

PARENT EDUCATIONAL HANDOUT FOR POST-OPERATIVE REHAB CARE
AFTER A TENDON TRANSFER SURGICAL PROCEDURE FOR TODDLERS WITH
NBPP

A Thesis submitted to the faculty at Stanbridge University in partial fulfillment of the
requirements for the degree of Master of Science in Occupational Therapy

By

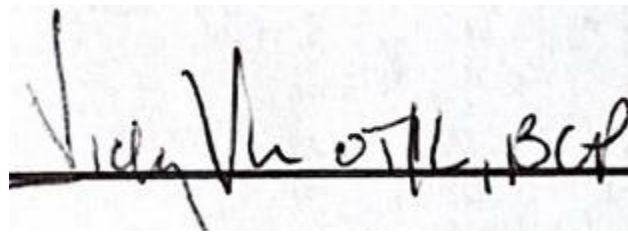
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Certification of Approval

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Abstract

Due to the lack of information and resources regarding neonatal brachial plexus palsy (NBPP), it is imperative that parents receive proper education on how to care for their child post tendon transfer surgery. Postsurgical tendon transfer care is crucial to the child's functional development and, if not properly managed, will limit the full functional outcomes for the child. As this is a major surgery, parents often find themselves unprepared and lack the confidence to play and interact with their child. Occupational therapists play a critical role teaching parents how to properly engage their children in meaningful occupations, such as play. The purpose of this thesis project was to create an informational handout that educated parents and caretakers of toddlers with NBPP who will undergo tendon transfer surgery on the proper care and rehabilitation expectations for post tendon transfer surgery. Through evidence-based research and interviews with five families who have undergone the surgery, we compiled three common themes that impacted their daily lives. The themes were modifications, support, and therapy. Due to unexpected circumstances, the effectiveness of the handout was not properly assessed. Though well reviewed, future research could be conducted to evaluate the success of this tool and usefulness for the parents.

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Parent Educational Handout for Post-operative Rehab Care After Tendon Transfer
Surgical Procedure for Toddlers with NBPP

According to the Occupational Therapy Practice Framework (American Occupational Therapy Association, 2014), occupational therapy is defined as the therapeutic use of everyday life activities (occupations) for the purpose of enhancing or enabling participation in roles, habits, and routines in the home, school, workplace, community and other settings. For a child, the developmental process is crucial as he/she grows to determine how they will participate in their life. A brachial plexus injury can impede a toddler's motor development which can later affect their ability to participate in meaningful occupations, such as play. Some problems that can occur include a lack of control of voluntary movement, a lack of tone and muscle for supportive function, and a limited range of motion (World Health Organization, 2017). Though conservative treatment and spontaneous recovery are attainable, these treatments do not guarantee an improvement of functional levels of the arm (Malessy & Pondaag, 2011). Thus, by treating children who have not improved in functional arm use, surgeries such as tendon transfers are crucial for recovery. Ultimately, as a child improves in arm function, this will enable them to participate in various meaningful occupations.

According to Smith, Danter, Yang, and Wilson (2018), neonatal brachial plexus palsy (NBPP) occurs in 0.5 to 3 per 1000 live births and causes a persistent deficit in 20% to 30% of patients. Through research and evidence-based practice, there has been found to be a limited amount of resources for caregivers of toddlers with NBPP. This project is an educational handout for families experiencing NBPP. The handout serves as a resource to caregivers to inform them on the post-operative expectations and care.

Statement of Problem

Based on professional insight and evidence-based research, parents lack the proper education on how to care for their toddlers with brachial plexus injuries post tendon transfer surgery. The lack of resources have been found to cause stress, anxiety, depression, and poorer quality of life in parents with toddlers with NBPP (Alyanak, Kilincaslan, Kutlu, Bozkurt, & Aydiin, 2013). NBPP is an unexpected event and parents find themselves in a difficult situation, as many lack the education and preparation of caring for these children (Firat, Oskay, Akel, & Oksuz, 2012).

According to Durlacher, Verchere and Zwicker (2015), parents have expressed the importance of education when caring for their children post operation. For example, the use of visual aids and educational devices that can be utilized at home once discharged to help further educate parents and remind them about precautions and care techniques (Durlacher et al., 2015). Receiving proper education can help families establish more appropriate expectations and attainable goals for their child (Louden, Allgier, Overton, Welge & Mehlman, 2015). It also emphasizes the importance of patient compliance in relation to success when maintaining treatment gains (Ho, Roy, Stephens & Clarke, 2009). Ho et al. (2009) found that children who were compliant throughout the whole treatment process had better improvements than those who did not. Thus, it is imperative that the child and family understand the long-term commitment needed to maintain the benefits of treatment.

The anticipated outcome for the project is to create an informational handout that will educate parents and caretakers of toddlers with NBPP on the proper care and rehab expectations for post tendon transfer surgery. The ultimate goal of the project is to

increase confidence and handling skills in parents and caretakers of these toddlers.

Family involvement is critical to realize the potential for long-lasting positive effects on a child's physical, cognitive and psychosocial development (Craig et al., 2015). Focusing on education and care can help empower families, ease stress, and enhance their well-being (Louden et al., 2015).

Literature Review

The brachial plexus of the human body is formed by the ventral rami of the C5-T1 nerve roots (Abzug & Kozin, 2010). It originates in the spinal cord at the neck and supplies motor movement of the muscles of the arm, elbow, wrist, and hand, and provides the basis for all sensibility and function of the upper extremity (Abzug et al., 2010).

