

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 births¹
- Stretch causes temporary or permanent arm weakness²
- Therapy is indicated in all cases
- Surgery to nerves is indicated in persistent cases²
- Patient education regarding this condition is imperative
- Most printed materials provide standard medical information
- Storybook format materials were created

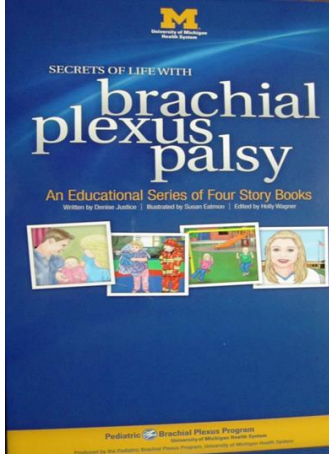
Objectives

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



Dear Reader,

I hope you will find this short story series about brachial plexus palsy educationally and emotionally satisfying. Each book is dedicated to a different stage in the life of a child with brachial plexus palsy. Marie is the main character, and has been diagnosed with brachial plexus palsy. The first book, "Marie Enters the World," depicts the early stages of development and her family's initial response to her condition. The second book, "Marie Goes to Preschool," reflects on Marie's adaptation to daily activities as a toddler, such as dressing and coloring. The third book, "Marie Goes to First Grade," portrays some of the emotional struggles that Marie experiences as she grows and faces new situations, such as acceptance of her condition by her peers on the playground. The fourth book, "Marie Goes to Junior High," brings forth some of the changes in self-esteem and the maturation process that occurs within this age group.

My goal in writing this series of books is to provide patient and caregiver education via a non-threatening mechanism and to facilitate dialog with families regarding the emotional aspects of brachial plexus palsy. The ideas for these books have been derived from common factors that I have witnessed among patients and families over the past 19 years while working with children with brachial plexus palsy. From these books, patients and families can learn 1) to have a working knowledge of the anatomy of brachial plexus palsy, 2) that their feelings are not unusual, and 3) that medical professionals are available to help these children gain as much function and independence as possible. By conveying these ideas, this series reveals the "Secrets of Life with Brachial Plexus Palsy."



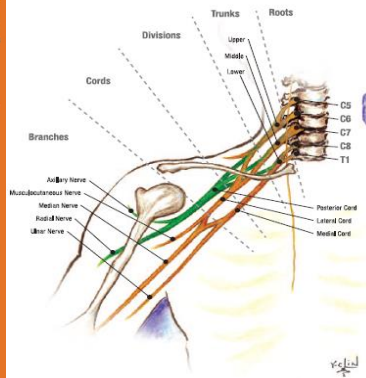
Dear Reader,

As a parent of a wonderful 9-year-old boy with brachial plexus palsy, I could definitely relate to these beautifully written books. As Marie (the main character) and her family go from birth to junior high school, you will discover some of the accomplishments and challenges that arise due to her brachial plexus palsy. The years in which Marie and her family deal with these problems will give you ideas about how to handle similar situations with your own child.

Your child's weak arm doesn't define who he/she is. If you and your child develop a good attitude and high self-esteem, your child can go as far as they wish to go!

Sincerely,
Susan Edmon

Science Fair Project
Diagram of the Brachial Plexus
By Marie Jay
2nd Hour

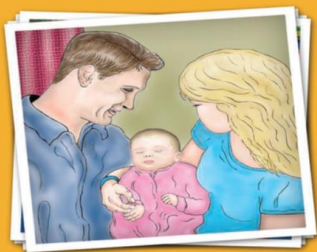


Book 1

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 Edmon | Edited by Holly Wagner



Book 2

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 Edmon | Edited by Holly Wagner



Book 3

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 Edmon | Edited by Holly Wagner



Book 4

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 Edmon | Edited by Holly Wagner



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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

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

Results

Improved Emotions on NBPP Questionnaire

Emotional Response Regarding NBPP	Pre-Reading	Post-Reading	Difference	P-value
Worry: Walking	19%	11%	-8%	0.08
Comfort: Medical Terms	68%	83%	19%	0.05
Parent Anxiety - NBPP	57%	35%	-22%	0.32

Results

No Change in Emotions on PROMIS

	Pre-Reading	Post-Reading	P-value
Anger	48 ± 12	48 ± 10	.85
Anxiety	51 ± 11	48 ± 10	.09
Fatigue	47 ± 9	47 ± 8	.49
Emotional support	57 ± 8	57 ± 8	.88
Informational support	59 ± 9	58 ± 9	.74
Depression	48 ± 9	47 ± 10	.34

Conclusions

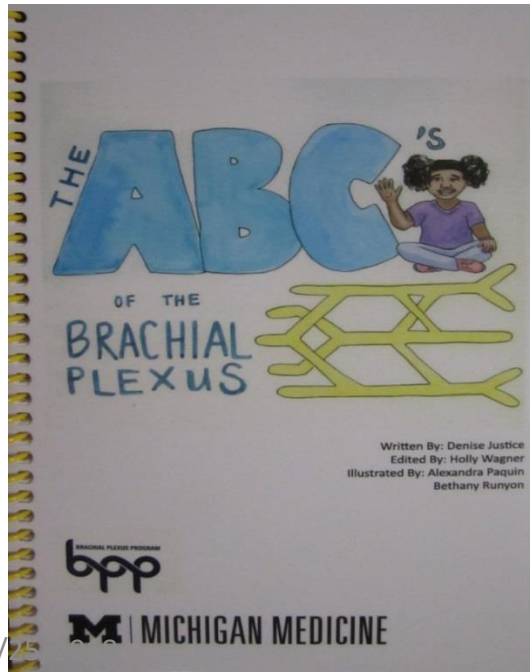
- Storybooks improved parents understanding of their child's condition
- Use of storybooks can encourage parents
 - Engagement in medical decision making
 - Communication with providers
 - Satisfaction with interventions

