TOWARD A CLASSIFICATION OF NEONATAL BRACHIAL PLEXUS PALSY INTERVENTION

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ABSTRACT

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This dissertation resulted in a taxonomy-driven classification defining the process of care for patients with neonatal brachial plexus palsy (NBPP) using practice-based evidence (PBE) methodology. The comprehensive taxonomy-driven classification categorized and defined patient characteristics, evaluations, and interventions for patients with NBPP. This dissertation was comprised of three interrelated studies. Based on a retrospective medical record review, study one identified patient characteristics, evaluations, and interventions documented by an interdisciplinary team treating patients with NBPP in a pediatric, orthopedic hospital as a first step toward developing the taxonomy-driven classification. Study one resulted in comprehensive categories of patient characteristics, types of imaging used, and surgical interventions. Study two completed the taxonomy-driven classification by further categorizing and defining evaluation guidelines and therapeutic interventions for patients with NBPP. Study two also developed documentation, based on the classification, for systematic data collection. Study three identified the taxonomy-driven classification as a feasible and reliable method to document the process of care for patients with NBPP in a pediatric, orthopedic hospital setting.

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CHAPTER I

INTRODUCTION: STATEMENT OF THE PROBLEM AND SPECIFIC AIMS

Neonatal brachial plexus palsy (NBPP) is an injury to the brachial plexus, nerves in the upper part of the neck and shoulder, which occurs in 1-2 cases per 1000 live births before or during the birth process (Foad, Mehlman, & Ying, 2008). The injuries to the nerves range from mild with spontaneous recovery to more severe resulting in permanent impairment of the child's upper extremity. Physicians often prescribe occupational therapy (OT) and physical therapy (PT) for patients with NBPP as a form of conservative management and post-operatively to achieve optimal recovery. However, the literature reveals limited and inconsistent findings on therapy interventions for NBPP (Bialocerkowski, Kurlowicz, Vladusic, & Grimmer, 2005). In addition, the literature does not include a comprehensive taxonomy-driven classification of the components of the process of care used to treat patients with NBPP leaving a need to develop a classification. A classification will bring order and rigor to the overall process of care, including therapy intervention, and allow therapists to comprehensively research the effectiveness of therapy intervention for patients with NBPP. Without evidence to support the effectiveness of therapy, patients may not receive optimal care and third party payers may decrease reimbursement or deny therapy services.

The research team aimed to use practice-based evidence (PBE) methodology to develop a taxonomy-driven classification to categorize and define the process of care including patient characteristics, assessment, and intervention for patients with NBPP, and develop documentation based on the classification to identify the active ingredients, or the key surgical and therapeutic interventions, that yield optimal outcomes for patients with NBPP.

Aim of Study 1: Establish an interdisciplinary team and identify patient characteristics, assessments, and interventions documented by an interdisciplinary team treating patients with NBPP as a first step toward developing the taxonomy-driven classification.

Aim of Study 2: Complete the taxonomy-driven classification by creating evaluation guidelines and further delineating therapeutic interventions for patients with NBPP. Develop documentation based on the classification to systematically capture collected data.

Aim of Study 3: Determine the feasibility and reliability of implementing the taxonomy-driven classification into clinical practice

CHAPTER II

BACKGROUND AND SIGNIFICANCE

Literature Review

Literature on rehabilitation therapy frequently refers to therapy intervention as a "black box" due to the lack of detail describing its specific components (Ballinger, Ashburn, Low, & Roderick, 1999; Bode, Heinemann, Semik, & Mallinson, 2004; Conroy, Hatfield, & Nichols, 2005; Dejong, Horn, Gassaway, Slavin, & Dijkers, 2004; DeJong, Horn, Conroy, Nichols, & Healton, 2005). Instead of research studies describing the process or components of therapy, they often group therapy intervention into a package described as "typical" treatment or use time as a descriptor of therapy intensity. The outcomes of research studies investigating the relationship between intensity, or time of therapy intervention, and functional outcomes show weak correlations (Bode et al., 2004; Chen, Heinemann, Granger, & Linn, 2002; Heinemann, Hamilton, Linacre, Wright, & Granger, 1995). Researchers and clinicians need more information on the process of therapy intervention to fully understand the relationship between therapy intervention and outcomes. The lack of research studies examining the comprehensive process of therapy and its individual components leaves therapists with minimal evidence supporting the effectiveness of practice, and limited evidence to guide practice results in variations in the cost and quality of healthcare services between clinicians and geographic regions (Horn, DeJong, Ryser, Veazie, & Teraoka, 2005). Lack of sufficient evidence to support the effectiveness of therapy interventions may also lead to decreased reimbursement or denial of therapy services by third party payers.

There is a need to "disassemble the black box" and create classifications that bring order and rigor to the description of therapy intervention (Dejong, Horn, Gassaway, Slavin, & Dijkers, 2004, p.678).

Classifications provide a common nomenclature to describe elements of therapy intervention and mechanisms to quantify therapy intervention. This gives therapists a way to clearly communicate about

intervention and researchers the ability to assess the effectiveness of the therapy process. Ultimately, the development of therapy classifications will allow therapists to identify the most cost effective and efficient therapy that produces the best outcomes. The adult post-acute care setting exhibits a growing interest in developing classifications to define intervention for diagnoses including stroke, spinal cord injury, and joint replacement (Dejong, Horn, Gassaway, Slavin, & Dijkers, 2004; DeJong et al., 2009; Gassaway et al., 2005; Gassaway, Whiteneck, & Dijkers, 2009; G. Whiteneck, Dijkers, Gassaway, & Lammertse, 2009). Researchers and therapists also need to develop classifications to define intervention for pediatric diagnoses.

Therapy Classification Projects

Three major classification projects include the Post Stroke Rehabilitation Outcomes Project (PSROP), the SCI Rehab Project, and Joint replacement Outcomes in Inpatient rehabilitation facilities and Nursing Treatment Sites (JOINTS). PSROP was a large multicenter stroke rehabilitation study including seven centers with nearly 1400 stroke rehabilitation patients from 2001 to 2003 (Dejong, Horn, Gassaway, Slavin, & Dijkers, 2004; DeJong et al., 2005). The project developed classifications for OT, PT, and speech language pathology for therapists working with stroke patients. The research described the duration, intensity, and components of treatment regimens, and identified treatment practices associated with better outcomes for patients with various levels of impairment following a stroke (Gassaway et al., 2005).

The SCI Rehab project is an ongoing multicenter study including six inpatient rehabilitation facilities with 1500 patients with traumatic spinal cord injury. The project developed classification systems for PT, OT, therapeutic recreation, speech language pathology, psychology, nursing, and social work (Abeyta et al., 2009; Cahow et al., 2009; Gordan et al., 2009; Johnson et al., 2009; Natale et al., 2009; Ozelie et al., 2009; Wilson et al., 2009). The project also identified a process and technology to successfully capture the level of detail defined in the classifications. The SCI Rehab project continues to collect data to determine patient outcomes including neurologic recovery, functional independence, discharge to home, medical

complications and rehospitalizations, return to productive activity, extent of societal participation, and perceived quality of life (G. Whiteneck, Gassaway, Dijkers, & Jha, 2009).

JOINTS was a multisite study including 22 facilities and 2,158 patients with knee or hip replacements. JOINTS identified a range of PT and OT interventions for patients with joint replacements (DeJong et al., 2009). The data collected from the study identified the differences between OT and PT intervention intensity and activities in an inpatient rehabilitation facility versus a freestanding skilled nursing facility. Reported limitations in the literature included not capturing physician or nursing contributions, not establishing inter-rater reliability with the data collection process and difficulty with identifying the amount of time spent on each intervention type. The three projects reviewed provide instrumental examples of using PBE to analyze the effectiveness of therapy interventions. They begin to disassemble the "black box" of therapy intervention for patients status post stroke, spinal cord injury, and joint replacements. However, a need exists to improve the process and develop classifications for additional patient populations.

Neonatal Brachial Plexus Palsy

A non-systematic literature review was completed in February 2011 using CINAHL and Medline databases on therapy intervention and NBPP including articles from 1990-2011. The search yielded 110 articles. Key words included "brachial plexus palsy", "therapy", "participation", "assessment", and "epidemiology". Articles were excluded if they primarily focused on surgical intervention or traumatic brachial plexus injuries leaving 46 articles for further review.

The 46 articles reviewed consisted of 19 commentaries, 9 articles focused on assessment, 1 qualitative study, 1 systematic review, and 16 quantitative studies including case studies, surveys, retrospective chart reviews, and analysis of prospective databases. Therapy activities identified in the literature included range of motion, splinting, kinesiotaping, constraint induced therapy, electrical stimulation, and functional activities (Bialocerkowski et al., 2005; Buesch et al., 2010; Ho, Roy, Stephens, & Clarke, 2010; Lagerkvist, Johansson, Johansson, Bager, & Uvebrant, 2010; Partridge & Edwards, 2004; Smith, Rowan, Benson,

Ezaki, & Carter, 2004; Strömbeck & Fernell, 2003; Yasukawa & Cassar, 2009). Out of the 16 quantitative studies, only 4 prospective studies investigated the effectiveness of specific therapy interventions including 3 case studies, each with 2 participants. The 4th study included 16 participants, 8 in a control group and 8 in the experimental group.

This non-systematic literature review may embody biases due to the methods used to complete the literature review. However, out of the 110 articles reviewed, the most rigorous study assessing the effectiveness of therapy intervention contained 16 patients demonstrating the difficulties associated with participant recruitment and prospective research. These findings demand a different approach to comprehensively research the effectiveness of therapy intervention provided for patients with NBPP.

Neonatal Brachial Plexus Palsy: Need for Classification

As indicated, research on therapy intervention for infants and children with NBPP mostly consists of commentaries and case studies. The literature presents a variety of treatment options without sufficient data or rigor in the research design to definitively support or refute the effectiveness of the intervention. The abundant amount of literature classifying therapy as a "black box" combined with a lack of literature supporting therapeutic intervention for patients with NBPP substantiates the need to develop a taxonomy-driven classification. The classification will define the process of care, including therapy intervention and therapists' actions, allowing researchers to comprehensively investigate the components of therapeutic intervention for patients with NBPP.

Practice-Based Evidence Methodology

Therapists need evidence supporting the effectiveness of therapy interventions for patients with NBPP. However, lack of data combined with expense, time, and the limited amount of variables tested at one time negates the usefulness of randomized controlled trials (RCT) to meet this need (DeJong et al., 2005). To maximize the effectiveness of RCTs researchers first need to study the key elements of therapy for patients with NBPP on a broader scale. One solution is to use a PBE approach, a form of observational and participatory action research. PBE methodology harnesses the complexity of patient and treatment

differences in the actual practice of care by examining what happens in the care process, without altering the treatment regimen to evaluate the efficacy of a particular intervention (G. Whiteneck, Gassaway, Dijkers, & Jha, 2009). PBE methodology captures in-depth, comprehensive information about patient characteristics, processes of care, and outcomes (Horn & Gassaway, 2007).

PBE goes beyond observational based research by controlling for patient characteristics and creating a taxonomy-driven classification developed by clinicians defining the process of care to identify the key components of effective intervention (Gassaway et al., 2005).

The complete PBE method includes seven rigorous steps: (1) establish a multisite, transdisciplinary clinical practice team to (1a) define key patient characteristics presumed to affect outcomes and/or effectiveness of therapies, (1b) identify and define individual components of each discipline's care process, (1c) create discipline specific documentation tools, (1d) incorporate documentation into routine facility practices, (2) use the Comprehensive Severity Index (CSI) to control for differences in patient severity of illness, (3) implement an intensive data collection protocol that captures data on patient characteristics, care processes, and outcomes, (4) create a study database suitable for statistical analyses, (5) successively test hypotheses based on questions that motivated the study originally, (6) implement and evaluate findings from step 5 to determine whether the new or modified interventions replicate results identified in earlier phases, and (7) incorporate validated study findings into standard practice of care (Horn & Gassaway, 2007). This dissertation encompassed step one of PBE methodology followed by a summative analysis of feasibility and reliability of the evaluation guidelines and data collection process, developed and implemented as part of the study. The findings from the analysis determined that the classification reached sufficient articulation for progression into the next steps of PBE methods. Long term, this research aims to provide meaningful and responsive data to answer the following broad research questions.

Overarching Research Questions:

1. How do patient characteristics explain variations in outcomes?

2. Controlling for patient characteristics, which surgical and therapeutic interventions correlate with optimal outcomes?

Limitations

This dissertation included three studies setting a foundation to answer the above questions. However, this dissertation was limited to include the processes of care provided by an interdisciplinary team in a single hospital-based, pediatric NBPP clinic. The next generation of this research needs to expand the use of the classification to multiple sites with a similar setting. Including additional sites would further develop the classification to encompass all elements of therapy intervention across different geographic regions. Patients may have also received Early Childhood Intervention (ECI), school based therapy, home health therapy, or outpatient therapy services, which could have a positive or negative impact on outcomes. There is a need to expand the taxonomy-driven classification and data collection process to include community based therapy to understand the impact of community based therapy on patient outcomes.

The resulting NBPP taxonomy-driven classification is not a treatment protocol for clinicians to implement into practice, but it is a tool for therapists and researchers to use to identify what therapists are doing during therapy sessions. The classification is also not a theoretical model and was not developed based on an occupational therapy theory. Instead, an interdisciplinary team developed the NBPP classification using an inductive approach based on clinical experience to categorize and define the process of care for patients with NBPP. This dissertation is an initial investigation to name and frame the components of intervention provided in a hospital based NBPP clinic.

CHAPTER III

STUDY ONE: TOWARD A CLASSIFICATION OF NEONATAL BRACHIAL PLEXUS PALSY INTERVENTION

Methods

Study one was the first study in the series of three studies. Prior to initiating the study, the research team obtained approval from the Institutional Review Board (IRB) for all three studies in the series and consented patients participating in the study. Study one initiated work on step one of PBE methods by establishing an interdisciplinary team, identifying key patient characteristics presumed to have an effect on outcomes, and beginning to identify and define each discipline's care process, as a first step toward developing a taxonomy-driven classification for patients with NBPP (Horn & Gassaway, 2007).

DeJong et al., (2004) describes two approaches to developing taxonomy-driven classifications including a theory-driven, top-down, deductive approach, and an experience-driven, bottom-up, inductive approach. This study used an inductive approach. An inductive method relies on "front-line" clinicians, and existing materials, such as medical records, to describe and characterize what clinicians actually do by sorting, categorizing, and summarizing information describing treatment into a common language (Dejong, Horn, Gassaway, Slavin, & Dijkers, 2004).

Establishing an Interdisciplinary Team

The principle investigator (PI), for the purposes of this dissertation, invited members of an established interdisciplinary team staffing a NBPP clinic at a nationally recognized pediatric, orthopedic hospital to participate in this study including two hand surgeons, one physician assistant, one physical therapist, three occupational therapists, two research coordinators, two nurses, and one psychologist. All members of the team agreed to actively participate with the exception of nursing and psychology, who participated as consultants on an as needed basis during the course of the study. The interdisciplinary team

established for this study focused on classifying patient characteristics, assessment, surgical interventions, and therapeutic interventions for patients with NBPP.

Procedures

The research team received IRB approval to retrospectively review medical records of 336 patients with the diagnosis of NBPP, who were enrolled and consented in a previous study, to identify patient characteristics, assessment, surgical interventions, and therapeutic interventions documented in the medical records. The research team obtained an alphabetical list of the 336 consented patients from the research coordinator. Three members of the interdisciplinary team including two occupational therapists and one physician assistant retrospectively reviewed the medical records in alphabetical order until the descriptive terms related to patient characteristics, assessments, and interventions became repetitive.

The reviewers completed extensive reviews of the medical records including demographic information, therapy documentation, physician dictation, operative summaries, and radiology dictations. The reviewers independently entered the information identified in the medical records into a database under the following sections: (1) patient characteristics, (2) evaluation, (3) therapy intervention, and (4) imaging and surgical intervention (Appendix A). The four sections in the database were created to capture all processes included in PBE methodology including (1) key patient characteristics, (2) all treatment and care processes, and (3) multiple outcome measures (Horn & Gassaway, 2007).

The reviewers entered information into the database until the descriptive terms and phrases related to patient characteristics, assessments, and interventions became repetitious after reviewing 27 medical records. The PI reviewed the information compiled in the database by creating spreadsheets of all of the descriptive terms and phrases for each of the four sections. The PI then sorted the information in each section into subsections and categories that emerged as a result of the sorting process. Finally, the information was summarized into tables for each section setting the foundation for developing a classification to categorize and describe the process of care for patients with NBPP in a pediatric, orthopedic hospital setting. To validate the summarized findings, the PI reviewed three additional medical

records, for a total of 30 records, and confirmed that the descriptive terms and phrases, identified in the final three medical records, fit within the broader subsections and categories presented in the summarized findings. The interdisciplinary team reviewed the summarized findings, made recommendations and adjustments, which were agreed upon by the team, and then used the summarized findings as a foundation for completing the taxonomy-driven classification for patients with NBPP in study two.

Results

The interdisciplinary team reviewed 30 medical records including 240 clinical visits of patients aged 0-18 years seen in a NBPP clinic by an interdisciplinary hand team in a pediatric, orthopedic hospital. The number of visits per patient ranged from 2-24 with an average of 8 visits and a median of 6 visits per patient. The information obtained from the medical record review was sorted and summarized into tables as a first step toward developing a taxonomy-driven classification for patients with NBPP. The summarized findings follow for each section: (1) patient characteristics, (2) evaluation, (3) therapy intervention, and (4) imaging and surgical intervention.

Patient Characteristics

The information compiled in the database in the patient characteristics section was sorted into three sub-sections: patient's demographic information, patient's medical history, and patient's family history, which emerged as a result of the sorting process. The team reviewed the summarized information, and recommended additions and corrections to the list of patient characteristics. Table 1 (Appendix B) shows the complete list of patient characteristics identified by the interdisciplinary team. Identifying and documenting patient characteristics will allow researchers to analyze and account for differences in outcomes for patients receiving similar interventions in future studies.

Evaluation

The information in the database under the evaluation section was sorted into three sub-sections including subjective, body function/structure, and activity/participation in accordance with the domains of the International Classification of Functioning, Disability, and Health (ICF) (WHO, 2001). Subjective

information reviewed in the database included patient or parent concerns. Body function and structure information reviewed in the database included range of motion, strength, sensation, and pain. Information reviewed on activity and participation included developmental milestones, activities of daily living (ADLs), and participation in physical education and sports.