NBPP is caused by traumatic stretching of the brachial plexus during the delivery of an infant. In the majority of cases, the upper shoulder of the infant is blocked by the mother's symphysis pubis (Malessy & Pondaag, 2011). As a result, these patients have flaccid paresis of their stretched or affected arm, resulting in loss of abduction and external rotation of the shoulder, flexion of the elbow, and supination of the forearm (Abzug et al., 2010). In addition, hand function may be impaired due to the muscle weakness of the proximal structures in the affected upper extremity (Abzug et al., 2010).

NBPP is categorized into two different types of injuries, Erb's palsy and complete brachial plexus palsy (Bahm, Ocampo-Pavez, Disselhorst-Klug, Sellhaus, & Weis, 2009). Erb's palsy is a paralysis of the arm caused by injury to the upper trunk (C5-C6) of the brachial plexus (Singh & Kolamala, 2015). Infants with Erb's palsy present an adducted and internally rotated arm, extended elbow, pronated forearm, flexed wrist, and extended fingers, also known as the "policeman's tip hand" (Malessy & Pondaag, 2011). Complete

brachial plexus palsy involves injury to the entire brachial plexus (C5-T1) (Malessy & Pondaag, 2011). This can result in the permanent loss of arm function, skeletal malformations, cosmetic deformities, and occupational limitations (Malessy & Pondaag, 2011).

In most patients with NBPP, it is possible that paresis is temporary and spontaneous recovery may be obtained (Chantaraseno, Precha, Supinchyangur & Cholpranee, 2014). If muscle contractions in the deltoid or biceps are seen by the first 3 months of age, a full functional recovery can emerge (Chantaraseno et al., 2014). It was also found that normal or near-normal muscle strength in elbow flexion, external rotation of the shoulder, and forearm supination by 3 months of age was associated with complete recovery (Lagerkvist, Johansson, Johansson, Bager, & Uverbrant, 2010). However, it is recommended that a microsurgical repair is to be done on those who do not recover spontaneously in order to improve loss of function and maximize recovery (Chantaraseno et al., 2014; Bahm et al., 2009). According to Heise, Martins, and Siqueira (2015), performing surgery early “provides a larger time window for nerve regeneration and theoretically would have a better outcome” (p. 805).

A common surgical procedure performed on infants who do not recover spontaneously from NBPP is nerve surgery (Malessy & Pondaag, 2011). Nerve surgery should be done by the time an infant reaches 2 to 3 months of age, especially if the infant has impaired hand function (Malessy & Pondaag, 2011). Without nerve surgery, secondary deformities around the shoulder may develop at an early age due to inadequate primary nerve reconstruction (Terzis & Kokkalis, 2008). For example, an infant may develop subluxation or posterior dislocation of the glenohumeral joint, which can cause

severe functional impairments (Terzis & Kokkalis, 2008). Microsurgery not only improves function but may increase the possibilities for a secondary surgical procedure called a tendon transfer. A tendon transfer is a surgical procedure that moves a working muscle and tendon to replace a non-functional muscle or tendon. It is one of the most common surgical interventions used to treat NBPP (Van Der Holst et al., 2015).

Once the nerve surgery has been performed, the child is monitored medically for two consecutive weeks post operation, then every three months afterwards to ensure proper nerve regeneration (Ma & Chuang, 1998). If a child still does not gain function in the arm and shoulder beyond 12 months of age post nerve surgery, a tendon transfer is recommended. Thus, tendon transfers are specialized to toddlers with NBPP who have not yet gained functional movement of their affected upper extremity after treatments (Ma & Chuang, 1998). Those who develop secondary shoulder dysfunctions may also benefit from a tendon transfer (Terzis & Kokkalis, 2008). Tendon transfers are done through a single posterior incision located slightly posterior to the axilla (Werthel, Wagner, & Elhassan, 2018). The latissimus dorsi and teres major tendons are identified and released, then transferred posteriorly to the long head of the triceps muscle on the rotator cuff as superiorly as possible, which converts the two tendons into external rotators to improve shoulder function (Valleja, Toh, Arai & Harata, 2002).

Studies have shown that tendon transfers of the latissimus dorsi and teres major provide clear, functional, and clinical improvement (Cohen, Rampal, Aubart-Cohen, Seringe, & Wicart, 2010; Bahm et al., 2009). According to Jung-ming, Yu-dong, Xiao-Jun, Shen-yu, and Xin (2012), comprehensive rehabilitation which includes tendon transfer surgery, is more effective in treating dysfunction after brachial plexus injuries

compared to nonintegrated rehabilitation. Tendon transfers of the latissimus dorsi and teres major are considered to be the gold standard and yield satisfactory results (Aydin et al., 2011). According to Water and Bae (2008), patients with brachial plexus palsy who received a tendon transfer showed significant improved global shoulder function and improved Mallet scores from 10 points to 18 points. The Mallet is a functional grading system used to assess five upper extremity positions, including shoulder abduction and external rotation, in children with NBPP on a scale of 1 through 5 (Pearl et al., 2014).

