

**The Implementation of Obstetrical Brachial Plexus Palsy Education**

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**Table of Contents**

Abstract.....	5
Introduction.....	6
Needs Assessment.....	7
Community Profile.....	7
Interview Process.....	8
Problem Statement.....	8
Literature Review.....	9
Brachial Plexus Injuries.....	9
Functional Impact of Brachial Plexus Injuries.....	11
Understanding Injury.....	12
The Gap.....	13
Guiding Models.....	14
Project Plan and Process.....	15
Project Plan.....	15
Project Process.....	18
Project Implementation.....	21
Project Evaluation.....	22

Discussion and Impact.....24

Conclusion.....25

Appendix A.....30

Appendix B.....31

Appendix C.....33

Appendix D.....34

Appendix E.....35

Appendix F.....37

Appendix G.....38

### **Abstract**

Brachial plexus injuries are a fairly common diagnosis seen within the outpatient pediatric setting. Obstetrical brachial plexus injuries occur in approximately 0.9 per 1000 live births (Lin & Samora, 2022). Due to lack of awareness, as well as the wide range of severity and prognosis, many caregivers of infants and children find it difficult to explain their child's injury in a child-friendly manner. This difficulty has the potential to negatively impact the child's self-esteem, self-efficacy, and self-advocacy skills. The capstone student, as well as the site's stakeholders identified this gap within the current educational material being provided at the brachial plexus clinic. This doctoral capstone project involved creating evidence based and child-friendly educational materials for children and caregivers of children with obstetric brachial plexus palsy. Following the implementation of the created educational materials, participants reported increased comfort and confidence discussing obstetric brachial plexus palsy with their child. Additionally, caregivers also reported they feel these materials have the potential to lead to improving the child's ability to advocate for themselves.

*Keywords:* brachial plexus, obstetric, education, occupational therapy

### **The Implementation of Obstetrical Brachial Plexus Palsy Education**

A brachial plexus injury is a type of nerve injury that results from damage to the nerve network (brachial plexus) that sends signals originating in the spinal cord throughout the upper extremities (Mayo Foundation for Medical Education and Research, 2020). Brachial plexus injuries typically occur during birth or as a result of trauma. Brachial plexus injuries that occur at birth are known as obstetrical brachial plexus injuries. The clients typically seen at the capstone site's brachial plexus clinic acquired a brachial plexus injury at birth, leading to this population being the target population for this capstone project (Brachial Plexus & Peripheral Nerve Injuries, n.d.).

Many children with brachial plexus injuries may have increased pain, decreased motor control, muscle weakness, decreased range of motion and decreased sensation. These deficits can greatly impact occupational participation and performance. In turn, caregivers of children with brachial plexus injuries have increased responsibilities compared to other caregivers. One of those imperative responsibilities is ensuring their child can effectively communicate their injury and abilities to others. It is noted that children with obstetrical brachial plexus palsy may be more likely to experience compromised self-efficacy and self-esteem due to the reaction of others about their disability (Duff & DeMatteo, 2015).

The purpose of this capstone project is to provide caregivers of children and children with brachial plexus injuries educational material to improve the child's understanding of their injury and provide them with the tools and ability to explain their injury to others. The educational material has the potential to improve the child's self-efficacy, self-esteem, and ability to advocate for themselves by accurately explaining their injury and abilities to others.

### **Needs Assessment**

The needs assessment process consisted of an interview with the two primary occupational therapists at the capstone site's brachial plexus clinic. The interview was held over Zoom, due to scheduling conflicts. The interview asked detailed questions to gain a better understanding of the site and brachial plexus injuries, as well as the site's strengths, barriers and needs. The questions utilized throughout the interview process were based off the American Occupational Therapy Association (AOTA) Occupational Profile.

### **Community Profile**

Completion of the community profile enabled better understanding of the site and the community. The doctoral capstone site is a large hospital located in central Indiana. The site has many specialty clinics. One of the specialty clinics is the brachial plexus clinic. The brachial plexus clinic occurs twice a month on Wednesdays. Children from all over the state of Indiana attend this clinic to be evaluated by a multidisciplinary team of surgeons, doctors, and occupational therapists. The ages of the clients can vary greatly, however most clients attending the clinic are under 3. It is best to begin working with the clients as soon as possible after the injury, which typically occurs at birth. Most clients that attend this program have one occupational therapy appointment per week and are seen at this clinic every three to six months. Since clients and caregivers attend this clinic from all over the state of Indiana, many families drive long distances for their appointments. In addition, the clients and caregivers who attend this clinic are all of varying ethnicities, gender, socioeconomic status, and support systems.

**Interview Process**

The interview process aimed to gain a better understanding of brachial plexus injuries, the site and identifying a need that would be beneficial. In addition, completion of the interview was beneficial for both parties to better understand each other as well as the overall goals of this capstone project. During the completion of the interview, information was obtained regarding typical plans of care, brachial plexus injuries and caregiver education. The interview provided site specific information that will be valuable for this project while also enabling both parties to identify a need that will be the focus of this project.

***Question Articulation Process***

The questions asked throughout the interview with stakeholders aimed to gain a better understanding of the site, population, treatment plans, current educational materials, and any challenges the site is currently facing. Answers to these questions identified a need at the site and a specific project and experience for the student. The answers to the interview questions, found in Appendix A, enabled the project of client education within the brachial plexus clinic to come to light.

**Problem Statement**

The capstone site's brachial plexus clinic sees children of various ages with obstetrical brachial plexus palsy. The brachial plexus clinic at this site implements substantial caregiver education regarding range of motion exercises, positioning, the importance of tactile input on the affected upper extremity and community engagement. However, the site does not currently implement education material for the clients regarding their injury. Creating and providing educational material for children to learn about their brachial plexus injury, how to describe it to

others and how to advocate for themselves will likely lead to improved self-efficacy and self-esteem leading to increased functional occupational participation.

