Neonatal Encephalopathy Study
Ellis et al 1999

- Prospective community-based cohort study of all births from January 1995 to July 1996.
- 131/21,609 births NE (6/1000 LB).
- Next born term controls.
- Outcome measures: DDST, Amiel-Tison Neurological Exam, Bayley II (in abnormal cases)
- One year follow-up 102 NE (78%) and 106 controls (51%).
- Moderate HIE 71% (CI 54 – 84) death/disability.
- Severe HIE 97% (CI 82 – 99) death/disability
CHALLENGE FOR THIS WORKSHOP

WHAT CAN WE RECOMMEND TO IMPROVE OUR MEASURES OF DEVELOPMENT?
International Classification of Function

Health Condition (disorder/disease)

Body Function & Structure

Activity

Participation

Environmental Factors

Personal Factors

Contextual Factors

WHO 2002
Focus on the Whole Child!
Observe Over Time
The Important Role of Family in Measurement

- Irrational attachment
- The most important caregiver
- High quality informants
Measurement Tools Realistic
To the Low and Middle Income Environment

- Feasible
- Economical
- Culturally sensitive
“…precision of the estimate of disadvantaged children would be improved with internationally comparable data for maternal education and stimulation in the home.”

“Internationally comparable and feasible measures of child development would produce the best estimate of disadvantaged children, and there is an urgent need to develop such measures both to more accurately assess the problem and to assess the interventions”
“...most of the research concerns the effect on developmental levels in early childhood and on later cognitive outcomes, and most of the effect sizes ... relate cognitive deficits...social-emotional functioning could be as important to success in school as and in adult life”

“Future research needs to include greater recognition of all aspects of development, with inclusion of social-emotional outcomes”
20/35 Intervention Programs in Developing Countries Meeting the following criteria:

1. randomized controlled trial/matched comparison
2. intervention before the age of 6 years
3. effectiveness or programme evaluation trials (not efficacy)
4. Child development assessed
5. Targeted disadvantaged children
6. Developing country
Child Development in Developing Countries 3

- Simplified Boehm Basic Concept Test (cognitive) (2)
- WPPSI-III (cognitive) (2)
- Play Observation Scale
- Raven’s Colored Progressive Matrices
- Stanford-Binet IQ Test
- Griffiths Mental Development Scales
- Receptive Vocabulary
- Motor and Mental Development using WHO Milestones
- Gross and fine motor skills and psychosocial skills
- Ugandan Version of the British Abilities Scale
- Early Child Development Checklist
- Bayley Scales of Infant Development
- Einstein Scale

Local School Readiness Assessment Test.
Primary school pass rate (2).
Academic achievement tests.
Repetition rate for grade 1.
Yearly dropout rate after 4 years.
Third grade mathematics and Spanish Achievements.
School attainment.
Turkish school achievement test.

Parent knowledge and practice
Mothers knowledge and practices of childrearing
Maternal knowledge
Home scale and subscales
Preventive health behaviors
Parenting practices
Help skills and development index

What Can We Conclude From Existing Work That is Positive

- There is recognition that development is an important outcome measure!

- Recognition that there is much more to development than cognition.

- Range of testing materials that have been adapted to low and middle income cultures.

- There are assessment tools that can be effectively used in a range of study designs (screening, second level, diagnostic).
What Can We Conclude From Existing Work That is Not So Positive

- There is no agreed on standard methodology for measuring development.
- There is no consistently recommended time sequence for developmental testing.
- The psychometric properties of adapted tools are not always defined.
- Measurement tools for the family, community environment are variable in quality, and consistency.
What Can We Conclude From Existing Work That is Not So Positive

There is very little focus on measuring and understanding resilience in children from low and middle income countries. (e.g. Dr. Galler - pediatrician with hx PCM)
Taking a Different Perspectives
The magnitude of the problem and the opportunities to intervene demand attention and focus on evaluating effective interventions.
What Might Be Done To Address The Issue

Define a core set of measures that would be standard for use in cohort and RCT studies being conducted in low and middle income countries.

How would we go about doing this?
What We Might Do!

Commission on Developmental Measurement Of Children in Low and Middle Income Countries

- Define a set of core tests that investigators should use in cohort or RCT studies.
- Define standard ages for testing and nature of tests at these ages.
- Develop consistent methodology for adaptation of tests to be culturally/socially compatible.
- Conduct psychometric testing to ensure quality of recommended tests.
Why it Might Not Work!

- Who would establish and fund the Commission?
- Would anybody listen to them?
- How long would it take?
What We Might Do!

**Establish an Investigator Consortium**

- Identify a group of investigators interested in cohort/RCT studies who agree to use a common set of core measurement tools.

- Establish a common working group to define the tools and timing of use of the tools.

- Establish common methods for establishing and reporting the psychometric properties of the tools.
Establish an Investigator Consortium

Why it Might Not Work!

- Difficulty in defining sufficient core of investigators.
- Competitive environment limits collaboration.
- Cost to support the infrastructure not in place.
What We Might Do!

Granting Agency Requirement for Funding

- Granting agency or agencies that support cohort/RCT trials in low and middle income countries require the use of a core set of developmental measures.

- Agency or agencies fund a methodology working group that performs the same functions as the “commission”.

- The power to enforce collaboration and likely much better bang for the investment.
Why it Might Not Work!

- Agency or agencies would need to make a sustained commitment to cohort/RCT studies.

- May not be willing to do the up front investment in defining and supporting measurement development and standardization.
WHO Hub for Early Child Development
Commission on Social Determinants of Health
Hertzman, Clyde

- Need for international program of monitoring progress in ECD at the population level.
- Focus on low and middle income countries.
- Danger of instrument proliferation… never achieve benchmarks.
- Need a single evaluation tool!

http://www.earlylearning.ubc.ca/WHO
Can We Conquer Our Fears

There Really Is No Excuse Not To!
Keep the Pressure On Measurement!
CHALLENGE FOR THE DISCUSSION

WHAT CAN WE RECOMMEND TO IMPROVE OUR MEASURES OF DEVELOPMENT?