The Active Movement Scale is another measurement tool that is used to quantify upper extremity strength by observing spontaneous, active movement both without and against gravity on an 8-point scale (Curtis, Stephens, Clarke & Andrews, 2002). It is a highly advantageous tool to use with toddlers with NBPP because it allows for easy movements that can be observed in both a natural and clinical setting (Curtis et al., 2002). It can be applied before and after surgery, which can help determine the effectiveness of the tendon transfer and can be used for the entire treatment of a child, which is an ideal tool for documenting the natural course of NBPP (Curtis et al., 2002).

Role of the Occupational Therapist

NBPP inhibits and interferes with a toddler's participation in their meaningful occupations, such as play. Occupational therapists are health care professionals that can work with toddlers to participate in their meaningful occupations. As play is an occupation that is critical and essential to a child's development, it is important to focus on it when their participation is hindered (Anderson-McNamee, 2010). Caregivers are the main source of interaction for children and their play skills. Studies have shown that because of NBPP limitations, parents do not have concrete ideas about their child's

milestones and how to play and interact with their child (Dusing, Van Drew, & Brown, 2012). This can add stress on the caregivers, so it is important for occupational therapists to consider the stress load that NBPP can cause (Louden et al., 2015). Regarding NBPP and its implications, occupational therapists can provide empathy, education, and strategies to families (Ho & Ulster, 2011). For example, occupational therapists can provide home programs that include modifications and adaptations for the child to utilize to engage in meaningful occupations (Craig, Carroll, Ludwig, & Sturdivant, 2018). Singh and Kolamala (2015) found that providing parents detailed information on how to handle and take care of their child enhances the child's recovery.

A study that evaluated the effectiveness of an education day held at a brachial plexus clinic highlighted the importance of the relationship between the families and occupational therapists (Ho & Ulster, 2011). McLean, Harvey and Mutimer (2015) found that parents are concerned about their child's disability and factors of their medical care, such as surgery and treatment. Parents were also concerned about their child's physical appearance, as well as potential isolation from social settings (Chang et. al, 2017). The creations of parent education materials are an unmet need that should be addressed, as parents are key in the treatment of brachial plexus injuries (Tanta et al., 2012). According to Zhou, Gu, Xu, Zhang, and Zhao (2012), comprehensive rehabilitation, such as occupational therapy, was more effective in treating dysfunction after brachial plexus injury compared to nonintegrated rehabilitation. Therefore having professional guidance can help ease stress by educating parents on proper care and information.

Splinting

Splinting is a common post-operative care technique that is used to immobilize a surgical site to prevent tension and decrease contractures (Giele, 2009). Splinting can help facilitate proper movement and promote the healing process (Ramos & Zell, 2000). Depending on the type of therapy, parents are typically educated on a splinting protocol that provides information on how to care for a child with a splint. One splint design, known as the Statue of Liberty splint, keeps the elbow flexed at a 90-degree angle with the shoulder abducted and externally rotated (Giele, 2009). The structure of the splint can be uncomfortable, which has been found to influence the attitudes towards the splint by both the child and the parent (Daftary & Jywant, 2012). As uncomfortable as the Statue of Liberty splint may be, compliance is a key part to a child's progress when wearing the splint (Ho et al., 2009). Splints can be personalized by using different patterns and colors to decorate the material that the splint is made out of in order to increase compliance. Erel et al. (2008) found that after customization and education on its use, all patients were compliant with the splint and benefited from its adjustability.

NBPP is an injury caused by traumatic stretching of the brachial plexus during the delivery of an infant. This injury decreases shoulder and arm function in toddlers, which ultimately interferes with their main occupation of play. According to health care professionals and evidence-based practice, the most common and effective surgical treatment used to treat NBPP is a tendon transfer surgery releasing the latissimus dorsi and teres major to facilitate shoulder external rotation. Post-surgery, one of the main protocols of procedure involves the toddler wearing a Statue of Liberty splint, which has shown a significant increase in shoulder function and mobility. As parents play a key role

in their child's development and treatment of NBPP, it is important to provide education and resources to help ease their stress. However, the gap in the resources that are available for caregivers with children of NBPP proves that there is a need to create more educational resources.

Statement of Purpose

Through the conducted evidence-based research and interviews with health care professionals that work with toddlers with NBPP, we found a need for educational resources on post tendon surgery expectations and care. This project targeted parents and caretakers of toddlers with NBPP who will undergo tendon transfer surgeries, as they are the primary caretakers and play a key role in the recovery and treatment of NBPP. The purpose of this thesis project was to create a handout driven by parents and clinical expertise that will educate parents of toddlers with NBPP injuries on post-operative care for tendon transfer surgeries.

Hypothesis

The anticipated outcome for this research project was the creation of a handout that will educate parents and caretakers of toddlers with NBPP on proper care post tendon transfer surgery. Our ultimate goal is to increase confidence and handling skills in parents and caretakers of these toddlers post tendon transfer, as well as providing strategies to promote functional skills during the process of healing and recovery post-surgery.

Theoretical Framework

We used the Person, Environment, and Occupation (PEO) model for this thesis project. This model has three main components: person, environment, and occupation (Brown, 2014). The first component, person, is focused on the person's abilities and

experiences (Brown, 2014). The second component, environment, is focused on the client's physical, social and cultural environment (Brown, 2014). The third component, occupations, are intrinsic, meaningful and purposeful activities (Brown, 2014). The relationship between these three components are transactional and can facilitate or inhibit occupational performance (Brown, 2014).

