Pilot Study of the Pediatric Eating Assessment Tool (Pedi-EAT)

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Background

• Feeding problems exist across a variety of health conditions in young children, yet their presentation is not disease or condition specific (Aldridge, Dovey, Martin, & Meyer, 2010; Williams, Riegel, & Kerwin, 2009).

• All pediatric feeding problems have two common features: problematic feeding behaviors and restrictive or selective intake by food type, texture, or presentation (Estrem, 2015).

• Families report systems of care are poorly organized and can take years of navigation before effective treatment is located (Rogers, Magill-Evans, & Rempel, 2012; Stoner, Bailey, Angell, Robbins, & Polewski, 2006).
Background

• Research on feeding problems in children is limited due to poor access to sufficient sample sizes and lack of valid and reliable measures

• We need research to:
  • Characterize early symptoms & their relationship to long term problems
  • Increase understanding of underlying pathology & contributing factors
  • Tailor interventions to the individual child & family
  • Evaluate intervention effectiveness
Pediatric Eating Assessment Tool (Pedi-EAT)

• Our research team is developing a parent-report measure (the Pedi-EAT) to identify problematic feeding behaviors in children ages 6 months to 7 years old

• Followed DeVellis’ (2012) guidelines for development:
  • Items generated using parent interviews and a review of the literature
  • Items tested for content validity (relevance & clarity) by experts in pediatric feeding
  • Cognitive interviews done with parents (intended users) to ensure understanding
Development and Content Validation of the Pediatric Eating Assessment Tool (Pedi-EAT)

Suzanne M. Thoyre, Britt F. Pados, Jinhee Park, Hayley Estrem, Eric A. Hodges, Cara McComish, Marcia Van Riper, and Kimberly Murdoch

More information about development process available in the above publication
(2014; Volume 23, pages 46-59)
Purpose of the Feasibility Study

1.) Determine feasibility of recruitment from a clinic setting and retention over 6 months in preparation for a larger, multi-clinic study of the Pedi-EAT

2.) Evaluate change in problematic feeding behaviors of children receiving feeding therapy over 6 months

*We will be discussing the first purpose today, as we have completed time 1 of 3 data collection points*
Setting

• University of North Carolina Children’s Hospital
  • Academic Medical Center
  • Pediatric Tertiary Care Center

• Feeding and Dysphagia Team
  • Outpatient feeding evaluation and treatment
  • Multidisciplinary (GI, NP, SLP, & Nutrition)
  • 1,500 visits per year; two month wait list
Methods: Recruitment

• Patients with scheduled feeding team appointments were screened for eligibility:
  • 6 months to 7 years old
  • Parent who could speak/read English
• Contact information collected (email and/or phone number)
  • Survey sent to email address
  • If no email, then contacted by phone and asked for email
• Families received up to 3 email invitations and/or up to 3 phone calls for recruitment
Methods: Procedures

• Online survey including demographic information and Pedi-EAT (30-45 minutes to complete)

• If parent consented to medical record review, medical record data collected on growth, nutrition, feeding team assessment, treatment, and diagnostic testing

• Incentive provided: Valet Parking Voucher ($12)

• 3 Time Points:
  • Initial (Time 1), 3 mos (Time 2), and 6 mos (Time 3)
Barriers to Implementation

- Difficult to identify new patients given the EPIC database/scheduling system often had “return” patients in “new” slots and vice versa
- Majority of children were not “new” patients to the hospital (had seen at least 1 specialist prior to feeding “team”)
- Email addresses were often incorrect in the electronic medical records
- Parents may have screened emails/phone calls from unrecognized email addresses/numbers
Barriers to Implementation

• We were recruiting from a sample of parents who have many competing demands for their time e.g. multiple medical appts for child

• Parents may or may not have received our messages/emails
Facilitators to Implementation

- Contacting by phone (even if email listed)
  - Make a personal connection
  - Confirm email address
- Providing a high value valet parking voucher as a “thank you” for completing the survey
- Survey could be completed at any time
- Participants could save responses and return later
Sample

• Time 1
  • 175 parents invited to participate
  • 79 started survey (45% initiation rate)
  • 65 completed survey (37% completion rate)
    • 27% completion rate prior to calling all eligible
    • 43% completion after calling all eligible

• Time 2
  • 64 parents invited to date
  • 46 started survey (72% initiation rate)
  • 43 completed survey (67% completion rate)
Sample – Highly Complex Patients

