

DESCRIPTIONS OF PHYSICAL THERAPY MANAGEMENT FOR INFANTS  
WITH CONGENITAL MUSCULAR TORTICOLLIS IN THE UNITED STATES  
OF AMERICA

BY

Melanie D. O'Connell, PT, MSPT, PCS

Approved by the Dissertation Committee:

Sandra L. Kaplan, PT, DPT, PhD, Chair

Colleen P. Coulter, PT, DPT, PhD, PCS

J. Scott Parrott, PhD

Defense Readers:

Nancy R. Kirsch, PT, DPT, PhD

Robert M. Denmark, PhD

Submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy in Health Sciences  
Rutgers, The State University of New Jersey

2016

## ACKNOWLEDGEMENTS

It is with great joy that I write this page, because for me, it is the end of one journey, and the beginning of another. Looking back over the past ten years, I can see that the path toward a PhD is much more direct and efficient, when that is the sole focus. However, having entered this program in my thirties, I sought a dual role in both academics and clinical work, and refused to let go of my position at Saint Peter's University Hospital as pediatric physical therapist. This decision and the bumpy, winding road that followed, have only strengthened my view that there continues to be a need for integration of these two areas, and an emphasis on knowledge translation between physical therapists who perform research and physical therapists who provide clinical care. It is my hope that this dissertation serves as one such bridge... and hence, the start of a new journey. I would be remiss not to acknowledge those who supported and advised me along the way.

Thanks to God for providing me with sound mind and body to write this dissertation: to read the work of others, critically analyze the issues that are involved, bring my thoughts forward into action, and of course, to then write it all down. The human body, mind, and spirit have always amazed me, and it is no different when I think about the task achieved.

Thank you to my mom & dad, Arlene & Phillip DellaRocco, for being the greatest parents ever. You have taught me to never give up on your dreams and to never stop asking questions. It is why I am where I am today. I love you & I thank you always. Thank you also to my brother & my sister, Todd DellaRocco & Kim Kennedy, for being so supportive and understanding of my work. Every day that goes by, I learn more about the value of family because of you. I love you both. Thank you for always being there for me.

Thank you to the most amazing and the most wonderful husband ever, Shawn O'Connell. Your enduring love, patience, and belief in me has kept this project moving forward, even though I wanted to stop so many times. I could not have done this without you. Thank you for being the man you are. Thank you also for the three most beautiful blessings: Aidan, Robert, and Jack, all "dissertation babies." It is my hope that they understand the value of hard work, persistence, and self confidence. I love you all & I believe in you.

This dissertation would not have been possible without my incredibly forward thinking advisor and teacher, Sandra Kaplan, PT, DPT, PhD, Professor and Director of Post Professional Education Program, Rutgers University, who is without a doubt, the most objective and analytical woman in

scientific research whom I have ever had the pleasure to meet. Your persistence for perfection is immeasurably admirable and I consider myself lucky to have been your student. Thank you for teaching me not only through your words, but with your actions, too. You have helped tremendously in encouraging me through the challenging times, and I thank you for that.

Thank you to Scott Parrott, PhD, Associate Professor, Rutgers University, for your impressive statistical knowledge, and for continually helping me to understand the numbers. I truly appreciate that you agreed to be a part of this dissertation committee. Thank you also to Colleen P. Coulter, PT, DPT, PhD, PCS, Clinical Director, Children's Healthcare of Atlanta, who provided terrific insight and clinical knowledge along the way. Thank you for being such a great team player, despite the distance between us, and for always reminding me of the reality of the clinical environment.

Thank you to Phyllis Guarrera-Bowlby, PT, DPT, EdD, PCS, for reading my dissertation proposal, and to Nancy R. Kirsch, PT, DPT, PhD and Robert M. Denmark, PhD for reading my final dissertation. Your input was invaluable. Thank you also to my colleagues who assisted in being content experts: Carolanne Aaron, PT, PhD, PCS, Janet P. Burns, PT, Karen Huhn, PT, MSHS, PhD, Katie K. Marsala, PT, MPT, PCS, and Bethany Tunik, PT, DPT. I very much appreciate the time you spent reviewing or taking the the pilot survey, and helping to ensure its validity prior to distribution. Thanks to all of my colleagues at Saint Peter's University Hospital, especially Jeannine Creazzo, MLIS, AHIP, and Elizabeth Herron, MLS, from the Medical Library, who were both always so helpful and knowledgeable throughout my research, and to Kathy Krotz, PT, DPT and Ann Hays, PT, who have supported me in the clinical world since I became a physical therapist many years ago.

This paper would also not have been possible without the 200+ pediatric physical therapists around the country who participated in the survey and provided such wonderful clinical information on the physical therapy management of congenital muscular torticollis. Thank you to all the survey respondents. You have enabled a wealth of knowledge to be shared among all physical therapists who work with this precious infant population.

Lastly, I am thankful for all those who have researched congenital muscular torticollis before me. Your work has allowed for the thoughts and ideas that you will find within. Thank you for having shared your knowledge with me & now, I am able to share mine with you.

For all of the above, I am forever grateful.

## TABLE OF CONTENTS

ACKNOWLEDGEMENTS .....	2
LIST OF TABLES .....	11
LIST OF FIGURES.....	12
ABSTRACT.....	13
CHAPTER I: INTRODUCTION.....	14
Research Questions.....	17
CHAPTER II: REVIEW OF THE LITERATURE.....	19
Referral of Infants with CMT to Physical Therapy .....	23
Screening for Causes of CMT .....	24
The Importance of Early Referral to PT for Infants with CMT .....	29
Entry Points to PT for Infants with CMT .....	31
The Value of Ultrasound for Infants with CMT .....	33
Physical Therapy Initial Examination of Infants with CMT .....	35
Recommended Components of a PT Examination for an Infant with CMT .....	37
Past Medical History & Subjective Information .....	37
Date of examination, infant's date of birth & infant's age. ....	37
Gender.....	38
Family history of CMT. ....	38
Labor & delivery history. ....	38
Baby position in utero. ....	39
Feeding. ....	40
Objective Measures.....	42
Side of torticollis.....	42

Presentation of initial head tilt.....	43
Vision.....	45
Craniofacial asymmetry.....	47
Skin appearance.....	49
Type of congenital muscular torticollis.....	50
Passive cervical rotation.....	53
Passive cervical lateral flexion.....	55
Active cervical rotation.....	57
Lateral head righting/ Active cervical lateral flexion .....	59
Neck flexor strength.....	62
Hip symmetry.....	63
Motor development.....	65
General PROM & AROM of the upper and lower extremities.....	69
Muscle tone & neurological reflex testing.....	70
Physical Therapy Interventions for Infants with CMT.....	73
Recommended PT Interventions for an Infant with CMT .....	74
Primary Interventions .....	75
Passive stretching (PROM exercises).....	75
Home exercise program.....	76
Active range of motion exercises & positioning .....	77
Strengthening exercises & developmental therapy.....	79
Secondary Interventions.....	80
Myokinetic stretching technique.....	80
Microcurrent therapy.....	81

Kinesiology taping. ....	82
Tubular orthosis for torticollis (TOT Collar™) & soft cervical orthosis.....	85
Tscharnutter Akademie for Motor Organization (TAMO).....	87
Soft tissue massage.....	88
Recommended Tapering Schedule .....	91
Recommended Equipment Devices for Infants with CMT.....	92
Cranial Orthosis or Helmet.....	93
Head Positioner Devices .....	95
Medical and Surgical Interventions for CMT.....	96
Physical Therapy Discharge & Discontinuation for Infants with CMT .....	97
Recommended Criteria for Discharge from PT for Infants with CMT .....	97
Recommended Criteria for Discontinuation of PT for Infants with CMT .....	101
Recommended Period of Follow-up .....	102
Survey Modes .....	105
Internet Surveys.....	106
Internet Survey Distribution.....	107
Internet Survey Security .....	108
Internet Surveys & IRB .....	109
Total Survey Error.....	109
Total Survey Error Framework.....	109
Tailored Design.....	111
CHAPTER III: METHODS .....	113
Research Aims, Questions & Hypotheses.....	113
Research Design .....	114

Survey Methodology – Total Survey Error.....	115
Survey Methodology – Tailored Design .....	117
Instrumentation .....	118
The Survey Cover Letter (Appendix B) .....	118
The Survey (Appendix C) .....	119
Format of the Survey.....	119
Method of Administration for the Survey .....	120
Subjects.....	121
Data Collection & Analysis .....	123
CHAPTER IV-A: Referral and Screening Patterns of Infants with Congenital Muscular Torticollis in the United States of America: A Survey of Pediatric Physical Therapists .....	126
Introduction and Purpose .....	127
Methods.....	132
Survey Development.....	132
Survey Administration & Recruitment.....	133
Participants & Procedures.....	134
Data Collection & Analysis .....	135
Results.....	135
The Respondent Sample.....	135
Referral Patterns of Infants with CMT .....	139
Actions Taken Upon Referral to PT .....	142
Discussion.....	143
Referral Patterns of Infants with CMT .....	143
Summary of the Referral Patterns of Infants with CMT .....	157

Study Limitations.....	159
Further Research.....	161
Conclusions .....	161
References .....	163
CHAPTER IV-B: Patterns of Measurement Recorded at Examination and Discharge of Infants with Congenital Muscular Torticollis - A Survey of Pediatric Physical Therapists in the United States of America .....	
Introduction .....	170
Purpose .....	173
Methods.....	174
Survey Development.....	174
Survey Administration & Recruitment.....	174
Participants & Procedures.....	175
Results.....	176
The Respondent Sample.....	176
CMT Examination Patterns .....	178
Measurements Recorded during Examination of Infants with CMT.....	180
Methods of Measurement.....	183
Prognostic Factors.....	185
CMT Discharge Patterns .....	185
CMT Group Outcomes Measurements .....	188
Discussion.....	189
CMT Examination Patterns .....	189
Measurements Recorded during Examination of Infants with CMT.....	192
Methods of Measurement.....	195



CMT Discharge Patterns .....	202
CMT Group Outcomes Measurements .....	207
Study Limitations.....	208
Further Research.....	210
Conclusions .....	211
References .....	213
CHAPTER IV-C: Intervention Patterns for Infants with Congenital Muscular Torticollis: A Survey of Pediatric Physical Therapists in the United States of America .....	219
Introduction .....	220
Purpose .....	221
Methods.....	222
Survey Development.....	222
Survey Administration & Recruitment.....	222
Participants & Procedures.....	223
The Respondent Sample.....	224
CMT Treatment Patterns Among US PTs .....	226
Patterns Regarding the Frequency of CMT Treatment.....	232
PT Use of Clinical Practice Guidelines for CMT Treatment.....	234
Discussion.....	237
CMT Treatment Patterns .....	237
Patterns Regarding the Frequency of CMT Treatment.....	244
Study Limitations.....	248
Further Research.....	249
Conclusions .....	250

References .....	251
CHAPTER V: CONCLUSIONS.....	256
REFERENCES.....	261
APPENDIX A – Summary of Literature Review .....	275
APPENDIX B – Survey Cover Letter .....	285
APPENDIX C - Survey.....	287
APPENDIX D – Survey Results .....	315

## LIST OF TABLES

Chapter II: Table 1: Levels of Evidence Used for Literature Review..	20
Chapter III: Table 2: Use of “Total Survey Error” Framework to Reduce Potential Error.....	115
Chapter IV-A: Table 1: Respondent Characteristics.....	137
Chapter IV-A: Table 2: Parental Report of Medical Intervention...	140
Chapter IV-B: Table 1: Respondent Characteristics.....	175
Chapter IV-B: Table 2: Methods Used for Development of Exam...	178
Chapter IV-B: Table 3: Measures Recorded in CMT Exam.....	179
Chapter IV-B: Table 4: Important Factors for Discharge.....	185
Chapter IV-C: Table 1: Respondent Characteristics.....	221
Chapter IV-C: Table 2: Methods Used for Development of CMT Treatment Approach.....	223
Chapter IV-C: Table 3: Interventions Identified by Respondents without Supporting Evidence for CMT.....	225
Chapter IV-C: Table 4: Selected Frequency of Treatment.....	229
Chapter IV-C: Table 5: Association between SoP Membership and Use of Guidelines for CMT Treatment.....	230
Chapter IV-C: Table 6: Association between Years of Experience and Use of Guidelines for CMT Treatment.....	231
Chapter IV-C: Table 7: Association between Workplace Setting and Use of Guidelines for CMT Treatment.....	232

## LIST OF FIGURES

Chapter IV-A: Figure 1: Distribution of Survey Respondents...	136
Chapter IV-A: Figure 2: Regional Representation of Survey Respondents who Identified States.....	137
Chapter IV-B: Figure 1: Regional Representation of Survey Respondents who Identified States.....	175
Chapter IV-B: Figure 2: Variety of Motor Assessments for CMT...	182
Chapter IV-C: Figure 1: Regional Representation of Survey Respondents who Identified States.....	221

## ABSTRACT

### DESCRIPTIONS OF PHYSICAL THERAPY MANAGEMENT OF INFANTS WITH CONGENITAL MUSCULAR TORTICOLLIS IN THE UNITED STATES OF AMERICA

Melanie D. O'Connell, PT, MSPT, PCS

Rutgers, The State University of New Jersey  
2016

Chair: Dr. Sandra L. Kaplan

**Purpose:** To describe patterns of physical therapy management used by PTs in the USA who treat infants with congenital muscular torticollis (CMT). Practice trends for PT referral, screening, examination, intervention, and discharge of infants with CMT are compared to current literature, including recent clinical practice guideline (CPG) recommendations. **Methods:** An online survey was completed by volunteers solicited through the Section on Pediatrics monthly e-newsletters and a posting on its website, and through purposeful identification of PTs in children's hospitals and private practices. **Results:** 220 pediatric physical therapists in the USA participated in the survey with at least one participant from every state and the District of Columbia. Significant findings include: a relatively late age of referral to PT; positive report of screening for non-muscular causes; measurement of the recommended components at initial examination and discharge, but not using recommended objective tests, with 50% visually estimating cervical ROM; use of interventions that are congruent with the recommended best evidence, but limited familiarity with supplemental interventions, and limited variability in frequency of treatment. A small subset (0.5%-15.1%) of US PTs is using interventions which do not have evidence to support their use with CMT. The majority of PTs (76%) report discharge with full ROM, midline head posture and symmetrical reactions; and a minority of patients with CMT (10%) return for a second episode of care after they have been discharged. **Conclusion:** The data yields practice patterns that are partially consistent with current CMT literature and CPG recommendations. Most, but not all, US PTs show appropriate screening procedures; Greater consensus is needed on the methods of objective measurement that should be used for CMT; and US PTs should be seeking out interventions with evidence to support their clinical use with CMT.

## CHAPTER I: INTRODUCTION

Congenital muscular torticollis (CMT) is an idiopathic condition of infancy in which a newborn postures into ipsilateral neck flexion and contralateral neck rotation due to shortening of the sternocleidomastoid muscle. It is the third most common pediatric orthopedic deformity (Binder, Eng, Gaiser, & Koch, 1987; Do, 2006; Öhman & Beckung, 2005) and has become a popular diagnosis for referral to pediatric physical therapy. Physical therapists (PTs) who treat CMT are often challenged by parents, caretakers, other healthcare professionals, and third party payors regarding management and best practice for these infant patients.

CMT has been associated with changes in the skull and facial structure (de Chalain & Park, 2005; Oh, Hoy, & Rogers, 2009; Omid-Kashani, Hasankhani, Sharifi, & Mazlumi, 2008; Yu, Wong, Lo, & Chen, 2004), an increased risk for early motor milestone delays (Öhman, Nilsson, Lagerkvist, & Beckung, 2009; Schertz et al., 2008), and hip dysplasia (Minihane et al., 2008; von Heideken et al., 2006; Walsh & Morrissy, 1998). Changes in the skull and facial structure have been associated with early neurodevelopmental delays (Schertz, et al., 2008), particularly in motor skills (Speltz et al., 2010), and an increased need for special services in school (Miller & Clarren, 2000). The prevalence of CMT in young infants has been reported to be as high as 16% (Stellwagen, Hubbard, Chambers, & Jones, 2008). It is hypothesized that the “Back to Sleep” campaign, instituted by the

American Academy of Pediatrics (AAP) to avoid Sudden Infant Death Syndrome, triggered a “six-fold increase” in plagiocephaly from 1992-1994 (Persing et al., 2003), the most common diagnosis associated with CMT.

Much of the literature on CMT is written by medical doctors (Celayir, 2000; Chen, Chang, Hsieh, Yen, & Chen, 2005; Cheng, Metreweli, Chen, & Tang, 2000; Cheng et al., 2001; Demirbilek & Atayurt, 1999; Hsu et al., 1999), is performed in foreign countries where services may differ (Celayir, 2000; Cheng, et al., 2001; Chon, Yoon, & You, 2010; Demirbilek & Atayurt, 1999; Joyce & de Chelain, 2005; Öhman, Nilsson, Lagerkvist, et al., 2009; Omidikashani, et al., 2008; Petronic et al., 2010; L. A. van Vlimmeren, Helders, van Adrichem, & Engelbert, 2006; Yim et al., 2010), or uses impairment based outcomes such as passive range of motion of the cervical spine (Binder, et al., 1987; Celayir, 2000; Cheng, et al., 2001; Emery, 1994; Öhman & Beckung, 2008). Additionally, some studies lack an accurate, reproducible description of the intervention applied (Chon, et al., 2010; Kim, Kwon, & Lee, 2009; Öhman & Beckung, 2005); and there is no standard classification process for patients with CMT (Binder, et al., 1987; Cheng, et al., 2001; Emery, 1994). These concerns may pose difficulty for integration of the literature into clinical practice.

Prior research does, however, provide evidence for the effectiveness of PT for patients with CMT (Binder, et al., 1987; Cheng, et al., 2001; Demirbilek & Atayurt, 1999; Emery, 1994; Kim, et al., 2009; Öhman &

Beckung, 2005; Rahlin, 2005; Taylor, 1997). Treatment success ranges from 69% to 99% of patients achieving resolution of CMT with PT (Binder, et al., 1987; Emery, 1994). Resolution of CMT generally encompasses full passive cervical rotation (Binder, et al., 1987; Cheng, et al., 2001; Emery, 1994) within a relatively short duration of treatment from 1.4 months (Cheng, et al., 2001) to 10.3 months (Petronic, et al., 2010). The success of PT for infants with CMT has been associated with the infant's age at the start of treatment, the type of CMT, and the initial deficit in cervical rotation (Cheng, et al., 2001).

Despite the overall positive impact of PT on CMT as shown by individual research studies, and recent publication of clinical practice guidelines (CPG) from the Section on Pediatrics (SoP) of the American Physical Therapy Association (Kaplan, Coulter, & Fethers, 2013), it was not known if PTs in the USA who work with infants and young children with CMT are integrating the results of the available literature to their practice.

Prior to this study, a current description of practice among pediatric PTs in the USA who treat CMT had not been identified. There is research from Canada (Fradette, Gagnon, Kennedy, Snider, & Majnemer, 2011), New Zealand (Luxford, Hale, & Piggot, 2009), and a network of PTs from Denmark and Sweden (Omid-Kashani, et al., 2008), which has provided some insight regarding the integration of research into clinical practice on CMT, however, these countries have different healthcare systems and PT practices which limits the carryover of results from one country to another. In order for PTs in



the USA to determine if they are practicing according to the best evidence, a description of current practice among US PTs is needed.

### Research Questions

The two main objectives of this research are to describe physical therapy services provided by PTs in the USA that treat infants with congenital muscular torticollis through a national survey, and to determine if that service description is consistent with the best available clinical evidence on CMT. The basic research questions that were addressed in this descriptive study are:

1. What are the patterns of physical therapy management among physical therapists in the USA who treat infants with CMT?

Specifically,

- a.) What are the patterns of referral to PT among infants with CMT?
- b.) What are the trends in PT examination and discharge, with focus on measurement and documentation of outcomes?
- c.) What are the patterns of PT intervention for infants with CMT, including the most common methods and frequency of services utilized?

2. How does this physical therapy practice description compare to the best available clinical evidence?

## CHAPTER II: REVIEW OF THE LITERATURE

The purpose for this review of literature is to summarize the best available evidence on the management of CMT and identify suggested best practices, so that a current description of the PT management of CMT can be compared. Each topic in this review of literature is organized to summarize the available evidence on CMT, identify research gaps, and provide my own assessment of “suggested best practice,” with a confidence level which corresponds to the quality of the evidence. A summary of the levels of evidence for literature related directly to the topic can be found in the right side margin. Suggested best practice statements are my conclusions of best practice based upon the available evidence but are not intended to be suggestive of a specific clinical practice guideline. Suggested best practice statements are necessary for comparison with actual clinical practice. There may not be a suggested best practice under each topic, as the evidence may not support a best practice, or the content may be outside the scope of physical therapy practice. When a suggested best practice is offered, the level of confidence is indicated by the terms: strong, moderate, or weak. For the purpose of this review, the following generally applies: a strong level of confidence refers to level 1-2 evidence, moderate refers to level 3-4 evidence, and weak refers to level 5 evidence. For ease of review, a summary table of the review of literature on CMT links the suggested best practice, and the

research gap found in the literature, with the relevant survey questions (Appendix A).

Table 1: Levels of Evidence Used for Literature Review

*Levels of Evidence & Corresponding Description*

Level	Description of Evidence
1a	Systematic Review of Randomized Controlled Trials (RCT)
1b	Individual Randomized Controlled Trial
1c	All or none - Met when all patients died before the treatment became available, but some now survive on it; or when some patients died before the treatment became available, but none now die on it.
2a	Systematic Review of cohort studies
2b	Individual cohort study (including low quality RCT; e.g., <80% follow-up)
2c	"Outcomes" Research; Ecological studies
3a	Systematic Review of case-control studies
3b	Individual Case-Control Study
4	Case-series (and poor quality cohort and case control studies)
5	Expert opinion without explicit critical appraisal, or based on physiology, bench research or "first principles"

*Note.* From "Oxford Centre for Evidence-based Medicine Levels of Evidence" by B. Phillips, C. Ball, D. Sackett, D. Badenoch, S. Straus, B. Haynes, and M. Dawes, 1998, Updated by J. Howick, 2009. [www.cebm.net](http://www.cebm.net)

Multiple databases were searched routinely to obtain literature for this study. This entailed an electronic search through the Rutgers University Library System and through the Saint Peter's University Hospital Medical Library in New Brunswick, New Jersey. The databases included: OVID

(Medline), CINAHL, OVID Healthstar, Health and Psychosocial Instruments (HAPI), The Cochrane Library, PEDro, The National Guidelines Clearinghouse and Google Scholar. An electronic search was also performed on the American Physical Therapy Association's research portal, Hooked On Evidence. Additional sources of articles included a manual review of article references, textbooks related to various content (pediatric physical therapy, neuroscience, postsurgical orthopedic guidelines, goniometry, and torticollis), and a subscription to ScienceDirect. Keywords in this search were: torticollis, congenital muscular torticollis, physical therapy, infant, plagiocephaly, helmet therapy, outcomes, measurement and goals. Evidence tables were organized to list the individual articles found and a level of evidence for each article was assigned as per the Oxford Centre for Evidence-based Medicine Levels of Evidence (OCEBM) (OCEBM, 2009) (Table 1). The 2009 OCEBM Levels of Evidence is used for this review to establish consistency in the search methodology which began prior to the development of the 2011 OCEBM Levels of Evidence.

### Congenital Muscular Torticollis Versus Other Types of Torticollis

The term, torticollis, translates literally to "twisted neck" (Cheng, Tang, Chen, Wong, & Wong, 2000; Do, 2006). It describes the posture of a laterally flexed or rotated head position, but does not clarify the

underlying cause of the posture. Although congenital muscular torticollis (CMT) has been found to be the most common form of torticollis, Ballock and Song (1996) found that 20% of their subjects who presented with a torticollis posture were found to have a nonmuscular etiology. Causes of a non-muscular torticollis may include cervical vertebral dysfunctions, ocular disorders, or even central nervous system tumors. There has also been a case report of a child with torticollis due to saccular dysfunction (Hallberg, Standing, & Ahsan, 2013). Varying etiologies have given rise to other torticollis terms such as ocular torticollis or spasmodic torticollis (Chon, et al., 2010). Torticollis can be due to osseous, non-osseous, or neurogenic causes (Freed, 2004; Nucci, Kushner, Serafino, & Orzalesi, 2005), with CMT being the most common form of a non-osseous torticollis (Ballock & Song, 1996).

Congenital muscular torticollis (CMT) is the third most common pediatric orthopedic deformity (Binder, et al., 1987; Do, 2006; Öhman & Beckung, 2005), with one study reporting incidence as high as 16% in normal newborns (Stellwagen, et al., 2008). Fibrosis or thickening of the sternocleidomastoid may be found with CMT (Karmel-Ross, 2006), resulting in muscle tightness and abnormal postural alignment. Although the exact etiology of CMT is unknown, intrauterine crowding, vascular occlusion, and compartment syndrome are included in the list

of possible causes (Do, 2006). Without treatment, CMT can lead to positional plagiocephaly (Do, 2006) and significant skeletal changes (Yu, et al., 2004). Physical therapy treatment for infants with CMT yields good to excellent results in 91.1% of infants with CMT, as measured by improved range of motion, improved craniofacial symmetry, decreased head tilt, and improved parental satisfaction (Cheng, Tang, et al., 2000).

### Referral of Infants with CMT to Physical Therapy

In this country, “The physical therapist may, where permitted by law, be the entry point into the health care system...” (APTA, 1990). This specifically occurs when direct access by the consumer has been utilized. In contrast, physical therapy services may also be requested by referral from another health care professional. This section serves to describe the referral process of an infant with CMT, including: how to screen for non-muscular causes of CMT; how to properly describe infants referred with CMT; the importance of early referral; the potential entry points for PT; and the value of medical imaging done prior to or at the time of referral.

### *Screening for Causes of CMT*

When an infant is referred to PT for torticollis, the first action should be to screen the patient for causes of CMT. Screening refers to the identification of signs and symptoms that may indicate a cause for the abnormal posture. This is done to ensure that the intervention sought falls within the scope of PT practice, or if a non-muscular cause is suspected, to ensure that consultation with other healthcare professionals ensues for the benefit of the patient (Cincinnati Children's Hospital, 2009; Fosnaught, 2002). If non-muscular causes of CMT are suspected, the combined effort of a multidisciplinary team may be needed to thoroughly complete the differential diagnosis (Cincinnati Children's Hospital, 2009; Nucci, et al., 2005).

4

The clinical practice guideline (CPG) on CMT from the Section on Pediatrics (SoP) of the American Physical Therapy Association (APTA) (Kaplan, et al., 2013) recommends a screen of five systems: musculoskeletal, neurological, integumentary, cardiorespiratory, and gastrointestinal. The Cincinnati Children's Hospital Medical Center recommends a visual screen, hip screen, and neurological screen (2009). In a visual screen, the physical therapist should check that the infant shows midline visual attention with both eyes (Cincinnati Children's Hospital, 2009) and can smoothly track an object from side to side without obvious asymmetry (Lundy-Ekman, 2007). The

2-4



physical therapist may also look for signs of ptosis, loss of the pupillary reflex, or nystagmus (Lundy-Ekman, 2007). In a hip screen, the physical therapist should look for “asymmetry, hip clunk, or leg length discrepancy” (Cincinnati Children's Hospital, 2009). Hip range of motion should also be checked for restrictions. A limitation of 5-10° of hip abduction could be a sign of hip dysplasia (Leach, 2006). The neurological screen should include an assessment of muscle tone and reflex testing in the infant. The physical therapist may look for a predominance of the Asymmetrical Tonic Neck Reflex (ATNR), abnormal muscle tone, or sustained clonus (Cincinnati Children's Hospital, 2009). Additional screening should include general observation of the head and neck region (Cincinnati Children's Hospital, 2009), to include: head flattening which may be indicative of plagiocephaly, or protrusion along the clavicle which may be indicative of a clavicular fracture. Neck range of motion should also be evaluated to check for a boney end feel which could be a sign of an osseous deficit (Cincinnati Children's Hospital, 2009). If a non-muscular cause is suspected after screening, the physical therapist should consult with the infant's pediatrician to inform her of the findings, and discuss recommendation for referral to a specialist, or for further medical testing (Ballock & Song, 1996; Cincinnati Children's Hospital, 2009; Kaplan, et al., 2013).

Ballock and Song (1996) reported that almost 20% of patients referred to a pediatric orthopedic facility for medical evaluation of torticollis had a non-muscular etiology. There has also been a case of “death after spinal manipulation” in an infant with a cervical spine tumor (Ballock & Song, 1996). The literature, although void of any randomized controlled trials (Level 1 studies), shows us that the risk associated with not screening patients for non-muscular causes of CMT could be devastating. It is important that all PTs screen their patients referred to them with CMT for non-muscular causes.

Suggested Best Practice: PTs who treat infants with torticollis posture should screen for non-muscular causes of torticollis.

(Confidence Level: Strong)

### *Initial Presentation of the Infant with CMT*

When a muscular cause for the torticollis posture is suspected, the physical therapist should document a description of the infant at the time of initial presentation to PT, to include the three factors which have been shown to be significantly associated with outcome: the clinical type of CMT (Binder, Eng, Gaiser & Koch, 1987; Cheng, Wong et al., 2001), the child’s age at presentation (Petronic et al., 2010; Demirbilek & Atayurt, 1999; Cheng, Wong et al., 2001), and the limitation in range of cervical rotation (Cheng, Wong et al., 2001;

Emery, 1994). Infants with a sternomastoid tumor, a greater deficit in cervical rotation ( $15^\circ$  or more), and a late age at presentation (more than 1 month) will have worse overall outcomes and a greater need for surgery (Cheng, et al., 2001).

The clinical types of CMT include: sternomastoid tumor, muscular, or postural. The sternomastoid type refers to a tumor that can be palpated in the sternocleidomastoid muscle (SCM); Muscular type refers to tightness and thickening in the SCM without a palpable tumor; Postural type refers to infants with a head tilt, but no tightness nor thickening of the SCM (Cheng, et al., 2001). It is important for PTs to determine the type of CMT at initial presentation because the length of treatment ( $p < 0.0001$ ) and the need for surgery ( $p = 0.0018$ ) are significantly associated with the type of CMT (Cheng, et al., 2001). The most favorable outcomes are seen in infants with a postural CMT, and the least favorable outcomes are seen in infants with a sternomastoid tumor (Cheng, et al., 2001).

2c

Older age at referral may result in longer treatment durations and worse overall outcomes (Cheng, et al., 2001; Petronic, et al., 2010) for infants with CMT. Petronic et al. (2010) show that infants with CMT who start PT prior to one month of age have a median treatment duration of  $1.5 \pm 0.3$  months, and more than 98% of this age

2c

group achieve good outcomes, defined as straight head posture, more than 100° cervical rotation, and more than 65° lateral flexion. Infants with CMT who start PT between 1-3 months of age have a median duration of treatment of  $5.9 \pm 0.6$  months, with 88% achieving good outcomes; and infants with CMT who start PT between 6-12 months of age have a median duration of treatment of  $9.8 \pm 0.6$  months, with less than 20% of this age group achieving good outcomes (Petronic, et al., 2010). Another study by Carenzio et al (2015) adds to this literature, reporting a 2.5 month treatment duration until full resolution of CMT for infants who initiated PT at a mean age of 2.5 months. 2c

Among infants with CMT, a deficit in passive cervical rotation between the left and right side of more than 15° is significantly associated with a longer duration of treatment ( $p < 0.0001$ ), and a greater risk for surgery ( $p < 0.0001$ ) (Cheng, et al., 2001). Lee et al (2013) report similar findings regarding the correlation Passive cervical rotation has typically been the measure of choice in the literature on CMT because it has been shown to have better interexaminer reliability than measurement of side flexion (Cheng, et al., 2001). 2c

When these three factors are consistently documented to describe the initial presentation of the infant with CMT, then it is

possible to have an accurate description of the patient upon referral to PT. Kaplan et al. (2013) have proposed CMT classification grades based on these factors, and one additional factor, age at identification. They recommend that all PTs classify the level of CMT severity to one of seven grades (Kaplan, et al., 2013). Although this classification system is not yet validated, it could allow for ease of data comparison among PTs across the country. Regardless of whether PTs are using the suggested CMT classification grades (Kaplan, et al., 2013), or if they are documenting the three factors separately, these elements should be consistently included in the medical record. It is important to know if PTs in the USA document these three elements for all patients diagnosed with CMT.

Suggested Best Practice: PTs should document the initial presentation of infants with CMT to include at least three elements: the type of CMT, the age at presentation to PT, and the limitation in cervical rotation. (Confidence Level: Strong)

### *The Importance of Early Referral to PT for Infants with CMT*

Longer treatment durations result in higher costs for services, place more stress on parents to commit to frequent PT visits, and also stress the growing and increasingly mobile infant. Physical therapists who treat infants with CMT at an older age may struggle with trying to

provide the appropriate stretch while keeping the infant calm and comfortable (Kim, et al., 2009; Rahlin, 2005).

Although common complaints among parents, the characteristic “head tilt” and limited cervical rotation of CMT (Hsu, et al., 1999) are not the only symptoms. Other co-morbidities related to CMT are crucial reasons for early diagnosis and treatment. Congenital muscular torticollis has been associated with changes in the skull and facial structure (Jeong, Min, Woo & Yim, 2015; de Chalain & Park, 2005; Oh, et al., 2009; Omid-Kashani, et al., 2008; Yu, et al., 2004), increased risk for early motor milestone delays (Öhman, Nilsson, Lagerkvist, et al., 2009; Schertz, et al., 2008), transient motor asymmetry (Watemberg, Ben-Sasson, & Goldfarb, 2016), and hip dysplasia (Minihane, et al., 2008; von Heideken, et al., 2006; Walsh & Morrissy, 1998). Changes in the skull and facial structure have been associated with early neurodevelopmental delays (Schertz, et al., 2008), particularly in motor skills (Speltz, et al., 2010), and an increased need for special services in school (Miller & Clarren, 2000). There is no known survey in the USA that describes the age of infants with CMT upon referral to PT.

### *Entry Points to PT for Infants with CMT*

With all 50 states and the District of Columbia having direct access for a physical therapy evaluation (APTA, 2015), any infant or young child suspected of abnormal head and neck posturing may be referred to physical therapy for “torticollis” by any person. Despite the potential sources of referral that may exist within an infant’s home, health care professionals may be the most common referral source to PT, as their knowledge and expertise are often valued by parents and caretakers. From the midwife or labor and delivery nurse to the obstetrician or pediatrician, there are multiple healthcare professionals who observe the infant at birth and have the opportunity to refer for a PT evaluation.

Screening for CMT by the pediatrician is currently not a standard process until the two-month check-up (Hagan, 2008). There is no known clinical guideline or policy statement issued by the AAP specific to CMT. In 2008, the AAP updated the Bright Futures Guidelines for the Health Supervision of Infants, Children, and Adolescents, with a third edition (Hagan, 2008). Bright Futures is a nationally recognized health initiative led by the Maternal and Child Health Bureau of the Health Resources and Services Administration with the purpose of “promoting and improving the health, education, and well-being of infants, children, adolescents, families, and

communities” (Hagan, 2008). The AAP instituted the Bright Futures Guidelines as a “uniform set of recommendations for health care professionals” (AAP). According to these guidelines, infants are optimally scheduled for eight well check-ups in the first year of life, from the first newborn visit in the hospital to their 12 month visit at the doctor’s office (Hagan, 2008). The guidelines specifically recommend that physicians check for torticollis at the two-month visit as part of the infant’s physical exam. In the Bright Futures Guidelines, Theme 2: Promoting Child Development, health care professionals are instructed to identify any “delays in gross motor milestones, asymmetry of movement, or muscle hypertonia or hypotonia” and refer for early intervention (Hagan, 2008).

Although there is a recommendation for pediatricians to check for CMT at the two-month well baby visit, there is no other specific screening for CMT, and no formal recommendation for referral to PT for an infant identified with CMT. The Bright Futures Guidelines institute standard care of an infant by physicians, but also place an emphasis on parental/familial concerns. Families who are aware of an infant’s abnormal posture and bring this to the doctor’s attention may have greater opportunity for early identification and treatment of CMT by a PT, resulting in better outcomes. This is emphasized by the model of “family-centered care” which is highlighted in a survey among



Canadian PTs who treat CMT (Fradette, et al., 2011). Evidence regarding family-centered care shows that families who are more involved in the decision making process are more likely to adhere to treatment and have better outcomes (Fradette, et al., 2011). Among infants with CMT in the USA, it would be useful to know who typically identifies a concern with the infant's posture, who typically refers the infant to PT, and the chief reason for seeking PT services.

### *The Value of Ultrasound for Infants with CMT*

The American Academy of Pediatrics (AAP) recommends that imaging of the cervical spine be performed in all newborns with torticollis, with ultrasound being the primary choice (Ozuah, 2008). Ultrasonographic evaluation may also be valuable to ensure proper diagnosis of a sternomastoid tumor or fibrosis in the muscle (Hsu et al., 1999). Ultrasound offers an evaluation of the muscle and surrounding tissues with relatively low cost, short exam time, and patient comfort, while negating any exposure to radiation (Hsu, et al., 1999). Ultrasound images correlate significantly with the clinical type of CMT and the lack of cervical rotation (Cheng, Metreweli, et al., 2000), and have been used in a predictive model for confirming the diagnosis of CMT versus non-CMT in newborns (Chen, et al., 2005).

5

2c

Other methods of imaging are available but have drawbacks. Plain radiographs have limited value in yielding true-positive results for suspected craniocervical abnormality (Snyder & Coley, 2006), while magnetic resonance imaging (MRI) and computed tomography (CT) require the infant to undergo general anesthesia and be given a contrast medium (Hsu, et al., 1999).

As per the Normative Model of Physical Therapist Professional Education: Version 2004 (APTA, 2004), PTs “should identify medical tests that will assist in making an accurate diagnosis.” Although the AAP recommends ultrasound of the cervical spine for all patients with CMT, this is not typically seen in clinical practice, nor does it seem necessary for all patients with CMT. For infants who demonstrate a postural or muscular type of CMT without a palpable nodule of the SCM, and who show a positive response to stretching, ultrasound of the muscle is typically not needed. For infants with a palpable tumor however, an ultrasound may be valuable for confirming the presence of a sternomastoid lesion and documenting the size and location for future comparison. Additionally, if the infant appears uncomfortable with stretching or position changes as evidenced by change in color, respiration, or behavior, then an ultrasound of the neck musculature is warranted. As per the CPG from the SoP, PTs should request copies of medical images that have been completed in order to better inform

their prognosis and plan of care (Kaplan, et al., 2013). It is important to determine if PTs in the USA consult with medical doctors to recommend imaging studies or whether they request reports of medical testing that has been performed.

2

Suggested Best Practice: If a sternomastoid tumor is identified or if the infant demonstrates an adverse physiological response to stretching, the PT should consult with the referring physician or primary medical doctor to recommend an ultrasound of the sternocleidomastoid and surrounding tissue. The physical therapist should also request a report of any pertinent imaging studies completed prior to or at the time of referral to PT. (Confidence Level: Moderate)

### Physical Therapy Initial Examination of Infants with CMT

There are three known published clinical guidelines that physical therapists may refer to in the examination of infants with CMT. The first is "Postsurgical Rehabilitation Guidelines for the Orthopedic Clinician" published by the Hospital for Special Surgery (Corradi-Scalese, 2006). In this book, there is one chapter dedicated solely to the physical therapy examination and treatment of CMT, both surgical and non-surgical. Although this guideline provides a vast amount of information for the physical therapist treating CMT, there is little detail

on how the PT should proceed with an examination of the patient beyond performing PROM of cervical lateral flexion and rotation. This guideline on CMT from the Hospital for Special Surgery is a chapter in a larger book available only with purchase of the book, thus it is not a publicly available guideline.

The Cincinnati Children's Hospital published "Evidence Based Care Guideline for Management of Congenital Muscular Torticollis in Children age 0-36 months," (CCHMC-CPG) (Cincinnati Children's Hospital, 2009), designed to help pediatric therapists examine and treat patients with CMT, while recommending outside referral if needed. It provides a useful algorithm for patient evaluation to help guide clinicians but gives a vague description of the recommended objective measures for a PT examination and does not clarify how to measure them. The CCHMC-CPG does not identify the clinical type of CMT, which is significantly associated with duration of treatment ( $p<.0001$ ) and need for surgery ( $p=.0018$ ) (Cheng, et al., 2001). This guideline is publicly available (guidelines.gov - NGC:007301) and begins to apply evidence based practices in the evaluation of literature.

2c

The third guideline from the SoP of the APTA (SoP-CPG) (Kaplan, et al., 2013) became available online as a draft for public comment in June 2013, and was published in its final form in October

2013. This extensive clinical practice guideline on CMT makes evidence based recommendations for best practice based on literature searches through May 2013. It is the most current and comprehensive, published evidence based guideline for CMT, covering four main areas: identification and referral, examination, intervention, and discharge. It is not known whether PTs use any of these guidelines, or whether PTs examine items in accordance with CPG recommendations.

#### *Recommended Components of a PT Examination for an Infant with CMT*

This section includes a brief description of the recommended subjective and objective measures, the clinical evidence supporting inclusion in the PT examination, and where applicable, the best known method of measurement.

#### *Past Medical History & Subjective Information*

##### *Date of examination, infant's date of birth & infant's age.*

The APTA's position on documentation is that the PT examination should be "documented, dated and authenticated" by the physical therapist who performs the exam (APTA, 2009). It is best practice to record the month, day, and year of the infant's initial physical therapy examination. For infants with CMT, date of birth and age at the time of the initial examination should also be recorded. An

age of more than one month at presentation significantly correlates with a longer duration of treatment ( $p<.0001$ ), and a greater risk for surgery ( $p<.001$ ) (Cheng, et al., 2001). 2c

Suggested Best Practice: Physical therapists should document the infant's age at the time of the initial PT examination. (Confidence Level: Strong)

#### *Gender.*

Congenital muscular torticollis is more common in males, with a 3:2 ratio of male to female (Cheng, Tang, et al., 2000). This is also a consistent finding among the three clinical types of CMT (Cheng, et al., 2001).

Suggested Best Practice: Physical therapists should document the baby's gender. (Confidence Level: Weak)

#### *Family history of CMT.*

There are documented cases of a positive family history in CMT (Hosalkar, Gill, Gujar, & Shaw, 2001). 4

Suggested Best Practice: Physical therapists should ask caregivers if there are any known cases of CMT within their families, and document this in the record. (Confidence Level: Moderate)

#### *Labor & delivery history.*

The use of forceps or vacuums at the time of delivery is significantly correlated with infants having sternomastoid tumors ( $p<.001$ ), and greater limitations in passive neck rotation ( $p<.001$ ) (Cheng, Tang, et al., 2000).

2c

Suggested Best Practice: Physical therapists should ask caregivers about the use of forceps or vacuums during delivery, and document this in the record. (Confidence Level: Strong)

### *Multiple birth infants.*

Multiple birth infants are at higher risk for deformational plagiocephaly than singleton babies, with torticollis being a significant risk factor (Littlefield, Kelly, Pomatto, & Beals, 1999). In twins, the lower in utero infant is more likely to have positional plagiocephaly and torticollis (Littlefield, Kelly, Pomatto, & Beals, 2002).

4

Suggested Best Practice: Physical therapists should ask: (a) if it was a multiple birth delivery; and (b) if there was a multiple birth, the order of the infant. (Confidence Level: Moderate)

### *Baby position in utero.*

Infants who present as breech have significantly higher correlations with a sternomastoid tumor ( $p<.001$ ), and greater limitation in passive neck rotation ( $p<.001$ ) (Cheng, Tang, et al., 2000).

2c

Newborns who present in breech position are at higher risk for

torticollis, deformation of the skull, and hip dislocation (Hsieh, Tsai, Lin, Chang, & Tsai, 2000).

Suggested Best Practice: Physical therapists should document if the baby was in breech position at the time of birth. (Confidence Level: Strong)

### *Feeding.*

Newborn feeding schedules range from 8-12 times per day, with a relative decrease as the infant becomes older (Murkoff, 2003). Due to the frequent occurrence of this activity, and the positioning it entails, it is generally recommended to caretakers that a variety of positions be used (Murkoff, 2003). Mothers who breastfeed will generally switch positions in order to alternate breasts (Murkoff, 2003). However, caretakers who bottle feed may need to be reminded to switch arms for feedings. This is recommended in order to give the baby a “different perspective” (Murkoff, 2003), and to protect the caretaker from aches or pains that can result from prolonged positioning (Murkoff, 2003).

5

Infants with jaw asymmetry related to CMT have been shown to have difficulty with feeding (Wall & Glass, 2006), as do infants with unilateral sternocleidomastoid tension (Genna, 2015). It is important to address this problem early, so as to avoid potential dehydration or hospitalization of the infant from not feeding. PTs can assist parents

4



and caregivers by asking parents about the baby's feeding, and communicating with the medical doctor if further assistance is needed.

For infants with CMT, it is also recommended that caretakers vary their feeding positions. However, as much as possible, the infant should be positioned so that there is a stretch to the involved side (Karmel-Ross, 2006), and handled in a manner that promotes strengthening of the weaker neck muscles (Öhman, Mårdbrink, Stensby, & Beckung, 2011). Öhman, Mårdbrink, Stensby, & Beckung (2011) showed that consistent adherence to proper handling strategies (how to pick up the infant, how to carry the infant) resulted in symmetric head posture and improved muscle function for infants with CMT. Physical therapists should educate parents on optimal positioning alignment for the infant (Freed, 2004; Karmel-Ross, 2006), and on handling strategies that strengthen the weaker neck muscles (Öhman, et al., 2011).

2c

Additionally, physical therapists should ask caregivers about the presence of reflux or gastrointestinal problems. Feeding problems related to gastroesophageal reflux should be addressed (Freed, 2004), and infants should be referred to their medical doctor if there is a concern for the infant's growth. Reflux may be indicative of a non-muscular cause for the torticollis posturing. Sandifer's Syndrome is

one example of a disorder in which gastrointestinal reflux can occur, resulting in torticollis posturing (Cooperman, 1997).

Suggested Best Practice: Physical therapists should ask caretakers about any problems related to feeding. Concerns about reflux or the infant's ability gain weight should be documented and reported to the medical doctor. If needed, referral to a lactation consultant or a pediatric gastroenterologist may ensue. (Confidence Level: Moderate); Physical therapists should document that they have educated parents about optimal positioning alignment for the infant, and handling strategies that strengthen the weaker neck muscles. (Confidence Level: Strong)

### *Objective Measures*

The following items are recommended in the initial PT examination and documentation of the infant with CMT.

#### *Side of torticollis.*

Right side involvement is found to be significantly associated with the duration of treatment ( $p < .0001$ ), but not the overall outcome, nor the need for surgery (Cheng, et al., 2001). There is no relationship between side of torticollis and the incidence of the type of CMT (Cheng, Tang, et al., 2000).

Suggested Best Practice: Physical therapists should document the side of CMT involvement. (Confidence Level: Strong)

*Presentation of initial head tilt.*

One of the most common clinical characteristics of CMT is a tilted head. In this posture, the infant presents with a laterally flexed neck, resulting in a tilted head position. Severity of head tilt has been significantly correlated with a greater limitation in passive neck rotation (Cheng, Tang, et al., 2000). “Head tilt” has also been referred to as “head tilting angle” (Kim, et al., 2009), “habitual head deviation from midline” (Rahlin & Sarmiento, 2010), “resting posture” (Cincinnati Children's Hospital, 2009), and “infant posture” (Kaplan, et al., 2013). It is the visual assessment of how much cervical lateral flexion the child demonstrates without manipulation from the therapist, and is often identified in supine. This is different from passive cervical lateral flexion in which the PT manipulates lateral flexion of the infant’s head to the end of the available range of motion.

Method of measurement: “Head tilt” has been recorded as a subjective measure using terms such as “none, mild, moderate, and severe” (Cheng, Tang, et al., 2000), and as an objective measure using a goniometer (Emery, 1994), a protractor (Kim, et al., 2009), or still photography (Rahlin & Sarmiento, 2010). Measurement of head tilt

using a protractor is documented with high intra-rater reliability and an intra-class correlation coefficient of 0.94-0.98 (Kim, et al., 2009). Still photography for measurement of head tilt is documented with a Pearson  $r$  of 0.80-0.85 for intra-rater reliability and 0.72-0.99 for inter-rater reliability (Rahlin & Sarmiento, 2010). Although the benefit of a still photograph in the infant's medical record is obvious, this method requires more time setting up the camera, and downloading and printing the photographs, unless there are digital options.

When an infant is able to sit independently without support, head tilt can be observed and measured in sitting with the infant looking straight ahead at a person or toy placed at eye level. The PT should be certain that the infant is sitting on the floor equally on her ischial tuberosities, so that there is no weight shift of the trunk affecting her head position. This measurement requires two people: the PT to take the measurement from behind, and a parent to engage the child to look straight ahead. From personal experience, a large protractor is not ideal for measuring head tilt in sitting, as the infant will most likely be distracted and attempt to rotate her body to see it. The preferred method of measurement of head tilt in sitting is with a goniometer. The fulcrum of the goniometer should be over the C7 spinous process, the proximal arm in line with the thoracic spinous processes and the moveable arm in line with the midline of the head (Norkin, 1995).

Suggested Best Practice: At a minimum, PTs should observe and record the presence of head tilt in infants with CMT (Confidence Level: Strong). Ideally, PTs should also measure and record the degree of head tilt; For an infant who is not able to sit, head tilt should be measured using a protractor in supine (Kim et. al, 2009 – high intra-rater reliability). If the infant is able to sit independently, measure and record the head tilt in sitting as measured with a goniometer – Level 5 evidence. Further research is needed regarding this measurement.

#### *Vision.*

Since almost 20% of infants and children who present with a torticollis posture will have a non-muscular disorder (Ballock & Song, 1996), it is important that the differential diagnosis include screening for ocular disorders. Nucci et al. (2005) found that in 63 children with abnormal head posture, the cause was ocular in 25 of them, advocating for a multi-disciplinary approach in the evaluation of children with abnormal posturing.

4

The most common cause of an ocular torticollis is paresis of the superior oblique muscle, also known as fourth cranial nerve palsy (Ballock & Song, 1996; Freed, 2004). Other causes of an ocular torticollis may include: melanoblastoma of the choroid, thrombosis of the retinal vein, retinal detachment, congenital nystagmus, and diplopia

(Cooperman, 1997). Boricean and Bărar (2011) propose ophthalmologic evaluation for every child who presents with an abnormal head posture, due to the multitude of ophthalmologic causes for a head turn or a head tilt.

Method of measurement: Special “vision kits” can be ordered which include a penlight to accurately assess vision (VisionAssociates, 2012), however these are not typically available in PT clinics. A simpler method can be used to test the infant’s vision by examining her ability to focus on a familiar face or small baby toy held in the center of her visual field, and then moved to the right or the left (Murkoff, 2003). For cranial nerve testing in adults, the examiner typically uses her finger to have the patient track to about 50° adduction, then up or down (Lundy-Ekman, 2007). Before and during movement of the object, the PT should check for symmetry between the left and right eye, and the ability of the infant to smoothly track without turning her head (Lundy-Ekman, 2007; VisionAssociates, 2012). With trochlear nerve palsy, the patient will exhibit difficulty looking inferiomedially (Lundy-Ekman, 2007). Any deficits noted during this visual tracking exam should be documented, discussed with the referring doctor, and then consultation with a specialist (ophthalamologist) may ensue. The PT should also look for any signs of ptosis, loss of the pupillary reflex (pupil constricting in response to light), or nystagmus (Lundy-Ekman, 2007).

Suggested Best Practice: Physical therapists should perform a basic visual screen for all infants with CMT during the initial examination. PTs should document not only the findings of their visual assessment, but also their communication with the referring doctor about those findings. If visual deficits are observed, the infant may benefit from referral to a pediatric ophthalmologist. (Confidence Level: Moderate)

*Craniofacial asymmetry.*

Accurate measurement of craniofacial asymmetry in infants with CMT is important because of the skeletal deformities that can occur with plagiocephaly (Yu, et al., 2004), and the need for early intervention of plagiocephaly to attain a successful outcome (Xia, 2008). It has also been found that craniofacial asymmetry is significantly correlated with greater limitation in passive cervical rotation (Cheng, Tang, et al., 2000).

2a-2c

Method of measurement: Measures of craniofacial asymmetry include: (a) the use of calipers (Graham, 2005); (b) head tracings with a “flexi-curve” device (Loveday, 2001); or (c) a clinical classification table (Argenta, 2004). Radiographs and computed tomography scans may also be used for the examination of plagiocephaly, however because of the increased cost, time, and radiation exposure to infants,

these are generally reserved for unusual cases or to rule out a true craniosynostosis (Argenta, 2004).

Intra-rater reliability for the use of calipers to obtain anthropometric measurements of the head is established at an acceptable level ( $\kappa=0.98$ ,  $\kappa=0.99$ ), but inter-rater reliability is not ( $\kappa=0.42$ ) (Mortenson & Steinbok, 2006). A common concern of the traditional metal calipers is their safety with fidgety babies, and the resulting lack of accuracy (Loveday, 2001). The head tracing method using a flexible curve device does not have any published data on reliability (Loveday, 2001).

Authors of the “Clinical Classification of Positional Plagiocephaly Table” report more than 95% concordance among multiple examiners (Argenta, 2004). This classification technique is reported to be reproducible, cost-effective, and easily understood (Argenta, 2004). It involves examination of the infant’s head from four positions and a determination of the presence or absence of deformity. In general, PTs in the USA do not receive any formal education in the use of calipers with infants and may feel more comfortable with a classification table. Both the CCHMC-CPG (Cincinnati Children's Hospital, 2009) and the SoP-CPG (Kaplan, et al., 2013) recommend the table by Argenta (2004).



Suggested Best Practice: Physical therapists should measure and record plagiocephaly with the objective classification scale for plagiocephaly designed by Argenta (2004). (Confidence Level: Strong)

*Skin appearance.*

Infants with CMT may demonstrate ecchymosis in the neck (Cheng, et al., 2001), a clavicular fracture (Cheng, et al., 2001), a visually observable mass along the sternocleidomastoid (Cheng, et al., 2001), and asymmetrical neck skin folds (Freed, 2004) with resulting erythema or inflammation on the affected side. The presence of a mass is particularly important because this is significantly associated with the need for surgery in infants with CMT ( $p=0.0018$ ) (Cheng, et al., 2001). Inspecting the skin condition of an infant with CMT is not only recommended by expert opinion (Cincinnati Children's Hospital, 2009; Freed, 2004), but also is included as part of the integumentary system review per the Guide to Physical Therapist Practice (APTA, 2003) and in the SoP-CPG (Kaplan, et al., 2013). The review should include a description of: skin pliability, number of folds, depth of folds, color, degree of redness, presence of skin breakdown, description of breakdown, and scar formation (APTA, 2003). If there is a clavicular fracture or other known fracture, the infant should be cleared by the physician prior to initiating physical therapy. Any unusual findings that

are suspicious for abuse or neglect of the infant must be reported to the appropriate officials for further investigation.

Suggested Best Practice: Physical therapists should document a standard review of the integumentary system on infants with CMT that is consistent with the Guide to Physical Therapist Practice (APTA, 2003). The results of the skin inspection should be documented in the medical record. (Confidence Level: Moderate)

*Type of congenital muscular torticollis.*

The exact etiology of CMT remains unknown, however one recurring hypothesis is that a disruption in the sternocleidomastoid occurs because of intrauterine crowding or compartment syndrome in the perinatal period (Lin & Chou, 1997). In this process, there is ischemia to the muscle, which in turn leads to degeneration of the muscle fibers and then fibrosis (Lin & Chou, 1997). For children less than three months of age, ultrasonographic imaging reveals that muscle fibers are invaded by cellular fibrous tissue (Lin & Chou, 1997), which may lead to a sternomastoid tumor. These fibrotic muscle fibers begin to restore at a faster pace after five months in age, eventually leading to a smaller lesion as the child ages (Lin & Chou, 1997). Lin & Chou (1997) show that the lesion to muscle ratio decreased from 83.6% at two months, to 59.9% at nine months, and less than 40% at

or after one year of age. These findings correspond with clinical observation that a sternomastoid tumor may be present in early infancy, but then resolves as the child ages.

