THE USE OF SCREENING AND MONITORING FOR CHILDREN WITH MEDICAL ILLNESS: A PREVENTION-BASED MODEL OF NEUROPSYCHOLOGICAL SERVICE DELIVERY

Kristina K. Hardy, PhD & Karin S Walsh, Psy.D. Neuropsychology Division Children's National Health System The George Washington University Medical Center



Background

- Chronic illness in childhood can confer increased risk for disruption in neuropsychological development
 - Pediatric cancers
 - Sickle-cell disease
 - Neurofibromatosis
 - Congenital heart disease
 - HIV
 - Diabetes
 - Epilepsy



Background

 Neuropsychological services are generally not included in a health prevention model

No neuropsych "check ups"

- Most providers rely on a comprehensive approach to assessment
- Children are often not referred until problems are apparent and impairing



Objectives

- Introduce a tiered model of neuropsychological evaluation used in pediatric research
- Show examples of the feasibility and utility of this approach
- Summarize why this model can facilitate a number of research and clinical goals related to caring for children with medical illness



Challenges in Clinical Evaluation

- Typical neuropsychological evaluation takes hours of provider and patient/family time
 - Impractical when evaluating sick children
 - Difficult to "squeeze in" an assessment
- Most traditional neuropsych tests were not designed to be repeated in less than a year
 - Problematic when there is a need to track acute changes



Guiding model: Youngstrom

- Eric Youngstrom's Evidence-based Assessment model (2008; 2012)
- Emphasizes assessment *utility*
 - *"Our most widely used tools do not have a literature establishing their validity in terms of individual prognosis or treatment, and viewed through the lens of utility they look superfluous Youngstrom, 2012, p 2*



Assessment utility: 3 Ps

Prediction

• Test results are associated with some criterion of importance

Prescription

• Test results can guide the choice of treatment

Process

• Test results can inform the treatment process or response



Youngstrom's idea

Can we apply Evidence-Based Medicine (EBM) methods to psychological assessment?

 "Each piece of evidence needs to demonstrate that is it valid and that it has the potential to help the patient."

Youngstrom, 2012, p 3



Assessment and Treatment Model



Hardy, Olson, & Walsh, under review



Example 1: Cognitive changes during treatment for Pediatric Leukemia

When during treatment do cognitive changes begin? Who is most vulnerable?



Example 1: Emergence of Late Effects in Leukemia



Percentage of participants with abnormal scores (1.5 SD) at each timepoint



Example 2: Clinical Response in NF1

Does cognitive functioning change in response to a novel treatment for plexiform neurofibromas?



Study drug initiated

Computer testing and questionnaires completed in clinic by nurses, RAs, psychologists



Clinical Application: <u>Surveillance and Cognitive</u> <u>Assessment of Neurological Disorders Clinic</u> (SCAN)

- Focused assessment clinic targeting:
 - Children at high-risk for cognitive deficits or identified on screening
 - Establishment of "baseline" evaluations for ongoing monitoring or referral to full evaluation
 - Temporally and fiscally efficient



Summary

- Research use
 - Brief batteries may increase compliance and data fidelity
 - Force us to be focused and selective in research questions
 - Uniform battery allows for meaningful comparisons across studies
- Clinical use
 - Target known cognitive vulnerabilities
 - Less time and patient burden



Summary

- Collaborative multidisciplinary approach to neuropsychological care
- Promotes flexible, evidence-based approach to neuropsychological care
- Emphasis on prevention