According to Brown (2014), these three components are constantly changing, and as these factors change, so does occupational performance. Occupational therapy practice uses a top-down approach that identifies what occupations the person engages in (Brown, 2014). This is followed by an assessment that targets the barriers and facilitators within the person, environment, and occupation that affect occupational performance (Brown, 2014). Our thesis project was focused on helping families who are facing challenges in these three components. Our goal was to assist parents to increase their confidence when caring for their child post operation. Impairments like brachial plexus injuries can inhibit a child's interaction with self, environment, and occupations. These kinds of barriers then limit their occupational performance in their meaningful activities.

For our thesis project we designed an educational handout, the content of which was shaped by the input of parents and clinical expertise to educate parents with children with NBPP on post tendon transfer care. It is crucial that parents of children with NBPP are well informed about the splint, the difficulties that they may experience with it, and corresponding handling skills. The PEO is relevant and foundational to our thesis project because NBPP limits the toddler to participate in meaningful activities and occupations post-surgery utilizing the affected arm. This ultimately affects how both the child and parent interact with their environment.

Coaching and Consultation Model

The coaching and consultation model is a theory-based conceptual model. The coaching aspect of this model is a reciprocal process between the healthcare professional and recipient (Case-Smith, 2015). The healthcare professional, or in this case the occupational therapist, addresses the goals of the parent and child and how they can analyze and solve the problem (Case-Smith, 2015). This model recognizes that when clients are informed and make their own decisions regarding their child, they are more inclined to participate and comply (Case-Smith, 2015). The occupational therapist in this model suggests adaptations and modifications of the client's environment to help clients reach their goal and desired outcome (Case-Smith, 2015).

The core principles of the coaching and consultation model include using open ended questions, guiding parents on the problem, analyzing the problem, suggesting adaptations or modifications, identifying the parents' role, and discussing potential outcomes (Case-Smith, 2015). Our thesis project referred to these core principles as a guide to interview parents and create an educational handout. This model stresses the importance of educating parents on what to expect in addition to adaptations and modifications that can be made post-surgery. The parent and health care professionals discuss the triumphs and obstacles, check perceptions, and analyze various strategies (Case-Smith, 2015). The coaching and consultation model is a strength-based and family-centered approach that is focused on building self-efficacy and self-determination in families and children (Case-Smith, 2015).

Methodology

The target population of this project was parents and caretakers of toddlers with NBPP that are in need of tendon transfer surgeries. Due to the lack of knowledge and resources regarding proper care for post rehab care of tendon transfer surgeries, it was determined that this population would benefit from supportive resources.

Our team conducted a literature review to further understand the nature of NBPP and how it affects the daily lives of toddlers and their families. Through this review, we found a gap in the research that determined the lack of educational resources, which led to the creation of this thesis project. We also completed a needs assessment by interviewing Dr. Leis, support therapists, and parents of toddlers with NBPP who have undergone tendon transfer surgery at Children's Hospital of Orange County (CHOC) via email and by phone. The interview process with families who have already undergone a tendon transfer surgery included a questionnaire (Appendix A) to gain a family-centered care perspective that will determine areas of importance that will be most beneficial for families in developing the educational handout. These questionnaires aimed to find which obstacles parents have encountered during post-care, and any modifications that would be beneficial, as well as demographic information. The data gathered from the questionnaire revealed a common theme of challenges and successes. These main obstacles formed the core information in creating the handout to help future families navigate post-operative expectations.

One of the advantages of this methodology is that it was built upon personal experiences and situations to create the brachial plexus postsurgical rehab educational handout. Through this educational piece, the goal was to increase knowledge of post-

operative care. In addition to a one on one meeting with the occupational therapist and surgeon, the handout will be another way to facilitate discussion and education to parents to increase their knowledge. Singh and Kolamala (2015) found that providing parents detailed information on how to handle and take care of their child enhances the child's recovery.

Through the use of interviews with the parents/caregivers, determining how brachial plexus injuries impact families provides more information on how resources may help and educate future families in order to best meet their clinical and social needs (Louden et al., 2015). This ultimately gives future parents the confidence and skills to be able to care for their child post tendon transfer surgery. Feeling empowered with knowledge can help them feel supported knowing that other families have gone through similar experiences (Ho & Ulster, 2011). Sharing other's experiences can hopefully create a family-to-family support that will help others find a common ground that can help provide a sense of comfort or camaraderie in knowing they are not alone (Louden et al., 2015).

Limitations

One of the limitations of the project is that there is only one target population, which are the patients at CHOC. This narrows the scope of experiences and evidence. Due to only a few families at CHOC having undergone tendon transfer surgery, another limitation for this project is a small sample size. There is no conflict of interest with any parties involved in this project.

In addition, due to unforeseen circumstances, pre- and post-surveys were unable to be conducted. Therefore, the effectiveness of the educational handout was not thoroughly evaluated.