• Medical Diagnoses
  • 4 Cystic Fibrosis
  • 8 Cerebral Palsy
  • 9 Cardiac defect
  • 2 Cleft palate
  • 2 Laryngeal cleft
  • 4 Seizure disorder
  • 2 Tracheoesophageal fistula
  • 15 Chromosomal abnormalities

• Functional Diagnoses:
  • 29 Developmentally delayed
  • 12 Sensory Processing Disorder
  • 28 Speech/Language Delay

* 16 had no diagnosis other than GERD or constipation
Child Sample

• 34 male/ 31 female

• Ages:
  • 6 – 12 months: 9
  • 12 – 18 months: 6
  • 18 – 24 months: 13
  • 2 – 3 years: 15
  • 3 – 4 years: 6
  • 4 – 5 years: 7
  • 5 – 6 years: 7
  • 6 – 7 years: 1
Child Sample

- **Feeding Tubes**
  - 29% (19/65) had a feeding tube
    - 63% (12/19) of those taking 75-100% of calories by tube
  - 6.5% (3/46) without a tube currently had a gastrostomy tube in the past
  - 17% (8/46) without a tube currently had a nasogastric/orogastric tube in the past
Parent Sample

- Primarily mothers (97%), White (78%), Two-parent family (82%)
- 20% (13/65) met federal criteria for poverty
- Insurance Coverage
  - 51% (33/65) Medicaid
  - 54% (35/65) Private Insurance
  - 9% (6/65) Military Benefits
  - 16% (10/65) had more than 1 type of insurance coverage
When did the problem begin?

- 52% (34/65) stated the feeding problem began at birth
- 23.1% (15/65) between 6 and 9 months (transition to solid foods)
- 9.2% (6/65) between 1 and 5 months
- 1 parent stated at 2 years
- 1 parent did not know
How long did it take to get help?

• 29% (14/49) indicated it took 6 months or longer to get help with feeding
  • For 29% (4/14) of these it took 1 – 1.5 years
  • For 2 families it took 2 years
  • For 2 families it took 3 years
Parent Goals for Feeding Therapy

• Only 33.8% (22/65) indicated their goal was for their child to take all food and drink by mouth
• 64.6% (42/65) – increase quantity of food by mouth
• 64.6% (42/65) – increase variety of food by mouth
• Other parent goals:
  • Move off thickened foods/liquids
  • Discontinue bottle
  • Chewing
How much money do families spend on care specific to feeding?

- Copays, supplies, prescriptions, specialty formulas
  - 34% (22/65) pay more than $200 per month
  - 17% (11/65) pay $100-200 per month
Clinical Implications

• Providers need a low threshold for referral for feeding services, particularly when children have known risk factors

• Over 60% of the sample reported onset of the feeding problem prior to 6 months of age
  • Early referral is critical to minimizing problematic feeding behaviors
  • When there is a delay in receiving feeding services, developmental time can be lost

• Caring for a child with a feeding problem is costly for a family and the journey is long
Future Plans for the Pedi-EAT

• Field test to complete psychometric testing, remove unnecessary items, and identify the underlying factor structure

• Establish an age-normed scoring system
Conclusions

• Accurate charting and entry of patient type and contact information will facilitate being able to use the data we are documenting for research that is needed in this field.

• Parents were most easily recruited when they had a phone contact rather than email.

• Parents found the on-line survey method acceptable.

• Retention of the sample for Time 2 has been moderate.
SLPs Providing Feeding Therapy...

• If working in EI or home health, develop a virtual team...these children often need a team of specialists
• Find GI, nutrition, PT, psychologist you can refer to/collaborate with
• Keep in touch with referring physicians
• SLPs can offer to provide in-service to primary healthcare providers...educate physicians on the benefits of providing early referral
• Share the following reasons to refer...
Reasons to Refer

An infant who:
• has difficulty breast or bottle feeding
• sleep feeds
• coughs or chokes with feeds

Parents who:
• dread feeding their child
• make separate or special meals for their child, different from the family meal

(from Krisi Brackett, MS, CCC-SLP)
Reasons to Refer

A child who:

• is not taking any solids by a year
• has gagging and vomiting on solids
• avoids food groups or eats less than 5 foods
• eats the same food every day
• eats brand specific foods
• grazes and does not eat regular meals
• is stuck on the bottle past age 2
• pockets or holds food in their cheeks or spits food out
• is having trouble gaining weight or has poor intake
How can you help?

http://feedingflock.web.unc.edu/

The Feeding Challenges Registry of Families
Questions?

Partnering with families to nurture children with feeding difficulties

http://feedingflock.web.unc.edu/

www.pediatricfeedingnews.com
References