### **Literature Review**

A review of literature was conducted to examine available literature regarding pediatric brachial plexus injuries and the importance of the children's ability to understand and explain their injury. The information gathered through the review of literature was utilized to develop this capstone project. Databases utilized for the collection of the literature include GoogleScholar, PubMed and CINAHL complete. Search terms included: "neonatal", "obstetrical", "pediatrics", "brachial plexus injury", "brachial plexus palsy" and "occupational therapy". Criteria for inclusion included articles published within the last 10 years, participants under the age of 18 and articles applicable to the focus of this capstone project. The research included in this review is relevant to the focus and purpose of the doctoral capstone project.

### **Brachial Plexus Injuries**

Many brachial plexus injuries occur during birth, leading to the pediatric population being a population of which brachial plexus injuries are common. One focus of this literature review was researching the risk factors, incidence, severity, and prognosis of pediatric brachial plexus injuries. The incidence, severity, risk factors and prognosis of pediatric brachial plexus injuries are important to understand regarding this capstone project due to the complexity and specificity of the clients.

Evidence shows that there are many risk factors associated with obstetrical brachial plexus injuries. Obstetrical brachial plexus injuries are typically a result of applying traction during shoulder dystocia. Shoulder dystocia occurs when the infant's shoulder catches on the

mother's symphysis pubis or sacrum during birth, and shoulder dystocia is the most common cause of obstetrical brachial plexus injury. Evidence has also shown that there are various pregnancy and delivery complications that lead to increased risk of obstetrical brachial plexus injury. Gestational diabetes and infants measuring larger than the 90<sup>th</sup> percentile are both complications that lead to increased risk of a brachial plexus injury. Additionally, induction, the use of a vacuum or forceps and a prolonged delivery all also increase the risk of obstetrical brachial plexus injury (Duff and DeMatteo, 2015).

The incidence of pediatric brachial plexus injuries is an important factor to understand regarding this capstone project. Evidence shows that brachial plexus injuries are fairly common throughout the United States. Specifically, it is important to note that obstetrical brachial plexus injuries occur in approximately 0.9 per 1000 live births (Lin & Samora, 2022). Although obstetrical brachial plexus injuries typically occur as a result of a similar mechanism of injury, the severity of pediatric brachial plexus injuries can vary greatly. The severity of these injuries has the potential to range from a mild stretch injury to a complete nerve avulsion. Mild stretch injuries typically result in a rapid recovery, where the infant often regains full range of motion of the affected upper extremity. However, complete nerve avulsions occur when the nerve root is pulled and separated from the spinal cord. Due to the severity of a complete nerve avulsion, this type of injury typically results in a more unfavorable prognosis. Infants with a complete nerve avulsion may present with the presence of Horner's Syndrome and/or a flaccid affected upper extremity. Depending on injury severity and the infant's recovery, surgical interventions may be indicated. Overall, full recovery of obstetrical brachial plexus injuries is possible; however, it is noted that up to 35% of children with these injuries may experience life-long affected limb functional impairment (O'Berry et al., 2017). This statistic proves the importance of early

treatment intervention regarding these injuries, due to the substantial functional impact many of the clients within this population may experience.

### **Functional Impact of Brachial Plexus Injuries**

Another main area of focus regarding brachial plexus injuries was the functional impact of these injuries on clients, caregivers, and families. Individuals with brachial plexus injuries often experience pain, decreased sensation and limited range of motion of the affected upper extremity. Due to these deficits, substantial psychosocial impacts of these injuries are also common among this population. As a result of the psychosocial effects as well as pain, sensation, and movement deficits commonly experienced by this population, brachial plexus injuries often lead to substantial impacts on functional occupational participation as well as overall quality of life (Cole et al., 2020). The impacts on occupation and quality of life commonly experienced by this population will likely also have substantial impacts on caregivers and families. Many families are impacted by stress, working less hours to care for their child, traveling long distances to see brachial plexus injury specialists and carrying out home recommendations. Evidence has shown that having a child with a brachial plexus injury has the potential to substantially impact the family, with severity of injury being marginally correlated. Specifically, families may be impacted by social factors, personal strain, stress related to finances and mastery (Louden et al., 2015).

Social factors are another important factor that contribute to quality of life for children with brachial plexus palsy. Evidence has shown that quality of life for children as well as their families is heavily determined by social factors. Specific social factors identified included functional limitations, aesthetics, body image, emotional adjustment, and peer acceptance (Squitieri et al., 2013). Children with obstetrical brachial plexus injuries have an increased risk

of developing postural and developmental disorders. Due to the increased risk of developing these disorders, children with obstetrical brachial plexus palsy are also at risk for restrictions regarding functional occupational participation (Duff & DeMatteo, 2015). The impact of obstetrical brachial plexus injury on children and caregivers has the potential to substantially limit their participation in meaningful and desired occupations.

### **Understanding Injury**

Talking to children about their brachial plexus injury and abilities has the potential to lead to improved self-efficacy and self-esteem. It is important to talk to children about disabilities not only to better understand themselves, but to better understand their peers as well. Although there are multiple benefits to talking with your child about their brachial plexus injury and abilities, it may be a difficult conversation for many caregivers. It is recommended to start the conversation about various topic areas and then provide the child with multiple examples. Starting this conversation and ensuring children learn about disability will not only lead to better understanding of themselves and others but will also be imperative to build strong interpersonal relationships (NYC Department of Education, n.d.).

Many components relate to quality of life for children with disabilities. These components include thoughts and feelings, societal acceptance, formation of identity beyond disability, autonomy and hope for the future. Research shows that there is evident quality of life changes as the child's health condition changes and as the child matures (Ow et al., 2021). This is likely due to better understanding of themselves and their abilities. These findings highlight the importance of teaching children and adolescents about their injury to improve their overall quality of life, even for younger children who may not be as mature. Evidence has also shown that children with neonatal brachial plexus palsy may experience social difficulties when

participating in school and other activities, due to physical impairment and visible differences of the affected upper extremity (Chang et al., 2017). The possibility of experiencing social difficulties in children can lead to decreased self-esteem. These findings further emphasize the importance of teaching children about their brachial plexus injury so they can describe their diagnosis and abilities to others.