The type of lesion should be classified at the initial PT exam into one of three subgroups: (a) sternomastoid tumor group, in which there is a palpable tumor; (b) muscular group, in which the muscle is thickened but no tumor is present; or (c) postural group, in which there is no thickening, nor tumor in the muscle (Cheng, Tang, et al., 2000).

There is a significant difference regarding the duration of treatment among the three clinical groups ( $p < .0001$  for each), with the sternomastoid tumor group significantly associated with a longer duration of treatment, and the postural torticollis group significantly associated with shorter duration of treatment (Cheng, et al., 2001).

Presence of a sternomastoid tumor is significantly associated with a greater risk for surgery ( $p = .023$ ) (Cheng, et al., 2001).

2c

2c

Method of measurement: Palpation of the cervical muscles is necessary to determine the type of CMT. Manual palpation of the sternocleidomastoid muscle (SCM) is not clearly described in the literature. Cheng et al. reported a method for palpation of the SCM. In the method described, the infant lies supine with a small bolster under the neck to extend the head, while rotating the head  $45^\circ$  away from the

affected side (Cheng, Metreweli, et al., 2000). This allows the clinician to view the entire length of the SCM. If a tumor is present, it will not only be palpable, but usually visible as well. Care should be taken to closely monitor the infant with CMT in this extended position, as it could cause a laryngeal cough reflex, or a facial color change (Yim, et al., 2010), at which time the stretch should be discontinued. The presence or absence of a tumor or muscle thickening in the SCM should be documented, as well as the general location: upper, middle, and/or lower third of the SCM. Surgery appears to be more likely for tumors located only in the middle portion of the SCM (Lin & Chou, 1997), and greater severity of CMT is correlated with involvement of more than the distal third (Kaplan, et al., 2013). If the clinician is able to measure the size of the tumor with a tape measure, then this information may be helpful in documenting the overall effect of treatment intervention. Communication with the referring doctor should ensue and ultrasound imaging may also be useful.

4-5

**Suggested Best Practice:** Physical therapists should palpate the cervical musculature and document the type of CMT as sternomastoid tumor, muscular, or postural. If a tumor is present, the general location should be documented: upper, middle, or lower third of the SCM. (Confidence Level: Strong) An observable tumor should

be reported to the referring doctor and an ultrasound of the SCM is recommended to accurately track the size and location.

*Passive cervical rotation.*

Passive cervical rotation in an infant with CMT is the movement manipulated by the PT to rotate the infant's head to one side. Passive range of motion (PROM) into cervical rotation is often reported as an outcome measure in the literature on CMT (Lee et al, 2015; Cheng, Wong et al., 2001; Emery, 1994; Ohman & Beckung, 2005; Taylor & Norton, 1997; Celayir, 2000; Perbeck Klackenberg, Elfving, Haglund-Akerlind & Carlberg, 2005; Binder, Eng, Gaiser & Koch, 1987).

Although 110° of cervical rotation in infants has been described as the mean (Öhman, Nilsson, & Beckung, 2010), Ohman, Nilsson & Beckung (2010) report 90° of cervical rotation to be satisfactory due to a risk of decreased blood flow in some individuals with cervical rotation of 90° to 100°. Among infants with CMT, a deficit in passive rotation between the left and right side of more than 15° is significantly associated with a longer duration of treatment ( $p < .0001$ ), and a greater risk for surgery ( $p < .0001$ ) (Cheng, et al., 2001).

2c

Method of measurement: Measurement of cervical rotation is typically performed with the child supine, shoulders stabilized, and head held beyond the end of the table or plinth to allow for cervical

rotation of 90 degrees (Cheng, et al., 2001; Öhman & Beckung, 2008; Öhman, et al., 2010). Three people are needed to obtain an accurate measurement: one to stabilize the infant, one to rotate the head, and one to hold the measurement device. Based on clinical experience, the parent should stabilize the child and the PT should perform cervical rotation off the edge of a plinth or mat, while a co-worker holds the measurement device.

Tools to measure cervical ROM in the infant include: an arthrodial protractor (Cheng, Wong et al, 2001), a goniometer with two carpenter levels attached to the arms of the goniometer (Emery, 1994; Karmel-Ross & Lepp, 1997), 2-dimensional video analysis (Christensen, Castle & Hussey, 2015) and a standard goniometer (Klackenberg, 2005). Inter-rater reliability of passive cervical rotation in supine with the infant's head off the table when measured with an arthrodial protractor is documented as .71 in a pilot study (Cheng, et al., 2001), but no landmarks are identified. Emery (1994) cites inter-rater reliability with a device "similar" to the adapted goniometer as .86 to .96 in one study, and .58 to .89 in another. However, the first study used a head adapter to secure the goniometer to the patient's head (Tucci, 1986), while the second was performed on cooperative adults, not infants (Zachman, 1989). Intra-rater reliability of passive cervical rotation with a standard goniometer performed on infants lying supine

with their head on the table ranges from .77 to .95 (Klackenberg, 2005).

Based on clinical experience, infants do not tolerate devices that need to be secured to the head for accurate measurement. Secondly, a device that is proven reliable on adults may not be applicable for fidgety and non-consenting infants. Although there appears to be high intra-rater reliability with a standard goniometer as reported by Klackenberg (2005), measurements were taken with the infant's head on the table which only allows for approximately 70° or 80° of cervical rotation, and is low in comparison to other studies with a mean cervical rotation of 90°-110° (Öhman & Beckung, 2008). If the infant's head rests on a table, cervical rotation may be limited when the infant's cheek touches the support surface.

**Suggested Best Practice:** Physical therapists should measure and record passive cervical rotation in infants with CMT with an arthrodial protractor (Cheng, et al., 2001; Öhman & Beckung, 2008; Öhman, et al., 2010). The infant should be positioned in supine, with shoulders stabilized, and head held beyond the end of the table or plinth. Passive rotation should be measured on both the affected and unaffected sides. (Confidence Level: Strong)

*Passive cervical lateral flexion.*

Passive cervical lateral flexion, also known as side-bending, is the measurement obtained when the infant's head is passively flexed to the side, from vertical to an ear over shoulder position. Mean passive cervical lateral flexion in normal infants less than one year old is  $70^{\circ} \pm 2.2^{\circ}$  standard deviation (Öhman & Beckung, 2008). Although measurement of passive cervical lateral flexion in infants with CMT can be found in the literature (Cheng, et al., 2001; Emery, 1994; Öhman & Beckung, 2005), Cheng (2001) cites that passive cervical rotation is preferred over passive cervical lateral flexion because of increased inter-rater reliability with rotation. Yet, the SoP-CPG includes passive cervical lateral flexion as a recommended measurement in the examination process (Kaplan, et al., 2013), and the CCHMC-CPG states that the goals of therapy include passive and active cervical lateral flexion to at least  $5^{\circ}$  of within normal limits (Cincinnati Children's Hospital, 2009).

2

Method of measurement: Passive cervical lateral flexion can be measured with a large protractor and the infant in supine with shoulders stabilized (Öhman & Beckung, 2008). Öhman & Beckung (2008) referenced high intra-rater reliability values from Klackenberg et. al (2005) with an interclass correlation coefficient of 0.94-0.98, using this method. The PT could potentially record this measure alone, however, two people may be needed if the infant is very fidgety:

4



a parent to stabilize the infant in supine with shoulders secured on the table, and the PT to passively move the head, while reading the protractor for measurement. Passive cervical lateral flexion should be measured on both the affected and unaffected sides, so that the PT can determine if there is a difference between the right and left sides.

Suggested Best Practice: Physical therapists should measure and record passive cervical lateral flexion in both directions (Confidence Level: Strong). It can be recorded using a large protractor or similar tool placed behind the infant's head in supine (Klackenberg et. al, 2005 – high intra-rater reliability).

#### *Active cervical rotation.*

Active cervical rotation is the measure of neck rotation that an infant can achieve without manipulation from the PT. Many studies related to CMT use passive range of motion (PROM) for cervical rotation as an outcome measure. Few studies document that active range of motion (AROM) for cervical rotation was recorded (Cheng, et al., 2001; Joyce & de Chalain, 2005; Taylor, 1997), and none of these studies provide reliability for measures of active cervical rotation.

Active range of motion is an important and clinically relevant measurement, as it indicates symmetrical development and neck strength. The ultimate goal of physical therapy for a child with CMT is

to appropriately use the available passive range of motion that is acquired through stretching for functional use. The CCHMC–CPG states that the goals of therapy include passive and active cervical rotation to at least 5° of within normal limits (Cincinnati Children's Hospital, 2009), and the SoP–CPG recommends symmetrical active movements prior to discharge (Kaplan, et al., 2013). Active cervical rotation is a functional goal and should be accurately measured and recorded.

Method of measurement: Taylor (1997) measures active cervical rotation with a goniometer in sitting, but no reliability is published. Karmel-Ross & Lepp (1997) advocate for use of a goniometer with two carpenter levels attached to the arms of the goniometer to measure active cervical rotation in both supine, and in either supported or independent sitting, however no reliability is published about this method and the tool is not publically available (Karmel-Ross & Lepp, 1997).

Active cervical rotation should be observed with the infant sitting. If the infant is not able to sit by herself but can hold her head upright, as in a 4 month old, then the parent should support the infant's trunk in sitting. If the infant is not able to sit and hold her head up, even with support, as in a newborn, then AROM should be measured

in supine. The SoP–CPG recommends that a rotating stool be used by the PT who is holding the infant in sitting and then rotates the stool away from the caretaker to assess the infant's cervical rotation (Kaplan, et al., 2013). The PT could then observe active rotation from above watching for the movement of the baby's nose toward the shoulder (Kaplan, et al., 2013). PTs should observe for any difference in active cervical rotation between the left and right sides, and then document the visually estimated percentage of full range that the infant was able to achieve, as he/she turns the chin toward the shoulder.

Suggested Best Practice: Physical therapists should observe and record active cervical rotation in infants with CMT (Confidence Level: Strong). This could be recorded in supine for infants younger than 3 months, or using a rotating stool for infants older than 3 months. The infant sits on the PTs lap, and the PT observes active cervical rotation from above. Active cervical rotation should be observed on both the affected and unaffected sides, so that the PT can determine if there is a difference – Level 5 evidence. Further research is needed regarding this measurement.

#### *Lateral head righting/ Active cervical lateral flexion*

Lateral head righting is the ability of an infant to hold her head upright in a vertical position while her body is tilted horizontally to the

side (Öhman, Nilsson, & Beckung, 2009). It is a reflex developed early in life which requires muscular control of the head and neck (Öhman, Nilsson, & Beckung, 2009), and thus is a measure of strength. Lateral head righting to the left and right side has been shown to be symmetrical in healthy infants without CMT (Öhman & Beckung, 2008), but clinically, asymmetrical in infants with CMT (Öhman & Beckung, 2008; Öhman, Nilsson, & Beckung, 2009). Multiple studies on infants with CMT report lateral head righting as an outcome measure (Emery, 1994; Öhman & Beckung, 2005; Rahlin, 2005). There is no reported association between lateral head righting and the infant's overall outcome, however some authors feel this is an important functional outcome measure as it is a component of normal motor development and postural control (Öhman & Beckung, 2008; Öhman, Nilsson, & Beckung, 2009; Rahlin, 2005). It is important to note that head righting is a postural response that should be initiated by 4 months of age (Norberg, 2001). Prior to 4 months, it is not expected that an infant will be able to fully right her head.

Method of measurement: The five point Muscle Function Scale (Öhman & Beckung, 2008) should be used to assess the infant's ability to laterally right her head. The five point Muscle Function Scale (MFS) has been shown to have both inter-rater reliability and intra-rater reliability with estimates of weighted Kappa scores at 0.97 and 0.99,

respectively (Öhman & Beckung, 2008). Although a six point MFS has been developed and also shows high inter-rater and intra-rater reliability (Kappa > 0.9, ICC > 0.9) (Öhman, Nilsson, & Beckung, 2009), the five point scale is preferred because it is less confusing than the six point scale. The authors report that the MFS is designed to be used with picture and word descriptors rather than measurement in degrees, however the six point scale requires the PT to assess whether or not the infant is holding her head above or below 45° (Öhman, Nilsson, & Beckung, 2009). To use the five point MFS, the infant is held horizontally around the trunk without support for the head. Score the infant's ability to lift their head above horizontal and hold it for 5 seconds on their own. Scores are based on a scale of 0-4 points with "0" for holding head below horizontal, "1" for holding head on the horizontal line, "2" for holding head slightly above the horizontal line, "3" for holding head high above the horizontal line, and "4" for holding head very high above the horizontal line (Öhman & Beckung, 2008). It is expected that a healthy infant without CMT will show a symmetrical score on both sides (Öhman & Beckung, 2008), while an infant with CMT may demonstrate a two or three point difference in the scores between the affected and unaffected side (Öhman & Beckung, 2008).

Suggested Best Practice: Physical therapists should measure and record lateral head righting in infants with CMT on both the

affected and unaffected sides (Confidence Level: Moderate). This should be measured using the five point MFS (Öhman & Beckung, 2008) – high inter-rater & intra-rater reliability.

*Neck flexor strength.*

Neck flexor strength refers to an infant's ability to lift her head forward, as is typically done when performing a sit-up. It is facilitated in infants through a technique known to pediatric PTs as the "pull-to-sit". One study documents neck flexor strength for infants with CMT (Taylor, 1997). Although there is no known association between neck flexor strength in an infant with CMT and her overall outcome, there is evidence that head lag persisting after four months of age is linked with poor developmental outcomes (Snyder & Coley, 2006). Since the ultimate goal of physical therapy for a child with CMT is to be able to appropriately use the available passive range of motion that has been acquired, measuring neck flexor strength appears to be a functionally important goal and should be accurately recorded.

4

2c

Method of measurement: Neck flexor strength can be measured during a pull-to-sit transition from supine to sitting. The PT should hold the infant's hands and pull her up from supine to a full upright sitting position. By four months, the infant should be able to lift her head and hold it steady throughout the transition, without evidence

of a head lag (Snyder & Coley, 2006). If weakness is suspected, the PT should place her hands behind the infant's shoulders for increased support while performing the pull-to-sit maneuver and support the head if needed. Neck flexor strength can be assessed at approximately four months of age and the findings documented as: complete or incomplete, and symmetrical or asymmetrical (Taylor, 1997). Complete refers to the infant's ability to lift her head throughout the transition from fully supine to a seated position, without evidence of a head lag. Symmetrical refers to the infant's ability to hold her head straight without tilting to one side during the transition.

Suggested Best Practice: Physical therapists should measure and record neck flexor strength in infants with CMT who are 4 months of age or older, using the pull-to-sit technique (Confidence Level: Moderate).

#### *Hip symmetry.*

Cheng, Tang, et al. (2000) report that hip dysplasia in infants with CMT is shown to be significantly associated with presence of a sternomastoid tumor ( $p<.001$ ), and greater limitation of passive neck rotation ( $p<.001$ ). The CCHMC-CPG recommends that examination of an infant with CMT include a hip screen for "asymmetry, hip clunk, or leg length discrepancy" (Cincinnati Children's Hospital, 2009), and the

SoP-CPG recommends screening for “symmetrical alignment of the... hip girdle, ...and hip dysplasia” (Kaplan, et al., 2013).

2

Method of measurement: In order to perform an appropriate hip exam, it is very important that hip ROM be examined (Leach, 2006), as well as any abnormal posturing of the lower extremities in play. Infants generally have 75°-90° of hip abduction (Leach, 2006). A limitation of 5°-10° could be indicative of hip dysplasia, and is typically the only clinical sign of hip dysplasia in infants older than 1 month (Leach, 2006). Other possible signs include: asymmetrical hip folds, leg length discrepancy, or a positive Barlow or Ortolani sign (Leach, 2006). The Barlow and Ortolani tests have limited diagnostic value though, if the infant contracts her hip muscles during testing, or if the infant is older than 2-3 months (Leach, 2006). Any positive findings should be reported to the primary pediatrician for further medical work-up. Without positive findings, the infant may also be referred for further medical work up if multiple risk factors for hip dysplasia are present: first-born, female, breech, family history of hip dysplasia (Leach, 2006). Joiner, Andras & Skaggs (2014) recommend hip imaging via ultrasound or radiograph for all infants with CMT. If hip dysplasia is present, the PT should follow orthopedic recommendations for treatment, and caution should be taken when positioning or handling the infant's hips and legs.



Suggested Best Practice: Physical therapists who work with infants with CMT should determine if there is hip dysplasia (Confidence Level: Strong). Signs of hip dysplasia may include the presence of: (a) limited hip abduction; (b) asymmetric hip folds; (c) a positive Barlow or Ortolani sign if younger than 2-3 months; or (d) a leg length discrepancy. Physical therapists should document their findings and consult with the primary medical doctor or referring physician if there are any positive findings for hip dysplasia.

#### *Motor development.*

According to the CCHMC–CPG, motor development is a recommended item of the PT examination, however, no specific reasoning is established and no specific method is recommended (Cincinnati Children's Hospital, 2009). The SoP-CPG also recommends that motor development be examined, and suggests using a standardized scale to measure and record it (Kaplan, et al., 2013). Examination of motor development is essential for an infant with CMT, as supported by evidence from Schertz et al. which shows an increased risk for delay in gross motor skills in this population (2008), and from Ohman, Nilsson, Langerkvist et al, which shows that infants with CMT score significantly lower in motor performance compared to infants without CMT (2009). Transient motor asymmetry

is also now noted in the literature (Waternberg, Ben-Sasson & Goldfarb, 2016)

Method of measurement: The lack of a standardized test of motor function specifically for infants with CMT makes it difficult to accurately provide a reference for the infant's motor abilities to caretakers and other healthcare professionals, as well as third party payers. Instead, pediatric physical therapists may attempt to provide a narrative description of the newborn's motor abilities. A less subjective option is the use of a newborn motor assessment appropriate for this age population. Such standardized tests include the Test of Infant Motor Performance (TIMP), and the Alberta Infant Motor Scale (AIMS). These two tools are selected based on: their emphasis on motor skills in the infant population, strong psychometric properties, availability to the clinical setting of these patients, and their overall popularity among pediatric physical therapists.

Version 5 of the TIMP (recommended for clinical practice) was designed to evaluate infants from 34 weeks post conceptual age to four months post term based on a combination of observed and facilitated movements (Campbell, 2005). Age standards were determined from a sample of 990 infants in the USA from various cultural backgrounds (Campbell et al., 2007). The TIMP has been

shown to have very good test-retest reliability ( $r = 0.89$ ) (Campbell, 1999), and has been found to be discriminative (Campbell & Hedeker, 2001), predictive (Campbell, Kolobe, Wright, & Linacre, 2002), and evaluative (Spittle, 2008). The TIMP is a relatively inexpensive tool that requires minimal equipment and set-up. The test manual, test forms, and age calculator can be purchased for approximately \$116 (IMPS, 2010). A rattle, squeaky toy, and shiny red ball are needed to complete all 42 items, with an average testing time of 33 minutes (Campbell, 2005).

The AIMS was designed to be a discriminative and evaluative tool in infants 18 months of age or younger (Mayson, 2007). The standards for the AIMS are based on 2202 infants born in Alberta, Canada, ages 1 week to 18 months (Mayson, 2007). It has been shown to have excellent inter-rater reliability, test-retest reliability and concurrent validity (Piper & Darrah, 1994). The AIMS was found to be most accurate at estimating the developmental level between 4-10 months of age with a sensitivity of 77%, specificity of 82% at 4 months of age, and a sensitivity of 86%, specificity of 93% at 8 months of age (Darrah, Piper, & Watt, 1998). The AIMS is also a relatively inexpensive tool costing approximately \$110.00 for the manual and score sheets ([www.amazon.com](http://www.amazon.com)). It consists of a maximum of 58 items which require an “observed or not observed” response from the

clinician and 20-30 minutes to administer (Mayson, 2007). Any toys that are appropriate for the 0-18 month age range can be used during the test.

Although neither the TIMP nor the AIMS have been tested for sensitivity to change with intervention for infants with CMT, both tests could be used as a measure of motor development, and as a means of standardized testing which allows a reference to typical development. Limitations of the TIMP include the restricted age range, and length of time for administration and self-study prior to use. Limitations of the AIMS include a lack of items related to asymmetrical movement (differentiating left from right side), as is important in CMT, and a reduced number of items (14) in the 0-4 month range, resulting in a lower predictive validity for this age range. If the clinician chooses to use the TIMP on an infant younger than four months, but then follows the infant throughout the first year, a different test will need to be administered after 4 months of age. According to Campbell, Kolobe, Wright & Linacre (2002), the TIMP scores at three months of age are highly predictive of scores on the Alberta Infant Motor Scale at 12 months of age. Overall sensitivity and specificity scores of the TIMP at three months of age to the AIMS at 12 months were 92% and 76% respectively. Most significantly, the negative predictive validity of the

TIMP at 3 months to the AIMS at 12 months was found to be 98% (Campbell, et al., 2002).

Suggested Best Practice: Physical therapists should measure and record motor development in infants with CMT (Confidence Level: Strong). Physical therapists should use the TIMP as a measure of motor development in infants with CMT who are 0-4 months old. After four months of age, the AIMS should be used as a measure of motor development, but care should be taken by the clinician to document additional comments regarding asymmetries identified.

*General PROM & AROM of the upper and lower extremities.*

Limb movement measures are recommended in both the CCHMC-CPG (Cincinnati Children's Hospital, 2009) and the SoP-CPG (Kaplan, et al., 2013). Based on clinical experience and supporting evidence from Hylton (1997), infants with CMT often develop a preferential use of one side of the body compared to the other, most likely due to the favored ipsilateral cervical rotation observed with CMT. Also, observation of extremity ROM is recommended to rule out “brachial plexus injuries, clavicle fractures, neurological impairments, hypermobility, or CNS lesions”(Kaplan, et al., 2013).

5

2

Method of measurement: Movement should be observed actively first with a simple visual assessment of the infant at play, and

then any abnormal findings or asymmetry between sides can be objectively measured with a goniometer and recorded (Norkin, 1995). Similarly, passive motion of the infant's arms and legs at rest can be performed by the PT and then, any abnormalities or asymmetries from right to left can be objectively measured with a goniometer and recorded (Norkin, 1995).

Suggested Best Practice: Physical therapists should examine passive and active range of motion of both arms and legs during an infant's first visit. AROM should be examined visually first, and any discrepancies or limitations should then be objectively measured with a goniometer. PROM should be examined manually first, and then any discrepancies or limitations should be objectively measured with a goniometer. Findings should be documented in the medical record. (Confidence Level: Moderate)

#### *Muscle tone & neurological reflex testing.*

Due to the possibility of a spasmodic torticollis, or other neurological reason for abnormal posturing (Ballock & Song, 1996), it is recommended that the PT examination of an infant with CMT include an assessment of the infant's muscle tone and reflexes to screen for intact neurological function (Cincinnati Children's Hospital, 2009; Kaplan, et al., 2013). It is important to note that an isolated finding of

one abnormal reflex may not necessarily be indicative of neurological dysfunction in the infant (Pathways.org, 1992).

Similarly, the physical therapist exam of an infant with CMT should include reflex testing as part of the comprehensive exam (Cincinnati Children's Hospital, 2009; Kaplan, et al., 2013), but should not be used as the sole indicator of neurological dysfunction. The Babinski reflex and the asymmetric tonic neck reflex (ATNR) should be assessed (Cincinnati Children's Hospital, 2009) for symmetry between sides and for persistence beyond the normal time of integration. The ATNR and the Babinski reflex should typically be integrated by about 6 and 12 months of age, respectively (Norberg, 2001). Postural responses such as head and trunk righting should be assessed in older infants (Norberg, 2001; Öhman, Nilsson, & Beckung, 2009; Rahlin, 2005).

Method of measurement: Although the Modified Ashworth Scale for grading muscle spasticity is a popular tool among healthcare professionals and has been shown to be reliable with adults, reliability has not been established with children (Olney & Wright, 2006). For this reason, the PT may instead, record the presence of hypotonia or hypertonia, and the exact location or part of the body. To test for primitive reflexes, the Babinski is assessed by stroking the bottom of

the infant's foot and eliciting extension of the great toe. Persistence beyond 12 months of age should be documented ([www.mesacc.edu](http://www.mesacc.edu)).

To test for ATNR, the PT should turn the infant's head to one side and elicit an extension of the arm and leg on the side to which the head is turned, with flexion of arm and leg on the opposite side, also known as the "fencing position or fencing reflex" (Norberg, 2001). The ATNR should be integrated by 6 months of age (Norberg, 2001). To test for the head righting response, the Muscle Function Scale should be used with infants 4 months of age or older (Öhman, Nilsson, & Beckung, 2009). To test for trunk righting response, the infant should be at least 8 months of age and be able to sit independently (Norberg, 2001). The PT "gently but abruptly" pushes the infant to the side while he/she is sitting and observe the infant's trunk flex toward the side that was pushed while arm and leg outstretch to avoid falling (Norberg, 2001). This can also be done with the child seated on a therapy ball. The PT sits in front of the child and secures the child with their hands on the child's thighs. The PT then provides postural displacement at various angles and assesses asymmetry between sides or failure to avoid falling from lack of trunk control (Walsh & Morrissy, 1998). Based on clinical experience, an infant with CMT may also demonstrate asymmetry between the left and right side postural responses when attempting to elicit the head or trunk righting reaction. For this reason,



it is important to remember that reflexes should be a guideline in the exam, and not the sole indicator of neurological dysfunction (Pathways.org, 1992).

Suggested Best Practice: Physical therapists should perform a thorough exam of muscle tone, primitive reflexes, postural reflexes and overall motor development to determine whether a referral for full neurological workup is warranted. Findings should be documented in the medical record. If abnormalities are present, discussion with the referring doctor should ensue. (Confidence Level: Moderate)

### Physical Therapy Interventions for Infants with CMT

Interventions for CMT range from stretching to surgical release of the tight musculature to parent education on active movement exercises with varying levels of evidence (Tessmer, Mooney, & Pelland, 2010). Physical therapists (PTs) who work with infants diagnosed with CMT may be challenged by the selection of interventions that are currently available. This section provides a review of the various treatments available to PTs for use with an infant with CMT, and the current evidence to support those interventions. This section does not instruct the clinician on how to implement the interventions. Physical therapists should be mindful of ensuring that there

are no medical complications or contraindications to a specific intervention. For example, passive neck stretching should not be done with a child who has Down Syndrome or a cervical spine fracture (Karmel-Ross, 2006). Physical therapists who treat CMT should consult additional sources for specific implementation of interventions (Cincinnati Children's Hospital, 2009; Kaplan, et al., 2013; Karmel-Ross, 2006; Karmel-Ross & Lepp, 1997). A discussion on frequency and duration of treatment can be found at the end of this section.

### *Recommended PT Interventions for an Infant with CMT*

Interventions provided directly by a physical therapist for CMT include: passive range of motion (PROM) or stretching (Binder, et al., 1987; Cheng, et al., 2001; Öhman & Beckung, 2005; Öhman, et al., 2010; Taylor, 1997); instruction in a HEP (Demirbilek & Atayurt, 1999; Emery, 1994); active range of motion (AROM) and positioning techniques (Cheng, Tang, et al., 2000); myokinetic stretching (Chon, et al., 2010); microcurrent therapy (Kim, et al., 2009); and kinesiology taping (Öhman, 2012). Additional interventions that may be found in the literature on CMT include exercises to promote gross motor development and bracing, however these are typically used in combination with “conservative (physical therapy) treatment” (Binder, et al., 1987; Cincinnati Children's Hospital, 2009; Öhman & Beckung, 2005). “Conservative treatment” encompasses passive stretching, active movement, strengthening, and positioning (Cincinnati Children's Hospital, 2009). Without

isolating the specific intervention provided by the physical therapist, it is difficult to determine the effectiveness of each. For the purpose of this review, the author attempted to select intervention studies which isolated one or two specific treatments, but reference may be made to studies which combine interventions, as their contribution to research on CMT is essential in showing the success of conservative physical therapy treatment.

This section is divided into two parts: (a) primary interventions, and (b) secondary interventions. A primary intervention is defined as the first line of treatment recommended to PTs who treat infants with CMT. These interventions are supported by a stronger body of evidence. A secondary intervention is the second line of treatment, implemented when further improvement is needed and has not been achieved solely with the use of primary interventions. It is recommended that PTs use secondary interventions in conjunction with primary interventions to achieve a successful outcome. The body of evidence to support a secondary intervention is not as strong.

### *Primary Interventions*

#### *Passive stretching (PROM exercises).*

Cheng, et al. (2001) provide the strongest evidence to support passive stretching exercises by a PT in the treatment of CMT. This study demonstrates that 88-94% of infants with CMT, who began treatment in their first year, including those with a sternomastoid tumor,

showed good or excellent results at a mean 4.5 year follow-up, when treated with a standardized manual stretching program by a physical therapist and a home program of active positioning. The median duration of treatment was 2.5-3.7 months. Three additional studies (Binder, et al., 1987; Öhman & Beckung, 2005; Taylor, 1997) of children with CMT who received treatment in physical therapy programs are consistent with findings that physical therapy, inclusive of stretching exercises, is effective in improving outcomes.

Suggested Best Practice: Physical therapists should perform passive stretching exercises as part of the treatment for an infant with CMT. (Confidence Level: Strong)

*Home exercise program.*

Emery (1994) reports that CMT in infants under two years of age can be successfully managed through a daily home exercise program (HEP) performed by the parents or caretakers. Full recovery, as measured by full passive cervical rotation and lateral flexion of the neck, is achieved in all but one of 100 infants. The mean treatment duration was 4.7 months (SD = 5.06, range = 1-36). Study limitations include a high attrition rate, and a short follow-up period. Demirbilek and Atayurt (1999) also report the effectiveness of a HEP to treat CMT, but the study is limited by a vague protocol and a poor description of the outcome measures. In a comparative study, (Öhman, et al., 2010),

2c

stretching by a PT is more effective than stretching by the parent, with an increase in cervical ROM and symmetric head posture being achieved significantly quicker in the PT group (mean = 2.5 months, SD = 2.0) than in the parent group (mean = 4.5 months, SD = 1.9).

Further research is recommended due to the small sample size of 20 infants (Öhman, et al., 2010). In another study (Öhman, et al., 2011), the active participation of caregivers in a handling program provides strong support for the effectiveness of HEP. Based on clinical experience, providing parents with a home exercise program allows caretakers to be actively involved in the care of their child and provides continuity of care in between PT visits. One study shows that adherence to the HEP is related to the maternal perception of torticollis severity and perception of the importance of the HEP (Rabino, Peretz, Kastel-Deutch, & Tirosh, 2013). It also provides a method of intervention for those infants whose caretakers may not be able to consistently attend weekly PT sessions due to a busy work schedule, difficulty with transportation, or a long commute to the PT facility.

Suggested Best Practice: Physical therapists should instruct caretakers in a home exercise program for the treatment of CMT and follow up with them on its implementation. (Confidence Level: Strong)

*Active range of motion exercises & positioning.*

Active range of motion (AROM) exercises and positioning techniques are used simultaneously by Cheng, et al. (2000) to treat a subset of infants whose restrictions are not severe. Cheng, et al. (2000) use a program of active stimulation exercises and positioning (without stretching exercises) on infants with a 10° or less deficit in rotation range. Five percent of the 266 cases are transferred to a manual stretching protocol after four weeks due to lack of improvement, but all patients show excellent results in the end, with no surgery required.

2c

Öhman, Mårdrbrink, Stensby, & Beckung (2011) show that consistent compliance with proper handling strategies alone (how to pick up the infant, how to carry the infant, and prone positioning when awake) results in symmetric head posture and improved muscle function for infants with CMT. The main limitation with this study is that there is no description of the type of CMT in the participants. However, there is data which suggests that the majority of infants did not have muscle tightness at the start of treatment, which is indicative of postural torticollis (Öhman, et al., 2011). This is the first study to show that handling strategies alone can be used to improve muscle imbalance in infants with CMT (Öhman, et al., 2011). Other studies include AROM and positioning as part of a successful treatment for

2c

CMT when used with other interventions (Demirbilek & Atayurt, 1999; Rahlin, 2005).

4-5

Suggested Best Practice: Physical therapists should include AROM and positioning exercises in the treatment for all infants with CMT regardless of their rotation deficit, to promote active movement and play on the involved side and to ensure symmetry of posture and function. (Confidence Level: Strong)

*Strengthening exercises & developmental therapy.*

Other PT interventions include: strengthening exercises for the head and neck to include lateral head righting (Karmel-Ross, 2006; Karmel-Ross & Lepp, 1997; Öhman, et al., 2011); strengthening exercises for the trunk and body to include equilibrium responses (Karmel-Ross & Lepp, 1997); and exercises that address gross motor developmental and symmetry of movements (Karmel-Ross & Lepp, 1997; Tessmer, et al., 2010). Strengthening exercises are included in the description of conservative PT treatment, and typically are incorporated into other effective intervention studies (Binder, et al., 1987; Emery, 1994; Taylor, 1997). Öhman, Mårdrbrink, Stensby, & Beckung (2011) show that handling strategies combined with strength exercises are effective as the sole intervention for improving muscle function in infants with CMT. Due to the small and heterogenous sample size, further research is needed to determine which patients

2c-5

with CMT are most appropriate for this intervention (Öhman, et al., 2011). Strengthening exercises and developmental activities are also supported by clinical guidelines, yet lack a clear description of their recommended implementation (Cincinnati Children's Hospital, 2009; Kaplan, et al., 2013).

Suggested Best Practice: Physical therapists should provide treatment for weak muscle groups that may be inhibiting the infant's ability to achieve midline postural control and develop typical motor skills with symmetry of movement. This may include head and neck strengthening, strengthening exercises for the trunk and limbs, as well as developmentally appropriate exercises to promote functional play. (Confidence Level: Strong)

### *Secondary Interventions*

#### *Myokinetic stretching technique.*

The myokinetic stretching technique is a form of myofascial release that combines active and passive movement of the tight muscle until a release is palpated (Chon, et al., 2010). Treatment with myokinetic stretching is shown to be effective for reducing the muscle thickness of the sternocleidomastoid, and for improving cervical ROM and head symmetry (Chon, et al., 2010). The statistically significant conclusions are impressive, however the confounding variables include: (a) the daily monitored home exercise program of stretching



and massage; (b) the high frequency of treatment, five times per week; and (c) the young age of the subjects, three months of age or younger. Other factors to consider are the potential side effects of “reflexive contraction, local hypertonia, or pain” (Chon, et al., 2010). At this time, there is not enough evidence to include the myokinetic stretching technique as a primary intervention in the treatment of infants with CMT, but it may be an alternative prior to more invasive approaches.

#### *Microcurrent therapy.*

Microcurrent therapy is “low-intensity alternative current” (Kim, et al., 2009) which is delivered at 100-200 microamperes, and is thought to restore homeostasis of  $\text{Ca}^{2+}$  within the muscle (Kim, et al., 2009). Kim, Kwon, and Lee (2009) compare six sessions of microcurrent therapy applied to the SCM to six sessions of manual stretching in 15 infants with CMT. Preliminary data suggests that the group that received microcurrent had significant improvements in head tilt angle, rotation range, and reduced incidence of crying compared to the group that received manual stretching. Rotation range in the microcurrent group increased from  $70^{\circ} \pm 11.5^{\circ}$  to  $80^{\circ} \pm 6.7^{\circ}$  in two weeks. Limitations to this study included: (a) a small sample size, (b) that full recovery is not achieved, and (c) there is no long term follow-up. A more recent study also reproduces positive results of microcurrent therapy (Kwon & Park, 2014). In this study, two groups of 10 infants

with CMT were each treated with therapeutic exercise and ultrasound, while one of the two groups received microcurrent, and the other a placebo. The results showed that the group which received the microcurrent had significantly greater rotation ROM ( $p<0.05$ ), lesser thickness of the SCM ( $p<0.05$ ), and shorter treatment time ( $p=0.002$ ) (Kwon & Park, 2014).

2c

Clinically, PTs and parents may be uncomfortable with the concept of using electrical stimulation to the SCM of an infant, as this area is relatively small, and proximal to the carotid artery. A specialized probe and a sleepy baby may be needed to accurately follow the protocol of the authors, however the exact procedures and parameters of the microcurrent are not detailed in one study (Kim, et al., 2009). Some intervention details are provided in the second study, but this is a small sample size, and all infants started treatment prior to one month of age (Kwon & Park, 2014). PTs may need to consider microcurrent as an effective intervention in the treatment of CMT, however replication of these studies in the US and continuing education courses on this technique may be needed to strengthen clinician confidence.

Suggested best practice: Research on microcurrent in the US with specific intervention details is needed.

### *Kinesiology taping.*

Kinesio® Tape is designed to stabilize an injured or painful joint through its application on the surrounding muscle (Kinesio-USA, 2010).

The unique elasticity of Kinesio® Tape is felt to mimic underlying muscle tissue and thereby “re-educate the neuromuscular system” (Kinesio-USA, 2010). The effect of kinesiology taping for infants with CMT is supported by the CCHMC-CPG (Cincinnati Children's Hospital, 2009), as a supplemental intervention by the Sop-CPG (Kaplan, et al., 2013) and by one study in which 28 infants improve the muscular balance of their lateral neck flexors with the application of tape (Öhman, 2012).

Öhman (2012) assessed infants using the Muscle Function Scale (MFS) before and immediately after taping. Prior to taping, the difference in the strength of the lateral neck flexors between the affected and unaffected side is 2 grades (mean score unaffected side = 1.5, mean score affected side = 3.5). After taping, the difference between the unaffected side and affected side is much smaller (mean score unaffected side = 2.4, mean score affected side = 2.6), resulting in improved muscle balance of the lateral neck flexors ( $p < .001$ ) (Öhman, 2012). This is, however, a retrospective study, in which three different taping methods are used: (a) tape is applied to the unaffected SCM and trapezius as a muscle facilitator, (b) tape is applied to the affected SCM as a muscle relaxant, or (c) tape is applied to both the unaffected and affected sides. In Öhman's (2012) study, the method in which tape is applied as a muscle relaxant to the affected side had the

greatest improvement, yet the author cites a potential confounding factor as the difficulty with tape application to achieve the optimal position (Öhman, 2012). Ohman (2015) narrowed down her next study to focus on the imbalance of the lateral neck flexors, and showed a significant change in MFS scores among infants with CMT. Further research on the effect of taping on infants with CMT is needed to determine the long term, rather than immediate, effect of kinesiology taping (Öhman, 2012).

Kinesio Taping® is promoted by the Kinesio Taping® Association International, which has developed training to become a Certified Kinesio Taping® Practitioner (CKTP) (Kinesio-USA, 2010). Although a CKTP is not necessary for the treatment of CMT, an understanding of kinesiology taping for the infant with CMT is desirable, and the application used by Öhman (2012) is recommended. Kinesio® Tape is sold for eleven dollars per roll of 16.4 feet and is readily available through the Internet ([www.kinesiotaping.com](http://www.kinesiotaping.com)). Factors involved in the decision to use kinesiology taping include: knowledge and comfort of the PT in using Kinesio® Tape, parental agreement, ease of application on the infant, and positive response from the infant. At this time, there is not enough evidence to support the use of kinesiology taping as a primary intervention in the treatment of CMT, but it may be an alternative prior to more invasive approaches.

Suggested best practice: Physical therapists may use Kinesio® Tape as an adjunct intervention for the treatment of CMT.  
(Confidence: Weak)

*Tubular orthosis for torticollis (TOT Collar™) & soft cervical orthosis.*

The TOT Collar™ is made of a soft flexible polyvinyl chloride (PVC) tubing that loops around the child's neck and holds two nylon struts in place which are designed to prevent the head tilt typically seen in infants with CMT, and thereby facilitate active cervical lateral flexion to a vertical midline position (Symmetric-Designs). The use of the TOT Collar™ (Symmetric-Designs) is supported by its inclusion in one outcome study (Emery, 1994), expert opinion (Jacques & Karmel-Ross, 1997), the CCHMC-CPG (Cincinnati Children's Hospital, 2009), and as a supplemental intervention by the SoP-CPG (Kaplan, et al., 2013). A pre-fabricated small adult foam cervical collar may also be fitted for the same purpose as the TOT Collar; however, it is supported only by expert opinion (Cincinnati Children's Hospital, 2009; Jacques & Karmel-Ross, 1997; Kaplan, et al., 2013). Specifically, the CCHMC-CPG for CMT recommends use of a TOT Collar™, soft orthosis, or Kinesio® Tape for those children who have more than a 10° head tilt and have not shown progress in 2-3 months (Cincinnati Children's Hospital, 2009).

As recommended by Symmetric Designs (the parent company of the TOT Collar™), the infant should be able to independently right her head, be at least four months old, and show consistent lateral flexion of 5° or more (Symmetric-Designs) to be a candidate for use. The TOT Collar™ is not developed for use in infants at rest (Symmetric-Designs). It should be removed whenever the infant is sleeping or resting with their head supported, as the sole purpose is to facilitate upright head control in play. Prior to using the TOT Collar™ or soft orthosis in an infant with CMT, PTs should ensure that parents are able to follow the safety instructions for proper use and application, and that they will be compliant with the wearing schedule. Based on previous clinical experience, fitting an infant with the TOT Collar™ or soft orthosis can be difficult and time consuming. Additionally, the concept of a collar around the infant's neck may be uncomfortable for some PTs and parents. Jacques & Karmel-Ross (1997) provide a detailed description of the TOT Collar™ and soft orthosis application and use. The TOT Collar™ is sold for approximately \$53.00, while a soft cervical orthosis is \$12.75 ([www.alimed.com](http://www.alimed.com)). Factors involved in the decision include: knowledge and comfort of the PT with using a TOT Collar™ or soft cervical orthosis, parental agreement, ease of fitting, ease of application, parent ability to demonstrate proper application, and positive response of the infant to the collar. At this

time, there is not enough evidence to support the use of the TOT Collar™ or soft cervical orthosis as a primary intervention in the treatment of CMT.

Suggested best practice: Physical therapists may use the TOT Collar™ as an adjunct intervention for the treatment of CMT.

(Confidence: Weak)

*Tscharnutter Akademie for Motor Organization (TAMO).*

TAMO therapy is designed to help an individual respond motorically to a variety of natural settings through emphasis on “adaptation to gravity and the supporting surface” (Rahlin, 2005). One case study (Rahlin, 2005) supports the use of TAMO for infants with CMT, and the SoP-CPG supports TAMO as a supplemental intervention (Kaplan, et al., 2013). The case study provides evidence of full recovery as documented by full PROM, midline head position, and symmetrical righting reactions in a 6.5 month old baby boy after eight sessions of TAMO (Rahlin, 2005). Limitations to this study include: (a) the single case study design; and (b) the use of other interventions in conjunction with TAMO, including AROM, soft tissue mobilization, and parent instruction in a HEP. At this time, there is not enough evidence to support the use of TAMO therapy as a primary intervention in the treatment of CMT.

### *Soft tissue massage.*

Massage is supported in the treatment of CMT by expert opinion (Karmel-Ross & Lepp, 1997). No specific intervention studies on CMT isolate the effectiveness of this intervention or provide an accurate description of implementation. At this time, there is no evidence to support the use of soft tissue massage as a primary intervention in the treatment of CMT.

5

### *Recommended Frequency of PT for Infants with CMT*

The CPG from the SoP makes no specific recommendations as to the frequency of service delivery, except to state that, “no specific... intensity of treatment is appropriate for all cases” (Kaplan, et al., 2013). However, the CCHMC-CPG suggests that all infants with CMT start treatment within two weeks of the initial exam (Cincinnati Children's Hospital, 2009). It further recommends that infants who are 0-4 months at the start of treatment be seen by PT once every other week; infants who are 4-12 months be seen by PT once a week; and infants who are 12 months or older be seen once every one to two weeks for PT (Cincinnati Children's Hospital, 2009). Re-assessment is suggested at every session to monitor any change in ROM, strength and development (Cincinnati Children's Hospital, 2009). It is recommended that PT increase to two times per week if there is poor



compliance or a need for further family training, and decrease if there is good compliance and improved ROM or developmental skills (Cincinnati Children's Hospital, 2009). Typical duration for PT is less than six months, with a range of 0-36 months (Cincinnati Children's Hospital, 2009). No recommendation is made as to the specific stretches, the intensity and duration of the stretch, or the specific instructions to parents for the HEP. These recommendations regarding frequency of PT treatment are supported by “expert opinion or consensus” (Cincinnati Children's Hospital, 2009) and no studies have been found that compare the impact of different visit frequencies.

Direct intervention studies report a higher frequency of PT. Examples include: (a) PT 3x/week for 30 minutes of microcurrent therapy x 2 weeks (Kim, et al., 2009); (b) PT 3x/week for three repetitions of 15 neck stretches with “gentle force” held for one second followed by a 10 second rest, for 1.4 - 3.7 months (median duration) (Cheng, et al., 2001); and (c) PT 5x/week for 30 minutes of myokinetic stretching for approximately 1-3 months (Chon, et al., 2010). In these studies, the treatment frequency was standardized to decrease variability of the intervention.

Intervention studies that report a lower frequency of PT (less than 1x/week) also report a HEP with multiple (2 person) stretches being performed frequently throughout the day (Celayir, 2000;

Demirbilek & Atayurt, 1999; Emery, 1994). Examples include a HEP consisting of: (a) two (2 person) stretches held for 10 seconds each at the available end range, repeated 5 times, two times per day (Emery, 1994); (b) three (2 person) stretches held for ten seconds each, repeated ten times, before each feeding or maximally eight times per day (Celayir, 2000); and (c) 40 repetitions of rotation with “maximal stretching” to be performed 4-5x/day (Demirbilek & Atayurt, 1999).

Christensen et al, (2013) provide a relatively current review of the literature with regard to frequency of treatment, ranging from once per month to five times per week. The authors note that in a study by Ohman et al. (2010), infants who received PT 3x/week achieved greater cervical ROM in a significantly shorter time than those who received home stretching only. Christensen et al (2013), also provide a detailed algorithm regarding frequency of care, which accounts for type of CMT, rotational deficit, and infants age.

Typical PT practice may not be able to mimic the frequency of treatment identified in the intervention literature due to parental obligations with work, financial issues, difficulty with transportation, schedule limitations of the PT facility, or even the need for child care for siblings in the family during PT sessions. For this reason, the algorithm offered (Christensen, et al., 2013) seems like an appropriate general guideline. At this time, there is not enough research on the

frequency of PT treatment for infants with CMT to make a specific recommendation, but the algorithm by Christensen et al (2013), provides a good start.

### *Recommended Tapering Schedule*

Per one guideline, a PT may decrease the frequency of visits to once every other week for cases in which there is good parental compliance with the HEP, improvement in ROM, and progress with motor development (Cincinnati Children's Hospital, 2009). The PT may increase the frequency to twice per week for cases in which there is poor compliance from the family or if more training is needed (Cincinnati Children's Hospital, 2009). When an infant has been followed by the PT for more than six months, without significant change in her symptoms, it is recommended that the PT schedules visits once every one to two weeks, and recommends referral for consultation with specialists (Cincinnati Children's Hospital, 2009).

5

Factors which are involved in this decision to taper therapy visits include the age of the patient, the severity of the CMT, the infant's progress, the parental compliance with the HEP, the number of PT sessions authorized by the insurance company, the ability of the parents to continue with PT upon return to work, and the PT's schedule for availability of visits. Physical therapists should often re-examine

5

the frequency of care that an infant is receiving, and make adjustments as needed.

As per the CCHMC-CPG (Cincinnati Children's Hospital, 2009), a higher frequency of care is desired (two times per week) for cases in which there is greater severity of symptoms or difficulty for parents to perform the HEP. Physical therapy should gradually decrease in frequency to once every other week as the child progresses closer to discharge (Cincinnati Children's Hospital, 2009).

#### *Recommended Equipment Devices for Infants with CMT*

Equipment available to the families and caretakers of infants with CMT may include: a cranial orthosis or helmet, Kinesio® Tape, a TOT collar™ or soft cervical orthosis, or a head positioner device. This section is specific to the need for ordering these devices for home exercise programs (HEP) for the parents or caretakers or as secondary intervention approaches to combine with handling and stretching. Overall, the literature does not provide support for the use of these devices as isolated treatment interventions; however, the potential value of such equipment should not be excluded when implemented with other interventions.

It is important to note that if the PT determines that the parent or caretaker will not use the recommended device appropriately, then it is

in her best clinical judgment to refrain from making an equipment recommendation, and find an alternative intervention. Through personal clinical experience, certain parents or caretakers may be eager to use available equipment with the hopeful, but not evidence based, approach for a “quick fix.” Before providing any equipment to the family, the physical therapist should ensure that the equipment recommendation is in the best interest of the infant.

### *Cranial Orthosis or Helmet*

Helmet therapy is used in the treatment of plagiocephaly to promote growth of the skull in the areas that are flat while “discouraging it in prominent areas” (www.cranialtech.com, 1997-2011). This is done in the first year of life when brain growth occurs most rapidly. The literature supports the use of an active repositioning program or use of cranial orthoses for infants with plagiocephaly (Graham, 2005; Loveday, 2001; Rogers, Oh, & Mulliken, 2009; Steinberg, Rawlani, Humphries, Rawlani, & Vicari, 2015), one of the most common co-morbidities of CMT.

2a-5

Orthotic helmet therapy for cranial remolding has been proven effective, however should not be considered the gold standard for all cases of plagiocephaly (Steinberg, et al., 2015). Steinberg, Rawlani, Humphries, Rawlani, & Vicari (2015) demonstrate a high percentage of

2c

complete correction among both the conservative therapy group (77.1%) and the helmet therapy group (96.1%). They advocate for treatment guided by “patient-specific risk factors” (Steinberg, et al., 2015). A prior systematic review of cohort studies reported that based on expert opinion, infants less than 4 months old and those with mild or moderate plagiocephaly may benefit from repositioning, while older infants (6-12 months old) or those with more severe plagiocephaly may benefit from helmet therapy (Xia, 2008). Steinberg et al. (2015) tends to echo these findings, but provides more specific recommendations: conservative therapy initially for patients who are younger than 6 months, have a cranial ratio of  $<0.95$ , diagonal difference  $<10\text{mm}$ , and absence of developmental delay or persistent torticollis; and family counseling regarding increased likelihood of conservative therapy failure with option to directly treat with helmet therapy if patient is older than 7-8 months, has a cranial ratio  $>1.0$ , a diagonal difference  $>15\text{mm}$ , and developmental delay or persistent torticollis. They emphasize that delaying helmet therapy in favor of conservative therapy does not exclude the potential for complete correction, provided that brain growth has not decelerated (Steinberg, et al., 2015).

Suggested Best Practice: Physical therapists should recommend a referral to a cranial specialist for further assessment of

infant's skull shape if suspect plagiocephaly or other cranial deformation. Confidence Level: Strong)

### *Head Positioner Devices*

Head positioner devices for use in the infant's swing or baby seat at home are supported by expert opinion (Karmel-Ross & Lepp, 1997) but have not been tested for effectiveness. These may either be pre-fabricated, sold over the counter at large retail baby stores, or can be made by the parents and PTs by using rolled up hand towels. The purpose of a head positioner device is to prevent the infant from tilting their head toward the involved side while they are reclined in an infant's swing or baby seat and are used with constant adult supervision. Head positioners should not be used in the baby's crib. Although head positioner devices are generally well accepted by parents, the main limitation to their use is that there are no studies which have tested their effectiveness and no literature to describe a protocol for implementation.

5

PTs should evaluate the child with the device in place to determine its effectiveness at safely promoting proper head and trunk alignment, thus preventing head tilt toward the involved side.

5

### *Medical and Surgical Interventions for CMT*

Interventions typically provided directly by a physician for CMT include instruction in a home exercise program (HEP) with follow-up (Celayir, 2000), Botox injections (Joyce & de Chalain, 2005; Oleszek, Chang, Apkon, & Wilson, 2005), and surgery (Lee, Lim, Song, & Park, 2010; Omid-Kashani, et al., 2008; Shim & Jang, 2008; Shim, Noh, & Park, 2004). In a survey of pediatricians from Montreal, Quebec, Canada, forty-eight percent of pediatricians report that they initiate a HEP which may include positioning and passive stretching for infants with CMT (Fradette, et al., 2011). Celayir (2000) shows that CMT may be effectively treated with a physician directed home exercise program and consistent follow-up. Studies show that Botox injections may help to improve cervical rotation in patients with CMT (Joyce & de Chalain, 2005; Oleszek, et al., 2005), however adverse effects such as dysphagia and cervical weakness must also be considered. Multiple studies on the success of surgical intervention can also be found in the literature (Shim & Jang, 2008; Shim, et al., 2004). As per one clinical guideline in the treatment of CMT, surgery should be reserved for those cases in which significant symptoms persist after 6 months of treatment, such as less than 75° of cervical rotation, or a palpable tumor in the sternocleidomastoid muscle (Cincinnati Children's Hospital, 2009). However, there are studies which report successful



outcomes after surgery in children five years and older (Canale, Griffin, & Hubbard, 1982; Shim & Jang, 2008; Shim, et al., 2004). Based on these findings, Shim and Jang (2008) suggest that the most important factor for surgery is not age, but the ability of the child to cooperate with the post-surgical program of bracing and exercises.

#### Physical Therapy Discharge & Discontinuation for Infants with CMT

Discharge from PT occurs when the physical therapist has stopped treating the patient because the goals and expectations set for the patient have been achieved (APTA, 2006). This differs from discontinuation of PT services which occurs when the physical therapist has stopped treating the patient because the patient is no longer making progress toward the goals or the physical therapist does not feel that the patient will benefit from continuation of services (APTA, 2006). Both topics, discharge and discontinuation of PT, are discussed below.

#### *Recommended Criteria for Discharge from PT for Infants with CMT*

The literature on CMT incorporates a variety of discharge criteria. Prospective studies on CMT typically define treatment duration as the time from initial examination until full PROM is

achieved (Celayir, 2000; Cheng, et al., 2001; Emery, 1994). The focus may be on full passive cervical rotation (Celayir, 2000; Cheng, et al., 2001), or full passive cervical rotation and lateral flexion (Emery, 1994). Other studies do not focus on PROM as the main discharge criteria but also use posture, neck muscle endurance, or craniofacial symmetry (Binder, et al., 1987; Öhman & Beckung, 2005; Rahlin, 2005; Taylor, 1997). Interestingly, the studies that use multiple discharge criteria besides PROM are often retrospective studies, and may be more indicative of true clinical practice. Although some studies report cervical AROM and parental satisfaction in their outcomes (Cheng, et al., 2001; Öhman & Beckung, 2005; Taylor, 1997), no studies were found which reported using these measures as discharge criteria.

2c-5

According to the SoP-CPG, the infant with CMT may be discharged from physical therapy when (Kaplan, et al., 2013):

1. There is full PROM within 5° of the nonaffected side;
2. Symmetrical active movement patterns;
3. Age appropriate motor development;
4. No visible head tilt;
5. Parents know what to monitor as the child grows (Hummer &

MacEwen, 1972).

According to the CCHMC-CPG (Cincinnati Children's Hospital, 2009), infants should be discharged from PT when the following goals are achieved:

1. Cervical PROM and AROM to within 5° of normal for rotation and lateral flexion;
2. Symmetrical posture in all positions;
3. Head in midline the majority of the time; and
4. Symmetrical gross motor skills (Cincinnati Children's Hospital, 2009).

According to the Hospital for Special Surgery Guideline (Corradi-Scalese, 2006), infants should be discharged from PT when all of the following goals are achieved:

1. Full PROM and AROM of cervical rotation and lateral flexion;
2. Head in midline 95% of the time in all positions;
3. Able to hold head in midline while playing with a toy in all positions;
4. Full active rotation in their highest developmental position without compensation;
5. No preference of sides shown in rolling, reaching, or UE weight bearing;

6. Age appropriate anti-gravity neck strength;
7. Parents independent with HEP (Corradi-Scalese, 2006).

The goals for discharge written in these guidelines are comprehensive and thorough. Although they are probably more indicative of true clinical practice than the discharge criteria reported in studies, it is uncertain whether PTs use all, some, or none of these goals with their patients.