Implications for OT

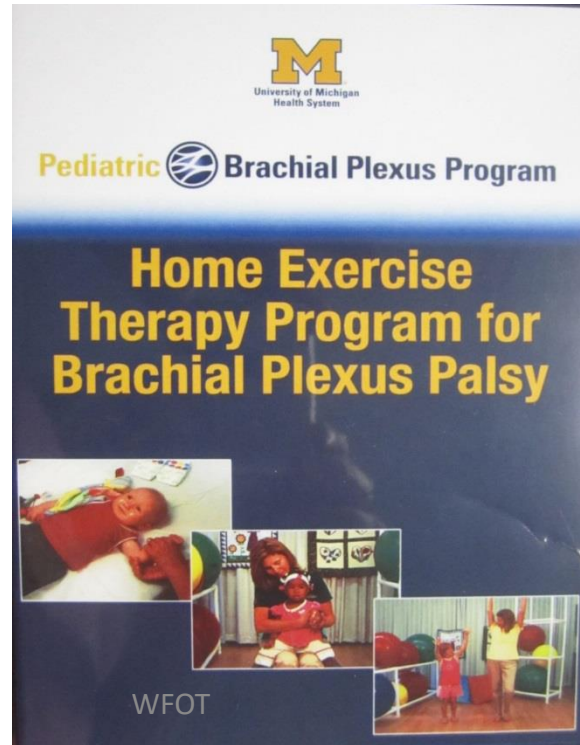
- Patient education should be incorporated into daily sessions
- Therapists should frequently review
 - Motor function of each nerve
 - Surgical indicators
- Therapists should consider using the “Talk Back Method”³
- Patient education materials can be created by therapists
 - Avoid jargon
 - 12 pt serif font⁴, reading level ~5th grade

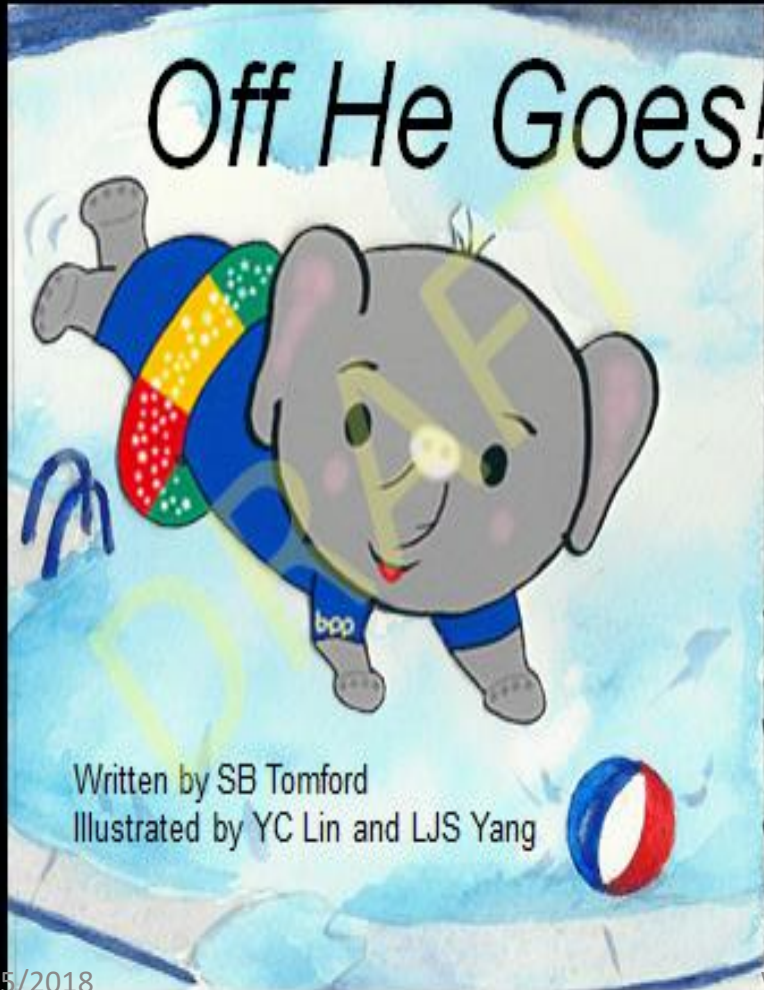
Other Patient Education

ABC's of the
Brachial Plexus
a Terminology Book



Range of Motion
In DVD Format





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Future Plans

- Convert patient education materials to digital format
- More story book style patient education materials



Thank You

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References

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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.
3. [Wick JY](#)¹. Checking for comprehension: mastering teach-back techniques. [Consult Pharm](#). 2013 Sep;28(9):550-4. doi: 10.4140/TCP.n.2013.550.
4. [http://journal.chestnet.org/article/S0012-3692\(15\)49699-0/pdf](http://journal.chestnet.org/article/S0012-3692(15)49699-0/pdf)