Ethical and Legal Considerations

Vicky Vu, our thesis advisor, introduced our project to prospective families explaining our purpose and objectives with a use of a flyer (see Appendix B). Prior to participant interaction, participating families and caregivers from CHOC received an email explaining our purpose and objectives, along with consent forms provided by Stanbridge University (see Appendix C) and CHOC (see Appendix D) made with Microsoft Forms. In addition, a photo consent release form was given (see Appendix E). Once in contact with participating families, participants were able to contact us through our secured Stanbridge email for any further explanations and questions of the materials provided. Participants had the freedom to consult with anyone involved with the thesis project. Once consent forms were received, they were locked and stored in the locked Institutional Review Board (IRB) cabinet at Stanbridge University's MSOT office. Any information received in the interview, whether completed over email or by phone, will be kept either anonymous or confidential. Only the research team will have access to both raw and computerized data. Raw data is stored in the locked IRB cabinet in the MSOT office on Stanbridge University's campus. Computerized data is stored on a password-encrypted memory card and will be destroyed after the completion of this project.

Outcomes

Between 2013 and 2019, seven families had undergone a tendon transfer surgery at CHOC. Families received a flyer that informed them of the study and five families

agreed to participate. As part of the interview process, data on the demographics of the participating families were collected. The two main demographics collected were gender of the toddler and the ethnicity of the parents. Amongst the five families that were interviewed, four toddlers were female, and one toddler was male (see Appendix F, Figure 1). In addition, it was reported that three parents identified as Latino/Hispanic, one parent as Asian, and one parent as White/Caucasian (see Appendix F, Figure 2).

Through the process of interviewing families that have undergone a tendon transfer, common themes were found in their responses. These common themes have been divided into three main categories: modifications, support, and therapy (see Appendix G, Figure 3). Although these themes overlapped and were prevalent in each family, some shared more concerns in certain areas than others. For example, all five families stressed the importance of modifications while only two families emphasized the importance of therapy. These three themes were considered when creating and finalizing the educational handout given to parents of toddlers with NBPP (see Appendix H).

Theme 1: Modifications

A major theme that parents identified was modifications. Due to the nature of the splint and the amount of time that a splint is needed to be worn, parents had difficulty with activities of daily living, instrumental activities of daily living, and play. Some major modifications that parents came across included changing their strategies on dressing, bathing, and playing, as well as changing their car seats in order to accommodate for the splint. For example, most car seats for younger children are made with a high back with “wings” along the edge of the back that keeps the child secure in their car seat. However, with a Statue of Liberty splint, a typical car seat limits the child

from being able to hold their arm in the appropriate position. A modification that could be made in regard to car seats would be to use a seat with a lower back. This would allow the child to sit comfortably in the car seat with their splint. When bathing, the Statue of Liberty splint must be taken off in order to properly clean all extremities of the child. The affected arm must be held in place in order to protect the area of surgery and continue to promote healing. In addition, the caretaker needs to consider play activities that keep the splinted arm in place and prevent potential harm to the surgical site. For example, going to the playground to swing or activities that involve sitting may be a safe alternative to engage the child in play.

Theme 2: Support

Another theme that parents identified was the need for support. As a tendon transfer is a major surgery, many parents described being hesitant and worried about the surgery. One concern that was identified by a mother was her fear of her child being put under anesthesia at such a young age. Parents expressed that if they were to speak to other parents who had already experienced a tendon transfer surgery, they would feel more comfortable and validated in their decision to receive treatment. Through the support and encouragement from other parents, doctors, and therapists, future parents and toddlers who will undergo surgery will feel more at ease.

Theme 3: Therapy

The final theme reported by parents was the importance of therapy. Although only two parents expressed the advantages of therapy, it was found that therapy was beneficial to all of the participating toddlers. One mother included that as challenging as it can be, being patient is key and positive results will come from it. Families participated in a

variety of therapies throughout their child's recovery process, such as aqua therapy. Aqua therapy is done in water in order to reduce the effects of gravity while increasing joint flexibility, range of motion and strength. CHOC provides a post-operative protocol that parents are advised to follow after surgery. This protocol includes splint wearing schedule and a timeline for therapy services.

Conclusion

From this study, the three themes that were identified by the parents were modifications, support, and therapy. Although the parents shared other concerns, these three themes were found to be the most impactful in their daily life. Educational pieces, such as a handout, can play a crucial role in preparing parents and caregivers on how to care for their toddlers with NBPP. Past experiences from families who have already undergone surgery and clinical expertise from healthcare professionals helped to identify the caring needs and expectations that NBPP presents. Specifically with occupational therapy, this research project aimed to address the influence that NBPP permits on one's participation in their meaningful occupations. We hope that this educational handout can help support and direct parents and caregivers on how to care for their children with NBPP. Though well reviewed, the effectiveness of the handout was not thoroughly evaluated due to unforeseen circumstances. Future research and projects can expand on the effectiveness of the handout by conducting pre- and post-surveys. Another suggestion that may aid the expansion of resources is to create an educational video that focuses on each major theme. For example, a video could address how to modify a car seat for a child wearing the Statue of Liberty splint. Through creating these informational tools, we

hope to increase the efficacy of treatments after tendon transfer surgery for all families and toddlers experiencing NBPP.

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Appendix A

Tendon Transfer Questionnaire

Tendon Transfer Questionnaire

Questions for families that have gone through the process of a tendon transfer surgery

Hi nbpp, when you submit this form, the owner will be able to see your name and email address.