It is important to remember that each patient is unique, and therefore the goals for each patient with CMT may be different. Although the guidelines provide a specific set of discharge criteria, there may be other factors that need to be considered for each patient. The guidelines represent a baseline of recommended practice. Additional criteria for discharge may be used (Cincinnati Children's Hospital, 2009) based on the professional judgment of the physical therapist. Despite the criteria that are used for discharge, PTs should be responsible for following up on the effectiveness of the treatment provided with regular and consistent follow-up appointments or by providing scheduled rest periods in the episode of care and resuming at a later time when the child may be more cooperative, as is reported with infants who started PT at a late age (Öhman, et al., 2011).

*Recommended Criteria for Discontinuation of PT for Infants with CMT*

The literature varies as to the recommended criteria for discontinuation from PT among infants with CMT. For a patient who is not making progress with conservative PT, alternative solutions may be needed, and PT may be placed on hold or discontinued for a period of time to address alternative options with the medical doctor. It is not clear though how much time should be allowed to observe progress in infants with CMT. The literature reports that if there is no improvement within 3 months (Demirbilek & Atayurt, 1999); 6 months (Cheng, et al., 2001); or 12 months (Cincinnati Children's Hospital, 2009); then discontinuation of PT may occur. Upon discontinuation from PT, a PT re-examination should be performed and there should be communication with the infant's medical doctor (Cincinnati Children's Hospital, 2009; Kaplan, et al., 2013), so that other interventions or surgery may be considered.

2c-5

Other reasons for discontinuation of services that are not found in the literature include: parental satisfaction with the progress that the infant has made in PT, limitations on the patient's healthcare insurance coverage, inability to pay for services, or the inability to obtain transportation to medical appointments. If services are not available, then the PTs should ensure that parents are able to adequately perform a HEP, and that follow-up appointments can be made,

preferably with the PT, but if not, then most certainly with the medical doctor.

Physical therapists should discontinue conservative care as the sole service for infants with CMT when there is no further improvement after 3-12 months of PT. The exact amount of time is dependent upon the professional judgment of the PT in collaboration with the parents and primary pediatrician, as well as the age of service initiation. A PT re-examination should be performed, as well as communication with the medical doctor. Recommendations for referral to other healthcare specialists may be made, and the PT should collaborate with them as needed. It is not known how frequently PTs who work with infants with CMT recommend referral to other healthcare specialists.

#### *Recommended Period of Follow-up*

Follow-up refers to the PT appointment that comes after discharge from conservative PT services. The range of follow-up reported in studies varies from two weeks (Kim, et al., 2009), to one month (Emery, 1994), to four and one-half years (Cheng, et al., 2001) post discharge. The SoP-CPG makes recommendation for follow-up screening 3-12 months after discharge (Kaplan, et al., 2013). All guidelines also recommend that parents should be educated about the potential for intermittent relapses of a head tilt (Cincinnati Children's

Hospital, 2009; Corradi-Scalese, 2006; Kaplan, et al., 2013), particularly during: times of stress, achievement of developmental milestones (Corradi-Scalese, 2006), fatigue, growth spurts, achievement of independent walking, or periods of illness (Cincinnati Children's Hospital, 2009; Kaplan, et al., 2013).

The CCHMC-CPG recommends that the parents perform the HEP when a head tilt is noted; and if the head tilt occurs for more than 10-14 days, then a PT reassessment should occur (Cincinnati Children's Hospital, 2009). The SoP-CPG also recommends reevaluation by PT if “preferential positioning” continues (Kaplan, et al., 2013). The Hospital for Special Surgery recommends that parents perform the HEP three times per day for 3-6 months after discharge, regardless of the intermittent relapses in head control (Corradi-Scalese, 2006). It is not clear why the Hospital for Special Surgery recommends such an aggressive protocol for the parental HEP, when the infant is discharged with full AROM, full PROM, midline head control, good neck strength, and no sign of a preference for sides. It may be that this type of HEP is recommended because of documented cases in which CMT has recurred after initial treatment with conservative PT (Shim, et al., 2004).

2-5

**Suggested Best Practice:** At this time, it is recommended that a follow-up PT appointment be made for all patients with CMT who have

been discharged from PT services, due to the possibility of recurrence after initial treatment (Shim, et al., 2004), and reported compliance with PT at a later age (Öhman, et al., 2011). Based on the rapid growth and motor development of infants in the first year of life, best practice would advocate for a follow-up within three months, or sooner if symptoms recur. (Confidence Level: Moderate)



## Review of Literature on Survey Methodology

Survey research will be used to address the basic research questions of the study. This method was selected because of the ability of a survey to describe current practice of a wide target population (PTs in the USA who treat CMT) through a smaller sample of the population (Deutscher et al., 2009).

### *Survey Modes*

Various modes of surveys are available to researchers, including self administered paper and pencil questionnaires, face to face interviews, phone interviews, and web questionnaires (Dillman, 2009; Hyman, 2010). Each survey mode allows for its own unique advantages and disadvantages. Interviews provide human interaction and personal attention to the respondents, but require more time on the part of the surveyor (Dillman, 2009). Mail surveys allow for data collection of many individuals in an efficient and timely manner compared to personal interviews or individual observations (Deutscher, et al., 2009), but may require an extensive amount of paper. Internet surveys are unique in that they offer access to an even larger sample without the cost of postage (Hyman, 2010) and may be preferred by individuals who spend a great deal of time online, yet internet surveys provide no human interaction.

Currently, surveyors often choose multiple modes of data collection, known as mixed-mode survey design (Dillman, 2009). This may be due to: advances in technology which allow for easier data collection and analysis than previously; surveyor attempts to overcome errors resulting from single-mode survey design; or the need for quick responses on a smaller budget (Dillman, 2009). Despite the reason, mixed-mode surveys have been termed the “norm” in survey design (Dillman, 2009).

This study of current physical therapy management of congenital muscular torticollis will use a self administered Internet questionnaire through SurveyMonkey® (SurveyMonkey.com), with the option of a self administered paper and pencil questionnaire. A paper questionnaire will be offered in order to reduce coverage bias for participants who do not have access to a personal computer, and because some participants may prefer to complete a lengthy (11 page) survey on paper.

### *Internet Surveys*

There are many unique features available to surveyors who use the Internet to distribute and collect responses. A few of the basic fundamentals are discussed below. For the purpose of this research, SurveyMonkey® (SurveyMonkey.com), an online company which assists in the development and collection of internet questionnaires, will be used. All of the information

reviewed below is pertinent to SurveyMonkey® (SurveyMonkey.com), and this study.

### *Internet Survey Distribution*

Internet surveys allow for multiple methods of distribution. These include, but are not limited to: creating a web link which can be posted on social networks; creating e-mail invitations to the survey; or putting the survey on a website (SurveyMonkey.com). E-mail invitation to the survey is similar to sending the survey using the postal service because there is an actual address of a potential respondent. It is more personal than posting a web link to which any individual may respond. It also offers the ability to track who has or has not responded to the invitation, and limits that participant to respond only one time to the survey. The respondent completes the survey using their personal invitation, with the option to stop the survey at any point and resume at a later time (SurveyMonkey.com).

Posting a web link allows people who may not be known to the surveyor to respond to the survey and reduces the potential for coverage error. It does not allow tracking an e-mail address however, the surveyor could potentially track an Internet Protocol (IP) address if desired (SurveyMonkey.com). Respondents who complete the survey via a web link do not have the ability to stop and return to the survey at a later time, and they could potentially answer the survey more than once.

### *Internet Survey Security*

Internet surveys guarantee security through the option of an enhanced security system, known as the Secure Sockets Layer (SSL). Secure Sockets Layer was developed to allow private documents to be sent through the Internet (SurveyMonkey.com). It works by sending an encrypted Uniform Resource Locator (URL) to respondents. This will secure the link and survey pages that are sent from the surveyors account to the respondent, and then back into the surveyors account upon completion (SurveyMonkey.com). SurveyMonkey® uses Verisign certificate Version 3, 128 bit encryption (SurveyMonkey.com). A link that has been secured with SSL encryption will contain an “s” in the “http” address (SurveyMonkey.com).

On SurveyMonkey®, the data that is collected by the surveyor is owned by that surveyor (SurveyMonkey.com). SurveyMonkey® does not own the data, and will not sell the survey, nor use the survey responses for their own purposes (SurveyMonkey.com). If a list of e-mail addresses is provided to SurveyMonkey® for e-mail invitation of the survey, they will not sell those addresses, nor use them in any other way than that described by the survey creator (SurveyMonkey.com). Survey data is kept securely on databases within the USA (SurveyMonkey.com).

### *Internet Surveys & IRB*

SurveyMonkey® allows for survey creators to provide the necessary elements which are needed by an Institutional Review Board, including but not limited to: secure transmission, anonymity if desired, informed consent, the option to not answer any particular question, and the option to withdraw their survey at the end, as well as database security and confidentiality of information (SurveyMonkey.com). The school logo can also be branded onto the survey (SurveyMonkey.com).

### *Total Survey Error*

There is an inherent risk of error with all survey research but methods are established which help to minimize error, and produce valid responses.

### *Total Survey Error Framework*

The “total survey error framework” is a process used to ensure that the survey will be designed, conducted, analyzed, and evaluated with the intent of seeking the best overall quality of research (Groves, 2009). The researcher seeks to make certain that all choices made within the survey process produce valuable results in the end. This is achieved by minimizing error as much as feasibly possible through a systematic evaluation of the survey process. Methods that will be used in this study to minimize the occurrence of error are discussed in Chapter 3. The potential errors that could occur with survey research are defined as follows:

Lack of construct validity – Simply stated, the survey needs to measure what it's supposed to measure (Hyman, 2010). For this research, the questions need to provide a description of current physical therapy practice in the USA. To ensure that a survey has construct validity, content experts may be asked to determine if the questionnaire makes sense and if it relates to the overall research questions (Hyman, 2010).

Measurement Error – Are the respondent's answers accurate? Inaccurate responses usually occur as a result of poor wording or poor layout which results in confusion or disinterest of the respondent (Dillman, 2009). If the respondent does not take the survey seriously, they may choose the same responses throughout the entire survey, without regard to the question. If included in the final analysis, these responses contribute to measurement error.

Processing Error – Did the administrator process the responses correctly? This may occur with paper and pencil administration in which the answers need to be reviewed and transcribed from paper into a computer file for analysis (Hyman, 2010). This may be minimized with "computer assisted administration" in which the interviewer doesn't need to transcribe data and the answers are instead directly integrated into a software program for analysis (Hyman, 2010).

Coverage Error – Coverage error occurs when not all of the population has a chance to be included in the survey, and when those that are included

are different from those that are not (Dillman, 2009). This may occur if the survey mode doesn't allow sufficient access to the population or if the list from which the sample is selected is incomplete or not current (Dillman, 2009).

Sampling Error – Sampling error "...results from surveying only some, rather than all, members of the survey population" (Dillman, 2009). It is directly related to sample size (Hyman, 2010). The larger the sample size, the smaller the chance of sampling error (Hyman, 2010). If the investigator chooses not to take a census, and instead, uses a sample of the population, then she accepts some degree of sampling error. Cost and time are the main reasons to perform sample surveys (Hyman, 2010).

Nonresponse Error – This typically occurs when part of the sample does not respond to the survey, and those who do not respond are different from those who do. This is minimized by trying to get the whole sample to participate, so that different types of people respond (Dillman, 2009).

### *Tailored Design*

The second approach used in the implementation of this survey is "tailored design" (Deutscher, et al., 2009) which involves: decreasing four sources of survey error (coverage, sampling, non-response, and measurement); using a collection of communications to increase respondent rate; and social exchange theory which underlies survey strategies to establish trust between the interviewer and the respondent (Deutscher, et al.,

2009). For this study, any attempt to personalize contacts, provide an incentive, and incorporate a trusting relationship between the surveyor and the respondent can be categorized as using a “tailored design” (Deutscher, et al., 2009).



## CHAPTER III: METHODS

### Research Aims, Questions & Hypotheses

The two main objectives of this research are to describe physical therapy (PT) services provided by PTs that treat infants with congenital muscular torticollis (CMT) in the USA, and to determine if that description is consistent with the best available clinical evidence on CMT. This study will be useful to PTs who treat CMT as it will identify trends in service delivery among clinicians in the USA, and detect similarities or discrepancies between clinical practice and the best available clinical evidence.

The basic research questions to be addressed in this descriptive study are:

1. What are the patterns of physical therapy management among physical therapists in the USA who treat infants with CMT?

Specifically,

- a.) What are the patterns of referral to PT among infants with CMT?
- b.) What are the trends in PT examination and discharge, with focus on measurement and documentation of outcomes?

c.) What are the patterns of PT intervention among infants with CMT, including the most common methods and frequency of services utilized?

2. How does this current physical therapy practice description compare to the best available clinical evidence?

The anticipated outcomes of this study are:

1. A description of the current state of referral in the USA among infants with CMT to PT services and how this compares to the recommended best evidence.
2. A description of the patterns of PT examination and discharge for infants with CMT in the USA, with focus on measurement and documentation; and how this compares to the recommended best evidence.
3. A description of the patterns of PT intervention for infants with CMT in the USA, with focus on the most common methods and frequency of service delivery; and how this compares to the recommended best evidence.

### Research Design

A mixed mode survey design was developed in which pediatric PTs would either: 1.) complete the survey online via e-mail invitation, 2.) complete a paper survey with mail return, or 3.) complete the survey online

via an open access web link posted in an e-newsletter from the Section on Pediatrics (SoP) of the American Physical Therapy Association (APTA). This method of a mixed mode survey design was chosen to reduce cost, improve the speed of data collection, and reduce the chance of coverage, sampling, or non-response errors, which could occur in a single-mode survey design (Deutscher, et al., 2009).

#### *Survey Methodology – Total Survey Error*

Two approaches used in the development of this survey were the “total survey error framework” based on the work of Groves et al. (2009) and the “tailored design method” based on the work of Dillman, Smyth, and Christian (2009). Table 2 outlines the potential errors that may occur with survey research, based on Groves (2009), and how these errors were addressed in this study to minimize their occurrence.

Table 2: Use of “Total Survey Error” Framework (Groves, 2009) to Reduce Potential Error

<u>Potential Error</u>	<u>Strategies Used to Reduce Potential Error</u>
Lack of Construct Validity	Pilot tested for construct validity of the survey content with subsequent revisions made prior to issuing the surveys (using a convenience sample of pediatric therapists)
Measurement Error	<ol style="list-style-type: none"> <li>1. Internal consistency reliability assessed using two similar questions which measured the same construct (using subset of the pilot testers)</li> <li>2. Statement included that the survey is confidential, and emphasized the value of honest responses to reduce response bias</li> </ol>
Processing Error	<ol style="list-style-type: none"> <li>1. Only one person (principal investigator) coded the text answers to reduce coding variance. Any confusion or conflicts during this process were reviewed with committee advisor to ensure agreement in coding.</li> <li>2. “Computer assisted administration” (Hyman, 2010) of online surveys</li> </ol>
Coverage Error	<ol style="list-style-type: none"> <li>1. Sample of PTs from every state who treat CMT</li> <li>2. Offered a mixed-mode survey design of respondents either completing the survey through e-mail invitation, open access to the web link, or on paper with mail return</li> <li>3. Used multiple resources such as the SoP listserve, SoP newsletter, and APTA state communications, meetings or conferences to solicit therapists to participate in the survey</li> <li>4. Spread news of survey through word of mouth with therapists</li> </ol>
Sampling Error	Used opening question in the survey which ensured that all respondents who completed the survey met the inclusion criteria: 1.) Licensed PT in the USA, 2.) Has treated 2 children with CMT in the past six months
Nonresponse Error	<ol style="list-style-type: none"> <li>1. Offered multiple modes of the survey (e-mail invitation, open access web link, paper survey with mail return)</li> <li>2. Resent the survey to those with known addresses who did not respond</li> </ol>

### *Survey Methodology – Tailored Design*

In the “tailored design method,” Dillman (2009) places an emphasis the value of social exchange with respondents. Methods (Deutscher, et al., 2009) that were employed to invoke social exchange and thereby increase participation included:

- Personalizing contacts as much as feasibly possible;
- Offering information about the survey in the cover letter;
- Soliciting help in the cover letter by stating that participation in the survey helps patients, physical therapists, and the profession of physical therapy;
- Saying ‘thank you’ in each correspondence with the respondents;
- Placing engaging questions early in the survey;
- Using questions that are easily comprehended;
- Helping the respondents to realize the importance of their individual participation to the group effort, by informing the sample that their participation is needed to gain national representation;
- Providing encouragement and motivation throughout the survey;

In keeping with the “tailored design method,” the above methods were used throughout administration of the survey (Deutscher, et al., 2009).

### Instrumentation

The survey, entitled, “Heads Up! A Survey of Physical Therapy Management for Infants with Congenital Muscular Torticollis,” was designed to be a confidential survey, completed one time by physical therapists in the USA who work with infants with CMT. It was offered: 1. online via e-mail invitation, 2. online using a web link from the Section on Pediatrics newsletter, or 3. on paper via USA Postal Service. The former UMDNJ , now Rutgers University, School of Health Related Professions logo was used on the survey.

#### *The Survey Cover Letter (Appendix B)*

A cover letter was enclosed with the survey to provide respondents with necessary information such as their requested involvement, and the benefits of their participation (Deutscher, et al., 2009). Information required by the Internal Review Board (IRB) of Rutgers University, formerly UMDNJ, for informed consent was also included in the cover letter. The cover letter was designed to be professional, personal, and engaging in order to facilitate the social exchange relationship (Deutscher, et al., 2009), and to convey a message to persuade PTs who treat CMT to complete the survey. For Internet mode users, the same cover letter was included in the delivery of the online survey using SurveyMonkey.com®.

### *The Survey (Appendix C)*

The survey entitled, "Heads Up! A Survey of Physical Therapy Management for Infants with Congenital Muscular Torticollis," was designed by this researcher under advisement of the dissertation committee. Pilot testing of the survey occurred in April 2013 to ensure construct validity of the questions and reliability of the tool. A convenience sample of six PTs with expertise in pediatrics were asked to take or review the pilot survey. Three PTs provided internal consistency by completing the pilot survey, while four PTs were given a review checklist for each question to determine clarity of the question and comprehensiveness of the response list. (One pediatric PT both completed and reviewed the pilot survey.) Revisions were made to the survey based on their responses, and the final version of the survey was available online in May 2013. Survey distribution ended November 2013.

#### *Format of the Survey*

The survey was divided into seven sections for ease and organization of responses. The sections included: 1. Referral, 2. Examination, 3. Intervention, 4. Discharge, 5. Outcomes, 6. Clinical Setting, and 7. Professional Development. This order was based on the clinical sequence of events from referral of a patient to PT through discharge, and resulting outcome measures. Clinical setting and professional experience were placed at the end of the survey as these were demographic and more mundane questions, while more important, thought provoking questions came earlier in

the sequence. Ninety close-ended and open-ended questions were used in the survey, including: multiple choice, yes/no, and fill-in-the-blank. Close-ended questions were used when the anticipated responses were known. Open-ended questions were used to acquire new information and answers that could not be anticipated (Apeldoorn et al., 2010). Although a variety of formatting was used and varied among the questions, there was a sequential flow of information which was valuable for the overall research questions of this dissertation. Two key guidelines used in the ordering of the questions within each section included “funneling,” placing easier questions prior to more complex questions (Apeldoorn, et al., 2010), and placing the most important questions first which engaged the respondent’s interest (Deutscher, et al., 2009). The format sought to minimize clutter, ensured appropriate white space, and delineated questions and sections of the survey so that the respondent could visually organize the information (Deutscher, et al., 2009).

#### *Method of Administration for the Survey*

The survey was a self-administered questionnaire which could be taken online or on paper with the intent of a onetime mailing or e-mailing, though a second survey could be sent to individuals who do not respond to enhance the response rate. This mixed mode design of using a paper survey mode and multiple online survey modes was selected as a better method than single mode alone because of the overall length of the survey (Apeldoorn, et al., 2010); the ability to offer participants an alternate mode if



they prefer (Deutscher, et al., 2009); the increased potential to reach the target population; and because of the relatively low response of pediatric PTs to a relatively recent survey which used the browser based mode, linked to the Section on Pediatrics listserv (Fritz, 2007). The online survey was conducted using SurveyMonkey.com® for both the e-mail invitation mode and the “open access web link” mode.

### Subjects

The target population for this survey was pediatric physical therapists in the USA who treat young patients with CMT. The challenge of reaching this target population was that although it was known that there are approximately 5,000 physical therapists and physical therapist assistants who belong to the Section on Pediatrics of the American Physical Therapy Association (APTA) ([www.pediatricapta.org](http://www.pediatricapta.org)), not all pediatric PTs belong to the APTA or the Section on Pediatrics (SoP) and not all pediatric PTs treat children with CMT. Therefore, this target population was felt to be a relatively small subset of physical therapists and was truly an unknown population in size and in location.

In order to increase the representation of this small subset, an attempt was made to gain national coverage through direct invitation to the survey of at least five PTs from each state who treat CMT, targeting a total sample of 250. PTs who were identified in the convenience sample were invited to

participate in the survey by e-mail invitation. All respondents in this survey completed the online version.

Methods that were used to create the sample of convenience included: inviting known fellow co-workers and colleagues who treat CMT; e-mail to APTA SoP state representatives for solicitation of pediatric PTs who treat CMT; phone call or direct e-mail to the directors of physical therapy departments at children's hospitals within the USA (publicly available on the internet or through the National Association of Children's Hospitals); phone call or direct e-mail to managers of private pediatric PT businesses in various states throughout the USA (publicly available on the internet); word of mouth and snowball effect with pediatric PTs who treat CMT. Additionally, for those PTs who treat CMT and were not identified in the convenience sample developed by the primary researcher, an open invitation to complete the survey online using a web link was posted on the Section on Pediatrics e-newsletter (June-September 2013). This was offered in order to increase coverage and reduce sampling error, however it was not expected to produce a strong enough yield on its own based on previous research using this method (Fritz, 2007).

To be included in the survey, respondents must have been licensed physical therapists that have examined and treated a minimum of two young children or infants with CMT in the past six months. Exclusion criteria were physical therapist assistants and physical therapists who were not English

speaking or who did not practice in the USA. Physical therapist assistants were excluded because of the large emphasis of the survey on the initial examination and evaluation procedures.

### Data Collection & Analysis

Responses from the online survey were imported by this investigator onto a Microsoft Excel workbook. Within the workbook were seven spreadsheets which each pertained to a specific section of the survey: Referral, Exam, Intervention, Discharge, Outcomes, Clinical Setting, and Professional Development. For close ended questions, each response already had a coding number which was entered into the data file (Hyman, 2010). The codes had no value, and were used for classification purposes only (Hyman, 2010). For open ended questions, the responses were organized and analyzed to develop codes which could be entered into the data file (Hyman, 2010). For all of the questions and tables that had an “other” response, they were handled as pre-coded if “other” was not selected. If “other” was selected and defined, the primary researcher had to establish that the response was exclusive of the other responses. If so, the steps for open ended responses were followed.

Descriptive statistics were calculated using the Statistical Package for the Social Sciences®, version 13.0 (SPSS, 2004). All questions were analyzed for frequency distributions, using both frequency counts and

percentages. Frequency tables were created in SPSS to summarize the data (Hyman, 2010). In addition to the descriptive analyses, other comparative statistics were run to check for associations among the various groups of respondents and their reported use of clinical guidelines. All of these results provided the answer to the first research question regarding a current description of PT management in young children with CMT in the USA.

The second research question seeks to identify similarities and discrepancies in the current practice description established from the results of the survey to the best available clinical evidence. In order to answer this question, the evidence on best practice as described in Chapter 2, the review of the literature, was used for comparison with the current description obtained from the survey. The primary researcher systematically compared each recommendation made in Chapter 2 to the results obtained from the survey.

Based on these results, a current description of PT management for infants with CMT in the USA was produced, and similarities and discrepancies with the recommended best evidence on CMT were identified. For ease of organizing and interpreting the data, three manuscripts were produced (and are attached respectively in Chapter 4a, 4b, 4c):

1. Referral and Screening Patterns of Infants with Congenital Muscular Torticollis in the United States of America: A Survey of Pediatric Physical Therapists,

2. Patterns of Measurement Recorded at Examination and Discharge of Infants with Congenital Muscular Torticollis: A Survey of Pediatric Physical Therapists in the United States of America,

3. Intervention Patterns for Infants with Congenital Muscular Torticollis: A Survey of Pediatric Physical Therapists in the United States of America.

#### CHAPTER IV-A: Referral and Screening Patterns of Infants with Congenital Muscular Torticollis in the United States of America: A Survey of Pediatric Physical Therapists

**Purpose:** A national survey of physical therapist (PT) practice allows for a comparison of actual practice for Congenital Muscular Torticollis (CMT) to the best available evidence, including the recently issued CMT Clinical Practice Guideline (CPG). **Methods:** An extensive literature review on CMT was performed to summarize the best available evidence and identify suggested best practices. Survey questions were developed to align with the results of the literature review. The online survey was pilot tested, revised, and its web link was posted in the Section on Pediatrics monthly e-newsletters from June through September 2013. **Results:** 197 pediatric physical therapists in the USA completed the referral portion of the survey, with at least one participant from every state & the District of Columbia. Significant findings include: Infants with CMT are most often referred to PT between 3-6 months of age; Almost one-third of parents reported being told by the pediatrician to wait before starting PT, with the most frequently reported wait time, 3-4 months; that most US PTs are screening infants referred with torticollis for non-muscular causes, and seek the results of previously completed imaging studies. Practice patterns are consistent with CPG Action Statements 4 and 6; and inconsistent with CPG Action Statement 2. It is not clear if the respondents have referral practices that align with Action Statements 1, 3, and 5. **Conclusion:** The findings of this survey show that most, but not all, US PTs, who work with infants with CMT, report referral and screening practices which tend to be consistent with the literature, and are in agreement with two of the first six Action Statements from the CPG on CMT.

## Introduction and Purpose

Congenital muscular torticollis (CMT) is an idiopathic condition of infancy in which a newborn postures into ipsilateral neck flexion and contralateral neck rotation due to shortening of the sternocleidomastoid muscle. It is the third most common pediatric orthopedic deformity (Binder, Eng, Gaiser, & Koch, 1987; Do, 2006; Öhman & Beckung, 2005), however the neurodevelopmental sequelae associated with this diagnosis are equally important (Schertz, Zuk, & Green, 2012). CMT is typically characterized by the asymmetrical head posture of an infant, along with limitations in their cervical range of motion and strength. Fibrosis or thickening of the sternocleidomastoid may be found with CMT (Karmel-Ross, 2006), resulting in muscle tightness and abnormal postural alignment. Although the exact etiology of CMT is unknown, intrauterine crowding, vascular occlusion, and compartment syndrome are included in the list of possible causes (Do, 2006).

Prior research provides evidence for the effectiveness of physical therapy (PT) for infants with CMT (Binder, et al., 1987; Cheng et al., 2001; Demirbilek & Atayurt, 1999; Emery, 1994; Kim, Kwon, & Lee, 2009; Öhman & Beckung, 2005; Rahlin, 2005; Taylor, 1997), and early referral to PT has been linked with more successful outcomes and shorter treatment duration (Carenzio, Carlisi, Morani, Tinelli, Brak, Bejor & Dalla Toffola, 2015; Lee, Koh,

Lee, Jung, Lee, Kang & Bang, 2013; Cheng, et al., 2001; Petronic et al., 2010) for these babies. Similarly, late referral to PT has been associated with worse overall outcomes, longer treatment duration (Cheng, et al., 2001; Petronic, et al., 2010), and may place more stress on parents of older babies to commit to more frequent PT visits, resulting in higher total costs for services. Additionally, PTs who treat older infants with CMT struggle with trying to provide the appropriate stretch while keeping the infant calm and cooperative (Kim, et al., 2009; Rahlin, 2005).

An infant who does not receive treatment or who is referred to PT at a later age may be more at risk for other complications. Untreated CMT may lead to: positional plagiocephaly (Do, 2006); changes in the skull and facial structure (Jeong, Min, Woo & Yim, 2015; de Chalain & Park, 2005; Oh, Hoy, & Rogers, 2009; Omid-Kashani, Hasankhani, Sharifi, & Mazlumi, 2008; Yu, Wong, Lo, & Chen, 2004), an increased risk for early motor milestone delays (Öhman, Nilsson, Lagerkvist, & Beckung, 2009; Schertz et al., 2008), and hip dysplasia (Minihane et al., 2008; von Heideken et al., 2006; Walsh & Morrissy, 1998). Changes in the skull and facial structure have been associated with early neurodevelopmental delays (Schertz, et al., 2008), particularly in motor skills (Speltz et al., 2010), and an increased need for special services in school (Miller & Clarren, 2000; Schertz, Zuk, & Green, 2012).



Despite the growing incidence of CMT and related co-morbidities, little is known about the practice patterns of PTs who provide care for infants with CMT in the USA. Specifically, the process of referral, by which infants with CMT are initially identified and referred to PT, has limited description in the literature. In New Zealand, Luxford et al. (2009) describe the top three referral sources, as reported by PTs, to be pediatricians (100%), general practitioners (81%), and Plunket nurses (parenting & family support nurse) (67%). Using the same survey as Luxford et al. (2009), Öhman et al. (2013) reported on a network of PTs from Sweden and Denmark, and found that the top three referral sources in this network are “child health care centers,” also known as “well baby clinics,” (81%), pediatricians (73%), and “special units for children” (46%). In Canada, Fradette et al. (2011) report that all of the pediatricians in their survey, (n=18), agree that any infant with CMT should receive intervention, either by a PT or through instruction and follow-up with the pediatrician. Almost half (48%) choose to provide positioning and stretching advice themselves, in lieu of or prior to referring the infant to PT (Fradette, et al., 2011). Factors that were used to determine referral to PT were categorized according to the International Classification of Functioning, Disability, and Health – Children and Youth (ICF-CY), and included: impaired range of motion (ROM), a palpable mass, plagiocephaly, difficulty maintaining head position, developmental delay, difficulty feeding, parental concerns, ability of the parent to perform a home exercise program (HEP), and available

resources (Fradette, et al., 2011). While these studies indicate that pediatricians in New Zealand (Luxford, et al., 2009), Canada (Fradette, et al., 2011), and perhaps in Sweden and Denmark (Öhman, et al., 2013) appear to agree with intervention for infants with CMT, it does not indicate agreement among pediatricians in the USA, nor does it indicate that there is agreement on other factors related to the referral process, such as how children with CMT should be initially identified, at what age they should be referred for treatment, and whether they should be treated through medical follow-up or through referral to PT. Without a description of referral patterns, differences among physical therapists in the USA (US PTs) cannot be compared, thereby limiting the ability to determine best practice.

For the purpose of this paper, screening an infant referred for torticollis refers to the identification of signs and symptoms that may indicate a non-muscular cause for the abnormal posture and thus a possible reason not to treat without further diagnostic testing. Although there is literature to describe the screening of newborns for asymmetry and torticollis (Stellwagen, et al., 2008; Leo A. van Vlimmeren, Helden, van Adrichem, & Engelbert, 2004), there is not any survey literature to describe how US PTs screen their patients for non-muscular causes of CMT. Screening serves to identify suspected red flags, alerting PTs for potential complications, and warranting referral back to the pediatrician or to other healthcare professionals who should be involved in the care of the patient. In some cases, the combined

effort of a multidisciplinary team may be needed to thoroughly complete the differential diagnosis (Cincinnati Children's Hospital, 2009; Nucci, Kushner, Serafino, & Orzalesi, 2005). Effectively screening a patient for other conditions or problems is imperative for PTs, because up to 20% of patients diagnosed with torticollis may have a non-muscular etiology (Ballock & Song, 1996). It is not known how frequently US PTs screen their patients referred with a diagnosis of torticollis for non-muscular causes, nor what screening tests they perform.

Describing PT referral and screening patterns for CMT in the USA is particularly timely due to the recent publication of Clinical Practice Guidelines (CPG) for CMT (Kaplan, Coulter, & Fethers, 2013) published by the Section on Pediatrics (SoP) of the American Physical Therapy Association (APTA). This document makes recommendations for best practice based on literature through May 2013 and became available for public access in October 2013. The survey to describe PT practice patterns in the USA preceded the CPG publication by four months, with two months of overlap. This paper describes the referral and screening patterns of US PTs who provide care for infants with CMT.

## Methods

The aims of this survey are to describe the patterns of referral and screening for infants with CMT reported by PTs in the USA, and determine if the referral and screening patterns are consistent with the best available clinical evidence on CMT.

### *Survey Development*

The survey was developed based on an extensive review of the literature and was available online from the end of May through November 2013, using SurveyMonkey® (SurveyMonkey.com). The survey consisted of 90 total questions, dealing with PT practices related to the referral, screening, examination, intervention, discharge, and outcomes of infants with CMT, as well as the PT's clinical setting and professional development. This paper reports on the first 22 questions of the survey dealing with referral and screening patterns.

Content validity of the survey was established, prior to its online administration, by a panel of four PTs with pediatric experience who were sought to ensure that the questions were clear and that the response list adequately reflected all probable answers. Three PTs with pediatric experience took the pilot survey to establish preliminary internal consistency. Their responses to linked questions were correlated (100%), which was later

confirmed by a sample of respondents (n=188) that completed the actual survey (97.9%).

### *Survey Administration & Recruitment*

A mixed mode survey distribution was offered in which pediatric PTs could either: complete a paper survey with mail return; complete the survey online via direct e-mail invitation from the primary investigator; or complete the survey online via an open access web link posted in an e-newsletter from the SoP ([pediatricapta.org](http://pediatricapta.org)). The target population was pediatric PTs in the USA who treat young patients with CMT. To increase the representation of this small subset, national coverage was sought through direct invitation to the survey of at least five PTs from each state who treat CMT, targeting a total sample of 250. Recruitment methods included: e-mail to state representatives for solicitation of pediatric PTs who treat CMT; phone call or direct e-mail to the directors of PT departments at children's hospitals within the USA (publicly available on the internet or through the National Association of Children's Hospitals); phone call or direct e-mail to managers of private pediatric PT businesses in various states throughout the USA (publicly available on the internet); word of mouth and snowball effect with pediatric PTs who treat CMT inviting known fellow co-workers and colleagues who treat CMT but who were unaware of the survey content. Additionally, an open invitation to complete the survey online using a web link was posted on the

SoP e-newsletter (pediatricapta.org) (June – September 2013) to attract qualified PTs who were not identified in the convenience sample.

### *Participants & Procedures*

Eligible participants were licensed PTs that had examined and treated a minimum of two young children or infants with CMT in the past six months. Exclusion criteria were PTAs (because of the large emphasis of the survey on the initial examination and evaluation procedures) and PTs who were not English speaking or who did not practice in the USA.

A cover letter which also served as a letter of informed consent (Appendix B) was included with the survey web link; clicking on the “Next” button at the bottom of the page indicated consent. Participation was voluntary, and only the first two eligibility questions required a response: “Are you a licensed PT in the USA?” and “Have you examined and treated at least two infants with CMT in the past six months?” If the answer to either question was ‘no’, the respondent was unable to access the remainder of the survey (Appendix C). They were thanked and notified of exclusion. Nonresponse error was minimized because SurveyMonkey® (SurveyMonkey.com) anonymously records these excluded responses (Deutscher et al., 2009). PTs that accessed the online survey through e-mail invitation were able to take breaks during the survey, save their prior responses, and resume at a more convenient time. PTs that accessed the survey through the open access web

link needed to complete the survey in a single session. Participants were advised prior to initiating the survey that it may take approximately 45 minutes to complete, and a progress bar was posted at the bottom of each page to show the percentage of questions completed. The study was approved by the Rutgers University Institutional Review Board (Pro2012002460).

### *Data Collection & Analysis*

The responses were exported from SurveyMonkey® (SurveyMonkey.com) into Microsoft® Office Excel 2007 (microsoft.com) for analysis. Random ID numbers were assigned to each survey and all responses were coded and tallied. Narrative responses to open ended questions were read, sorted, and organized to establish common themes. Descriptive statistics (frequency counts, percentages, and tables) were calculated for each question using the Statistical Package for the Social Sciences®, version 13.0 (SPSS, 2004).

## **Results**

### *The Respondent Sample*

Survey administration lasted six months (May 24 - Nov 27, 2013), yielding 234 respondents: 136 PTs responded through the open access web link and 98 PTs responded through an e-mail invitation. At least one participant from each state in the USA and Washington DC fully completed

the survey to provide national representation. Of the 234 respondents, 14 did not meet the eligibility criteria; 220 met the eligibility criteria and started the survey and 197 (89.5%) completed the Referral and Screening Section of the survey (Appendix D). This resulted in an initial drop-off of 23 (10.5%) respondents. Regional distribution of the 197 respondents who completed the Referral and Screening questions ranged from 9-18% among the seven regions defined by the SoP (Figure 2) ([pediatricapta.org](http://pediatricapta.org)). These PTs have approximately 16 years experience working as a pediatric PT, and treat, on average, five patients with CMT each week (Table 1). They are primarily members of the APTA (70%) and the SoP (65.4%), and most have taken continuing education courses related to CMT (66.4%) (Table 1). The three most common places of employment in this sample included: hospital based outpatient clinic (41.6%), independently owned outpatient clinic (20.8%), and early intervention setting (19.3%) (Table 1).



Figure 1: Distribution of Survey Respondents

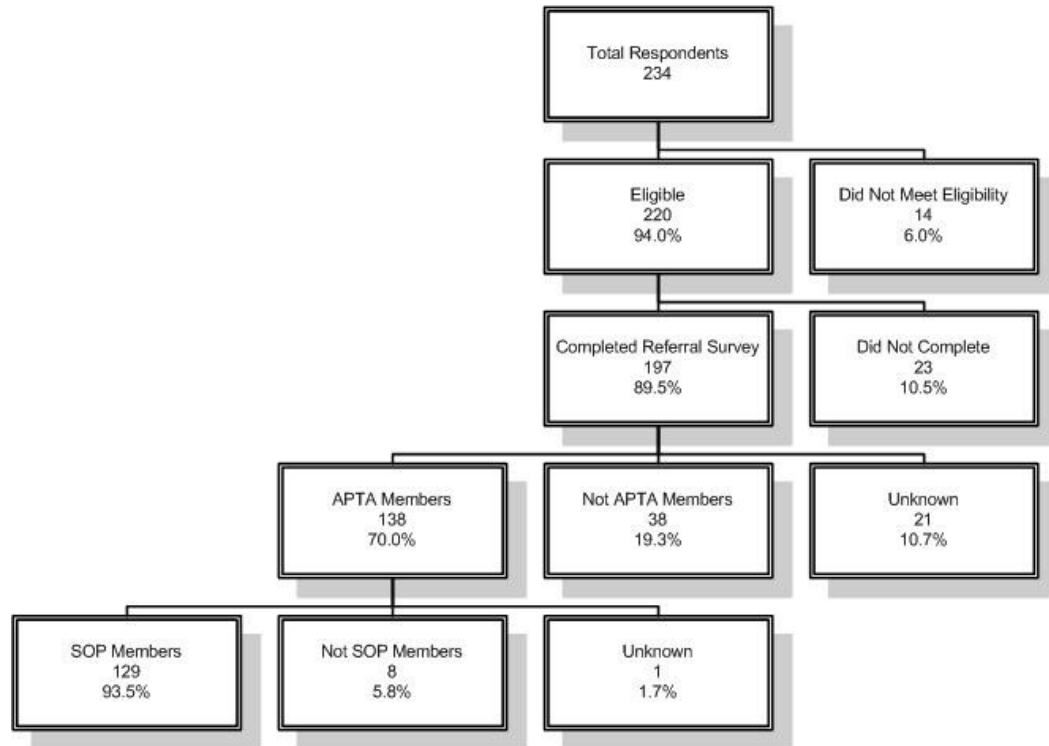
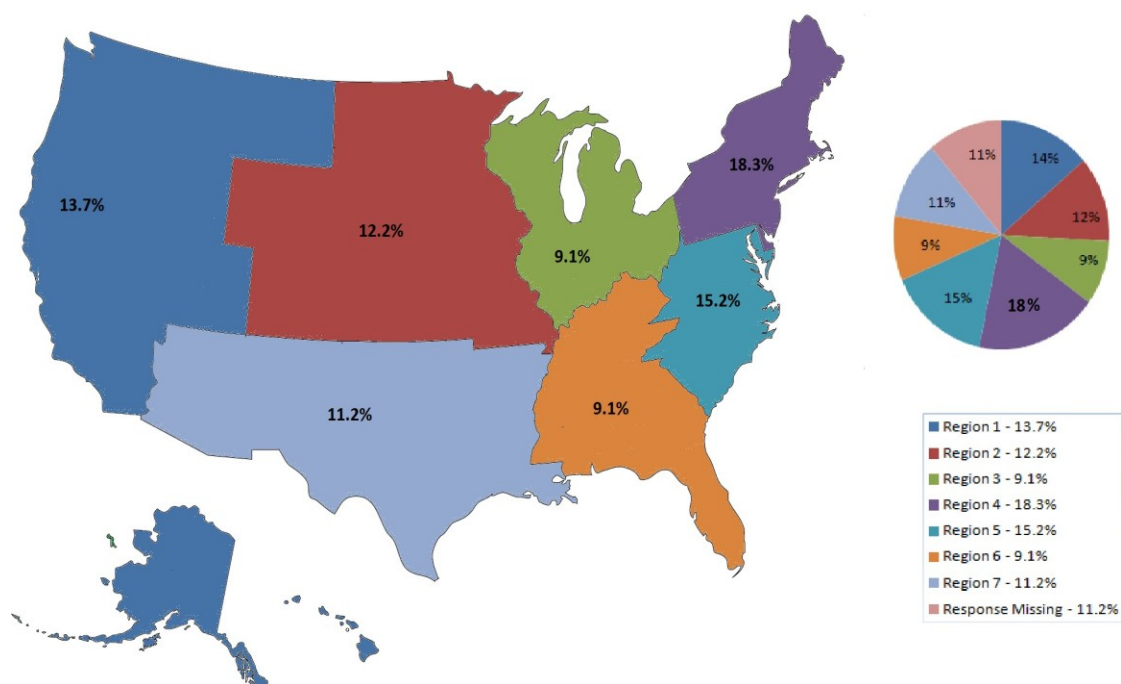


Table 1: Respondent Characteristics

		Yes	No	Missing
APTA Member		138 (70%)	38 (19.2%)	21 (10.6%)
SOP Member		129 (65.4%)	46 (23.3%)	22 (11.1%)
Board Certified Clinical Specialist		47 (23.8%)	128 (64.9%)	22 (11.1%)
Work in hospital-based outpatient setting		82 (41.6%)	94 (47.7%)	21 (10.6%)
Have taken CMT continuing education Course(s)		131 (66.4%)	45 (22.8%)	21 (10.6%)
	Mean	Range	Std. Dev.	Missing
# Years Practicing PT	17.89	1-49	11.89	23
# Years Practicing Pediatric PT	15.87	1-45	10.93	22
# Years Treating CMT	11.43	1-42	8.21	23
Typical Caseload of Patients/Week	23.39	3-50	9.32	8
Typical Caseload of CMT Patients/Week	4.48	1-25	3.56	6

Figure 2: Regional Representation of Survey Respondents who Identified States



### *Referral Patterns of Infants with CMT*

*Identification of the Problem.* Survey respondents (57.9%) report that the parent is typically the first person to identify a concern with the child's posture, followed by the pediatrician or family doctor (34.4%). It is not known at what age the problem is typically identified. The top three common concerns among parents reported by PTs are that the infant: prefers to only look to one side (71.0%); has an abnormal head shape (61.0%); and presents with a head tilt (54.3%).

*Referral to PT.* The first person reported to typically refer the infant to PT is the pediatrician or family doctor (84.8%), followed by the parent requesting a referral from the doctor (8.1%), a specialist (neurologist, plastic surgeon, orthopedist) referring the infant (2.9%), or friends and family (1.4%), and day care providers (0.5%) suggesting PT to the parent. Despite the availability of direct access in 47 states, no respondent selected the option, "Parent independently decides to use direct access to physical therapy services."

The most common age of referral reported is 3-4 months (67.8%), followed by 5-6 months (36.7%). It is not known when infants with CMT are commonly identified, however, 30.4% of the respondents report that parents were *always* or *usually* told by the pediatrician to wait before starting PT, and 17.0% report that parents were *always* or *usually* told to do stretches on their

own before referral to PT, indicating that referral to PT may not be occurring simultaneously with identification (Table 2). If told to wait before beginning PT, the most common wait time reported was 3-4 months (41.1%).

Variations in the above referral patterns are observed, and not all pediatricians take the “wait & see” approach: 40.4% of respondents report that parents are *always* or *usually* told to start PT immediately (Table 2). Yet, another 18.8% report that parents are *always* or *usually* told by their pediatrician that the observed asymmetry will resolve on its own (Table 2), even though there are no known studies on the natural progression of CMT to support that prognosis.

Similar disparities can be seen in the age of referral. There is a vast age range reported, which includes babies as young as two days, and one patient as old as 18 years, who are coming to PT for their first episode of care. Yet, only 5.5% of respondents report that patients with CMT have been referred within the first week of life, which reflects that this does not appear to be common practice in the US.

Table 2: Parental Report of Medical Intervention

Do parents report being told by their pediatrician...					
	Always	Usually	Some-times	Rarely	Never
that the observed assymetry will resolve on its own?	2 (1%)	37 (17.8%)	136 (65.4%)	24 (11.5%)	9 (4.3%)
to wait for a period of time before referral to PT?	3 (1.5%)	59 (28.9%)	91 (44.6%)	37 (18.1%)	14 (6.9%)
to see a specialist before referral to PT?	0 (0%)	7 (3.4%)	32 (15.7%)	135 (66.2%)	30 (14.7%)
that parents should do stretches but don't need immediate referral to PT?	5 (2.4%)	30 (14.6%)	103 (50.2%)	51 (24.9%)	16 (7.8%)
to start PT immediately?	6 (3%)	76 (37.4%)	100 (49.3%)	19 (9.4%)	2 (1%)

*Initial Presentation.* Respondents report three physical features to be very common, occurring in more than 80% of initial referrals for CMT: lateral head tilt (88.9%); passive rotation deficit of 5-15 degrees (57.3%); and plagiocephaly (50.3%). These features parallel the top three parental concerns reported in this survey. Respondents also report that, on average, the majority of infants referred to PT with CMT are of the muscular type (56.2%), followed by the postural type (35.4%), with the sternomastoid tumor type being the least common (8.4%).

### *Actions Taken Upon Referral to PT*

*Screening for Non-Muscular Causes.* The majority of respondents (59.2%) report that they *always* screen for non-muscular causes of CMT prior to a full initial examination, followed by 25.2% who report that they *usually* do, and 6.8% who report that they *rarely or never* do. The top three screens performed are for: plagiocephaly (87.0%), vision (81.3%), and development (76.0%). Musculoskeletal and neurological screens were reported by 72.6% and 63.5% of respondents, respectively. The least common screens include: cardiovascular (12.0%), integumentary (28.8%), and gastrointestinal (40.4%).

*Medical Imaging.* Respondents (83.1%) report that infants with CMT *rarely or never* have imaging studies performed prior to referral to PT and that the PTs *rarely or never* consult with the primary medical doctor about imaging tests that may be helpful for diagnosis or prognosis (57.7%). However, when medical imaging tests are completed, 69.8% *always* or *usually* acquire the results of the test, while 16.7% *rarely or never* acquire the results. The two imaging tests reported by US PTs to be most useful for management of patients with CMT were cervical x-rays (51.9%), followed by hip x-rays (20.7%), and cervical ultrasound (20.2%).

The majority of the respondents (61.2 %) report that imaging studies are most useful for diagnostic reasons. Within the category of diagnostic reasons, the most common sub-categories were: 1.) Rule out a bony anomaly

or vertebral/spinal malformation (51.2%), 2.) Provide a “differential diagnosis,” (22.0%), 3.) Rule out hip dysplasia (16.3%), and 4.) Rule out SCM tumor or pseudo-tumor (6.5%). One-fourth (24.5%) of the respondents report that imaging studies are not useful for their management of patients with CMT.

## Discussion

This study describes the patterns of referral and screening for infants with CMT, as reported by a relatively large sample of PTs in the USA. It is the fourth survey study of PTs about their management of patients with CMT, and the first one to represent practice in the USA. The responses from 197 PTs provide an initial description for comparison with recommended best practices.

### *Referral Patterns of Infants with CMT*

*Identification of the Problem.* Survey results suggest that parents are typically the first to identify a postural asymmetry, followed by pediatricians, with three common parental observations of the infant being: only looks to one side, has an abnormal head shape, or tilts the head to the side. It is not known when parental identification of asymmetry commonly occurs, but almost 70% of respondents report 3-4 months, followed by 5-6 months, as the most common ages of referral to PT for infants with CMT, and about one third of the

respondents share that parents are *always* or *usually* told to wait before beginning PT.

The CPG on CMT (Kaplan, et al., 2013) recommends: 1.) Identification within the first 2 days of birth, and 2.) Referral to the primary pediatrician and a PT when the problem is identified (Action Statements #1 and #2 respectively, as per the CPG on CMT). Although there are studies which recommend that providers assess for asymmetries in newborns (Stellwagen, et al., 2008; Leo A. van Vlimmeren, et al., 2004), pediatricians in the USA are not guided to evaluate a baby for CMT until the two-month check-up (Hagan, 2008) . Although there is a recommendation for pediatricians to specifically check for CMT at the two-month well baby visit (Hagan, 2008), there are no other recommended visits to evaluate for CMT, and no formal recommendation for referral to PT for an infant identified with CMT. This medical guidance most likely contributes to the reported variability of age at referral, and the variability of proposed medical interventions (Table 2).

If US doctors are waiting until the two month well baby visit to evaluate for CMT, then infants who already show signs and symptoms of CMT at birth are not being identified as early as possible. An age of more than one month at presentation significantly correlates with a



longer duration of treatment ( $p < .0001$ ), and a greater risk for surgery ( $p < .001$ ) (Cheng, et al., 2001). Healthcare professionals involved in the pre-natal care of the infant (e.g. obstetricians, midwives and prenatal birthing class instructors) are in the best position to provide early education to parents and caretakers about CMT, while those involved with immediate post-natal care (e.g. pediatricians, obstetrical nurses, midwives, and lactation counselors) are in the optimal position for recognition and identification of postural and skeletal asymmetries, especially plagiocephaly and facial asymmetry, which have very high odds ratios (plagiocephaly – 22.3; 95% CI, 7.01-70.95; facial asymmetry – 21.75; 95% CI, 6.6 – 71.7) for the prediction of CMT (Chen, Chang, Hsieh, Yen, & Chen, 2005). Ultimately, delaying identification of CMT results in delayed intervention and longer episodes of care with less successful outcomes (Cheng, et al., 2001; Petronic, et al., 2010).

*Referral to PT.* Almost one-third (30.4%) of survey respondents share that parents are *always* or *usually* told to wait to begin PT, and 17.0% share that parents are *always* or *usually* told to do stretches on their own before going to PT (Table 2). US PTs also report the most frequent “wait time” from identification to referral as 3-4 months (41.1%). This finding that there is a delayed referral to PT, despite earlier identification by parents and pediatricians, is consistent

with practice in New Zealand (Luxford, et al., 2009), where 33% of the PTs surveyed were concerned with “not receiving timely referrals,” and in Canada (Fradette, et al., 2011), where 48% of the doctors surveyed report initiating intervention themselves first, and later referring to PT if needed. Although this survey did not specifically request information regarding the age of the infant when asymmetry is first identified (CPG Action Statement #1), respondents report that referral to PT is not occurring simultaneously with identification of CMT, as recommended by the CPG on CMT, Action Statement #2 (Kaplan, et al., 2013).

A description by survey response of the typical age at which infants in the USA are referred to PT is not found in the literature. The survey results suggest that the most common age of referral to PT is 3-4 months (67.8%), followed by 5-6 months (36.7%). Older age at referral for infants with CMT may result in longer treatment durations and worse overall outcomes (Cheng, et al., 2001; Petronic, et al., 2010). Infants with CMT who start PT prior to one month of age have a median treatment duration of  $1.5 \pm 0.3$  months, and more than 98% of this age group achieve good outcomes, defined as straight head posture, more than  $100^\circ$  cervical rotation, and more than  $65^\circ$  lateral flexion (Petronic, et al., 2010). Infants with CMT who start PT later, between 1-3 months of age, have a median duration of treatment of  $5.9 \pm 0.6$  months, with 88% achieving good outcomes, and infants with CMT who start PT between 6-12 months of age have a median duration of treatment of  $9.8 \pm 0.6$

months, with less than 20% of this age group achieving good outcomes (Petronic, et al., 2010). Thus, earlier referral for treatment translates to shorter intervention periods and greater odds of full restitution of range of motion and postural symmetry. Longer treatment durations result in higher costs for services, less optimistic outcomes, and place more stress on parents to commit to frequent PT visits. PTs who treat infants with CMT at an older age may also struggle with trying to provide the appropriate stretch while keeping the infant calm and cooperative (Kim, et al., 2009; Rahlin, 2005).

Early referral to PT is not only beneficial for the infant, but for the family as well. Öhman, Nilsson & Beckung (2010) document the effectiveness of PT treatment over daily parental stretching in a comparative study between two groups of ten infants with CMT, one group receiving PT three times per week, and the other receiving daily stretches by the parent. The group which received PT showed improved ROM (rotation more than or equal to 90° and lateral flexion with no difference between left and right sides), and symmetric head posture about two months prior to the other group (Öhman, et al., 2010). As one Canadian pediatrician stated, “After many years showing the parents how to do the exercises themselves at home and following them up regularly but finally ending up with residual malformations, I now refer them from the get-go to physiotherapy; they are more motivated” (Fradette, et al., 2011). Parents who adhere to a PT program receive not only the individualized skilled services of a physical therapist for their baby, but also parental

education and recommendations on how to hold, handle, feed, play, and position their baby to achieve optimal outcomes. This is particularly important as demonstrated by Öhman et al. (2011), who showed that parents and caretakers who consistently performed specific handling strategies with their infants, as taught to them by a PT, were effectively able to help their child achieve symmetric head posture. PTs may also help parents with adherence to a treatment program, since one predictor of adherence is the maternal perception of the severity of the torticollis and the effect it has on the infant's activities and future function (Rabino et al. 2013).

As of this publication, there are no known natural progression studies of CMT; that is, watchful waiting without any conservative intervention. There are case reports of older children being referred with unresolved CMT for first treatments (Shim, Noh, & Park, 2004; Tse, Cheng, Chow, & Leung, 1987). This emphasizes that all healthcare professionals involved in the care of a newborn have an important role in educating others about CMT and advocating for early referral to PT. If parents and caregivers were aware of the consequences and potential negative effects of CMT on development and cranial /head shape, (Schertz, et al., 2012)(de Chalain & Park, 2005; Oh, et al., 2009; Omid-Kashani, et al., 2008; Yu, et al., 2004)(Öhman, et al., 2009; Schertz, et al., 2008)(Minihane, et al., 2008; von Heideken, et al., 2006; Walsh & Morrissy, 1998), they may

be more inclined to speak with their pediatricians and request earlier intervention. Indeed, it is far more likely that with such education, there would be a push for early intervention.

*Initial Presentation.* Research on CMT characteristically describes ipsilateral cervical side flexion with contralateral cervical rotation (Do, 2006; Öhman & Beckung, 2008). In this survey, the parents primary concerns are that their babies: 1.) only look to one side, 2.) have abnormal head shapes, and 3.) have tilted head postures. Three similar features were also found to be the most commonly reported by PTs: 1.) lateral head tilt, 2.) passive rotation deficit of 5-15° which restricts looking to one side, and 3.) plagiocephaly. These observations contribute to the typical presentation of an infant with CMT and validate parental concerns.