### **The Gap**

Following the review of the literature, two gaps regarding pediatric brachial plexus injuries stood out. The first gap identified is that the site is not currently implementing educational materials aimed to improve each child's understanding of their brachial plexus injury. The second gap that was identified is regarding the lack of available literature within this area of occupational therapy practice. Diminishing these gaps can positively impact occupational therapy practice and therapeutic outcomes.

First, it does not appear that the capstone site is currently implementing educational material to teach children about their brachial plexus injury. According to the literature, providing caregivers with resources to teach their child about their injury has the potential to improve client autonomy, self-efficacy, self-esteem and improve understanding of themselves and others. In addition, this educational material would likely increase the overall quality of life for clients. This gap was determined due to the available literature stating the importance of teaching children about their injury; however, it is not currently being done at this site.

In addition, through the search of literature, it does not appear that this area of occupational therapy practice is heavily researched. Specifically, the area regarding understanding injuries and education for children with brachial plexus injuries. The topics of

implementing brachial plexus injury education and child understanding of their injury need to be further researched in order to implement best practice within the field of occupational therapy.

### **Guiding Models**

Two models were found to be imperative to guiding this doctoral capstone project. These models were utilized as a theoretical base and provided direct guidance to the implementation of this project.

#### **Model of Human Occupations**

The Model of Human Occupations was utilized to guide this capstone project. The Model of Human Occupation is a model that can be utilized throughout the lifespan and conceptualizes that humans have an innate desire for mastery. This model also emphasizes the importance of understanding the physical and social environments to truly understand occupation and problems related to occupation (University of Illinois Chicago, n.d.). The Model of Human Occupations was critical for guiding this project since clients and caregiver will need to be motivated to learn how to not only understand brachial plexus injuries but also how to self-advocate through learning how to effectively communicate their injury and abilities to others.

#### **Expanded Awareness Model**

The second model that is important regarding this project is the expanded awareness model. The expanded awareness model emphasizes the importance of two interrelated components. The first component is the knowledge of specific aspects related to cognition, characteristics related to tasks and strategies related to function. The second component emphasized within the expanded awareness model is understanding of self as well as capabilities and limitations. The expanded awareness model also explains that knowledge and beliefs have an

influence on the client's perceptions of demands, anticipations and expectations related to a task (OT Theory, n.d.). This model will be critical to this project because the created educational materials will aim to improve each client's knowledge and understanding of brachial plexus injuries, and specifically the interrelated components explained in the expanded awareness model. Improving the client's understanding and recognition of their injury, as well as how it affects their ability to complete tasks, will promote functional occupational participation and overall quality of life, by creating realistic expectations for clients and caregivers.

### **Project Plan and Process**

#### **Project Plan**

The doctoral capstone consisted of a 14-week project and experience. The plan for this doctoral capstone project was to create educational materials for children and caregivers of children with brachial plexus injuries. Specifically, the student planned to create a way to educate both pediatric clients, as well as their caregivers, about brachial plexus injuries. Through this plan, the student aimed to increase the child's independence, self-esteem, and ability to advocate for themselves. Prior to the start date of the doctoral capstone experience, goals and objectives were formulated. The goals served as a foundational guide for the doctoral capstone student and ensured that they were on track throughout the 14-week experience.

#### ***Project Goals and Objectives***

Student learning objectives for this doctoral capstone project were created by the student in collaboration with the site mentor. The student learning objectives align with the Indiana University Occupational Therapy curricular threads. The IU OT curricular threads include socially responsive healthcare, critical inquiry and reflective practice as well as leadership and

advocacy. The following student learning objectives were created with consideration of the IU OT curricular threads:

- **Student Learning Objective 1: Socially Responsive Healthcare**
  - The student will provide evidence-based, inclusive, and client-centered educational information to children and caregivers within the outpatient pediatric setting.
- **Student Learning Objective 2: Critical Inquiry and Reflective Practice**
  - The student will demonstrate the ability to effectively evaluate available evidence and apply evidenced based decision making to created educational material, to expand available resources regarding pediatric brachial plexus injuries.
- **Student Learning Objective 3: Leadership and Advocacy**
  - The student will demonstrate the ability to effectively advocate, collaborate and communicate with clients, caregivers, and families, to promote holistic well-being and quality of life for the target population.

The goals for the doctoral capstone project were also collaboratively created by the student, with guidance from the site mentor. The collaborative efforts to create each goal ensured the doctoral capstone project would be attainable, sustainable, and meaningful to the site. The following goals and objectives were created:

	<b>Goals</b>	<b>Objectives</b>
<b>1</b>	The student will obtain new knowledge as well as utilize	Objective 1: The student will research strategies regarding explaining injuries and abilities to children.
		Objective 2: The student will apply available evidence as well as the principles of health literacy to the creation of the educational material.

	<p>previous knowledge regarding pediatric brachial plexus injury, to create evidence-based educational material for caregivers to talk to their child about their injury and abilities.</p>	
		<p>Objective 3: The student will inquire with professionals who are a part of the brachial plexus clinic team for feedback on created educational material.</p>
		<p>Objective 4: The student will make necessary and recommended changes to the educational material.</p>
2	<p>The student will provide education on created educational material to caregivers of children who attend the site's brachial plexus clinic to improve perceived ability, confidence and comfort discussing injury with their child.</p>	<p>Objective 1: The student will implement created educational material at the site's brachial plexus clinic for parents willing to participate.</p>
		<p>Objective 2: The student will demonstrate the ability to effectively communicate with caregivers by answering questions about the created educational material.</p>
		<p>Objective 3: The student will follow-up with the parents in 2-3 weeks after the implementation of the created educational material to gauge effectiveness and receive suggestions from caregivers.</p>
3	<p>The student will demonstrate advanced clinical skills regarding pediatric brachial plexus injuries.</p>	<p>Objective 1: The student will demonstrate the ability to independently complete an evaluation of a child with brachial plexus injury.</p>
		<p>Objective 2: The student will demonstrate the ability to independently complete an evaluation of an infant with a brachial plexus injury.</p>
		<p>Objective 3: The student will demonstrate the ability to independently conduct a basic brachial plexus injury treatment session for a child.</p>
		<p>Objective 4: The student will demonstrate the ability to independently conduct a basic brachial plexus injury treatment session for an infant.</p>

