Development and Psychometric Testing of the Neonatal Growth Measurement Survey
Jan M. Foote

DISCLOSURES
- I have no actual or potential conflicts of interest in relation to this presentation.

OBJECTIVES
- Discuss the clinical implications of neonatal growth measurements.
- Describe methods used to develop a valid and reliable survey.
RESEARCH & EVIDENCE-BASED PRACTICE:
IT TAKES A VILLAGE

- PI: Jan M. Poote, DNP, ARNP, CPNP, FNP-BC
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- BSN Student: Amelia Fleming, BSN, RN
- Data Manager: Maria Hein, MSW
- Statistician: Yelena Perkhounkova, PhD
- PhD Student/Statistician: Nicole Bohr, MSN, RN
- Mentor: Ann Marie McCarthy, PhD, RN, PNP

ACKNOWLEDGEMENTS

Funding: UIHC Nursing Research, EBP, & Quality grant

[Image: Collaboration between UIHC Hospitals and College of Nursing]

ACKNOWLEDGEMENTS (continued)

<table>
<thead>
<tr>
<th>Expert Reviewers</th>
<th>Nursing Participants</th>
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<tbody>
<tr>
<td>Joanna Andrew, MSN, RN, CNS</td>
<td></td>
</tr>
<tr>
<td>Anne Barker, MS, RD, LD</td>
<td></td>
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<tr>
<td>Jennifer Cook, MD</td>
<td></td>
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<tr>
<td>Teresa Johnson, PhD, RN</td>
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<tr>
<td>Susan Lathrop, MSN, ARNP, CPNP</td>
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<tr>
<td>Rebecca Sievert, DNP, ARNP, NNP-BC</td>
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<tr>
<td>Brenda Walker, MSN, RNC</td>
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+ BACKGROUND

- Growth is an important & sensitive indicator of health
- Neonatal measurements (head circumference, weight, length) are used to:
  - Assess fetal growth
  - Determine fluid and nutritional needs
  - Calculate medication doses
  - Determine surveillance needs
  - Provide baseline criteria to assess the adequacy of future growth

+ PROBLEM

- Measurements are frequently inaccurate and unreliable
  - Casual techniques
  - Faulty instruments
  - Measurement errors lead to:
    - Misclassification as small, appropriate, or large for gestational age
    - Incorrect clinical judgments & decision-making
    - Overlooking potentially serious health problems
    - Unnecessary referrals and evaluations

+ PURPOSE

- Develop the Neonatal Growth Measurement Survey
- Test the validity and reliability of the survey
**METHODS: PHASE 1**

- Survey development
  - Knowledge, attitude, & practice behavior items were developed from best practices
  - Bases of practice knowledge items were modified from Gerrish et al. (2007) *Developing Evidence-Based Practice* questionnaire

**METHODS: PHASE 2**

- Expert panel review & focus groups (IRB approved)
  - Content validity, clarity, & feasibility were assessed by 6 clinical experts & an external expert
  - Focus groups were held at each study site to review & revise items

**METHODS: PHASE 3**

- Descriptive pilot study (IRB approved)
  - Settings: Mother-baby units & NICUs of 2 Midwest children's hospitals
  - Participants: Convenience sample of 20 nurses from each of the 4 units
  - Procedures: Online survey distributed twice (4 weeks apart)
  - Analyses: Test-retest reliability, internal consistency reliability
### RESULTS: PHASES 1 & 2

Content Items by Section

<table>
<thead>
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<th># Items</th>
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<td>General</td>
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<tr>
<td>Head circumference</td>
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<tr>
<td>Weight</td>
<td>4</td>
</tr>
<tr>
<td>Length</td>
<td>4</td>
</tr>
<tr>
<td>Attitudes (Likert scale)</td>
<td></td>
</tr>
<tr>
<td>Head circumference</td>
<td>5</td>
</tr>
<tr>
<td>Weight</td>
<td>5</td>
</tr>
<tr>
<td>Length</td>
<td>5</td>
</tr>
<tr>
<td>Practical behavior (multiple choice)</td>
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</tr>
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<td>Head circumference</td>
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</tr>
<tr>
<td>Weight</td>
<td>10</td>
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<tr>
<td>Length</td>
<td>11</td>
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<td>Growth charts</td>
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<td>Skills of practical knowledge (Likert scale)</td>
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<tr>
<td>Knowledge</td>
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<td>Barriers</td>
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### RESULTS: PHASE 3