Survey respondents report that the majority (56.2%) of infants referred to PT with CMT are categorized in the muscular group (limited ROM, and a thickened SCM, but no palpable tumor), followed by the postural type (35.4%), and the sternomastoid tumor type (8.4%). This is an important finding because there is a difference regarding the duration of treatment among the three clinical groups ( $p < .0001$  for each), with the sternomastoid tumor group significantly associated with a longer duration of treatment, and the postural torticollis group

significantly associated with a shorter duration of treatment (Cheng, et al., 2001). Additionally, the presence of a sternomastoid tumor is significantly associated with a greater risk for surgery ( $p = .023$ ) (Cheng, et al., 2001). With this knowledge, US PTs are better equipped to educate, prognose, and communicate with parents and caretakers about expected outcomes. Furthermore, it provides PTs with the ability to appropriately integrate scientific findings, especially when other studies classify according to the same operational definitions, and to perform their own outcome studies regarding the infant's success with PT intervention.

*Screening for Non-Muscular Causes.* While the majority of US PTs (84.4%) appear to be practicing according to the recommended CPG Action Statement #4: "Screen Infants" (Kaplan, et al., 2013), there is a subset which report they *rarely or never* screen (6.8%). This finding may be partly explained by the wording of the survey question: "Do you screen for non-muscular causes of torticollis prior to a full initial examination?" Understanding that clinical practice does not typically allow for a separate screening appointment or that screening processes may be perceived as part of a typical examination, five respondents volunteered that they do not screen their patients *prior to a full initial examination*, but that this process occurs simultaneously with the exam. These comments shed light on interpretation of the

question and help to reflect accurate clinical practice. If those respondents are included in the screening question as positive responses, the majority of PTs who *always or usually* screen increases to 85.9%, and the PTs who *rarely or never* screen drops to 5.3%.

However, even with the recalculated percentages, there could be serious, and even devastating, affects for the infants of those PTs who do not screen. Ballock & Song (1996) report “death after spinal manipulation for torticollis” in an infant with a cervical spine tumor. They also report that up to 20% of patients diagnosed with torticollis may have a non-muscular etiology (Ballock & Song, 1996). Similarly, Tomczak & Rosman (2012) and Nuysink et al. (2008) outline various other underlying disorders which could present as torticollis or “symptomatic asymmetry” respectively. These authors emphasize the importance of differential diagnosis and screening to rule out other serious disorders (Ballock & Song, 1996; Nuysink, et al., 2008; Tomczak & Rosman, 2012).

Not only does screening serve to identify suspected red flags and serious conditions, but it also ensures proper clinical decision making, and the conscientious use of resources. This is especially important for infants who present with a condition that would not be responsive to PT, such as a visual loss, hearing deficit, or

gastrointestinal problem. Proper screening eliminates delivery of services to patients who would not benefit, thereby avoiding excessive costs, unnecessary PT treatments, and the potential for serious health consequences if the appropriate medical intervention is not received in a timely manner.

For PTs, a review of the literature on the differential diagnosis of torticollis may provide a beneficial foundation to ensure appropriate screening for patients with CMT. Tomczak & Rosman (2012) offer an informative classification of the different presentations of torticollis posturing. They classify torticollis as nonparoxysmal (nondynamic) or paroxysmal (dynamic), and then further classify by the pathogenesis of the condition: osseous, ocular, central nervous system, providing descriptions of each (Tomczak & Rosman, 2012). Nuysink et al. (2008) present a useful table of the signs and symptoms which may be associated with disorders of asymmetry, while Ballock & Song (1996) offer a valuable algorithm which may be very helpful in the differential diagnosis of torticollis. These studies provide PTs with invaluable resources in the management of their patients with CMT.

Currently, all 50 states, the District of Columbia, and the US Virgin Islands have some level of direct access, where any infant or young child suspected of abnormal head and neck posturing may be



referred to PT by any person, and no longer needs physician referral (APTA, 2015). PTs must screen the four systems as recommended by the Guide to PT Practice (APTA, 2001): Musculoskeletal, Neurological (includes vision), Integumentary, and Cardiovascular, and the fifth recommended by the CPG, Gastrointestinal (Kaplan, et al., 2013). This will reduce the risk of harm to the infant, but also ensure that the correct problem is treated, and align with recommendations for current PT practice (APTA, 2001; Kaplan, et al., 2013).

*Medical Imaging.* The survey results show that 2.8% of infants referred to PT *always or usually* arrive with previously completed imaging tests, and that 69.8% of US PTs *always or usually* acquire the results of previously completed imaging tests for their patients with CMT, while 16.7% *rarely or never* do. Additionally, 57.7% of the respondents reported that they *rarely or never* consult with the medical doctor to discuss imaging tests that may be helpful for diagnosis or prognosis. These results suggest that although very few infants arrive to PT with previously completed imaging studies, the majority of US PTs retroactively seek the results of imaging studies, yet many may not feel comfortable recommending an imaging study to the doctor.

Most US PTs are seeking the results of diagnostic testing; this is consistent with Luxford et al. (2009), who reports that 81% of New Zealand PTs *always or often* inquire about x-rays or diagnostic tests.

However, it is not consistent with Öhman et al. (2013), who report that 55% of PTs from a network of PTs mostly in Sweden *rarely* or *never* seek information on x-rays or diagnostic tests during their first assessment of an infant with CMT. It is not clear why this difference exists, however, one reason may be due to the demographics of the sample, and the PTs place of employment. Öhman et al. (2013) explain that there are two main Children's Hospitals in Sweden, which share information throughout the network of PTs. If many of the PTs in their survey are employed at these hospitals, information regarding x-rays and other diagnostic tests may be more readily accessible. In this survey among US PTs, almost half of the respondents (47.7%) primarily treat infants with CMT outside of the hospital setting, with most working in independently owned outpatient clinics (20.8%), or in the early intervention program (19.3%). These PTs may not have an infant's diagnostic images available to them, and may need to request such information from the parents.

The American Academy of Pediatrics (AAP) recommends that imaging of the cervical spine be performed in all newborns with torticollis, with ultrasound being the primary choice (Ozuah, 2008). Although the AAP recommends ultrasound of the cervical spine for all patients with CMT, this is not typically seen in clinical practice (as evidenced above), nor does it appear that US PTs value ultrasound

imaging, as much as they do a cervical x-ray. When asked which imaging studies were most useful for their management of patients with CMT, the most common response was cervical x-ray (51.9%), while one-fifth of PTs find hip x-rays (20.7%), or cervical ultrasounds (20.2%) as the most useful diagnostic test for their management of infants with CMT. The preference of US PTs toward a cervical x-ray may be supported by the reasoning of the respondents as to how medical imaging helps to manage their patients with CMT. The most common response was for diagnostic reasons (61.2%), and within that category, ruling out a spinal problem, or bony anomaly, such as a hemivertebrae, accounted for more than half (51.2%) of those responses. Few PTs responded that medical imaging helps to rule out a pseudo-tumor or mass within the muscle belly (6.5%), as could be confirmed by ultrasound.

Despite their reasoning on the preference toward a cervical x-ray, PTs should be aware that cervical x-rays are not suggested for all infants presenting with torticollis (Snyder & Coley, 2006). Results of a retrospective chart review on 502 infants who presented with non-traumatic torticollis and had a cervical x-ray showed that four (0.8%) had true bony vertebral abnormalities (Snyder & Coley, 2006). The authors concluded that cervical radiographs be obtained when there is failure to progress with PT or when there are atypical clinical findings

(Snyder & Coley, 2006). Ballock & Song (1996) recommend that only those patients who do not have a history of trauma at birth, and do not have SCM tightness, should have an x-ray to rule out scoliosis and Klippel-Feil syndrome. They propose an algorithm for the evaluation of torticollis in children, which may be useful for PTs (Ballock & Song, 1996).

The results of this survey suggest that the majority of US PTs are in alignment with CPG Action Statement #6: “Request Images and Reports.” However, almost one-fourth of the respondents (24.5%) report that “Imaging studies are not useful for my management of patients with CMT,” and there appears to be variability among the medical community on which test(s) to perform. Without a defined algorithm or guideline for which imaging test to recommend, when to recommend it, and for whom, PTs should be cognizant of all the imaging tests available, the benefits and drawbacks associated with each, and be able to make an informed decision on what may be useful for the patient. Specifically, for infants with a palpable tumor, an ultrasound may be valuable for confirming the presence of a sternomastoid lesion, documenting the size and location for future comparison, (Hsu et al., 1999) and determining the prognosis of resolution (Hsu, et al., 1999). Likewise, if the infant presents with limited hip abduction, asymmetric hip folds (Nuysink, et al., 2008), a

positive Barlow or Ortolani sign if younger than 2-3 months, or a leg length discrepancy (Leach, 2006), a hip x-ray would be merited, since a subluxed hip may translate into spinal asymmetries noticed in the cervical area (Cheng, Tang, Chen, Wong, & Wong, 2000). Ultimately, US PTs who receive referrals for infants with torticollis may even find it beneficial to seek out continuing education classes on medical imaging studies. Regardless, the CPG for CMT has a moderate strength recommendation that PTs should seek out the results of previously completed imaging studies, and request other relevant test(s) from the medical doctor as needed (Kaplan, et al., 2013). Decisions regarding which test to obtain, or for whom, should be done on a case by case basis.

### *Summary of the Referral Patterns of Infants with CMT*

This survey study of US PTs provides an initial description of patterns observed in the referral and screening of infants with CMT in the USA. It was validated by an expert panel of pediatric PTs prior to its distribution, and was then completed by 197 PTs around the country with representation from each of the fifty states and the District of Columbia. It is the largest CMT survey of PTs found in the literature, and the first to describe practice in the United States.

Significant findings from this survey of experienced US PTs include that infants with CMT are referred to PT, usually by the pediatrician between 3-6 months of age. They are identified with asymmetries by their parents prior to their referral to PT, but it is not known how long before referral this generally occurs. Almost one-third of respondents report that parents are told by the pediatrician to wait before starting PT, with the most frequently reported wait time of 3-4 months. Most of the respondents are screening infants referred with torticollis for non-muscular causes, and are seeking the results of previously completed imaging studies; however, not all PTs are doing this.

Clinically, it is imperative that PTs seek out methods to improve upon these patterns of referral, so that infants with CMT are received to PT at an earlier age and upon identification of asymmetry. Implementation of earlier referral to PT may then significantly improve the rate and the fullness of their recovery. It is also imperative that *all* PTs, not just a percentage of the whole, are screening infants who are referred to PT with CMT for non-muscular causes. This could have significant implications for the well-being of the infant, including the exclusion of a more serious disorder, avoidance of unnecessary or possibly harmful treatment, and timely referral for the appropriate medical intervention specific to that infant's condition.

### Study Limitations

Three main limitations to this survey study exist. First, it represents the views of US PTs, and does not survey pediatricians or parents of infants with CMT. Although the main purpose of this referral survey was to describe the patterns of referral to PT for infants with CMT as observed by US PTs, this topic also concerns the practices of the pediatricians and parents involved in their care. Separate surveys specific to those populations would need to be administered in order to appreciate any similarities or differences with US PTs.

Secondly, the survey sample is mainly comprised of PTs who belong to the SoP of the APTA (65.4%). This is most likely due to the recruitment methods used in this survey. It was known by the research team that there are approximately 5,000 physical therapists and physical therapist assistants who belong to the Section on Pediatrics of the American Physical Therapy Association ([pediatricapta.org](http://pediatricapta.org)). However, the challenge of reaching the target population of US PTs who treat CMT is that there are no registries of PTs who treat infants with CMT; not all pediatric PTs belong to the Section on Pediatrics; and not all pediatric PTs treat children with CMT. Therefore, the target population was felt to be a relatively small subset of physical therapists of unknown size and location. A convenience sample was established to help identify this population, and additionally a web link was posted on the SoP website ([www.pediatricapta.org](http://www.pediatricapta.org)). Despite using methods to recruit both

members and non-members of the SoP, the methods used to recruit members in the SoP outweighed those to recruit the non-members. Resultantly, the majority of the respondents (65.5%) were SoP members, while 23.3% were not, and 11.2% did not respond to the question. Although this may be representative of bias in the survey, responses would be biased toward those who are members of the SoP, who voluntarily pay annual dues to belong to the APTA, and who receive regular journal publications to keep their practice informed. Thus, the bias of this survey is in the direction of the more informed clinician.

Third, the referral and screening section of this survey consisted of 22 thought provoking questions, which included narrative responses, and may have required additional time demands from the respondents. From 220 PTs starting the first question, to 197 (89.5%) completing the Referral and Screening Section of the survey, 23 (10.5%) respondents elected to stop taking the survey. The non-completion rate may be due to the survey length or the inability of respondents who accessed the survey via the open access web link to log off and later return to their work. It was known and relayed to the respondents before they started the survey that those who had responded via a direct e-mail invitation would have a unique weblink, which would allow them to save their answers and log back on at a more convenient time. However, those who accessed the survey via the open access web link (58.1%) could not do this. Fortunately, almost 90% of the respondents



completed the survey, allowing representation from each state in the USA, and the District of Columbia.

### Further Research

It is necessary to validate the findings of this survey of US PTs with parents and pediatricians. All three parties play an integral role in the management of infants with CMT, and the observations of PTs brought forth in this survey should be compared to the observations of others who are involved in the care of these patients. PTs also need research on whether identification of asymmetry and early referral to PT in the immediate post-natal period will improve outcomes, or result in false positive cases. As a result, US PTs and MDs could then collaborate on an evidence based standard of care for referral. Community wide education for parents, caretakers, and all of the medical community is also needed, followed by further studies to document changes in the referral of these infants to PT. Lastly, further research is needed to observe if there are any changes in PT practice, since survey completion (November 2013), and APTA CPG publication (October 2013).

### Conclusions

The findings of this survey show that the referral and screening practices of US PTs who work with infants with CMT tend to be consistent

with the literature, and are at least partially agreeable with evidence based practice, as reported by a relatively large and geographically diverse group of experienced pediatric PTs. It shows that most pediatric PTs in the USA are practicing in agreement with two of the first six Action Statements of the CPG on CMT (Kaplan, et al., 2013).

## References

- American Physical Therapy Association (APTA). (2001). Guide to physical therapist practice. *Physical Therapy*, 81(1), 1-768.
- American Physical Therapy Association (APTA). (2012). *FAQ: Direct Access at the State Level*. Retrieved June 5, 2012, from <http://www.apta.org/StateIssues/DirectAccess/FAQs/>
- Ballock, R. T., & Song, K. M. (1996). The prevalence of nonmuscular causes of torticollis in children. *Journal of Pediatric Orthopedics*, 16(4), 500-504.
- Binder, H., Eng, G. D., Gaiser, J. F., & Koch, B. (1987). Congenital muscular torticollis: results of conservative management with long-term follow-up in 85 cases. *Arch Phys Med Rehabil*, 68(4), 222-225.
- Carenzio, G., Carlisi, E., Morani, I., Tinelli, C., Barak, M., Bejor, M., & Dalla Toffola, E., (2015). Early rehabilitation treatment in newborns with congenital muscular torticollis. *European Journal of Physical and Rehabilitation Medicine*, 51(5): 539-545.
- Cincinnati Children's Hospital. (2009). Evidence-Based Care Guideline for Management of Congenital Muscular Torticollis in children age 0-36 months. In Cincinnati Children's Hospital Medical Center (Ed.).
- Chen, M.-M., Chang, H.-C., Hsieh, C.-F., Yen, M.-F., & Chen, T. H.-H. (2005). Predictive model for congenital muscular torticollis: analysis of 1021 infants with sonography. *Archives of Physical Medicine & Rehabilitation*, 86(11), 2199-2203.
- Cheng, J. C., Tang, S. P., Chen, T. M., Wong, M. W., & Wong, E. M. (2000). The clinical presentation and outcome of treatment of congenital muscular torticollis in infants--a study of 1,086 cases. *Journal of Pediatric Surgery*, 35(7), 1091-1096.
- Cheng, J. C., Wong, M. W., Tang, S. P., Chen, T. M., Shum, S. L., & Wong, E. M. (2001). Clinical determinants of the outcome of manual stretching in the treatment of congenital muscular torticollis in infants. A prospective study of eight hundred and twenty-one cases. [Evaluation Studies]. *Journal of Bone & Joint Surgery - American Volume*, 83-A(5), 679-687.

- de Chalain, T. M. B., & Park, S. (2005). Torticollis associated with positional plagiocephaly: a growing epidemic. *Journal of Craniofacial Surgery*, 16(3), 411-418.
- Demirbilek, S., & Atayurt, H. F. (1999). Congenital muscular torticollis and sternomastoid tumor: results of nonoperative treatment. *Journal of Pediatric Surgery*, 34(4), 549-551.
- Deutscher, D., Horn, S. D., Dickstein, R., Hart, D. L., Smout, R. J., Gutvirtz, M., & Ariel, I. (2009). Associations Between Treatment Processes, Patient Characteristics, and Outcomes in Outpatient Physical Therapy Practice. *Archives of Physical Medicine and Rehabilitation*, 90(8), 1349-1363. doi: 10.1016/j.apmr.2009.02.005
- Do, T. T. (2006). Congenital muscular torticollis: current concepts and review of treatment. [Review]. *Current Opinion in Pediatrics*, 18(1), 26-29.
- Emery, C. (1994). The determinants of treatment duration for congenital muscular torticollis. [Research Support, Non-U.S. Gov't]. *Physical Therapy*, 74(10), 921-929.
- Fradette, J., Gagnon, I., Kennedy, E., Snider, L., & Majnemer, A. (2011). Clinical Decision Making Regarding Interevention Needs of Infants with Torticollis. *Pediatric Physical Therapy*, 249-256.
- Hagan, J. F., Shaw, J. S., & Duncan, P. (Ed.). (2008). *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, Third Edition*. Elk Grove Village, IL: American Academy of Pediatrics.
- Hsu, T. C., Wang, C. L., Wong, M. K., Hsu, K. H., Tang, F. T., & Chen, H. T. (1999). Correlation of clinical and ultrasonographic features in congenital muscular torticollis. [Comparative Study]. *Archives of Physical Medicine & Rehabilitation*, 80(6), 637-641.
- Jeong, K.-Y., Min, K.-J., Woo, J., & Yim, S.-Y. (2015). Craniofacial asymmetry in adults with neglected congenital muscular torticollis. *Annals of Rehabilitation Medicine*, 39(3): 440-450.
- Kaplan, S., Coulter, C., & Feters, L. (2013). Physical therapy management of congenital muscular torticollis: An evidence-based clinical practice guideline. *Pediatric Physical Therapy*, 25(4), 348-394.

- Karmel-Ross, K. (2006). Congenital Muscular Torticollis. In S. Campbell, Vander Linden, D., Palisano, R. (Ed.), *Physical Therapy for Children, Third Edition* (pp. 359-380). St. Louis: Elsevier Inc.
- Kim, M. Y., Kwon, D. R., & Lee, H. I. (2009). Therapeutic effect of microcurrent therapy in infants with congenital muscular torticollis. [Controlled Clinical Trial]. *Pm & R*, 1(8), 736-739.
- Leach, J. (2006). Orthopedic Conditions. In S. Campbell, Vander Linden, D., Palisano, R. (Ed.), *Physical Therapy for Children, Third Edition* (pp. 491-495). St. Louis: Elsevier Inc.
- Lee, J.-Y., Koh, S.-E., Lee, I.-S., Jung, H., Lee, J., Kang, J.-I., & Bang, H. (2013). The cervical range of motion as a factor affecting outcome in patients with congenital muscular torticollis. *Annals of Rehabilitation Medicine*, 37(2): 183-190.
- Luxford, B., Hale, L., & Piggot, J. (2009). The physiotherapy management of infants with congenital muscular torticollis: a survey of current practice in New Zealand. *New Zealand Journal of Physiotherapy*, 37(3), 127-135.
- Microsoft® Office Excel (2007). <https://www.microsoft.com/en-us/search/result.aspx?q=excel&form=MSHOME>
- Miller, R. I., & Clarren, S. K. (2000). Long-term developmental outcomes in patients with deformational plagiocephaly. *Pediatrics*, 105(2), E26.
- Minihane, K. P., Grayhack, J. J., Simmons, T. D., Seshadri, R., Wysocki, R. W., & Sarwark, J. F. (2008). Developmental dysplasia of the hip in infants with congenital muscular torticollis. *American Journal of Orthopedics*, 37(9), E155-158; discussion E158.
- Nucci, P., Kushner, B. J., Serafino, M., & Orzalesi, N. (2005). A multi-disciplinary study of the ocular, orthopedic, and neurologic causes of abnormal head postures in children. [Research Support, Non-U.S. Gov't]. *American Journal of Ophthalmology*, 140(1), 65-68.
- Nuysink, J., van Haastert, I. C., Takken, T., & Helders, P. J. M. (2008). Symptomatic assymetry in the first six months of life: differential diagnosis. *European Journal of Pediatrics*, 167, 613-619. doi: 10.1007/s00431-008-0686-1

- Oh, A. K., Hoy, E. A., & Rogers, G. F. (2009). Predictors of severity in deformational plagiocephaly.[Erratum appears in J Craniofac Surg. 2009 Sep;20(5):1629-30]. *Journal of Craniofacial Surgery*, 20 Suppl 1, 685-689.
- Öhman, A., & Beckung, E. (2005). Functional and cosmetic status in children treated for congenital muscular torticollis as infants. *Advances in Physiotherapy*, 7, 135-140.
- Öhman, A., & Beckung, E. R. E. (2008). Reference values for range of motion and muscle function of the neck in infants. [Multicenter Study Research Support, Non-U.S. Gov't]. *Pediatric Physical Therapy*, 20(1), 53-58.
- Öhman, A., Mårdbrink, E.-L., Orefelt, C., Seager, A., Tell, L., & Klackenberg, E. A. (2013). The physical therapy assessment and management of infants with congenital muscular torticollis. A survey and a suggested assessment protocol for CMT. *Journal of Novel Physiotherapies*. doi: 10.4172/2165-7025.1000165
- Öhman, A., Mårdbrink, E.-L., Stensby, J., & Beckung, E. (2011). Evaluation of Treatment strategies for muscle function in infants with congenital muscular torticollis *Physiotherapy Theory & Practice*, 27(7), 463-470.
- Öhman, A., Nilsson, S., & Beckung, E. (2010). Stretching treatment for infants with congenital muscular torticollis: physiotherapist or parents? A randomized pilot study. [Randomized Controlled Trial Research Support, Non-U.S. Gov't]. *Pm & R*, 2(12), 1073-1079.
- Öhman, A., Nilsson, S., Lagerkvist, A.-L., & Beckung, E. (2009). Are infants with torticollis at risk of a delay in early motor milestones compared with a control group of healthy infants? *Developmental Medicine & Child Neurology*, 51(7), 545-550.
- Omidi-Kashani, F., Hasankhani, E. G., Sharifi, R., & Mazlumi, M. (2008). Is surgery recommended in adults with neglected congenital muscular torticollis? A prospective study. *BMC Musculoskeletal Disorders*, 9, 158.
- Ozuah, P. O. & Skae, C. C. (2008). Pediatric Care Online - AAP Textbook of Pediatric Care, Chapter 225: Torticollis. Retrieved May 29, 2012, from American Academy of Pediatrics.

- Pediatric American Physical Therapy Association (2012). *About Us*. Retrieved July 27, 2012, from <https://pediatricapta.org/about-pediatric-physical-therapy/index.cfm#aboutus>
- Petronic, I., Brdar, R., Cirovic, D., Nikolic, D., Lukac, M., Janic, D., Knezevic, T. (2010). Congenital muscular torticollis in children: distribution, treatment duration and out come. *European journal of physical & rehabilitation medicine.*, 46(2), 153-157.
- Rahlin, M. (2005). TAMO therapy as a major component of physical therapy intervention for an infant with congenital muscular torticollis: a case report.[Erratum appears in *Pediatr Phys Ther.* 2005 Winter;17(4):257]. [Case Reports]. *Pediatric Physical Therapy*, 17(3), 209-218.
- Schertz, M., Zuk, L., & Green, D. (2012). Long-term neurodevelopmental follow-up in children with congenital muscular torticollis. *Journal of Child Neurology*. doi: 10.1177/0883073812455693
- Schertz, M., Zuk, L., Zin, S., Nadam, L., Schwartz, D., & Bienkowski, R. S. (2008). Motor and cognitive development at one-year follow-up in infants with torticollis. [Multicenter Study]. *Early Human Development*, 84(1), 9-14.
- Shim, J., Noh, K., & Park, S. (2004). Treatment of congenital muscular torticollis in patients older than 8 years. [Comparative Study]. *Journal of Pediatric Orthopedics*, 24(6), 683-688.
- Snyder, E. M., & Coley, B. D. (2006). Limited value of plain radiographs in infant torticollis. *Pediatrics*, 118(6), e1779-1784.
- Speltz, M. L., Collett, B. R., Stott-Miller, M., Starr, J. R., Heike, C., Wolfram-Aduan, A. M.,...Cunningham, M. L. (2010). Case-control study of neurodevelopment in deformational plagiocephaly. [Research Support, N.I.H., Extramural]. *Pediatrics*, 125(3), e537-542.
- Statistical Package for the Social Sciences (SPSS). (2004). SPSS Graduate Pack 13.0 for Windows® (Version 13.0). Chicago, IL: Statistical Package for the Social Sciences, Inc
- SurveyMonkey.com (2012). Retrieved July 27, 2012 from <https://www.surveymonkey.com/>

- Taylor, J. L. N. (1997). Developmental muscular torticollis: Outcomes in young children treated by physical therapy. *Pediatric Physical Therapy*, 9, 173-178.
- Tomczak, K., & Rosman, N. P. (2012). Torticollis. *Journal of Child Neurology*, 28(3), 365-378. doi: 10.1177/0883073812469294
- Tse, P., Cheng, J., Chow, Y., & Leung, P. C. (1987). Surgery for neglected congenital torticollis. *Acta Orthop. Scand.*(58), 270-272.
- von Heideken, J., Green, D. W., Burke, S. W., Sindle, K., Denneen, J., Haglund-Akerlind, Y., & Widmann, R. F. (2006). The relationship between developmental dysplasia of the hip and congenital muscular torticollis. *Journal of Pediatric Orthopedics*, 26(6), 805-808.
- Walsh, J. J., & Morrissy, R. T. (1998). Torticollis and hip dislocation. *Journal of Pediatric Orthopedics*, 18(2), 219-221.
- Yu, C.-C., Wong, F.-H., Lo, L.-J., & Chen, Y.-R. (2004). Craniofacial deformity in patients with uncorrected congenital muscular torticollis: an assessment from three-dimensional computed tomography imaging. [Research Support, Non-U.S. Gov't]. *Plastic & Reconstructive Surgery*, 113(1), 24-33.



#### CHAPTER IV-B: Patterns of Measurement Recorded at Examination and Discharge of Infants with Congenital Muscular Torticollis - A Survey of Pediatric Physical Therapists in the United States of America

**Purpose:** To describe the results of a survey of PTs in the USA who evaluate infants with congenital muscular torticollis (CMT). Practice trends in the examination, discharge, and outcome measurement of infants with CMT are compared to current literature, including recent clinical practice guideline (CPG) recommendations. **Methods:** An online survey was completed by volunteers solicited through multiple methods. **Results:** 177 pediatric physical therapists in the USA completed the examination, discharge and outcomes portions of the survey, with at least one participant from every state & the District of Columbia. Significant findings include that although the majority of PTs in this sample do not use a clinical guideline to inform their CMT examination (57%), they are measuring the recommended components in their initial examination and discharge of patients with CMT. PTs in this sample do not use the objective tests for their methods of measurement as recommended in the literature and published clinical practice guidelines for CMT, with 50% visually estimating cervical ROM. Most respondents (76%) discharge CMT patients with full ROM, midline head posture and symmetrical reactions, and 24% recommend a follow-up appointment after discharge. The majority do not collect group outcomes for CMT patients (60%), but positive changes are reported among those that do. A minority (10%) of patients with CMT return for a second episode of care after they have been discharged from physical therapy. **Conclusion:** Practice patterns are partially consistent with current CMT literature, including partial congruence with the published CPG recommendations. For the physical therapy profession to move toward the development of outcomes registries, greater consensus is needed on the methods of measurement that should be used for CMT.

## Introduction

From the initial examination of an infant with Congenital Muscular Torticollis (CMT), physical therapists (PTs) are planning for their eventual discharge. Measurement of outcomes is essential to pediatric PTs so that they can document progress and achievement of goals toward which the child or family is working, provide evidence to consumers, referring physicians, and third party payers on the effectiveness of physical therapy (PT), and ultimately, prepare the patient for discharge from PT services.

From a well-designed and implemented PT examination, PTs are able to determine which body structures, functions, and activities are limited, and then establish achievable goals to improve the patient's quality of life. It is necessary to accurately measure and document the impairments and functional limitations that are observed, so that realistic goals can be set to improve upon those baseline measures. It is not known how pediatric PTs in the USA proceed with their measurements during examination and discharge of an infant with CMT. This paper will address four clinically important issues: US PTs use of guidelines to inform their CMT examination; impairments and/or limitations that are measured at the initial examination and discharge

of an infant with CMT; methods of performing those measurements; and use of group outcome measures to inform practice.

There are three known published clinical practice guidelines (CPGs) that PTs may refer to on the examination and discharge of infants with CMT (Cincinnati Children's Hospital, 2009; Corradi-Scalese, 2006; Kaplan, Coulter, & Feters, 2013). Although a literature search will reveal these CPGs and many articles on the measurement of infants with CMT, there are other sources of unpublished information which US PTs may be utilizing to guide their examination and discharge processes. These sources include: pathways or guidelines established at their place of work and specific to their facility; word of mouth from mentoring PTs; continuing education seminars; under graduate and post graduate education; "on the job" training; and personal experience. It is unclear if US PTs are using evidence to guide practice, and if they are, which sources are used.

Many studies on infants with CMT are performed by physicians and emphasize impairment and body structure (cellular) outcomes, or the success of medical procedures to diagnose CMT or predict surgical outcomes (Binder, Eng, Gaiser, & Koch, 1987; Celayir, 2000; Chen, Chang, Hsieh, Yen, & Chen, 2005; Cheng, Metreweli, Chen, & Tang, 2000; Cheng et al., 2001; Demirbilek & Atayurt, 1999; Emery, 1994; Hsu et al., 1999; Anna Maria Ohman & Beckung, 2008). Surveys from Canada (Fradette, Gagnon, Kennedy, Snider,

& Majnemer, 2011) and New Zealand (Luxford, Hale, & Piggot, 2009) indicate that these PTs attend to impairments, as well as functional and environmental measures, but it is not known if US PTs do the same. This study provides a current description of the patterns of measurement recorded by PTs at the initial exam and discharge of infants with CMT.

Beyond knowing which measurements to record, PTs must also know how to take the measurements. They need reliable and valid, objective measurements to chart progress for a specific patient and to compare treatment outcomes within patient groups. Accurate data collection is necessary not only for individual PTs, but also for the profession of physical therapy as a whole, as it moves toward a new era of outcomes registries ([www.apta.org/Registry](http://www.apta.org/Registry), 2014) and the need to demonstrate the effectiveness of PT services. Concern on how to perform reliable, objective measurements on fidgety, non-consenting infants has been described (Fradette, et al., 2011; Luxford, et al., 2009; Öhman et al., 2013; Scott Freed, 2006). Indeed, visual estimation of the range of motion (ROM) in infants with CMT is reported to occur among 86% of PTs in New Zealand (Luxford, et al., 2009), and among 94% of PTs in Denmark and Sweden (Öhman, et al., 2013). However, Canadian PTs also reported that reliability and validity, "...influenced their decision to implement a particular tool in clinical practice" (Fradette, et al., 2011). This suggests that PTs want to use objective, valid measures, but the difficulty in doing so may be due to the lack of a convenient and

psychometrically valid tool for assessing cervical ROM in infants with CMT (Fradette, et al., 2011; Luxford, et al., 2009; Öhman, et al., 2013).

This survey of US PTs will help to determine if there are similar measurement trends for infants with CMT in the USA. Patterns of measurement at examination and discharge will be reported, as well as any group outcome measures that may be recorded. Actual practice will then be compared to recommended best practice as determined from the literature, and suggestions for improvements in practice will be made.

### Purpose

The purposes of this survey are to: 1.) Determine if guidelines are used by US PTs to direct their CMT examination, 2.) Identify which measurements are recorded by PTs at the initial examination and discharge of patients with CMT, 3.) Determine how these measurements are performed, 4.) Reveal if group outcome measures are collected to inform practice, and 5.) Compare the overall findings of this survey with recommended best practice.

## Methods

### *Survey Development*

The survey was developed based on an extensive review of the literature and was approved by the Rutgers University Institutional Review Board (Pro2012002460). It consisted of 90 total questions, dealing with PT practices related to the referral, screening, examination, intervention, discharge, and outcomes of infants with CMT, as well as clinical setting and professional development. This study is focused solely on the 28 survey questions dealing with initial examination, discharge, and outcomes (Appendix C). Of these, 17 questions (#23-39) pertained to measurements taken at initial examination, 6 questions (#55-60) on discharge measurements, and 5 questions (#61-65) on group outcomes measurement.

### *Survey Administration & Recruitment*

A mixed mode survey distribution was offered in which pediatric PTs could either: complete a paper survey with mail return; complete the survey online via direct e-mail invitation from the primary investigator; or complete the survey online via an open access web link posted in an e-newsletter from the American Physical Therapy Association (APTA) Section on Pediatrics (SoP) ([www.pediatricapta.org](http://www.pediatricapta.org)). The target population was pediatric PTs in the USA who treat young patients with CMT. To increase the representation of this small subset, national coverage was sought through direct invitation to the survey of at least five PTs from each state who treat CMT, targeting a

total sample of 250. Methods used to recruit the sample included: e-mail to state representatives for solicitation of pediatric PTs who treat CMT; phone call or direct e-mail to the directors of PT departments and managers of private pediatric PT businesses at children's hospitals within the USA (publicly available on the internet or through the National Association of Children's Hospitals); word of mouth and snowball effect with pediatric PTs who treat CMT inviting known fellow co-workers and colleagues who treat CMT but who were unaware of the survey content. Additionally, an open invitation to complete the survey online using a web link was posted on the SoP e-newsletter ([www.pediatricapta.org](http://www.pediatricapta.org)) (June – September 2013) to attract qualified PTs who were not identified in the convenience sample.

### *Participants & Procedures*

Eligible participants were licensed PTs that had examined and treated a minimum of two young children or infants with CMT in the past six months. Exclusion criteria were PTAs (because of the large emphasis of the survey on the initial examination and evaluation procedures) and PTs who were not English speaking or who did not practice in the USA. Survey administration lasted six months (May 24 - Nov 27, 2013). The responses were exported from SurveyMonkey® ([SurveyMonkey.com](http://SurveyMonkey.com)) onto Microsoft® Office Excel 2007 ([www.microsoft.com](http://www.microsoft.com)) Worksheets for analysis. Random ID numbers were assigned to each survey and all responses were coded and tallied. Narrative responses to open ended questions were read, sorted, and

organized to establish common themes. Descriptive statistics (frequency counts, percentages, and tables) were calculated for each question using the Statistical Package for the Social Sciences®, version 13.0 (SPSS, 2004).

## Results

### *The Respondent Sample*

The survey yielded 234 respondents: 136 (58.1%) PTs responded through the open access web link and 98 (41.9%) PTs responded through an e-mail invitation. At least one participant from each state in the USA and Washington DC fully completed the survey to provide national representation. Of the 234 respondents, 14 did not meet the eligibility criteria; 220 who met the eligibility criteria started the survey and 177 (80.5%) completed the Examination, Discharge, and Outcomes Sections of the survey (Appendix D). This resulted in a drop-off of 43 (19.5%) respondents. Regional distribution of the 177 respondents who completed the examination, discharge and outcomes sections of the survey ranged from 10-20% among the seven regions defined by the SoP ([www.pediatricapta.org](http://www.pediatricapta.org)) (Figure 1). On average, these PTs have approximately 16 (SD=10.93) years experience in pediatrics. The majority of respondents are members of the APTA (77.9%) and the SoP (72.9%), and most have taken continuing education courses related to CMT (74.0%) (Table 1). The three most common places of employment in this sample included: hospital based outpatient clinics (46.3%), independently owned outpatient clinics (23.2%), and early intervention settings (21.5%).



Figure 1: Regional Representation of Survey Respondents who Identified States

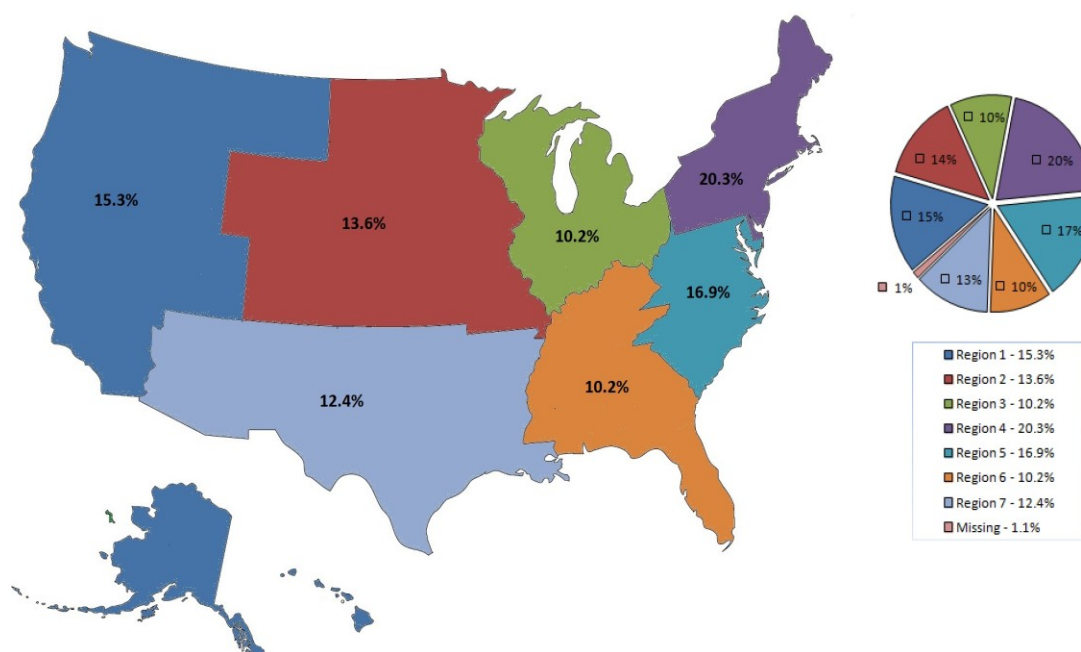


Table 1: Respondent Characteristics (N=177)

		Yes	No	Missing
APTA Member		138 (77.9%)	38 (21.5%)	1 (0.6%)
SOP Member		129 (72.9%)	46 (26.0%)	2 (1.1%)
Board Certified Clinical Specialist		47 (26.6%)	128 (72.3%)	2 (1.1%)
Work in hospital-based outpatient setting		82 (46.3%)	94 (53.1%)	1 (0.6%)
Have taken CMT continuing education Course(s)		131 (74.0%)	45 (25.4%)	1 (0.6%)
	Mean	Range	Std. Dev.	Missing
# Years Practicing PT	17.89	1-49	11.89	3
# Years Practicing Pediatric PT	15.87	1-45	10.93	2
# Years Treating CMT	11.43	1-42	8.21	3

### *CMT Examination Patterns*

*Sources of Guidance.* More than half of the sample (56.7%) does not use a clinical guideline to inform their examination of an infant with CMT, while just under half (43.3%) does. For those who reported use of an evidence-based guideline, pathway, or protocol, the most common sources cited were: location specific pathways or guidelines developed at their place of work which have not been published (35.5%); and the Cincinnati Children's Hospital Medical Center guideline on CMT (CCHMC-CPG) (Cincinnati Children's Hospital, 2009) (26.9%). The next most common sources included: a series of articles on "Assessment and Treatment of Congenital Muscular Torticollis" (Karmel-Ross, 1997) (16.1%); and continuing education (CE) seminars on torticollis, but for which an electronic database search (OVID – Medline; PubMed; googlescholar) did not yield any publications related to torticollis (10.8%). The three least common sources cited included: the APTA SoP CMT Clinical Practice Guidelines (SoP-CPG) (Kaplan, et al., 2013) (6.4%), which were released for public comment six months prior to the survey closure, and in its final published form, two months prior to closure of the survey; primary research articles (3.2%); and the Hospital for Special Surgery CMT guideline (HSS-CPG) (Corradi-Scalese, 2006) (1.1%).

In a single choice, forced ranked order question about strategies that PTs use to develop their examination approach, this sample reported the following to be "most important": 1.) lessons taught at CE courses (23.2%),

2.) personal review of the literature (19.5%), and 3.) evidence based guidelines (16.8%) (Table 2). This question format forces the respondent to consider all of the methods, rather than viewing each one as independent of the others. If the columns for “most important” and “very important” are combined, the overall trend for the top three methods are: 1.) personal review of the literature (45%), 2.) lessons taught at CE courses (39.1%), and 3.) evidence based guidelines (34.5%). For both analyses, the same three methods are selected to be of greatest importance, which indicates agreement that these are the methods most valued by these PTs to guide their exam of an infant with CMT. Similarly, “processes or protocols developed at the workplace” are viewed as the least important method, as determined both by the greatest number of votes (37.7%), and when combined with the votes given for somewhat important (52.7%). Later in the survey, similar responses are found from Question #81 which asks, “What training has been the most beneficial for your overall management of patients with CMT?” The top three answers are 1.) personal experience (69.9%), 2.) CE courses (67.0%), and 3.) personal review of the literature (64.2%) (Appendix D).

Table 2: Methods Used for Development of CMT Exam

**25.** Please rank order the importance of the following five strategies for developing your examination approach. (Please rate all five strategies, but you should only select one response per column.) My CMT examination approach is developed by...

	Most Important	Very Important	Important	Somewhat Important	Least Important	Missing
a.) My own personal review of the literature. <b>N=220</b>	43 (19.5%)	<b>56</b> <b>(25.5%)</b>	35 (15.9%)	26 (11.8%)	15 (6.8%)	45 (20.5%)
b.) Lessons taught to me by colleague(s). <b>N=220</b>	22 (10.0%)	40 (18.2%)	<b>52</b> <b>(23.6%)</b>	40 (18.2%)	18 (8.2%)	48 (21.8%)
c.) Lessons taught at continuing education courses. <b>N=220</b>	<b>51</b> <b>(23.2%)</b>	35 (15.9%)	44 (20.0%)	32 (14.5%)	19 (8.6%)	39 (17.7%)
d.) A process or protocol developed at my workplace. <b>N=220</b>	26 (11.8%)	14 (6.4%)	22 (10.0%)	33 (15.0%)	<b>83</b> <b>(37.7%)</b>	42 (19.1%)
e.) A published evidence-based guideline/ pathway/ protocol. <b>N=220</b>	37 (16.8%)	39 (17.7%)	34 (15.4%)	38 (17.3%)	34 (15.4%)	38 (17.3%)

### *Measurements Recorded during Examination of Infants with CMT*

When asked how often PTs document various measurements in their CMT exam (given a Likert scale of: *never, rarely, sometimes, usually, a/ways*), respondent PTs most commonly report that they *a/ways* document all 28 items listed in Question #26 in their typical CMT exam (Table 3).

However, the following seven items were the least frequently documented among the *always* category (Table 3): family history of CMT (39.5%), baby position in utero (35.9%), type of CMT (39.1%), skin integrity (40.0%), hip symmetry (45.5%), presence of hip dysplasia (47.7%), and neurological reflex testing (29.0%). Similarly, more than 10% of PTs surveyed report that they *rarely* or *never* document six of the same items: family history of CMT (20.9%), baby position in utero (12.7%), type of CMT (14.5%), skin integrity (12.3%), presence of hip dysplasia (12.7%), and neurological reflex testing (17.7%) (Table 3).

Table 3: Measures Recorded in CMT Exam

**26.** How often do you record the following objective information in a typical CMT exam? Check 1 box per row.

N=220 for all (a-ab)	Always	Usually	Sometimes	Rarely	Never
a.) Date of examination	<b>189</b> <b>(85.9%)</b>	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
b.) Family history of CMT	<b>87</b> <b>(39.5%)</b>	29 (13.2%)	27 (12.3%)	33 (15.0%)	13 (5.9%)
c.) Maternal Labor & Delivery	<b>171</b> <b>(77.7%)</b>	13 (5.9%)	5 (2.3%)	0 (0.0%)	0 (0.0%)
d.) Baby position in utero	<b>79</b> <b>(35.9%)</b>	40 (18.2%)	42 (19.1%)	21 (9.5%)	7 (3.2%)
e.) Gender	<b>184</b> <b>(83.6%)</b>	4 (1.8%)	0 (0.0%)	0 (0.0%)	1 (0.5%)
f.) Age of child	<b>189</b> <b>(85.9%)</b>	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
g.) Side of Torticollis	<b>188</b> <b>(85.4%)</b>	1 (0.5%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
h.) Type of CMT (Postural,	<b>86</b>	33	38	21	11

Muscular, SMT)	<b>(39.1%)</b>	(15.0%)	(17.3%)	(9.5%)	(5.0%)
	<b>163</b>	19	3	4	0
i.) Passive Cervical Rotation	<b>(74.1%)</b>	(8.6%)	(1.4%)	(1.8%)	(0.0%)
	<b>164</b>	18	4	3	0
j.) Active Cervical Rotation	<b>(74.5%)</b>	(8.2%)	(1.8%)	(1.4%)	(0.0%)
k.) Passive Cervical Lateral Flexion	<b>162</b>	18	5	4	0
	<b>(73.6%)</b>	(8.2%)	(2.3%)	(1.8%)	(0.0%)
l.) Lateral Head Position (static)	<b>170</b>	17	1	0	0
	<b>(77.3%)</b>	(7.7%)	(0.5%)	(0.0%)	(0.0%)
m.) Lateral head righting	<b>151</b>	30	6	2	0
	<b>(68.6%)</b>	(13.6%)	(2.7%)	(0.9%)	(0.0%)
n.) Neck Flexor Strength	<b>120</b>	36	21	8	4
	<b>(54.5%)</b>	(16.4%)	(9.5%)	(3.6%)	(1.8%)
o.) Craniofacial Asymmetry	<b>155</b>	26	6	1	1
	<b>(70.4%)</b>	(11.8%)	(2.7%)	(0.5%)	(0.5%)
p.) Skin Integrity	<b>88</b>	36	35	22	5
	<b>(40.0%)</b>	(16.4%)	(15.9%)	(10.0%)	(2.3%)
q.) Feeding Problems	<b>113</b>	35	29	11	1
	<b>(51.4%)</b>	(15.9%)	(13.2%)	(5.0%)	(0.4%)
r.) Vision	<b>124</b>	36	17	6	3
	<b>(56.4%)</b>	(16.4%)	(7.7%)	(2.7%)	(1.4%)
s.) Shoulder Symmetry	<b>117</b>	38	22	8	4
	<b>(53.2%)</b>	(17.3%)	(10.0%)	(3.6%)	(1.8%)
t.) Hip Symmetry	<b>100</b>	46	24	15	4
	<b>(45.5%)</b>	(20.9%)	(10.9%)	(6.8%)	(1.8%)
u.) Motor Development	<b>174</b>	13	1	0	0
	<b>(79.1%)</b>	(5.9%)	(0.5%)	(0.0%)	(0.0%)
v.) ROM of UEs	<b>120</b>	36	21	10	2
	<b>(54.5%)</b>	(16.4%)	(9.5%)	(4.5%)	(0.9%)
w.) ROM of LEs	<b>115</b>	38	20	12	4
	<b>(52.3%)</b>	(17.3%)	(9.1%)	(5.4%)	(1.8%)
x.) Presence of Hip Dysplasia	<b>105</b>	38	17	20	8
	<b>(47.7%)</b>	(17.3%)	(7.7%)	(9.1%)	(3.6%)
y.) Neurological Reflex Testing	<b>64</b>	44	39	30	9
	<b>(29.0%)</b>	(20.0%)	(17.7%)	(13.6%)	(4.1%)
z.) Muscle Tone	<b>137</b>	36	10	6	0
	<b>(62.3%)</b>	(16.4%)	(4.5%)	(2.7%)	(0.0%)
aa.) Presence of nodule/thick band in SCM	<b>129</b>	34	18	4	3
	<b>(58.6%)</b>	(15.5%)	(8.2%)	(1.8%)	(1.4%)
ab.) Pain	<b>119</b>	24	24	13	7
	<b>(54.1%)</b>	(10.9%)	(10.9%)	(5.9%)	(3.2%)

\*Missing respondents excluded from table for sizing restrictions. Each measure had a minimum of 14.1% (n=31) up to a maximum of 15.5% (n=34) respondents who did not answer the question.

### *Methods of Measurement*

For each of the objective measurements listed in Question #26, a follow-up question asked about the method used to obtain that measurement. For both passive and active cervical rotation, about half of the respondent PTs report that they visually estimate these measurements, (50.5% and 54.5%, respectively), followed by standard goniometry (16.8%; 13.6%), still photography (6.4%; 7.3%), cervical goniometry (5.9%; 5.9%), and a variety of other methods (0.4% - 2.3%), including a homemade goniometer, tape measure, protractor, arthrodiagonal protractor, smartphone applications that measure ROM with built-in cameras, and videotape. Approximately 14-15% (n=33) did not answer these questions.

The majority of the sample report that they use neck righting reactions (69.1%) to measure lateral head righting in infants with CMT, while 13.2% use the Muscle Function Scale (Öhman & Beckung, 2008; Öhman, Nilsson, & Beckung, 2009). Similarly, almost half use a narrative description of pain (45.9%), and a narrative description of craniofacial asymmetry (43.2%), rather than a standard infant pain scale (24.1%), or a standard plagiocephaly scale (7.7%). Interestingly, about a third of these PTs (31.8%) use other objective and technical tools to measure craniofacial asymmetry, such as cranial vault calipers, still photography, or flexible rulers.

The respondents use a wide variety of objective measures for the assessment of hip dysplasia and motor development, with the Ortolani maneuver (19.1%) and presence of hip clicking (19.1%), being the most frequent methods for hip dysplasia, and the Peabody Developmental Motor Scale (30.4%) as the most frequently used motor assessment. Of note, a total of 13 different scales of motor development were reported for use with infants with CMT (Figure 2).

Figure 2: Variety of Motor Assessments for CMT

**36.** What tool or method do you typically use to describe motor development in patients with CMT?

<input type="radio"/> Peabody Developmental Motor Scale (PDMS).....	<b>67</b>	<b>(30.4%)</b>
<input type="radio"/> Alberta Infant Motor Scale (AIMS).....	<b>38</b>	<b>(17.3%)</b>
<input type="radio"/> No specific test but observation of motor development.....	<b>38</b>	<b>(17.3%)</b>
<input type="radio"/> Other: _____(optional write-in)...Responses included: ELAP (Early Learning Accomplishment Profile), HELP (Hawaii Early Learning Profile), Batelle Developmental Inventory, 2 <sup>nd</sup> Ed., Mullen Scales of Early Learning, Gesell Developmental Assessment of Young Children (DAYC), Brigance Inventory of Early Development, Ages & Stages Questionnaire, INFANIB.....	<b>18</b>	<b>(8.2%)</b>
<input type="radio"/> Bayley Scales of Infant Development (BSID).....	<b>16</b>	<b>(7.3%)</b>
<input type="radio"/> Test of Infant Motor Performance (TIMP).....	<b>6</b>	<b>(2.7%)</b>
<input type="radio"/> Bruinks Osteretsky.....	<b>0</b>	<b>(0.0%)</b>
<input type="radio"/> I don't routinely measure motor development.....	<b>0</b>	<b>(0.0%)</b>
Missing.....	<b>37</b>	<b>(16.8%)</b>
<b>Total =</b>		<b>220 (100%)</b>



### *Prognostic Factors*

It is important for PTs to determine the prognosis of their patients with CMT, so that they can appropriately develop a plan of care and share this information with the caretakers. Although the survey did not specifically ask if PTs determine a prognosis, it is implicated in their response to a question regarding the importance of various clinical attributes for predicting improvement. In this question (#65), the majority of this sample reported the following attributes to be *most* or *very* important for a successful outcome: parental adherence to treatment (76.8%), age at presentation (69.6%), initial degree of head tilt (68.6%), type of CMT (65.9%), initial degree of passive cervical rotation (63.2%), presence of plagiocephaly (62.7%), initial degree of active cervical rotation (62.3%), the degree of craniofacial asymmetry (59.5%), and other co-morbidities (55.4%). These findings suggest that the PTs in this sample are using the objective data collected during their examination to predict improvement and formulate a prognosis for their infants with CMT.

### *CMT Discharge Patterns*

A multifaceted approach is used to discharge patients with CMT. Respondents regard the following criteria to be *most important* in determining discharge (Table 4): straight head posture (72.3%), achieving developmental milestones (71.8%), full passive cervical lateral flexion (70%), and full passive

cervical rotation (68.2%). The following factors trail slightly behind, but are still viewed by many PTs to be *very important* in determining discharge (Table 4): full active cervical rotation (65.5%), full active cervical lateral flexion (64.1%), within 5° of full passive range of motion (PROM) (61.8%), within 5° of full active range of motion (AROM) (61.8%), parental compliance with the HEP (home exercise program) (61.8%), parental satisfaction (61.2%), and symmetrical righting reactions (60.5%). The factor which ranked the lowest in determining discharge is the age of the child (19.5%) (Table 4).

Respondents state that 75.7% of CMT patients are discharged with full resolution of symptoms, where “full resolution” is defined as: full PROM, full AROM, midline head position, and symmetrical righting reactions. Upon discharge from PT, 23.6% of these PTs schedule a follow-up visit, while 56.4% do not and 20% did not answer the question. At least ten respondents commented separately that they gradually wean the frequency of visits to once a month or less, prior to actual discharge, with one PT reporting that the patient is followed to the age of three. This sample of PTs reports that 10.3% of patients with CMT who were previously discharged, return for a second episode of care.

Table 4: Important Factors for Discharge

56. How important are the following criteria in determining discharge of patients with CMT?

(N=220 for all)	Most Important	Very Important	Important	Somewhat Important	Least Important	Not at all Important
a.) Straight Head Posture	75 (34.1%)	<b>84</b> <b>(38.2%)</b>	11 (5.0%)	3 (1.3%)	0 (0.0%)	0 (0.0%)
b.) Full Passive Cervical Lateral Flexion	67 (30.5%)	<b>87</b> <b>(39.5%)</b>	16 (7.3%)	7 (3.2%)	1 (0.4%)	0 (0.0%)
c.) Full Passive Cervical Rotation	69 (31.4%)	<b>81</b> <b>(36.8%)</b>	22 (10.0%)	7 (3.2%)	1 (0.4%)	0 (0.0%)
d.) Within 5 degrees of Full PROM	46 (20.9%)	<b>86</b> <b>(39.1%)</b>	28 (12.7%)	10 (4.5%)	1 (0.5%)	2 (0.9%)
e.) Full Active Cervical Lateral Flexion	51 (23.2%)	<b>90</b> <b>(40.9%)</b>	30 (13.6%)	9 (4.1%)	0 (0.0%)	0 (0.0%)
f.) Full Active Cervical Rotation	58 (26.4%)	<b>86</b> <b>(39.1%)</b>	30 (13.6%)	6 (2.7%)	0 (0.0%)	0 (0.0%)
g.) Within 5 degrees of Full AROM	50 (22.7%)	<b>86</b> <b>(39.1%)</b>	26 (11.8%)	11 (5.0%)	0 (0.0%)	2 (0.9%)
h.) Achieving Developmental Milestones	<b>96</b> <b>(43.6%)</b>	62 (28.2%)	14 (6.4%)	3 (1.4%)	3 (1.4%)	1 (0.4%)
i.) Age of the Child	11 (5.0%)	32 (14.5%)	33 (15.0%)	35 (15.9%)	<b>40</b> <b>(18.2%)</b>	24 (10.9%)
j.) Symmetrical Righting Reactions	54 (24.5%)	<b>79</b> <b>(35.9%)</b>	34 (15.5%)	11 (5.0%)	2 (0.9%)	0 (0.0%)
k.) Parental Compliance with HEP	59 (26.8%)	<b>77</b> <b>(35.0%)</b>	25 (11.4%)	9 (4.1%)	5 (2.3%)	1 (0.4%)
l.) Parental Satisfaction	49 (22.3%)	<b>86</b> <b>(39.1%)</b>	32 (14.5%)	10 (4.5%)	0 (0.0%)	0 (0.0%)

\*Missing respondents excluded from table for sizing restrictions. Each measure had a minimum of 18.2% (n=40) up to a maximum of 21.4% (n=47) respondents who did not answer the question.