### ***Evaluation Plan***

The capstone student planned to assess the effectiveness of this project through gathering and analyzing qualitative data. The student planned to gather qualitative data through open-ended questionnaires that would be sent to caregivers of clients with brachial plexus injuries. The questions asked on the questionnaire were created by the student to assess the effectiveness of the materials. The student planned to assess the effectiveness through inquiring about the caregiver's perceived comfort and confidence discussing brachial plexus injuries with their child. Additionally, the student planned for the questionnaire to inquire about the child's ability to explain their brachial plexus injury to others.

### **Project Process**

Prior to heading on site for the doctoral capstone experience, the student completed a needs assessment, gap analysis and literature review. These components were completed prior to beginning the project, as they aimed to determine a need for the site and gather background information. The capstone student then created a 14-week plan, to create a timeline that was achievable and goal-oriented. The comprehensive 14-week plan created by the capstone student can be found in Appendix B.

### ***Initial Weeks***

The initial weeks (week 1 through 3) were focused on getting oriented to the site, determining if changes needed to be made to the project goals and objectives and beginning research for the educational materials. The student also spent substantial time reviewing articles recommended by the site mentor. It was also determined in the initial three weeks that the

educational material would include a short video for the clients, as well as a handout for the caregivers. During the first three weeks, the student also spent time observing the site mentor during evaluations of infants with brachial plexus injuries. Additionally, the student observed the site mentor during treatment sessions of infants and children with BPI. The student researched a brachial plexus specific assessment, the Active Movement Scale (AMS), and practiced scoring while the site mentor completed the assessment.

### ***Weeks Four Through Six***

The next three weeks (weeks 4 through 6) were focused on beginning to create the educational materials, as well as advancing the student's clinical skills. The student began recruiting individuals to participate in the video and creating the handout for caregivers. The student spent a substantial amount of time during these weeks focused on creating a video script, as well as applying evidenced-based research while creating the caregiver education handout. The student began to complete the caregiver interview portion of infant evaluations and performed the Active Movement Scale on multiple infants. The student also created multiple reference charts. The created reference charts explain the functional impact of common orthoses utilized for children with brachial plexus injuries and the outcome of common surgical procedures done for this population. The splint reference chart can be found in Appendix C and the surgical procedures reference chart can be found in Appendix D.

### ***Weeks Six Through Ten***

Weeks six through ten involved the student finalizing the educational materials and continuing to advance clinical skills. During these weeks, the student emailed the participants instructions for the video as well as the created video script with prompts. The student also

completed the caregiver education handout and completed the Suitability Assessment of Materials (SAM) assessment to assess health literacy and reading level. The student then requested feedback from the site mentor on the caregiver education handout. The video participants sent their recordings to the capstone student and the editing process began during week 10.

The student continued to advance clinical skills in relation to evaluating and treating infants and children with brachial plexus injuries throughout these weeks. The student continued to complete evaluations of infants with brachial plexus injuries. The student also gained experience participating in treatment sessions for infants and children with brachial plexus injuries. The student created an intervention to educate a 4-year-old client on their brachial plexus injury to improve understanding of the injury. A picture of the intervention created by the student can be found in Appendix F.

### ***Final Weeks***

The final weeks (weeks 11 through 14) were focused on continuing to advance clinical skills, project implementation, creating a sustainability plan and assessing the effectiveness of the created materials. During the final four weeks, a QR code for the video was created to ensure it will be accessible following the completion of this capstone project. The final weeks were also spent assessing the effectiveness of the project through analyzing collected qualitative data, as well as continuing to implement the project as appropriate throughout treatment sessions. During week 14, the student presented a final presentation about the capstone project to the rehab team at the capstone site.

### **Project Implementation**

This doctoral capstone project was submitted to the Indiana University Internal Review Board. Following submission of the project to the Internal Review Board (IRB), a determination was made declaring this capstone project as “not human subject research”. This determination indicated that this doctoral capstone project did not need to be further reviewed and the project could proceed. The participants for this project were caregivers of children with brachial plexus injuries.

### **Advancement of Clinical Skills**

The capstone student advanced their clinical skills regarding evaluating and treating infants and children with brachial plexus injuries. Throughout the experience, the capstone student had the opportunity to administer various brachial plexus specific assessments (Active Movement Scale and Modified Mallet Scale). The capstone student also had the opportunity to participate in treatment sessions for infants and children with brachial plexus injuries. The student gained advanced knowledge regarding passive range of motion, joint compressions, massage, and vibration to the affected upper extremity. The student also gained additional experience with handling and gross motor development.

### **Caregiver Resource Development**

The capstone project was implemented in two separate parts. First, the capstone student implemented the caregiver education handout which aimed to assist the caregivers with discussing brachial plexus injuries with their child. The handout was created following researching the best way to talk to children about disabilities, as well as assessing for health literacy. The finalized caregiver educational handout can be found in Appendix E. The caregiver

educational handout was discussed throughout treatment sessions. Following education on the handout, the student instructed each caregiver to talk to their child about their BPI within the next two weeks. The student then sent an open-ended questionnaire to each caregiver for project evaluation.