#### Demographics (N=62)

<table>
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<tr>
<th>Education</th>
<th>n</th>
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<tbody>
<tr>
<td>RN</td>
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<tr>
<td>AAS</td>
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<tr>
<td>Highest degree</td>
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<td>Associate</td>
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<tr>
<td>Diploma</td>
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<td>Bachelor</td>
<td>36</td>
</tr>
<tr>
<td>Master</td>
<td>10</td>
</tr>
<tr>
<td>Neonatal experience (years)</td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>14.3</td>
</tr>
<tr>
<td>Range</td>
<td>1 - 42</td>
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<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>Mother/Baby</td>
<td>23</td>
</tr>
<tr>
<td>NICU</td>
<td>39</td>
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<tr>
<td>Hospital</td>
<td></td>
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<tr>
<td>A</td>
<td>25</td>
</tr>
<tr>
<td>B</td>
<td>37</td>
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</table>

### RESULTS: PHASE 3

#### Pilot Study

<table>
<thead>
<tr>
<th>Test/Related % Agreement and Correlations</th>
<th>Internal Consistency (α)</th>
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<tbody>
<tr>
<td></td>
<td>Time 1</td>
</tr>
<tr>
<td>Knowledge</td>
<td></td>
</tr>
<tr>
<td>Test-related % agreement</td>
<td></td>
</tr>
<tr>
<td>Correlation</td>
<td></td>
</tr>
<tr>
<td>Internal Consistency (α)</td>
<td></td>
</tr>
</tbody>
</table>

#### Note:
- Range of fully agreement: adjacent agreement shown in parenthesis.
- Pearson correlation between time 1 and time 2 mean Spearman’s correlation between time 1 and time 2.
**DISCUSSION**

- A multi-step process led to the development of the Neonatal Growth Measurement Survey
- The survey was validated by multidisciplinary expert reviewers
- Test-retest reliability
  - Percent agreement was high for most items
  - All correlations were significant at ≤ 0.05 level with exception of one item in the Attitudes section asking about importance of head circumference measurement
- Internal consistency reliability
  - Knowledge items were low (most likely due to heterogeneity)
  - Attitude and Bases of Practice Knowledge items were high

**OBSERVATIONS**

- 87% did not understand the Frankfort plane.
- 47% thought one measurer & use of a tape measure would provide an accurate and reliable length measurement.
- Most respondents did not know which growth charts they were using to record measurements of term or preterm neonates.

**RESEARCH & CLINICAL IMPLICATIONS**

- Pilot study results are useful for refining the survey items with lower reliability and reducing the total number of items
- A valid & reliable instrument for measuring nurses’ knowledge, attitudes, and practices for neonatal growth measurement is important for future research
- A national study will be conducted to understand current measurement practices and barriers to EBP
- Nursing interventions will be developed to improve neonatal growth measurement accuracy and reliability
- Long-term impact that we hope to achieve:
  - Improved neonatal health outcomes
References


Screening for Retinopathy in Children and Adolescents with Diabetes Mellitus

Erika A McCann, RN, BS, BSN, MS, Lawrence J Swanson, MD, Vincent C Arena, PhD, Garry W Smyda, BS, Ken K Nischal, MD, FRCS(ophth) and Ingrid M Libman, MD, PhD

Contents
- Background
- Aims
- Methods
- Results
- Conclusions
- Clinical Implications
- Future Discussions and Research
- References

Background
- Diabetic Retinopathy (DR) is a leading cause of blindness!
  - Non-proliferative/proliferative
  - Often asymptomatic
  - Can be proceeded by poor glucose control
- Known Risk factors:
  - Pregnancy
  - High blood pressure
  - High cholesterol
  - Smoking

Screening performed typically at outside Ophthalmologist
- Method used to evaluate DR is not standardized
- Reports tend to be erratic
- Many patient’s are not aware that it should be done through dilation or annually
- Many patients that should be screened are missed or fail to follow-up