### *CMT Group Outcomes Measurements*

Approximately one-third (37%) of survey respondents report that group data on the management of CMT is collected and analyzed at their workplace in order to improve patient outcomes. The most commonly analyzed outcomes include: the achievement of patient goals (75%); the number of PT visits used (56.3%); parental satisfaction (51.6%); and the use of standardized measures in documentation (40.6%). Per survey respondents, this data is most commonly shared with staff (89.3%) and administration (53.6%) within their work facility. To a lesser extent, these PTs report that they also share data with: third party payors (10.7%), consumers (10.7%), professional publications (8.9%), promotional materials (5.4%), and referring physicians (1.8%).

Beyond the collection, analysis, and sharing of group outcomes, 40% of PTs in the survey who monitor group data report that their service delivery has changed as a result of the outcomes data. One quarter (25%) report that outcome data have assisted with the prognosis of patients by helping to determine the plan of care, the duration of PT, or the frequency of visits. Another 25% report that outcome data have shifted their approach to interventions with the best outcomes. Other service delivery changes based on data include: development of standardized pathways among clinicians (20%); earlier referral to PT and increased collaboration with physicians (20%); selection of standardized measurement tools or techniques to be used

by clinicians or clinic sites (15%); improvement of forms and/or handouts (15%); development of standardized referral processes for adjunct interventions, such as helmets, TOT collars, and Botox (10%); and the expansion of PT services within their facility (5%).

## Discussion

### *CMT Examination Patterns*

*Sources of Guidance.* At the time of this survey, May 24 – Nov 27, 2013, there were three published guidelines on CMT for PTs. The HSS-CPG, “Postsurgical Rehabilitation Guidelines for the Orthopedic Clinician,” (Corradi-Scalese, 2006) is one chapter within a book from the Hospital for Special Surgery, that is only available by purchase, thus it is not a freely available guideline. Although this guideline provides a great deal of information on CMT, there is little detail on how a PT should proceed with the CMT examination beyond performing PROM of cervical lateral flexion and rotation. The CCHMC-CPG (Cincinnati Children’s Hospital, 2009) was developed by the Cincinnati Children’s Hospital Medical Center for guidance in the examination and treatment of patients with CMT. It recommends objective measures for the examination but does not clarify how to measure them, nor does it emphasize determination of the clinical type of CMT, which is significantly associated with duration of treatment ( $p < .0001$ ) and prognosis for surgery ( $p = .0018$ ) (Cheng, et al., 2001). The CCHMC-CPG was the only publicly available guideline (guidelines.gov - NGC:007301) on CMT until June

2013. The Section on Pediatrics of the American Physical Therapy Association then provided a CPG on CMT (SoP-CPG) (Kaplan, et al., 2013), which became available online as a draft for public comment in June 2013, and was published in its final form in October 2013. The SoP-CPG makes evidence based recommendations for best practice based on literature searches through May 2013.

Limited knowledge of both the SoP-CPG (Kaplan, et al., 2013) and the HSS-CPG (Corradi-Scalese, 2006) may explain why the most frequently reported *published guideline* used by this sample during their CMT exam was the CCHMC-CPG (Cincinnati Children's Hospital, 2009), but that was only reported by 26% of respondents. The most frequently used source overall was a *non-published, location specific guideline/ pathway/ or protocol*.

Potential reasons for this choice include that: 1.) the CCHMC-CPG (Cincinnati Children's Hospital, 2009) was not considered current, as it was developed in 2009, and there are more recent studies to guide parts of the examination process; 2.) individual PTs may not have the time nor the resources to conduct current literature reviews on existing CPGs, and to integrate that knowledge to practice, or 3.) PTs may tend to follow a pre-existing CMT exam form developed at their workplace, rather than attempt to revise or change it.

The irony of this finding is that the most frequently used source to inform PT examination is a non-published, location specific guideline

developed by the workplace, but this type of source was also reported to be least valued in comparison to other sources. Strategies selected as having greater importance in the development of the CMT exam included: their own personal review of the literature, lessons taught at CE courses, published evidence based guidelines, and lessons taught by colleagues. This contradiction of the sample PTs using workplace guidelines, but not valuing them, is not easily explained, but may be related to the clinical culture of documentation and productivity, rather than the academic culture of research and inquiry. Clinicians may not feel that they are supported by their workplace to provide evidence-based practice (EBP), which requires time and resources for current literature review and knowledge translation (Melnyk, Fineout-Overholt, Stillwell, & Williamson, 2010). There are multiple barriers which limit healthcare professionals from providing EBP, including: lack of knowledge or wrong information about EBP, limited support from administration, and the absence of EBP mentors in clinical settings (Wallen, 2010). It is particularly important that PTs begin to recognize if their clinical practice is not in sync with evidence based research, and if not, focus on ways to close the gap through journal clubs, mentorship programs, or by seeking administrative support (Wallen, 2010).

Respondents regard their own independent reviews of literature and lessons learned in CE courses to be of great importance in the development of their CMT exam. This is later reinforced by Question #81 (Appendix D), in

which sample PTs report the most beneficial training for their overall management of CMT is: 1.) Personal experience, 2.) CE courses, and 3.) Personal review of the literature. This points to the need for knowledge translation within the workplace and in CE courses. Clinicians would greatly benefit if provided with the time and opportunity to access and analyze CPGs, systematic reviews and full text articles, so that they can convey their knowledge to colleagues, and work collectively to implement EBP. Likewise, individuals who provide CE courses on CMT should provide evidence-based recommendations to their course participants, and differentiate between practice methods that have higher and lower levels of evidence.

#### *Measurements Recorded during Examination of Infants with CMT*

Respondents most frequently report that they *always* perform all the measurements found in Table 3. There are, however, six measurements that more than 10% of PTs *rarely or never* document at the initial CMT exam. It is not known why the following items are highest among the “*rarely or never* documented,” but research supports their inclusion in the initial CMT exam.

There are documented cases of a positive family history in the occurrence of CMT (Hosalkar, Gill, Gujar, & Shaw, 2001); and newborns who present in breech position have a higher risk for torticollis, deformation of the skull, and hip dislocation (Hsieh, Tsai, Lin, Chang, & Tsai, 2000). Despite the evidence, survey results suggest that 20.9% of the sample PTs *rarely or*



*never* document family history, which is consistent with the survey by Öhman et al. (2013) in which 25% of PTs from Sweden and Denmark *rarely* or *never* document it either. Potential explanations are that PTs simply forget to ask, or do not understand the importance of these items. Having fields on their CMT exam form which ask about family history and breech position may trigger PTs to inquire and document the caretaker's response, and thereby provide PTs with data regarding predictors of CMT, which could ultimately be shared with the perinatal community (parents, obstetricians, midwives).

While approximately 85% of respondents document the type of CMT an infant presents with at the initial examination, about 15% of the sample PTs do not. PTs should be minimally classifying their patients into one of three subgroups: (a) sternomastoid tumor group, in which there is a palpable tumor; (b) muscular group, in which the muscle is thickened but no tumor is present; or (c) postural group, in which there is no thickening, nor tumor in the muscle (Cheng, Tang, Chen, Wong, & Wong, 2000). Kaplan et al. (2013) even recommend classification of CMT into one of seven grades. The type of CMT is particularly important because there is a significant difference regarding the duration of treatment among the three clinical groups ( $p < .0001$  for each), with the sternomastoid tumor group associated with a longer duration of treatment, and the postural torticollis group associated with shorter duration of treatment (Cheng, et al., 2001). Presence of a sternomastoid tumor is also significantly associated with a greater risk for surgery ( $p = .023$ )

(Cheng, et al., 2001). Without knowledge and documentation of the type of CMT, it will be more difficult for PTs to prognose the expected outcomes, establish realistic goals, or even have a serious discussion with parents about the likelihood of surgical intervention in the future. Classification simply allows more accurate comparison of CMT subgroups.

While the majority of the sample PTs (65%) *always* or *usually* screen for hip dysplasia, almost 13% do not, despite prior publications which have brought this discussion to the table (Luxford, et al., 2009; Öhman, et al., 2013). All PTs should be examining hip ROM, as well as abnormal posturing of the lower extremities. Cheng, Tang, et al. (2000) report that hip dysplasia in infants with CMT is shown to be significantly associated with presence of a sternomastoid tumor ( $p<.001$ ), and greater limitation of passive neck rotation ( $p<.001$ ). A limitation of 5°-10° in hip abduction could be indicative of hip dysplasia, and is typically the only clinical sign of hip dysplasia in infants older than 1 month (Leach, 2006). Other signs of hip dysplasia include: asymmetrical hip folds, leg length discrepancy, or a positive Barlow or Ortolani sign (Leach, 2006); although a positive Barlow or Ortolani maneuver should be analyzed cautiously, due to varying levels of sensitivity (AHRQ, 2006; Sulaiman et al., 2011). Most importantly, PTs should be examining for hip dysplasia in their infants with CMT so that a “missed diagnosis” does not present later in childhood, requiring bracing or surgery (Kaplan, et al., 2013). Joiner, Andras & Skaggs (2014) even recommend ultrasound in babies less

than six months or a radiograph for infants over six months of age to rule out hip dysplasia.

Almost 18% of the sample report that they *rarely* or *never* perform neurological reflex testing at the initial examination. Although it is not suggested that reflex testing be performed and evaluated in isolation of other neurological testing (Pathways.org, 1992), it is still very important to measure and document reflex responses, so that the infant can be appropriately screened for intact neurological function (Cincinnati Children's Hospital, 2009). On the positive side, only 2.7% of sample PTs report that they *rarely* examine muscle tone, and although this should also *always* be examined, no one reported that they *never* examine muscle tone. However, according to the literature and published CPGs, to perform a comprehensive initial exam, PTs should examine the infant's muscle tone and reflexes. These two clinical measurements are both necessary to help PTs establish a broader picture of the infant's neurological status.

### *Methods of Measurement*

Visual estimation has been described as the most popular method of measurement for assessment of cervical ROM among PTs in New Zealand (Luxford, et al., 2009) and Sweden and Denmark (Öhman, et al., 2013). Similarly, half (50.5%) of this sample report that they visually estimate passive cervical rotation, one third (33.6%) use a variety of objective tools, 15% did

not answer the question, and 0.9% report that they typically do not measure passive cervical rotation. Visual estimation was also the preferred method of measurement by sample PTs for active cervical rotation (54.5%), passive lateral flexion (44.5%), and static head tilt position when measured in supine (38.6%), or in sitting (43.2%).

It is not well understood why pediatric PTs do not choose to objectively measure ROM and static head tilt position, but instead prefer to visually estimate these measurements. Potential reasons include the fidgety nature of the infant and toddler population which may make obtaining an accurate measurement difficult and sometimes stressful for parents and patients (Scott Freed, 2006); the lack of time which clinicians may have in a busy clinic environment; and the confidence of experienced clinicians who have had prior success with their method of visual estimation. In general, there is the absence of a “gold standard” tool that can be easily reproduced by just one examiner. Even to use an arthrodiagonal protractor, multiple sets of hands are required to simultaneously stabilize the infant, facilitate cervical ROM, and hold the measuring device. Although these are valid reasons, and certainly support PTs decisions to forego objective measurements, these arguments may not be strong enough to justify the importance of visual estimation at the initial examination of an infant with CMT as good practice.

It may be more time consuming, and possibly require more people to use an objective tool rather than visual estimation, but there is established reliability with the use of objective tools, such as arthrodiol protractors (Cheng, et al., 2001; Öhman, Nilsson, & Beckung, 2010; Öhman & Beckung, 2008), adapted goniometers (with level attached) (Emery, 1994), standard goniometers (Perbeck Klackenberg, 2005), and still photography (Rahlin & Sarmiento, 2010), whereas there is no documented evidence of the reliability for visual estimation. Furthermore, there is strong evidence that the severity of the limitation in passive cervical rotation is correlated with the overall outcome of that infant and the potential need for surgery (Cheng, et al., 2001). Clinicians need to accurately know the degree of that limitation, so that they can effectively prognose and have realistic discussions with parents regarding the infant's prognosis. PTs may be able to visually estimate the infant's ROM during PT visits that occur between more formal measures, but they should not rely on their own visual estimation for important measures, such as at initial examination, discharge, or for progress along the way.

Despite a higher percentage of PTs using visual estimation, about one fifth of respondents are using standard goniometers as the chosen objective tool in a CMT exam for the infant's active and passive cervical rotation (13.6%, 16.8%), passive lateral flexion (19.1%), and static head tilt position in sitting or supine (20.0%, 23.6%). This is perhaps due to the availability of standard goniometers in PT facilities, as compared to arthrodiol protractors or

specialized, adapted goniometers. Respondents may also prefer the convenience and efficiency of one device for all measurements in a CMT exam, as opposed to alternating other devices (camera for photography, tape measure, i-phone app for measurement) during and across exams. Also, devices such as video analysis are just too time consuming (average time of 23.96 minutes), and not clinically feasible (Christensen, Castle, & Hussey, 2015). Yet, even in the absence of a “gold standard,” there should be consistency in the selection of a measurement tool for infants with CMT. If pediatric PTs, who work with a very specialized population, do not establish a similarly specialized standard regarding the selection of measurement tools, then they will have no basis with which to compare outcomes.

Arthrodial protractors have established intra-rater reliability for static head position (Perbeck Klackenberg, 2005), passive cervical rotation (Cheng, et al., 2001), and passive lateral flexion (Öhman & Beckung, 2008). Arthrodial protractors are relatively inexpensive and non-invasive for the infant. The difficulty in using an arthrodial protractor for passive cervical rotation is that three people are needed: one to stabilize the infant, one to rotate the head, and one to hold the protractor. From a clinical perspective, it is understood if other methods are intermittently used throughout the duration of the infant’s PT, but for times when a reliable measurement is needed, such as at the initial examination, final discharge, or when a noticeable change is

observed in the patient's posture, an arthrodial protractor would be the current tool of choice.

For other measures that are recorded during the initial CMT exam, the survey suggests that narrative descriptions of observations are preferred. Respondents most typically choose to describe the infant's craniofacial asymmetry and pain response through a narrative description rather than using reliable, standardized scales, such as the clinical classification table for plagiocephaly by Argenta (2004) or the FLACC scale for pain (Manworren & Hynan, 2003; Merkel, Voepel-Lewis, & Malviya, 2002). Similarly, they prefer to use a description of the infant's neck righting reactions, rather than the Muscle Function Scale, which has both inter and intra-rater reliability (Kappa > 0.9, ICC > 0.9) (Öhman & Beckung, 2008), to describe the infant's ability to laterally right her head.

This preference to narratively describe conditions for which standard scales exist, is not well understood. Potential reasons include time constraints of the clinician to learn the instructions and scoring system for each scale; limited awareness of the appropriate objective tests to use; or limited time for administration of the test within the initial examination session. A relatively simple solution to the time constraints would be for these scales to be included within the packet of initial examination forms, so that PTs could easily access, perform, and score objective tests with greater ease and

efficiency. If PTs are not using objective scales because they are not aware of their existence, then this is a prime example of why practicing clinicians would benefit from time allocated for current literature review, or peer discussions about practice, and further emphasizes the need for knowledge translation in the clinical setting. The SoP-CPG (Kaplan, et al., 2013) currently recommends that PTs use the Argenta scale for plagiocephaly (Argenta, 2004), the FLACC scale for pain (Merkel, et al., 2002), and the MFS for head righting (Öhman & Beckung, 2008). They are publicly available tools with established reliability that are simple to administer and provide specific, detailed information on the infant without the need for narrative summaries or written descriptions. Group data can then be easily compiled to study clinic outcomes, or could be used to contribute to a multisite registry of infants with CMT.

The survey results indicate that 15 methods are being used to document an infant's motor development during a CMT examination. The Peabody Developmental Motor Scales (PDMS) (Folio & Fewell, 2000) is the most used by this sample (30.4%), with the Alberta Infant Motor Scale (AIMS) (Mayson, 2007) (17.3%) or a narrative description (17.3%) as the second two most common methods. Another 12 motor scales accounted for an additional 18.2% of exams (Figure 2). Measuring and documenting motor development in the infant with CMT is an essential piece of the CMT examination, not only to provide a description of the patient within his medical record, but most



importantly because there is research to suggest that infants with CMT are at greater risk for motor delays (Öhman, Nilsson, Lagerkvist, & Beckung, 2009; Schertz, Zuk, & Green, 2012; Schertz, et al., 2008) or transient motor asymmetry (Watemberg, Ben-Sasson, & Goldfarb, 2016). However, it should be noted that there is one case-control study which reports no association between infants with CMT and motor delays at preschool (Öhman & Beckung, 2013). If motor development is not properly examined and documented, then PTs could potentially fail to identify motor delays in infants with CMT, thereby missing out on the benefits of early intervention.

The results of this survey suggest that the sample PTs are measuring and documenting motor development, however such a variety of developmental scales makes it difficult to collect data and compare outcomes. There are two motor tests for this population that may stand out because of their strong psychometric properties; these are the (Test of Infant Motor Performance) TIMP (Campbell, 2005) and the AIMS (Mayson, 2007). Since the sample PTs report that they are examining infants with CMT, even in the NICU at a post conceptual age of 32 weeks, it would be prudent to select standardized tests that match the ages of the infants.

The TIMP is designed to evaluate infants from 34 weeks post conceptual age to four months post term (Campbell, 2005), while the AIMS was designed for infants 18 months of age or younger (Mayson, 2007).

Although the AIMS has been shown to have excellent inter-rater reliability, test-retest reliability and concurrent validity (Piper & Darrah, 1994), it's main limitations for infants with CMT are that: 1.) Some items do not differentiate between the left and right side, thereby necessitating additional documentation, and 2.) There are a limited number of items in the 0-4 month range, resulting in lower predictive validity for this age group. The TIMP scores at three months of age are highly predictive of scores on the AIMS at 12 months of age (Campbell, Kolobe, Wright, & Linacre, 2002); the overall sensitivity and specificity scores of the TIMP at three months of age to the AIMS at 12 months were 92% and 76% respectively. Most significantly, the negative predictive validity of the TIMP at 3 months to the AIMS at 12 months was found to be 98% (Campbell, et al., 2002). It is for these reasons that the evidence supports the recommendation that the TIMP be used in infants up to four months of age, and the AIMS be used thereafter.

### *CMT Discharge Patterns*

This sample of PTs report a high percentage of symptom resolution (75.7%) among their patients with CMT, in congruence with the literature which shows treatment success ranging from 69% to 99% of patients achieving resolution of CMT with PT (Binder, et al., 1987; Cheng, et al., 2001; Emery, 1994). Resolution of CMT may be defined

as full passive cervical rotation (Celayir, 2000; Cheng, et al., 2001), or full passive cervical rotation and lateral flexion (Emery, 1994).

“Resolution” for this survey, however, was defined as full PROM, full AROM, midline head position, and symmetrical righting reactions, which holds the rate of resolution reported by the respondents to a higher standard of care, and thereby, shows an impressive success rate.

Question 56 (Table 4) demonstrates that the sample PTs use a multifaceted approach toward the discharge criteria for their CMT patients. The survey suggests that respondents are not making their decision to discharge patients solely on one measurement of impairment, but rather on multiple measures, which provide greater functional pictures of the children. Similarly, the SoP-CPG (Kaplan, et al., 2013) recommends that the discharge criteria include “full passive ROM within 5° of the non-affected side, symmetrical active movement patterns throughout the passive range, age-appropriate motor development, no visible head tilt, and the parents/caregivers understand what to monitor as the child grows.”

This survey suggests that the majority of respondents are in compliance with the most recent guidelines, but also go a step further in making certain that infants/families are measured at discharge for additional achievements which include: achieving full passive and

active cervical ROM rather than measurement to within 5° of full ROM, and parental satisfaction. It is not clear why the respondents may view full ROM as more important than within 5° of full ROM. This could be due to their own review of CMT literature where the focus is on achieving full cervical PROM (Celayir, 2000; Cheng, et al., 2001; Emery, 1994); lack of familiarity with specific discharge recommendations from both the CCHMC-CPG (Cincinnati Children's Hospital, 2009) and the SoP-CPG (Kaplan et al., 2013), which recommend measurement to within 5°; or simply that 5° from full rotation allows for a potential greater standard error of measurement when using manual goniometry. It is also interesting to note that 61.2% of the respondents regard parental satisfaction to be "very or most important" for discharge. This could indicate that these PTs are consistent with the medical model outlined by the American Academy of Pediatrics (AAP) Bright Futures Guidelines for the Health Supervision of Infants, Children, and Adolescents (Hagan, 2008). The Bright Futures Guidelines provide physicians with recommended standards of care with an emphasis on parental/familial concerns (Hagan, 2008). Although parental satisfaction is not a factor that is necessary for the discharge of a patient with CMT, it is reassuring that most respondents are asking about parental concerns and aiming for parental satisfaction at time of discharge. This is not only consistent

with a culture of family-centered care (Fradette, et al., 2011), but parental satisfaction has also been shown to improve adherence to treatment and to lessen parental feelings of distress (Law, et al., 2003).

After discharge from PT, only 23.6% of the respondents report that they schedule a follow-up visit for their patients with CMT, while 56.4% reported they do not, and 20% did not answer the question. The SoP-CPG recommends a “follow-up screening...three to twelve months post-discharge...*or* when the child initiates walking” (Kaplan, et al., 2013).

Although the majority of these PTs are not in sync with the recommended guidelines, it is important to note that there were at least ten respondents who mentioned that they gradually wean down the frequency of visits to once a month or less, prior to actual discharge. From a clinical standpoint, “weaning down” before discharging the patient may be a relatively common practice among these PTs, especially since, as one respondent stated, “...(I am) unsure of how you would bill (for the follow-up appointment) if (the patient was) discharged.” Therefore, it is not known if the percentages above are a true reflection of practice because of the literal interpretation of the question and multiple choice answers, which stated that follow-up was occurring “after discharge,” instead of near the end of PT intervention. To better inform practice, researchers should be aware of the difference regarding follow-up which occurs during the process of “weaning down” the PT intervention versus discharge of the patient from PT and a separate follow-up screening to

occur at a later date. Nonetheless, it appears that a minority of the sample PTs are following-up on their patients with CMT after discharge, a practice that should be encouraged, especially because there are documented cases of CMT recurrence (Shim, Noh, & Park, 2004) and developmental concerns (Schertz, et al., 2012)

In this survey, 10.3% of patients with CMT who were previously discharged, reportedly return for a second episode of care. This is a very important clinical finding and provides subjective evidence of a rate of recurrence, which to date has not yet been documented in the literature. Furthermore, such information provides greater understanding and appreciation for the variety of presentations of a patient with CMT (first versus second episode of care), and supports the need for additional guidance and research on infants/children who have already been treated and discharged, but for whom symptoms have recurred. This data reinforces the importance of long term follow-up by a physical therapist, as well as the importance of discharge criteria to include that the parent/caregiver is able to appropriately monitor the child's growth (Kaplan, et al., 2013). Lastly, PTs should make every effort to educate other healthcare professionals or caregivers with whom the infant/child may regularly interact (nurses, pediatricians, dentists, specialists, day care providers), so that if additional PT intervention is needed, it may occur in a timely manner.

### *CMT Group Outcomes Measurements*

As third party payors are heading toward more vigilant monitoring of service delivery, the profession of physical therapy is also moving toward a new era of outcomes registries, ([www.apta.org/Registry](http://www.apta.org/Registry), 2014) to demonstrate the effectiveness of PT for its consumers. Likewise, some facilities or individual providers may also be monitoring group outcomes within their own workplace to improve upon patient care. As per this survey, 37% (64/173) of respondents are collecting and analyzing group data at their work site to provide better service. Although this is not the majority, it does indicate a growing awareness of the importance of group outcomes. This concept is further supported by the promising ways in which service delivery has been reported by respondents to change as a result of the group data. These include: better ability to prognose and select treatment interventions; the development of a standardized pathway of care for CMT patients within a facility; increased referral rates to PT; and the expansion of PT services.

It is important for the PT profession that reporting positive results of group data are not restricted to the workplace, but are also shared with the public. Work sites do not often provide clinicians with extra time for group data collection, analysis, or formal dissemination. This points to the need for facilities to instill time for research, literature review, staff development and training, or even marketing. By allowing clinicians individual responsibilities to

investigate outcomes, PTs may be better able to contribute to the evidence on CMT management.

### Study Limitations

There are two main limitations of this study. First, the respondent sample is mainly comprised of PTs who belong to the SoP of the APTA (72.9%). This is most likely due to the recruitment methods used. It was known by the research team that there are approximately 5,000 physical therapists and physical therapist assistants who belong to the Section on Pediatrics of the American Physical Therapy Association ([www.pediatricapta.org](http://www.pediatricapta.org)). However, the challenge of reaching the target population of US PTs who treat CMT is that there are no registries of PTs who treat infants with CMT; not all pediatric PTs belong to the Section on Pediatrics; and not all pediatric PTs treat children with CMT. Therefore, the target population was felt to be a relatively small subset of physical therapists of unknown size and location. A convenience sample was established to help identify this population, and additionally a web link was posted on the SoP website ([www.pediatricapta.org](http://www.pediatricapta.org)). Resultantly, the majority of the respondents (72.9%) were SoP members, while 26% were not, and 1.1% did not respond to the question. Although these percentages could represent survey bias, responses would be biased toward those who are members of the SoP, who



voluntarily pay annual dues to belong to the APTA, and who receive regular journal publications to keep their practice informed. Thus, the bias of this survey is in the direction of the more informed clinician.

Secondly, the examination, discharge, and outcomes sections of this survey consisted of 28 thought provoking questions, which included narrative responses, and may have required additional time demands from the respondents. From the 220 PTs starting the first question, 177 (80.5%) completed the Examination, Discharge, and Outcomes Sections of the survey, and 43 (19.5%) respondents elected to stop taking the survey. The non-completion rate may be due to the survey length or the inability of respondents who accessed the survey via the open access web link to log off and later return to their work. It was known and relayed to the respondents before they started the survey that those who had responded via a direct e-mail invitation would have a unique web link, which would allow them to save their answers and log back on at a more convenient time. However, those who accessed the survey via the open access web link (58.1%) could not do this. Fortunately, 80% of the respondents completed the Examination, Discharge and Outcomes Portion of the survey, allowing representation from each state in the USA, and the District of Columbia.

### Further Research

The SoP-CPG (Kaplan et al.,2013) was released to the public only two months prior to the closure of this six-month-long survey, and may partially explain why it is not frequently referenced by this sample of PTs to direct CMT examinations. However, now that the CPG from the APTA has been publicly available for over a year, further research is necessary to determine the awareness and implementation of these new guidelines by PTs in the USA.

The results of the survey appear to show that many clinicians rely on their own review of literature or CE courses to guide their examination, and that few clinicians collect information on group outcomes, with even fewer sharing their data with the public. Further research on what guides PTs in their examination practices, and the processes they use to collect group outcomes would help to validate these findings. It would be interesting to see if US PTs are welcoming of a culture of learning in the workplace. Further research is needed to determine PT's acceptance with time allotted in their work schedule for literature review, knowledge translation, research projects, outcomes studies, information sharing, or marketing in the community. The desire for PTs to participate in a learning environment needs to be identified, if that model is to be successful.

It would also be beneficial to determine if US PTs are in favor of using nationally standardized forms during their examination and discharge of infants with CMT. The findings from this survey suggest that even though the respondents are measuring appropriate components in their CMT exams, they do not use recommended objective tests for their measurements and they report using a variety of other tests. If standardization of the CMT examination were to include specific objective testing (Argenta scale for plagiocephaly, FLACC scale for pain, MFS for head righting), it is not known if PTs would be agreeable to use these forms, or whether they fear less practice autonomy. A standardized CMT examination form would ensure that PTs are collecting and analyzing specific data, as well as allow for more accurate assessment of group outcomes across the population. Research is needed to determine if US PTs would accept a national standard for examination forms in PT practice.

### Conclusions

This survey provides an initial description of patterns observed in the examination, discharge, and outcomes of infants with CMT, among a sample of PTs in the USA. It was validated by an expert panel of pediatric PTs prior to its distribution, and was then completed by 177 PTs around the country with representation from each of the fifty states and the District of Columbia.

It is the largest CMT survey of PTs found in the literature, and the first to describe practice in the United States. The findings of this survey show that the examination, discharge and outcome practices of the respondent PTs are partially consistent with evidence based practice. It shows that most pediatric PTs in this sample are practicing in agreement with four of the seven Action Statements of the CPG on CMT (Kaplan, et al., 2013), which relate to examination and discharge practices (7-11 & 15-16) (Kaplan, et al., 2013)

## References

- Agency for Healthcare Research and Quality (AHRQ). (2006). Screening for Developmental Dysplasia of the Hip: Evidence Synthesis Number 42. <http://www.ahrq.gov/downloads/pub/prevent/pdfser/hipdyssyn.pdf>
- American Physical Therapy Association (APTA). (2014). *Physical Therapy Outcomes Registry*. Retrieved December 5, 2014 from <http://www.ptoutcomes.com/AboutUs/>
- Argenta. (2004). Clinical Classification of Positional Plagiocephaly *The Journal of Craniofacial Surgery*, 15(3), 368-372.
- Binder, H., Eng, G. D., Gaiser, J. F., & Koch, B. (1987). Congenital muscular torticollis: results of conservative management with long-term follow-up in 85 cases. *Arch Phys Med Rehabil*, 68(4), 222-225.
- Campbell, S. (2005). The Test of Infant Motor Performance: Test User's Manual, Version 2.0
- Campbell, S., Kolobe, T., Wright, B., & Linacre, J. (2002). Validity of the Test of Infant Motor Performance for prediction of 6-, 9-, and 12-month scores on the Alberta Infant Motor Scale. *Developmental Medicine & Child Neurology*, 44, 263-272.
- Celayir, A. C. (2000). Congenital muscular torticollis: early and intensive treatment is critical. A prospective study. [Clinical Trial]. *Pediatrics International*, 42(5), 504-507.
- Cincinnati Children's Hospital. (2009). Evidence-Based Care Guideline for Management of Congenital Muscular Torticollis in children age 0-36 months. In Cincinnati Children's Hospital Medical Center (Ed.).
- Chen, M.-M., Chang, H.-C., Hsieh, C.-F., Yen, M.-F., & Chen, T. H.-H. (2005). Predictive model for congenital muscular torticollis: analysis of 1021 infants with sonography. *Archives of Physical Medicine & Rehabilitation*, 86(11), 2199-2203.
- Cheng, J. C., Metreweli, C., Chen, T. M., & Tang, S. (2000). Correlation of Ultrasonographic imaging of congenital muscular torticollis with clinical assessment in infants. *Ultrasound in Medicine & Biology*, 26(8), 1237-1241.

- Cheng, J. C., Tang, S. P., Chen, T. M., Wong, M. W., & Wong, E. M. (2000). The clinical presentation and outcome of treatment of congenital muscular torticollis in infants--a study of 1,086 cases. *Journal of Pediatric Surgery*, 35(7), 1091-1096.
- Cheng, J. C., Wong, M. W., Tang, S. P., Chen, T. M., Shum, S. L., & Wong, E. M. (2001). Clinical determinants of the outcome of manual stretching in the treatment of congenital muscular torticollis in infants. A prospective study of eight hundred and twenty-one cases. [Evaluation Studies]. *Journal of Bone & Joint Surgery - American Volume*, 83-A(5), 679-687.
- Christensen, E., Castle, K.B., & Hussey, E. (2015). Clinical feasibility of 2-dimensional video analysis of active cervical motion in congenital muscular torticollis. *Pediatric Physical Therapy*, 27(3):276-83.
- Corradi-Scalese, D., Sparrow, A., Amoroso, L. (2006). Chapter 27 – Congenital Muscular Torticollis. In J. Cahill, Cavanaugh, J., Wolff, A., Corradi-Scalese, D., Rudnick, H. (Ed.), *Postsurgical Rehabilitation Guidelines for the Orthopedic Clinician, Hospital for Special Surgery*: Mosby Elsevier.
- Demirbilek, S., & Atayurt, H. F. (1999). Congenital muscular torticollis and sternomastoid tumor: results of nonoperative treatment. *Journal of Pediatric Surgery*, 34(4), 549-551.
- Emery, C. (1994). The determinants of treatment duration for congenital muscular torticollis. [Research Support, Non-U.S. Gov't]. *Physical Therapy*, 74(10), 921-929.
- Folio, M.R. & Fewell, R.R. (2000). *Peabody Developmental Motor Scales, Second Edition (PDMS-2). Test User Manual*.
- Fradette, J., Gagnon, I., Kennedy, E., Snider, L., & Majnemer, A. (2011). Clinical Decision Making Regarding Intervention Needs of Infants with Torticollis. *Pediatric Physical Therapy*, 249-256.
- Freed, S. S. (2006). *Practice Tip: Torticollis Intervention Programs*. Paper presented at the Combined Sections Meeting (CSM).
- Hagan, J. F., Shaw, J. S., Duncan, P. (Ed.). (2008). *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, Third Edition*. . Elk Grove Village, IL: American Academy of Pediatrics.

- Hosalkar, H., Gill, I. S., Gujar, P., & Shaw, B. A. (2001). Familial torticollis with polydactyly: manifestation in three generations. [Case Reports]. *American Journal of Orthopedics*, 30(8), 656-658.
- Hsieh, Y. Y., Tsai, F. J., Lin, C. C., Chang, F. C., & Tsai, C. H. (2000). Breech deformation complex in neonates. *Journal of Reproductive Medicine*, 45(11), 933-935.
- Hsu, T. C., Wang, C. L., Wong, M. K., Hsu, K. H., Tang, F. T., & Chen, H. T. (1999). Correlation of clinical and ultrasonographic features in congenital muscular torticollis. [Comparative Study]. *Archives of Physical Medicine & Rehabilitation*, 80(6), 637-641.
- Joiner, E.R.A., Andras, L.M., & Skaggs, D.L. (2014). Screening for hip dysplasia in congenital muscular torticollis: is physical exam enough? *Journal of Children's Orthopaedics*, 8(2): 115-119.
- Kaplan, S., Coulter, C., & Fetters, L. (2013). Physical therapy management of Congenital muscular torticollis: An evidence-based clinical practice guideline. *Pediatric Physical Therapy*, 25(4), 348-394.
- Karmel-Ross, K. E. (Ed.). (1997). *Torticollis: Differential diagnosis, assessment, and treatment, surgical management, and bracing*. Binghamton, NY: The Haworth Press.
- Law, M., Hanna, S., King, G., Hurley, P., King, S., Kertoy, M., & Rosenbaum, P. (2003). Factors affecting family-centred service delivery for children with disabilities. *Child: Care, Health & Development*, 29(5), 357-366.
- Leach, J. (2006). Orthopedic Conditions. In S. Campbell, Vander Linden, D., Palisano, R. (Ed.), *Physical Therapy for Children, Third Edition* (pp. 491-495). St. Louis: Elsevier Inc.
- Luxford, B., Hale, L., & Piggot, J. (2009). The physiotherapy management of infants with congenital muscular torticollis: a survey of current practice in New Zealand. *New Zealand Journal of Physiotherapy*, 37(3), 127-135.
- Manworren, R., & Hynan, L. (2003). Clinical validation of FLACC: preverbal patient pain scale. *Pediatric Nursing*, 29(2), 140-146.

- Mayson, T. (2007). Evidence Summary for Pediatric Rehabilitation Professionals, Outcomes Measures: The AIMS. *Evidence Summary for Pediatric Rehabilitation Professionals* Retrieved June 19, 2012, from [www.therapybc.ca/eLibrary/docs/Resources](http://www.therapybc.ca/eLibrary/docs/Resources).
- Melnyk, B. M., Fineout-Overholt, E., Stillwell, S. B., & Williamson, K. M. (2010). Evidence-Based Practice: Step by Step: The Seven Steps of Evidence-Based Practice. *American Journal of Nursing*, 110(1), 51-53.
- Merkel, S., Voepel-Lewis, T., & Malviya, S. (2002). Pain assessment in infants and young children: the FLACC scale. *American Journal of Nursing*, 102(10), 55-58.
- Microsoft® Office Excel (2007). <https://www.microsoft.com/en-us/search/result.aspx?q=excel&form=MSHOME>
- Öhman, A. M., & Beckung, E. (2008). Reference values for range of motion and muscle function of the neck in infants. [Multicenter Study Research Support, Non-U.S. Gov't]. *Pediatric Physical Therapy*, 20(1), 53-58.
- Öhman, A., & Beckung, E. (2013). Children who had congenital torticollis as infants are not at higher risk for a delay in motor development at preschool age. *PM&R* 5(10): 850-855.
- Öhman, A., Mårdbrink, E.-L., Orefelt, C., Seager, A., Tell, L., & Klackenberg, E. A. (2013). The physical therapy assessment and management of infants with congenital muscular torticollis. A survey and a suggested assessment protocol for CMT. *Journal of Novel Physiotherapies*. doi: 10.4172/2165-7025.1000165
- Öhman, A. M., Nilsson, S., & Beckung, E. R. (2009). Validity and reliability of the muscle function scale, aimed to assess the lateral flexors of the neck in infants. [Validation Studies]. *Physiotherapy Theory & Practice*, 25(2), 129-137.
- Öhman, A., Nilsson, S., & Beckung, E. (2010). Stretching treatment for infants with congenital muscular torticollis: physiotherapist or parents? A randomized pilot study. [Randomized Controlled Trial Research Support, Non-U.S. Gov't]. *PM & R*, 2(12), 1073-1079.



- Öhman, A., Nilsson, S., Lagerkvist, A.-L., & Beckung, E. (2009). Are infants with torticollis at risk of a delay in early motor milestones compared with a control group of healthy infants? [Comparative Study Research Support, Non-U.S. Gov't]. *Developmental Medicine & Child Neurology*, 51(7), 545-550.
- Pathways.org. (1992). *Early Infant Assessment Redefined*. Glenview, IL: Pathways Awareness Foundation.
- Pediatric American Physical Therapy Association (2012). Retrieved July 27, 2012, from <https://pediatricapta.org/>
- Perbeck Klackenberg, E. P., Elfving, B., Haglund-Akerlind, Y., Carlberg, E.B. (2005). Intra-rater reliability in measuring range of motion in infants with congenital muscular torticollis. *Advances in Physiotherapy*, 7, 84-91.
- Piper, M., & Darrah, J. (Eds.). (1994). *Motor Assessment of the Developing Infant*. Philadelphia: WB Sanders.
- Rahlin, M., & Sarmiento, B. (2010). Reliability of still photography measuring habitual head deviation from midline in infants with congenital muscular torticollis. [Validation Studies]. *Pediatric Physical Therapy*, 22(4), 399-406.
- Schertz, M., Zuk, L., & Green, D. (2012). Long-term neurodevelopmental follow-up in children with congenital muscular torticollis. *Journal of Child Neurology*. doi: 10.1177/0883073812455693
- Schertz, M., Zuk, L., Zin, S., Nadam, L., Schwartz, D., & Bienkowski, R. S. (2008). Motor and cognitive development at one-year follow-up in infants with torticollis. [Multicenter Study]. *Early Human Development*, 84(1), 9-14.
- Shim, J. S., Noh, K. C., & Park, S. J. (2004). Treatment of congenital muscular torticollis in patients older than 8 years. [Comparative Study]. *Journal of Pediatric Orthopedics*, 24(6), 683-688.
- Statistical Package for the Social Sciences (SPSS). (2004). *SPSS Graduate Pack 13.0 for Windows® (Version 13.0)*. Chicago, IL: Statistical Package for the Social Sciences, Inc

Sulaiman, A.R., Yusof, Z., Munajat, I., Lee, N.A.A., Rad, M.M. & Zaki, N. (2011). Developmental dysplasia of hip screening using ortolani and barlow testing on breech delivered neonates. *Malaysian Orthopaedic Journal*, 5(3), 13-16.

SurveyMonkey.com (2012). Retrieved July 27, 2012 from <https://www.surveymonkey.com/>

Wallen, G., Mitchell, S., Melnyk, B., Fineout-Overholt, E., Miller-Davis, C., Yates, J., & Hastings, C. (2010). Implementing evidence-based practice: effectiveness of a structured multifaceted mentorship programme. *Journal of Advanced Nursing*, 66(12), 2761-2771.

Watemberg, N., Ben-Sasson, A., & Goldfarb, R. (2016). Transient motor asymmetry among infants with congenital torticollis – description, characterization, and results of follow-up. *Pediatric Neurology*, 59:36-40.

#### CHAPTER IV-C: Intervention Patterns for Infants with Congenital Muscular Torticollis: A Survey of Pediatric Physical Therapists in the United States of America

**Purpose:** To describe interventions, speciality referrals, frequency of treatment, and duration of episode of care used by PTs in the USA who treat infants with congenital muscular torticollis (CMT). Practice trends for the intervention of infants with CMT are compared to current literature, including recent clinical practice guideline (CPG) recommendations. **Methods:** An online survey was completed by volunteers solicited through the Section on Pediatrics monthly e-newsletters and a posting on its website, and through purposeful identification of PTs in children's hospitals and private practices. **Results:** 186 pediatric physical therapists in the USA completed the intervention questions, with at least one participant from every state & the District of Columbia. Significant findings include that a slight majority of respondents do not use a CPG to inform their CMT treatment (52.3%), they are using interventions which are congruent with the recommended best evidence. The most frequently chosen strategy for developing their treatment approach is continuing education (25.0%). There is limited familiarity with supplemental interventions, and limited variability with their recommended frequencies of treatment. Lastly, a small subset (0.5%-15.1%) uses interventions which do not have evidence to support their use with CMT. **Conclusion:** The data yields practice patterns that are partially consistent with current CMT literature and CPG recommendations. US PTs should be seeking out interventions with evidence to support their clinical use with CMT.

## Introduction

The success of physical therapy (PT) intervention for infants with CMT is well documented in the literature (Cheng, Tang, Chen, Wong, & Wong, 2000; Petronic et al., 2010). Varying presentations of CMT lead to a variety of outcomes, as older infants with greater limitations in range of motion (ROM) tend to have worse outcomes than younger infants with less ROM limitations (Cheng, Tang, et al., 2000; Kaplan, Coulter, & Fethers, 2013; Petronic, et al., 2010). Regardless, the effectiveness of PT on these infants is supported by the literature.

Surveys about the PT management of CMT have been done in other countries (Fradette, Gagnon, Kennedy, Snider, & Majnemer, 2011; Luxford, Hale, & Piggot, 2009; Öhman et al., 2013). These include two similar surveys which highlight multiple intervention techniques that PTs in New Zealand (Luxford, et al., 2009) and PTs from Sweden and Denmark (Öhman, et al., 2013) use for their treatment of infants with CMT. In both surveys, the treatments which PTs perceived to be the most effective were passive stretching, facilitation of active range of motion (AROM), and handling advice (Luxford, et al., 2009; Öhman, et al., 2013), while PTs from Sweden and Denmark also perceived strength exercises to be most effective (Öhman, et

al., 2013). These surveys describe PT congruence of clinical practice with the recommended literature, and also demonstrate that PTs adjust their implementation of passive stretching based on the infant's response and tolerance (Luxford, et al., 2009; Öhman, et al., 2013). PTs from Canada highlighted the importance of family centered care in their survey and emphasized involving family when making decisions about the parameters of care (Fradette, et al., 2011). Canadian PTs also concluded that a “well implemented home program” is a necessary ingredient for better outcomes in the resolution of CMT (Fradette, et al., 2011).

PT interventions vary and there is a growing body of research dedicated to determining the most effective and appropriate treatments for these patients. It is not known which interventions PTs in the United States (US) use for their care of infants with CMT. A description of intervention patterns used by US PTs is necessary to compare current practice to recommended practice, to determine if guidelines for care of infants with CMT are being followed and to influence professional education.

### Purpose

The main purpose of this survey is to describe how US PTs commonly treat infants with CMT. This includes a description of their usage of guidelines; patterns of intervention; common sources of knowledge; and how

their overall practice regarding the treatment of CMT compares with recommended best practice.

## Methods

### *Survey Development*

The survey was developed based on an extensive review of the literature and approved by the Rutgers University Internal Review Board (Pro2012002460). It consisted of 90 total questions, dealing with PT practices related to the referral, screening, examination, intervention, discharge, and outcomes of infants with CMT (Appendix C). PTs were also asked about their clinical setting and professional development. This paper focuses on the fifteen questions (#40-54) related to CMT treatment.

### *Survey Administration & Recruitment*

A mixed mode survey distribution was used consisting of a paper survey with mail return, online survey via direct e-mail invitation from the primary investigator, or online survey via an open access web link posted in an e-newsletter from the American Physical Therapy Association (APTA) Section on Pediatrics (SoP) ([www.pediatricapta.org](http://www.pediatricapta.org)). The target population was pediatric PTs in the USA who treat young patients with CMT. To increase the representation of this small subset, national coverage was sought through direct invitation to the survey of at least five PTs from each state who treat CMT, targeting a total sample of 250. Multiple methods were used to recruit the sample including: e-mails to Pediatric Section state

representatives, phone calls or direct e-mails to the directors of PT departments in children's hospitals and managers of private pediatric PT businesses, and word of mouth by respondents inviting other colleagues who treat CMT. Additionally, an open invitation to complete the online survey was posted in the SoP e-newsletter ([www.pediatricapta.org](http://www.pediatricapta.org)) (June – September 2013) to attract qualified PTs who were not identified in the convenience sample.

### *Participants & Procedures*

Eligible participants were licensed PTs that had examined and treated a minimum of two young children or infants with CMT in the past six months. Exclusion criteria were PTAs (because of the large emphasis of the survey on the initial examination and evaluation procedures) and PTs who were not English speaking or who did not practice in the USA. Survey administration lasted six months (May 24 - Nov 27, 2013). Responses were exported from SurveyMonkey® ([SurveyMonkey.com](http://SurveyMonkey.com)) onto Microsoft® Office Excel 2007 ([www.microsoft.com](http://www.microsoft.com)) worksheets for analysis. Random ID numbers were assigned to each survey and all responses were coded and tallied. Narrative responses to open ended questions were read, sorted, and organized to establish common themes. Descriptive statistics (frequency counts, percentages, and tables) were calculated for each question using the Statistical Package for the Social Sciences®, version 13.0 (SPSS, 2004).

## Results

### *The Respondent Sample*

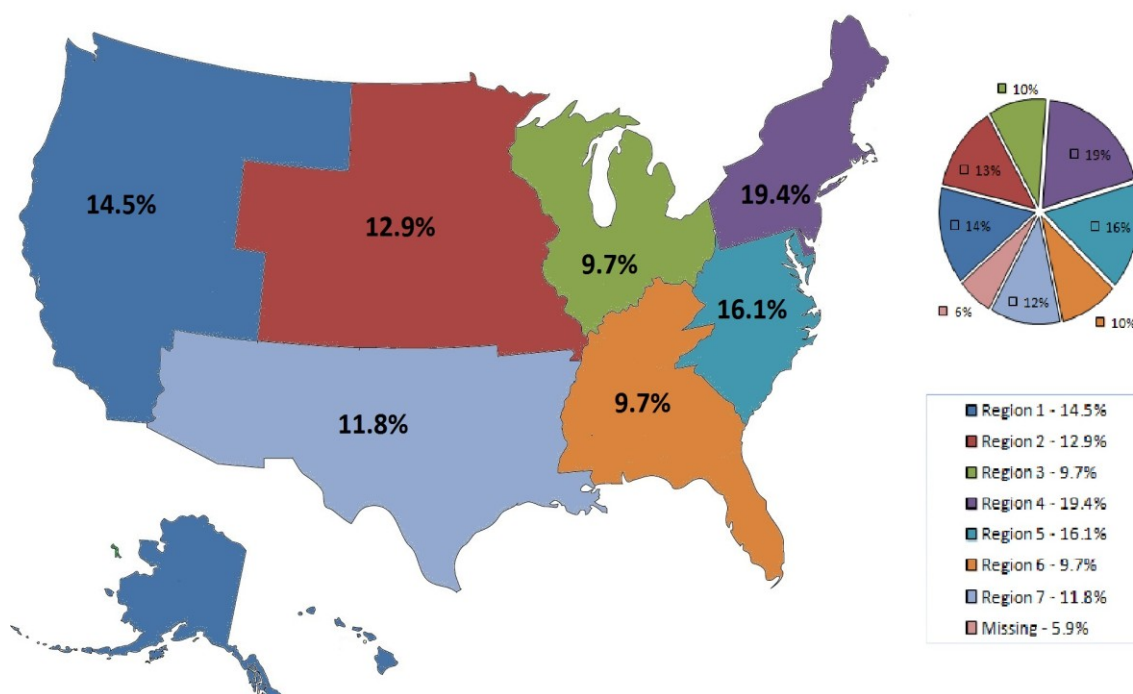
The survey yielded 234 respondents with at least one participant from each state in the USA and Washington DC. Of the 234 respondents, 14 did not meet the eligibility criteria; 220 who met criteria started the survey and 186 (84.5%) completed the Treatment Section of the survey (Appendix D). Regional distribution of the 186 respondents ranged from 10-20% among the seven regions defined by the SoP ([www.pediatricapta.org](http://www.pediatricapta.org)) (Figure 1). On average, these PTs have approximately 16 (SD=10.93) years experience in pediatrics. The majority of respondents are members of the APTA (74.2%) and the SoP (69.4%), and most have taken continuing education courses related to CMT (70.4%) (Table 1). The three most common places of employment included: hospital based outpatient clinics (44.1%), independently owned outpatient clinics (23.2%), and early intervention settings (21.5%).



Table 1: Respondent Characteristics (N=186)

		Yes	No	Missing
APTA Member		138 (74.2%)	38 (20.4%)	10 (5.4%)
SOP Member		129 (69.4%)	46 (24.7%)	11 (5.9%)
Board Certified Clinical Specialist		47 (25.3%)	128 (68.8%)	11 (5.9%)
Work in hospital-based outpatient setting		82 (44.1%)	94 (50.5%)	10 (5.4%)
Have taken CMT Cont Ed Course(s)		131 (70.4%)	45 (24.2%)	10 (5.4%)
	Mean	Range	Std. Dev.	Missing
# Years Practicing PT	17.89	1-49	11.89	3
# Years Practicing Pediatric PT	15.87	1-45	10.93	2
# Years Treating CMT	11.43	1-42	8.21	3

Figure 1: Regional Distribution of the Respondent PTs



### *CMT Treatment Patterns Among US PTs*

*Sources of Guidance.* Just over half of the respondent PTs (52.3%) reported that they do not use a guideline to inform their treatment of infants with CMT, while one-third (30.9%) report that they do use a guideline and 16.8% did not answer the question. Of those PTs who use a guideline, the top two sources are the Cincinnati Children's Hospital Medical Center Guideline (CCHMC-CPG) (Cincinnati Children's Hospital, 2009) (31.0%) or a location specific (workplace), non-published guideline (26.8%). The 3<sup>rd</sup> most referenced source are published books on CMT (19.7%).

Using a single choice, forced ranked order of strategies, respondent PTs report that their approach toward CMT treatment is developed *most importantly* through: continuing education lessons (25.0%) and their own personal review of the literature (18.2%), while published evidence based guidelines (14.5%) and lessons taught by colleagues (14.1%) trail behind. PTs report that workplace protocols are *least important* (38.6%) in developing their treatment approach for CMT (Table 2).

Table 2: Methods Used for Development of CMT Treatment Approach

**42.** Please rank order the importance of the following five strategies for developing your treatment approach. (Please rate all five strategies, but you should only select one response per column.) My CMT treatment approach is developed by...

	Most Important	Very Important	Important	Somewhat Important	Least Important	Missing
a.) My own personal review of the literature. <b>N=220</b>	40 (18.2%)	<b>56</b> <b>(25.5%)</b>	36 (16.4%)	30 (13.6%)	17 (7.7%)	41 (18.6%)
b.) Lessons taught to me by colleague(s). <b>N=220</b>	31 (14.1%)	37 (16.8%)	<b>60</b> <b>(27.3%)</b>	35 (15.9%)	11 (5.0%)	46 (20.9%)
c.) Lessons taught at continuing education courses. <b>N=220</b>	<b>55</b> <b>(25.0%)</b>	42 (19.1%)	39 (17.7%)	25 (11.4%)	18 (8.2%)	41 (18.6%)
d.) A process or protocol developed at my workplace. <b>N=220</b>	22 (10.0%)	14 (6.3%)	16 (7.3%)	36 (16.4%)	<b>85</b> <b>(38.6%)</b>	47 (21.4%)
e.) A published evidence-based guideline/ pathway/ protocol. <b>N=220</b>	32 (14.55%)	32 (14.55%)	31 (14.1%)	<b>41</b> <b>(18.6%)</b>	45 (20.5%)	39 (17.7%)

*Types of Interventions.* Survey respondents are, in general, using interventions recommended in the available evidence. Specifically, the majority of the respondents *always* or *usually* use the following evidence-based interventions for the treatment of their patients with CMT: passive range of motion (PROM) (70.9%) (Binder, Eng, Gaiser, & Koch, 1987; Cheng, Tang, et al., 2000; Öhman & Beckung, 2005; Taylor, 1997); positioning programs (83.2%) (Cheng, Metreweli, Chen, & Tang, 2000; Öhman,

Mårdbrink, Stensby, & Beckung, 2011); active range of motion (AROM) (81.4%) (Demirbilek & Atayurt, 1999; Rahlin, 2005); strengthening exercises via head righting reactions (81.4%) (Karmel-Ross, 1997; Öhman, et al., 2011), strengthening exercises via trunk equilibrium responses (75.5%) (Karmel-Ross, 1997), developmental exercises (76.8%) (Binder, et al., 1987; Emery, 1994; Öhman, et al., 2011; Taylor, 1997; Tessmer, Mooney, & Pelland, 2010); and parental instruction in home exercise programs (HEP) (83.2%) (Demirbilek & Atayurt, 1999; Emery, 1994; Öhman, et al., 2011; Ohman, Nilsson, & Beckung, 2010). All these techniques have moderate to strong evidence to support their use as primary interventions for CMT.

There are a number of less commonly used interventions in the treatment of CMT reported by survey respondents. Just under half of the PTs surveyed report *always* or *usually* using soft tissue massage (STM) (43.2%) (Karmel-Ross, 1997) or neurodevelopmental treatment (NDT) (42.3%) (Cayo et al., 2015). Less than one-fifth of the respondents report that they *always* or *usually* use the following interventions described in the literature: Kinesio® Tape (Kinesio-USA, 2010) (13.6%); Tscharnuter Akademie for Motor Organization (TAMO) (Rahlin, 2005) (2.7%); Tubular Orthosis for Torticollis (TOT) Collar™ (Symmetric-Designs) (2.3%); and myokinetic stretching (Chon, Yoon, & You, 2010) (1.8%). About one half of respondents report that they *never* use microcurrent (45.4%), which is supported as a secondary intervention in the treatment of CMT (Kaplan, et al., 2013). Another half

report that they do not know what TAMO (Rahlin, 2005) (48.2%) or myokinetic stretching (Chon, et al., 2010) (48.2%) are; both have evidence for use as secondary interventions (Kaplan, et al., 2013). Almost one quarter of the respondents (22.6%) identified the following interventions for CMT (Table 3), but for which no published evidence has been found to describe the approach or demonstrate effectiveness for infants with CMT.