### **Client Resource Development**

The second part of this capstone project involved educating pediatric clients about their brachial plexus injury. This education was provided through a short video, with the participants in the video being children and young adults with brachial plexus injuries. The ages of the four participants ranged from 3 years old to 22 years old. The implementation of the video involved recruiting participants to be involved as well as sending out recording instructions and a video prompt. The instructions, questions and video prompts that were sent out to each participant can be found in Appendix G. Following the return of the recorded videos by each participant, the video editing process began by the student. The pre-recorded video clips were put together for a video. Once the video was complete, a QR code in which the video could be accessed was created. The QR code was added to the handout in order to improve accessibility of the video by clients and caregivers.

### **Project Evaluation**

The effectiveness of this project was evaluated through open-ended questionnaires. The items of the questionnaire inquired about perceived competence and confidence discussing BPI with their child, the benefits of implementing the educational material as well as their child's ability to advocate for themselves and explain their injury to others. Each questionnaire consisted of six open-ended questions. Once the participants completed the questionnaire, the capstone

student analyzed the qualitative data to find themes related to each overarching goal of this project.

### **Theme I: Improved Confidence Discussing BPI**

Out of three participants, all of the caregivers described feelings of increased confidence discussing brachial plexus injuries with their child after the implementation of the handout. Many of the participants acknowledged that the handout assisted them in discussing brachial plexus injuries with their child by providing a resource they did not previously have access to, which in turn increased their confidence. Additionally, many of the participants found the handout to be straight-forward, clear, and concise. The participants stated they found the handout to be especially helpful with increasing confidence due to these descriptors.

### **Theme II: Improved Comfort Discussing BPI**

All participants noted they felt more comfortable discussing brachial plexus injuries with their child. They also noted they did not previously feel as comfortable discussing brachial plexus injuries, as compared to utilizing the created handout. The participants noted that prior to being provided this handout, they explained brachial plexus injuries to the best of their abilities.

### **Theme III: Improved Child's Ability to Advocate for Themselves**

Two out of the three participants also noted that discussing brachial plexus injuries with their child has the potential to improve their ability to advocate for themselves. They explained they felt that having this conversation with their child made them more likely to be able to explain their abilities and limitations to others. They also felt having this conversation with their child identified specific areas they may need to discuss more in-depth.

### **Capstone Discussion and Impact including Sustainability Plan**

The results of the open-ended questionnaires indicate the effectiveness of this project. Specifically, the themes found in the qualitative data indicate that all participants felt improved confidence and comfort discussing brachial plexus injuries with their child. In addition, two of the three participants felt that utilizing the handout to discuss brachial plexus injuries with their child had the potential to improve their child's ability to advocate for themselves. Overall, this capstone project was found to be beneficial to caregivers of children with obstetric brachial plexus palsy. One limitation of this capstone project was the small sample size, this consisted of three participants. An additional noted limitation was the sampling method that was utilized to gather the participants. Participants were selected through convenience sampling due to the participants being caregivers of children with obstetric brachial plexus palsy.

#### **Impact**

Despite the previously described limitations, it is important to note that the implementation of obstetric brachial plexus palsy education had an impact on the target population. The qualitative data gathered by the capstone student suggests the participants gained confidence and comfort discussing brachial plexus injuries with their child. Additionally, the qualitative data gathered suggests the implementation of obstetric brachial plexus palsy education has the potential to improve children's ability to advocate for themselves.

The reported increase in caregiver's confidence and comfort, as well as the report of having the potential to improve their child's ability to advocate for themselves indicates that the target population was positively impacted. The reported increase in each caregiver's confidence and comfort discussing brachial plexus injuries will positively impact the population by ensuring

the topic is frequently talked about. This in turn will ensure children with obstetric brachial plexus palsy have the ability to explain their needs, abilities, and limitations to others.

Additionally, the qualitative data gathered indicates that the capstone student was able to advocate for the profession of occupational therapy by educating caregivers of the vast scope of practice.

### **Sustainability**

The capstone student aimed to provide the site with an effective sustainability plan to ensure continuation of the capstone project. To address the sustainability of the caregiver handout, an informal presentation was held by the capstone student to the rehab team. The student explained the purpose of the handout in order to ensure occupational therapists would continue to implement the project with appropriate caregivers. The occupational therapists who are a part of the brachial plexus clinic team agreed to fulfill the roll of implementing this handout. To address the sustainability of the client video, the student created a QR code connected to the video. The QR code was added to a handout to ensure accessibility for clients and caregivers. Members of the brachial plexus clinic team also agreed to provide the QR code handout to appropriate clients.

### **Conclusion**

This project aimed to create and provide educational materials to the capstone site for children and caregivers of children with obstetric brachial plexus palsy. Through the created educational materials, the capstone student aimed for children to learn about their brachial plexus injury, how to describe it to others and advocate for themselves. The capstone student provided the site with valuable educational materials including a caregiver handout and a client video. The

created educational materials had a positive impact on the target population, evidenced by reported increases of caregiver comfort and confidence discussing brachial plexus injuries with their child. By creating the educational materials and providing the capstone site with an effective sustainability plan, the capstone student ensured the site is fully equipped to educate caregivers on discussing obstetrical brachial plexus palsy with their child and therefore, will promote holistic health and well-being for the target population.

### References

- Abzug, J. M., Kozin, S. H., & Neiduski, R. (2020). *Pediatric hand therapy*. Elsevier.
- Brachial Plexus & Peripheral Nerve Injuries. Riley Children's Health. (n.d.) Retrieved January 20, 2023 from <https://www.rileychildrens.org/health-info/brachial-plexus-peripheral-nerve-injuries>
- Chang, K., Austin, A., Yeaman, J., Phillips, L., Kratz, A., Yang, L., Carlozzi, N. (2017). Health-Related Quality of Life Components in Children with Neonatal Brachial Plexus Palsy: A Qualitative Study. *The Journal of Injury, Function and Rehabilitation*, 9(4), 383-391.
- Cole, T., Nicks, R., Ferris, S., Paul, E., O'Brien, L., & Pritchard, E. (2020). Outcomes after occupational therapy intervention for traumatic brachial plexus injury: A prospective longitudinal cohort study. *Journal of hand therapy : official journal of the American Society of Hand Therapists*, 33(4), 528–539. <https://doi.org/10.1016/j.jht.2019.08.002>
- Duff, S. V., & DeMatteo, C. (2015). Clinical assessment of the infant and child following perinatal brachial plexus injury. *Journal of Hand Therapy*, 28(2), 126–134. doi: 10.1016/j.jht.2015.01.001
- How to Teach Children About Disabilities and Inclusion. Baylor University. (2021, March 23). Retrieved March 1, 2023 from <https://onlinegrad.baylor.edu/resources/teaching-children-disabilities-inclusion/>
- Lin, J. S., & Samora, J. B. (2022, March 5). Brachial Plexus Birth Injuries. *Orthopedic Clinics of North America*. Retrieved November 4, 2022, from <https://www.sciencedirect.com/science/article/abs/pii/S0030589821002923?via%3Dihub>