Subjective. The subjective information in the database included 65 patient and parent concerns identified in the medical record review. Nine types of patient and parent concerns emerged during the sorting process (Appendix B, Table 2). The information compiled in the database revealed patient and parent concerns documented most frequent to least frequent as follows: therapy questions (18%), child's development/use of upper extremity (17%), decreased range of motion (ROM) and strength (16%), decreased ability/independence with functional activities (12%), pain (12%), scapular winging (8%), questions about surgery/surgical follow-up (8%), questions/concerns related to PE/sports (6%), and limb length and size (3%).

Body function and structure. According to the World Health Organization (WHO), the ICF defines body functions as physiological functions of the body systems and body structures as the anatomical parts of the body such as organs, limbs and their components (2001). The information from the database related to evaluation of body function and structure was sorted into the following categories, which emerged as a result of the sorting process: shoulder joint, range of motion, strength, sensation, pain and size. The categories were further delineated to include specific components evaluated within each category to comprehensively represent the compiled data (Appendix B, Table 3).

Activity and participation. The ICF defines activity as the execution of a task or action by an individual and participation as involvement in a life situation (WHO, 2001). The compiled information from the database related to the patient's activities and participation included developmental skills, ADLs, physical education, and sport participation (Appendix B, Table 4). Overall, the information compiled in the evaluation section primarily focused on body function and structure domains with limited information on activity and participation. Based on the summarized data from the medical record review, the PI proposed

developing evaluation guidelines for the NBPP clinic to encompass all pertinent domains of the ICF and to standardize the administration of outcome measures. The interdisciplinary team completed the evaluation guidelines in study two.

Therapy Intervention

Information including statements, words, and phrases related to therapy intervention was sorted into eight categories of therapy intervention that emerged as a result of the sorting process (Appendix B, Table 5). After reviewing and summarizing the data, the PI determined that the documentation on therapy intervention in the medical record lacked detail and consistency needed for research and recommended continued development of the therapy intervention portion of the taxonomy-driven classification.

Therapists' documentation reviewed in the retrospective medical record review provided an overview of intervention provided without describing the patient/family's response to intervention and lacked detail about the therapists' actions during therapy sessions. The interdisciplinary team further delineated the eight intervention categories and completed the taxonomy-driven classification in study two.

Imaging and Surgical Intervention

Lists of imaging and surgical interventions were created based on the medical record review. The review of information compiled in the database related to imaging and surgical intervention revealed three types of imaging and eight types of surgical events. The interdisciplinary team reviewed the list, and the PI made corrections and additions based on the team's feedback. Table 6 (Appendix B) shows the types of imaging and Table 7 (Appendix B) shows closed procedures, and open surgical interventions for patients with NBPP. The interdisciplinary team determined that this section did not need additional development due to the systematic and thorough documentation available in the medical record.

Conclusion

Study one resulted in the establishment of an interdisciplinary team and comprehensive lists of patient characteristics, types of imaging, and types of surgical interventions based on a retrospective medical record review. The results of study one revealed the need for further development of evaluation

guidelines and further delineation of therapeutic interventions for patients with NBPP. The information compiled in the evaluation section primarily focused on body function and structure domains with limited information on activity and participation. The PI recommended that the interdisciplinary team develop evaluation guidelines to ensure the inclusion of all areas of the ICF and to standardize the administration of outcome measures.

The lack of detail about the process of therapy within research studies has led researchers to describe therapy intervention as a "black box" (Dejong, Horn, Gassaway, Slavin, & Dijkers, 2004; DeJong, Horn, Conroy, Nichols, & Healton, 2005). The results of this study revealed eight categories of therapy intervention for patients with NBPP, which begins to "disassemble the black box" (Dejong et al., 2004, p. 678). However, the inconsistent, and the limited amount of detail documented on therapy intervention substantiated the need for further work to describe therapists' actions and the process of care when working with patients with NBPP. Overall, the completion of study one initiated work on step one of PBE methods by establishing an interdisciplinary team, identifying key patient characteristics, and beginning to identify and define the process of care. The summarized data from the retrospective medical record review set the foundation for study two, which completed the development of the taxonomy-driven classification including patient characteristics, evaluation guidelines, and intervention.

CHAPTER IV

STUDY TWO: DEVELOPING A TAXONOMY-DRIVEN CLASSIFICATION AND

DOCUMENTATION

Methods

This was the second study in a series of three studies included in this dissertation. Study one concluded with comprehensive categories of information for patient characteristics, types of imaging, and surgical interventions based on a retrospective medical record review. At the end of study one, the PI recommended developing evaluation guidelines and further delineation of therapeutic intervention to complete the taxonomy-driven classification, which was the first aim of study two. Completing the taxonomy-driven classification including patient characteristics, evaluation, and intervention completed steps 1a and 1b of the PBE methods. The second aim of study two was to develop documentation based on the classification to systematically collect data not included in the medical record, once the classification is implemented into practice, which completed step 1c of the PBE methods.

Evaluation Guidelines

The interdisciplinary team met five times to develop the evaluation guidelines for patients with NBPP in a pediatric, orthopedic hospital setting. The team developed the evaluation guidelines using the ICF as a guide to comprehensively identify domains requiring assessment. During the first two meetings, the team reviewed the ICF and identified (1) domains of the ICF assessed by the team in the NBPP clinic, (2) how the team assessed each domain, and (3) pertinent domains needing additional standardized assessment. Appendix C shows the template used to review the ICF and the results of the completed form.

During the third meeting, the team reviewed the definitions of each of the 25 domains identified as needing additional assessment (Appendix D) and identified possible assessments for each domain. At the fourth meeting, the team reviewed assessments and excluded assessments from the evaluation guidelines if

(1) a more comprehensive assessment met the need, (2) the assessment did not add valuable information to the clinical exam, or (3) the assessment was unfeasible to administer within the clinic setting (Appendix E).

A final list of assessments matched with the ICF domains was complied to ensure that the evaluation guidelines covered each domain identified as needing standardized assessment (Appendix D). The team established three triggers to initiate assessments including the child's age, the clinical examination, or open surgical intervention. A visual model of the evaluation guidelines was developed, the team individually reviewed the guidelines, and came to consensus on the final evaluation guidelines for NBPP clinic at the fifth meeting (Appendix F).

Therapy Intervention and Documentation

The interdisciplinary team met five times to develop the therapy intervention portion of the NBPP taxonomy-driven classification. The methods used to develop the NBPP classification were based on the process reported in the literature to develop taxonomies for the SCIRehab project (Gassaway, 2009). First, the team reviewed the summarized findings from study one, as well as, existing classifications from the literature including the SCIRehab Project (Gassaway et al., 2009; Ozelie et al., 2009; Wilson et al., 2009), the JOINTs project (DeJong et al., 2009), and the PSROP (Gassaway et al., 2005). The team also reviewed the Occupational Therapy Taxonomy of Rehabilitation Interventions (OT-TRI) (Schultz, Whisner, Geddie, Shierk, 2012). Schultz et al., (2012) in collaboration with doctoral students at Texas Woman's University developed the OT-TRI following a thorough review of existing taxonomies from the rehabilitation literature, as well as, the second edition of the Occupational Therapy Practice Framework (Roley et al., 2008). The interdisciplinary team primarily drew from the OT-TRI and the SCI Rehab Project taxonomies to develop the therapy intervention portion of the taxonomy-driven classification for patients with NBPP.

Secondly, the interdisciplinary team collaboratively discussed therapeutic interventions presumed to have a significant impact on outcomes for patients with NBPP using the categories of intervention identified in study one as a foundation. The categories of intervention from study one included (1) range of motion and strength, (2) positioning and sensation, (3) modalities, (4) splinting, (5) hand use, ADLs and

instrumental activities of daily living (IADLs) at home and school, (6) psychosocial needs / education on diagnosis, (7) transportation/car seat, and (8) referrals. The team discussed each area of intervention regarding inclusion of specific components and the level of detail needed in each category until consensus was reached. The team also discussed overall session information that needed to be included and processes to document the patient and family's response to intervention. All of the terms in the classification were defined and a documentation form was created to capture components of the classification that were not included in the standard clinical documentation procedures. At the final meeting, the PI trained the therapists participating in the study on documentation procedures based on the taxonomy-driven classification.

Results

This study resulted in the development of the NBPP evaluation guidelines, the therapy intervention portion of the taxonomy-driven classification, and documentation to capture collected data. An overview of the evaluation guidelines, therapy intervention portion of the classification, and documentation procedures follows.

Evaluation Guidelines

Appendix F displays a visual model of the evaluation guidelines. The bottom of the visual model shows ages ranging from 0-18 years. Each horizontal bar represents an assessment in the evaluation guidelines spanning the age range for when it is appropriate to administer the assessment. The assessments are grouped into three categories based on the triggers for administering the assessments with additional details to guide administration listed under the assessment titles. Assessments identified in the retrospective medical record review from study one are included in the evaluation guidelines plus additional assessments identified by the team to comprehensively and systematically measure outcomes.

Assessments triggered by patient's age. Based on the NBPP evaluation guidelines developed by the interdisciplinary team, the therapist administers two assessments based on the patient's age including a Developmental and Functional Checklist and the Pediatrics Outcomes Data Collection Instrument

(PODCI). The Developmental and Functional Checklist (Appendix G) is a checklist of skills based on developmental milestones and independence with ADLs developed by the therapists participating in the study for patients aged 0-18 years presenting with unilateral upper limb involvement. A new screening tool was developed due the inability to identify an assessment with good clinical utility that screens for developmental delays and decreased independence with daily activities for patients with a unilateral upper extremity impairment ages 0-18 years. The therapist uses the Developmental and Functional Checklist as a screening tool at each clinical visit. If the therapist identifies significant delays in development or decreased independence based on the child's age and ability, the therapist can administer additional standardized assessments including the Ages and Stages Questionnaire (ASQ) or the Canadian Occupational Performance Measure (COPM).

The (ASQ) is a series of 11 developmental questionnaires composed of three sections: a brief set of demographic items; 30 simply worded questions focusing on an infant's or child's developmental repertoire; and a brief section asking seven open-ended questions. The questionnaires are designed to be completed by parents and caregivers of young children from 4 to 48 months of age (Bricker, 1997).

The COPM is a measure of a client's self-perception of occupational performance in the areas of self-care, productivity, and leisure. The therapist administers the COPM using a semi-structured interview in which the client identifies significant issues in daily activities, which are causing difficulty (Law et al., 1994). During the interview, the therapist collaborates with the patient, and patient's family to establish goals. The patient or family member, depending on the patient's age, rates the goals based on their importance, performance and satisfaction. Children age eight or older are typically able to complete the ratings independently. The therapist can modify the COPM for children under the age of eight by eliminating the paid/unpaid work and household management categories and have the patients' parent complete the rating scales (Cusick, Lannin, & Lowe, 2007).

The PODCI is also triggered by the patient's age when presenting to clinic. The PODCI is a functional health outcomes scale for children and adolescents, focusing on musculoskeletal health. The

scale assesses upper extremity function, transfers and mobility, physical function and sports, comfort (pain free), happiness and satisfaction, and expectations for treatment. The PODCI includes a pediatric questionnaire that the patient's parent completes for children ages 2-10. There is also an adolescent self-report and an adolescent parent report questionnaire for children ages 11-18 (Daltroy LH, Liang MH, Fossel AH, & Goldberg, 1998). The evaluation guidelines show that the PODCI is administered at transitional years for the patient including starting school, ages 5-6, starting junior high, ages 10-11, starting high school, ages 14-15 and graduating from high school, age 18.

Assessments triggered by clinical examination. Assessments triggered by clinical examination include Body Mass Index (BMI), passive range of motion (PROM), Active Movement Scale (AMS), active range of motion (AROM), modified Mallet Classification, FACES, Semmes Weinstein Monofilaments, stereognosis, and grip and pinch. The therapist should administer these assessments if the clinical exam including review of the medical record, observation, or interview indicates the need for standardized assessment. The description of each assessment and indicators to use each assessment follows.

BMI is a simple anthropometric measure of weight divided by squared height that is used as a screening tool for obesity (Duncan, Duncan, & Schofield, 2009; Mei et al., 2002). A high number of children with NBPP are at risk for becoming obese children and adults. Physicians use the BMI as needed to monitor the child's risk for obesity and educate the patient's family.

PROM is the amount of movement possible at the joint when an outside force moves the limb. The therapist assesses PROM of the upper extremity or selected joints at each clinic visit based on the patient's presentation. PROM includes: (1) scapular humeral angles, (2) shoulder abduction, adduction, flexion, extension, internal rotation, external rotation, (3) elbow flexion, extension, (4) forearm supination, pronation, (5) wrist flexion, extension, radial deviation, ulnar deviation, (6) finger flexion, extension, and (7) thumb flexion and extension.

The AMS is an eight grade ordinal scale used to evaluate active movement in infants and young children with NBPP by observing spontaneous movement without and against gravity (Curtis, Stephens,

Clarke, & Andrews, 2002). According to the NBPP evaluation guidelines, a therapist can administer the AMS from birth to age five years, or until the child can accurately follow directions to complete standard AROM measurements. The therapist assesses active movement using either the AMS or AROM at each clinic visit unless there is an indication not to assess AROM. AROM is the amount of movement possible at the joint when the patient voluntarily moves the limb by muscle contraction.

The modified Mallet Classification assesses five shoulder movements by asking the patient to actively demonstrate abduction, external rotation, placing the hand behind the neck, placing the hand behind the back, and placing the hand to mouth. Each item is graded on a scale of I (no movement) to V (normal movement) (van der Sluijs, van Doorn-Loogman, Ritt, & Wuisman, 2006). The evaluation guidelines show use of the modified Mallet Classification starting at three years or when the patient can reliably follow directions to demonstrate the five movements. The therapist typically administers the modified Mallet at each clinical visit unless there is an indication not to assess active movement.

The Wong-Baker FACES Pain Rating Scale is an ordinal measure consisting of six pictures of faces ordered from "no hurt" to "hurts worst" (Hockenberry & Wilson, 2009) that is recommended for use for children ages three and older. The evaluation guidelines show the FACES Pain Rating Scale used at each clinic visit for children ages three and older.

Semmes Weinstein Monofilaments are one of the most commonly used assessments to measure cutaneous sensation ranging from normal to unresponsive (Collins, Visscher, De Vet, Zuurmond, & RSGM, 2010). The evaluation guidelines show that a therapist can administer the Semmes Weinstein Monofilament assessment starting at age six or when the patient can reliably follow the directions to complete the assessment. The assessment should be administered if the patient or patient's family reports decreased sensation in the patient's involved upper extremity.

Stereognosis is the ability to recognize an object through active touch without the aid of vision (Benton Al & Schultz, 1949). Stereognostic capacity improves between the ages of three years and six years meaning that testing prior to the age of six years may not be completely accurate (Benton Al &

Schultz, 1949). The evaluation guidelines show stereognosis testing starting at age 6 years if the patient or patient's parent verbalizes concerns with the patient's hand sensation or ability to manipulate items with vision occluded.

Grip strength is the force applied by the hand. Types of pinch include tip (two-point) pinch, key (lateral) pinch, and palmar (three point) pinch. The literature reports norms for grip and pinch strength for children ages 6 to 19 years of age (Wiemer, 1986). The evaluation guidelines show that a therapist can assess grip and pinch strength starting at the age of six years based on clinical examination. Grip and pinch strength should be tested if the patient reports weakness or if weakness in the patient's hand is observed.

Assessments triggered by surgical intervention. Assessments triggered by open surgical procedures include the Assisting Hand Assessment (AHA) and the COPM. The therapist administers both assessments to obtain baseline data prior to surgical intervention and change in function following surgical intervention. The therapist can also administer the assessments for therapy treatment planning and change in function following therapeutic intervention, but due to time constraints in the clinic setting, the assessments are reserved for before and after open surgical interventions.

The AHA is a 22-item measure that evaluates the assisting or affected hand in carrying out bimanual activities of children with hemiplegic cerebral palsy or brachial plexus palsy aged 18 months to 12 years (Krumlinde-Sundholm, Holmefur, Kottorp, & Eliasson, 2007). The purpose of the AHA is to evaluate assisting hand function, plan treatment, and to evaluate the effects of intervention. The test involves videotaping a semi structured play session using standard toys requiring two hands for successful play. The AHA takes approximately 15 minutes to administer and additional time is required for video set up and scoring. The play conductor / scorer must be certified in the use of the AHA by successfully completing a two and a half day course and further independent evaluation of the AHA administration and scoring (Urlic & Wallen, 2009).

Therapy Intervention

The interdisciplinary team developed the therapy intervention portion of the taxonomy-driven classification to provide therapists with a tool to categorize and describe their actions during a therapy session with a patient with NBPP in a clinical setting within a pediatric, orthopedic hospital. In this setting, therapists work with patients and their families in conjunction with an interdisciplinary team as they present to be seen by a hand surgeon. Therapists typically complete an evaluation and then set up a home program for the patient and their family. The frequency of patient visits vary based on the patient's needs and can range from two weeks to several years between clinic visits. The therapy intervention portion of the taxonomy-driven classification includes overall session information, the patient and family's response to intervention, and eight categories of intervention.

Overall session information. Table 8 (Appendix H) presents the overall session information including basic information, collaboration, negative factors impacting the therapy session, and therapist's actions during the session. Collaboration refers to health care professionals the therapist collaborates with regarding the patient's session. The team defined collaboration as direct interaction with a professional at the orthopedic hospital or in the community related to the patient's plan of care during the patient's clinic visit including face to face and telephone conversations. Negative factors impacting the session are patient or family behaviors or beliefs that impede the therapist's ability to complete an evaluation or treatment. Therapist's actions are observable actions the therapist does during a session with patient and family including psychosocial facilitation, verbal support, physical support, modification, and education.

Overall patient and family response. Table 9 (Appendix H) exhibits the items and definitions for the patient and family's response to a therapy session. The patient and family response items were developed based on the Pittsburgh Rehabilitation Participation Scale (Lenze et al., 2004) and the modified version created for the SCIRehab Psychology Taxonomy (Wilson et al., 2009). The patient's response focuses on their ability to complete actions and engage in conversation when it is age appropriate. The family's response focuses on the caregiver's level of engagement with the therapist during the session.

Because the therapists provide the majority of intervention through a home program, the patient and family's participation is imperative for successful outcomes.

Intervention categories. Tables 10-17 (Appendix H) show the eight intervention categories. The intervention categories include six home programs, plus transportation and car seat needs, and referrals. Each category of intervention includes the purpose, or the goal of intervention, specific components of intervention, and the format of the intervention. The therapist provides intervention using the following format options (1) verbal instructions, (2) demonstration, and (3) a written handout. All eight of the intervention categories use the same format options.