Table 3: Interventions Identified by Respondents without Supporting Evidence for CMT

Technique	Website	Per website, is this technique recommended specifically for infants with torticollis?	Does this website cite published evidence based data demonstrating the effectiveness of this technique for torticollis?
Total Motion Release© (TMR) N=28 (15.1%)	(totalmotionpt.com)	Yes	No
Myofascial Release® (MFR) N=8 (4.3%)	(myofascialrelease.com)	Yes	No
CranioSacral Therapy© (CST) N=8 (4.3%)	(upledger.com)	No. Recommended for "infantile disorders."	No. There are two unpublished case reports regarding this treatment for infants with torticollis found in the "searchable database" under a link for the International Alliance of Healthcare Educators.
Muscle energy technique N=3(1.6%)	No	No. Recommended for "limited ROM."	No
McConnell Taping N=1 (0.5%)	(mcconnell-institute.com)	No. Recommended for	No

		"neck pain."	
Crosstape (KUMBRINK- CROSSTAPE®) N=1 (0.5%)	(k-taping.ca)	No. Recommended to "decrease trapezius muscle tension."	No
Cranial banding N=1 (0.5%)	Various websites for companies that make cranial helmets/ bands. For example, Cranial Technologies (cranialtech.com)	Yes on cranialtech.com	No. There is an article which reports effectiveness for torticollis (not evidence based research), found on the cranialtech.com website under "Featured News," "Parents" section, September 2014.
Turtle© N=1 (0.5%)	(turtle.com)	No. Recommended for "head and neck asymmetry."	No. There are many articles cited regarding the effectiveness of repositioning, but not with the Turtle©.
TheraTogs©N=1(0.5%)	(theratogs.com)	No	No
Benik© cap N=1(0.5%)	(benik.com), but no mention of a "cap" on their website.	No	No
Cuevas Medek Exercises® (CME® N=1 (0.5%)	(cuevasmedek.com)	No. Recommended for "infants suffering abnormal developmental evolution, caused by a...non- degenerative syndrome affecting the CNS."	No
Integrative Manual Therapy© (IMT) N=1 (0.5%)	(imtwellnesscenter.com)	No. Recommended for "pain, dysfunction, disability, and disease in...people of all ages, including infants."	No

*Infant Equipment, Positioning Devices, and Orthoses.* Equipment is *sometimes*, but not frequently used by PTs to treat CMT. About one-fifth of respondents report that they *usually* or *always* use Kinesio® Tape (20.4%) or a physioball (19.6%) to facilitate movement for better postural alignment. These numbers increase when respondents who *sometimes* use equipment are included: Kinesio® Tape (59.1%); or a physioball (56%). *Rarely* and *never* used equipment include: foam collars (70.4%); gel cushion head rests (63.7%); TOT collars™ (52.3%); and head positioner devices (43.6%). Respondents wrote in *Other* equipment that they use, including: the Boppy® Tummy Time (2); the Boppy® Noggin Nest Head Support (2); foam head positioners (2); plagio cradle (1); Turtle© (1); Snuggin Go® baby seat support (1); and towels or washcloths (1). Of note, a cranial orthosis or helmet was reported as being *always* or *usually* used by 9.6% of respondent PTs to manage plagiocephaly, a frequent co-morbidity observed in infants with CMT.

*Referral for Specialty Consultation or Procedure.* Respondents commonly refer their patients with CMT for specialty consultations or procedures. After combining the positive (*always*, *usually*, *sometimes*) responses, the three most common referrals are to: cranial orthotists (69.5%); opthalamologists (54.5%); and neurologists (52.2%). Almost half of respondents make recommendations to: orthopedists (47.7%) or for cervical x-rays (45.9%). Recommendations *rarely* or *never* made by respondents include: surgery (71.8%); botox (70.5%); and ultrasound imaging (57.7%).

Write-in responses for specialists included: a gastroenterologist (1); neurosurgeon (1); plastic surgeon (1); pulmonologist (1); allergist (1); genetics (1); developmental optometrist (1); and behavioral optometrist (1).

### *Patterns Regarding the Frequency of CMT Treatment*

Survey respondents reported that treatment frequency for patients with CMT is determined most importantly by: the severity of the head tilt (55.5%) or cervical rotation restriction (45.0%); the parent's ability to adhere to the HEP (32.7%), and the age of the child (31.8%). Although an initial frequency of treatment may be selected, respondents report that this schedule may change throughout the duration of PT, dependent on multiple factors. An increase in the scheduled frequency most often occurs if the child is not progressing well (47.3%), or if the family is not adhering to the HEP (26.4%), while a decrease most often occurs if the family adheres well to the HEP (44.5%) or the child is progressing well (31.4%).

Typical schedules by age group and type of CMT are illustrated in Table 4. Once per week is the most commonly selected visit frequency for all age groups and types of CMT. As per the survey respondents: 2x/month is second most popular among the newborn to six month olds with the mildest postural type of CMT; 2x/week is second most popular among infants who are seven months and older or who have the muscular or tumor type of CMT; 3x/week is rarely used and 4-5x/week is never used (Table 4).



The two most common lengths of time per treatment session are 60 minutes (43.2%) and 45 minutes (25.4%). The typical episode of care for a patient with CMT is three to six months (40.0%), followed by six to nine months (22.7%).

Table 4: Selected Frequency of Treatment

**44.** What is the typical frequency of PT visits that you recommend in the first four weeks of treatment for an infant who shows a postural preference (no muscle tightness nor mass), and who is...

	1x/week	2x/week	3x/week	4x/week	5x/week	1x/month	2/month	Missing
0-3 months old <b>N=220</b>	<b>94</b> <b>(42.7%)</b>	15 (6.8%)	3 (1.4%)	0 (0.0%)	0 (0.0%)	17 (7.7%)	52 (23.6%)	39 (17.7%)
4-6 months old <b>N=220</b>	<b>117</b> <b>(53.2%)</b>	25 (11.4%)	2 (0.9%)	0 (0.0%)	0 (0.0%)	8 (3.6%)	29 (13.2%)	39 (17.7%)
7+ months old <b>N=220</b>	<b>99</b> <b>(45.0%)</b>	40 (18.2%)	3 (1.4%)	0 (0.0%)	0 (0.0%)	11 (5.0%)	26 (11.8%)	41 (18.6%)

**45.** What is the typical frequency of PT visits that you recommend in the first four weeks of treatment for an infant who shows a muscular torticollis (muscle tightness but no mass), and who is...

	1x/week	2x/week	3x/week	4x/week	5x/week	1x/month	2/month	Missing
0-3 months old <b>N=220</b>	<b>112</b> <b>(50.9%)</b>	33 (15.0%)	6 (2.7%)	0 (0.0%)	0 (0.0%)	5 (2.3%)	27 (12.3%)	37 (16.8%)
4-6 months old <b>N=220</b>	<b>111</b> <b>(50.5%)</b>	55 (25.0%)	6 (2.7%)	0 (0.0%)	0 (0.0%)	1 (0.5%)	10 (4.5%)	37 (16.8%)
7+ months old <b>N=220</b>	<b>100</b> <b>(45.5%)</b>	62 (28.2%)	8 (3.6%)	0 (0.0%)	0 (0.0%)	4 (1.8%)	8 (3.6%)	38 (17.3%)

**46.** What is the typical frequency of PT visits that you recommend in the first four weeks of treatment for an infant who shows a sternomastoid tumor (palpable mass in SCM), and who is...

	1x/week	2x/week	3x/week	4x/week	5x/week	1x/month	2/month	Missing
0-3 months old <b>N=220</b>	<b>93</b> <b>(42.3%)</b>	53 (24.1%)	8 (3.6%)	0 (0.0%)	0 (0.0%)	3 (1.4%)	13 (5.9%)	50 (22.7%)
4-6 months old <b>N=220</b>	<b>86</b> <b>(39.1%)</b>	65 (29.5%)	10 (4.5%)	0 (0.0%)	0 (0.0%)	1 (0.5%)	7 (3.2%)	51 (23.2%)
7+ months old <b>N=220</b>	<b>77</b> <b>(35.0%)</b>	66 (30.0%)	15 (6.8%)	0 (0.0%)	0 (0.0%)	2 (0.9%)	7 (3.2%)	53 (24.1%)

### *PT Use of Clinical Practice Guidelines for CMT Treatment*

*Professional Affiliation.* Only one third of the PTs surveyed report using a guideline to support their clinical decisions. A Pearson's chi-square test was used to test the association between being a member of the (APTA) Section on Pediatrics (SoP) and guideline use (Table 5). Based on the results, [ $\chi^2 (1) = 0.322, p > .05$ ] no significant association was found.

Table 5: Association between SoP Membership and Use of Guidelines for CMT Treatment

	Value	Degrees of freedom	Asymp. Sig (2 sided)
Pearson Chi-Square	0.322	1	0.570

*Experience.* A Spearman's rho correlation was used to test the association between PTs' years of experience and use of a clinical guideline for CMT intervention (Table 6). At this time, there is not enough evidence to reject the null hypothesis [ $r^s = -0.034$ ,  $p > .05$ ]. Based on the results, [ $r^s = -0.034$ ,  $p > .05$ ] no significant association was found.

Table 6: Association between Years of Experience and Use of Clinical Guideline

		Guideline	Experience
Guideline	Correlation	1.000	-0.034
	Coefficient		0.661
	Significance (2-tailed)	183	172
	N		
Experience	Correlation	-0.034	1.000
	Coefficient	0.661	
	Significance (2-tailed)	172	175
	N		

*Workplace Setting.* Respondent PTs report that the four most common work settings for treating infants with CMT are: hospital based outpatient facility (46.6%), independently owned outpatient facility (23.3%), early intervention program – children identified through IDEA (Individuals with Education Act) (21.6%), and home based PT – children not identified through IDEA (7.9%). One individual (0.5%) also reported that they treat infants with CMT primarily in the neonatal intensive care unit. A Pearson's chi-square test was used to explore associations between the four most common

workplace settings and use of clinical guidelines for CMT treatment, and only one was found. Results (Table 7) suggest that there is no greater chance of CPG use with PTs who work in privately owned outpatient clinics ( $z = 0.1$ ,  $z = -0.1$ ); hospital based outpatient clinics ( $z = 1.2$ ,  $z = -0.9$ ); and home based settings ( $z = 0.4$ ,  $z = -0.3$ ) than would be expected. However, in the early intervention setting, PTs were significantly less likely to use guidelines than expected ( $z = -2.1$ ); Pearson chi-square =  $\chi^2 = 9.508$  (3),  $p < .05$ .

Table 7: Association between Workplace Setting and Use of Guidelines for CMT Treatment

		Uses Guideline for treatment of CMT	Does not Use Guideline for treatment of CMT
Privately owned outpatient clinic	Count	15	25
	Expected Count	14.6	25.4
	% of Total	8.7%	14.5%
	Std. Residual	0.1	-0.1
Hospital based outpatient clinic	Count	36	45
	Expected Count	29.5	51.5
	% of Total	20.8%	26%
	Std. Residual	1.2	-0.9%
Early Intervention (IDEA)	Count	6	32
	Expected Count	13.8	24.2
	% of Total	3.5%	18.5%
	Std. Residual	-2.1	1.6
Home based PT (not through IDEA)	Count	6	8
	Expected Count	5.1	8.9
	% of Total	3.5%	4.6%
	Std. Residual	.4	-.3

## Discussion

### *CMT Treatment Patterns*

*Sources of Guidance.* PTs in this sample may use the CCHMC-CPG (Cincinnati Children's Hospital, 2009) more for direction with CMT treatment rather than the examination (as described previously in Manuscript 2) because its content emphasizes treatment. Additionally, the most common place of employment for PTs who completed the survey was in hospital based outpatient settings (44.1%), where PTs may be required to complete the facility's examination form based on a workplace protocol. In contrast, treatment intervention is not typically directed by a form, but rather by the patient's needs, the PT's skills and knowledge of interventions, and the therapist's style of interacting with the patient. Likewise, this survey suggests that most respondents do not use guidelines to choose interventions, but of those that do, the CCHMC-CPG (Cincinnati Children's Hospital, 2009) was most often chosen to help guide them in their clinical decisions.

At the time of this survey, May 24 – Nov 27, 2013, there were three published guidelines regarding the PT management of CMT. The HSS-CPG, "Postsurgical Rehabilitation Guidelines for the Orthopedic Clinician," (Corradi-Scalese, 2006) is one chapter within a book from the Hospital for Special Surgery, that is only available by purchase, thus it is not a freely available guideline. The CCHMC-CPG (Cincinnati Children's Hospital, 2009) was developed by the Cincinnati Children's Hospital Medical Center for guidance

in the examination and treatment of patients with CMT, and was the only publicly available guideline (guidelines.gov - NGC:007301) on CMT until June 2013. The CPG from the Section on Pediatrics (SoP-CPG) (Kaplan, et al., 2013) became available online as a draft for public comment in June 2013, and was published in its final form in October 2013. The SoP-CPG makes evidence based recommendations for best practice based on literature searches through May 2013.

It is possible that survey respondents may not have been “up to date” with recent publications, particularly the SoP-CPG (Kaplan, et al., 2013), which had just become available online as a draft during the administration of the survey (June 2013). Alternatively, respondents were awaiting the final version of the SoP-CPG (October 2013) before implementing it as 210 out of 234 respondents (89.7%) completed the survey prior to October 2013, and most did not refer to the CPG as a source.

Publication of guidelines, however, does not ensure their implementation (Melnyk, Fineout-Overholt, Gallagher-Ford, & Kaplan, 2012). In a survey of 1015 registered nurses who were members of the American Nurses Association, nurses did not consistently perform evidence-based practices (EBP), despite research that EBP resulted in better outcomes. Reasons included limited acceptance of EBP by colleagues, nurse leaders, and managers (Melnyk, et al., 2012). PTs also cite difficulties with adopting

EBP, such as lack of time and lack of incentive in the workplace (Schreiber, Stern, Marchetti, & Provident, 2009).

This study explored the association between PT membership, years of experience, and workplace setting with PTs use of guidelines for treatment of CMT. Interestingly, there were no significant associations between SoP membership or PTs years of experience and their use of guidelines for treatment (Tables 5 & 6). Membership with the SoP provides a wealth of information and knowledge for members that is not easily accessible to non-members, such as the most recent publication of CMT guidelines, which one might assume would generate a more informed clinician. However, based on the results of this survey, the respondents reported that continuing education courses were the *most important* strategy for developing their CMT treatment approach, not use of a guideline or publications. Despite the relative non-use of guidelines, data from the survey suggests that the majority of PTs are using evidence-based interventions (ROM, positioning, strengthening, parental education) in their typical treatment of infants with CMT. Also, data from the outcomes portion of the survey shows that 75.7% of the respondent PTs report full resolution of symptoms among their patients with CMT. Therefore, it is quite likely that the survey respondents do not seek guidance from CMT guidelines, as they already observe positive results with their current interventions.

Survey results suggest that PTs in the EIP setting are significantly less likely to use CMT guidelines than expected. This finding, although perhaps a bit disappointing, is really not groundbreaking, considering that CMT is not typically a qualifying diagnosis for early intervention in many states.

Therefore, the infants and young children who are being treated through the EIP most likely have other diagnoses as the primary reasons for EIP services. PTs in the EIP setting may be treating CMT as a secondary diagnosis, and may not be familiar with CMT guidelines for treatment. However, this should not be interpreted to allow PTs who work in a particular setting to disregard guidelines for diagnoses that they may be treating.

*Types of Intervention.* Although the majority of respondents appear to be choosing evidence based practice interventions, there are supplemental interventions, supported by the literature, with which almost half of respondents are not familiar, or have *never* used. For example, almost half of the respondents answered that they do not know about TAMO (48.2%) or myokinetic stretching (48.2%), despite that myokinetic stretching has one study with Level 2c evidence (Chon, et al., 2010). One reason for this finding may be that the published evidence for myokinetic stretching is not in the Pediatric PT Journal, but rather, found in the Journal of Back & Musculoskeletal Rehabilitation (Chon, et al., 2010), which is most likely not a common resource for pediatric PTs. Additionally, continuing education for these treatments is rare, and survey respondents report continuing education



as a main source of knowledge. Therefore, if no courses are being offered, then there may be a lack of familiarity with the topic. Furthermore, if PTs are successful with the primary interventions, they may not look for alternatives. Finally, most infants referred to PT with CMT are of the muscular or postural type (91.6%), with only 8.4% of patients reported to be in the sternomastoid tumor category, so their conditions are not the most severe, making typical stretching an effective intervention.

Microcurrent is a supplemental intervention in the SoP-CPG (Kaplan, et al., 2013), however since the guideline publication, an additional randomized controlled study provides strong support for its use (Kwon & Park, 2014). Half of respondent PTs report that they *never* use (45.4%) microcurrent, and another 34.1% report that they do not know about it. The results of two Korean studies suggest that the episode of care can be substantially reduced when microcurrent is added to a home program of stretching (Kim, Kwon, & Lee, 2009; Kwon & Park, 2014). PTs may need to consider microcurrent as an effective intervention in the treatment of CMT, however replication of these studies in the US and continuing education courses on this technique may be needed to strengthen clinician confidence.

Lastly, there are many interventions (Table 3) that survey respondents (n=1-28) (.05-15.1%) report using for which no peer reviewed evidence could be found for efficacy in patients with CMT. Most likely, these approaches are learned at continuing education courses, since the PTs in this sample most

commonly selected continuing education courses as their *most important* strategy for developing their CMT approach (Table 2). If instructors at continuing education courses are recommending a technique for infants with CMT, then they should also be presenting research to support their use with CMT. If no evidence exists, then that should be shared with course participants as well. Likewise, PTs who attend continuing education courses should seek out references or request references from the instructor prior to deciding if the course is evidence based. The PT profession should uphold a standard of care which does not avoid the evidence, or lack thereof, but which shares the knowledge that exists, and promotes studies to demonstrate the efficacy of all available techniques. Additionally, clinicians who use interventions which don't have supporting evidence for their use with CMT should share this information with parents, obtain consent from parents to use these treatments, document any objective changes, and publish their results. (Kaplan, et al., 2013).

*Infant Equipment, Positioning Devices, and Orthoses.* Less than 20% of survey respondents report that they *usually* or *always* use the devices listed on the survey (Question #51) in their CMT treatments. Although there is evidence to support the use of some of these devices (Kinesio® Tape, TOT collar™) as supplemental interventions (Öhman, 2015), PTs may be hesitant to use external equipment or devices with the infant population for a number of reasons. These may include difficulties encountered with the description of

the technique, the ability to reproduce the approach, and lack of appropriate training. Clinical factors involved in the decision to use any piece of equipment include knowledge and comfort of the PT in using the equipment, parental agreement, ease of fitting, ease of application, parent ability to demonstrate proper application, cost of the equipment, and the response of the infant. Despite the relatively low cost for KinesioTape and TOT collars, the proper application of these devices on an active and mobile infant may pose challenges that deter clinicians from using them.

*Referral for Specialty Consultation or Procedure.* Respondents *sometimes*, but not *usually*, recommend specialists to be involved in the care of their patients with CMT. About 20% or less of the PTs in this survey report that they *usually* or *always* recommend a specialist (orthopedist, neurologist, ophthalmologist, cranial orthotist). Although this may appear to indicate limited collaboration among PTs and specialists, it may be more indicative of the type of patients treated by the PTs in this survey. If the majority of the patients are uncomplicated muscular cases, then there may not be a need to refer the patient to a specialist. Furthermore, it is possible that pediatricians may refer their CMT patients to specialists prior to a PT evaluation, negating the need for PTs to make those referrals.

### *Patterns Regarding the Frequency of CMT Treatment*

Survey respondents report that their selected frequency of treatment is determined most importantly by severity of head tilt, rotation limitation, parental ability to adhere to the HEP, and the infant's age (Question 43). Yet, the most common frequency was 1x/week regardless of the infant's age or type of CMT (Table 4). This may initially appear to be a contradiction of responses: that certain variables are important factors to the frequency of care, yet the most common frequency was 1x/week across all age groups and types of CMT. However, the second most popular response for frequency of care was 2x/week for those with a muscular or sternomastoid tumor type, and 2x/month for those with a postural type (0-6 months), with the first and second choice gap closing in, as the child's age and the severity worsened (Table 4).

Approximately, one-quarter to one-half of respondents will change the frequency of PT sessions per week based on how well the infant is progressing. Although the SoP-CPG (Kaplan, et al., 2013) makes no specific recommendations for frequency of care, the literature does support that earlier and more intensive care leads to better outcomes and a shorter duration of PT (Burstein, 2004; Canale, Griffin, & Hubbard, 1982; Celayir, 2000; Cheng, Tang, & Chen, 1999; Chon, et al., 2010; Petronic, et al., 2010). The results are congruent with prior CMT surveys (Fradette, et al., 2011; Luxford, et al., 2009) in which PTs consider multiple factors to decide upon frequency of care, as is recommended by the literature (Kaplan, et al., 2013).

However, there is currently no evidence to suggest that a greater frequency of PT treatments per week is more effective than a lesser frequency. There is evidence that stretching by a PT 3x/week is more effective than daily stretching by the parents (Öhman, et al., 2010), but this study is limited by a small sample size and questionable parental adherence to the HEP. A later study by Öhman et al. (2011) increases the frequency of the HEP and changes the HEP intervention. In this study, infants who received specific handling strategies taught to parents by PTs, and performed throughout the day, every day, may have similar outcomes as infants who received PT 3x/week and who also received the daily handling protocol, without a significant difference in treatment duration (Öhman, et al., 2011). Such research helps to highlight the importance of the handling intervention, and how it most likely afforded the infants greater opportunities for strengthening throughout the day (Öhman, et al., 2011). Additionally, it is important to note that adherence with the home program is correlated with the maternal perception of the severity of the torticollis and the importance of the home program (Rabino, Peretz, Kastel-Deutch, & Tirosh, 2013). These studies may support the idea that more frequent PT visits are not necessarily more effective if specific handling strategies are vigilantly performed by caretakers every day, throughout the day; however, further research with a larger sample size and more specific descriptive information about the population (type of CMT, severity of ROM restriction) is needed to support this theory.

The reported frequency of PT sessions per week differed from published research protocols that tend to have higher treatment frequencies. Fifteen different factors were identified as important to the decision about frequency of care, four of which included: the parent's schedule, the number of visits authorized through health insurance, the availability of PT appointments, and the distance that the family travels to PT. These four factors are generally not factors in research protocols which may provide treatment 3-5x/week, (Cheng et al., 2001; Chon, et al., 2010; Kim, et al., 2009), since interventions (and travel, lodging) provided through research protocols are usually free. Therefore, it is much more likely for research interventions to occur at a greater frequency than in a practical setting, where a high frequency of attendance may not be supported by families or insurance coverage.

The most commonly reported episode of care for a patient with CMT is three to six months (40.0%), followed by six to nine months (22.7%). This is the first known survey on the management of CMT to request data on treatment duration, but it is their perceived duration of treatment, not derived from actual chart review. These findings indicate that almost one half of patients with CMT in the US participate in PT for three to six months, while almost one quarter participates for six to nine months. In the referral section of this survey, respondents reported that the most common age of referral to PT is 3-4 months (67.8%), so an infant with CMT may likely be treated by a

PT from 3 through 9 months of age. This calculation prompts the question as to whether PT duration could be lessened, but maintain its effectiveness, especially in light of other studies which have shown positive results in less than three months (1.4 months for postural torticollis, 2.5 months for muscular torticollis) (Cheng, et al., 2001), or even just in two weeks (Kim, et al., 2009). Understandably, PTs in this survey were not asked to separate their patients by severity when questioned about duration. However, it is well known that early referral to PT produces better outcomes within a shortened period of time (Cheng, et al., 2001; Petronic, et al., 2010). Data from the referral section of this survey indicates that about one-third (30.4%) of the respondent PTs reported that parents were *always or usually* told by the pediatrician to wait before starting PT, with the most commonly reported wait time of 3-4 months (41.1%). Combining referral data with intervention data sheds light on the need to educate parents, doctors, and third party payors about the positive effects of early referral to PT for infants with CMT. Furthermore, it brings attention to the need for more research on particular interventions, such as microcurrent (Kim, et al., 2009; Kwon & Park, 2014) or myokinetic stretching (Chon, et al., 2010), and also on the potential benefit of an increased frequency of care (3-5x/week) (Cheng, et al., 2001; Chon, et al., 2010; Kim, et al., 2009). It is essential that PTs not view this data about the average duration of PT simply as congruent with recommended practice, but more as a baseline upon which current practice can be improved.

### Study Limitations

There are two main limitations of this survey research. First, the survey sample is mainly comprised of PTs who belong to the SoP of the APTA (69.4%). This is most likely due to the recruitment methods used in this survey. It was known by the research team that there are approximately 5,000 physical therapists and physical therapist assistants who belong to the Section on Pediatrics of the American Physical Therapy Association ([www.pediatricapta.org](http://www.pediatricapta.org)). However, the challenge of reaching the target population of US PTs who treat CMT is that there are no registries of PTs who treat infants with CMT; not all pediatric PTs belong to the Section on Pediatrics; and not all pediatric PTs treat children with CMT. Therefore, the target population was felt to be a relatively small subset of physical therapists of unknown size and location. A convenience sample was established to help identify this population. Despite using methods to recruit both members and non-members of the SoP, the sample resulted in more SoP members than non-members. Consequently, the majority were SoP members. Although this may be a source of bias in the survey, responses would be biased toward those who are members of the SoP, who voluntarily pay annual dues to belong to the APTA, and who receive regular journal publications to keep their practice informed. Thus, the bias of this survey is in the direction of the potentially more informed clinician.



Secondly, the treatment questions were in the third section of the survey and consisted of 15 thought provoking questions (Questions #40-54), including narrative responses, and may have required additional time demands from the respondents. Of the 220 who met the eligibility criteria and started the survey, 186 (84.5%) completed the treatment questions; a drop-off of 34 (15.5%) respondents. The non-completion rate may be due to the survey length or the inability of respondents who accessed the survey via the open access web link to log off and later return to their work.

### Further Research

Further research is needed to determine parental satisfaction and overall views about the physical therapy care which their children with CMT received. It would be beneficial to validate the findings of this survey with parents and caretakers, to see if parents of children with CMT in the USA who received PT services also reflect a positive experience and overall good outcomes. Additionally, further research regarding the effectiveness of secondary interventions, such as microcurrent and myokinetic stretching, for infants with CMT in the US is necessary before considering these treatments as viable primary interventions. Lastly, the majority of survey respondents completed this survey prior to publication of the SoP-CPG (Kaplan, et al., 2013). Further research is needed to determine if there are any changes

regarding US PTs use of clinical guidelines for infants with CMT since publication of the most recent CMT guidelines by the SoP APTA.

### Conclusions

Overall, the results of this survey support that the majority of survey respondents (sample of US PTs) are providing treatment for infants with CMT which is congruent with the recommended best evidence described in a 2013 CPG, despite that the majority also report that they do not use a guideline for direction of their CMT treatment. Exceptions to congruence with recommended evidence based care include a lack of familiarity with supplemental interventions, a multitude of interventions used by the respondents without evidence to support their use, and the general preference by respondent PTs for weekly (1x/week) PT sessions of all patients with CMT. Further research would be beneficial, especially since the publication of the SoP-CPG (Kaplan, et al., 2013).

## References

- Benik. Retrieved October 13, 2015, from <http://www.benik.com>
- Binder, H., Eng, G. D., Gaiser, J. F., & Koch, B. (1987). Congenital muscular torticollis: results of conservative management with long-term follow-up in 85 cases. *Arch Phys Med Rehabil*, 68(4), 222-225.
- Burstein, F. D. (2004). Long-term experience with endoscopic surgical treatment for congenital muscular torticollis in infants and children: a review of 85 cases. *Plastic & Reconstructive Surgery*, 114(2), 491-493.
- Canale, S. T., Griffin, D. W., & Hubbard, C. N. (1982). Congenital muscular torticollis. A long-term follow-up. *Journal of Bone & Joint Surgery - American Volume*, 64(6), 810-816.
- Cayo, C., Diamond, M., Bovre, T., Mullens, P., Ward, P., Haynes, M., . . . Franjoine, M. R. (2015). The NDT/Bobath (Neuro-Developmental Treatment/Bobath) Approach. *NDTA Network*, 22(2), 1.
- Celayir, A. C. (2000). Congenital muscular torticollis: early and intensive treatment is critical. A prospective study. [Clinical Trial]. *Pediatrics International*, 42(5), 504-507.
- Cheng, J. C., Metreweli, C., Chen, T. M., & Tang, S. (2000). Correlation of Ultrasonographic imaging of congenital muscular torticollis with clinical assessment in infants. *Ultrasound in Medicine & Biology*, 26(8), 1237-1241.
- Cheng, J. C., Tang, S. P., & Chen, T. M. (1999). Sternocleidomastoid pseudotumor and congenital muscular torticollis in infants: a prospective study of 510 cases. *Journal of Pediatrics*, 134(6), 712-716.
- Cheng, J. C., Tang, S. P., Chen, T. M., Wong, M. W., & Wong, E. M. (2000). The clinical presentation and outcome of treatment of congenital muscular torticollis in infants--a study of 1,086 cases. *Journal of Pediatric Surgery*, 35(7), 1091-1096.
- Cheng, J. C., Wong, M. W., Tang, S. P., Chen, T. M., Shum, S. L., & Wong, E. M. (2001). Clinical determinants of the outcome of manual stretching in the treatment of congenital muscular torticollis in infants. A prospective study of eight hundred and twenty-one cases.

[Evaluation Studies]. *Journal of Bone & Joint Surgery - American Volume*, 83-A(5), 679-687.

Chon, S.-C., Yoon, S.-I., & You, J. H. (2010). Use of the novel myokinetic stretching technique to ameliorate fibrotic mass in congenital muscular torticollis: an experimenter-blinded study with 1-year follow-up. *Journal of Back & Musculoskeletal Rehabilitation*, 23(2), 63-68.

Cincinnati Children's Hospital Medical Center (2009). Evidence-Based Care Guideline for Management of Congenital Muscular Torticollis in children age 0-36 months.

Corradi-Scalese, D., Sparrow, A., Amoroso, L. (2006). Chapter 27 – Congenital Muscular Torticollis. In J. Cahill, Cavanaugh, J., Wolff, A., Corradi-Scalese, D., Rudnick, H. (Ed.), *Postsurgical Rehabilitation Guidelines for the Orthopedic Clinician, Hospital for Special Surgery*: Mosby Elsevier.

Cuevas Medek. Retrieved October 13, 2015, from <http://cuevasmedek.com>

Demirbilek, S., & Atayurt, H. F. (1999). Congenital muscular torticollis and sternomastoid tumor: results of nonoperative treatment. *Journal of Pediatric Surgery*, 34(4), 549-551.

Do, T. T. (2006). Congenital muscular torticollis: current concepts and review of treatment. [Review]. *Current Opinion in Pediatrics*, 18(1), 26-29.

Emery, C. (1994). The determinants of treatment duration for congenital muscular torticollis. [Research Support, Non-U.S. Gov't]. *Physical Therapy*, 74(10), 921-929.

Fradette, J., Gagnon, I., Kennedy, E., Snider, L., & Majnemer, A. (2011). Clinical Decision Making Regarding Intervention Needs of Infants with Torticollis. *Pediatric Physical Therapy*, 249-256.

Integrative Manual Therapy. Retrieved October 13, 2015, from <http://imtwellnesscenter.com>.

KUMBRINK-CROSSTAPE®. How to use KUMBRINK-CROSSTAPE® Retrieved October 20, 2015, from [k-taping.ca](http://k-taping.ca).

Kaplan, S., Coulter, C., & Fethers, L. (2013). Physical therapy management of congenital muscular torticollis: An evidence-based clinical practice guideline. *Pediatric Physical Therapy*, 25(4), 348-394.

- Karmel-Ross, K., & Lepp, M. (1997). Assessment and Treatment of Children with Congenital Muscular Torticollis In K. Karmel-Ross (Ed.), *Torticollis: Differential diagnosis, assessment, and treatment, surgical management, and bracing* (pp. 21-67). Binghamton, NY: The Haworth Press.
- Kim, M. Y., Kwon, D. R., & Lee, H. I. (2009). Therapeutic effect of microcurrent therapy in infants with congenital muscular torticollis. [Controlled Clinical Trial]. *Pm & R*, 1(8), 736-739.
- Kinesio-USA. (2010). About Kinesio Retrieved August 22, 2012 from <http://www.kinesiotaping.com>
- Kwon, D. R., & Park, G. Y. (2014). Efficacy of microcurrent therapy in infants with congenital muscular torticollis involving the entire sternocleidomastoid muscle: a randomized placebo-controlled trail. *Clinical Rehabilitation*, 28(10), 983-991.
- Luxford, B., Hale, L., & Piggot, J. (2009). The physiotherapy management of infants with congenital muscular torticollis: a survey of current practice in New Zealand. *New Zealand Journal of Physiotherapy*, 37(3), 127-135.
- McConnell Institute: Expanding orthopaedic healthcare knowledge globally Retrieved October 20, 2015, from <http://mcconnell-institute.com>.
- Melnyk, B. M., Fineout-Overholt, E., Gallagher-Ford, L., & Kaplan, L. (2012). The state of evidence-based practice in US nurses: critical implications for nurse leaders and educators. *Journal of Nursing Administration*, 42(9), 410-417.
- Microsoft® Office Excel (2007). <https://www.microsoft.com/en-us/search/result.aspx?q=excel&form=MSHOME>
- Myofascial Release. What is Myofascial Release? Retrieved October 13, 2015, from [http:// myofascialrelease.com](http://myofascialrelease.com).
- Öhman, A. (2015). The immediate effect of kinesiology taping on muscular imbalance in the lateral flexors of the neck in infants: A randomized masked study. *PM&R*, 7(5): 494-498.
- Öhman, A., & Beckung, E. (2005). Functional and cosmetic status in children treated for congenital muscular torticollis as infants. *Advances in Physiotherapy*, 7, 135-140.

- Öhman, A., Mårdbrink, E.-L., Orefelt, C., Seager, A., Tell, L., & Klackenberg, E. A. (2013). The Physical therapy assessment and management of infants with congenital muscular torticollis. A survey and a suggested assessment protocol for CMT. *Journal of Novel Physiotherapies*. doi: 10.4172/2165-7025.1000165
- Öhman, A., Mårdbrink, E.-L., Stensby, J., & Beckung, E. (2011). Evaluation of Treatment strategies for muscle function in infants with congenital muscular torticollis *Physiotherapy Theory & Practice*, 27(7), 463-470.
- Öhman, A., Nilsson, S., & Beckung, E. (2010). Stretching treatment for infants with congenital muscular torticollis: physiotherapist or parents? A randomized pilot study. [Randomized Controlled Trial Research Support, Non-U.S. Gov't]. *Pm & R*, 2(12), 1073-1079.
- Pediatric American Physical Therapy Association (2012). Retrieved July 27, 2012, from <https://pediatricapta.org>
- Petronic, I., Brdar, R., Cirovic, D., Nikolic, D., Lukac, M., Janic, D., Knezevic, T. (2010). Congenital muscular torticollis in children: distribution, treatment duration and out come. *European journal of physical & rehabilitation medicine.*, 46(2), 153-157.
- Rabino, S.R., Peretz, S.R., Kastel-Deutch, T., & Tirosh, E. (2013). Factors affecting parental adherence to an intervention program for congenital torticollis. *Pediatric Physical Therapy*, 25(3):298-303.
- Rahlin, M. (2005). TAMO therapy as a major component of physical therapy intervention for an infant with congenital muscular torticollis: a case report.[Erratum appears in *Pediatr Phys Ther*. 2005 Winter;17(4):257]. [Case Reports]. *Pediatric Physical Therapy*, 17(3), 209-218.
- Schreiber, J., Stern, P., Marchetti, G., & Provident, I. (2009). Strategies to promote evidence-based practice in pediatric physical therapy: a formative evaluation pilot project. *Physical Therapy*, 89(9), 918-933.
- Statistical Package for the Social Sciences (SPSS). (2004). SPSS Graduate Pack 13.0 for Windows® (Version 13.0). Chicago, IL: Statistical Package for the Social Sciences, Inc
- SurveyMonkey.com (2012). Retrieved July 27, 2012 from <https://www.surveymonkey.com/>

Symmetric-Designs. The T.O.T. Collar for Congenital Muscular Torticollis. In S. Designs (Ed.). Salt Spring Island, BC, Canada.

Taylor, J. L. N. (1997). Developmental muscular torticollis: Outcomes in young children treated by physical therapy. *Pediatric Physical Therapy*, 9, 173-178.

Tessmer, A., Mooney, P., & Pelland, L. (2010). A developmental perspective on congenital muscular torticollis: a critical appraisal of the evidence. [Review]. *Pediatric Physical Therapy*, 22(4), 378-383.

Theratogs. What are TheraTogs? Retrieved October 13, 2015, from <http://www.theratogs.com>

Turtle. Retrieved October 13, 2015, from <http://www.turtle.com>

Total Motion PT. What is TMR? Retrieved October 13, 2015, from [http://www. totalmotionpt.com](http://www.totalmotionpt.com)

Upledger Institute. What is CranioSacral Therapy? Retrieved October 13, 2015, from <http://www.upledger.com>

## CHAPTER V: CONCLUSIONS

Despite the growing incidence of CMT and related co-morbidities, little was known about contemporary PT examination and treatment of CMT in the USA. It seemed likely that physical therapists in this country would have difficulty integrating the research on CMT into practice because much of the literature is medically oriented or based on impairment outcomes. It was not known if pediatric PTs in the USA who treat CMT are practicing according to the best available clinical evidence because of these potential barriers. The only way to determine this was to obtain a current description of practice. Although surveys of PT practice for CMT have been done in New Zealand (Luxford, et al., 2009), Canada (Fradette, et al., 2011), and among a network of PTs from Denmark and Sweden (Omidi-Kashani, et al., 2008), this had not yet been done in the USA. A description of PT practice in the USA through a national survey allows for a comparison of actual practice to the best available evidence. The result is not only a current description of practice but also the identification of similarities and discrepancies which exist between actual practice and the best available evidence.

This study describes current PT management of CMT in the USA through a national survey, to include: referral, examination, intervention, outcomes, and discharge. This study also determines the extent to which current practice is concordant with the best available evidence.



Three manuscripts are organized to identify the current state of PT practice for infants with CMT in the USA, and determine alignment with the recommended best evidence. In general, most PTs are practicing as per recommendations outlined, with the primary exceptions being: a relatively late age of referral to PT services, as suggested from the referral manuscript; visual estimation of cervical ROM and limited use of standardized tests to document outcome measures, as suggested from the examination manuscript; and a small percentage who use interventions with no evidence to support their use in CMT, as suggested from the intervention manuscript. These exceptions though, should not be viewed as faults, but rather areas for improvement.

Specifically, further research is needed with regard to the referral of infants with CMT. This survey was completed by physical therapists in the USA. It would be beneficial to validate the findings of this survey with parents and pediatricians. Similar questions regarding the age of identification, the age of referral to PT, the outcome of treatment, and their overall experience with physical therapy would help to ensure accuracy of the findings reported in this survey, and shed further light on the topic of referral of infants with CMT to PT. Additionally, more research is needed on the effect of physical therapy in the immediate postnatal period. Research thus far is mostly organized to identify the infant's age by month, with the majority of infants in a research study being more than one month old. There are few studies which

treat infants who are less than one month old. More specifically, there is no published research with the sole purpose to compare the physical therapy outcomes of infants with CMT who are less than one month old. If younger ages continue to show better outcomes, even in the immediate postnatal period (less than one month old), then further education and review of guidelines is needed for all healthcare professionals involved during delivery and postpartum. The results of these studies could have significant implications not just for physical therapists and pediatricians, but also for obstetricians, nurses, and midwives, as well.

Beyond referral, the findings from this survey suggest that even though the respondents are measuring appropriate components in their CMT exams, they do not use recommended objective tests for their measurements and they report using a variety of other tests. It would be beneficial to determine if US PTs are in favor of using nationally standardized forms during their examination and discharge of infants with CMT. A standardized CMT examination form would ensure that PTs are collecting and analyzing specific data, as well as allow for more accurate assessment of group outcomes across the population. Standardization of the CMT examination could include specific recommended objective testing, such as the Argenta scale for plagiocephaly, the FLACC scale for pain, and the MFS for head righting, as outlined in the CPG for CMT (Kaplan et al, 2013). Although one case report suggests positive responses from PTs and much improved consistency of

documentation when using a standardized CMT form (Gutierrez & Kaplan, 2016), it is not known if PTs nationwide would be agreeable to use such forms, or whether they fear less practice autonomy. Further research is needed to determine if US PTs would accept a standardized CMT examination form with recommended objective testing. If so, then it would also be necessary to ensure that PTs who use such forms are properly educated about the administration, timing, and scoring of the specific tests recommended, as well as to ensure that the workplace environment is supportive of evidence based practice.

Lastly, there are many interventions that survey respondents report using for which no peer reviewed evidence could be found for efficacy in patients with CMT. These include, but are not limited to, Total Motion Release©, Myofascial Release®, and Craniosacral Therapy©. However, a small percentage of the respondent PTs (4.3-15.1%) report using these interventions, despite a lack of evidence for infants with CMT. Most likely, these approaches are learned at continuing education courses, since the PTs in this sample most commonly selected continuing education courses as their *most important* strategy for developing their CMT approach. If instructors at continuing education courses are recommending a technique for infants with CMT, then they should also be presenting research to support their use with CMT. If no evidence exists, then that should be shared with course participants as well. Likewise, PTs who attend continuing education courses

should seek out references or request references from the instructor prior to deciding if the course is evidence based. The PT profession should uphold a standard of care which does not avoid the evidence, or lack thereof, but which shares the knowledge that exists, and promotes studies to demonstrate the efficacy of all available techniques. Additionally, clinicians who use interventions which don't have supporting evidence for their use with CMT should share this information with parents, obtain consent from parents to use these treatments, document any objective changes, and publish their results. (Kaplan, et al., 2013).

The survey results along with the above noted implications provide focus for future research on CMT, and give clinicians clarity regarding current practice. Based on the results, the survey suggests that the majority of respondent PTs are integrating the evidence on CMT into clinical practice. However, there are still some practices, such as: the late age of referral; limited standardized testing; and the implementation of non-evidence based interventions among a small percentage of the sample, which suggest the need for further research and knowledge translation. As a profession, we need to ensure that all PTs provide the best possible evidence based care for infants with CMT.

## REFERENCES

- AliMed®. [www.alimed.com](http://www.alimed.com). Retrieved August 22, 2012 from <http://www.alimed.com/foam-cervical-collar.html>
- American Academy of Pediatrics (AAP). Bright Futures Goals Retrieved June 22, 2012 from <https://brightfutures.aap.org/>
- American Physical Therapy Association (APTA). (1990). Referral Relationships. from American Physical Therapy Association - House of Delegates. Retrieved from <http://www.apta.org/>
- American Physical Therapy Association (APTA). (2003). *Interactive Guide to Physical Therapist Practice* from American Physical Therapy Association Criteria for Standards of Practice for Physical Therapy (2006). Retrieved from <http://www.apta.org/>
- American Physical Therapy Association (APTA) (Ed.). (2004). *A Normative Model of Physical Therapist Professional Education*.
- American Physical Therapy Association (APTA). (2009). Guidelines: Physical Therapy Documentation of Patient/Client Management, BOD G03-05-16-41. *Relationship to Vision 2020, Professionalism* Retrieved June 5, 2012 from <http://www.apta.org/>
- American Physical Therapy Association (APTA). (2015). FAQ: Direct access at the state level. Retrieved March 28, 2016 from <http://www.apta.org/>
- Apeldoorn, A. T., Ostelo, R. W., van Helvoirt, H., Fritz, J. M., de Vet, H. C. W., & van Tulder, M. W. (2010). The cost-effectiveness of a treatment-based classification system for low back pain: design of a randomised controlled trial and economic evaluation. *BMC Musculoskeletal Disorders*, 11(1), 58. doi: 10.1186/1471-2474-11-58
- Argenta, L. (2004). Clinical Classification of Positional Plagiocephaly. *The Journal of Craniofacial Surgery*, 15(3), 368-372.
- Ballock, R. T., & Song, K. M. (1996). The prevalence of nonmuscular causes of torticollis in children. *Journal of Pediatric Orthopedics*, 16(4), 500-504.

- Binder, H., Eng, G. D., Gaiser, J. F., & Koch, B. (1987). Congenital muscular torticollis: results of conservative management with long-term follow-up in 85 cases. *Arch Phys Med Rehabil*, 68(4), 222-225.
- Boricean, I., & Barar, A. (2011). Understanding Ocular Torticollis in Children. *Oftalmologia*, 55(1).
- Campbell, S. (1999). Test-Retest Reliability of the Test of Infant Motor Performance. *Pediatric Physical Therapy*, 11, 60-66.
- Campbell, S. (2005). The Test of Infant Motor Performance: Test User's Manual, Version 2.0
- Campbell, S., & Hedeker, D. (2001). Validity of the Test of Infant Motor Performance for discriminating among infants with varying risk for poor motor outcome. *Journal of Pediatrics*, 139, 546-551.
- Campbell, S., Kolobe, T., Wright, B., & Linacre, J. (2002). Validity of the Test of Infant Motor Performance for prediction of 6-, 9-, and 12-month scores on the Alberta Infant Motor Scale. *Developmental Medicine & Child Neurology*, 44, 263-272.
- Campbell, S., Liao, P., Girolami, G., Kolobe, T., Osten, E., & Lenke, M. (2007). The Test of Infant Motor Performance: A Self-Instructional CD Program, Version 4.1
- Canale, S. T., Griffin, D. W., & Hubbard, C. N. (1982). Congenital muscular torticollis. A long-term follow-up. *Journal of Bone & Joint Surgery - American Volume*, 64(6), 810-816.
- Carenzio, G., Carlisi, E., Morani, I., Tinelli, C., Barak, M., Bejor, M., & Dalla Toffola, E., (2015). Early rehabilitation treatment in newborns with congenital muscular torticollis. *European Journal of Physical and Rehabilitation Medicine*, 51(5): 539-545.
- Celayir, A. C. (2000). Congenital muscular torticollis: early and intensive treatment is critical. A prospective study. [Clinical Trial]. *Pediatrics International*, 42(5), 504-507.
- Chen, M.-M., Chang, H.-C., Hsieh, C.-F., Yen, M.-F., & Chen, T. H.-H. (2005). Predictive model for congenital muscular torticollis: analysis of 1021 infants with sonography. *Archives of Physical Medicine & Rehabilitation*, 86(11), 2199-2203.

- Cheng, J. C., Metreweli, C., Chen, T. M., & Tang, S. (2000). Correlation of ultrasonographic imaging of congenital muscular torticollis with clinical assessment in infants. *Ultrasound in Medicine & Biology*, 26(8), 1237-1241.
- Cheng, J. C., Tang, S. P., Chen, T. M., Wong, M. W., & Wong, E. M. (2000). The clinical presentation and outcome of treatment of congenital muscular torticollis in infants--a study of 1,086 cases. *Journal of Pediatric Surgery*, 35(7), 1091-1096.
- Cheng, J. C., Wong, M. W., Tang, S. P., Chen, T. M., Shum, S. L., & Wong, E. M. (2001). Clinical determinants of the outcome of manual stretching in the treatment of congenital muscular torticollis in infants. A prospective study of eight hundred and twenty-one cases. [Evaluation Studies]. *Journal of Bone & Joint Surgery - American Volume*, 83-A(5), 679-687.
- Chon, S.-C., Yoon, S.-I., & You, J. H. (2010). Use of the novel myokinetic stretching technique to ameliorate fibrotic mass in congenital muscular torticollis: an experimenter-blinded study with 1-year follow-up. *Journal of Back & Musculoskeletal Rehabilitation*, 23(2), 63-68.
- Christensen, E., Castle, K.B., & Hussey, E. (2015). Clinical feasibility of 2-dimensional video analysis of active cervical motion in congenital muscular torticollis. *Pediatric Physical Therapy*, 27(3):276-83.
- Christensen, C., Landsettle, A., Antoszewski, S., Ballard, B., Carey, H., & Pax Lowes, L. (2013). Conservative management of congenital muscular torticollis: An evidence-based algorithm and preliminary treatment parameter recommendations. *Physical & Occupational Therapy in Pediatrics*, 33(4), 453-466.
- Cincinnati Children's Hospital. (2009). Evidence-Based Care Guideline for Management of Congenital Muscular Torticollis in children age 0-36 months. In C. C. s. H. M. Center (Ed.).
- Cooperman, D. R. (1997). The Differential Diagnosis of Torticollis in Children. In K. Karmel-Ross (Ed.), *Torticollis: Differential Diagnosis, Assessment and Treatment, Surgical Management and Bracing* (pp. 1-11). Binghamton, NY: The Haworth Press.
- Corradi-Scalese, D., Sparrow, A., Amoroso, L. (2006). Chapter 27 - Congenital Muscular Torticollis. In J. Cahill, Cavanaugh, J., Wolff, A., Corradi-Scalese, D., Rudnick, H. (Ed.), *Postsurgical Rehabilitation*

Guidelines for the Orthopedic Clinician, Hospital for Special Surgery:  
Mosby Elsevier.

Cranial Technologies (1997). What is the DOC Band®? Retrieved  
September 7, 2012 from <http://www.cranialtech.com/>

Darrah, J., Piper, M., & Watt, M. (1998). Assessment of gross motor skills of  
at-risk infants: predictive validity of the Alberta Infant Motor Scale.  
*Developmental Medicine & Child Neurology*, 40, 485-491.

de Chalain, T. M. B., & Park, S. (2005). Torticollis associated with positional  
plagiocephaly: a growing epidemic. *Journal of Craniofacial Surgery*,  
16(3), 411-418.

Demirbilek, S., & Atayurt, H. F. (1999). Congenital muscular torticollis and  
sternomastoid tumor: results of nonoperative treatment. *Journal of  
Pediatric Surgery*, 34(4), 549-551.

Deutscher, D., Horn, S. D., Dickstein, R., Hart, D. L., Smout, R. J., Gutvirtz,  
M., & Ariel, I. (2009). Associations Between Treatment Processes,  
Patient Characteristics, and Outcomes in Outpatient Physical Therapy  
Practice. *Archives of Physical Medicine and Rehabilitation*, 90(8),  
1349-1363. doi: 10.1016/j.apmr.2009.02.005

Dillman, D., Smyth, J., Christian, L. . (2009). *Internet, Mail, and Mixed-Mode  
Surevys: The Tailored Design Method*. Hoboken, NJ: John Wiley &  
Sons, Inc.

Do, T. T. (2006). Congenital muscular torticollis: current concepts and review  
of treatment. [Review]. *Current Opinion in Pediatrics*, 18(1), 26-29.

Emery, C. (1994). The determinants of treatment duration for congenital  
muscular torticollis. [Research Support, Non-U.S. Gov't]. *Physical  
Therapy*, 74(10), 921-929.

Fosnaught, M. (2002). Direct access offers PTs a variety of new options.  
*APTA.org; PT in Motion*, (February). Retrieved from  
<http://www.apta.org/>

Fradette, J., Gagnon, I., Kennedy, E., Snider, L., & Majnemer, A. (2011).  
Clinical Decision Making Regarding Interevention Needs of Infants with  
Torticollis. *Pediatric Physical Therapy*, 249-256.



- Freed, S. S., & Coulter-O'Berry, C. (2004). Identification and Treatment of Congenital Muscular Torticollis in Infants. *Journal of Prosthetics and Orthotics*, 16(4 (Supplement)), S18-S23.
- Fritz, J. M. B., & Gerard P. (2007). Preliminary Examination of a Proposed Treatment-Based Classification System for Patients Receiving Physical Therapy Interventions for Neck Pain. *Physical Therapy*, 87(5), 513-524.
- Genna, C.W. (2015). Breastfeeding infants with congenital torticollis. *Journal of Human Lactation*, 31(2): 216-20.
- Graham, J. M., Gomez, M., Halberg, A. Earl, D.L., Kreutzman, J.T., Cui, J., & Guo, X. . (2005). Management of deformational plagiocephaly: repositioning versus orthotic therapy. *Journal of Pediatrics*, 146, 258-262.
- Groves, R. M., Fowler, F.J., Couper, M.P., Lepkowski, J.M., Singer, E., & Tourangeau, R. (Ed.). (2009). *Survey Methodology – Second Edition*. Hoboken, NJ: John Wiley & Sons, Inc.
- Gutierrez, D. & Kaplan, S.L. (2016). Aligning documentation with congenital muscular torticollis clinical practice guidelines: Administrative case report. *Physical Therapy*, 96(1), 111-120.
- Hagan, J. F., Shaw, J. S., & Duncan, P. (Ed.). (2008). *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, Third Edition*. . Elk Grove Village, IL: American Academy of Pediatrics.
- Hallberg, A., Standring, R.T., Ahsan, S. (2013). Congenital torticollis and saccular dysfunction: A case report. *JAMA Otolaryngology Head & Neck Surgery*, 139(6):639-42.
- Hosalkar, H., Gill, I. S., Gujar, P., & Shaw, B. A. (2001). Familial torticollis with polydactyly: manifestation in three generations. [Case Reports]. *American Journal of Orthopedics*, 30(8), 656-658.
- Hsieh, Y. Y., Tsai, F. J., Lin, C. C., Chang, F. C., & Tsai, C. H. (2000). Breech deformation complex in neonates. *Journal of Reproductive Medicine*, 45(11), 933-935.
- Hsu, T. C., Wang, C. L., Wong, M. K., Hsu, K. H., Tang, F. T., & Chen, H. T. (1999). Correlation of clinical and ultrasonographic features in

congenital muscular torticollis. [Comparative Study]. *Archives of Physical Medicine & Rehabilitation*, 80(6), 637-641.

Hummer, C. D., & MacEwen, G. D. (1972). The coexistence of torticollis and congenital dysplasia of the hip. *Journal of Bone & Joint Surgery - American Volume*, 54(6), 1255-1256.

Hylton, N. (1997). Infants with Torticollis: The Relationship between Asymmetric Head and Neck Positioning and Postural Development. In K. Karmel-Ross (Ed.), *Torticollis: Differential diagnosis, assessment, and treatment, surgical management, and bracing* (pp. 91-117). Binghamton, NY: The Haworth Press.

Hyman, M., & Sierra, J. (2010). *Marketing Research Kit for Dummies*. Hoboken: Wiley Publishing, Inc.

Infant Motor Performance Scales, LLC (IMPS). (2010). What is the TIMP? Retrieved June 19, 2012, from <http://www.thetimp.com>

Jacques, C., & Karmel-Ross, K. (1997). The Use of Splinting in Conservative and Post-Operative Treatment of Congenital Muscular Torticollis. In K. Karmel-Ross (Ed.), *Torticollis: Differential Diagnosis, Assessment and Treatment, Surgical Management and Bracing* (pp. 81-90). Binghamton, NY: The Haworth Press.

Jeong, K.-Y., Min, K.-J., Woo, J., & Yim, S.-Y. (2015). Craniofacial asymmetry in adults with neglected congenital muscular torticollis. *Annals of Rehabilitation Medicine*, 39(3): 440-450.

Joiner, E.R.A., Andras, L.M., & Skaggs, D.L. (2014). Screening for hip dysplasia in congenital muscular torticollis: is physical exam enough? *Journal of Children's Orthopaedics*, 8(2): 115-119.

Joyce, M. B., & de Chalain, T. M. B. (2005). Treatment of recalcitrant idiopathic muscular torticollis in infants with botulinum toxin type a. *Journal of Craniofacial Surgery*, 16(2), 321-327.

Kaplan, S., Coulter, C., & Feters, L. (2013). Physical therapy management of congenital muscular torticollis: An evidence-based clinical practice guideline. *Pediatric Physical Therapy*, 25(4), 348-394.

Karmel-Ross, K. (2006). Congenital Muscular Torticollis. In S. Campbell, Vander Linden, D., Palisano, R. (Ed.), *Physical Therapy for Children, Third Edition* (pp. 359-380). St. Louis: Elsevier Inc.