- Louden, E., Allgier, A., Overton, M., Welge, J., & Mehlman, C. T. (2015). The impact of pediatric brachial plexus injury on families. *The Journal of hand surgery*, 40(6), 1190–1195. <https://doi.org/10.1016/j.jhsa.2015.03.020>
- Mayo Foundation for Medical Education and Research. (2020, April 15). *Brachial Plexus Injury*. Mayo Clinic. Retrieved March 26, 2022, from <https://www.mayoclinic.org/diseases-conditions/brachial-plexus-injury/symptoms-causes/syc-20350235>
- NYC Department of Education. (n.d.). *Talking about disability*. Retrieved September 29, 2022, from <https://www.schools.nyc.gov/learning/special-education/help/talking-about-disability>
- O’Berry, P., Brown, M., Phillips, L., & Evans, S. H. (2017, July 12). *Obstetrical Brachial Plexus Palsy*. *Current Problems in Pediatric and Adolescent Health Care*. Retrieved September 29, 2022, from <https://www.sciencedirect.com/science/article/abs/pii/S1538544217301190?via%3Dihub>
- OT Theory. (n.d.). *Expanded Awareness Model*. Expanded Awareness Model . Retrieved October 5, 2022, from <https://ottheory.com/therapy-model/expanded-awareness-model>
- Ow, N., Appau, A., Matout, M., & Mayo, N. E. (2021, February 7). *What is Qol in children and adolescents with physical disabilities? A thematic synthesis of pediatric QOL literature - quality of life research*. SpringerLink. Retrieved October 5, 2022, from <https://link.springer.com/article/10.1007/s11136-021-02769-6>
- Squitieri, L., Larson, B. P., Chang, K. W. C., Yang, L. J. S., & Chung, K. C. (2013, October 25). *Understanding quality of life and patient expectations among adolescents with neonatal*

*brachial plexus palsy: A qualitative and Quantitative Pilot Study*. The Journal of Hand Surgery. Retrieved October 14, 2022, from <https://www.clinicalkey.com>

University of Illinois Chicago. (n.d.). *Kielhofner's Model of Human Occupation*. About the Model of Human Occupation . Retrieved November 1, 2022, from

<https://moho.ahs.uic.edu/about/>

## **Appendix A**

### Interview Questions

- 1.) What does a day at the brachial plexus clinic look like?
- 2.) Who is involved in the multidisciplinary care team?
- 3.) What are the ages of the children who typically attend the brachial plexus clinic?
- 4.) How often is the brachial plexus clinic?
- 5.) What is the typical plan of care for a pediatric brachial plexus injury?
- 6.) What do typical treatment sessions look like?
- 7.) How often is each child seen at the brachial plexus clinic?
- 8.) Are any caregiver resources currently being provided at the clinic?
- 9.) What are some challenges you have noticed while working with this population?

**Appendix B****14 Week Plan:****Week 1 (01/09 - 01/13):**

- Site orientation 01/09
- BP clinic and hand clinic 01/11
- Make edits to student learning plan and 14-week plan
- Begin research for educational material

**Week 2 (01/16 - 01/20) :**

- Continue research for educational material
- Clinical skills check-in

**Week 3 (01/23 - 01/27) :**

- BP clinic 01/25
- Continue research for educational material

**Week 4 (01/30 - 02/03) :**

- Discuss research findings with site mentor
- Continue research and begin creating educational material
- Clinical skills check-in

**Week 5 (02/06 - 02/10):**

- BP clinic 02/08
- Continue to create educational material

**Week 6 (02/13 - 02/17):**

- Clinical skills check-in
- Continue to create educational material

**Week 7 (02/20 - 02/24):**

- BP clinic 02/22
- Continue to create educational material

**Week 8 (02/27 - 03/03):**

- Midterm evaluation / plan OT and BP team final presentation times

- Send draft of created educational materials for site mentor to review
- Clinical skills check-in

**Week 9 (03/06 - 03/10):**

- BP clinic 03/08
- Edit educational material based off recommended changes

**Week 10 (03/13 - 03/17):**

- Educational materials finalized by 03/17
- Make necessary edits to educational material
- Clinical skills check-in

**Week 11 (03/20 - 03/24) :**

- BP clinic 03/22
- Begin implementation of caregiver education handout and video

**Week 12 (03/27 - 03/31) :**

- Implementation of educational materials
- Work on final presentation
- Clinical skills check-in

**Week 13 (04/03 - 04/07) :**

- Begin caregiver interviews
- Work on final presentation

**Week 14 (04/10 - 04/14) :**

- Final evaluation 04/14 11:00am
- Caregiver interviews
- Final presentation on 04/12

## Appendix C

Splint	Picture	Purpose
Mckie		thumb abduction and thumb opposition
Supinator Strap		forearm supination
SupER Splint		forearm supination and shoulder external rotation
Benik		Thumb abduction with or without wrist support
Elbow		<p>elbow flexion contractures</p> <ul style="list-style-type: none"> <li>- may be used to maintain an elbow flexion contracture so it does not worsen</li> <li>- Use of elbow splint at night following serial casting to maintain gains</li> </ul>