Home program: range of motion and strength. Table 10 (Appendix H) depicts information on the intervention category for home programs regarding range of motion and strengthening. This intervention category contains five possible goals to increase PROM, AROM, or strength in the patient's involved upper extremity. The specific components of intervention include the targeted upper extremity movement and the strategies used to achieve the goal. The movement section includes all joints of the upper extremity: shoulder, elbow, forearm, wrist, fingers, and thumb and the planes of movement at each joint. Grip and pinch and reciprocal patterns are also included as movement types. Strategies to improve range of motion or strength consist of specific exercises or play/function based activities. Based on the child's age, ability, and needs, therapists create a specific home program targeting improvements in range of motion and strength with the goal of improving the child's overall functional ability.

Home program: positioning and sensation. Table 11 (Appendix H) shows the goals and strategies for the intervention category for home programs related to positioning and sensation. This intervention category includes goals for positioning and sensation when the patient presents with decreased movement, pain, decreased sensation, returning sensation, or edema. The following examples demonstrate how therapists use the intervention strategies to address the purpose or the goal of the intervention.

For example, therapists educate families of young children with NBPP on positioning to protect the involved upper extremity, especially when the child presents with minimal or no active movement. They

can also educate the patient's family on modified tummy time (placing the child's involved upper extremity in external rotation while on their tummy) to decrease the risk of posterior shoulder dislocation. To increase awareness and promote sensation to the child's upper extremity, therapists will educate the family to use soft textures for tactile stimulation. As sensation returns in the younger child, some will bite their fingers, which can lead to open sores on the child's fingers. Therapists educate the patient's family on strategies to decrease finger biting, such as, having the child wear a Band-Aid, mitten, or glove on their hand. Older children and teens sometimes present with a limb length discrepancy contributing to pain in their neck and superior shoulder as they try to equalize the placement of their hands in space. Therapists educate the patient and family on positioning to decrease the stretch while the patient is sitting, studying, or typing by placing their involved arm on a raised surface to decrease tension and increase comfort. If a patient has decreased sensation, therapists provide education on protecting the upper extremity from heat, cold, and sharp objects. Therapists can also educate the patient to elevate the upper extremity after surgical intervention to reduce edema.

Home program: modalities. Table 12 (Appendix H) depicts information in the intervention category for home programs regarding modalities. The goals for using a modality as part of a home program include reducing pain, positioning, promoting active movement, skin care, and scar care. Types of modalities typically recommended include kinesiotaping, heat, cryotherapy, skin care, scar care, and electrical stimulation. In this setting, therapists use modalities conservatively and only include modalities in a home program to address very specific goals. Therapists encourage patient's families to follow up if they have concerns with using modalities at home. The therapist may refer the patient to a community-based therapist to monitor the use of modalities as needed.

Home program: splinting. Table 13 (Appendix H) outlines the information for the therapy intervention category for splinting. The purpose of the splints includes positioning, increasing range of motion, and post-operative protection. This intervention category delineates the type, fabrication, and wear schedule of splints typically provided to patients with NBPP.

Home program: activities of daily living and hand use. Table 14 (Appendix H) represents the information for the intervention category regarding home programs to increase independence with ADLs, IADLs, and hand use in the patient's home and school environments. Basic ADLs include dressing, bathing, grooming, toileting and feeding. IADLs include care of pets, chores, meal prep and driving. Typical school concerns for children with NBPP include cutting, writing, managing supplies, computer use, and physical education. Overall, patients present with decreased range of motion and strength in their hands or in other joints of the involved upper extremity, and/or decreased sensation, which leads to decreased use of their non-dominant hand during functional activities. Strategies used to increase independence and bilateral hand use include adapting the environment, adapting the task, using adapted equipment, providing written instructions on restrictions and recommended accommodations for school, and activities to promote bilateral hand use.

Home program: psychosocial and education on diagnosis. Table 15 (Appendix H) shows the intervention category for home programs related to psychosocial needs and education on the patient's diagnosis. Therapists and other members of the interdisciplinary team provide basic psychosocial support to patients regarding bullying and teasing, expressing feelings, and understanding their diagnosis. The team provides the patient and family with concrete explanations of the patient's diagnosis and simple responses to use as coping strategies. The team encourages families to talk about the child's diagnosis and practice using simple, age appropriate responses when a peer asks or teases the child about their condition. The team also encourages families to follow up with the interdisciplinary team if the strategies are not successful, or if they feel they need additional support. The physician will then refer the patient to a child life specialist or a psychologist for continued intervention.

Education on transportation and car seats. Patients presenting in shoulder spica casts post-operatively may not fit in their current car seat for safe transportation. A therapist assesses the fit of the patient's current car seat to determine if the patient can use their car seat, or if they need a car seat that accommodates spica casts for safe transport (Appendix H, Table 16).

Referrals. Table 17 (Appendix H) lists common reasons for a referral and common referral sources. The interdisciplinary team identifies a need for a referral, and the physician makes the referral to a professional within the hospital system or within the community.

Documentation Using the Taxonomy-Driven Classification

Appendix I provides an example of the Classification of NBPP Intervention Documentation Form, which was developed to capture information using the taxonomy-driven classification. This documentation form captures information regarding each therapy session including collaboration, negative factors impacting the session, the therapist's actions, assessments, the patient and family's participation during the session, and specific information on therapy intervention provided during the session. The form does not include the remaining portions of the taxonomy-driven classification including patient characteristics, imaging, and surgical interventions, or duplicate information found on the standard NBPP documentation form routinely used in the NBPP clinic because the interdisciplinary team documents this information in the patient's medical record. The goal of the Classification of NBPP Intervention Documentation Form is to add information to systematically capture the 'active ingredients' of a therapy session and not duplicate what the interdisciplinary team is already documenting.

To use the Classification of NBPP Intervention Documentation Form, therapists check next to each professional they collaborated with during the session and negative factors that occurred during the session. They also check next to each of the therapist's actions that they demonstrated during the session and circle the most predominant of the therapist's actions based on the amount of time spent doing the action. The therapists check next to each assessment completed in the evaluation section. The evaluation section of the form only lists assessments not included on the standard NBPP documentation form. All of the other assessments presented in the evaluation guidelines are included on the therapist's standard NBPP documentation form.

In the patient and family response to intervention section, therapists select one item representing the patient and family's overall response to the therapy session. The final section of the documentation form

allows therapists to document interventions provided during the session. The therapist uses an extended version of the classification with numbers and definitions for each item in the therapy intervention portion of the classification (Appendix J). Therapists use the numeric codes to fill in the goal of the intervention, the specifics regarding the intervention, and the format of intervention on the documentation form.

Conclusion

Study two fulfilled the requirements of steps 1a and 1b of PBE methods, identifying and defining key patient characteristics and the individual components of the process of care by completing a comprehensive, taxonomy-driven classification for patients with NBPP including patient characteristics, evaluation, and intervention. Study two also fulfilled the requirements of step 1c, creating discipline specific documentation tools, of PBE methodology. Specifically, study two resulted in the development of evaluation guidelines and documentation based on the taxonomy-driven classification for systematic data collection not included in the medical record. The evaluation guidelines provide therapists with a guide for administering standardized assessments needed to analyze the outcomes of intervention provided. The therapy intervention portion of the taxonomy-driven classification describes the patient and family response, negative factors impacting a session, therapist's actions, and categorizes defined interventions. The documentation form enhances the documentation process by providing therapists with a tool to systematically document the components of each therapy session. Once feasibility and reliability of implementing the classification is established, therapists can study the active ingredients of therapy that correlate with positive outcomes. Study three examined the feasibility and reliability of implementing the taxonomy-driven classification into practice.

CHAPTER V

STUDY THREE: DETERMINING FEASIBILITY AND RELIABILITY

Methods

Study three completed step 1d of PBE methodology, incorporating documentation into routine facility practices. The interdisciplinary team completed a pilot study to assess the feasibility and the reliability of implementing the new classification and data collection process into routine facility practices. The team conducted the pilot study by prospectively enrolling patients as they presented for treatment in the NBPP clinic. Phase one of the pilot study analyzed the feasibility of implementing the taxonomy-driven classification including the evaluation guidelines and Classification of NBPP Intervention

Documentation Form. Phase two of the study analyzed the inter-rater reliability of the Classification of NBPP Intervention Documentation Form.

Feasibility

The interdisciplinary team determined feasibility by analyzing the cost and time required to implement processes using the classification compared to the standard process of care. Analysis included a comparison of the cost of assessments, the number of staff, and time needed to implement each process using descriptive statistics. Four experienced therapists tracked direct time spent with the patient including evaluation, treatment, and documentation on ten patient encounters using the standard process and ten patient encounters implementing the classification (Appendix K). Experienced therapists included occupational and physical therapists who have independently and successfully staffed the brachial plexus clinic for at least six months and were members of the interdisciplinary team for this study. The therapists randomly selected patients as they presented to the brachial plexus clinic.

Reliability

Pairs of experienced therapists independently documented on 30 patient encounters to determine inter-rater reliability of the Classification of NBPP Intervention Documentation Form. Both of the therapists were present during the same evaluation and treatment session and then individually completed the documentation form (Appendix I). The data collected from the completed Classification of NBPP Intervention Documentation Forms was analyzed to determine inter-rater reliability using Cohen's Kappa for categorical data and percentage of agreement for coded data representing therapy intervention. The interdisciplinary team used 30 patient encounters to analyze inter-rater reliability and 20 patient encounters to assess feasibility because this is historically an effective sample size without over taxing the clinicians and patients.

Feasibility Results

Therapists spent similar amounts of time on evaluation, treatment, and documentation when implementing the classification compared to the standard process of care. For evaluations, the average amount of time increased by 2.5 minutes using the evaluation guidelines. The average time spent on treatment decreased by 2.5 minutes using the classification. And, on average the therapists needed an additional 2.7 minutes to complete documentation including the Classification of NBPP Intervention Documentation Form that captures information from the classification. Overall, the therapists' average time for patient care and documentation using the classification increased by less than three minutes compared to the standard process of care making the number of staff and the cost of staff needed to implement the classification very comparable to the standard number of staff needed in the brachial plexus clinic.

The cost of assessments were analyzed by dividing costs into two categories: (1) initial start up costs, and (2) maintenance costs. Initial costs included training, purchasing the manual, materials, and initial documentation forms. Maintenance costs included purchasing or reproducing additional documentation forms. Assessments in the evaluation guidelines with initial costs included the COPM,

ASQ, Semmes Weinstein, stereognosis, grip and pinch, and the AHA. All of the remaining assessments in the evaluation guidelines are available in the literature or online at no cost. All of the assessments require some maintenance cost to either purchase forms or copy reproducible documentation forms.

Assessments used in the standard process of care, prior to the implementation of the evaluation guidelines and classification, included the PODCI, AMS, AROM, PROM, modified Mallet Classification, Wong-Baker FACES Pain Rating Scale, BMI, grip and pinch, and Semmes Weinstein Monofilaments. Assessments added with the development of the evaluation guidelines included the Developmental and Functional Checklist, ASQ, stereognosis, AHA, and the COPM. The analysis revealed higher initial start up costs using the evaluation guidelines compared to the standard process of care and equal maintenance costs for the two processes. Overall, the interdisciplinary team found implementing the classification feasible based on comparable costs and time requirements compared to the standard process of care.

Reliability Results

Table 18 (Appendix L) shows the overall inter-rater reliability for the categorical data on the Classification of NBPP Intervention Documentation Form using Cohen's Kappa. The Kappa values indicate how often the raters agreed in their ratings, or the percentage of agreement corrected for chance. A value of one indicates total or perfect agreement. The "level of agreement" describes the strength of agreement for the Kappa values. These labels should be viewed as qualitative descriptors. 100% agreement is perfect, > 80% is excellent, > 60% is good, 40-60% is moderate, and <40% is fair-poor agreement (Portney & Watkins, 2009).

The overall reliability of the Classification of NBPP Intervention Documentation Form was excellent (mean Kappa of 0.80). The inter-rater reliability for each category on the form ranged from moderate to perfect (Appendix L, Table 18). Tables 19-23 (Appendix L) show the level of agreement for each item in the five categories on the documentation form. All items under collaboration and negative factors had an excellent or perfect level of agreement. Items under therapist's actions ranged from good to fair-poor levels of agreement with an overall moderate level of agreement. The evaluation category had

perfect agreement. The overall level of agreement for patient and family participation was good. The level of agreement for patient participation was moderate and excellent for family participation.

Percentage of agreement was used to analyze inter-rater reliability for coded data representing therapy interventions provided during treatment sessions instead of Cohen's Kappa due to the large number of variables. The overall percentage of agreement for coded data was good at 75%. The inter-rater reliability for coding the interventions increased during the study as the therapists became accustomed to the classification. The percentage of agreement for the first 15 patients was 60%, and the percentage of agreement for the last 15 patients was 90% (Appendix L, Table 24).

Conclusion

Study three concluded with a feasible and reliable taxonomy-driven classification that defines, categorizes, and captures patient characteristics, evaluations, and interventions for children with NBPP in a hospital based clinic setting. The study also completed step 1d of PBE methodology, documentation into routine facility practices. As a result of the findings, the research team recognized the need for minor revisions to the therapy intervention portion of the classification based on the data collected in study three.

Revisions made to the classification included redefining collaboration, therapist's actions, and one item on the patient participation scale. The revisions also included adding an intervention format option, and intervention strategies. Collaboration was redefined to include the therapist and all professionals the therapist and the patient have contact with during the clinic visit. This change fulfilled the goal of documenting members of the interdisciplinary team contributing to each patient encounter instead of only documenting professionals the therapist had direct communication with during the patient visit.

Therapist's actions and patient participation were revised because they demonstrated moderate to fair-poor inter-rater reliability. Revisions made to the therapist's action category included combining the four psychosocial facilitation types into two types to improve clarity. Verbal support, physical support, and modification were further defined by adding details to their definitions to improve future reliability. The inter-rater reliability for the family participation scale was excellent, but the inter-rater reliability for the

patient participation scale was moderate. The score of "four" for patient participation represents a patient engaged in the therapy session. A score of "four" was redefined to include only children over the age of eight who can fully engage in the session. Redefining the fourth item on the scale will improve the overall reliability of the patient participation scale.

Based on therapists' feedback after implementing the classification into routine clinical practice, a format option was added for therapists to observe the patient or family return demonstration of the home programs. Strategies identified during data collection in study three that were not already included in the classification were also added. The revisions are included in the extended version of the classification (Appendix J).

CHAPTER VI

DISCUSSION AND IMPLICATIONS

Overview

This dissertation resulted in the completion of three studies and the development of a taxonomy-driven classification for patients with NBPP. In study one, the researchers aimed to establish an interdisciplinary team, identify patient characteristics, assessments, and interventions documented by the interdisciplinary team treating patients with NBPP in a pediatric, orthopedic hospital. Study one resulted in the establishment of an interdisciplinary team, and comprehensive lists of patient characteristics, types of imaging, and types of surgical interventions based on a retrospective medical record review. The results of study one revealed the need for further development of evaluation guidelines and further delineation of therapeutic interventions for patients with NBPP prior to future research.

In study two, the researchers aimed to complete the taxonomy-driven classification by developing evaluation guidelines, defining therapeutic intervention, and developing documentation based on the classification to capture collected data. Study two resulted in the complete taxonomy driven-classification including (1) a comprehensive list of patient characteristics, (2) types of imaging and therapy evaluation guidelines, and (3) types of surgical interventions and defined therapeutic intervention. Study two also resulted with the development of documentation based on the classification to capture data not included in the medical record.

In study three, the researchers aimed to determine the feasibility and reliability of implementing the taxonomy-driven classification into clinical practice. Study three identified the taxonomy-driven classification as a feasible and reliable method to document the process of care for patients with NBPP in a pediatric, orthopedic hospital setting. Overall, the researchers developed a taxonomy-driven classification using PBE methodology defining the process of care for patients with NBPP, and documentation based on the classification to identify the active

ingredients, or the key surgical and therapeutic interventions, that yield optimal treatment outcomes for children with NBPP in future studies.

Disassembling the "Black Box": Preliminary Findings

The data collected during the reliability portion of study three, begins to disassemble the "black box" by unveiling the active ingredients of therapy intervention when working with patients with NBPP in a clinic setting. The preliminary data showed negative factors impeding the therapist from completing a thorough evaluation or treatment session 20% of the time. Regarding therapist's actions, at least one of the two therapists present during the session selected "affirms effort" 93% of the time and selected "encourages" 97% of the time. The therapists selected "active listening and paraphrasing" 83% of the time, and "collaborates with patient/family" 100% of the time. The high percentages of selection for the four types of therapist's actions shows the importance of psychosocial facilitation and the therapeutic relationship as an active ingredient of therapy intervention, which is seldom discussed or included in research focusing on orthopedic conditions.

The data showed therapists provided verbal cues 87% of the time and provided physical assist 83% of the time. Therapists recommended modifications to the environment or task less frequently at 17% and 30% respectively. Therapists provided or recommended equipment 30% of the time, provided education 87% of the time, and recommended additional assessments or referrals 10% of the time. Therapists identified "provides education" as the most predominant therapist's action 67% of the time. The preliminary data also showed therapists rating the patient's engagement in the therapy session as resistive 10% of the time, passive 2% of the time, active 73% of the time, and engaged 15% of the time. Therapists rated the family's participation as active or engaged 100% of the time.

Based on 30 patient clinic visits, therapists coded 77 sets of intervention including 633 codes. The following shows the percentage of coded sets for each of the intervention categories: range of motion and strength - 68%, positioning and sensation - 6%, ADLs, IADLs, hand use - 5%, psychosocial / education on diagnosis - 1%, modalities - 3%, splinting - 12%, referrals - 5%. Using descriptive statistics, the

preliminary data begins to quantitatively describe the elements or the active ingredients of the therapy process. Describing what the therapist is doing and the patient's response will allow researchers to understand the correlations between intervention provided and outcomes in future studies.

Future Research

This dissertation completed step one of PBE methodology followed by a summative analysis of feasibility and reliability of the evaluation guidelines and data collection process, developed and implemented as part of the study. The findings from the analysis determined that the classification reached sufficient articulation for progression into the next steps of PBE methods. The next steps include: (2) use the Comprehensive Severity Index (CSI) to control for differences in patient severity of illness, (3) implement an intensive data collection protocol that captures data on patient characteristics, care processes, and outcomes, (4) create a study database suitable for statistical analyses, (5) successively test hypotheses based on questions that motivated the study originally, (6) implement and evaluate findings from step 5 to determine whether the new or modified interventions replicate results identified in earlier phases, and (7) incorporate validated study findings into standard practice of care (Horn & Gassaway, 2007). Completing the remaining steps will meet the long-term aim of this research, which is to provide meaningful data that is responsive to the following broad research questions.

Overarching Research Questions:

- 1. How do patient characteristics explain variations in outcomes?
- 2. Controlling for patient characteristics, which surgical and therapeutic interventions correlate with optimal outcomes?