- Karmel-Ross, K., & Lepp, M. (1997). Assessment and Treatment of Children with Congenital Muscular Torticollis In K. Karmel-Ross (Ed.), *Torticollis: Differential diagnosis, assessment, and treatment, surgical management, and bracing* (pp. 21-67). Binghamton, NY: The Haworth Press.
- Kim, M. Y., Kwon, D. R., & Lee, H. I. (2009). Therapeutic effect of microcurrent therapy in infants with congenital muscular torticollis. [Controlled Clinical Trial]. *Pm & R*, 1(8), 736-739.
- Kinesio-USA. (2010). About Kinesio Retrieved August 22, 2012 from <http://www.kinesiotaping.com>
- Klackenberg, E. P., Elfving, B., Haglund-Akerlind, Y., Carlberg, E.B. (2005). Intra-rater reliability in measuring range of motion in infants with congenital muscular torticollis. *Advances in Physiotherapy*, 7, 84-91.
- Kwon, D. R., & Park, G. Y. (2014). Efficacy of microcurrent therapy in infants with congenital muscular torticollis involving the entire sternocleidomastoid muscle: a randomized placebo-controlled trial. *Clinical Rehabilitation*, 28(10), 983-991.
- Leach, J. (2006). Orthopedic Conditions. In S. Campbell, Vander Linden, D., Palisano, R. (Ed.), *Physical Therapy for Children, Third Edition* (pp. 491-495). St. Louis: Elsevier Inc.
- Lee, I. J., Lim, S. Y., Song, H. S., & Park, M. C. (2010). Complete tight fibrous band release and resection in congenital muscular torticollis. *Journal of Plastic, Reconstructive & Aesthetic Surgery: JPRAS*, 63(6), 947-953.
- Lee, J.-Y., Koh, S.-E., Lee, I.-S., Jung, H., Lee, J., Kang, J.-I., & Bang, H. (2013). The cervical range of motion as a factor affecting outcome in patients with congenital muscular torticollis. *Annals of Rehabilitation Medicine*, 37(2): 183-190.
- Lin, J. N., & Chou, M. L. (1997). Ultrasonographic study of the sternocleidomastoid muscle in the management of congenital muscular torticollis. *Journal of Pediatric Surgery*, 32(11), 1648-1651.
- Littlefield, T. R., Kelly, K. M., Pomatto, J. K., & Beals, S. P. (1999). Multiple-birth infants at higher risk for development of deformational plagiocephaly. *Pediatrics*, 103(3), 565-569.

- Littlefield, T. R., Kelly, K. M., Pomatto, J. K., & Beals, S. P. (2002). Multiple-birth infants at higher risk for development of deformational plagiocephaly: II. is one twin at greater risk? *Pediatrics*, 109(1), 19-25.
- Loveday, B. P. T., & de Chalain, T. B. (2001). Active Counterpositioning or Orthotic Device to Treat Positional Plagiocephaly? . *The Journal of Craniofacial Surgery*, 12(4).
- Lundy-Ekman. (2007). Cranial Nerves. In Lundy-Ekman (Ed.), *Neuroscience: Fundamentals for Rehabilitation - Third Edition*(3rd ed., pp. 360-370). St. Louis: Saunders Elsevier.
- Luxford, B., Hale, L., & Piggot, J. (2009). The physiotherapy management of infants with congenital muscular torticollis: a survey of current practice in New Zealand. *New Zealand Journal of Physiotherapy*, 37(3), 127-135.
- Mayson, T. (2007). Evidence Summary for Pediatric Rehabilitation Professionals, Outcomes Measures: The AIMS. *Evidence Summary for Pediatric Rehabilitation Professionals* Retrieved June 19, 2012, from [www.therapybc.ca/eLibrary/docs/Resources](http://www.therapybc.ca/eLibrary/docs/Resources)
- Mesa Community College (2012). The Developmental Psychology Student Netletter - Infants Retrieved July 27, 2012 from <https://www.mesacc.edu/>
- Miller, R. I., & Clarren, S. K. (2000). Long-term developmental outcomes in patients with deformational plagiocephaly. *Pediatrics*, 105(2), E26.
- Minihane, K. P., Grayhack, J. J., Simmons, T. D., Seshadri, R., Wysocki, R. W., & Sarwark, J. F. (2008). Developmental dysplasia of the hip in infants with congenital muscular torticollis. *American Journal of Orthopedics*, 37(9), E155-158; discussion E158.
- Mortenson, P. A., & Steinbok, P. (2006). Quantifying positional plagiocephaly: reliability and validity of anthropometric measurements. [Research Support, Non-U.S. Gov't]. *Journal of Craniofacial Surgery*, 17(3), 413-419.
- Murkoff, E. H. (Ed.). (2003). *What to Expect When You're Expecting*: What to Expect LLC.
- Norberg, S. (2001). Early Signs of Impaired Motor Development in Infants and Toddlers. *A Pediatric Perspective - Gillette Children's Specialty Healthcare (July/August 2001)*, 10, 1-6.

- Norkin, C., White, D. (Ed.). (1995). *Measurement of Joint Motion: A Guide to Goniometry, Second Edition*. Philadelphia: F.A. Davis.
- Nucci, P., Kushner, B. J., Serafino, M., & Orzalesi, N. (2005). A multi-disciplinary study of the ocular, orthopedic, and neurologic causes of abnormal head postures in children. [Research Support, Non-U.S. Gov't]. *American Journal of Ophthalmology*, 140(1), 65-68.
- Oh, A. K., Hoy, E. A., & Rogers, G. F. (2009). Predictors of severity in deformational plagiocephaly.[Erratum appears in J Craniofac Surg. 2009 Sep;20(5):1629-30]. *Journal of Craniofac Surgery*, 20 Suppl 1, 685-689.
- Öhman, A. (2012). The Immediate Effect of Kinesiology Taping on Muscular Imbalance for Infants with Congenital Muscular Torticollis. *Pm & R*, 4(7): 504-8.
- Öhman, A. (2015). The immediate effect of kinesiology taping on muscular imbalance in thte lateral flexors of the neck in infants: A randomized masked study. *PM&R*, 7(5): 494-498.
- Öhman, A., & Beckung, E. (2005). Functional and cosmetic status in children treated for congenital muscular torticollis as infants. *Advances in Physiotherapy*, 7, 135-140.
- Öhman, A., & Beckung, E. (2008). Reference values for range of motion and muscle function of the neck in infants. [Multicenter Study Research Support, Non-U.S. Gov't]. *Pediatric Physical Therapy*, 20(1), 53-58.
- Öhman, A., & Beckung, E. (2013). Children who had congenital torticollis as infants are not at higher risk for a delay in motor development at preschool age. *PM&R* 5(10): 850-855.
- Öhman, A., Mårdbrink, E.-L., Stensby, J., & Beckung, E. (2011). Evaluation of treatment strategies for muscle function in infants with congenital muscular torticollis *Physiotherapy Theory & Practice*, 27(7), 463-470.
- Öhman, A., Nilsson, S., & Beckung, E. (2009). Validity and reliability of the muscle function scale, aimed to assess the lateral flexors of the neck in infants. [Validation Studies]. *Physiotherapy Theory & Practice*, 25(2), 129-137.
- Öhman, A., Nilsson, S., & Beckung, E. (2010). Stretching treatment for infants with congenital muscular torticollis: physiotherapist or parents? A

randomized pilot study. [Randomized Controlled Trial Research Support, Non-U.S. Gov't]. *Pm & R*, 2(12), 1073-1079.

Öhman, A., Nilsson, S., Lagerkvist, A.-L., & Beckung, E. (2009). Are infants with torticollis at risk of a delay in early motor milestones compared with a control group of healthy infants? *Developmental Medicine & Child Neurology*, 51(7), 545-550.

Oleszek, J. L., Chang, N., Apkon, S. D., & Wilson, P. E. (2005). Botulinum toxin type a in the treatment of children with congenital muscular torticollis. [Comparative Study Research Support, Non-U.S. Gov't]. *American Journal of Physical Medicine & Rehabilitation*, 84(10), 813-816.

Olney, S., & Wright, M. (2006). Cerebral Palsy. In S. Campbell, Vander Linden, D., Palisano, R. (Ed.), *Physical Therapy for Children, Third Edition*. St. Louis: Saunders Elsevier.

Omidi-Kashani, F., Hasankhani, E. G., Sharifi, R., & Mazlumi, M. (2008). Is surgery recommended in adults with neglected congenital muscular torticollis? A prospective study. *BMC Musculoskeletal Disorders*, 9, 158.

Oxford Centre for Evidence-based Medicine (OCEBM). (2009). Oxford Centre for Evidence-based Medicine - Levels of Evidence (March 2009), *Levels of Evidence Table*, Produced by: Phillips, B., Ball, C., Sackett, D., Badenoch, D., Straus, S., Haynes, B., & Dawes, M., Updated by Howick, J., Retrieved from <http://www.cebm.net> on June 6, 2012

Ozuah, P. O., & Skae, C. C. (2008). Pediatric Care Online - AAP Textbook of Pediatric Care, Chapter 225: Torticollis. Retrieved May 29, 2012, from American Academy of Pediatrics

Pathways.org. (1992). Early Infant Assessment *Redefined*. Glenview, IL: Pathways Awareness Foundation.

Pediatric American Physical Therapy Association (2012). Retrieved July 27, 2012, from <https://pediatricapta.org>

Persing, J., James, H., Swanson, J., Kattwinkel, J., American Academy of Pediatrics Committee on Practice and Ambulatory Medicine, Section on Plastic Surgery, & Section on Neurological Surgery. (2003). Prevention and management of positional skull deformities in infants. *Pediatrics*, 112(1 Pt 1), 199-202.

- Petronic, I., Brdar, R., Cirovic, D., Nikolic, D., Lukac, M., Janic, D., . . . Knezevic, T. (2010). Congenital muscular torticollis in children: distribution, treatment duration and out come. *European journal of physical & rehabilitation medicine.*, 46(2), 153-157.
- Piper, M., & Darrah, J. (Eds.). (1994). *Motor Assessment of the Developing Infant*. Philadelphia: WB Sanders.
- Rabino, S.R., Peretz, S.R., Kastel-Deutch, T., & Tirosh, E. (2013). Factors affecting parental adherence to an intervention program for congenital torticollis. *Pediatric Physical Therapy*, 25(3):298-303.
- Rahlin, M. (2005). TAMO therapy as a major component of physical therapy intervention for an infant with congenital muscular torticollis: a case report.[Erratum appears in *Pediatr Phys Ther.* 2005 Winter;17(4):257]. [Case Reports]. *Pediatric Physical Therapy*, 17(3), 209-218.
- Rahlin, M., & Sarmiento, B. (2010). Reliability of still photography measuring habitual head deviation from midline in infants with congenital muscular torticollis. [Validation Studies]. *Pediatric Physical Therapy*, 22(4), 399-406.
- Rogers, G. F., Oh, A. K., & Mulliken, J. B. (2009). The role of congenital muscular torticollis in the development of deformational plagiocephaly. *Plastic & Reconstructive Surgery*, 123(2), 643-652.
- Schertz, M., Zuk, L., & Green, D. (2012). Long-term neurodevelopmental follow-up in children with congenital muscular torticollis. *Journal of Child Neurology*. doi: 10.1177/0883073812455693
- Schertz, M., Zuk, L., Zin, S., Nadam, L., Schwartz, D., & Bienkowski, R. S. (2008). Motor and cognitive development at one-year follow-up in infants with torticollis. [Multicenter Study]. *Early Human Development*, 84(1), 9-14.
- Shim, J., & Jang, H. (2008). Operative treatment of congenital torticollis. *Journal of Bone & Joint Surgery - British Volume*, 90(7), 934-939.
- Shim, J., Noh, K., & Park, S. (2004). Treatment of congenital muscular torticollis in patients older than 8 years. [Comparative Study]. *Journal of Pediatric Orthopedics*, 24(6), 683-688.
- Snyder, E. M., & Coley, B. D. (2006). Limited value of plain radiographs in infant torticollis. *Pediatrics*, 118(6), e1779-1784.

- Speltz, M. L., Collett, B. R., Stott-Miller, M., Starr, J. R., Heike, C., Wolfram-Aduan, A. M.,...Cunningham, M. L. (2010). Case-control study of neurodevelopment in deformational plagiocephaly. [Research Support, N.I.H., Extramural]. *Pediatrics*, 125(3), e537-542.
- Spittle, A., Doyle, L., Boyd, R. (2008). A systematic review of the clinimetric properties of neuromotor assessments for pre-term infants during the first year of life. *Developmental Medicine & Child Neurology*, 50, 254-266.
- Statistical Package for the Social Sciences (SPSS). (2004). SPSS Graduate Pack 13.0 for Windows® (Version 13.0). Chicago, IL: Statistical Package for the Social Sciences, Inc
- Steinberg, J. P., Rawlani, R., Humphries, L. S., Rawlani, V., & Vicari, F. A. (2015). Effectiveness of conservative therapy and helmet therapy for positional cranial deformation. *Plastic and Reconstructive Surgery*, 135(March), 833-842.
- Stellwagen, L., Hubbard, E., Chambers, C., & Jones, K. L. (2008). Torticollis, facial asymmetry and plagiocephaly in normal newborns. *Archives of Disease in Childhood*, 93(10), 827-831.
- SurveyMonkey.com (2012). Retrieved July 27, 2012 from <https://www.surveymonkey.com/>
- Symmetric-Designs. The T.O.T. Collar for Congenital Muscular Torticollis. In S. Designs (Ed.). Salt Spring Island, BC, Canada.
- Taylor, J. L. N. (1997). Developmental muscular torticollis: Outcomes in young children treated by physical therapy. *Pediatric Physical Therapy*, 9, 173-178.
- Tessmer, A., Mooney, P., & Pelland, L. (2010). A developmental perspective on congenital muscular torticollis: a critical appraisal of the evidence. [Review]. *Pediatric Physical Therapy*, 22(4), 378-383.
- Tucci, S., Hicks, J. E., Gross, E. G., Campbell, W., Danoff, J. (1986). Cervical motion assessment: a new, simple and accurate method. [Comparative]. *Arch Phys Med Rehabil*, 67(4), 225-230.
- van Vlimmeren, L. A., Helders, P. J. M., van Adrichem, L. N. A., & Engelbert, R. H. H. (2004). Diagnostic strategies for the evaluation of asymmetry



in infancy-a review. [Review]. *European Journal of Pediatrics*, 163(4-5), 185-191.

van Vlimmeren, L. A., Helders, P. J. M., van Adrichem, L. N. A., & Engelbert, R. H. H. (2006). Torticollis and plagiocephaly in infancy: therapeutic strategies. [Review]. *Pediatric Rehabilitation*, 9(1), 40-46.

VisionAssociates. (2012). Retrieved June 9, 2012 from <http://www.visionkits.com>

von Heideken, J., Green, D. W., Burke, S. W., Sindle, K., Denneen, J., Haglund-Akerlind, Y., & Widmann, R. F. (2006). The relationship between developmental dysplasia of the hip and congenital muscular torticollis. *Journal of Pediatric Orthopedics*, 26(6), 805-808.

Wall, V., & Glass, R. (2006). Mandibular asymmetry and breastfeeding problems: Experience from 11 cases. *J Hum Lact*, 22(3), 328-334.

Walsh, J. J., & Morrissy, R. T. (1998). Torticollis and hip dislocation. *Journal of Pediatric Orthopedics*, 18(2), 219-221.

Waternberg, N., Ben-Sasson, A., Goldfarb, R. (2016). Transient motor asymmetry among infants with congenital torticollis – description, characterization, and results of follow-up. *Pediatric Neurology*, 59:36-40.

Xia, J., Kennedy, K., Teichgraeber, J., Wu, K., Baumgartner, J., Gateno, J. . (2008). Nonsurgical treatment of deformational plagiocephaly: A systematic review. *Archives of Pediatrics & Adolescent Medicine* 162(8), 719-727.

Yim, S.-Y., Lee, I. Y., Cho, K. H., Kim, J. K., Lee, I. J., & Park, M.-C. (2010). The laryngeal cough reflex in congenital muscular torticollis: is it a new finding? *American Journal of Physical Medicine & Rehabilitation*, 89(2), 147-152.

Yu, C.-C., Wong, F.-H., Lo, L.-J., & Chen, Y.-R. (2004). Craniofacial deformity in patients with uncorrected congenital muscular torticollis: an assessment from three-dimensional computed tomography imaging. [Research Support, Non-U.S. Gov't]. *Plastic & Reconstructive Surgery*, 113(1), 24-33.

Zachman, Z., Traina, AJ, Keating, JC Jr, Bolles, ST, Braun-Porter, L. (1989). Interexaminer reliability and concurrent validity of two instruments for the measurement of cervical ranges of motion. [RCT]. *Journal of Manipulative & Physiological Therapeutics*, 12(3), 205-210.

## APPENDIX A – Summary of Literature Review

### Section 1: Referral

Suggested Best Practice	References & Level of Evidence	Research Gap	Survey Questions which Correspond
PTs who treat infants with torticollis posture should screen for non-muscular causes of torticollis. (Confidence Level: Strong)  Strong: Risk of not screening could be devastating.	(Kaplan, et al., 2013): Levels 2-4  (Ballock & Song, 1996; Cincinnati Children's Hospital, 2009): Level 4	It is not known how frequently PTs in the USA screen patients referred with a diagnosis of torticollis for non-muscular causes. It is also not known what screening tests PTs perform.	9,10
PTs should document the initial presentation of infants with CMT to include at least three elements: the type of CMT, the age at presentation to PT, and the limitation in cervical rotation. (Confidence Level: Strong)	(Cheng, et al., 2001), (Emery, 1994): Level 2c	It is not known if PTs in the USA document these three elements for all patients diagnosed with CMT.	18,19,20
		There is no literature which describes the age that infants in the USA who have CMT are referred to PT.	7,8,18
		There is no literature to describe who typically identifies a concern with the infant's posture, who typically refers the infant to PT, or the chief reason for seeking PT.	3,4,5
If a sternomastoid tumor is identified or the infant shows an adverse physiological reaction to stretching, the PT should	(Ozuah, 2008): Level 5  My own clinical experience: Level 5	It is not known if PTs in the USA consult with medical doctors to recommend imaging studies, what tests are	11-15

consult with the referring physician or primary medical doctor. The PT should also request a report of imaging studies that were done prior to or at time of PT referral. (Confidence Level: Moderate)	(Chen, et al., 2005): Level 2c  (Kaplan, et al., 2013): Level 2	typically recommended by PTs, or whether they request reports of medical testing that has been performed.	
--	---	---	--

## Section 2: Initial Examination

Suggested Best Practice	References & Level of Evidence	Research Gap	Survey Questions which Correspond
		It is not known if PTs in the USA use a clinical guideline, pathway or protocol to direct the examination of an infant with CMT.	23,24,25
At initial examination, PTs should document the date of the exam, the infant's birth date, age, position in utero, side of CMT, and use of forceps or vacuum at time of delivery (Confidence Level: Strong)	(Cheng, et al., 2001): Level 2c	There is no literature which reports how often PTs in the USA who examine infants with CMT document the date of the exam, the infant's birth date, age, position in utero, side of CMT, and use of forceps at delivery.	26
At initial exam, PTs should document the presence of a familial history of CMT, if it was a multiple birth delivery; and if there was a multiple birth, the order of the infant. (Confidence Level: Moderate)	(Hosalkar, et al., 2001): Level 4  (Littlefield, et al., 2002): Level 4	There is no literature which reports how often PTs in the USA who examine infants with CMT document the presence of a familial history of CMT, if it was a multiple birth, and if so, the order of the infant.	26

<p>Physical therapists should ask caretakers about any problems related to feeding. Concerns about reflux or the infant's ability to gain weight should be documented and reported to the medical doctor. (Confidence Level: Moderate);</p> <p>PTs should document that they have educated parents about optimal positioning alignment, and handling strategies that strengthen weaker muscles. (Confidence Level: Strong)</p>	<p>(Wall &amp; Glass, 2006): Level 4</p> <p>((Öhman, et al., 2011): Level 2c</p>	<p>There is no literature which reports how often PTs in the USA who examine infants with CMT document the presence of feeding problems in the infant.</p>	26
<p>Physical therapists should measure and record the degree of head tilt in infants with CMT. (Confidence Level: Strong);</p> <p>For an infant who is not able to sit, head tilt should be measured using a protractor in supine (Kim et al, 2009 – high intra-rater reliability). If the infant is able to sit independently, record the head tilt in sitting as measured with a goniometer - Level 5 evidence. Further research is needed for this measurement.</p>	<p>(Cheng, et al., 2001): Level 2c</p> <p>Methods: (Emery, 1994), (Kim, et al., 2009), (Norkin, 1995)</p>	<p>There is no literature which reports how often PTs in the USA who examine infants with CMT document the degree of head tilt. It is not known how PTs in the USA measure head tilt in infants with CMT.</p>	26,30
<p>Physical therapists should measure and record passive cervical rotation in infants with CMT with an arthrodial protractor . The infant should be positioned in supine, with shoulders stabilized, and head held beyond the end of the table or plinth. Passive rotation should be measured on both the affected and unaffected sides. (Confidence Level: Strong)</p>	<p>(Cheng, et al., 2001) Level 2c</p> <p>Method: (Cheng, et al., 2001) (Öhman &amp; Beckung, 2008) (Öhman, et al., 2010)</p>	<p>There is no literature which reports how often PTs in the USA who examine infants with CMT document passive cervical rotation. It is not known how PTs in the USA measure passive cervical rotation in infants with CMT.</p>	26,27

Physical therapists should measure and record active cervical rotation in infants with CMT (Confidence Level: Strong).  This could be recorded in supine for infants less than 3 months, or using a rotating stool for infants older than 3 months. Active cervical rotation should be measured on both the affected and unaffected sides, so that the PT can determine if there is a difference – Level 5 evidence. Further research is needed regarding this method.	(Kaplan, et al., 2013) Level 2  Method: (Kaplan, et al., 2013)	There is no literature which reports how often PTs in the USA who examine infants with CMT document active cervical rotation. It is not known how PTs in the USA measure active cervical rotation in infants with CMT.	26,28
Physical therapists should measure and record plagiocephaly with the objective classification scale for plagiocephaly designed by Argenta. (Confidence Level: Strong)	(Xia, 2008) Level 2a  (Cheng, Tang, et al., 2000) Level 2c  Method: (Kaplan, et al., 2013) (Cincinnati Children's Hospital, 2009)	There is no literature which reports how often PTs in the USA who examine infants with CMT document plagiocephaly. It is not known how PTs in the USA measure plagiocephaly in infants with CMT.	26,33
Physical therapists should document a standard review of the integumentary system on infants with CMT that is consistent with the Guide to Physical Therapist Practice. The results of the skin inspection should be documented in the medical record. (Confidence Level: Moderate)	(Cheng, et al., 2001) Level 2c  (Kaplan, et al., 2013) Level 5	There is no literature which reports how often PTs in the USA who examine infants with CMT document skin appearance.	26
Physical therapists should palpate the cervical musculature and document the type of CMT: sternomastoid tumor, muscular, or postural. If a tumor is present, the general location: upper, middle, and/or lower third of the SCM, and size should also be	Level 2 Evidence: (Cheng, Tang, et al., 2000) (Cheng, et al., 2001) (Kaplan, et al., 2013) (Lin & Chou, 1997)	There is no literature which reports how often PTs in the USA who examine infants with CMT document the type of CMT or the presence of a nodule or thick band in the SCM.	26

documented. (Confidence Level: Strong)	Method: (Cheng, Metreweli, et al., 2000) (Yim, et al., 2010)		
Physical therapists should measure and record passive cervical lateral flexion in both directions (Confidence Level: Strong). Measure with a large protractor or similar tool placed behind the infant's head in supine – Klackenberg et al, 2005 – high intra-rater reliability.	(Kaplan, et al., 2013), Level 2  Method: (Klackenberg, 2005) (Öhman & Beckung, 2008)	There is no literature which reports how often PTs in the USA who examine infants with CMT document passive cervical lateral flexion. It is not known how PTs in the USA measure passive cervical lateral flexion in infants with CMT.	26,29
Physical therapists should measure and record lateral head righting in infants with CMT on both the affected and unaffected sides (Confidence Level: Moderate). Measure using the five point Muscle Function Scale – Ohman & Beckung, 2008 – high intra & inter-rater reliability.	(Öhman & Beckung, 2005), Level 4  (Rahlin, 2005), Level 4  Method: (Öhman & Beckung, 2008) (Öhman, Nilsson, & Beckung, 2009)	There is no literature which reports how often PTs in the USA who examine infants with CMT document lateral head righting. It is not known how PTs in the USA measure lateral head righting in infants with CMT.	26,31
Physical therapists should measure and record neck flexor strength in infants with CMT who are 4 months of age or older, using the pull-to-sit technique. (Confidence Level: Moderate)	(Snyder & Coley, 2006) Level 2c  (Taylor, 1997), Level 4  Method: (Snyder & Coley, 2006)	There is no survey literature which reports how often PTs in the USA who examine infants with CMT document neck flexor strength. It is not known how PTs in the USA measure neck flexor strength in infants with CMT.	26,32
Physical therapists who work with infants with CMT should determine if there is hip dysplasia (Confidence Level: Strong). Signs may include: (a) limited hip abduction; (b) asymmetric hip folds; (c) a positive Barlow or Ortolani	(Cheng, Tang, et al., 2000), Level 2c  (Kaplan, et al., 2013), Level 2	There is no survey literature which reports how often PTs in the USA who examine infants with CMT document hip dysplasia. It is not known how PTs in the	26,35

sign if younger than 2-3 months; or (d) a leg length discrepancy.	Method: (Leach, 2006)	USA identify hip dysplasia in infants with CMT.	
Physical therapists should measure and record motor development in infants with CMT. (Confidence Level: Strong). PTs should use the TIMP as a measure of motor development in infants with CMT who are 0-4 months old. After four months of age, the AIMS should be used as a measure of motor development, but care should be taken by the clinician to document additional comments regarding asymmetries.	(Schertz, et al., 2008), Level 2a  (Kaplan, et al., 2013), Level 2  Methods: (Campbell, 2005) (Darrah, et al., 1998)	There is no literature which reports how often PTs in the USA who examine infants with CMT document motor development. It is not known how PTs in the USA describe motor development in infants with CMT.	26,36
Physical therapists should examine passive and active range of motion of both arms and legs during an infant's first visit. AROM should be examined visually first, and any discrepancies or limitations should then be objectively measured with a goniometer. PROM should be examined manually first, and then any discrepancies or limitations should be objectively measured with a goniometer. Findings should be documented in the medical record. (Confidence Level: Moderate)	(Hylton, 1997), Level 4  (Kaplan, et al., 2013), Level 2	There is no literature which reports how often PTs in the USA who examine infants with CMT document range of motion of the arms and legs.	26
Physical therapists should perform a thorough exam of muscle tone, primitive reflexes, postural reflexes and overall motor development to determine whether a referral for full neurological workup is warranted. Findings should be documented in the medical record. (Confidence Level: Moderate)	(Ballock & Song, 1996), Level 4  (Cincinnati Children's Hospital, 2009), Level 4  (Kaplan, et al., 2013), Level 2	There is no literature which reports how often PTs in the USA who examine infants with CMT document muscle tone and reflex testing. It is not known how PTs in the USA perform reflex testing and measure muscle tone in infants with CMT.	26,37,38



## Section 3: Interventions

Suggested Best Practice	References & Level of Evidence	Research Gap	Survey Questions which Correspond
		It is not known if PTs in the USA use a clinical guideline, pathway or protocol to direct the treatment of an infant with CMT.	40,41,42
Physical therapists should instruct parents in a HEP and perform passive stretching exercises, AROM, positioning (including handling strategies), and strengthening exercises as primary interventions for an infant with CMT (Confidence Level: Strong)	(Cheng, et al., 2001), Level 2c (Emery, 1994), Level 2c (Öhman, et al., 2011), Level 2c	It is not known which interventions PTs in the USA consistently choose to implement in the care of infants with CMT.	50
There is not enough evidence to include myokinetic stretching, microcurrent, kinesiology taping, TOT collar or soft cervical orthoses, TAMO, biofeedback, neurodevelopmental techniques, or soft tissue massage as primary interventions in the treatment of infants with CMT.	(Chon, et al., 2010) (Kim, et al., 2009) (Kinesio-USA, 2010) (Symmetric-Designs) (Rahlin, 2005)	It is not known how frequently US PTs use these secondary interventions.	
At this time, there is not enough research on the frequency of PT treatment for infants with CMT to make a specific recommendation, but the algorithm by Christensen et al (2013), provides a good start.	(Christensen, et al., 2013)	It is not known what factors are most important to PTs in deciding the frequency of treatment for infants with CMT.	43-49

Physical therapists should often re-examine the frequency of care that an infant is receiving, and make adjustments as needed. A higher frequency of care is desired for cases in which there is greater severity of symptoms or difficulty for parents to perform the HEP. Physical therapy should gradually decrease as the child progresses closer to discharge.	(Cincinnati Children's Hospital, 2009)	There is not enough research on the frequency of PT treatment for infants with CMT to make a specific recommendation.	
Physical therapists should recommend a referral to a cranial specialist for further assessment of infant's skull shape if suspect plagiocephaly or other cranial deformation. Confidence Level: Strong)	(Steinberg, et al., 2015), Level 2c	It is not known how often PTs recommend referral for a cranial orthosis or helmet.	51,52
		There is not enough evidence to justify the purchase of kinesiology tape or a TOT collar/ soft cervical orthosis as a primary intervention for infants with CMT, however there is evidence to suggest that a TOT collar may be a beneficial adjunct to the HEP of certain infants. It is not known how often PTs in the USA recommend these devices for infants with CMT.	51
PTs should evaluate the child with the device in place to determine its effectiveness at safely promoting proper head and trunk alignment, thus preventing head tilt toward the involved side. (Level 5).		It is not known how often PTs in the USA recommend head positioner devices for infants with CMT.	51

		It is not known how frequently PTs who work with infants with CMT recommend referral to other healthcare specialists.	52
--	--	---	----

#### Section 4: Discharge/ Discontinuation

	It is not known what the most common reasons are for discharge or discontinuation of an infant with CMT in the USA.	55-58
Although the guidelines provide a specific set of discharge criteria, there may be other factors that need to be considered for each patient. The guidelines represent a baseline of recommended practice. Additional criteria for discharge may be used based on the professional judgment of the physical therapist.	It is not known what factors PTs feel are most important in determining discharge or discontinuation of infants with CMT in the USA.	55-58
Physical therapists should discontinue conservative care as the sole service for infants with CMT when there is no further improvement after 3-12 months of PT. The exact amount of time is dependent upon the professional judgment of the PT in collaboration with the parents and primary pediatrician, as well as the age of service initiation.	It is not known what factors PTs feel are most important in determining discharge or discontinuation of infants with CMT in the USA.	55-58
It is recommended that a follow-up PT appointment be made for all patients with CMT who have been discharged from PT services, due to the possibility of recurrence after initial treatment , and reported compliance with PT at a later age . Based on the rapid	It is not known if PTs in the USA who work with infants with CMT schedule follow-up appointments at the time of discharge.	59

growth and motor development of infants in the first year of life, best practice would advocate for a follow-up within three months, or sooner if symptoms recur. (Confidence Level: Moderate)		
--	--	--

## APPENDIX B – Survey Cover Letter

***Welcome! Thank you for your interest in this survey on torticollis. Before you begin, please read the following consent letter which is a requirement of survey research at UMDNJ. After reading this letter, if you consent to participate in the survey, click on the “Next” button at the bottom of the page. If you have accessed this survey with your own unique link, you may exit at any point and resume at a later time if desired. Your answers are not submitted until you click on the “Done” button at the end of the survey. If you have any questions, feel free to contact me at the number listed below. Many thanks!!***

This consent letter is part of an informed consent process for a research study and it will give you information that will help you to decide whether you wish to volunteer for this research study. It will help you understand what the study is about and what will happen in the course of the study. If you have questions at any time during the research study, you should feel free to ask them and should expect to be given answers that you completely understand.

My name is Melanie D. O’Connell. I am a Board Certified Clinical Specialist in Pediatric Physical Therapy, and a Pre-Doctoral Fellow in the Department of Interdisciplinary Studies at University of Medicine and Dentistry of New Jersey in Newark. I am conducting a research project under the advisement of Sandra L. Kaplan, PT, PhD, to describe the current physical therapy management of Congenital Muscular Torticollis (CMT) in our country. The title of this research project is: “A Description of Physical Therapy Management for Infants with Congenital Muscular Torticollis in the United States of America.” To help achieve this objective, physical therapists that treat CMT are being asked to complete and return the following survey.

It is expected that approximately 250 physical therapists across the USA will participate in this survey. Participation is voluntary and will end once you complete and return the survey. You are not required to participate. If you choose not to participate, nothing bad will happen to you because of your decision.

If you decide to participate in this study, the information you give to us will be kept private and any protected health information that you provide, such as your name or e-mail address, will be kept confidential. We will ensure that your information is kept confidential by using a random number code on the survey instead of your name, e-mail address, or any other information that may be used to identify you. Only I, Melanie D. O’Connell, or a member of the research personnel, will be able to link the code number to your e-mail address and this information will only be kept until the study is complete (September 2013). The results of the survey will be reported as group data, and no association of responses will be linked to individual respondents.

In addition to key members of the research team, the following people are allowed to inspect survey results:

- The Institutional Review Board (a committee that reviews research studies)
- Officials of the University of Medicine and Dentistry of New Jersey
- The Department of Health and Human Services, Office for Human Research Protections (OHRP) (a regulatory agency that oversees human subject research)

You will not benefit personally by taking part in this study. You may feel uncomfortable answering some of the questions. If you do not want to complete the survey after you begin, you do not have to do so. If you feel that you have been harmed as a result of your participation in this study and/or if you have any questions about taking part in this study, you can call me, Melanie D. O'Connell (study investigator), Dept of Interdisciplinary Studies at 973-972-2459. If you have questions about your rights as a research subject, please call: IRB Chair Person, Robert Fechtner, or IRB Director: Carlotta Rodriguez at (973) 972-3608.

## APPENDIX C - Survey

### ***Instructions***

For multiple choice questions, please click on the button next to your selected response. Most of the questions allow only one response. For questions that allow more than one response, this will be indicated. If a question does not apply to your practice, you may skip it.

There is a progress bar at the bottom of each page which shows the percentage of questions you have completed. In order to advance to the next page and save your answers, click on the “Next” Button at the bottom of the page.

If you have accessed this survey with your own unique link and you want to take a break, but resume the survey later, you should save your answers from the current page by clicking “Next,” then click on the “Exit” Button in the top right corner. You may later resume the survey by accessing it from your unique link in the e-mail invitation.

When you are done, and want to submit your answers, click on the “Done” Button. You will not be allowed to return to the survey after you click “Done.”

Thank you again for your willingness to share your expertise and time.

## **HEADS UP! A SURVEY OF PHYSICAL THERAPY MANAGEMENT FOR INFANTS WITH CONGENITAL MUSCULAR TORTICOLLIS (CMT)**

INSTRUCTIONS: Please fill in the circle for the answer that BEST describes your practice. The first two questions require a response.

1. Are you a licensed physical therapist working in the United States of America?

- ☐<sub>1</sub> Yes  
☐<sub>2</sub> No

**\*If the answer to Question #1 is YES... please PROCEED to Question #2.**

**\*If the answer to Question #1 is NO..... please STOP here, and return the survey in envelope. Thanks!**

2. Have you examined and treated at least two patients with Congenital Muscular Torticollis (CMT) in the past six months?

- ☐<sub>1</sub> Yes  
☐<sub>2</sub> No

**\*If the answer to Question #2 is YES... please PROCEED with the survey.**

**\*If the answer to Question #2 is NO..... please STOP here, and return the survey in envelope. Thanks!**



### **SECTION 1: Referral**

This section of questions will be used to determine the referral patterns of patients with CMT, as observed by physical therapists in the USA.

3. Who is the first person to typically identify a concern with the child's posture?

- ☐<sub>1</sub> Parent
- ☐<sub>2</sub> Friend or Family Member other than parent Pediatrician/ Family Doctor
- ☐<sub>3</sub> Pediatrician or Family Doctor
- ☐<sub>4</sub> Day Care Provider or Staff Member
- ☐<sub>5</sub> Other (Please specify): \_\_\_\_\_

4. Who is the first person to typically refer the parents to PT for their child's head and neck position?

- ☐<sub>1</sub> Parent independently decides to use direct access to physical therapy services
- ☐<sub>2</sub> Parent requests referral to PT from doctor
- ☐<sub>3</sub> Pediatrician/ Family Doctor refers the parent to PT
- ☐<sub>4</sub> Specialist (neurologist, plastic surgeon, orthopedist) refers the parent to PT
- ☐<sub>5</sub> Friend or Family Member suggests PT to the parent
- ☐<sub>6</sub> Day Care Center Provider or Staff Member suggests PT to the parent
- ☐<sub>7</sub> Other (Please specify): \_\_\_\_\_

5. What is typically the parent's primary concern? (May select more than one.)

- ☐<sub>1</sub> Doctor requested PT evaluation
- ☐<sub>2</sub> Head tilt (problem with lateral flexion)
- ☐<sub>3</sub> Prefers to only look to one side (problem with rotation)
- ☐<sub>4</sub> Can't lift head up (problem with extension)
- ☐<sub>5</sub> Facial asymmetry
- ☐<sub>6</sub> Abnormal head shape
- ☐<sub>7</sub> Feeding difficulty
- ☐<sub>8</sub> Not meeting developmental milestones
- ☐<sub>9</sub> Other: \_\_\_\_\_

6. Do parents report being told by their pediatrician...

- a.) That the observed asymmetry will resolve on its own?  
☐<sub>1</sub> Always   ☐<sub>2</sub> Usually   ☐<sub>3</sub> Sometimes   ☐<sub>4</sub> Rarely   ☐<sub>5</sub> Never
- b.) To wait for a period of time before referral to PT?  
☐<sub>1</sub> Always   ☐<sub>2</sub> Usually   ☐<sub>3</sub> Sometimes   ☐<sub>4</sub> Rarely   ☐<sub>5</sub> Never
- c.) To see a specialist (orthopedist, neurologist) before referral to PT?  
☐<sub>1</sub> Always   ☐<sub>2</sub> Usually   ☐<sub>3</sub> Sometimes   ☐<sub>4</sub> Rarely   ☐<sub>5</sub> Never

d.) That the parents should do stretches, but don't need immediate referral to PT?

- ☐<sub>1</sub> Always   ☐<sub>2</sub> Usually   ☐<sub>3</sub> Sometimes   ☐<sub>4</sub> Rarely   ☐<sub>5</sub> Never

e.) To start PT immediately?

- ☐<sub>1</sub> Always   ☐<sub>2</sub> Usually   ☐<sub>3</sub> Sometimes   ☐<sub>4</sub> Rarely   ☐<sub>5</sub> Never

f.) If told to wait for PT, typically how long do they wait?

\_\_\_\_\_

Questions 7 & 8 refer to the youngest and oldest patient ever referred to you with CMT for their **FIRST EPISODE of PT.** (This does NOT include children who were discharged and have returned for further treatment or children who were treated at another facility before seeing you.) Please be sure to specify the child's age using either: days, weeks, months, or years.

7. What age was the youngest child ever referred to you? \_\_\_\_\_ (days / weeks / months / years - circle)

8. What age was the oldest child ever referred to you? \_\_\_\_\_ (days / weeks / months / years - circle)

9. Do you screen for non-muscular causes of torticollis prior to a full initial examination?

- ☐<sub>1</sub> Always   ☐<sub>2</sub> Usually   ☐<sub>3</sub> Sometimes   ☐<sub>4</sub> Rarely   ☐<sub>5</sub> Never

10. If yes, what type of screening do you typically perform? Circle all that apply.

- ☐<sub>1</sub> Visual screen  
☐<sub>2</sub> Neurological screen  
☐<sub>3</sub> Hip Screen  
☐<sub>4</sub> Head shape or plagiocephaly  
☐<sub>5</sub> Skin screen  
☐<sub>6</sub> Musculoskeletal screen  
☐<sub>7</sub> Gastrointestinal screen  
☐<sub>8</sub> Cardiovascular screen  
☐<sub>9</sub> Developmental screen  
☐<sub>10</sub> Other: \_\_\_\_\_

11. How often do infants referred to you with CMT arrive with previously completed imaging tests (x-ray, US, MRI...)?

- ☐<sub>1</sub> Always   ☐<sub>2</sub> Usually   ☐<sub>3</sub> Sometimes   ☐<sub>4</sub> Rarely   ☐<sub>5</sub> Never

**12.** After your evaluation of a patient with CMT, how often do you consult with the primary medical doctor about medical imaging tests that might be helpful for diagnosis or prognosis?

- ☐<sub>1</sub> Always   ☐<sub>2</sub> Usually   ☐<sub>3</sub> Sometimes   ☐<sub>4</sub> Rarely   ☐<sub>5</sub> Never

**13.** Which imaging studies do you typically find most useful for the management of patients with CMT? (Circle all that apply)

- ☐<sub>1</sub> Cervical X-ray  
☐<sub>2</sub> Cervical Ultrasound  
☐<sub>3</sub> Cervical MRI or CT Scan  
☐<sub>4</sub> Spine (thoracic & lumbar) images  
☐<sub>5</sub> Hip X-ray  
☐<sub>6</sub> Hip Ultrasound  
☐<sub>5</sub> Imaging studies are not useful for my management of patients with CMT

**14.** How do these imaging studies influence your management of patients with CMT?

---



---

**15.** When medical imaging tests are completed, do you acquire the results of those studies?

- ☐<sub>1</sub> Always   ☐<sub>2</sub> Usually   ☐<sub>3</sub> Sometimes   ☐<sub>4</sub> Rarely   ☐<sub>5</sub> Never

**16.** In your practice, do you use a process or system to classify patients with CMT?

- ☐<sub>1</sub> Yes  
☐<sub>2</sub> No

**17.** If so, what classification system do you use with your patients with CMT? Please name the author(s) or describe the system.

---



---



---

**18.** Rank in order (from most common to least common) the age at which your patients with CMT are typically first referred for PT evaluation. (Of the six age ranges listed below, select #1 for the most common, #2 for the second most common, #3 for the third most common, #4..., #5..., and #6 for the least common age at referral.)

- |                            |         |
|----------------------------|---------|
| a.) Less than 1 month..... | # _____ |
| b.) 1-2 months.....        | # _____ |
| c.) 3-4 months.....        | # _____ |

- d.) 5-6 months..... # \_\_\_\_\_  
 e.) 7-12 months..... # \_\_\_\_\_  
 f.) More than 12 months..... # \_\_\_\_\_

**19.** Thinking about the infants with CMT who you have examined, how common is...

a.) A lateral head tilt?

- ☐<sub>1</sub> Very Common (80% or more)  
☐<sub>2</sub> Somewhat Common (60-79%)  
☐<sub>3</sub> Common (40-59%)  
☐<sub>4</sub> Not Common (20-39%)  
☐<sub>5</sub> Rare (Less than 20%)  
☐<sub>6</sub> I don't measure this, so I can't estimate

b.) A passive rotation deficit of 5-15 degrees?

- ☐<sub>1</sub> Very Common (80% or more)  
☐<sub>2</sub> Somewhat Common (60-79%)  
☐<sub>3</sub> Common (40-59%)  
☐<sub>4</sub> Not Common (20-39%)  
☐<sub>5</sub> Rare (Less than 20%)  
☐<sub>6</sub> I don't measure this, so I can't estimate

c.) A passive rotation deficit of more than 15 degrees?

- ☐<sub>1</sub> Very Common (80% or more)  
☐<sub>2</sub> Somewhat Common (60-79%)  
☐<sub>3</sub> Common (40-59%)  
☐<sub>4</sub> Not Common (20-39%)  
☐<sub>5</sub> Rare (Less than 20%)  
☐<sub>6</sub> I don't measure this, so I can't estimate

d.) Plagiocephaly?

- ☐<sub>1</sub> Very Common (80% or more)  
☐<sub>2</sub> Somewhat Common (60-79%)  
☐<sub>3</sub> Common (40-59%)  
☐<sub>4</sub> Not Common (20-39%)  
☐<sub>5</sub> Rare (Less than 20%)  
☐<sub>6</sub> I don't measure this, so I can't estimate

e.) Confirmed hip dysplasia?

- ☐<sub>1</sub> Very Common (80% or more)  
☐<sub>2</sub> Somewhat Common (60-79%)  
☐<sub>3</sub> Common (40-59%)  
☐<sub>4</sub> Not Common (20-39%)  
☐<sub>5</sub> Rare (Less than 20%)  
☐<sub>6</sub> I don't measure this, so I can't estimate

**20.** Thinking about the infants with CMT who you have examined, estimate the percentage that fit each of these categories. (The sum of your choices should equal 100%).

a.) Postural Group (Baby tilts head but there is no limitation in ROM and no fibrotic change in SCM.)..... \_\_\_\_\_ %

b.) Muscular Group (Limited ROM and thickened SCM but no palpable tumor ..... \_\_\_\_\_ %

c.) Sternomastoid Tumor Group (Palpable tumor in SCM.)..... \_\_\_\_\_ %

Total = 100%

**21.** What is your typical caseload of patients per week? \_\_\_\_\_

**22.** What is your typical caseload of patients with CMT per week? \_\_\_\_\_

## **SECTION 2: Examination**

This section of questions will be used to determine the patterns of physical therapy examination for patients with CMT, as described by physical therapists in the USA.

**23.** Do you routinely use an evidence based clinical guideline, pathway, or protocol to direct the initial examination of your patients with CMT?

☐<sub>1</sub> Yes

☐<sub>2</sub> No

**24.** If yes, who developed the examination guideline, pathway, or protocol that you use?

---



---

**25.** Please rank order the importance of the following five strategies for developing your examination approach. (Please rate all five strategies, but you should only check one response per column & per row.) My CMT examination approach is developed by...

	Most Important 1	Very Important 2	Important <sub>3</sub>	Somewhat Important <sub>4</sub>	Least Important <sub>5</sub>
a.) My own personal review of the literature.					
b.) Lessons taught to me by colleague(s).					
c.) Lessons taught at continuing education courses.					
d.) A process or protocol developed at my workplace.					
e.) A published evidence-based guideline/ pathway/ protocol.					

**26.** How often do you record the following objective information in a typical CMT exam? Check 1 box per row.

	Always <sub>1</sub>	Usually <sub>2</sub>	Some- times <sub>3</sub>	Rarely <sub>4</sub>	Never <sub>5</sub>
a.) Date of examination					
b.) Family history of CMT					
c.) Maternal Labor & Delivery					
d.) Baby position in utero					
e.) Gender					
f.) Age of child					
g.) Side of Torticollis					
h.) Type of CMT (Postural, Muscular, SMT)					
i.) Passive Cervical Rotation					
j.) Active Cervical Rotation					
k.) Passive Cervical Lateral Flexion					
l.) Lateral Head Position (static)					
m.) Lateral head righting					
n.) Neck Flexor Strength					
o.) Craniofacial Asymmetry					
p.) Skin Integrity					
q.) Feeding Problems					
r.) Vision					
s.) Shoulder Symmetry					
t.) Hip Symmetry					
u.) Motor Development					
v.) ROM of UEs					
w.) ROM of LEs					
x.) Presence of Hip Dysplasia					
y.) Neurological Reflex Testing					
z.) Muscle Tone					
aa.) Presence of nodule/thick band in SCM					
ab.) Pain					
ac.)					
Other: _____					

**27.** What device/ method do you typically use to measure passive neck rotation in patients with CMT?

- ☐<sub>1</sub> Standard Goniometer  
☐<sub>2</sub> Cervical Goniometer  
☐<sub>3</sub> Protractor  
☐<sub>4</sub> Tape Measure  
☐<sub>5</sub> Still Photography  
☐<sub>6</sub> Visual Estimation  
☐<sub>7</sub> I don't routinely measure cervical PROM  
☐ Other (Please specify): \_\_\_\_\_

**28.** What device/ method do you typically use to measure active neck rotation in patients with CMT?

- ☐<sub>1</sub> Standard Goniometer  
☐<sub>2</sub> Cervical Goniometer  
☐<sub>3</sub> Protractor  
☐<sub>4</sub> Tape Measure  
☐<sub>5</sub> Still Photography  
☐<sub>6</sub> Visual Estimation  
☐<sub>7</sub> I don't routinely measure cervical PROM  
☐ Other (Please specify): \_\_\_\_\_

**29.** What device/method do you typically use to measure passive neck lateral flexion in patients with CMT?

- ☐<sub>1</sub> Standard Goniometer  
☐<sub>2</sub> Cervical Goniometer  
☐<sub>3</sub> Protractor  
☐<sub>4</sub> Tape Measure  
☐<sub>5</sub> Still Photography  
☐<sub>6</sub> Visual Estimation  
☐<sub>7</sub> I don't routinely measure cervical AROM  
☐ Other (Please specify): \_\_\_\_\_

**30.** What device/method do you use to measure the infant's static head tilt position when the infant is...

	Standard Goniometer <sub>1</sub>	Cervical Goniometer <sub>2</sub>	Pro-tractor <sub>3</sub>	Tape Measure <sub>4</sub>	Still Photo <sub>5</sub>	Visual Estimate <sub>6</sub>	I don't routinely measure it in this position <sub>7</sub>
a.) Lying supine?							



b.)Sitting upright?							
---------------------	--	--	--	--	--	--	--

Other (Please specify): \_\_\_\_\_

**31.** How do you typically measure lateral head righting in your patients with CMT?

- ☐<sub>1</sub> Manual Muscle Test
- ☐<sub>2</sub> Neck Righting Reactions
- ☐<sub>3</sub> Pull-to-Sit Maneuver
- ☐<sub>4</sub> Muscle Function Scale
- ☐<sub>5</sub> I don't routinely measure cervical strength
- ☐ Other (Please specify): \_\_\_\_\_

**32.** How do you typically measure neck flexor strength in your patients with CMT?

- ☐<sub>1</sub> Manual Muscle Test
- ☐<sub>2</sub> Neck Righting Reactions
- ☐<sub>3</sub> Pull-to-Sit Maneuver
- ☐<sub>4</sub> Muscle Function Scale
- ☐<sub>5</sub> I don't routinely measure neck flexor strength
- ☐ Other (Please specify): \_\_\_\_\_

**33.** How do you typically measure craniofacial asymmetry in your patients with CMT?

- ☐<sub>1</sub> Subjectively (min, mod, severe)
- ☐<sub>2</sub> Anthropometric measurements using cranial vault calipers
- ☐<sub>3</sub> Flexible ruler
- ☐<sub>4</sub> Still photography
- ☐<sub>5</sub> Laser scan
- ☐<sub>6</sub> A standardized plagiocephaly scale
- ☐<sub>7</sub> I don't routinely measure craniofacial asymmetry
- ☐ Other (Please specify): \_\_\_\_\_

**34.** What method best describes how you assess visual attention & tracking in patients with CMT?

- ☐<sub>1</sub> Move a brightly colored object or familiar face across their visual field
- ☐<sub>2</sub> Shine a penlight to check the pupillary reflex
- ☐<sub>3</sub> Specific Cranial nerve testing for optic, oculomotor, and trochlear nerves
- ☐<sub>4</sub> No specific test but use general observation of the child's eye movements during the exam
- ☐<sub>5</sub> I don't routinely examine vision
- ☐ Other (Please specify): \_\_\_\_\_

**35.** How do you typically identify potential hip dysplasia in your patients with CMT?

- ☐<sub>1</sub> Ortolani Maneuver
- ☐<sub>2</sub> Barlow Maneuver
- ☐<sub>3</sub> Abnormal hip range of motion

- ☐<sub>4</sub> Asymmetry of hip folds
- ☐<sub>5</sub> Leg length discrepancy
- ☐<sub>6</sub> No specific test but palpate for hip clicking with general movement on exam
- ☐<sub>7</sub> I don't routinely check for hip dysplasia
- ☐ Other (Please specify): \_\_\_\_\_

**36.** What tool or method do you typically use to describe motor development in patients with CMT?

- ☐<sub>1</sub> Alberta Infant Motor Scale (AIMS)
- ☐<sub>2</sub> Test of Infant Motor Performance (TIMP)
- ☐<sub>3</sub> Bayley Scales of Infant Development (BSID)
- ☐<sub>4</sub> Peabody Developmental Motor Scale (PDMS)
- ☐<sub>5</sub> Bruinks Osteretsky
- ☐<sub>6</sub> No specific test but general observation of motor development
- ☐<sub>7</sub> I don't routinely measure motor development
- ☐ Other (Please specify): \_\_\_\_\_

**37.** What neurological responses do you check in your patients with CMT? (Select all that apply.)

- ☐<sub>1</sub> ATNR
- ☐<sub>2</sub> Babinski
- ☐<sub>3</sub> Neonatal neck righting
- ☐<sub>4</sub> Moro
- ☐<sub>5</sub> Equilibrium responses
- ☐<sub>6</sub> Palmar grasp
- ☐<sub>7</sub> Plantar grasp
- ☐<sub>8</sub> Flexor withdrawal
- ☐<sub>9</sub> Positive support
- ☐<sub>10</sub> Lateral Head Righting (4+ months)
- ☐<sub>11</sub> I don't routinely check neurological responses
- ☐ Other (Please specify): \_\_\_\_\_

**38.** How do you typically measure and describe muscle tone in your patients with CMT?

- ☐<sub>1</sub> Modified Ashworth Scale
- ☐<sub>2</sub> Manually examine and describe using terms: Hypo, Hyper, Normal, Abnormal, Mixed
- ☐<sub>3</sub> I don't routinely measure/document muscle tone
- ☐ Other (Please specify): \_\_\_\_\_

**39.** How do you typically measure and describe pain in your patients with CMT?

- ☐<sub>1</sub> Standard Face Pain Scale
- ☐<sub>2</sub> FLACC Pain Scale
- ☐<sub>3</sub> Narrative description of baby's response during exam
- ☐<sub>4</sub> Standardized Infant Pain Scale
- ☐<sub>5</sub> I don't routinely measure/document pain

☐ Other (Please specify): \_\_\_\_\_

### **SECTION 3: Treatment**

This section of questions will be used to determine the patterns of physical therapy treatment for patients with CMT, as described by physical therapists in the USA.

**40.** Do you routinely use an evidence based clinical guideline, pathway, or protocol to direct the treatment of your patients with CMT?

☐<sub>1</sub> Yes

☐<sub>2</sub> No

**41.** If yes, who developed the treatment guideline, pathway, or protocol that you use?

---



---

**42.** Please rank order the importance of the following five strategies for developing your treatment approach. (Please rate all five strategies, but you should only select one response per column.) My CMT treatment approach is developed by...

	Most Important <sub>1</sub>	Very Important <sub>2</sub>	Important <sub>3</sub>	Somewhat Important <sub>4</sub>	Least Important <sub>5</sub>
a.) My own personal review of the literature.					
b.) Lessons taught to me by colleague(s).					
c.) Lessons taught at continuing education courses.					
d.) A process or protocol developed at my workplace					
e.) A published evidence-based guideline/ pathway/ protocol.					

**43.** What are the three most important factors that determine frequency of scheduled appointments (1x/week, 2x/week, 3x/week...) for a patient with CMT? Select three choices.

	Following a guideline/ pathway/ protocol <sub>1</sub>		Parental schedule <sub>8</sub>
	Severity of head tilt <sub>2</sub>		Availability of PT appointments <sub>9</sub>
	Severity of the limitation in cervical rotation <sub>3</sub>		Doctor request <sub>10</sub>
	Parent request <sub>4</sub>		PT perception of parent's ability to adhere to HEP <sub>11</sub>
	Number of visits authorized by insurance <sub>5</sub>		Parent's comfort in their own ability to adhere to HEP <sub>12</sub>
	Age of the child <sub>6</sub>		Distance family travels to PT <sub>13</sub>
	Type of CMT <sub>7</sub>		Presence of co-morbidities <sub>14</sub>
	Other: _____ <sub>15</sub>		

**44.** What is the typical frequency of PT visits that you recommend in the first four weeks of treatment for an infant who shows a postural preference (no muscle tightness nor mass), and who is...

	1x/week <sub>1</sub>	2x/week <sub>2</sub>	3x/week <sub>3</sub>	4x/week <sub>4</sub>	5x/week <sub>5</sub>	1x /month <sub>6</sub>	2x/ month <sub>7</sub>
0-3 months old							
4-6 months old							
7+ months old							

**45.** What is the typical frequency of PT visits that you recommend in the first four weeks of treatment for an infant who shows a muscular torticollis (muscle tightness but no mass), and who is...

	1x/week <sub>1</sub>	2x/week <sub>2</sub>	3x/week <sub>3</sub>	4x/week <sub>4</sub>	5x/week <sub>5</sub>	1x/month <sub>6</sub>	2x/month <sub>7</sub>
0-3 months old							
4-6 months old							
7+ months old							

**46.** What is the typical frequency of PT visits that you recommend in the first four weeks of treatment for an infant who shows a sternomastoid tumor (palpable mass in SCM), and who is...