* Required

1. Is English your primary language? *

Yes

No

2. If English is not your primary language, then what is your primary language?

Enter your answer

3. What ethnicity do you identify as? Please select all that apply. *

White/Caucasian

Latino/Hispanic

Asian

Black

Other

4. What is the gender of your child who underwent a tendon transfer surgery? *

Female

Male

Other

5. When did your child receive surgery? *

Enter your answer

6. Before surgery, did you feel that you had a good understanding of your expectation with caring for your child after surgery? *

Enter your answer

7. What obstacles did you face in caring for your child while wearing the splint (post-surgery)? *

Enter your answer

8. Where there any specific modifications (car seat modifications, stroller, etc.) did you need to make post-surgery? *

Enter your answer

8. Where there any specific modifications (car seat modifications, stroller, etc.) did you need to make post-surgery? *

Enter your answer

9. What would you have liked to have known before your child had surgery? *

Enter your answer

10. Do you have any recommendations regarding information that would be beneficial to families with a child who will undergo tendon transfer surgery in the future? *

Enter your answer

Submit

Appendix B

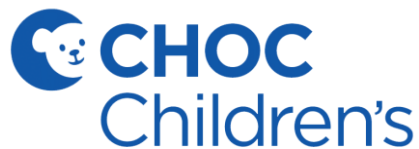
Flyer

We need you!

TO HELP US UNDERSTAND YOUR FAMILY'S
NEEDS AFTER SURGERY FOR A
BRACHIAL PLEXUS INJURY.

Occupational Therapy Graduate Students from
Stanbridge University are teaming up with CHOC
Brachial Plexus Clinic to create an educational video
that addresses post-tendon transfer care..

To participate contact us at NBPP@my.stanbridge.edu
by 9/13/19.

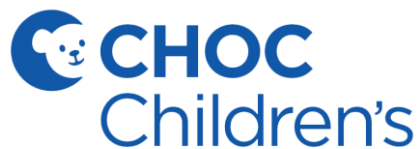


¡Necesitamos su ayuda!

EN MEJORAR NUESTRO CONOCIMIENTO DE LAS
NECESIDADES DE SU FAMILIA SOBRE LESIONES
SOSTENIDAS EN
EL PLEXUS BRAQUIAL.

Estudiantes graduados de terapia ocupacional de la
Universidad de Stanbridge están en colaboración con la
clínica de CHOC Brachial Plexus para crear un video
educativo sobre el proceso de cuidado, después de una
transferencia de tendón.

Para participar contáctenos al correo electrónico
NBPP@stanbridge.edu antes de 9/13/19



Appendix C

Stanbridge Questionnaire Consent Form

Questionnaire Consent Form

You are invited to participate in a research study that aims to increase knowledge about post-operative care for tendon transfer surgeries through the creation and use of an educational pamphlet. You will be asked to participate in a questionnaire regarding your experience of your child who has undergone tendon transfer surgery. Only the research advisor and students will have access to your responses. All responses will remain anonymous.

Time involvement: Your participation in the survey will take approximately 10 minutes.

Risk and benefits: We cannot and do not guarantee any benefits to you and your child from this study.

There is no payment for participation in this study. Participation is voluntary.

If you have read and signed this form you are allowing us to present any information collected from the questionnaire, including your demographics, and questionnaire responses, to be included in this study. Your participation in this study is voluntary and you have the right to withdraw at any point or time without penalty. You have the right to refuse to answer any specific questions.

If you have any questions, concerns, or complaints about this study you may contact the Faculty Advisor, Vicky Vu; 714-292-2731; vvu@my.stanbridge.edu.

Independent contact: If you are in some way dissatisfied with this research and how it is conducted, you may contact the Stanbridge University Vice President of Instruction at VP.instruction@stanbridge.edu

1. Do you consent to the use of your answers in our educational pamphlet? *

Yes

No

2. By typing your name below, you are consenting to participate in our study. *

Enter your answer

Appendix D

CHOC Consent Form



PATIENT CONSENT TO PHOTOGRAPH AND AUTHORIZATION FOR USE OR DISCLOSURE

Patient's Name: _____ Patient's Date of Birth: _____

Patient's Medical Record Number (if known): _____

CONSENT TO PHOTOGRAPH AUTHORIZATION FOR USE OR DISCLOSURE

I hereby consent to myself/my child being photographed while at the hospital. The term "photograph" includes video, still photography, and sound transmission, in digital or any other format, and any other means of recording or reproducing images and/or audio. I hereby authorize the use of the photograph(s) by, or disclosure of the photograph(s) to:

- Children's Hospital of Orange County and its affiliates ("CHOC Children's")
- Any and all entities including, without limitation, the newspaper, television, radio, internet, and brochures, even if not specifically associated with CHOC marketing.
- Other (complete information): _____

(Persons/Organizations authorized to receive information)

INITIAL In addition to the use and disclosure of photographs mentioned above, my initials hereby authorize CHOC Children's to use and disclose information, including diagnosis, physician's name, medical history, treatment, and demographic information to the Person(s) /Organization(s) mentioned above.

PURPOSE

I hereby authorize the use or disclosure of the photograph(s) for all purposes including marketing/public relations, fundraising, news media, research, education, and my treatment, unless specified below.

- I DO NOT authorize the following uses:

EXPIRATION

This Authorization expires only upon revocation.

