Impacts of medical education materials on families of infants with Neonatal Brachial Plexus Palsy

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Introduction

• Neonatal brachial plexus palsy (NBPP) occurs 1.4 per 1,000 births\(^1\)
• Stretch causes temporary or permanent arm weakness\(^2\)
• Therapy is indicated in all cases
• Surgery to nerves is indicated in persistent cases\(^2\)
• Patient education regarding this condition is imperative
• Most printed materials provide standard medical information
• Storybook format materials were created
Objectives

To determine parents' understanding of their child's condition before and after reading the storybook series.
Methods

• Cross-sectional survey study
• 37 parents of infants with NBPP
• 2012-2016
• IRB approved
• No patient incentives
• Each family read storybook series
• Inclusion if English primary language and biological parent
Methods - Story Book Series

Marie Enters the World
Secrets of Life with Brachial Plexus Palsy
An Educational Series of Four Story Books
Written by Denise Justice | Illustrated by Susan Etnon | Edited by Holly Wagner

Marie Goes to Preschool
Secrets of Life with Brachial Plexus Palsy
An Educational Series of Four Story Books
Written by Denise Justice | Illustrated by Susan Etnon | Edited by Holly Wagner

Marie Goes to First Grade
Secrets of Life with Brachial Plexus Palsy
An Educational Series of Four Story Books
Written by Denise Justice | Illustrated by Susan Etnon | Edited by Holly Wagner

Marie Goes to Junior High
Secrets of Life with Brachial Plexus Palsy
An Educational Series of Four Story Books
Written by Denise Justice | Illustrated by Susan Etnon | Edited by Holly Wagner

Dear Family,

Here you will find this short story series about brachial plexus palsy understanding and awareness. Each book in the series is a different stage in the life of a child with brachial plexus palsy and is designed to help families navigate through the challenges and joys of their child’s development.

With stories written in a simple and accessible language, these books aim to educate and inform families about the different aspects of living with brachial plexus palsy. The series is divided into four parts:

1. Marie Enters the World
2. Marie Goes to Preschool
3. Marie Goes to First Grade
4. Marie Goes to Junior High

Each book is a unique journey, reflecting the different stages of development and the emotional and psychological experiences that families face. The series aims to provide support and understanding, helping families navigate the challenges and joys of raising a child with brachial plexus palsy.

Sincerely,

Denise Justice
Methods-Continued

Parents completed surveys pre and post reading storybooks

- **PROMIS (6 surveys)**
  1. Emotional distress – anger
  2. Emotional distress – anxiety
  3. Emotional distress – depression
  4. Fatigue
  5. Emotional support
  6. Informational support
Methods-Continued

• **Home Grown Survey**
  - 13 questions on NBPP anatomy
  - 16 questions on emotional response to NBPP

• **Statistics**
  - Normalized correct response percentage for NBPP questions
  - Standard statistical analysis for pre vs post reading
# Results

Increased Knowledge of Anatomy/Physiology on NBPP Questionnaire

<table>
<thead>
<tr>
<th>Correct Response Regarding NBPP Anatomy/Physiology</th>
<th>Pre-Reading</th>
<th>Post-Reading</th>
<th>Improvement</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>63%</td>
<td>73%</td>
<td>10%</td>
<td>0.001</td>
</tr>
<tr>
<td># Nerve Roots</td>
<td>58%</td>
<td>83%</td>
<td>25%</td>
<td>0.002</td>
</tr>
<tr>
<td>C8-T1 Motor Contribution</td>
<td>44%</td>
<td>78%</td>
<td>34%</td>
<td>0.005</td>
</tr>
<tr>
<td>C6 Motor Contribution</td>
<td>27%</td>
<td>59%</td>
<td>32%</td>
<td>0.006</td>
</tr>
</tbody>
</table>

5/25/2018 WFOT
## Results

### Improved Emotions on NBPP Questionnaire

<table>
<thead>
<tr>
<th>Emotional Response Regarding NBPP</th>
<th>Pre-Reading</th>
<th>Post-Reading</th>
<th>Difference</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Worry: Walking</td>
<td>19%</td>
<td>11%</td>
<td>-8%</td>
<td>0.08</td>
</tr>
<tr>
<td>Comfort: Medical Terms</td>
<td>68%</td>
<td>83%</td>
<td>19%</td>
<td>0.05</td>
</tr>
<tr>
<td>Parent Anxiety - NBPP</td>
<td>57%</td>
<td>35%</td>
<td>-22%</td>
<td>0.32</td>
</tr>
</tbody>
</table>

5/25/2018  WFOT
## Results

No Change in Emotions on PROMIS

<table>
<thead>
<tr>
<th></th>
<th>Pre-Reading</th>
<th>Post-Reading</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anger</td>
<td>48 ± 12</td>
<td>48 ± 10</td>
<td>.85</td>
</tr>
<tr>
<td>Anxiety</td>
<td>51 ± 11</td>
<td>48 ± 10</td>
<td>.09</td>
</tr>
<tr>
<td>Fatigue</td>
<td>47 ± 9</td>
<td>47 ± 8</td>
<td>.49</td>
</tr>
<tr>
<td>Emotional support</td>
<td>57 ± 8</td>
<td>57 ± 8</td>
<td>.88</td>
</tr>
<tr>
<td>Informational support</td>
<td>59 ± 9</td>
<td>58 ± 9</td>
<td>.74</td>
</tr>
<tr>
<td>Depression</td>
<td>48 ± 9</td>
<td>47 ± 10</td>
<td>.34</td>
</tr>
</tbody>
</table>
Conclusions

• Storybooks improved parents understanding of their child’s condition

• Use of storybooks can encourage parents
  – Engagement in medical decision making
  – Communication with providers
  – Satisfaction with interventions
Implications for OT

• Patient education should be incorporated into daily sessions
• Therapists should frequently review
  – Motor function of each nerve
  – Surgical indicators
• Therapists should consider using the “Talk Back Method”
• Patient education materials can be created by therapists
  – Avoid jargon
  – 12 pt serif font, reading level ~5th grade
Other Patient Education

ABC’s of the Brachial Plexus
a Terminology Book

Range of Motion
In DVD Format
Future Plans

• Convert patient education materials to digital format

• More story book style patient education materials
Thank You

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References


2. Wilson, TJ; Chang, KWC; Chauhan, SP; Yang, LJS. Peripartum and neonatal factors associated with persistence of neonatal brachial plexus palsy at 1 year: a review of 382 cases. JNS Peds. 2016. May; 17(5): 618-24.