National Guidelines
- ISPAD - 2014 Clinical Practice Guidelines
  - DR Screening at 10 yrs of age within 2-5 years of Diabetes Mellitus (DM) disease onset
  - Ophthalmologist should perform screening via dilated pupils
  - Recommended annually
  - Suggested Method: Fundal Photography
  - Screening commencement at diagnosis for type 2 DM

- ADA-2015 Standards of Medical Care
  - DR at 10 yrs of age within 3-5 years of DM disease onset

Diabetes Control and Complications Trial (DCCT)
DCCT

- Patient baseline characteristics
  - Recruited from 1983-1989
  - Average age ~ 26 years
  - Average duration of disease ~ 2.5 to 9 years
  - Average HbA1c ~ 8.9%

- Randomized to conventional therapy vs intensive therapy

DCCT- Conventional Therapy vs. Intensive Management

- Conventional Therapy
  - 1 or 2 daily injections of mixed intermediate insulin or rapid acting insulin
  - Does not require insulin dose adjustments based on food or exercise
  - Absence of hypoglycemia, glycosuria, ketonuria, and hyperglycemia are conventional goals

- Intensive Management
  - Testing blood glucose levels four or more times a day
  - Injecting insulin at least three times daily or using an insulin pump
  - Adjusting insulin doses according to food intake and exercise
  - Following a diet and exercise plan
  - Making monthly visits to a health care team composed of a physician, nurse educator, dietitian
More Recently...

- Improved Sensitivity!
  - Direct examination
    - Sensitivity 74% Specificity 85%
  - Camera, dilated, regular photographer
    - Sensitivity 85% Specificity 89%
  - Camera, dilated, specialized photographer
    - Sensitivity 90% Specificity 95%

Bragge et al. 2011
Meta-analysis of 20 studies
Screening for Retinopathy in Children and Adolescents with Diabetes Mellitus

Specific Aim
• Implement ISPAD and ADA guidelines as a quality initiative (QI) in children and adolescents while offering DR screening at the same time as their diabetes appointment and evaluate the prevalence DR and patient characteristics in all patients screened

Hypothesis
• The low frequency of Diabetes Retinopathy (DR) will not justify the current recommendations of screening
• Screening on same day/same location of diabetes clinic appointment will expedite identification of patients at risk for DR who would not have proactively have screening for DR performed elsewhere
Bloodwork ordered

No

Patient >= 10 yrs and T1DM >= 2 yrs

Proceed through clinic normally

Education by RN provided and Fundal photography recommended

Proceed through clinic normally

RN administers ophth drops & completes paper order form

Patient completes routine clinic evaluation with educator, dietician and MD

Patient takes paper order to Endocrine registration desk

Endocrine staff registers patient for fundal photography

Patient proceeds to Ophthalmology

Fundal photography performed

Patient proceeds to Laboratory for blood draw

Patient visit complete

Patient presents to Endocrine OP Suite

Quality Initiative

Methods

• Retrospective chart review of patient’s screened between February 1, 2015 to November 23, 2015

Methods

• Variables Extracted
  • Age
  • Gender
  • Race
  • Age at diabetes diagnosis
  • Duration of diabetes
  • Digital fundal photography results
  • Height
  • Weight
  • BMI
  • BMI percentile
  • Last three blood pressures (performed by diabetes clinic only)
Methods

- Variables Extracted, continued
  - HbA1c
    - POC HbA1c on day of retinopathy screen
    - Serum HbA1c on day of screen
      - Most recent serum HbA1c within past 15 months
    - POC HbA1c corresponding to most recent serum HbA1c within past 15 months
  - Total cholesterol
  - Triglycerides
  - HDL
  - LDL
  - Spot urine albumin:creatinine
  - Urine albumin excretion rate

- Variables Extracted, continued
  - c-peptide (at diagnosis)
  - GAD-65
  - ICA-512
  - Insulin AA
  - Medications
    - Metformin
    - Synthroid
    - Antihypertensives
    - Statins
  - Insulin dose
  - Insulin delivery method