## Appendix D

<b>SURGERY</b>	<b>JOINT</b>	<b>GOAL</b>	<b>IMPACT</b>
<b>Subscapularis release with or without joint capsule release</b>	Shoulder	Address shoulder imbalance, improve GH alignment, release internal rotation contracture	Improve ROM and shoulder stability
<b>Transfer of Latissimus Dorsi and/or Teres Major tendons to the posterior-superior rotator cuff</b>	Shoulder	Tendons become active abductors and external rotators or shoulder, improve GH alignment, release internal rotation contracture	Improve ROM and shoulder stability
<b>Humeral osteotomy</b>	Shoulder	Address internal rotation contracture, provides new set point for active shoulder rotation	Improve shoulder rotation ROM
<b>Lengthening of Biceps and Brachialis muscles</b>	Elbow	Address elbow flexion contracture (muscles shorten due to impaired growth – leads to ROM loss)	Improve elbow ROM
<b>Reroute distal biceps tendon</b>	Forearm	Reroute distal biceps tendon from active supinator to pronator function	Improve forearm pronation
<b>Radius and/or ulna derotational osteotomy</b>	Forearm	Addresses a fixed contracture, improve positioning of forearm	Improve forearm positioning and ROM
<b>Transfer of FCU or FCR to ECR longus/brevis</b>	Wrist	Address weak wrist extensor muscles	Improve wrist extension ROM
<b>Tendon transfers for active extension of involved digits</b>	Hand	Transfer of tendons to affected digits in order to improve digit extension	Improve active digit extension

### Appendix E

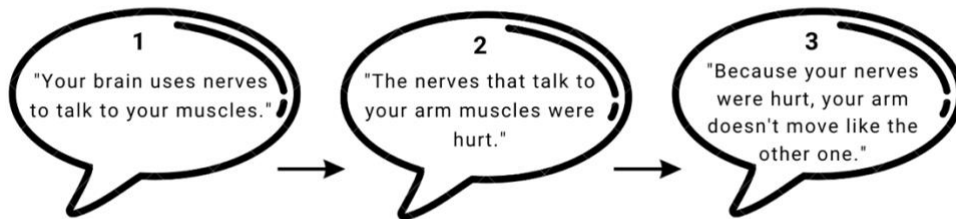
#### When should I start talking with my child about their brachial plexus injury?

Now! Start talking with your child about their brachial plexus injury early and often.

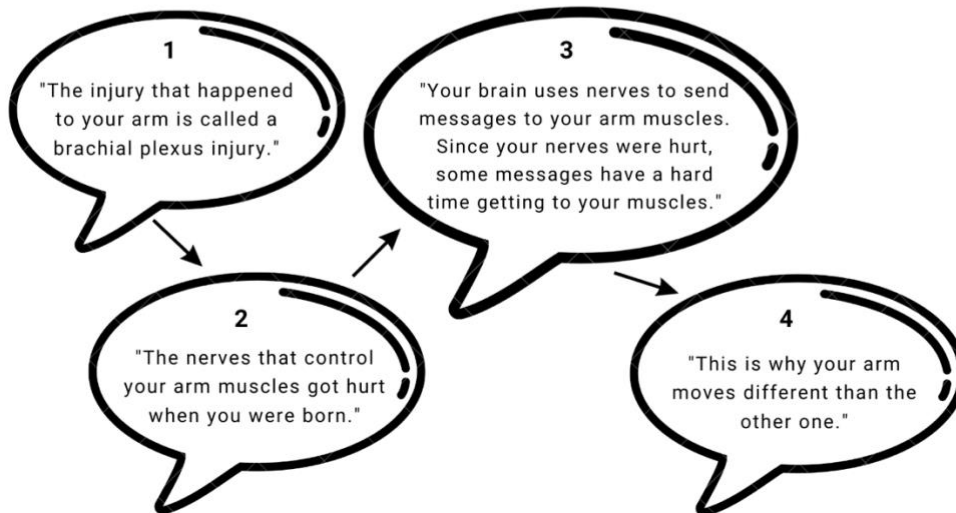
#### Why should I talk with my child about their brachial plexus injury?

Talking with your child about their brachial plexus injury can help them learn about their body and learn how to explain their injury to other people.

#### What should I say to my child who is under 5 years old?



#### What should I say to my child who is 5-9 years old?



## **Additional tips:**

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### **Encourage your child to tell others about their arm.**

Telling others about their arm can help your child learn to explain their disability and ask for help when needed.

### **Talk with your child about how they feel after telling others about their arm.**

Children often connect feelings with experiences.

Having these conversations will help your child learn about their feelings related to their arm.

### **Encourage your child to use the arm that moves differently but know it does not need to be their dominant arm.**

It is okay for your child's affected arm to be a helper hand for daily tasks.

For tasks like writing and cutting, it is important for your child to use their dominant hand.

