Assessing Mothers’ Knowledge of the Wisconsin Newborn Screening Program

Sara Wolfgram
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Background

- Wisconsin Newborn Screening (NBS):
  - Began in 1965
  - Heel prick performed before baby leaves hospital
  - Panel of 48 disorders
  - Required by state law
  - 68,000 babies screened each year
Background

- Benefits of NBS:
  - Prevents infant morbidity and mortality
  - Cost-effective
Background

- Parents do not receive standardized educational materials at appropriate reading levels (Kim, et al., 2003)
- Improved education leads to:
  - Improved follow-up rates
  - Decreased parental anxiety (AAP, 1999; Tluczek, 1992)
- AAP NBS Task Force (1999): recommend research be done to identify effective communication with parents

Objectives

- Assess mothers’ understanding of the Wisconsin Newborn Screening Program
- Identify effective methods for educating parents about NBS
Methods

- E-mail survey sent to 30 WI hospitals to determine method of NBS education
- 10 hospitals chosen representing 4 educational methods:
  1) Binder/folder issued prenatally
  2) Binder/folder issued at delivery
  3) Pamphlet given at time of testing
  4) Informed prenatally by provider as well as by hospital nursing staff

Methods

- Mothers from each of 10 hospitals contacted by telephone using NBS database
- Participants contacted while infants were between 3 – 5 weeks of age
Methods - Questionnaire

- 28 Items
- Section 1 - How mothers learned about NBS
  - “How did you first learn about NBS?”
  - “Did your doctor give you any information about NBS in writing, such as a pamphlet or brochure?”
- Section 2 – Mothers’ knowledge of NBS
  - “What is your understanding about the purpose of NBS?”
  - True/False: “Newborn screening is required by state law.”
- Section 3 – Demographic information

Participants

- Number of mothers contacted: 117
  - Declined: 11.1%
  - Excluded for health issues: 7.7%
  - Completed interview: 81.2%

- Final sample size: N = 95
Results – Knowledge Deficits

Disorders tested for:
- Cystic fibrosis
- PKU
- Sickle cell disease
- Congenital hypothyroidism
- Galactosemia
- Homocystinuria
- Fatty acid oxidation disorders
- Organic acidemias
- Tyrosinemia
- Arginosuccinic acidemia
- Biotinidase deficiency
- Citrullinemia
- Congenital adrenal hyperplasia
- Hypermethioninemia
- Maple syrup urine disease
- Hyperphenylalaninemia
- Hemoglobin disorders

Disorders correctly recalled by mothers:
- Cystic fibrosis
- PKU
- Sickle cell disease

86.3% of mothers were unable to correctly recall a single disorder.

Incorrectly named by mothers:
- Spina bifida
- Down syndrome
- Jaundice
- Blood type
- Hepatitis
- Autism
Results

“What is your understanding of the purpose of newborn screening?”
Don’t know or incorrect answer: 21.1%

“Have you received, or do you know when you will be receiving the results of your baby’s test?”
Don’t know or incorrect answer: 61.1%

Results – Who Educates Mothers

<table>
<thead>
<tr>
<th>Who informed mothers of NBS</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse</td>
<td>43.2</td>
</tr>
<tr>
<td>Physician</td>
<td>16.8</td>
</tr>
<tr>
<td>Lab technician</td>
<td>5.3</td>
</tr>
<tr>
<td>Other</td>
<td>9.5</td>
</tr>
<tr>
<td>Don’t remember</td>
<td>9.5</td>
</tr>
</tbody>
</table>
### Results – When Mothers are Educated

**Timing of Education**

<table>
<thead>
<tr>
<th>Education Event</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>During hospitalization for baby’s birth</td>
<td>42.1</td>
</tr>
<tr>
<td>Through previous pregnancy</td>
<td>24.2</td>
</tr>
<tr>
<td>Prenatally</td>
<td>21.1</td>
</tr>
<tr>
<td>Prior to conception</td>
<td>7.4</td>
</tr>
<tr>
<td>Do not remember/Not informed</td>
<td>5.3</td>
</tr>
</tbody>
</table>

### Results – How Mothers are Educated

**Materials received from provider**

<table>
<thead>
<tr>
<th>Method</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Written</td>
<td>27.4</td>
</tr>
<tr>
<td>Verbal</td>
<td>19.0</td>
</tr>
<tr>
<td>Both</td>
<td>34.7</td>
</tr>
<tr>
<td>Neither</td>
<td>19.0</td>
</tr>
</tbody>
</table>
Conclusions

- Objective 1: Assess mothers’ understanding of the Wisconsin Newborn Screening Program
  - Significant deficits found in mothers’ understanding of:
    - Purpose of NBS
    - NBS conditions
    - How results will be communicated

Conclusions

- Objective 2: Identify effective methods for educating parents about NBS
  - Lack of standardization regarding who informs mothers, when they are informed, and what materials are being given to mothers
  - No significant relationship between method of education (hospital group) and mothers’ knowledge
Implications

- Further research recommended to determine effective NBS education methods
- Need for standardization

Acknowledgements

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