The next steps needed to answer the above research questions requires continued data collection of all areas of the taxonomy-driven classification. The researcher team need to develop a comprehensive database to compile information from the medical record and the Classification of NBPP Intervention Documentation Form. Study three found that collecting data within the clinic setting using the paper documentation form was feasible, but the long term maintenance of manually entering data from each

session into a database is not a feasible option. Therefore, the team needs to create an electronic version of the documentation form that will automatically populate collected data into the database. The team also needs to develop a NBPP Taxonomy-Driven Classification User's Manual for therapist training to ensure reliable data collection in future studies.

This dissertation limited data collection to patients seen by an interdisciplinary team in a hospital based NBPP clinic. The next generation of this research should expand the use of the classification to multiple sites with a similar clinic setting. Including additional sites would further develop the classification to encompass all elements of therapy intervention across different geographic regions. This line of research should also expand data collection to include the role of community based therapy programs, such as, ECI, school based therapy, outpatient therapy, and home health therapy to investigate the impact of community based therapy on patient outcomes.

Impact on Occupational Therapy

Therapy intervention varies across settings and geographic regions with minimal evidence to support or refute interventions provided for patients with NBPP. The variations in treatment can create decreased continuity of care and suboptimal intervention for patients. Implementing the NBPP classification including systematic documentation procedures to multiple sites, across settings has the potential to improve the continuity of care for patients with NBPP. Expanding the use of the classification would bring awareness and promote discussion regarding the variations in therapeutic interventions for this patient population, and allow researchers to look at the effectiveness of the different treatment options provided without changing therapists' current practice.

Developing and implementing the classification for the purposes of this dissertation brought awareness to the complexity of therapeutic intervention to both the therapists and interdisciplinary team members. Using the systematic documentation procedures gave therapists the opportunity to reflect on their observable actions during a therapy session within the context of the comprehensive classification.

After implementing the classification, therapists began to more clearly communicate and define their role and interventions provided to patients and families.

The classification also provided a visual representation of the numerous components of therapy intervention, which supports the need to first research the process of therapy intervention instead of attempting to isolate and research the effectiveness of one component of intervention. The visual representation combined with defined terminology has the potential to provide a structured method for training new staff and students working with patients with NBPP. Finally, as previous literature of taxonomy development has inspired and guided the development of the NBPP classification, this classification also has the potential to trigger the development of additional classifications for other diagnoses.

Conclusions

In conclusion, the research team developed a taxonomy-driven classification for patients with NBPP and established the classification as a feasible and reliable data collection tool. The therapy intervention portion of the classification defines the process of therapy intervention including therapists' actions, allowing researchers to comprehensively and individually investigate the active ingredients of therapeutic intervention for patients with NBPP. This type of research has the potential to give therapists evidence to support the effectiveness of therapy, which therapists need to receive funding for their services, and to provide optimal care for patients with NBPP

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APPENDIX A

Database Fields for Medical Record Review

Database Fields for Medical Record Review

| Patient Characteristics | Data Field Options | Data Field Options Data field Format | |
|--------------------------------------|---|--------------------------------------|--|
| patient medical record number | | free text | |
| diagnosis | left BPP | drop down box | |
| | right BPP | | |
| | other | free text | |
| gender | male | drop down box | |
| | female | | |
| ethnicity | black, Hispanic, white, other, unknown | drop down box | |
| date of birth | month (1-12) | drop down box | |
| | day (0-31) | drop down box | |
| | year (1985-2020) | drop down box | |
| birth weight | | free text | |
| birth history | | free text | |
| Narakas level | 1. C5 C6 | drop down box | |
| | 2. C5-C7 | | |
| | 3. C5-T1 no horner | | |
| | 4. C5-T1 horner | | |
| age at presentation to clinic | | free text | |
| age at final follow up | | free text | |
| | | | |
| Evaluation | | | |
| current weight | | free text | |
| current height | | free text | |
| | automatically calculates BMI based on | | |
| BMI | height and weight | | |
| | automatically calculates in year + | | |
| age at time of | month based on age and date of clinic | | |
| evaluation/intervention | visit | | |
| subjective patient / parent concerns | | free text | |
| current therapy program | ECI | check all that apply | |
| Current therapy program | outpatient | check an that appry | |
| | home program | | |
| | other | free text | |
| | shoulder abduction (0-7 and not | nec text | |
| Active Movement Scale | entered) | drop down box | |
| 1 12 1 1 1 1 | shoulder adduction (0-7 and not | 1 | |
| | entered) | drop down box | |
| | shoulder flexion (0-7 and not entered) | drop down box | |
| | shoulder external rotation (0-7 and not | | |
| | entered) | drop down box | |
| | shoulder internal rotation (0-7 and not | 1 | |
| | entered) | drop down box | |

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| supination (0-7 and not entered) drop down box pronation (0-7 and not entered) drop down box wrist flexion (0-7 and not entered) drop down box wrist extension (0-7 and not entered) drop down box finger flexion (0-7 and not entered) drop down box finger extension (0-7 and not entered) drop down box thumb flexion (0-7 and not entered) drop down box thumb flexion (0-7 and not entered) drop down box thumb flexion (0-7 and not entered) drop down box thumb flexion (0-7 and not entered) drop down box comments free text turns head L/R equally (yes, no, not entered) drop down box prone head tilt to 45 (yes, no, not entered) drop down box prone head tilt to 45 (yes, no, not entered) drop down box grasp/transfer objects (yes, no, not entered) drop down box sitting (yes, no, not entered) drop down box sitting (yes, no, not entered) drop down box crawling (yes, no, not entered) drop down box erawling (yes, no, not entered) drop down box pulling to stand (yes, no, not entered) drop down box ambulating (yes, no, not entered) drop down box comments on development free text currently in PE (yes, no, not entered) drop down box comments on PE/sports free text shoulder adduction free text shoulder adduction free text shoulder external rotation free text shoulder external rotation free text shoulder flexion free text elbow extension free text shoulder flexion free text elbow extension free text elbow extension free text forearm pronation free text shoulder flexion free text elbow extension free text elbow extension free text shoulder adduction free text shoulder flexion free text forearm pronation free text shoulder flexion free text shoulder flexion free text shoulder adduction free text shoulder flexion free text forearm supination free text shoulder adduction free text shoulder flexion free text shoulder internal rotation free text forearm supination free text shoulder adduction free text shoulder internal rotation free | | elbow flexion (0-7 and not entered) | |
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| shoulder internal rotation free text shoulder external rotation free text | active range of motion | | |
| shoulder external rotation free text | | | |
| | | | |
| shoulder extension free text | | | |
| | | shoulder extension | free text |

| | T | Τ . | |
|--|---|---------------|--|
| | shoulder flexion | free text | |
| | elbow extension | free text | |
| | elbow flexion | free text | |
| | forearm pronation | free text | |
| | forearm supination | free text | |
| | wrist extension | free text | |
| | wrist flexion | free text | |
| pain | where | free text | |
| | behavioral scale (0-8, not entered) | drop down box | |
| | faces scale (0-5, not entered) | drop down box | |
| | what does it feel like | free text | |
| | how long it lasts | free text | |
| | how often | free text | |
| | what starts it | free text | |
| | what stops it | free text | |
| | comments on pain | free text | |
| grip and pinch strength | (tested, not tested) | drop down box | |
| grip und pinten swengen | grip right | free text | |
| | grip left | free text | |
| | lateral pinch right | free text | |
| | lateral pinch left | free text | |
| | tip pinch right | free text | |
| | tip pinch left | free text | |
| | tripod pinch right | free text | |
| | tripod pinch left | free text | |
| cancory | (WNL, tested, not tested) | drop down box | |
| sensory | comments on sensory | free text | |
| | · | | |
| | full sensory evaluation independent, age appropriate, needs | free text | |
| activities of daily living | assistance, adaptive devices | drop down box | |
| detivities of daily fiving | comments on ADLs | free text | |
| | global abduction (not testable, 1-5, not | nee text | |
| modified Mallet Classification | entered) | drop down box | |
| | global ER (not testable, 1-5, not | 1 | |
| | entered) | drop down box | |
| | hand to neck (not testable, 1-5, not | | |
| | entered) | drop down box | |
| | hand to spine (not testable, 1-5, not | 4 4 1 | |
| | entered) | drop down box | |
| | hand to mouth (not testable, 1-5, not entered) | drop down box | |
| assassmants | comment box | free text | |
| assessments | Comment box | nee text | |
| | splint (elbow extension, LBO, SBO, | | |
| Therapy Intervention | wrist cock up, other) | drop down box | |
| Therapy intervention whist cock up, other) drop down box | | | |

| | · | | |
|------------------------|--|----------------------|--|
| | splint comments | free text | |
| | HEP (yes, no) | drop down box | |
| | HEP comments | free text | |
| | education handout (yes, no) | drop down box | |
| | PE modification form (yes, no) | drop down box | |
| | PE modification form comments | free text | |
| | referral made (yes, no) | drop down box | |
| | referral to (ECI, outpatient, school | | |
| | therapy, psychology) | drop down box | |
| | referral to (other) comment | free text | |
| Plan of Care | patient/parent goal comment | free text | |
| Goals | verbalize understanding of: HEP, Splint wear/care, positioning, sensation, other | check all that apply | |
| | demonstrate understanding of: HEP, splint wear/care, positioning, sensation, | | |
| | other | check all that apply | |
| | STG comment/other | free text | |
| | return to clinic | free text | |
| | improve function, ROM, strength, comfort, other | check all that apply | |
| | maintain function, ROM, strength, comfort, other | check all that apply | |
| | LTG comment/other | free text | |
| Surgical | | | |
| Procedure/Intervention | closed reduction | free text | |
| | open reduction | free text | |
| | Botulinum toxin A | free text | |
| | humeral osteotomy | free text | |
| | tendon transfers | free text | |
| | nerve exploration | free text | |
| | nerve grafting | free text | |
| | other | free text | |
| | length of casting | free text | |
| | f/u plan of care | free text | |
| | F | | |
| Imaging | sonogram / results | free text | |
| | x-ray / results | | |
| | other | | |

APPENDIX B

Tables: Study 1 Results

Table 1

Patient Characteristics

| Patient Characteristics | | | |
|-------------------------------|---|---------------------------------|--|
| Demographic Information | Medical History | Family History | |
| patient name | diagnosis (BPP) | G P Ab | |
| patient medical record number | Narakas level | maternal age | |
| date of birth | other diagnoses | mother's ethnicity | |
| gender | history of prior/current medical care of patient | mother's pregnancy weight | |
| ethnicity | history of prior/current therapy intervention | mother's health history | |
| age at presentation to clinic | type of delivery | mother's weight gain | |
| age at final follow up | length of labor | history of gestational diabetes | |
| | number of weeks gestation | litigation | |
| | apgar scores | mother's level of education | |
| | NICU | income level | |
| | birth weight | family support members | |
| | birth length | | |
| | % of head circumference | | |
| | use of forceps/vacuum/extractions | | |
| | clavicle/humerus fracture | | |
| | history of upper extremity recovery (return of elbow flexion) | | |

Table 2

Types of Patient and Parent Concerns

| Patient and Parent Concerns |
|---|
| child's development/use of upper extremity |
| decreased ability/independence with functional activities |
| decreased ROM/strength |
| limb length/size |
| pain |
| questions about surgery/surgical follow-up |
| questions/concerns related to PE/sports |
| scapular winging |
| therapy questions (exercises/splints) |

Table 3

Evaluation Categories for Body Function and Structure

| Body Fur | Body Function and Structure: Joint, Motion, Strength, Sensation, Pain and Size | | | |
|--|---|--|--|--|
| | Shoulder Joint | | | |
| Shoulder placement | located; subluxed/dislocated; reduces with external rotation, does not reduce | | | |
| | Range of Motion | | | |
| Passive Range of Motion | shoulder, elbow, forearm, wrist, fingers, thumb | | | |
| Scapular/humeral angles | scapular winging present; scapular humeral – abduction; scapular humeral – adduction; scapular humeral – external rotation | | | |
| Active Range of Motion | shoulder, elbow, forearm, wrist, fingers, thumb | | | |
| Functional Range of Motion | reaches overhead, hand to top of head (wash/style hair); hand to belly button (fasteners); reaches hand to opposite shoulder (hygiene); reaches hand to back pocket; shakes hands with another person | | | |
| Compensatory Movements with Functional ROM | shoulder elevation; back extension; scapular movement | | | |
| Active Movement Scale (AMS) | shoulder, elbow, forearm, wrist, fingers, thumb | | | |
| Wrist position during AMS | radial deviation, ulnar deviation, neutral | | | |
| Modified Mallet Classification | global abduction; global ER; hand to neck; hand to spine, hand to mouth | | | |
| | Strength | | | |
| Grip and Pinch Strength | grip; lateral pinch; tip pinch, tripod pinch | | | |
| Sensation | | | | |
| Sensory | full sensory evaluation; finger biting; dry skin; comments | | | |
| Pain | | | | |
| Pain | where; behavioral scale, FACES scale, what does it feel like; how long it lasts; how often, what starts it; what stops it; comments on pain | | | |
| Size | | | | |
| Upper Extremity Length/Size | equal, difference present | | | |

Table 4

Evaluation Items for Activity and Participation

| Activity and Participation | | | | |
|----------------------------|--|--|--|--|
| Developmental Skills | turns head L/R equally (0-2 mo) | | | |
| | prone head lift to 45 degrees (0-3 mo) | | | |
| | hands toward midline (1-4 mo) | | | |
| | grasp/transfer objects (4-6 mo) | | | |
| | rolling (prone/supine (5-8 mo) | | | |
| | sitting (5-8 mo) | | | |
| | crawling (8-10 mo) | | | |
| | pulling to stand (9-12 mo) | | | |
| | ambulating (12-14 mo) | | | |
| Activities of Daily Living | independent, age appropriate, needs assistance, adaptive devices | | | |
| | comments on ADLs | | | |
| PE/sport participation | currently in PE | | | |
| | currently in sports | | | |
| | comments on PE/sports | | | |

Table 5

Types of Therapy Intervention

| Therapy Intervention | | | |
|---|--|--|--|
| hand use, activities of daily living and instrumental activities of daily living at home and school | | | |
| modalities | | | |
| positioning and sensation | | | |
| psychosocial needs / education on diagnosis | | | |
| range of motion and strength | | | |
| referrals and accommodations | | | |
| splinting | | | |
| transportation/car seat | | | |

Table 6

Types of Imaging

| Imaging |
|-------------|
| x-ray |
| ultra sound |
| MRI |
| СТ |
| Other |

Table 7
Surgical Procedures and Interventions

| Surgical Procedure/Intervention | | | |
|---|--|--|--|
| closed reduction | | | |
| closed reductions plus Botox | | | |
| open reduction | | | |
| latisimus transfers with IR contracture release | | | |
| internal rotation contracture release | | | |
| humeral osteotomy | | | |
| tendon transfers | | | |
| nerve exploration | | | |
| nerve grafting | | | |
| osteotomies - other | | | |
| Other | | | |

APPENDIX C

ICF Template and Results

ICF Template and Results

| When working with a person | with <u>NBPP</u> in <u>a c</u> | <u>clinic_</u> setting | identify how you a | ssess the following: |
|---|--|---|---|--|
| F= frequently | | O= observatio | n | |
| S= sometimes | | I= interview | | Y = yes |
| N= never | | SA = standard | ized assessment | N = no |
| | | Body Function | ons | |
| body functions are the physic body systems | ologic function of | impairments a | | dy function as a significant |
| Mental Functions | Assessment (of impairment / ability) | How is it | Specific Examples (include age range) | Is there a need for more standardized assessment? (possibly list discipline) |
| consciousness | F S N | O I SA | | mments: |
| orientation (time, place, person) | F S N | 0 | | omments: |
| intellectual (include retardation, dementia) | F S N | O . 1 A | developmental milestones | omments: |
| energy and drive functions | S N | O I SA | | V comments: motivation and |
| sleep | F | O I SA | |) mments: |
| attention | F S N | O SA | | omments: |
| memory | F | O I SA | | omments: |
| emotional functions | F S N | 0 1 A | | V comments: affect, sadness, |
| perceptual functions | F S N | O I SA | | omments: |
| higher level cognitive functions | F S N | O I SA | | omments: |
| language | S N | O : i i i i i i i i i i i i i i i i i i | | omments: |
| sequencing complex movement | F S N | O I SA | | omments: |
| temperament and personality | S N | O I SA | Ţ | comments: temperament personality |

| | | 1 | Г |
|--|---|--------------------------------|---|
| Sensory Functions and Pain | | | |
| seeing | F S N | O I SA | omments: |
| hearing | S | O I SA | omments: |
| vestibular (include balance functions) | S | O : 1: 5A | omments: |
| taste functions | F S N | O I SA | omments: |
| smell functions | F S N | O I SA | omments: |
| proprioceptive functions | F S N | O I SA | omments: |
| touch functions | F S N | o l s emmes Veinstein | comments: add to protocol ge, add information about finger biting, stereognosis |
| pain (diffuse, dull, sharp, phantom) | S N | o (s) ACES | comments: VAS, pain today, with activities |
| temperature and pressure | S | O : 1 SA | omments: |
| Voice and Speech Functions | | | |
| voice | F S N | O I SA | omments: |
| fluency and rhythm | F S N | O I SA | omments: |
| alternative vocalization functions | F S N | O I SA | omments: |
| Cardiovascular, Hematological, | for this section sta labs for blood wo | | ocedures such as blood pressure, |
| heart | S | o ssessed during ew patient | omments: |
| blood pressure | S | o sits, prior to greery and as | omments: |
| hematological (blood) | <u>(S)</u> | o s art of initial istory and | omments: |
| immunological (allergies, hypersensitivity) | S | O physical by physician or | omments: |
| respiration (breathing) | S | o sistant | omments: |

| Metabolic and Endocrine | | | | |
|---|-------|------------|--------------------------------|--------------------|
| Systems | | | | |
| digestive | S | O : | physical, pre- admit | omments: |
| defecation | S | O : 5A | physical, pre- admit | omments: |
| weight maintenance | F S N | O: 1 S | 3MI | omments: |
| endocrine glands (hormonal changes) | S | O : SA | physical, pre- admit | omments: |
| Genitourinary and Reproductive Functions | | | | |
| urinary functions | S | O : i ; ;A | physical, pre- admit | omments: |
| sexual functions | F N | O I SA | | omments: |
| Movement Related Functions | | | | |
| mobility of joint | S N | 0 1 5 | Scale, Mallet, -PROM/AROM | omments: |
| joint stability | F S N | 0 . A | | omments: |
| muscle power | F S N | 0 1 5 | Manual Muscle Test, Grip an | omments: |
| muscle tone | S N | O : 1 | _ | omments: |
| muscle endurance | S | O : 5A | = | comments: possibly |
| motor reflexes | S | O I SA | Moro, ATNR, palmar grasp | omments: |
| involuntary movements | F S N | O I SA | | omments: |
| control of voluntary movement | F S N | 0 : 1 SA | | omments: |
| gait patterns | S | O : SA | swing with walking and | omments: |
| skin | S | 0 1 A | patterns, finger biting | omments: |