### **Teach your child to recognize differences with a positive perspective.**

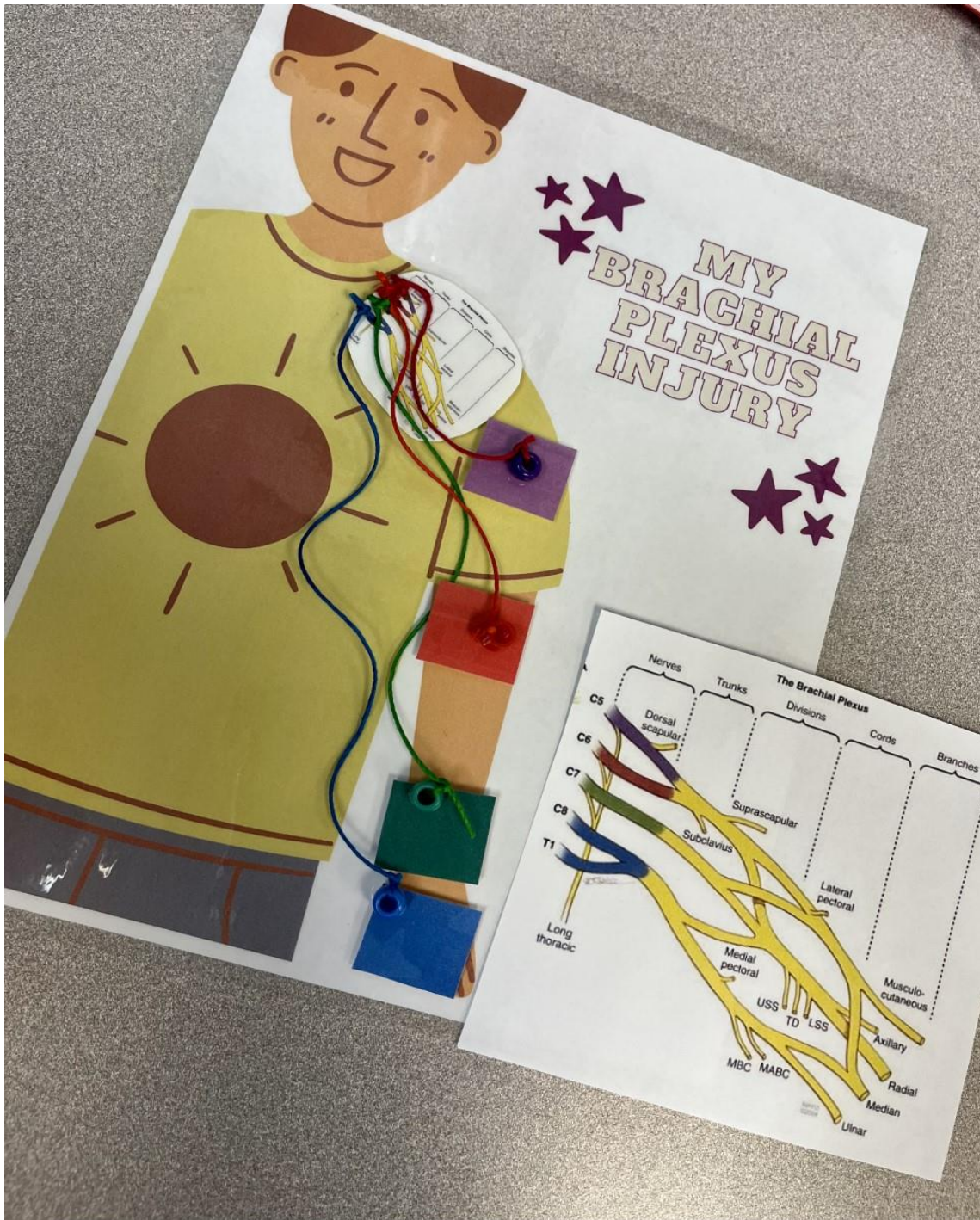
It is important for your child to see that everyone is unique and that everyone has their own differences.

Explain to your child that their arm is something unique about them!

### References:

How to Teach Children About Disabilities and Inclusion. Baylor University. (2021, March 23). Retrieved March 1, 2023 from <https://onlinegrad.baylor.edu/resources/teaching-children-disabilities-inclusion/>

Appendix F



## Appendix G

### THANK YOU FOR PARTICIPATING IN THIS VIDEO PROJECT!

- Please record your video in the landscape view (long/horizontal way).
- You can choose if you want to record multiple videos or just have one long video answering the questions – I will edit after!
- Do not feel you need to say every answer listed word for word! The answers are simply there to be a guide of possible responses.
- Feel free to add anything additional you would like to say to your video; you do not have to only stick to the list.
- Please also send a separate video of you completing one of your favorite hobbies or something you have learned to do in a unique way!

Reach out to me with any questions!

Libby McRae, OTS

## **Introduction**

“Hi my name is .... I am .... years old and I have a brachial plexus injury”

### **Topic 1: About BPI**

#### **What is a brachial plexus injury?**

“A brachial plexus injury is a nerve injury; this means that nerves that control my arm muscles were hurt”

“Your brain sends signals through your nerves to your muscles, telling your muscles to move your arm”

“Since my nerves were hurt, the messages from my brain can’t get to the muscle, so my arm does not move like the other one”

#### **How do brachial plexus injuries happen?**

“Some brachial plexus injuries happen during birth, and some happen during an accident”

“The nerves are stretched or broken during the birth or accident”

“Brachial plexus injuries look different for everyone”

“Some people have trouble moving their shoulder, some people have trouble moving their elbow and some people have trouble moving their whole arm and hand”

#### **What has treatment looked like?**

\*\*talk about what you have experienced with treatments

Example: doctor visits, therapy, surgery, splints, home exercises etc.

“I see a doctor who specializes in brachial plexus injuries”

“Some people with brachial plexus injuries have had surgery”

“I have had surgery to ....”

“I have been in therapy to help ....”

“I have learned to do ..... to keep my arm strong and help me do my everyday activities”

### **Topic 2: Self-Advocacy**

#### **How do you explain your brachial plexus injury to others?**

“If someone asks about my arm, I tell them my nerves got hurt when I was born or in an accident and that is why my arm moves differently”

“My arm moves differently than the other one, but I can still do ....”

“Sometimes I need to find different ways of doing things”

“Everyone is different, and my arm is one thing unique about me”

#### **Why is it important to ask for help or a break when you need it?**

“Everybody needs help sometimes, so it is good to ask or let someone know you need help”

“Breaks are important if my arm feels tired or sore because I need to listen to my body”

“Asking for help or a break helps you do the things you want and need to do”

### **Topic 3: Self-Esteem and Confidence**

#### **What makes you happy?**

#### **What are your favorite hobbies / what do you do for fun?**

**What do you like to do?**

**What are three words to describe yourself?**

**What are you proud of?**

**What have you learned to do differently because of your BPI?**

### **Conclusion**

**What is something you would tell your younger self?**

**Any words of encouragement?**