SIGNATURE

Date: _____ Time: _____ AM / PM

Signature: _____
(patient/representative/spouse/financially responsible party)

Print Name: _____
(patient/representative/spouse/financially responsible party)

If signed by someone other than patient, indicate relationship to the patient: _____



CONSENTIMIENTO DEL PACIENTE PARA SER FOTOGRAFIADO Y PARA AUTORIZAR EL USO O LA DIVULGACIÓN DE FOTOGRAFÍAS

Nombre del paciente: _____ Fecha de nacimiento del paciente: _____

Número de expediente médico del paciente (si se conoce): _____

CONSENTIMIENTO PARA FOTOGRAFIAR \ AUTORIZACIÓN PARA SU USO O DIVULGACIÓN

Por la presente consiento a que yo/ mi hijo sea fotografiado mientras esté en el hospital. El término "fotografía" incluye video, fotografía fija y transmisión del sonido, en formato digital o cualquier otro y cualquier otro medio de grabación o reproducción de imágenes o audio. Por la presente autorizo el uso de la (s) fotografía (s) por, o la divulgación de la (s) fotografía (s) para:

- Children's Hospital of Orange County y sus afiliados ("CHOC Children's")
- Cualquier y todas las entidades incluyendo, sin limitación, el periódico, la televisión, radio, internet y folletos, incluso si no están asociados específicamente con el departamento de mercadotecnia de CHOC.
- Otro (complete la información): _____

(Personas/ Organizaciones autorizadas a recibir información)

_____ **INICIALES** Además del uso y divulgación de las fotografías mencionadas, mis iniciales autorizan a CHOC Children's a usar y divulgar información, incluyendo diagnóstico, nombre del médico, historial médico, tratamiento e información demográfica a la (s) Persona (s) /Organización (es) mencionada anteriormente.

PROPÓSITO

Por la presente autorizo el uso o la divulgación de la (s) fotografía (s) para todos los propósitos incluyendo mercadotecnia/relaciones públicas, recaudación de fondos, los medios de comunicación, investigación, educación y mi tratamiento, a menos que se especifique debajo.

- NO autorizo los siguientes usos:

VENCIMIENTO

Esta autorización vence solamente si se revoca.

FIRMA

Fecha: _____ Hora: _____ AM / PM

Firma: _____

(paciente/representante/cónyuge/parte económicamente responsable)

Nombre en letra de imprenta: _____

(paciente/representante/cónyuge/ parte económicamente responsable)

Si este documento es firmado por alguien que no sea el paciente, indique la relación con el paciente: _____

Appendix E

Photo Release Consent Form

Picture Release Form

Without expectation of compensation or other remuneration, now or in the future, I hereby give my consent to Ellie McLeod, Abby Haboosheh, Megan Seo, Courtney Ong, their affiliates and agents, to use my photograph in their pamphlet, publications, academic papers, and other media activities (including the Internet).

This consent is given in perpetuity and does not require prior approval by me.

* Required

1. By typing your name below, you are releasing your photograph(s) for use in our pamphlet, publications, academic paper, and other media activities (including the Internet). *

Appendix F
Demographic Data

Gender

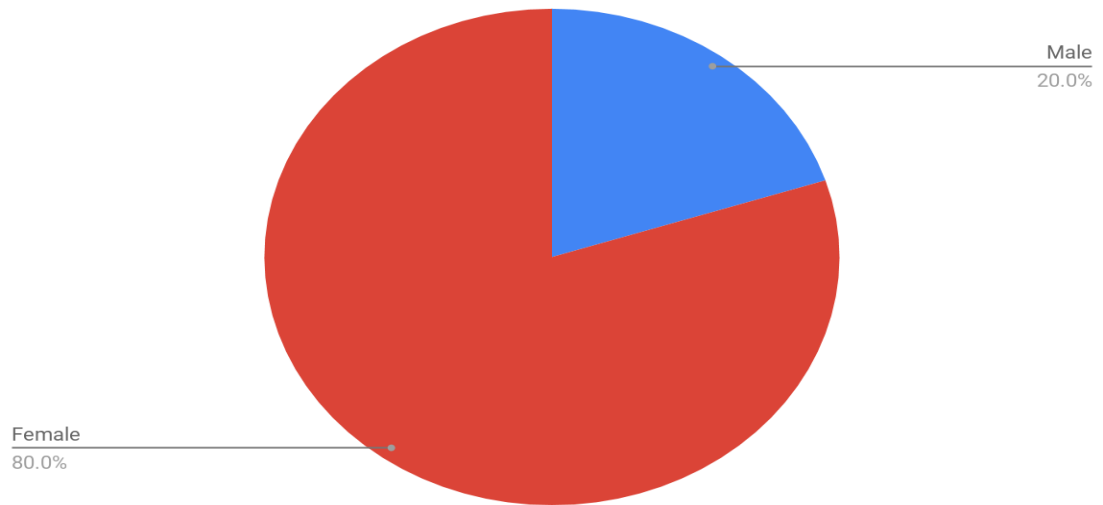


Figure 1. Gender of Toddlers Who Have Undergone Tendon Transfer Surgery.