Results

- Medical records indicate 374 patients in our practice with T1DM meet ISPAD screening criteria
- 147 patients met inclusion criteria and underwent screening at Pittsburgh location (From Feb 1, 2015 to November 23, 2015)
  - Reasons for exclusion:
    - Diabetes duration less than 2 years
    - Patient does not have T1DM or T2DM
- ~41 refused screening at Children’s Hospital of Pittsburgh
### Characteristics - All Subjects

<table>
<thead>
<tr>
<th>Trait</th>
<th>SD</th>
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<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>87 (59.2%)</td>
</tr>
<tr>
<td>Female</td>
<td>60 (40.8%)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
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<tr>
<td>White</td>
<td>118 (80.3%)</td>
</tr>
<tr>
<td>Black</td>
<td>25 (17%)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (2%)</td>
</tr>
<tr>
<td>Diabetes Type</td>
<td></td>
</tr>
<tr>
<td>T1DM</td>
<td>138 (93.9%)</td>
</tr>
<tr>
<td>T2DM</td>
<td>9 (6.1%)</td>
</tr>
<tr>
<td>Age at screening</td>
<td>15.4 years</td>
</tr>
<tr>
<td>Age at DM diagnosis</td>
<td>8.5 years</td>
</tr>
<tr>
<td>Duration of DM</td>
<td>6.9 years</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Trait</th>
<th>mean</th>
<th>SD</th>
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</thead>
<tbody>
<tr>
<td>Height</td>
<td>160.9 cm</td>
<td>17.2</td>
</tr>
<tr>
<td>Weight</td>
<td>63.1 kg</td>
<td>19.5</td>
</tr>
<tr>
<td>BMI</td>
<td>23.6 kg/m²</td>
<td>3.8</td>
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<tr>
<td>BMI %</td>
<td>69.5%</td>
<td>24.5</td>
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<tr>
<td>Systolic BP</td>
<td>115</td>
<td>11.4</td>
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<tr>
<td>Diastolic BP</td>
<td>71</td>
<td>7.7</td>
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<table>
<thead>
<tr>
<th>Trait</th>
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<th>SD</th>
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<tbody>
<tr>
<td>POCT HbA1c</td>
<td>8.9</td>
<td>2.0</td>
</tr>
<tr>
<td>Serum HbA1c</td>
<td>9.4</td>
<td>1.8</td>
</tr>
<tr>
<td>Total Cholesterol</td>
<td>174</td>
<td>18.8</td>
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<tr>
<td>Triglycerides</td>
<td>142</td>
<td>191</td>
</tr>
<tr>
<td>HDL</td>
<td>60</td>
<td>11.7</td>
</tr>
<tr>
<td>LDL</td>
<td>99</td>
<td>28.7</td>
</tr>
<tr>
<td>SD</td>
<td>Urine alb:cr</td>
<td>58.7 mg/g</td>
</tr>
<tr>
<td>----</td>
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</tr>
<tr>
<td>UACR</td>
<td>8.0 µg/min</td>
<td>± 9.4</td>
</tr>
<tr>
<td>Insulin dose</td>
<td>54 units/day</td>
<td>± 22.4</td>
</tr>
<tr>
<td>Insulin Delivery</td>
<td>MDI 96 (65.8%)</td>
<td>Pump 48 (32.8%)</td>
</tr>
<tr>
<td>Medications</td>
<td>Metformin 11 (7.5%)</td>
<td>Synthroid 10 (6.8%)</td>
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Retinopathy Incidence – All Subjects

- Digital Fundal Photography
- No Retinopathy 137 (93.2%)
- Retinopathy present 10 (6.8%)
  - 9 with "background" diabetic retinopathy
  - 1 with "proliferative" diabetic retinopathy

Associations with DR
### Retinopathy and Gender

<table>
<thead>
<tr>
<th></th>
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<th>Negative</th>
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<tbody>
<tr>
<td>Male</td>
<td>8 (9.3%)</td>
<td>78</td>
</tr>
<tr>
<td>Female</td>
<td>2 (3.3%)</td>
<td>58</td>
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*p = .20*

### Retinopathy and Race

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<tbody>
<tr>
<td>White</td>
<td>8 (6.8%)</td>
<td>110</td>
</tr>
<tr>
<td>Black</td>
<td>2 (8%)</td>
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*p = .87*