| | | Body Structur | res | | |
|---|--|--------------------|--|------|--|
| body structures are anatomic organs, limbs and their comp | impairments are problems in structure as a significant deviation or loss | | | | |
| | Assessment (of impairment / structure) | How is it assessed | Specific Examples (include age range) | sta | there a need for more andardized assessment? possibly list discipline) |
| brain | S | 0 1 5 | tructures of the | N | omments: |
| spinal cord and peripheral nerves | S | 0 (1 (5) | ody are issessed by | N | omments: nerve |
| the eye, ear and related structures | S | 0 1 5 | hysician or hysician | N | omments: Horners |
| structures involved in voice and speech | S | 0:(1:(5) | nitial history | N | omments: |
| cardiovascular system | S | 0 (1 (5) | ind physical, pre- idmission exam, with interview, | N | omments: |
| respiratory system | S | 0: 1 5 | bservation or maging, or | N | omments: |
| digestive system | S | O : (1) (S) | bservation Juring surgical | N | omments: |
| metabolism | S | 0 1 5 | procedures, for his section | | omments: |
| endocrine systems | S | 0:15 | tandardize ssessment | N | omments: |
| genitourinary and reproductive systems | S | 0 1 5 | efers to imaging r medical | N | omments: |
| skin and related structures | S | 0 1 5 | rocedures | , N | omments: |
| Structures related to movement | | , | | -1 (| <u> </u> |
| head and neck | F S N | 0 1 5 | issessed by MD, A or therapist | N | omments: |
| shoulder region | F S N | 0 1 5 | luring clinical xam through | N | omments: |
| upper extremity (arm, hand) | F S N | 0 1 5 | | N | omments: |
| pelvis | S | 0 . I S | or PA will assess with imaging as | N | omments: |
| lower extremity (leg, foot) | S | 0 (1 (5) | ndicated ncluding x-ray, | N | omments: |
| trunk | S | 0 (1 (5) | onogram, MRI, CT, other | N | omments: |

| activity is the execution of a t | | ivity and Partion Individual | | s are difficulties an individual | |
|---|---|---------------------------------|--|--|--|
| (is capable of doing), participation is involvement in a life situation (actually does) | | | may have in executing activities; participation restrictions are problems an individual may have in involvement in life situations | | |
| Learning and Applying Knowledge | Assessment (of limitations / ability) | How is it assessed | Specific Examples (include age range) | Is there a need for more standardized assessment? (possibly list discipline) | |
| | Per nce: | O : SA | | N omments: | |
| watching | F S N F S N | 0 1 A | | omments: | |
| listening | Per s ce: | O : 1 SA | Learning and applying knowledge skills | omments: | |
| | Per S rce: | O : SA | are typically assessed with an interview related | N omments: | |
| learning to read | F S N | O : I SA | to the child's overall school | omments: | |
| learning to write | Per s ce: | O : SA | performance, this is typically not an area of | omments: | |
| | Cy: | O I SA | concern for children with NBPP | n omments: | |
| learning to calculate (arithmetic) | Per S N | O : SA | | N omments: | |
| | F S N Per nce: | 0 1 5A 0 1 5A | | omments: | |
| solving problems | F S N | | | 100 | |
| General Tasks and Demands | Ca nacitu : | O: SA | this area is | omments: | |
| undertaking a single task | Perf s N | O : SA | assessed with interview as | omments: | |
| | C T T T T T T T T T T T T T T T T T T T | O : 13: 5A | needed, typically not a concern for patients with | omments: | |
| undertaking multiple tasks | Per ce: | O : SA | NBPP |) (N) omments: | |

| | | 1 | <u> </u> | 1 |
|---|------------------|------------|--|---|
| Communication | ••• | | | |
| communicating with | C | 0 L A | | omments: |
| receiving spoken messages | Per S N | O : i iA | | omments: |
| communicating with | C // /: F S N | O : SA | | omments: |
| receiving non verbal messages | Per s ice: | O : SA | | omments: |
| | C y: F S N | 0 L A | this area is | omments: |
| speaking | Per ce: | O : SA | assessed with interview as | omments: |
| | Ci S N | O : SA | needed, typically not a concern for | omments: |
| producing non verbal messages | Perl ce: | O : SA | patients with NBPP | omments: |
| | C· S N | 0 1 A | | N omments: |
| conversation | Per s ce: | O : SA | | omments: |
| communication management (telephones, computers, | C | O I SA | | omments: |
| communication boards, call lights, augmentative communication systems, etc) | Peri s ce: | O SA | | omments: |
| Mobility | | | 1 | |
| | Canacity: | (i);A | (| Y comments: currently |
| lifting and carrying objects | F S N | O : SA | | interview, possibly AHA and/or |
| | F S N | 0 : 1 SA | | V comments: currently assessed with observation and |
| fine hand use (picking up, grasping) | F S N | C SA | | interview, possibly AHA and/or |
| | F S N | O : (1) SA | | omments: |
| transfers | Per s nce: | O SA | | N omments: |
| | C y: | O SA | | omments: |
| walking | Per since: | O : SA | | omments: |

| moving around using | y: F S N | SA | omments: |
|--|---------------|------------|---|
| equipment (wheelchair, skates, etc) | Per S N | C: SA | omments: |
| | C y: | C SA | omments: |
| using transportation (car, bus, train, plane, etc) | Per s ce: | O : SA | iomments: |
| , ,, , | C y: | O I SA | iomments: |
| driving (riding bicycle and motorbike, driving car, etc) | Perf ce: | O SA | v comments: possibly a need a leisure assessment or SA with a leisure component |
| Self Care | | | |
| washing oneself (bathing, | s N | O : SA | omments: possibly use create a screening tool with ADLs |
| showering, drying, washing hands, etc) | mance: S N | O : SA | V comments: |
| caring for body parts | acity: | O : SA | omments: |
| (brushing teeth, shaving, grooming, etc) | rmance: | O : SA | V J comments: |
| 5. , | acity: | O : i.i. | omments: |
| toileting (bowel and bladder management, hygiene) | mance: S N | 0 | v comments: |
| . 70 | acity: | O I SA | omments: |
| dressing | mance: | C SA | y I comments: |
| Ü | nacity: | 0 1 ;A | omments: |
| eating (in mouth), feeding (to mouth) | rmance: | 0 : 1 : SA | v comments: |
| , | acity: | O : SA | iomments: |
| drinking | mance: | O I SA | v comments: |
| | | | |

| | F S N | C SA | N):omments: |
|---|-----------------------|----------|--------------------------|
| looking after one's health | Per s nce: | O : SA | omments: |
| personal device care (hearing aids contacts, | C y: | C: SA | omments: |
| glasses, orthotics, prosthetics, AE, contraceptive) | Performance: | C SA | omments: |
| rest and sleep (including | C | C SA | omments: |
| sleep preparation/participation) | Per s nce: | O I | omments: |
| Domestic Life | | | |
| | Canacity: F S N | C : SA | omments: |
| acquisition of goods and services (shopping, etc) | Per s nce: | C : SA | l comments: possibly for |
| | C y: F S N | O : 1 SA | omments: |
| preparation of meals (cooking, etc) | Per s nce: | O : 1 SA | comments: possibly for |
| doing housework (cleaning | C y: | O | omments: |
| house, washing dishes, laundry) | Per nce: | O SA | omments: |
| | C y: | O . SA | omments: |
| care of pets | Per nce: | O | omments: |
| | CL F S N | O I SA | omments: |
| child rearing | Perforn F S N | O I SA | omments: |
| | Capa F S N | O I SA | omments: |
| care of others (including supervising caregivers) | Perform F S N | O I SA | iomments: |
| health management and maintenance (physical | C S N | 0 : SA | omments: |
| fitness, nutrition, medication routines) | Perluurance: F S N | O SA | comments: look into PE |

| | C N | O I SA | | N | omments: |
|--|------------------|------------|---|-------|------------------------|
| religious observance | Perforn F S N | O I SA | | N | omments: |
| safety and emergency maintenance (safe | Capau F S N | O I SA | | N | omments: |
| environment, recognize hazard and plan action) | Perform N | O I SA | | N | omments: |
| Interpersonal Interactions and Relationships | | | | | |
| basic interpersonal interactions | S | 0 : SA | Y |) I d | comments: bullying and |
| complex interpersonal interactions | F S N | O I SA | | N | omments: |
| relating with strangers | F S N | O I SA | | N | omments: |
| formal relationships | F S N | O I SA | | N | omments: |
| family relationships | S | O I SA | | N) | omments: |
| intimate relationships | F S N | O I SA | | N) | omments: |
| Major Life Areas | | | | | 1 |
| informal education | S | O : 1 3A | | N) | omments: |
| school education | F S N | O : SA | participation at school, overall school | N | omments: |
| higher education | F S | O : SA | , | N | omments: |
| interests, pursuits, seeking and acquisition) | S | O I | | N | omments: |
| job performance | S | O : 13: 3A | | N. | omments: |
| volunteer exploration / participation | S | O : A | | N | omments: |
| retirement preparation and adjustment | F S N | O I SA | , | N | omments: |
| basic economic transactions | F S N | O I SA | , | N | omments: |
| economic self- sufficiency | F S N | O I SA | , | N | omments: |

| Community, Social and Civic Life | | | | | | |
|---|---|--------------------|-----------------------------------|---|--|--|
| community life | S | O : SA | _ | omments: | | |
| (exploration and participation) | F S N | O : SA | | comments: possibly CAPE | | |
| play (participation and exploration) | S N | O SA | | comments: possibly CAPE ODCI | | |
| religion and spirituality | F S N | O I SA | | omments: | | |
| human rights | F S N | O I SA | | n) :omments: | | |
| political life and citizenship | F S N | O I SA | | omments: | | |
| Environment | | | | | | |
| environmental factors make u their lives | up the physical, soc | cial and attitud | linal environment i | n which people live and conduct | | |
| | Assessment (of barriers and facilitators) | How is it assessed | Specific Examples (include age | Is there a need for more standardized assessment? | | |
| Products and Technology | | | range) | possibly list discipline) | | |
| for personal consumption (food medicine) | S | O : 1 SA | | omments: | | |
| for personal use in daily living | S | O : 5A | | omments: | | |
| outdoor mobility and transportation | S | O : SA | | omments: | | |
| products for communication | S. | O : SA | keyboard, school accommodations | omments: | | |
| building products and technology of buildings for | F S N | O I SA | | omments: | | |
| building products and technology of buildings for | F S N | O I SA | | omments: | | |
| Human Made Changes to | | | | | | |
| Environment | | | | | | |
| climate | F 5 N | O I SA | | omments: | | |
| light | F (N | O I SA | | omments: | | |
| | | | | | | |

| | | | | 1 |
|--|------------|------------|----------------------------------|-------------|
| Support and Relationships | | | | |
| immediate family | S N | 0 1 A | interaction during clinic | y comments: |
| friends | F S N | O : [1] | patient has friends | y comments: |
| colleagues, neighbors and community members | S | O : A | | omments: |
| people in position of authority | S | O | | omments: |
| personal care providers and personal assistants | F S N | O I SA | | omments: |
| health professionals | F S N | 0 1 | hand team, report of | n omments: |
| other professionals | F S N | O I SA | | omments: |
| Attitudes | | | | |
| individual attitudes of immediate family members | F S N | O : SA | many of the these | V comments: |
| individual attitudes of friends | <u>S</u> . | O : 13: 5A | areas are informally | omments: |
| personal care providers and personal assistants | F S N | O I SA | assessed based on observation | omments: |
| individual attitudes of health professionals | F S N | O : [] A | and informal interview. The | omments: |
| individual attitudes of other professionals | F S N | O I SA | team often has an awareness | omments: |
| societal attitudes | S. | O : SA | but does not specifically | omments: |
| social norms, practices and ideologies | I S | O | assess each area | omments: |

| Services, Systems and Policies | | * 1 | | |
|--|-------|--------|------------------------------------|---------------------------------------|
| Housing services, systems and policies | F S N | O I SA | | N comments: |
| communication services, systems and policies | IS | O SA | the team assess if the family | omments: for parents to inglish |
| transportation services, systems and policies | F S N | O I SA | needs additional | n comments: |
| legal services, systems and policies | S | O : SA | regarding these services and | omments: if litigation is in |
| social security services, systems and policies | F S. | O SA | information as needed or refers | omments: parents often put disability |
| services, systems and policies | S | C: SA | to a social | omments: |
| health services, systems and policies | F S | O . | additional information | omments: referral to nity therapy |
| services, systems and policies | S | O SA | | omments: information on s needed |

APPENDIX D

Domains Needing Additional Assessment

Domains Needing Additional Assessment

| Assessment Domain (based on ICF) Needing Additional Assessment | Assessment Included in Evaluation Guidelines Meeting the Need |
|--|---|
| Mental Functions | |
| energy and drive | COPM - goal setting, motivation, importance |
| emotional functions | PODCI – happiness with appearance, ability, health |
| temperament and personality | PODCI – happiness with appearance, ability, health, acceptance by peers |
| Sensory and Pain | |
| touch functions | Semmes Weinstein, Stereognosis |
| Pain | PODCI – activity and pain |
| Neuromusculoskeletal and Movement Related Functions | |
| muscle endurance | PODCI – ability to complete physical activities |
| Mobility | |
| lifting and carrying objects | PODCI, AHA |
| fine hand use | AHA, developmental checklist |
| Driving | COPM, developmental checklist |
| Self Care | |
| washing oneself | COPM, developmental checklist |
| caring for body parts | COPM, PODCI, developmental checklist |
| Toileting | COPM, developmental checklist |
| Dressing | COPM, PODCI, developmental checklist |
| eating/feeding | COPM, PODCI, developmental checklist |
| Drinking | COPM, developmental checklist |
| Domestic Life | |
| acquisition of goods and services | COPM |
| preparation of meals | COPM, developmental checklist |
| health management and maintenance | PODCI, BMI |
| Interpersonal Interactions and Relationships | |
| basic interpersonal interactions | PODCI, informal interview |
| Community, Social and Civic Life | |
| recreation and leisure | PODCI, COPM |
| Play | PODCI, AHA, COPM |
| Support and Relationships | |
| immediate family | observation and informal interview |
| Friends | PODCI, informal interview |
| Attitudes | |
| individual attitudes of immediate family members | Observation, classification |

APPENDIX E

Assessment Review

Assessment Review

| List of Assessments Reviewed | Included | | Exclusion Criteria | | Comments |
|--|----------|--|--|--------------|---|
| | | More comprehensive assessment available | no valuable information added to clinical exam | not feasible | |
| ABILHNAD- Kids | | | X | | most of the patients could complete all of the tasks |
| Active Movement Scale (AMS) | X | | | | |
| Activities Scale for Kids | | X | X | | |
| Adolescent Leisure Interest Profile | | | | X | due to time |
| Ages and Stages Questionnaire | Х | | | | |
| Assessment of Life Habits | | X | X | | the 0-4 year questionnaire - many of the items seemed too difficult for a young child or were not applicable |
| Assisting Hand Assessment (AHA) | X | | | | |
| Bayley-III | | X | x | | developmentally based, most patients meet developmental milestones, duplicates information on Ages and Stages and Developmental Screener |
| Body Mass Index (BMI) | X | | | | zg.z z e . e . e . e . e . e . e . e |
| Box and Block Test | | | х | | |

| Bruininks-Oseretsky Test of Motor Proficiency | | | X | | focus on motor proficiency vs. unilateral involvement |
|--|---|---|---|---|---|
| Canadian Occupational Performance Measure (COPM) | X | | | | |
| Children's Assessment of Participation and Enjoyment (CAPE) Preferences for Activities of Children (PAC) | | | | X | due to time |
| Child Health Questionnaire | | X | | | similar to items on PODCI, age range is 5-18yrs |
| Children Helping Out: Responsibilities, Expectations, Support (CHORES) | | | X | | most patients have the capability to complete chores at home |
| Denver II | | X | | | developmentally based, most patients meet developmental milestones, duplicates information on Ages and Stages and Developmental Screener |
| FACES pain scale | X | | | | |
| Goal Attainment Scaling (GAS) | | X | | | similar goal setting system as the COPM |
| Infant Toddler Quality of Life Questionnaire | | X | X | | |
| Kid Play Profile | | | | х | due to time |
| Michigan Hand Outcomes | | | X | | adult measure |

| Modified Mallet Classification | x | | | | |
|---|---|---|---|---|--|
| Mooney Pain Drawing | X | | | | |
| Nine Hole Peg Test | | | х | | |
| Peabody Developmental Motor Scales | | X | | | developmentally based, most patient meet developmental milestones, duplicates information on Ages and Stages and Developmental Screener |
| Pediatric Evaluation of Disability Inventory (PEDI) | | | | X | due to time |
| Pediatric Outcomes Data Collection Instrument (PODCI) | X | | | | |
| Pediatric Quality of Life Inventory | | X | X | | |
| Preschool Activity Card Sort | | | | X | due to time |
| Proprioception | | | X | | |
| Purdue Pegboard | | | X | | |
| Quality of Upper Extremity Skills Test (QUEST) | | | X | | assessment for children with cerebra |
| Short Child Occupational Profile (SCOPE) | | | | X | due to time |
| Semmes Weinstein Monofilament | X | | | | |
| Shriners Hospital Upper Extremity Evaluation (SHUEE) | | | x | | assessment validated for children wi |

| Stereognosis | X | | | | |
|--|---|---|---|---|---|
| The Beery-Buktenica Developmental Test of Visual-Motor Integration | | | x | | |
| The Melbourne Assessment of Unilateral Upper Limb Function | | | x | | assessment validated for children with cerebral palsy |
| The Pediatric Activity Card Sort | | | | X | due to time |
| The Perceived Efficacy and Goal Setting System | | X | X | | limited age range of 6-9 years |
| The Revised Developmental Screen Inventory | | X | | | developmentally based, most patients meet developmental milestones, duplicates information on Ages and Stages and Developmental Screener |
| Visual Analogue Scale - pain | | X | | | duplicates information from FACES |
| WeeFIM - Functional Independence Measure 0- 3 module | | X | X | | developmentally based, most patients meet developmental milestones, duplicates information on Ages and Stages and Developmental Screener |

APPENDIX F

NBPP Evaluation Guidelines

APPENDIX G

Developmental and Functional Checklist

Overview

The Developmental and Functional Checklist for Children with Unilateral Upper Extremity

Involvement is a checklist of skills based on developmental and functional milestones (Eliasson & Burtner, 2008) for patients aged 0-18 years presenting with unilateral upper limb involvement. Therapists can use the Developmental and Functional Checklist as a screening tool to identify the need for further standardized assessment and to assist with goal setting. If the therapist identifies delays in development or decreased independence based on the child's age and ability, the therapist should initiate an intervention program, and administer additional assessments as needed, such as, the Ages and Stages Questionnaire or the Canadian Occupational Performance Measure. The screening tool was developed with good clinical utility allowing a therapist to quickly and easily screen for developmental delays or decreased independence specifically for children with unilateral upper extremity involvement. The screening tool is not an outcome measure. The overall goal of the screening tool is to assess if the child can independently complete the tasks within the target age range, even if they complete the tasks using compensatory strategies.