Ethnicity

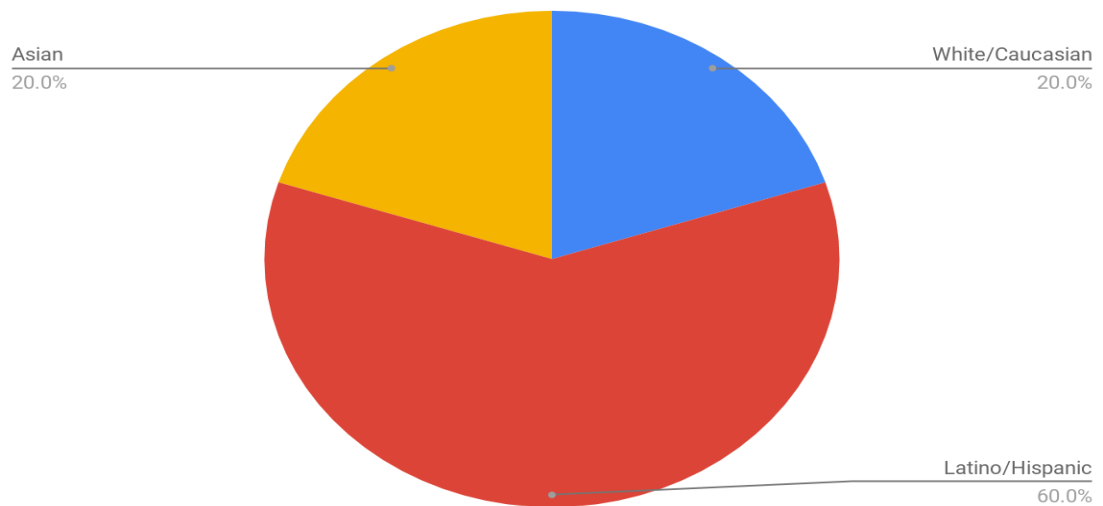


Figure 2. Ethnicities That the Parents of the Toddlers Identified With.

Appendix G

Themes Data

Themes

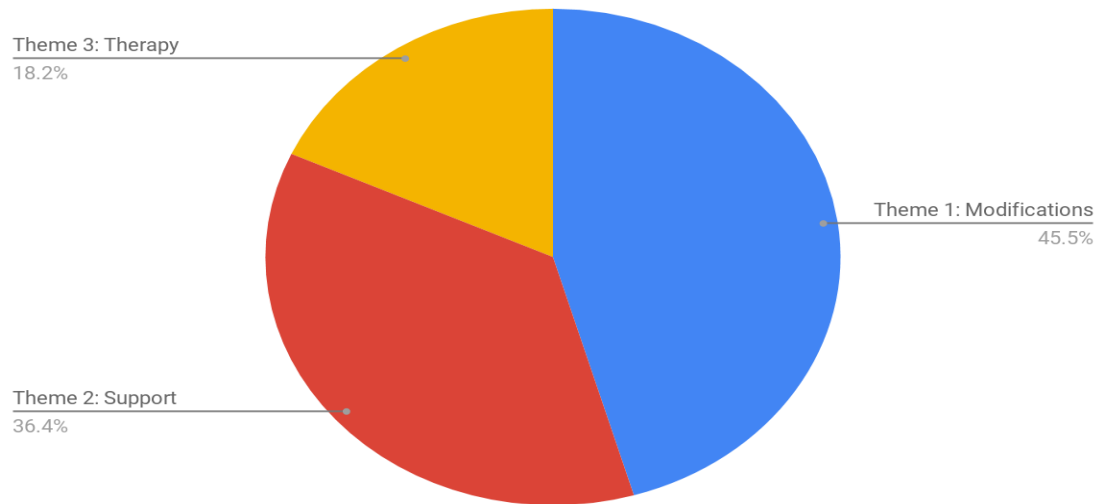


Figure 3. Common Themes That Were Found in the Interviews.

Appendix H

Educational Handout

POST SURGICAL TENDON TRANSFER CARE



WHAT IS A TENDON TRANSFER?

- It is a surgery that moves a working muscle and tendon to replace a non-working muscle/tendon.

STATUE OF LIBERTY

- To help with healing and proper movement, your child will be receiving a Statue of Liberty brace.
- The Statue of Liberty brace is placed immediately after surgery. It keeps the elbow bent at a 90 degree angle and placed at shoulder level.

WHAT TYPE OF THERAPY WILL MY CHILD RECEIVE?

- Physical therapy
 - Physical therapists will help with aqua therapy after the first 3 months.
 - Focus on increasing shoulder range of motion, strength, and mobility.
- Occupational therapy
 - Focus on activities that strengthen the shoulder.

WHAT TO EXPECT

- Brace must be worn at all times for the first 3 months.
- After the 3 months, the brace only needs to be worn while sleeping, for up to 1 year.
- Visit an orthotist for brace fitting immediately before surgery.
- Your doctor and team at the brachial plexus clinic will answer any questions you might have.



THINGS TO CONSIDER

- Car seats
 - Consider a lower back that can accommodate for a brace.
- Bathing/Dressing
 - Have an extra friend to hold arm in place while bathing to protect area of surgery.
- Play
 - Kick a ball
 - Playground
 - Swings
 - Bat and ball (with non-involved arm)
 - Riding a tricycle
 - Follow protocol from BP clinic

CONTACT US

CHOC Children's Rehabilitation Services
Brachial Plexus Program
(714) 509-4220
choc.org/programs-services/rehabilitation/



Institutional Review Board Approval

Dear Ms. Vu,

The IRB has reviewed and approved your modification request for application #01937.

IRB Application Number	01937
Date	05/11/2020
Level of Review	Full Board
Application Approved	X (Approved 07/2019)
Conditional Approval	
Disapproved	
Modification	X (Approved 05/11/2020)
Signature of IRB Chair	

Sincerely,

Dominique N. Wascher, Ph.D.
IRB Chair