### Retinopathy and Diabetes Type

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<td>T1DM</td>
<td>8 (6.2%)</td>
<td>130</td>
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<tr>
<td>T2DM</td>
<td>2 (22.2%)</td>
<td>7</td>
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*p = pending*
Retinopathy and Age (on day of screen)

<table>
<thead>
<tr>
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<th>mean age ± SD</th>
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<tbody>
<tr>
<td>Positive</td>
<td>18.5 ± 3.5 years</td>
</tr>
<tr>
<td>Negative</td>
<td>15.1 ± 2.8 years</td>
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p = .014

Retinopathy and Age at DM diagnosis

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<tr>
<td>Positive</td>
<td>8.75 ± 3.9 years</td>
</tr>
<tr>
<td>Negative</td>
<td>8.49 ± 3.9 years</td>
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p = .837

Retinopathy and DM duration

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<th>mean duration ± SD</th>
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<tr>
<td>Positive</td>
<td>9.8 ± 3.1 years</td>
</tr>
<tr>
<td>Negative</td>
<td>6.7 ± 3.5 years</td>
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p = .012
Retinopathy and POC HbA1c

mean +/- SD

- Positive: 11.3% +/- 2.7
- Negative: 8.8% +/- 1.9

p < .005

Retinopathy and Blood Pressure

mean +/- SD

- Positive: 120 / 77 +/- (14/7)
- Negative: 115 / 73 +/- (11/7)

p > 0.10

Retinopathy and other screening

- No significant differences
  - Total cholesterol
  - Triglycerides
  - HDL
  - LDL
  - Spot urine albumin:creatinine
  - Urine albumin excretion rate
**Retinopathy and Metformin**

<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>Metformin</td>
<td>2 (18.2%)</td>
<td>9</td>
</tr>
<tr>
<td>No Metformin</td>
<td>8 (5.9%)</td>
<td>128</td>
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</table>

*p = .17

**Retinopathy and Insulin Delivery Method**

<table>
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<th>Positive</th>
<th>Negative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiple Daily Injections</td>
<td>7 (7.3%)</td>
<td>89</td>
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<tr>
<td>Insulin Pump</td>
<td>3 (6.3%)</td>
<td>45</td>
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</table>

*p = 0.90

**Summary of Results**

- Mean age at DM onset 8.5 years and age at time of DR screening 15.4 years in which all subjects had an average DM duration of 6.9 years with an HbA1c of 8.9%.
- Ten subjects (6.8%) had evidence of DR and were older (18.5 vs 15.1 years; p=0.014) with longer disease duration (9.8 vs 6.7 years; p=0.012), and higher A1C (11.3 vs 8.8%; p<0.005) compared to those without.
- One subject (T2DM) had reached a stage of pre-proliferative DR.
Conclusions

- DR occurred in 6.8% of our patients in which they had a longer duration of disease, higher A1c, and were older in at time of screening

Clinical Implications

- The QI showcased the feasibility of implementing a DR screening program in conjunction to the diabetes clinic visit.
- Offering this service may improve compliance with expert guidelines, particularly for the segment of the clinical population at increased risk for complications.
- This QI, has elevated the effectiveness of the clinicians' services.

Discussion and Future Directions

- Continue QI
- Target patients with known DR and risk factors for DR and encourage annual screening
- Follow progression of those screened in house
- Compare outside retinopathy results to in-house results
- Reconsider criteria for screening?
- Continue research on the patient characteristics associated with DR
References

Development of a Pediatric Screening Tool: Phase 1: The Conceptualization of DPN in Youth

Joanne T. Moser, MSN, CRNP
The Children's Hospital of Philadelphia, Philadelphia, PA.
Katherine B. Bevans, PhD, Anna De LaMotte, MSED, David R. Langdon, MD, Terri H. Lipman, PhD, CRNP
May 14, 2016
Pediatric Endocrinology Nursing Society

Funded By:

Center for Pediatric Nursing Research and Evidence Based Practice
The Children's Hospital of Philadelphia
Philadelphia, Pennsylvania

Introduction:
- Background
- Purpose
- Methods
- Results
- Conclusions
Background:

- Peripheral Neuropathy (DPN) - co-morbidity of diabetes
- Evidence Based Practice Model adopted by Diabetes Center for Children (DCC)
- DPN not routinely assessed in USA
- PENS GRANT (2008)

Acknowledgement:
Purpose:
- Pediatric DPN Screening Tool was needed:
  - conceptually grounded
  - developmentally appropriate
- a useful tool to help DM providers identify children with DM at risk for developing problems with the nerves in their legs and feet

Methods: Overview of Research Model
- Based on PROMIS Methodology
  - Patient Reported Outcome Measurement Information System
- Well established set of methods used by instrument developers
  - based on reports that come directly from patients
- Uses "item banking" methods to create pools of items that measure a single health concept
- Mixed method approach: qualitative and quantitative

PROMIS Mixed Method Approach to Item Bank Development

<table>
<thead>
<tr>
<th>Domain Concept Specification</th>
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<tbody>
<tr>
<td>Context Report Form</td>
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<tr>
<td>Child/Patient Interviewers</td>
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<tr>
<td>Literature Review</td>
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<td>Existing Item Classification, New Item Creation, and Item Writing</td>
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<td>Item Pool Version 1.0</td>
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<tr>
<td>Cognitive interview</td>
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<tr>
<td>Validity-Bias Review</td>
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<tr>
<td>Reading Level analysis</td>
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<tr>
<td>Item Pool Version 2.0</td>
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<tr>
<td>Questionnaire Administration to Large Sample of Children/Parents</td>
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<tr>
<td>Factor analysis</td>
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<td>Pilot Internal Calibration</td>
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<tr>
<td>Execution Validated</td>
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<tr>
<td>Item Bank Version 1.0</td>
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Methods: The Framework

**DPN CONCEPTUAL MODEL**

- **Purpose:**
  - To further expand and specify the DPN Framework concepts and definitions

**Process:**
- Before the interview, interviewees were given the DPN Model for their review
- Interviewees asked questions about the framework's structure, organization, and component definitions
- Interviews audio recorded, transcribed, and subjected to thematic analysis

Methods: Content Expert Interviews

- **Content Experts:** 5 clinicians
- **Pediatric/adult diabetes and/or neuro**
- **Purpose:**
  - To further expand and specify the DPN Framework concepts and definitions
- **Process:**
  - Before the interview, interviewees were given the DPN Model for their review
  - Interviewees asked questions about the framework's structure, organization, and component definitions
  - Interviews audio recorded, transcribed, and subjected to thematic analysis

Methods: Semi-Structured Interviews

- **N=16**
  - 8-21 years of age who had DPN symptoms
  - 12 males (1AA, 11 Caucasian), 4 Caucasian females
  - Average HbA1c: 8% (range: 6.1%-11.3%)
  - Average duration of DM: 6.6 years (range: 9 months-17 years)
- **Purpose:**
  - To ensure that the conceptual framework covered DPN experiences from youth perspective

- **1AA**
  - Caucasian
  - Average HbA1c: 8% (range: 6.1%-11.3%)
  - Average duration of DM: 6.6 years (range: 9 months-17 years)
Methods: Semi-Structured Interviews

- Process:
  - Interviewer described typical DPN experience: “when kids have prickling or funny feelings in their feet—not counting when they are sitting on them!”
  - Can you tell me about your experiences?
  - Follow up questions: when? How long do they last? What’s going on when it starts?
  - Probes about their experiences with burning sensations, loss of feeling, painful or irritating feelings in skin, trouble telling hot from cold etc
  - Audiotaped, transcribed and subjected to thematic analysis

Quotes from Youth Interviews:

- “Feels like spikey balls on the bottom of my feet” (8 yr boy)
- “Feels like lightening bolts, lots of little ones” “extra miniature bees stinging”, “tons of mosquitoes crowding around my feet” (9 yr boy)
- “Feels like mosquitoes flying around my feet like a gust of air” (10 yr boy)
- “Feels like sharp needles from a pine tree”, “like an angry cat scratching” (11 yr boy)
- “Feels like a got zapped with lightening” (9 yr boy, 13 yr boy, 14 yr girl)
- Last Quote:
  - “A different feeling than normal a tingling feeling-like a bunch of sewing needles hitting the bottom of my feet or a bunch of bees in my shoes-stinging or poking me- feels uncomfortable, feels weird, doesn’t really hurt…” (16 yr girl)
Themes from Youth Interviews:

- Insects/animals: “ants crawling”, “bees stinging”, “mosquitoes stinging”
  “water spraying from whale spout”
- Electricity/Motion: “static”, “bolts”, “shocks”, “sparks”
- Temperature: “hot”, “burning”
- Size: “small”, “miniature”, “extra little”
- Sensation: generally “not painful”, “annoying”, “uncomfortable”

Initial DPN Item Pool

Methods: Cognitive Interviews

- N=13
  - 8-20 yrs (12 with symptoms of DPN)
  - 7 Caucasian males, 6 females (1AA, 5 Caucasian)
  - Average HbA1c= 8.4% (range: 6.5%-10.7%)
  - Average duration of DM: 8.6 yrs (range: 12 months-19 years)

- Purpose:
  - To identify problems with item comprehension, recall and other cognitive processes that could be changed through question rewording, reordering or more extensive instrument revisions
Methods: Cognitive Interviews

- **2 Step Process:**
  - Paper-and-pencil questionnaire
  - Interview using standard probes: Interviewees read each item aloud and stated the meaning in their own words
    - "How did you answer that question?" "Why did you choose that answer?"
  - Responses were audio recorded, transcribed and coded for the degree to which youth's understanding of the question was consistent with the item definition
  - Revised items were re-evaluated using the same cognitive interview procedure

- **Example:**
  - Concept: Burning
  - Item Content: I had burning pain in my feet/toes...
  - Item Usage: (Burning) In the past 4 wks...
  - Response: (always, almost always, sometimes, almost never, never)
    - What does that mean to you?
    - How did you answer that question?
    - Why did you choose that answer?
  - **Coding:**
    - Degree of understanding: (3) full, (2) partial, (1) poor
    - Logic of Response: (3) good, (2) unsure, (1) poor/wrong

Methods: Item Review and Rewriting

- **Example:**
  - **Original Item:** "I felt like mosquitoes were buzzing around my feet/toes.
  - or "I felt bees buzzing around my feet/toes."
  - Youth response: "Not bugs, maybe bees sting"
  - Youth response: "felt like mosquitoes flying around like a gust of air"
  - Youth response: "there is something off inside a buzz inside a buzzing sensation inside my feet... it's weird"
Methods: Item Review and Rewriting

- Revised Item: “I felt buzzing inside my feet or toes” or “I felt like mosquitoes were buzzing around inside my feet/toes.”
- Youth response: “Buzzing is like moving, shaking back and forth like a bee”
- Youth response: “Making you feel weird or uncomfortable—vibrating like a massage chair”—don’t relate to the concept of insect—mosquitoes buzzing would be itchy–“that’s not right”
- Youth response: “buzzing is like dancing or fast shaking—mosquito comparison doesn’t make sense to me”
- Clinician/Researcher feedback: suggested revising item to highlight “buzzing” as the concept versus the comparison to the concept of insect—mosquito—too difficult/itchy—bee-stinging

- Final Version: I felt buzzing inside my feet/toes.
Results:

- Development of a Pediatric DPN Screening Tool: Item Pool of 25 items
  - 22 items retained in original format
  - 21 items deleted from the initial pool
  - 3 items revised/retested and retained in their revised form
- Youth confirmed their experiences and were able to identify terms describing their symptoms (different from adults)
- Clinical Experts supported the DPN Conceptual Framework

Conclusions:

- Youth with type 1 DM do experience a range of DPN symptoms measurable by self-report
- Significant modification to adult terms were made to ensure content validity, understandability and relevance of a DPN screening tool for youth
- Future Research needed on the DPN Screening Tool:
  - Questionnaire Administration on large sample of youth
  - Psychometric-quantitative studies on the instrument

Thank You!!
DO YOU WANT TO CONTINUE THIS JOURNEY WITH ME?

Let’s Collaborate on a PENS Multi-Center Research Grant …