Administration

The therapist identifies the child's age and locates that section of the checklist. The therapist interviews the child and/or parent to discuss the child's ability for each item that is age appropriate on the checklist. The therapist can also observe the child completing the task if needed. The therapist then marks how well the child is completing the skill by marking if the skill is (1) established/independent, (2) emerging/needs assistance, (3) unable/dependent. The therapist can mark if the child has not had an opportunity to complete the task or if the child's parents have not expected their child to master the skill. The therapist can also write in if the child is using any adaptive equipment to complete the skill, or if the child completes the skill with the non-involved upper extremity. The therapist continues to interview the child and/or parent until all of the items within the child's age range are scored. If the child is independent or has mastered all of the skills within their age range there is no need for further assessment or for intervention related to developmental and functional milestones. If the child demonstrates difficulty with

the tasks within their age range, the therapist will continue the interview asking about skills typically mastered at a younger age until the child demonstrates mastery of three consecutive skills. If the child did not master all of the skills within their age range it is recommended that the therapist work with the family to develop goals and an intervention program to help the child meet developmental and functional milestones. Additional assessments can be administered at this time, especially if the therapist is interested in outcomes of intervention based on standardized assessment.

Developmental and Functional Checklist for Children with Unilateral Upper Extremity Involvement

| Patient's Name: | |
|------------------------|--|
| Medical Record Number: | |
| Therapist: | |
| Date: | |
| | |

Measure the child's typical performance of the task based on patient and caregiver interview

| | | Emerging / | | No | Uses an Assistive |
|--|---------------|------------|-----------|---------------|----------------------|
| | Established / | Needs | Unable / | Opportunity / | Device or Non- |
| Task | Independent | Assistance | Dependent | Not Expected | involved UE |
| 0-12 months | • | | | | |
| Turns head L/R equally (0-2 mo) | | | | | |
| Prone head lift to 45 degrees (0-3 mo) | | | | | |
| Hands toward midline (1-4 mo) | | | | | |
| Grasp/transfer objects (4-6 mo) | | | | | |
| Rolling (prone/supine (5-8 mo) | | | | | |
| Sitting (5-8 mo) | | | | | |
| Reaches to mouth while sitting - involved UE (6 | | | | | |
| mo) | | | | | |
| Holds bottle and brings to mouth 2 hands (6 mo-10 | | | | | |
| mo) | | | | | |
| Crawling (8-10 mo) | | | | | |
| Holds arm out for coat/open front shirt - involved | | | | | |
| UE (9 mo) | | | | | |
| Pulling to stand (9-12 mo) | | | | | |
| Feeds self finger foods pincer grasp - involved UE | | | | | |
| (10-12 mo) | | | | | |
| Removes unbuttoned coat (12 mo) | | | | | |
| 12-24 months (1-2 yrs) | | | | | |
| Throw a small ball with forward arm motion – | | | | | |

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| involved UE (12-18 mo) | | |
|---|--|--|
| Ambulating (12-18 mo) | | |
| Stacks small block or toy on top of another one – | | |
| involved UE (14-18 mo) | | |
| Removes mittens (14 mo) | | |
| Removes socks on request (2 yrs) | | |
| Removes untied/unfastened shoes (2 yrs) | | |
| Helps push down pants (2 yrs) | | |
| Helps pull up pants (2 yrs) | | |
| Puts arms in large arm holes - coat/shirt (2 yrs) | | |
| Rubs hands together to clean them (2 yrs) | | |
| 24-36 months (2-3 yrs) | | |
| Threads shoelace through a bead (2 yrs-2yrs 6 mo) | | |
| Removes long pants, elastic top, clearing over | | |
| bottom (2 yrs 6 mo) | | |
| Unbuttons most front and side buttons (3 yrs) | | |
| Removes t-shirt / dress (3 yrs) | | |
| 36-48 months (3-4 yrs) | | |
| Makes snips in paper – holds paper with involved | | |
| UE (3 yrs 6 mo – 4 yrs) | | |
| Opens front separating zipper (3 yrs 6 mo) | | |
| Manages toilet seat, toilet paper, flushes, attempts | | |
| to wipe for toileting (3 yrs 6 mo) | | |
| Puts on pull over garment (3yrs 6 mo) | | |
| Unbuckles belt or shoe (3yrs 9 mo) | | |
| Puts on pants oriented correctly (4 yrs) | | |
| Buckles belt or shoe (4 yrs) | | |
| Puts on socks correct orientation (4 yrs) | | |
| Puts on coat/open front shirt independently (4 yrs) | | |
| Snaps most front and side snaps (4 yrs) | | |
| Washes and dries hands thoroughly (4 yrs) | | |
| 19 60 months (1 5 vms) | | |
| 48-60 months (4-5 yrs) Zips front separating zipper - without hooking (4 | | |

| yrs 6 mo) | | |
|---|--|--|
| Pours self drink from large pitcher/carton (4 yrs 6 | | |
| mo) | | |
| Inserts belt in loops (4 yrs 6 mo) | | |
| Puts shoes on independently, Velcro fasteners (5 | | |
| yrs) | | |
| Brushes teeth including set up independently (5 | | |
| yrs) | | |
| 60-72 months (5-6 yrs) | | |
| Uses knife to cut soft foods (5 yrs 6 mo) | | |
| Zips, unzips, hooks, unhooks separating zipper (6 | | |
| yrs) | | |
| Snaps back snaps (6 yrs) | | |
| Ties front sash on apron or dress (6 yrs) | | |
| Washes and dries face thoroughly (6 yrs) | | |
| Toilets independently including wiping thoroughly | | |
| (6 yrs) | | |
| 72-84 months (6-7 yrs) | | |
| Buttons back buttons (6 yrs 3 mo) | | |
| Ties shoes independently (6 yrs 6 mo) | | |
| Spreads with knife (7 yrs) | | |
| Washes self in bath independently (7 yrs) | | |
| Brushes hair independently including tangles/parts | | |
| hair (7 yrs) | | |
| Manages school supplies | | |
| Participates in PE (push-ups/pulls-ups) | | |
| 84-96 months (7-8 yrs) | | |
| Washes self including back (7 yrs) | | |
| Cuts meat with knife (7-8 yrs) | | |
| Ties back sash on apron or dress (8 yrs) | | |
| Older than 8 years | | |
| Opens packages/containers | | |
| Ties necktie (10 yrs) | | |

| Styles hair independently including hairspray, | | | |
|---|------|------|--|
| rollers, etc (12 yrs) | | | |
| Types independently | | | |
| Simple meal prep | | | |
| Drives independently (16 yrs) | | | |
| Child is age appropriate - no goals needed Goal setting needed | | | |
| Comments: | | | |
| | | | |
| | | | |
| | | | |

APPENDIX H

Tables: Therapy Intervention Portion of the

Taxonomy-Driven Classification

Table 8
Overall Session Information

| Overall Session Information | | | | |
|-----------------------------|------------------------|------------------------------------|---|--|
| Basic Information | Collaboration | Negative Factors Impacting Session | Therapist's Actions | |
| date | hand surgeon | behavioral issue | affirms efforts | |
| patient name | physical therapist | cognitive issue | encourages | |
| patient number | occupational therapist | pain | active listening/paraphrasing | |
| therapist's name | nursing | fatigue | collaborates with pt/ family | |
| interpreter needed | physician assistant | patient sleeping | provides verbal cues | |
| | psychology | psychosocial factors | provides physical assist | |
| | child life | cultural issue | strategies to adapt the environment | |
| | radiology | | strategies to adapt task/s | |
| | therapeutic recreation | | provides/recommends equipment | |
| | orthotist | | provides education | |
| | dietitian | | recommends additional assessment or referrals | |

| Overall Patient and Family Response | | |
|--|--|--|
| Patient Participation Overall Session | | |
| resistive - resisted/ignored therapist's verbal/physical prompts/instruction - actively refuses to participate or resisted | | |
| passive - listened but failed to collaborate or take action during session - is inactive during the session | | |
| active - participated and interacted during session - engaged in play, verbalized understanding, returned demonstration | | |
| engaged - initiated discussions; took active role in problem solving, motivated (not applicable for young children) | | |
| Family Participation Overall Session | | |
| resistive - resisted/ignored therapist's verbal/physical prompts/instruction - actively refuses to participate | | |
| passive - listened but failed to collaborate or take action during session - is inactive during the session | | |
| active - participated and interacted during session - verbalized understanding, returned demonstration | | |
| engaged - initiated discussions; took active role in problem solving, motivated | | |

Table 10 Home Program: Range of Motion and Strength

| Home Program: Range of Motion and Strength | | | | |
|--|----------------------|---|-------------------------------|--|
| Purpose (goal is to address) | Movement | Strategies | Format | |
| passive range of motion | shoulder | specific exercises | verbal instructions/education | |
| active assist range of motion | flexion | theraband | demonstration | |
| active range of motion | extension | theraputty | handout provided | |
| strengthening | abduction | pendulum exercises | | |
| improve scapular humeral movement | adduction | place and hold | | |
| | horizontal adduction | combined with passive stabilization | | |
| | external rotation | scapular stabilization young child | | |
| | internal rotation | scapular stabilization older child | | |
| | scapula stabilizers | other | | |
| | elbow | play / function based activities | | |
| | flexion | reaching for play items | | |
| | extension | playing with large ball | | |
| | forearm | holding hula hoop with 2 hands above head | | |
| | supination | making tunnel out of cushions, crawling | | |
| | pronation | swimming | | |
| | wrist | putting on hats or necklaces overhead | | |
| | flexion | swinging on a swing | | |
| | extension | pushing a cart with weighted toys | | |
| | finger/thumb | reaching up for monkey bars | | |
| | flexion | climbing up stairs | | |
| | extension | twisting open containers | | |
| | adduction | playing dress up | | |
| | abduction | singing songs with hand motions | | |
| | grasp | opening drawers | | |
| | gross grasp | wheelbarrow | | |
| | pincer | other | | |
| | tripod | | | |
| | lateral (key) | | | |
| | reciprocal pattern | | | |

Table 11 *Home program: Positioning and Sensation*

| Home Program: Positioning/Sensation | | | |
|---|---|-------------------------------|--|
| Purpose (goal is to address) | Strategies | Format | |
| infant/toddler decreased movement | safety pin | | |
| infant/toddler decreased sensation | cuff and collar | verbal instructions/education | |
| child/teen with pain/limb length difference | towel/blanket roll | demonstration | |
| finger biting | sensory textures | handout provided | |
| awareness of decreased sensation | place arm on raised surface for typing/studying | | |
| positioning after surgery/edema control | mittens/gloves to cover hands | | |
| decrease risk of shoulder dislocation | elevation pillow | | |
| | education on tummy time | | |
| | education other | | |

Table 12 Home Program: Modalities

| Home Program: Modalities | | | |
|---------------------------------|------------------------|------------------------|-------------------------------|
| Purpose (goal is to address) | Туре | Location | Format |
| pain management | kinesiotape | shoulder | verbal instructions/education |
| positioning | heat | flexion | demonstration |
| promote active movement | hot pack | extension | handout provided |
| skin care | paraffin | abduction | |
| scar care | cryotherapy | adduction | |
| | ice pack | external rotation | |
| | ice massage | internal rotation | |
| | bio freeze | scapular stabilization | |
| | skin care education | elbow | |
| | scar care education | flexion | |
| | scar pad | extension | |
| | electrical stimulation | forearm | |
| | other | supination | |
| | | pronation | |
| | | wrist | |
| | | flexion | |
| | | extension | |
| | | finger/thumb | |
| | | flexion | |
| | | extension | |
| | | adduction | |
| | | abduction | |

Table 13 *Home Program: Splinting*

| | Splinting | | | | |
|---------------------------------|------------------------------|--------------------|---|-------------------------------|--|
| Purpose (goal is to address) | Туре | Fabrication | Wear Schedule | Format | |
| positioning | long basic opponens (LBO) | prefabrication | night time and naps | verbal instructions/education | |
| increase range of motion | short basic opponens (SBO) | static | night only | demonstration | |
| post-operative protection | wrist cock-up | dynamic | all the time except bathing and exercises | handout provided | |
| check fit/review/re- educate | resting hand splint | static progressive | other | | |
| | elbow extension splint | brand | | | |
| | supinator strap | size | | | |
| | pronator strap | custom | | | |
| | S4 garment | static | | | |
| | neoprene sleeve | dynamic | | | |
| | other | static progressive | | | |
| | | material | | | |
| | | adjustment | | | |
| | | static | | | |
| | | dynamic | | | |
| | | static progressive | | | |
| | | other | | | |

Table 14 Home Program: Activities of Daily Living and Hand Use

| Home Program: ADLs/IADLs (home and school), Hand Use | | | |
|--|---|------------------------|--|
| Purpose (goal is to address) | Strategies | Format | |
| | | verbal | |
| Activities of Daily Living | adapted environment | instructions/education | |
| dressing | adapted task | demonstration | |
| UE dressing | one handed typing | handout provided | |
| LE Dressing | one handed shoe tying | | |
| Fasteners | one handed dressing | | |
| bathing | one handed technique for bra | | |
| washing hair | one handed make-up | | |
| washing body | one handed technique to style hair | | |
| | other | | |
| grooming | adapted equipment | | |
| hair | button hook | | |
| brushing teeth | zipper pull | | |
| washing hands | shoe buttons | | |
| nails | elastic shoe laces | | |
| washing face | long handle hair brush | | |
| applying make-up | long handle hair washer | | |
| eye care | toothpaste holder | | |
| deodorant | one handed nail clipper | | |
| toileting | one handed cutting board | | |
| self feeding | stand for pots/pans | | |
| other | rocker knife | | |
| Instrumental Activities of Daily Living | one handed hair tie | | |
| care of pets | table top scissors | | |
| helping with chores | pencil grips | | |
| meal prep/cooking | other | | |
| driving | provide written restrictions/accommodations | | |
| other | no weight bearing on upper extremity | | |
| School Concerns | other | | |
| cutting | provide written recommended accommodations | | |
| writing | no push-ups/pull-ups | | |
| managing supplies | allow to stop with fatigue or pain | | |
| computer use | modify or eliminate impact activities | | |
| PE / School accommodations | use of adapted equipment at school | | |
| | | | |
| other Bilateral hand use, initiation of hand | other | | |
| use | bilateral hand skills: play/function based | | |
| | modified constraint | | |
| | other | | |

Table 15 Home Program: Psychosocial and Education on Diagnosis

| Home Program: Psychosocial / Education on Diagnosis | | | |
|---|--|-------------------------------|--|
| Purpose (goal is to address) | Strategies | Format | |
| bullying / teasing | increase dialogue between pt and caregiver | verbal instructions/education | |
| expressing self/ feelings | provide patient with example responses | demonstration | |
| education on diagnosis | provide explanation of diagnosis | handout provided | |
| | see referrals and accommodations section | | |

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Table 16
Education on Transportation and Car Seats

| Education on Transportation / Car Seat | | | |
|--|-------------------------------|---------------------|--|
| Purpose (goal is to address) | Format | | |
| transportation needs in cast | provide Hippo car Seat | verbal instructions | |
| | check fit of current car seat | demonstration | |
| | | handout provided | |

Table 17 Referrals

| Referrals | | | | |
|--|---|-------------------------------|--|--|
| Purpose (goal is to address) | Referral to | Format | | |
| bullying / teasing | child life | verbal instructions/education | | |
| behavioral concerns | therapeutic recreation | handout provided | | |
| community based therapy | psychology | | | |
| school based therapy | school/ECI | | | |
| participation in community activities/sports | outpatient/home health | | | |
| dietary concerns | family services / resource center / social worker | | | |
| orthotic needs | orthotics | | | |
| driving | dietitian | | | |
| future needs for school/work | DARS / Texas Rehab Commission | | | |
| other | other | | | |

APPENDIX I

Classification of Neonatal Brachial Plexus Palsy Intervention

Documentation Form

Classification of Neonatal Brachial Plexus Palsy

| Patient's Name: | |
|------------------------|--|
| Medical Record Number: | |
| Therapist: | |

| Intervention Documentation Form | | | | | Medic Therap | | ord Number: | | | |
|---------------------------------|---------------------------------------|---------------|-------------------------|--|----------------------------------|------------|----------------|------------------|---------------------------------------|--------------|
| Date: | | | | | | | | | | |
| Colla | Collaboration: (check all that apply) | | | | | | | | | |
| | Hand surgeon | | | Dietitian | · D | | | Nursing | | |
| | Physical | | • | | Therapeut | ic Recrea | ation | | Physician assistant | |
| | | onal therap | oist | | Orthotist | | | | Psychology | |
| | Child life | | 11 .1 . | 1 \ | Radiology | 7 | | | | |
| Negat | | rs: (check a | II that app | oly) | 1~ | | | | T = . | |
| | Behavior | al issue | | | Cognitive | | | | Pain | |
| | Fatigue | _ | | | Patient Sle | eeping | | | Psychosocial | factors |
| | Cultural | | | | | | | | | |
| Thera | * | | all that a | pply – | circle most p | oredomin | ant by a | amoun | · · · · · · · · · · · · · · · · · · · | |
| | Affirms | efforts | | | Encourages | | | | Active | |
| | | | | | | | | | listening/paraphrasing | |
| | | ates with pt | | | Provides ver | | | | Provides physical assist | |
| | | s to adapt t | he | | Strategies to | adapt ta | sk/s | | Provides/recommends | |
| | environn | | | | D . | 1 111.1 | | | equipment | |
| | Provides | education | | Recommends additional assessment/referrals | | | | | | |
| T21 | . (/ . 1 | 111 .1 | 1 | | assessment/r | referrals | | | | |
| Evaiu | | eck all that | | | GODIA | | | | | |
| | | Hand Ass | essment | | COPM | | | Dev/Fx checklist | | |
| | PODCI | ** 1.4 | | | Body Mass Index Semmes Weinstein | | | MMT | | |
| | | Humeral A | | | | | | | Stereognosis | |
| Patier | | , | ct I, highe | | el of participa | ation) | | | | r |
| | | sistive | | | assive | | Act | ive | | Engaged |
| Famil | • • • | | et 1, highe | | el of participa | ation) | | | | |
| Resistive | | | Pa | assive | | Act | ive | | Engaged | |
| Home | Programs | s / Intervent | tion: (writ | e in n | umerical valu | ies in eac | ch categ | ory fo | r each interventi | on provided) |
| Purpose/goal Movement / Strat | | egies , | / Type / Loca Referi | | bricatio | n / We | ear Schedule / | Format | | |
| | | | | | | | | | | |
| | | | | | | | | | | |
| | | | | | | | | | | |
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| 0.1 | | . /IC 11 1 | | | | | | | | |

| Juier comments/reedo | ack. | | |
|----------------------|------|--|--|
| | | | |
| | | | |
| | | | |

Appendix J

Classification - Extended Version with Definitions and Numbers for Coding

| Overall Session Information | | | | | |
|------------------------------------|---|--|--|--|--|
| Basic Information | | | | | |
| date | date of clinic visit (limited to brachial plexus palsy clinic at this time, excludes post-op hand, inpatient) | | | | |
| patient Name | patient's name | | | | |
| patient Number | patient's Medical Record Number | | | | |
| therapist's Name | therapist's name | | | | |
| interpreter needed | identify if an interpreter was needed to communicate with the patient or family | | | | |
| Collaboration | | | | | |
| hand surgeon | | | | | |
| physical therapist | | | | | |
| occupational therapist | | | | | |
| nursing | | | | | |
| physician assistant | collaboration is defined as direct interaction (with the therapist or the patient) with a professional at the pediatric I | | | | |
| psychology | or in the community related to the patient's plan of care (during the patient's clinical visit) - this includes face to face a | | | | |
| child life | telephone conversations; a referral does not count as collaboration and will be documented in the referrals section | | | | |
| radiology | | | | | |
| therapeutic recreation | | | | | |
| orthotist | | | | | |
| dietitian | | | | | |
| Negative Factors Impacting Session | | | | | |
| behavioral issue | the patient's or family's behavior impedes the therapist's ability to complete assessment and/or treatment | | | | |
| cognitive issue | the patient's or family's cognitive ability impedes the therapist's ability to complete assessment and/or treatment | | | | |
| pain | the patient's pain level impedes the therapist's ability to complete assessment and/or treatment | | | | |
| fatigue | the patient's or family's fatigue/decreased level of alertness impedes the therapist's ability to complete assessment and/or treatment | | | | |
| patient sleeping | patient is sleeping and is unable to be woken up or family does not allow patient to be woken up and it impedes assessment and/or treatment | | | | |

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| | the family's attitude toward the patient or negative family expectations impedes the therapist's ability to complete |
|---|---|
| psychosocial factors | assessment and/or treatment |
| | the patient's or family's cultural beliefs or customs impede the therapist's ability to complete assessment and/or |
| cultural issue | treatment |
| | therapist actions are observable actions that the therapist does during a session with patient and family including |
| Therapist Actions | psychosocial facilitation, verbal support, physical support, modification and education |
| Psychosocial Facilitation | |
| | therapist verbally praises patient or family for compliance with plan of care/attempt at plan of care, or for additional |
| affirms efforts / encourages | positive strategies; therapist encourages patient or family to initiate or continue plan of care (attempt to persuade) |
| | therapist listens to patient/family, paraphrases what she has heard and repeats it back to the family to confirm |
| active listening/paraphrasing; collaborates | understanding; therapist works with the family to establish goals and plan of care, requires active participation of both |
| with pt/ family | parties |
| Verbal Support | |
| | therapist provides verbal cues during the treatment portion of the session (do not document verbal cues used during |
| provides verbal cues | assessment), when patient is demonstrating an exercise or an activity and the therapist provides verbal support |
| Physical Support | |
| | therapist provides physical cues/assist during the treatment portion of the session (do not document physical assist used |
| provides physical assist | during assessment), when patient is demonstrating an exercise or an activity and the therapist provides physical support |
| Modification | |
| | therapist provides recommendations/suggestions or demonstrates ways to adapt the environment to increase the |
| strategies to adapt the environment | patient's function |
| | therapist provides recommendations/suggestions or demonstrates ways to adapt a task/s to increase the patient's |
| strategies to adapt task/s | function |
| provides/recommends equipment | therapist provides or recommends adapted or exercise equipment to increase the patient's function |
| Education | |
| | therapist provides patient/family with education (ex: diagnosis, treatment/home program, resources, parenting |
| provides education | techniques/skills, etc) |
| recommends additional | |
| assessment/referrals | therapist recommends additional assessment and referrals (allied health, school based, other) |

| Overall Patient / Family Response | | | | |
|---------------------------------------|--|--|--|--|
| Patient Participation Overall Session | | | | |
| resistive | resisted/ignored therapist's verbal/physical prompts/instruction - actively refuses to participate or resisted | | | |

| passive | listened but failed to collaborate or take action during session - is inactive during the session | | |
|--------------------------------------|--|--|--|
| active | participated and interacted during session - engaged in play, verbalized understanding, returned demonstration | | |
| engaged | initiated discussions; took active role in problem solving, motivated (Not applicable for young children) | | |
| Family Participation Overall Session | | | |
| resistive | resisted/ignored therapist's verbal/physical prompts/instruction - actively refuses to participate | | |
| passive | listened but failed to collaborate or take action during session - is inactive during the session | | |
| active | participated and interacted during session - verbalized understanding, returned demonstration | | |
| engaged | initiated discussions; took active role in problem solving, motivated | | |

| | | A: Home Program: Range of Motion and Strength | | | | | |
|-----|-------------------------|---|---|--|--|--|--|
| | | Purpose (goal is to address) | | | | | |
| | 1 | passive range of motion | therapist or equipment moves the joint through the range of motion with no effort from the patient | | | | |
| 103 | 2 | active assist range of motion | patient uses the muscles surrounding the joint to perform the exercise but requires some help from the therapist or equipment | | | | |
| | 3 | active range of motion | patient performs the exercise to move the joint without any assistance to the muscles surrounding the joint | | | | |
| | 4 | strengthening | patient performs exercises to increase strength in muscles | | | | |
| | | Movement | | | | | |
| | 5 | shoulder | joint connecting the arm with the torso | | | | |
| | 6 | flexion | movement of the humerus anteriorly in the sagittal plane | | | | |
| | 7 | extension | movement of the humerus posteriorly in the sagittal plane | | | | |
| | 8 | abduction | movement of the humerus laterally in the frontal plane | | | | |
| | 9 | adduction | movement of the humerus medially in the frontal plane | | | | |
| | 10 horizontal adduction | | movement of the arm toward midline in a transverse plane | | | | |
| Ī | 11 | horizontal abduction | movement of the arm away from the midline in a transverse plane | | | | |
| | 12 | external rotation | movement of the humerus laterally around the longitudinal axis of the humerus with the arm in adduction | | | | |

| 13 | internal rotation | movement of the humerus medially around the longitudinal axis of the humerus |
|----|---------------------|--|
| 14 | scapula stabilizers | muscles that stabilize the scapula |
| 15 | elbow | |
| 16 | flexion | movement of the supinated forearm anteriorly in the sagittal plane |
| 17 | extension | movement of the supinated forearm posteriorly in the sagittal plane |
| 18 | forearm | |
| 19 | supination | rotation of the forearm laterally around its longitudinal axis from midposition so that the palm of the hand faces up |
| 20 | pronation | rotation of the forearm medially around its longitudinal axis from midposition so that the palm of the hand faces down |
| 21 | wrist | |
| 22 | flexion | movement of the hand volarly in the sagittal plane |
| 23 | extension | movement of the hand dorsally in the sagittal plane |
| 24 | finger/thumb | |
| 25 | flexion | movement of fingers or thumb toward the volar surface - making a fist |
| 26 | extension | movement of fingers or thumb away from volar surface - opening hand |
| 27 | adduction | movement of fingers or thumb toward midline |
| 28 | abduction | movement of fingers or thumb away from midline |
| 29 | grasp | |
| 30 | gross grasp | making a fist or fist like movement to grasp an object |
| 31 | pincer | grasp pattern using thumb and index finger |
| 32 | tripod | grasp pattern using thumb, index and middle finger |
| 33 | lateral (key) | grasp pattern with thumb opposed to the middle phalanx of the index finger |
| 34 | reciprocal pattern | |
| | Strategies | |
| 35 | specific exercises | therapist provides strengthening and ROM exercises specific to patient's needs / deficits |
| 36 | theraband | therapist provides exercises using a theraband |

| 37 | theraputty | therapist provides exercises using theraputty |
|----|--|---|
| 38 | pendulum exercises | therapist provides HEP on pendulum exercises - ROM at the shoulder using body movement and momentum |
| 39 | place and hold | therapist provides exercises where the patient's UE is placed in a specific position and asked to hold the position |
| 40 | combined with passive scapular stabilization | therapist provides exercises that stabilize the scapula while the exercise is completed |
| 41 | scapular stabilization young child | therapist provides TSRHC HEP with play based activities that promote scapular stabilization |
| 42 | scapular stabilization older child | therapist provides TSRHC HEP with ROM and strengthening exercises that promote scapular stabilization |
| 43 | play / function based activities | therapist recommends specific play based and function based activities that promote ROM and strength |
| 44 | reaching for play items | to increase shoulder abduction, flexion, external rotation, supination, elbow extension, etc |
| 45 | playing with large ball | to improve scapular stabilization, shoulder flexion, shoulder extension, etc |
| 46 | holding hula hoop with 2 hands above head | to improve shoulder flexion, elbow extension, grasp, etc |
| 47 | making tunnel out of cushions, crawling | to improve reciprocal pattern, weight bearing through bilateral upper extremities |
| 48 | swimming | to improve overall use of upper extremity and reciprocal pattern |
| 49 | putting on hats or necklaces overhead | to improve shoulder flexion, shoulder abduction, external rotation, elbow extension, bilateral hand use |
| 50 | swinging on a swing | to improve external rotation, grasp |
| 51 | pushing a cart with weighted toys | to improve scapular stabilization |
| 52 | reaching up for monkey bars | to improve shoulder flexion, elbow extension, grasp |
| 53 | making snow angels | to improve shoulder abduction, elbow extension |
| 54 | twisting open containers | to increase independence and improve hand function |
| 55 | playing dress up | to increase independence with dressing, fasteners, bilateral upper extremity use |
| 56 | singing songs with hand motions | improve fine motor skills, active range of motion in upper extremity, bilateral hand use |
| 57 | opening drawers | improve shoulder extension, external rotation, grasp |
| 58 | wheelbarrow | improve scapular stabilization, weight bearing in upper extremities |
| 59 | modified constraint | to improve spontaneous use of involved upper extremity (glove, mitten, oven mitt, hand holding) |
| 60 | other | |

| | Format | |
|----|-------------------------------|---|
| 61 | verbal instructions/education | therapist provides verbal instructions and education on exercises / activities to improve ROM or strength |
| 62 | demonstration | therapist provides demonstration of exercises / activities to improve ROM or strength |
| 63 | handout provided | therapist provides handout explaining exercises / activities to improve ROM or strength |
| | therapist observes returned | |
| 64 | demonstration | therapist observes the patient or the family demonstrating the home program provided by the therapist |

| | B: Home Program: Positioning and Sensation | | |
|----|---|--|--|
| | Purpose (goal is to address) | | |
| 65 | infant/toddler decreased movement | pt has decreased movement/sensation in UE and positioning is needed to protect UE | |
| 66 | child/teen with pain/limb length difference | pt presents with pain in shoulder/neck due to limb length discrepancy | |
| 67 | finger biting | pt is biting fingers due to difference in sensation | |
| 68 | awareness of decreased sensation | pt has decreased sensation in UE and is unaware of potential harm | |
| 69 | positioning after surgery/edema control | pt is s/p surgical intervention and is at risk for swelling/edema | |
| 70 | decrease risk of shoulder dislocation | pt is at risk of shoulder dislocation/subluxation and needs recommendations to reduce the risk | |
| | Strategies | | |
| 71 | safety pin | safety pin is used to pin infants shirt sleeve to front of the shirt for positioning | |
| 72 | cuff and collar | loop around the back of the child's neck (like a collar) and wrist made out of velfoam and Velcro for positioning | |
| 73 | towel/blanket roll | a rolled up towel or blanket are placed in the infants swing, car seat, etc to position the involved UE | |
| 74 | sensory textures | pt's parents/caregivers encouraged to materials with soft textures (cotton ball, wash cloth, etc) to provide input to the involved UE | |
| 75 | place arm on raised surface for typing/studying | patients with limb length differences with pain in the involved shoulder/neck are encourage to position arm on raised surface to decrease stretch across the joint | |
| 76 | mittens/gloves to cover hands | mittens/gloves/sock used to cover hands to decrease/prevent finger biting | |
| 77 | elevation pillow | pillow used to after surgical intervention to decrease/prevent swelling/edema | |
| 78 | education on tummy time | education on modifying tummy time for infants to reduce the risk of posterior shoulder dislocation | |
| 79 | education other | provided education on positioning and sensation not included above | |
| | Format | | |
| 80 | verbal instructions/education | therapist provides verbal instructions and education on positioning and sensation | |

| 81 | demonstration | therapist provides demonstration of positioning and sensation |
|----|---|---|
| 82 | handout provided | therapist provides handout explaining positioning and sensation strategies/education |
| 83 | therapist observes returned demonstration | therapist observes the patient or the family demonstrating the home program provided by the therapist |

| | | C: Home Program: Modalities | | |
|-----|-----|------------------------------|--|--|
| | | Purpose (goal is to address) | | |
| | 84 | pain management | decrease pain in involved UE | |
| | 85 | positioning | promote positioning/posture to increase function, decrease pain | |
| | 86 | promote active movement | improve/increase active range of motion in involved UE | |
| | 87 | skin care | improve appearance/integrity of skin (typically s/p cast removal) | |
| | 88 | scar care | improve appearance of scar / decrease scar tissue | |
| 2 _ | | Туре | | |
| ¹ _ | 89 | kinesiotape | elastic therapeutic tape used to inhibit or promote muscle contraction | |
| | 90 | heat | warm and/or moist heat applied to muscles as a therapeutic modality | |
| | 91 | hot pack | type of heat modality | |
| | 92 | Paraffin | waxy solid that is heated and used as a type of heat modality | |
| | 93 | cryotherapy | cold/cool temperature applied to muscles as a therapeutic modality | |
| | 94 | ice pack | type of cryotherapy | |
| | 95 | ice massage | massage applied using ice as therapeutic modality | |
| | 96 | bio freeze | pain relieving gel | |
| | 97 | skin care education | patient educated on washing, applying lotion to skin | |
| | 98 | scar care education | patient educated on scar care and scar massage | |
| | 99 | scar pad | patient provided with self adhesive silicone product to soften, smooth, flatten scar | |
| | 100 | electrical stimulation | electrical current used to make a single muscle or group of muscles contract | |

| | Location | |
|-----|-------------------------------|--|
| 101 | shoulder | joint connecting the arm with the torso |
| 102 | flexion | movement of the humerus anteriorly in the sagittal plane |
| 103 | extension | movement of the humerus posteriorly in the sagittal plane |
| 104 | abduction | movement of the humerus laterally in the frontal plane |
| 105 | adduction | movement of the humerus medially in the frontal plane |
| 106 | external rotation | movement of the humerus laterally around the longitudinal axis of the humerus with the arm in adduction |
| 107 | internal rotation | movement of the humerus medially around the longitudinal axis of the humerus |
| 108 | scapular stabilization | muscles that stabilize the scapula |
| 109 | elbow | |
| 110 | flexion | movement of the supinated forearm anteriorly in the sagittal plane |
| 111 | extension | movement of the supinated forearm posteriorly in the sagittal plane |
| 112 | forearm | |
| 113 | supination | rotation of the forearm laterally around its longitudinal axis from midposition so that the palm of the hand faces up |
| 114 | pronation | rotation of the forearm medially around its longitudinal axis from midposition so that the palm of the hand faces down |
| 115 | wrist | |
| 116 | flexion | movement of the hand volarly in the sagittal plane |
| 117 | extension | movement of the hand dorsally in the sagittal plane |
| 118 | finger/thumb | |
| 119 | flexion | movement of fingers or thumb toward the volar surface - making a fist |
| 120 | extension | movement of fingers or thumb away from volar surface - opening hand |
| 121 | adduction | movement of fingers or thumb toward midline |
| 122 | abduction | movement of fingers or thumb away from midline |
| | Format | |
| 123 | verbal instructions/education | therapist provides verbal instructions and education on modalities |
| 124 | demonstration | therapist provides demonstration of using modalities |

| 125 | handout provided | therapist provides handout explaining modalities |
|-----|-----------------------------|---|
| | therapist observes returned | |
| 126 | demonstration | therapist observes the patient or the family demonstrating the home program provided by the therapist |

| | D: Splinting | | |
|-----|------------------------------|--|--|
| | Purpose (goal is to address) | | |
| 127 | positioning | patient has decreased positioning of joint in involved UE that can be supported with a splint | |
| 128 | increase range of motion | patient has decreased ROM at a joint that can be improved with splinting | |
| 129 | post-operative protection | patient is s/p surgical intervention and requires a splint to protect operative site | |
| 130 | check fit/review/re-educate | patient already has the splint and needs additional education or the fit of the splint needs to be checked | |
| | Туре | | |
| 131 | LBO | long basic opponens used to splint thumb and wrist | |
| 132 | SBO | short basic opponens used to splint thumb | |
| 133 | wrist cock-up | splint used to support or immobilize the wrist with the fingers free | |
| 134 | resting hand splint | resting hand splint used to splint hand and wrist in functional/resting position | |
| 135 | elbow extension splint | splint used to increase elbow extension | |
| 136 | supinator strap | strap used to increase supination | |
| 137 | pronator strap | strap used to increase pronation | |
| 138 | S4 garment | garment used to promote scapular stabilization and posture | |
| 139 | neoprene sleeve | flexible garment made out of neoprene used to provide support to a joint | |
| 140 | other | | |
| | Fabrication | | |
| 141 | prefabrication | splint is fabricated by a company | |
| 142 | static | splint that has no moving parts, primarily used to support, stabilize, protect or immobilize | |
| 143 | Dynamic | splint that has moving parts to restore movement | |

| 144 | static progressive | uses nondynamic components (turnbuckles, Velcro, etc) to create force to regain motion, adjustments made without remolding |
|-----|---|--|
| 145 | brand | brand of the prefabricated splint |
| 146 | Benik | prefabricated splint made by Benik |
| 147 | Ottobock | prefabricated splint made by Ottobock |
| 148 | other | |
| 149 | custom | splint is fabricated by a therapist, custom |
| 150 | static | splint that has no moving parts, primarily used to support, stabilize, protect or immobilize |
| 151 | dynamic | splint that has moving parts to restore movement |
| 152 | static progressive | uses nondynamic components (turnbuckles, Velcro, etc) to create force to regain motion, adjustments made without remolding |
| 153 | material | material used to make the custom splint (example: 1/6 inch aquaplast) |
| 154 | 1/16 inch aquaplast | a plastic material that softens in water and hardens when cooled that is 1/16 inch thick |
| 155 | 1/8 inch aquaplast | a plastic material that softens in water and hardens when cooled that is 1/8 inch thick |
| 156 | Other | |
| 157 | adjustment | therapist makes adjustments to current splint |
| 158 | static | splint that has no moving parts, primarily used to support, stabilize, protect or immobilize |
| 159 | dynamic | splint that has moving parts to restore movement |
| 160 | static progressive | uses nondynamic components (turnbuckles, Velcro, etc) to create force to regain motion, adjustments made without remolding |
| | Wear Schedule | the scheduled amount of time the patient wears the splint |
| 161 | night time and naps | patient wears the splint during nap time (younger children) and at night |
| 162 | night only | night |
| 163 | all the time except bathing and exercises | patient wears the splint all of the time (day and night) expect when taking a bath or doing exercises with the involved UE |
| 164 | other | |
| | Format | |
| 165 | verbal instructions/education | therapist provides verbal instructions and education on splint wear and care |
| 166 | demonstration | therapist provides demonstration on splint wear and care |

| 167 | handout provided | therapist provides handout explaining splint wear and care |
|-----|-----------------------------|---|
| | therapist observes returned | |
| 168 | demonstration | therapist observes the patient or the family demonstrating the home program provided by the therapist |

| | | E: Home Program: ADLs/IADLs (home and school), Hand Use | | |
|-----|-----|---|--|--|
| | | Purpose (goal is to address) | | |
| 1 | 169 | activities of daily living | activities that are oriented toward taking care of one's own body (OTPF-II) | |
| | 170 | dressing | selecting clothing and accessories appropriate to time of day, weather, and occasion; obtaining clothing from storage area; dressing and undressing in a sequential fashion; fastening and adjusting clothing and shoes; and applying and removing personal devices, prostheses, or orthoses (OTPF-II) | |
| _ 1 | 171 | UE dressing | upper body dressing (shirt, coat, bra, etc) | |
| 1 | 172 | LE dressing | lower body dressing (pants, underwear, socks, shoes, etc) | |
| 1 | 173 | fasteners | buttons, snaps, zippers, ties, etc | |
| 1 | 174 | bathing | obtaining and using supplies; soaping, rinsing, and drying body parts; maintaining bathing position; and transferring to and from bathing positions. (OTPF-II) | |
| 1 | 175 | washing hair | washing hair, gathering supplies, getting shampoo out of container, washing and rinsing | |
| 1 | 176 | washing body | washing body including gathering supplies, using soap/body wash and rinsing | |
| 1 | 177 | grooming | obtaining and using supplies; removing body hair (e.g., use of razors, tweezers, lotions);applying and removing cosmetics; washing, drying, combing, styling, brushing, and trimming hair; caring for nails (hands and feet); caring for skin, ears, eyes, and nose; applying deodorant; cleaning mouth; brushing and flossing teeth; or removing, cleaning, and reinserting dental orthotics and prosthetics. (OTPF-II) | |
| 1 | 178 | hair | combing/brushing, styling hair | |
| 1 | 179 | brushing teeth | gathering supplies, sequencing steps, putting toothpaste on toothbrush, brushing teeth, rinsing | |
| 1 | 180 | washing hands | gathering supplies, sequencing steps, using soap, washing, rinsing | |
| 1 | 181 | nails | gathering supplies, trimming, cleaning, painting nails | |
| 1 | 182 | washing face | gathering supplies, washing face, rinsing face | |
| 1 | 183 | applying make-up | putting make-up on (foundation, blush, mascara, lipstick, etc) | |
| 1 | 184 | eye care | putting in/taking out contacts, taking care of glasses, putting in eye drops, etc | |
| 1 | 185 | deodorant | opening deodorant, putting deodorant on | |

| 186 | toileting | obtaining and using supplies; clothing management; maintaining toileting position; transferring to and from toileting position; cleaning body; and caring for menstrual and continence needs (including catheters, colostomies, and suppository management). (OTPF-II) |
|-----|--|--|
| 187 | self feeding | the process of setting up, arranging, and bringing food [or fluid] from the plate or cup to the mouth; sometimes called self-feeding (OTPF-II) |
| 188 | instrumental activities of daily living | activities to support daily life within the home and community that often require more complex interactions than self-care used in ADL. (OTPF-II) |
| 189 | care of pets | arranging, supervising, or providing the care for pets and service animals. (OTPF-II) |
| 190 | helping with chores | completing or assisting with age appropriate chores in the home |
| 191 | meal prep/cooking | planning, preparing meals and cleaning up afterward |
| 192 | driving | control and operation of a motor vehicle |
| 193 | school concerns | patient or parent concerns related to school (academic, management of supplies, performance of activities at school |
| 194 | cutting | using scissors to cut |
| 195 | writing | the skill of writing words on paper |
| 196 | managing supplies | keeping up with and handling supplies (back pack, lunch box, zipper bag, locker, opening loch packages, etc) |
| 197 | computer use | using the computer to type, using the mouse to complete school work |
| 198 | PE / school accommodations | pt needs to obtain PE or school accommodations to independently and successfully access education |
| 199 | bilateral hand use, initiation of hand use | |
| | Strategies | |
| 200 | adapted environment | therapist makes recommendations to change the environment to promote success/independence |
| 201 | adapted task | therapist makes recommendations to change/adapt the task to promote success/independence |
| 202 | one handed typing | typing technique that only uses one hand for typing on a keyboard |
| 203 | one handed shoe tying | technique using one hand to tie shoes or non dominant hand as a support only |
| 204 | one handed dressing | technique using one hand for dressing, or non dominant hand as a support only |
| 205 | one handed technique for bra | technique using one hand for putting bra on or non dominant hand as a support only |
| 206 | one handed make-up | technique using one hand for putting make-up on or the non dominant UE as a support only |
| 207 | one handed technique to style hair | technique using one hand for styling hair or non dominant hand as a support only |
| 208 | adapted equipment | devices used to assist with completing activities of daily living or instrumental activities of daily living |
| 209 | button hook | a hook for drawing buttons through a button hole |

| 210 | zipper pull | device attached to zipper to assist with independent zipping | | |
|--|---|--|--|--|
| 211 | shoe buttons | round button placed in the shoe lace hole to assist in fastening a shoe | | |
| 212 | elastic shoe laces | shoelaces with elastic that do not require for shoes to be tied/untied to remove/put on the shoe | | |
| 213 | long handle hair brush | a hair brush with an extended handle to allow a person with decreased UE ROM to reach their hair | | |
| 214 | long handle hair washer | a brush with rubber tips and an extended handle to allow a person with decreased UE ROM to wash their hair | | |
| 215 | toothpaste holder | an assistive device that holds a tube of toothpaste to assist with independence with putting toothpaste on a toothbrush | | |
| 216 | one handed nail clipper | a nail clipper on a board and suction cups on the bottom to allow for one handed nail clipping | | |
| 217 | one handed cutting board | cutting board with assistive devices to increase independence with cutting food using one hand | | |
| 218 | stand for pots/pans | stand that can be used on the stove or counter top to hold a pot/pan in place to increase independence with one handed cooking | | |
| 219 | rocker knife | knife with a rounded blade that cuts using a rocking motion | | |
| 220 | one handed hair tie | hair tie that only requires one hand put hair in a pony tail | | |
| 221 | table top scissors | scissors that are placed on the table to increase independence with one handed cutting | | |
| 222 | pencil grips | a variety of foam or plastic devices that can be placed on a pencil to improve pencil grasp and/or comfort | | |
| 223 | provide written restrictions/accommodations | therapist/physician provides restrictions in writing for outside therapist or school | | |
| 224 | no weight bearing on upper extremity | examples of written restrictions/accommodations | | |
| 225 | provide written recommended accommodations | | | |
| 226 | no push-ups/pull-ups | | | |
| 227 | allow to stop with fatigue or pain | | | |
| 228 | modify or eliminate impact activities | | | |
| 229 use of adapted equipment at school | | | | |
| 230 | bilateral hand skills: play/function based | activities to promote bilateral hand use (ex: blocks, playdoh, putting toothpaste of toothbrush, etc) | | |
| 231 | modified constraint | educating parents on using a modified constraint program at home to promote use of involved UE during play/activities | | |
| 232 | other | | | |
| | Format | | | |
| 233 | verbal instructions/education | therapist provides verbal instructions and education on ADLs/IADLs for home or school | | |

| 234 | demonstration | therapist provides demonstration of ADLs/IADLs for home or school | |
|-----------------------------|--|---|--|
| 235 | 5 handout provided therapist provides handout explaining ADLs/IADLs for home or school | | |
| therapist observes returned | | therapist observes the patient or the family demonstrating the home program provided by the therapist | |

| | F: Home Program: Psychosocial | | |
|---|--|--|--|
| | Purpose (goal is to address) | | |
| 237 | bullying / teasing | patient presents with a concern that they are being bullied or teased | |
| 238 | expressing self/ feelings | patient has difficulty expressing themselves or their feelings related to their involved upper extremity | |
| 239 | education on diagnosis | patient is not able to verbalize a basic description of their diagnosis | |
| | Strategies | | |
| 240 | increase dialogue between pt and caregiver | therapist encourages the patient and family to talk about pt's diagnosis, feelings/concerns related to diagnosis | |
| 242 | provide patient with example responses | therapist provides pt/family with examples of how to answer questions about diagnosis or how to cope with bullying/teasing | |
| 242 | provide explanation of diagnosis | therapist provides education on NBPP diagnosis, gives pt/family words to explain diagnosis to peers | |
| | see referrals and accommodations section | | |
| | Format | | |
| 243 | verbal instructions/education | therapist provides verbal instructions and education on psychosocial home program | |
| 244 | demonstration | therapist provides demonstration of implementing psychosocial home program | |
| 245 handout provided therapist provides handout explaining strategies to hand | | therapist provides handout explaining strategies to handle psychosocial concerns | |
| 246 | therapist observes returned demonstration | therapist observes the patient or the family demonstrating the home program provided by the therapist | |

| | G: Education On Transportation / Car seat | | |
|-----|---|--|--|
| | Purpose (goal is to address) | | |
| 247 | transportation needs in cast | patient does not fit in current car seat due to cast s/p surgical intervention | |

| | Strategies | | |
|-----|---|---|--|
| 248 | provide Hippo car seat | patient is provided with a Hippo car seat to accommodate cast s/p surgical intervention | |
| 249 | check fit of current car seat | therapist checks fit of current car seat and makes recommendations | |
| | Format | | |
| 250 | verbal instructions | therapist provides verbal instructions and education on car seat | |
| 251 | demonstration | therapist provides demonstration of car seat | |
| 252 | handout provided | therapist provides handout explaining car seat | |
| 253 | therapist observes returned demonstration | therapist observes the patient or the family demonstrating the home program provided by the therapist | |

| | | H: Referrals | | | | |
|--|---|--|--|--|--|--|
| | | Purpose (goal is to address) | | | | |
| | 254 | bullying / teasing | patient presents with a concern that they are being bullied or teased | | | |
| 2 2 | 255 | behavioral concerns | patient presents with concerns related to behavior that are impacting development, independence, performance | | | |
| | 256 | community based therapy | patient presents with needs requiring additional therapeutic intervention | | | |
| | 257 | school based therapy | patient presents with needs requiring school based therapy intervention | | | |
| | 258 | participation in community activities/sports | patient presents with decreased participation in community activities and would like resources | | | |
| | 259 | dietary concerns | patient presents with concerns related to eating or weight management | | | |
| | 260 orthotic needs patient presents with a need for an upper extremity orthosis | | patient presents with a need for an upper extremity orthosis | | | |
| | 261 | driving | patient presents with concerns related to driving or adapting vehicle for driving | | | |
| | 262 | future needs for school/work | patient presents with questions or concerns related to higher education or employment | | | |
| | | Referral to | | | | |
| | 263 | child life | additional disciplines and community based therapy resources to address the above goals and needs | | | |
| 264 therapeutic recreation additional disciplines and community based therapy resources to add | | therapeutic recreation | additional disciplines and community based therapy resources to address the above goals and needs | | | |
| | 265 | psychology | additional disciplines and community based therapy resources to address the above goals and needs | | | |
| | 266 | school/ECI | additional disciplines and community based therapy resources to address the above goals and needs | | | |
| | 267 | 7 outpatient/home health additional disciplines and community based therapy resources to address the above goals and needs | | | | |

| 268 | family services / resource center / social worker | additional disciplines and community based therapy resources to address the above goals and needs | |
|-----|---|---|--|
| 269 | orthotics | additional disciplines and community based therapy resources to address the above goals and needs | |
| 270 | dietitian | additional disciplines and community based therapy resources to address the above goals and needs | |
| 271 | DARS / Texas Rehab Commission | The Texas Department of Assistive and Rehabilitative Services | |
| | Format | | |
| 272 | verbal instructions/education | therapist provides verbal instructions on referral source | |
| 273 | handout provided | handout provided related to referral | |

APPENDIX K

Feasibility Form

Classification of Neonatal Brachial Plexus Palsy Treatment Feasibility Study (cost and time)

| Patient's Name: |
|------------------------|
| Medical Record Number: |
| Therapist: |
| |

| Date: Current Process New process with classification |
|---|
| 1: Amount of time on assessment: |
| AMS Mallet AROM PROM ADLs AHA |
| COPM Developmental/Functional Checklist(new) |
| Current Developmental Screener Stereognosis BMI FACES |
| Semmes Weinstein other: other: |
| 2: Amount of time on treatment: |
| Home Program Equipment Referrals Forms |
| Splint Pre-fabricated Fabricated Adjustment |
| Evaluation Only other: other: |
| Additional information related to treatment: |
| |
| 3. Amount of time on documentation: (do not include this form) |
| Typical documentation Documentation (new form for classification) |
| Other comments/Feedback: |
| |
| Cost: |
| of assessments: |
| therapist's time: |
| |

APPENDIX L

Tables: Reliability Results

Table 18 Overall Inter-rater Reliability of Categorical Data

| Category | Карра | SE of Kappa | Level of Agreement |
|--|-------|-------------|--------------------|
| Collaboration | 0.975 | 0.015 | Excellent |
| Negative Factors | 0.907 | 0.093 | Excellent |
| Therapist's actions | 0.572 | 0.045 | Moderate |
| Most Predominant Therapist's action | 0.607 | 0.113 | Good |
| Evaluation | 1 | 0 | Perfect |
| Patient and Family Participation | 0.716 | 0.085 | Good |

Table 19 *Inter-rater Reliability: Collaboration*

| Collaboration | Карра | SE of Kappa | Level of Agreement |
|------------------------|-------|-------------|--------------------|
| Hand Surgeon | 1 | 0 | Perfect |
| Physical Therapist | 1 | 0 | Perfect |
| Occupational Therapist | 1 | 0 | Perfect |
| Child Life Specialist | 1 | 0 | Perfect |
| Dietitian | 1 | 0 | Perfect |
| Therapeutic Recreation | 1 | 0 | Perfect |
| Orthotist | 1 | 0 | Perfect |
| Radiology | 1 | 0 | Perfect |
| Nursing | 0.85 | 0.102 | Excellent |
| Physician Assistant | 0.839 | 0.157 | Excellent |
| Psychology | 1 | 0 | Perfect |

Table 20 *Inter-rater Reliability: Negative Factors*

| Negative Factors | Карра | SE of Kappa | Level of Agreement |
|---------------------|-------|-------------|--------------------|
| Behavioral Issue | 1 | 0 | Perfect |
| Fatigue | 1 | 0 | Perfect |
| Cultural Issue | 1 | 0 | Perfect |
| Cognitive Issue | 1 | 0 | Perfect |
| Patient Sleeping | 1 | 0 | Perfect |
| Pain | 0.839 | 0.157 | Excellent |
| Psychosocial Factor | 1 | 0 | Perfect |

Table 21
Inter-rater Reliability: Therapist's actions

| Therapist's actions | Kappa | SE of Kappa | Level of Agreement |
|--|-------|-------------|--------------------|
| Affirms Effort | 0.234 | 0.204 | Fair - Poor |
| Encourages | 0.043 | 0.164 | Fair – Poor |
| Active Listening / Paraphrasing | 0.368 | 0.181 | Fair - Poor |
| Collaborates with Patient and Family | 0.366 | 0.269 | Fair – Poor |
| Provides Verbal Cues | 0.154 | 0.187 | Fair - Poor |
| Provides Physical Assist | 0.085 | 0.183 | Fair – Poor |
| Strategies to Adapt the Environment | 0.268 | 0.258 | Fair - Poor |
| Strategies to Adapt the Task | 0.222 | 0.212 | Fair – Poor |
| Provides/Recommends Equipment | 0.627 | 0.169 | Good |
| Provides Education | 0.76 | 0.162 | Good |
| Recommends Additional Assessment / Referrals | 0.474 | 0.306 | Moderate |
| Most Predominant By Amount of Time | 0.572 | 0.045 | Moderate |

Table 22 *Inter-rater Reliability: Evaluation*

| Evaluation | Kappa | SE of Kappa | Level of Agreement |
|---|-------|-------------|--------------------|
| Assisting Hand Assessment | 1 | 0 | Perfect |
| Canadian Occupational Performance Measure | 1 | 0 | Perfect |
| Developmental/Functional Checklist | 1 | 0 | Perfect |
| PODCI | 1 | 0 | Perfect |
| Body Mass Index | 1 | 0 | Perfect |
| Manual Muscle Test | 1 | 0 | Perfect |
| Scapular Humeral Angle | 1 | 0 | Perfect |
| Semmes Weinstein | 1 | 0 | Perfect |
| Stereognosis | 1 | 0 | Perfect |

Table 23
Inter-rater Reliability: Patient and Family Participation

| Patient and Family Participation | Карра | SE of Kappa | Level of Agreement |
|----------------------------------|-------|-------------|--------------------|
| Patient Participation | 0.538 | 0.161 | Moderate |
| Family Participation | 0.8 | 0.107 | Excellent |

Table 24
Inter-rater Reliability of Intervention Coding

| | Percentage of agreement | Level of Agreement |
|--|-------------------------|--------------------|
| Intervention Coding Overall | 75 | Good |
| Intervention Coding: First 15 patients | 60 | Moderate |
| Intervention Coding: Last 15 patients | 90 | Excellent |