	1x/week <sub>1</sub>	2x/week <sub>2</sub>	3x/week <sub>3</sub>	4x/week <sub>4</sub>	5x/week <sub>5</sub>	1x/month <sub>6</sub>	2x/month <sub>7</sub>
0-3 months old							
4-6 months old							
7+ months old							

**47.** What factor most often causes you to increase the scheduled frequency?

---



---

**48.** What factor most often causes you to decrease the scheduled frequency?

---



---

**49.** How much time do you typically schedule for a treatment session of a patient with CMT?

- ☐<sub>1</sub> 15 minutes  
☐<sub>2</sub> 30 minutes  
☐<sub>3</sub> 45 minutes  
☐<sub>4</sub> 1 hour  
☐<sub>5</sub> 1.5 hours

○<sub>6</sub> 2 hours

**50.** How often do you use each of the following interventions in the treatment of patients with CMT? (Please rate each intervention.)

	Always <sub>1</sub>	Usually <sub>2</sub>	Some- times <sub>3</sub>	Rarely <sub>4</sub>	Never <sub>5</sub>	Don't Know this Tx <sub>6</sub>
PROM exercises: Stretching						
Positioning Program						
AROM exercises						
Strengthening: Head Righting Reactions						
Strengthening: Trunk Equilibrium Responses						
Developmental Exercises						
Neurodevelopmental Techniques						
Physioball						
Bolster or Wedge						
TAMO						
Microcurrent						
Total Motion Release						
Myokinetic Stretching						
Soft Tissue Massage						
Kinesio® Tape						
Tubular Orthosis for Torticollis (TOT collar™ )						
Parent Home Instruction						
Other (Please specify):						

**51.** How often do you recommend the following equipment/ positioning devices (recognizing that some may require consultation with the referring MD)? Please rate each of the following options.

	Always <sub>1</sub>	Usually <sub>2</sub>	Sometimes <sub>3</sub>	Rarely <sub>4</sub>	Never <sub>5</sub>
Gel cushion head rest					
TOT collar™					
Foam Collar					
Kinesio® Tape					
Head positioner device					

Physioball					
Cranial orthosis or helmet					
Other:					

**52.** How often do you consult with the referring doctor to recommend the following specialists or procedures? Please rate each of the following options.

	Always <sub>1</sub>	Usually <sub>2</sub>	Sometimes <sub>3</sub>	Rarely <sub>4</sub>	Never <sub>5</sub>
Cranial Orthotist					
Orthopedist					
Neurologist					
Ophthalmologist					
Cervical X-ray Ultrasound					
Ultrasound					
For Botox					
For Surgery					
Other: _____					

**53.** Given your best estimate, how many treatment sessions does a patient with CMT typically receive for an episode of care (initial exam to discharge)?

- ☐<sub>1</sub> 5 sessions  
☐<sub>2</sub> 6-10 sessions  
☐<sub>3</sub> 11-15 sessions  
☐<sub>4</sub> 16-20 sessions  
☐<sub>5</sub> 21-25 sessions  
☐<sub>6</sub> 26-30 sessions  
☐<sub>7</sub> More than 30 sessions  
☐ Other (Please specify): \_\_\_\_\_

**54.** Given your best estimate, what is the typical duration for an episode of care (initial exam to discharge) of a patient with CMT?

- ☐<sub>1</sub> One month or less  
☐<sub>2</sub> More than 1 month – up to 3 months  
☐<sub>3</sub> More than 3 months – up to 6 months  
☐<sub>4</sub> More than 6 months – up to 9 months  
☐<sub>5</sub> More than 9 months – up to 1 year  
☐<sub>6</sub> More than one year  
☐ Other (Please specify): \_\_\_\_\_



***You are more than halfway done!! Your input is extremely valuable! Fellow therapists & patients will appreciate your efforts. If you have accessed this survey with your own unique link and you want to take a break, click "Next" to save your previous responses & then "Exit". You may resume the survey later by clicking on your own unique link in the e-mail invitation.***

#### **SECTION 4: Discharge/ Discontinuation**

This section of questions will be used to determine the patterns of discharge or discontinuation of physical therapy for patients with CMT, as described by physical therapists in the USA.

**55.** In your best estimate, are the majority of your patients with CMT...

- ☐<sub>1</sub> discharged from PT by you based on your clinical decision.  
☐<sub>2</sub> discontinued from PT for reasons not based on your clinical decision.

**56.** How important are the following criteria in determining discharge of patients with CMT?

	Most Important <sub>1</sub>	Very Important <sub>2</sub>	Important <sub>3</sub>	Somewhat Important <sub>4</sub>	Least Important <sub>5</sub>	Not at all Important <sub>6</sub>
a.) Straight Head Posture						
b.) Full Passive Cervical Lateral Flexion						
c.) Full Passive Cervical Rotation						
d.) Within 5 degrees of Full PROM						
e.) Full Active Cervical Lateral Flexion						
f.) Full Active Cervical Rotation						
g.) Within 5 degrees of Full AROM						
h.) Achieving Developmental Milestones						
i.) Age of the Child						
j.) Symmetrical Righting Reactions						
k.) Parental Compliance with HEP						
l.) Parental Satisfaction						
m.) Other: Specify _____						

**57.** In your best estimate, when physical therapy for a patient with CMT has been discontinued, what is typically the reason for discontinuation? Please rate each potential reason separately. Physical Therapy is discontinued because:

a.) There is a health insurance limitation on visits or payment for services.  
☐<sub>1</sub> Always   ☐<sub>2</sub> Usually   ☐<sub>3</sub> Sometimes   ☐<sub>4</sub> Rarely   ☐<sub>5</sub> Never

b.) The parent decided that the patient no longer needs PT.  
☐<sub>1</sub> Always   ☐<sub>2</sub> Usually   ☐<sub>3</sub> Sometimes   ☐<sub>4</sub> Rarely   ☐<sub>5</sub> Never

c.) The physician decided that the patient no longer needs PT.  
☐<sub>1</sub> Always   ☐<sub>2</sub> Usually   ☐<sub>3</sub> Sometimes   ☐<sub>4</sub> Rarely   ☐<sub>5</sub> Never

d.) The parent/ caretaker no longer shows up for appointments.  
☐<sub>1</sub> Always   ☐<sub>2</sub> Usually   ☐<sub>3</sub> Sometimes   ☐<sub>4</sub> Rarely   ☐<sub>5</sub> Never

e.) The patient is referred for surgery.  
☐<sub>1</sub> Always   ☐<sub>2</sub> Usually   ☐<sub>3</sub> Sometimes   ☐<sub>4</sub> Rarely   ☐<sub>5</sub> Never

f.) Other: Please specify:

---

**58.** Given your best estimate, what percentage of your patients with CMT are discharged from PT with full resolution? (Full resolution defined as: full PROM, full AROM, midline head position, and symmetrical righting reactions)

\_\_\_\_\_ %

**59.** At time of discharge, when do you typically schedule a follow-up PT visit for your patients with CMT:

- ☐<sub>1</sub> 1 month after discharge  
☐<sub>2</sub> 3 months after discharge  
☐<sub>3</sub> 6 months after discharge  
☐<sub>4</sub> One year after discharge  
☐<sub>5</sub> I don't typically schedule a follow-up visit but recommend parents call if problem occurs.  
☐<sub>6</sub> I don't typically schedule a follow-up visit nor recommend it.  
☐<sub>7</sub> Other: Please specify:
- 

**60.** In your best estimate, what percentage of patients with CMT return after they were discharged for a second episode of care? \_\_\_\_\_ %

### **SECTION 5: Outcomes**

This section of questions will be used to determine the patterns of physical therapy outcomes for patients with CMT, as described by physical therapists in the USA.

**61.** What group data on CMT are being collected and analyzed by you or your facility to improve outcomes of patient care? (Circle all that apply.)

- a.) ☐ Number of visits to complete episode of care
- b.) ☐ Cost of services
- c.) ☐ Achievement of patient goals (posture, head tilt, ROM)
- d.) ☐ Parental satisfaction
- e.) ☐ Comparison of interventions
- f.) ☐ Use of standardized measures in documentation
- g.) ☐ The change in scores on standardized measures
- h.) ☐ Assessment of pain
- i.) ☐ Referral sources
- j.) ☐ Reasons for payment denial
- k.) ☐ No group data on the management of CMT is being analyzed at my workplace.
- l.) ☐ Other: \_\_\_\_\_

**62.** If group data is collected and analyzed, with whom are outcomes shared? Circle all that apply.

- a.) ☐ Staff
- b.) ☐ Administration
- c.) ☐ Third party payors
- d.) ☐ Consumers
- e.) ☐ Professional publications
- f.) ☐ Promotional materials
- g.) ☐ Other: \_\_\_\_\_

**63.** Has service delivery changed as a result of the group data on outcomes?

☐<sub>1</sub> Yes

☐<sub>2</sub> No

**64.** How has service delivery changed as a result of the group data on outcomes?

---



---



---

**65.** In your opinion, how important are each of the following clinical attributes in predicting improvement for your patients with CMT?

	Most Important 1	Very Important 2	Im- portant <sub>3</sub>	Somewhat Important <sub>4</sub>	Least Important 5
a.) Ethnicity					
b.) Gender					
c.) Maternal Delivery (vaginal vs. C-Section)					
d.) Length of baby at birth					
e.) Position in utero (vertex vs. breech)					
f.) Primiparity vs. multiple birth					
g.) Birth Order (first vs. second born)					
h.) Age at Presentation					
i.) Initial degree of passive cervical rotation					
j.) Type of CMT (tumor, postural, muscular)					
k.) Degree of craniofacial asymmetry					
l.) Presence of hip dysplasia					
m.) Initial degree of head tilt					
n.) Initial degree of active cervical rotation					
o.) Parental adherence to treatment					
p.) Presence of plagiocephaly					
q.) Other co-morbidities: Please specify: _____ _____					

## **SECTION 6: Clinical Setting**

This section of questions will be used to describe the clinical settings around the country in which patients with CMT are treated.

**66.** Where do you treat infants with CMT? If you work in more than one setting, check all that apply.

- ☐<sub>1</sub> Outpatient (independently owned) clinic
- ☐<sub>2</sub> Outpatient hospital based clinic or satellite
- ☐<sub>3</sub> Early Intervention Program (children identified through IDEA)
- ☐<sub>4</sub> Home Based Services (children not identified through IDEA)
- ☐<sub>5</sub> Other: \_\_\_\_\_

**67.** Where do you treat the greatest number of patients with CMT? Select one.

- ☐<sub>1</sub> Outpatient (independently owned) clinic
- ☐<sub>2</sub> Outpatient hospital based clinic or satellite
- ☐<sub>3</sub> Early Intervention Program (children identified through IDEA)
- ☐<sub>4</sub> Home Based Services (children not identified through IDEA)
- ☐<sub>5</sub> Other: \_\_\_\_\_

***Almost Done! You have about 25 Easy Questions left. Please keep going – Thank you!***

For the following 12 questions, refer to the clinical setting in which you treat the greatest number of infants with CMT.

**68.** In which state do you primarily treat infants with CMT? \_\_\_\_\_

**69.** In your state, is CMT alone a “qualifying diagnosis” to be eligible for services through the Early Intervention Program?

- ☐<sub>1</sub> Yes
- ☐<sub>2</sub> No
- ☐<sub>3</sub> Not Sure
- ☐ Other: \_\_\_\_\_

**70.** How would you describe the location of your practice?

- ☐<sub>1</sub> Rural
- ☐<sub>2</sub> Urban
- ☐<sub>3</sub> Suburban

**71.** What is the typical distance that families travel to receive P.T. services?

- ☐<sub>1</sub> None, I travel to them
- ☐<sub>2</sub> 1-5 miles
- ☐<sub>3</sub> 6-10 miles
- ☐<sub>4</sub> 11-20 miles
- ☐<sub>5</sub> 21-30 miles
- ☐<sub>6</sub> 31-40 miles
- ☐<sub>7</sub> 40+ miles

**72.** Are you required to pass a competency exam before working with patients with CMT?

- ☐<sub>1</sub> Yes
- ☐<sub>2</sub> No

**73.** Does your practice offer a torticollis clinic or group therapy for infants with CMT?

- ☐<sub>1</sub> Yes
- ☐<sub>2</sub> No

**74.** At your facility, do PTAs treat patients with CMT?

- ☐<sub>1</sub> Yes
- ☐<sub>2</sub> No

**75.** Do you co-treat your patients with CMT with...? (Check all that apply.)

- ☐ a.) OTs
- ☐ b.) SLPs
- ☐ c.) PTAs
- ☐ d.) COTAs
- ☐ e.) Orthotists
- ☐ f.) Educators
- ☐ g.) Early Intervention Specialists
- ☐ h.) Other: \_\_\_\_\_

### **SECTION 7: Professional Development**

**76.** Are you a member of the APTA?

- ☐<sub>1</sub> Yes  
☐<sub>2</sub> No

**77.** Are you a member of the Section on Pediatrics?

- ☐<sub>1</sub> Yes  
☐<sub>2</sub> No

**78.** Are you an Board Certified Pediatric Clinical Specialist?

- ☐<sub>1</sub> Yes  
☐<sub>2</sub> No

**79.** Have you completed a Board Certified Clinical Residency in Pediatrics?

- ☐<sub>1</sub> Yes  
☐<sub>2</sub> No

**80.** Have you taken CEU courses on CMT?

- ☐<sub>1</sub> Yes  
☐<sub>2</sub> No

**81.** In your opinion, what training has been the most beneficial for your overall management of patients with CMT? (Check all that apply.)

- ☐<sub>1</sub> PT Education: Entry level school  
☐<sub>2</sub> APTA Certified Pediatric Residency Program  
☐<sub>3</sub> Post Professional Education/ Advanced Studies (MS, MA, tDPT, PhD)  
☐<sub>4</sub> Continuing Education Courses  
☐<sub>5</sub> Webinars  
☐<sub>6</sub> "On the Job" Training  
☐<sub>7</sub> Personal Review of the Literature  
☐<sub>8</sub> Participation in online PT community  
☐<sub>9</sub> Personal Experience  
☐<sub>10</sub> Other: \_\_\_\_\_

**82.** If a standardized classification system were developed for the varying presentations of CMT, would you use it?

- ☐<sub>1</sub> Yes  
☐<sub>2</sub> No  
☐ Other (Please explain): \_\_\_\_\_



83. If a standardized examination form were available, would you use it?

☐<sub>1</sub> Yes

☐<sub>2</sub> No

☐ Other (Please specify): \_\_\_\_\_

84. How many years have you been practicing physical therapy?

\_\_\_\_\_

85. How many years have you practiced in pediatrics?

\_\_\_\_\_

86. How many years have you worked with infants with CMT?

\_\_\_\_\_

87. What aspect of CMT management would you like to see additional guidance on?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

88. If there were one resource/ document/ tool that might help to improve your practice, what would that be?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

89. How did you access and complete this survey?

☐<sub>1</sub> Accessed it from the web link posted in the e-newsletter from the Section on Pediatrics

☐<sub>2</sub> E-mailed [headsupcmt@yahoo.com](mailto:headsupcmt@yahoo.com) as seen on Section on Education Listserv

☐<sub>3</sub> E-mailed [headsupcmt@yahoo.com](mailto:headsupcmt@yahoo.com) as seen on Section on Pediatrics Listserv

☐<sub>4</sub> Received info from SOP State Rep & e-mailed [headsupcmt@yahoo.com](mailto:headsupcmt@yahoo.com)

☐<sub>5</sub> Colleague sent me the e-mail address for [headsupcmt@yahoo.com](mailto:headsupcmt@yahoo.com)

☐<sub>6</sub> Received request via phone call to my place of work

☐<sub>7</sub> Other: \_\_\_\_\_

**COMMENTS** Please share your comments about any aspect of this survey OR on the management of CMT that may not have been addressed.

---

---

---

---

---

**THANK YOU!!!** You have finished the survey! I truly appreciate the time and effort which you gave to complete this survey, and thereby contribute to the research on pediatric physical therapy. I sincerely thank you! As a token of my appreciation for your participation in this survey, you may receive a sheet of fun children's stickers. If you are interested, please send your name and address in a separate e-mail to [headsupcmt@yahoo.com](mailto:headsupcmt@yahoo.com), with "Stickers" posted as the subject. Thank you!

## APPENDIX D – Survey Results

### **SECTION 1: REFERRAL**

This section of questions will be used to determine the referral patterns of patients with CMT, as observed by physical therapists in the USA.

**3. Who is the first person to typically identify a concern with the child's posture?**

- |   |            |                |
|---|------------|----------------|
| <input type="radio"/> <sub>1</sub> Parent.....  | <b>121</b> | <b>(57.9%)</b> |
| <input type="radio"/> <sub>2</sub> Friend or Family Member other than parent Pediatrician/ Family Doctor..... | <b>7</b>   | <b>(3.3%)</b>  |
| <input type="radio"/> <sub>3</sub> Pediatrician or Family Doctor.....   | <b>72</b>  | <b>(34.4%)</b> |
| <input type="radio"/> <sub>4</sub> Day Care Provider or Staff Member.....                                     | <b>1</b>   | <b>(0.5%)</b>  |
| <input type="radio"/> <sub>5</sub> Other (Please specify): _____  | <b>8</b>   | <b>(3.8%)</b>  |

**209 responses**

**4. Who is the first person to typically refer the parents to PT for their child's head and neck position?**

- |  |            |                |
|--|------------|----------------|
| <input type="radio"/> <sub>1</sub> Parent independently decides to use direct access to physical therapy services..... | <b>0</b>   | <b>(0.0%)</b>  |
| <input type="radio"/> <sub>2</sub> Parent requests referral to PT from doctor.....                                     | <b>17</b>  | <b>(8.1%)</b>  |
| <input type="radio"/> <sub>3</sub> Pediatrician/ Family Doctor refers the parent to PT.....                            | <b>178</b> | <b>(84.8%)</b> |
| <input type="radio"/> <sub>4</sub> Specialist (neurologist, plastic surgeon, orthopedist) refers the parent to PT..... | <b>6</b>   | <b>(2.9%)</b>  |
| <input type="radio"/> <sub>5</sub> Friend or Family Member suggests PT to the parent.....                              | <b>3</b>   | <b>(1.4%)</b>  |
| <input type="radio"/> <sub>6</sub> Day Care Center Provider or Staff Member suggests PT to the parent.....             | <b>1</b>   | <b>(0.5%)</b>  |
| <input type="radio"/> <sub>7</sub> Other (Please specify): _____   | <b>5</b>   | <b>(2.4%)</b>  |

**210 responses**

**5. What is typically the parent's primary concern? (May select more than one.)**

- |  |           |                |
|--|-----------|----------------|
| <input type="radio"/> <sub>1</sub> Doctor requested PT evaluation..... | <b>35</b> | <b>(16.7%)</b> |
|--|-----------|----------------|

<input type="radio"/> <sub>2</sub> Head tilt (problem with lateral flexion).....	114	(54.3%)
<input type="radio"/> <sub>3</sub> Prefers to only look to one side (problem with rotation).....	149	(71.0%)
<input type="radio"/> <sub>4</sub> Can't lift head up (problem with extension).....	12	(5.7%)
<input type="radio"/> <sub>5</sub> Facial asymmetry.....	27	(12.9%)
<input type="radio"/> <sub>6</sub> Abnormal head shape.....	128	(61.0%)
<input type="radio"/> <sub>7</sub> Feeding difficulty.....	3	(1.4%)
<input type="radio"/> <sub>8</sub> Not meeting developmental milestones.....	15	(7.1%)
<input type="radio"/> <sub>9</sub> Other:_____	1	(0.5%)

**210 responses**

**6. Do parents report being told by their pediatrician...**

a.) That the observed asymmetry will resolve on its own?

<input type="radio"/> <sub>1</sub> Always	<input type="radio"/> <sub>2</sub> Usually	<input type="radio"/> <sub>3</sub> Sometimes	<input type="radio"/> <sub>4</sub> Rarely	<input type="radio"/> <sub>5</sub> Never
2 (0.9%)	37 (17.8%)	136 (65.4%)	24 (11.5%)	9 (4.3%)

**208 responses**

b.) To wait for a period of time before referral to PT?

<input type="radio"/> <sub>1</sub> Always	<input type="radio"/> <sub>2</sub> Usually	<input type="radio"/> <sub>3</sub> Sometimes	<input type="radio"/> <sub>4</sub> Rarely	<input type="radio"/> <sub>5</sub> Never
3 (1.5%)	59 (28.9%)	91 (44.6%)	37 (18.1%)	14 (6.9%)

**204 responses**

c.) To see a specialist (orthopedist, neurologist) before referral to PT?

<input type="radio"/> <sub>1</sub> Always	<input type="radio"/> <sub>2</sub> Usually	<input type="radio"/> <sub>3</sub> Sometimes	<input type="radio"/> <sub>4</sub> Rarely	<input type="radio"/> <sub>5</sub> Never
0 (0.0%)	7 (3.4%)	32 (15.7%)	135 (66.2%)	30 (14.7%)

**204 responses**

d.) That the parents should do stretches, but don't need immediate referral to PT?

<input type="radio"/> <sub>1</sub> Always	<input type="radio"/> <sub>2</sub> Usually	<input type="radio"/> <sub>3</sub> Sometimes	<input type="radio"/> <sub>4</sub> Rarely	<input type="radio"/> <sub>5</sub> Never
5 (2.4%)	30 (14.6%)	103 (50.2%)	51 (24.9%)	16 (7.8%)

**205 responses**

e.) To start PT immediately?

<input type="radio"/> <sub>1</sub> Always	<input type="radio"/> <sub>2</sub> Usually	<input type="radio"/> <sub>3</sub> Sometimes	<input type="radio"/> <sub>4</sub> Rarely	<input type="radio"/> <sub>5</sub> Never
6 (3.0%)	76 (37.4%)	100 (49.3%)	19 (9.4%)	2 (0.9%)

**203 responses**

f.) If told to wait for PT, typically how long do they wait? \_\_\_\_\_

**147 TOTAL responses to this question:**

**112 people responded with wait time:** ie) 2 months, 3 months, 4-6 months

**30 people responded with age of child:** ie) 3 months old or 4 month old well baby visit.

**5 people responded with “next well baby visit,”** but gave no indication of the time.

Of those who responded with a wait time (**112**), the following results apply:

a.) Less than a month.....	<b>8</b>	<b>(7%)</b>
b.) 1-2 months.....	<b>43</b>	<b>(38.4%)</b>
c.) 3-4 months.....	<b>46</b>	<b>(41.1%)</b>
d.) 5-6 months.....	<b>11</b>	<b>(9.8%)</b>
e.) More than 6 months.....	<b>4</b>	<b>(3.6%)</b>

Of those who responded with an age (**30**), the following results apply:

a.) 1-2 months old.....	<b>2</b>	<b>(6.7%)</b>
b.) 3-4 months old.....	<b>13</b>	<b>(43.3%)</b>
c.) 5-6 months old.....	<b>12</b>	<b>(40.0%)</b>
d.) More than 6 months old.....	<b>3</b>	<b>(10.0%)</b>

Questions 7 & 8 refer to the youngest and oldest patient ever referred to you with CMT for their **FIRST EPISODE of PT.** (This does NOT include children who were discharged and have returned for further treatment or children who were treated at another facility before seeing you.) Please be sure to specify the child's age using either: days, weeks, months, or years.

**7.** What age was the youngest child ever referred to you? \_\_\_\_\_ (days / weeks/ months/years - circle)

**Range = 2 days – 6 months Mean = 1.45 months Std dev = 1.02 months**

**8.** What age was the oldest child ever referred to you? \_\_\_\_\_ (days / weeks/ months/years – circle)

**Range = 1 – 18 years Mean = 2.36 years Std dev = 2.60 years**

**9.** Do you screen for non-muscular causes of torticollis prior to a full initial examination?

☐ Always      ☐ Usually      ☐ Sometimes      ☐ Rarely      ☐ Never

**122 (59.2%)    52 (25.2%)    18 (8.7%)    7 (3.4%)    7 (3.4%)**

**206 responses**

**10.** If yes, what type of screening do you typically perform? Circle all that apply.

- |   |            |                |
|---|------------|----------------|
| <input type="radio"/> <sub>1</sub> Visual screen.....               | <b>169</b> | <b>(81.3%)</b> |
| <input type="radio"/> <sub>2</sub> Neurological screen.....         | <b>132</b> | <b>(63.5%)</b> |
| <input type="radio"/> <sub>3</sub> Hip Screen.....                  | <b>134</b> | <b>(64.4%)</b> |
| <input type="radio"/> <sub>4</sub> Head shape or plagiocephaly..... | <b>181</b> | <b>(87.0%)</b> |
| <input type="radio"/> <sub>5</sub> Skin screen.....                 | <b>60</b>  | <b>(28.8%)</b> |
| <input type="radio"/> <sub>6</sub> Musculoskeletal screen.....      | <b>151</b> | <b>(72.6%)</b> |
| <input type="radio"/> <sub>7</sub> Gastrointestinal screen.....     | <b>84</b>  | <b>(40.4%)</b> |
| <input type="radio"/> <sub>8</sub> Cardiovascular screen.....       | <b>25</b>  | <b>(12.0%)</b> |
| <input type="radio"/> <sub>9</sub> Developmental screen.....        | <b>158</b> | <b>(76.0%)</b> |
| <input type="radio"/> <sub>10</sub> Other: _____.....               | <b>11</b>  | <b>(5.3%)</b>  |

**208 responses**

**11.** How often do infants referred to you with CMT arrive with previously completed imaging tests (x-ray, US, MRI...)?

- |   |  |  |   |  |
|---|--|--|---|--|
| <input type="radio"/> <sub>1</sub> Always | <input type="radio"/> <sub>2</sub> Usually | <input type="radio"/> <sub>3</sub> Sometimes | <input type="radio"/> <sub>4</sub> Rarely | <input type="radio"/> <sub>5</sub> Never |
| <b>3 (1.4%)</b>                           | <b>3 (1.4%)</b>                            | <b>29 (14.0%)</b>                            | <b>124 (59.9%)</b>                        | <b>48 (23.2%)</b>                        |

**207 responses**

**12.** After your evaluation of a patient with CMT, how often do you consult with the primary medical doctor about medical imaging tests that might be helpful for diagnosis or prognosis?

- |   |  |  |   |  |
|---|--|--|---|--|
| <input type="radio"/> <sub>1</sub> Always | <input type="radio"/> <sub>2</sub> Usually | <input type="radio"/> <sub>3</sub> Sometimes | <input type="radio"/> <sub>4</sub> Rarely | <input type="radio"/> <sub>5</sub> Never |
| <b>2 (0.9%)</b>                           | <b>7 (3.4%)</b>                            | <b>79 (38.0%)</b>                            | <b>98 (47.1%)</b>                         | <b>22 (10.6%)</b>                        |

**208 responses**

**13.** Which imaging studies do you typically find most useful for the management of patients with CMT? (Circle all that apply)

- |  |            |                |
|--|------------|----------------|
| <input type="radio"/> <sub>1</sub> Cervical X-ray.....                   | <b>108</b> | <b>(51.9%)</b> |
| <input type="radio"/> <sub>2</sub> Cervical Ultrasound.....              | <b>42</b>  | <b>(20.2%)</b> |
| <input type="radio"/> <sub>3</sub> Cervical MRI or CT Scan.....          | <b>39</b>  | <b>(18.8%)</b> |
| <input type="radio"/> <sub>4</sub> Spine (thoracic & lumbar) images..... | <b>26</b>  | <b>(12.5%)</b> |
| <input type="radio"/> <sub>5</sub> Hip X-ray.....                        | <b>43</b>  | <b>(20.7%)</b> |
| <input type="radio"/> <sub>6</sub> Hip Ultrasound.....                   | <b>33</b>  | <b>(15.9%)</b> |

☐<sub>5</sub> Imaging studies are not useful for my management of patients with CMT..... **51 (24.5%)**  
**208 responses**

**14. How do these imaging studies influence your management of patients with CMT?**

**201 respondents (with 218 responses)**

a.) General Differential Diagnosis.....	<b>27</b>	<b>(13.4%)</b>
Specified Differential Diagnosis foci:		
b.) R/O spine / skeletal issue/ bony anomaly.....	<b>49</b>	<b>(24.4%)</b>
c.) R/O hip dysplasia.....	<b>20</b>	<b>(10.0%)</b>
d.) R/O hemivertebrae or Klippel Feil Syndrome.....	<b>14</b>	<b>(7.0%)</b>
e.) R/O pseudo-tumor/ tumor/ mass.....	<b>8</b>	<b>(4.0%)</b>
f.) R/O craniosynostosis.....	<b>2</b>	<b>(1.0%)</b>
g.) R/O brain tumor.....	<b>2</b>	<b>(1.0%)</b>
h.) GI malformation.....	<b>1</b>	<b>(0.5%)</b>
i.) Determine treatment/ frequency/ plan of care...	<b>25</b>	<b>(12.4%)</b>
j.) Affect communication with caregivers.....	<b>4</b>	<b>(2.0%)</b>
k.) Provides overall safety.....	<b>18</b>	<b>(9.0%)</b>
l.) Referral to other specialists.....	<b>14</b>	<b>(7.0%)</b>
m.) Determine outcomes/ prognosis.....	<b>8</b>	<b>(4.0%)</b>
n.) Used for severe cases/ slow responders.....	<b>20</b>	<b>(10.0%)</b>
o.) Does not impact my management of CMT.....	<b>6</b>	<b>(3.0%)</b>

**15. When medical imaging tests are completed, do you acquire the results of those studies?**

<input type="radio"/> <sub>1</sub> Always	<input type="radio"/> <sub>2</sub> Usually	<input type="radio"/> <sub>3</sub> Sometimes	<input type="radio"/> <sub>4</sub> Rarely	<input type="radio"/> <sub>5</sub> Never
<b>75 (39.1%)</b>	<b>59 (30.7%)</b>	<b>26 (13.5%)</b>	<b>17 (8.9%)</b>	<b>15 (7.8%)</b>
<b>192 responses</b>				

**16. In your practice, do you use a process or system to classify patients with CMT?**

<input type="radio"/> <sub>1</sub> Yes.....	<b>23</b>	<b>(11.6%)</b>
<input type="radio"/> <sub>2</sub> No.....	<b>174</b>	<b>(88.3%)</b>
<b>197 responses</b>		

**17. If so, what classification system do you use with your patients with CMT? Please name the author(s) or describe the system.**

**33 responses**

a.) Subjective Classification(ie) mild/mod/severe.....	<b>1</b>	<b>(3.0%)</b>
--	----------	---------------

b.) Objective (using ROM msmts and/or the type of CMT, but no author named).....	9	(27.3%)
c.) Based on Primary Research ie) Cheng, Ohman, Christenson).....	6	(18.2%)
d.) Based on Author's work, but not Primary Research (Karmel-Ross).....	2	(6.1%)
e.) Based on Continuing Education Seminars (no published work on CMT) ie) Tom DaLonzio Baker; Susan Blum; Anne Pleva; Magda Oledska.....	5	(15.1%)
f.) Cincinnati Children's Hospital Medical Center.....	5	(15.1%)
g.) APTA CPG on CMT.....	1	(3.0%)
h.) A Plagiocephaly scale (WebPT, CHOA, Cranial Technologies).....	4	(12.1%)

**18.** Rank in order (from most common to least common) the age at which your patients with CMT are typically first referred for PT evaluation. (Of the six age ranges listed below, select 1 for the most common, 2 for the second most common, 3 for the third most common, 4..., 5..., and 6 for the least common age at referral.)

**199 responses**

a.) Less than 1 month...	<b>Most frequently ranked 5<sup>th</sup> - 65</b>	<b>(32.7%)</b>
b.) 1-2 months.....	<b>Most frequently ranked 3<sup>rd</sup> - 62</b>	<b>(31.2%)</b>
c.) 3-4 months.....	<b>Most frequently ranked 1<sup>st</sup> - 135</b>	<b>(67.8%)</b>
d.) 5-6 months.....	<b>Most frequently ranked 2<sup>nd</sup> - 73</b>	<b>(36.7%)</b>
e.) 7-12 months.....	<b>Most frequently ranked 4<sup>th</sup> - 75</b>	<b>(37.7%)</b>
f.) More than 12 months...	<b>Most frequently ranked 6<sup>th</sup> - 137</b>	<b>(68.8%)</b>

**19.** Thinking about the infants with CMT who you have examined, how common is...

a.) A lateral head tilt?

<input type="radio"/> <sub>1</sub> Very Common (80% or more).....	177	(88.9%)
<input type="radio"/> <sub>2</sub> Somewhat Common (60-79%).....	17	(8.5%)
<input type="radio"/> <sub>3</sub> Common (40-59%).....	5	(2.5%)
<input type="radio"/> <sub>4</sub> Not Common (20-39%).....	0	(0.0%)
<input type="radio"/> <sub>5</sub> Rare (Less than 20%).....	0	(0.0%)
<input type="radio"/> <sub>6</sub> I don't measure this, so I can't estimate.....	0	(0.0%)

**199 responses**

b.) A passive rotation deficit of 5-15 degrees?

<input type="radio"/> <sub>1</sub> Very Common (80% or more).....	113	(57.4%)
<input type="radio"/> <sub>2</sub> Somewhat Common (60-79%).....	31	(15.7%)



<input type="radio"/> <sub>3</sub> Common (40-59%).....	<b>40</b>	<b>(20.3%)</b>
<input type="radio"/> <sub>4</sub> Not Common (20-39%).....	<b>11</b>	<b>(5.6%)</b>
<input type="radio"/> <sub>5</sub> Rare (Less than 20%).....	<b>2</b>	<b>(1.0%)</b>
<input type="radio"/> <sub>6</sub> I don't measure this, so I can't estimate.....	<b>0</b>	<b>(0.0%)</b>
<b>197 responses</b>		

c.) A passive rotation deficit of more than 15 degrees?

<input type="radio"/> <sub>1</sub> Very Common (80% or more).....	<b>33</b>	<b>(16.7%)</b>
<input type="radio"/> <sub>2</sub> Somewhat Common (60-79%).....	<b>65</b>	<b>(32.8%)</b>
<input type="radio"/> <sub>3</sub> Common (40-59%).....	<b>50</b>	<b>(25.2%)</b>
<input type="radio"/> <sub>4</sub> Not Common (20-39%).....	<b>34</b>	<b>(17.2%)</b>
<input type="radio"/> <sub>5</sub> Rare (Less than 20%).....	<b>16</b>	<b>(8.1%)</b>
<input type="radio"/> <sub>6</sub> I don't measure this, so I can't estimate.....	<b>0</b>	<b>(0.0%)</b>
<b>198 responses</b>		

d.) Plagiocephaly?

<input type="radio"/> <sub>1</sub> Very Common (80% or more).....	<b>100</b>	<b>(50.5%)</b>
<input type="radio"/> <sub>2</sub> Somewhat Common (60-79%).....	<b>60</b>	<b>(30.3%)</b>
<input type="radio"/> <sub>3</sub> Common (40-59%).....	<b>31</b>	<b>(15.7%)</b>
<input type="radio"/> <sub>4</sub> Not Common (20-39%).....	<b>6</b>	<b>(3.0%)</b>
<input type="radio"/> <sub>5</sub> Rare (Less than 20%).....	<b>1</b>	<b>(0.5%)</b>
<input type="radio"/> <sub>6</sub> I don't measure this, so I can't estimate.....	<b>0</b>	<b>(0.0%)</b>
<b>198 responses</b>		

e.) Confirmed hip dysplasia?

<input type="radio"/> <sub>1</sub> Very Common (80% or more).....	<b>0</b>	<b>(0.0%)</b>
<input type="radio"/> <sub>2</sub> Somewhat Common (60-79%).....	<b>2</b>	<b>(1.0%)</b>
<input type="radio"/> <sub>3</sub> Common (40-59%).....	<b>4</b>	<b>(2.1%)</b>
<input type="radio"/> <sub>4</sub> Not Common (20-39%).....	<b>47</b>	<b>(24.1%)</b>
<input type="radio"/> <sub>5</sub> Rare (Less than 20%).....	<b>131</b>	<b>(67.2%)</b>
<input type="radio"/> <sub>6</sub> I don't measure this, so I can't estimate.....	<b>11</b>	<b>(5.6%)</b>
<b>195 responses</b>		

**20.** Thinking about the infants with CMT who you have examined, estimate the percentage that fit each of these categories. (The sum of your choices should equal 100%). **198 responses**

a.) Postural Group (Baby tilts head but there is no limitation in ROM and no fibrotic change in SCM.)

**Range = 0-95%      Mean = 35.42%      Std dev = 24.32%**

b.) Muscular Group (Limited ROM and thickened SCM but no palpable tumor.) **Range = 5-100%      Mean = 56.16%      Std dev = 24.4%**

c.) Stenomastoid Tumor Group (Palpable tumor in SCM.)

**Range = 0-50%                      Mean = 8.42%                      Std dev = 9.15%**

**21. What is your typical caseload of patients per week?                      189 responses**

**Range = 3-50                      Mean = 23.39                      Std dev = 9.324**

**22. What is your typical caseload of patients with CMT per week?**

**Range = 1-25                      Mean = 4.48                      Std dev = 3.562                      191 responses**

## **SECTION 2: EXAMINATION**

This section of questions will be used to determine the patterns of physical therapy examination for patients with CMT, as described by physical therapists in the USA.

**23.** Do you routinely use an evidence based clinical guideline, pathway, or protocol to direct the initial examination of your patients with CMT?

- ☐ No..... **106 (48.2%)**  
☐ Yes..... **81 (36.8%)**  
 Missing..... **33 (15.0%)**  
**Total = 220 (100%)**

**24.** If yes, who developed the examination guideline, pathway, or protocol that you use? \_\_\_\_\_

- a.) Location specific (workplace), not published..... **32 (34.8%)**  
 b.) Cincinnati Children's Hospital Medical Center..... **25 (27.2%)**  
 c.) Author(s) of book(s) on CMT (published)..... **15 (16.3%)**  
 d.) Instructor(s) from continuing education course(s) (not published)..... **10 (10.9%)**  
 e.) APTA Clinical Practice Guideline..... **6 (6.5%)**  
 f.) Authors of published primary research..... **3 (3.2%)**  
 g.) Hospital for Special Surgery..... **1 (1.1%)**  
**Total = 92 (100%)**

**25.** Please rank order the importance of the following five strategies for developing your examination approach. (Please rate all five strategies, but you should only select one response per column.) My CMT examination approach is developed by...

	Most Important	Very Important	Important	Somewhat Important	Least Important	Missing
a.) My own personal review of the literature. <b>N=220</b>	43 (19.5%)	<b>56</b> <b>(25.5%)</b>	35 (15.9%)	26 (11.8%)	15 (6.8%)	45 (20.5%)
b.) Lessons taught to me by colleague(s). <b>N=220</b>	22 (10.0%)	40 (18.2%)	<b>52</b> <b>(23.6%)</b>	40 (18.2%)	18 (8.2%)	48 (21.8%)
c.) Lessons taught at continuing education courses. <b>N=220</b>	<b>51</b> <b>(23.2%)</b>	35 (15.9%)	44 (20.0%)	32 (14.5%)	19 (8.6%)	39 (17.7%)
d.) A process or	26	14	22	33	<b>83</b>	42

protocol developed at my workplace. <b>N=220</b>	(11.8%)	(6.4%)	(10.0%)	(15.0%)	<b>(37.7%)</b>	(19.1%)
e.) A published evidence-based guideline/ pathway/ protocol. <b>N=220</b>	37 (16.8%)	<b>39 (17.7%)</b>	34 (15.4%)	38 (17.3%)	34 (15.4%)	38 (17.3%)

**26.** How often do you record the following objective information in a typical CMT exam? Check 1 box per row.

N=220 for all (a-ab)	Always	Usually	Sometimes	Rarely	Never	Missing
a.) Date of examination	<b>189 (85.9%)</b>	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	31 (14.1%)
b.) Family history of CMT	<b>87 (39.5%)</b>	29 (13.2%)	27 (12.3%)	33 (15.0%)	13 (5.9%)	31 (14.1%)
c.) Maternal Labor & Delivery	<b>171 (77.7%)</b>	13 (5.9%)	5 (2.3%)	0 (0.0%)	0 (0.0%)	31 (14.1%)
d.) Baby position in utero	<b>79 (35.9%)</b>	40 (18.2%)	42 (19.1%)	21 (9.5%)	7 (3.2%)	31 (14.1%)
e.) Gender	<b>184 (83.6%)</b>	4 (1.8%)	0 (0.0%)	0 (0.0%)	1 (0.5%)	31 (14.1%)
f.) Age of child	<b>189 (85.9%)</b>	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	31 (14.1%)
g.) Side of Torticollis	<b>188 (85.4%)</b>	1 (0.5%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	31 (14.1%)
h.) Type of CMT (Postural, Muscular, SMT)	<b>86 (39.1%)</b>	33 (15.0%)	38 (17.3%)	21 (9.5%)	11 (5.0%)	31 (14.1%)
i.) Passive Cervical Rotation	<b>163 (74.1%)</b>	19 (8.6%)	3 (1.4%)	4 (1.8%)	0 (0.0%)	31 (14.1%)
j.) Active Cervical Rotation	<b>164 (74.5%)</b>	18 (8.2%)	4 (1.8%)	3 (1.4%)	0 (0.0%)	31 (14.1%)
k.) Passive Cervical Lateral Flexion	<b>162 (73.6%)</b>	18 (8.2%)	5 (2.3%)	4 (1.8%)	0 (0.0%)	31 (14.1%)
l.) Lateral Head Position (static)	<b>170 (77.3%)</b>	17 (7.7%)	1 (0.5%)	0 (0.0%)	0 (0.0%)	32 (14.5%)
m.) Lateral head righting	<b>151 (68.6%)</b>	30 (13.6%)	6 (2.7%)	2 (0.9%)	0 (0.0%)	31 (14.1%)
n.) Neck Flexor Strength	<b>120 (54.5%)</b>	36 (16.4%)	21 (9.5%)	8 (3.6%)	4 (1.8%)	31 (14.1%)
o.) Craniofacial Asymmetry	<b>155 (70.4%)</b>	26 (11.8%)	6 (2.7%)	1 (0.5%)	1 (0.5%)	31 (14.1%)
p.) Skin Integrity	<b>88 (40.0%)</b>	36 (16.4%)	35 (15.9%)	22 (10.0%)	5 (2.3%)	34 (15.4%)
q.) Feeding Problems	<b>113 (51.4%)</b>	35 (15.9%)	29 (13.2%)	11 (5.0%)	1 (0.4%)	31 (14.1%)

r.) Vision	<b>124</b> <b>(56.4%)</b>	36 (16.4%)	17 (7.7%)	6 (2.7%)	3 (1.4%)	34 (15.4%)
s.) Shoulder Symmetry	<b>117</b> <b>(53.2%)</b>	38 (17.3%)	22 (10.0%)	8 (3.6%)	4 (1.8%)	31 (14.1%)
t.) Hip Symmetry	<b>100</b> <b>(45.5%)</b>	46 (20.9%)	24 (10.9%)	15 (6.8%)	4 (1.8%)	31 (14.1%)
u.) Motor Development	<b>174</b> <b>(79.1%)</b>	13 (5.9%)	1 (0.5%)	0 (0.0%)	0 (0.0%)	32 (14.5%)
v.) ROM of UEs	<b>120</b> <b>(54.5%)</b>	36 (16.4%)	21 (9.5%)	10 (4.5%)	2 (0.9%)	31 (14.1%)
w.) ROM of LEs	<b>115</b> <b>(52.3%)</b>	38 (17.3%)	20 (9.1%)	12 (5.4%)	4 (1.8%)	31 (14.1%)
x.) Presence of Hip Dysplasia	<b>105</b> <b>(47.7%)</b>	38 (17.3%)	17 (7.7%)	20 (9.1%)	8 (3.6%)	32 (14.5%)
y.) Neurological Reflex Testing	<b>64</b> <b>(29.0%)</b>	44 (20.0%)	39 (17.7%)	30 (13.6%)	9 (4.1%)	34 (15.5%)
z.) Muscle Tone	<b>137</b> <b>(62.3%)</b>	36 (16.4%)	10 (4.5%)	6 (2.7%)	0 (0.0%)	31 (14.1%)
aa.) Presence of nodule/thick band in SCM	<b>129</b> <b>(58.6%)</b>	34 (15.5%)	18 (8.2%)	4 (1.8%)	3 (1.4%)	32 (14.5%)
ab.) Pain	<b>119</b> <b>(54.1%)</b>	24 (10.9%)	24 (10.9%)	13 (5.9%)	7 (3.2%)	33 (15.0%)

**27.** What device/ method do you typically use to measure passive neck rotation in patients with CMT?

<input type="radio"/> Visual Estimation.....	<b>111</b>	<b>(50.5%)</b>
<input type="radio"/> Standard Goniometer.....	<b>37</b>	<b>(16.8%)</b>
<input type="radio"/> Still Photography.....	<b>14</b>	<b>(6.4%)</b>
<input type="radio"/> Cervical Goniometer.....	<b>13</b>	<b>(5.9%)</b>
<input type="radio"/> Protractor.....	<b>5</b>	<b>(2.3%)</b>
<input type="radio"/> Tape Measure.....	<b>3</b>	<b>(1.4%)</b>
<input type="radio"/> I don't routinely measure cervical PROM.....	<b>2</b>	<b>(0.9%)</b>
<input type="radio"/> i-goni app.....	<b>1</b>	<b>(0.4%)</b>
<input type="radio"/> Homemade goniometer.....	<b>1</b>	<b>(0.4%)</b>
<input type="radio"/> Videotape.....	<b>0</b>	<b>(0.0%)</b>
Missing.....	<b>33</b>	<b>(15.0%)</b>
<b>Total = 220</b>		<b>(100%)</b>

**28.** What device/ method do you typically use to measure active neck rotation in patients with CMT?

<input type="radio"/> Visual Estimation.....	<b>120</b>	<b>(54.5%)</b>
<input type="radio"/> Standard Goniometer.....	<b>30</b>	<b>(13.6%)</b>
<input type="radio"/> Still Photography.....	<b>16</b>	<b>(7.3%)</b>
<input type="radio"/> Cervical Goniometer.....	<b>13</b>	<b>(5.9%)</b>
<input type="radio"/> Protractor.....	<b>5</b>	<b>(2.3%)</b>
<input type="radio"/> Tape Measure.....	<b>2</b>	<b>(0.9%)</b>

<input type="radio"/> I don't routinely measure cervical PROM.....	1	(0.4%)
<input type="radio"/> Homemade goniometer.....	1	(0.4%)
<input type="radio"/> Videotape.....	1	(0.4%)
<input type="radio"/> i-goni app.....	0	(0.0%)
Missing.....	31	(14.1%)
<b>Total =</b>	<b>220</b>	<b>(99.8%)</b>

**29.** What device/method do you typically use to measure passive neck lateral flexion in patients with CMT?

<input type="radio"/> Visual Estimation.....	98	(44.5%)
<input type="radio"/> Standard Goniometer.....	42	(19.1%)
<input type="radio"/> Still Photography.....	16	(7.3%)
<input type="radio"/> Cervical Goniometer.....	15	(6.8%)
<input type="radio"/> Protractor.....	10	(4.5%)
<input type="radio"/> Tape Measure.....	2	(0.9%)
<input type="radio"/> I don't routinely measure cervical AROM.....	2	(0.9%)
<input type="radio"/> i-goni app.....	1	(0.5%)
<input type="radio"/> Homemade goniometer.....	1	(0.5%)
<input type="radio"/> Videotape.....	0	(0.0%)
Missing.....	33	(15.0%)
<b>Total =</b>	<b>220</b>	<b>(100%)</b>

**30.** What device/method do you use to measure the infant's static head tilt position when the infant is...

	Standard Gonio- meter	Cervical Gonio- meter	Protractor	Tape Measure	Still Photo	Visual Estimate	I don't routinely measure it in this position	Home- made Gonio- meter	Miss- ing
a.) Lying supine? <b>N=220</b>	52 (23.6%)	8 (3.6%)	8 (3.6%)	3 (1.4%)	26 (11.8%)	<b>85</b> <b>(38.6%)</b>	2 (0.9%)	1 (0.5%)	35 (15.9%)
b.) Sitting upright? <b>N=220</b>	44 (20.0%)	8 (3.6%)	5 (2.3%)	1 (0.4%)	29 (13.2%)	<b>95</b> <b>(43.2%)</b>	4 (1.8%)	1 (0.4%)	33 (15.0%)

**31.** How do you typically measure lateral head righting in your patients with CMT?

<input type="radio"/> Neck Righting Reactions.....	152	(69.1%)
<input type="radio"/> Muscle Function Scale.....	29	(13.2%)
<input type="radio"/> Pull-to-Sit Maneuver.....	4	(1.8%)

<input type="radio"/> I don't routinely measure cervical strength.....	3	(1.4%)
<input type="radio"/> Manual Muscle Test.....	0	(0.0%)
Missing.....	32	(14.5%)
<b>Total =</b>	<b>220</b>	<b>(100%)</b>

**32.** How do you typically measure neck flexor strength in your patients with CMT?

<input type="radio"/> Pull-to-Sit Maneuver.....	157	(71.4%)
<input type="radio"/> Neck Righting Reactions.....	19	(8.6%)
<input type="radio"/> Muscle Function Scale.....	8	(3.6%)
<input type="radio"/> I don't routinely measure neck flexor strength.....	5	(2.3%)
<input type="radio"/> Manual Muscle Test.....	0	(0.0%)
Missing.....	31	(14.1%)
<b>Total =</b>	<b>220</b>	<b>(100%)</b>

**33.** How do you typically measure craniofacial asymmetry in your patients with CMT?

<input type="radio"/> Subjectively (min, mod, severe.....)	95	(43.2%)
<input type="radio"/> Anthropometric measurements using cranial vault calipers.....	51	(23.2%)
<input type="radio"/> Still photography.....	17	(7.7%)
<input type="radio"/> A standardized plagiocephaly scale.....	17	(7.7%)
<input type="radio"/> I don't routinely measure craniofacial asymmetry...	6	(2.7%)
<input type="radio"/> Flexible ruler.....	2	(0.9%)
<input type="radio"/> Laser scan.....	0	(0.0%)
Missing.....	32	(14.5%)
<b>Total =</b>	<b>220</b>	<b>(99.9%)</b>

**34.** What method best describes how you assess visual attention & tracking in patients with CMT?

<input type="radio"/> Move a brightly colored object or familiar face across their visual field.....	155	(70.5%)
<input type="radio"/> No specific test but use general observation of the child's eye movements during the exam.....	23	(10.5%)
<input type="radio"/> Specific Cranial nerve testing for optic, oculomotor, and trochlear nerves.....	4	(1.8%)
<input type="radio"/> Other.....	3	(1.4%)
<input type="radio"/> Shine a penlight to check the pupillary reflex.....	2	(0.9%)
<input type="radio"/> I don't routinely examine vision.....	1	(0.4%)
Missing.....	32	(14.5%)
<b>Total =</b>	<b>220</b>	<b>(100%)</b>

**35.** How do you typically identify potential hip dysplasia in your patients with CMT?

<input type="radio"/> Ortolani Maneuver.....	<b>42</b>	<b>(19.1%)</b>
<input type="radio"/> No specific test but palpate for hip clicking with general movement during exam.....	<b>42</b>	<b>(19.1%)</b>
<input type="radio"/> Any combination of the answers (1-6).....	<b>27</b>	<b>(12.3%)</b>
<input type="radio"/> Abnormal hip range of motion.....	<b>26</b>	<b>(11.8%)</b>
<input type="radio"/> Barlow Maneuver.....	<b>17</b>	<b>(7.7%)</b>
<input type="radio"/> I don't routinely check for hip dysplasia.....	<b>15</b>	<b>(6.8%)</b>
<input type="radio"/> Asymmetry of hip folds.....	<b>13</b>	<b>(5.9%)</b>
<input type="radio"/> Leg length discrepancy.....	<b>6</b>	<b>(2.7%)</b>
<input type="radio"/> Missing.....	<b>32</b>	<b>(14.5%)</b>
<b>Total = 220</b>		<b>(99.9%)</b>

**36.** What tool or method do you typically use to describe motor development in patients with CMT?

<input type="radio"/> Peabody Developmental Motor Scale (PDMS).....	<b>67</b>	<b>(30.4%)</b>
<input type="radio"/> Alberta Infant Motor Scale (AIMS).....	<b>38</b>	<b>(17.3%)</b>
<input type="radio"/> No specific test but general observation of motor development.....	<b>38</b>	<b>(17.3%)</b>
<input type="radio"/> Other: _____(optional write-in)...Responses included: ELAP (Early Learning Accomplishment Profile), HELP (Hawaii Early Learning Profile), Batelle Developmental Inventory, 2 <sup>nd</sup> Ed., Mullen Scales of Early Learning, Gesell Developmental Assessment of Young Children (DAYC), Brigance Inventory of Early Development, Ages & Stages Questionnaire, INFANIB.....	<b>18</b>	<b>(8.2%)</b>
<input type="radio"/> Bayley Scales of Infant Development (BSID).....	<b>16</b>	<b>(7.3%)</b>
<input type="radio"/> Test of Infant Motor Performance (TIMP).....	<b>6</b>	<b>(2.7%)</b>
<input type="radio"/> Bruinks Osteretsky.....	<b>0</b>	<b>(0.0%)</b>
<input type="radio"/> I don't routinely measure motor development.....	<b>0</b>	<b>(0.0%)</b>
<input type="radio"/> Missing.....	<b>37</b>	<b>(16.8%)</b>
<b>Total = 220</b>		<b>(100%)</b>

**37.** What neurological responses do you check in your patients with CMT? (Select all that apply.)

<input type="radio"/> Lateral Head Righting (4+ months).....	<b>165/220</b>	<b>(75.0%)</b>
<input type="radio"/> ATNR.....	<b>156/220</b>	<b>(70.9%)</b>
<input type="radio"/> Equilibrium responses.....	<b>124/220</b>	<b>(56.4%)</b>
<input type="radio"/> Neonatal neck righting.....	<b>100/220</b>	<b>(45.5%)</b>
<input type="radio"/> Palmar grasp.....	<b>90/220</b>	<b>(40.9%)</b>
<input type="radio"/> Babinski.....	<b>78/220</b>	<b>(35.5%)</b>
<input type="radio"/> Positive support.....	<b>78/220</b>	<b>(35.5%)</b>
<input type="radio"/> Moro.....	<b>73/220</b>	<b>(33.2%)</b>



- ☐ Plantar grasp..... **68/220** **(30.9%)**
- ☐ Flexor withdrawal..... **51/220** **(23.2%)**
- ☐ I don't routinely check neurological responses **13/220** **(5.9%)**

**38.** How do you typically measure and describe muscle tone in your patients with CMT?

- ☐ Manually examine and describe using terms: Hypo, Hyper, Normal, Abnormal, Mixed..... **163** **(74.1%)**
- ☐ Modified Ashworth Scale..... **18** **(8.2%)**
- ☐ I don't routinely measure/document muscle tone... **4** **(1.8%)**
- Missing..... **35** **(15.9%)**
- Total = 220 (100%)**

**39.** How do you typically measure and describe pain in your patients with CMT?

- ☐ Narrative description of baby's response during exam **101** **(45.9%)**
- ☐ FLACC Pain Scale..... **44** **(20.0%)**
- ☐ I don't routinely measure/document pain..... **31** **(14.1%)**
- ☐ Standard Face Pain Scale..... **8** **(3.6%)**
- ☐ Parent Report..... **4** **(1.8%)**
- ☐ Standardized Infant Pain Scale..... **1** **(0.5%)**
- Missing..... **31** **(14.1%)**
- Total = 220 (100%)**

### **SECTION 3: TREATMENT**

This section of questions will be used to determine the patterns of physical therapy treatment for patients with CMT, as described by physical therapists in the USA.

**40.** Do you routinely use an evidence based clinical guideline, pathway, or protocol to direct the treatment of your patients with CMT?

- ☐ No..... **115 (52.3%)**  
☐ Yes..... **68 (30.9%)**  
 Missing..... **37 (16.8%)**  
**Total = 220 (100%)**

**41.** If yes, who developed the treatment guideline, pathway, or protocol that you use? \_\_\_\_\_

- a.) Cincinnati Children's Hospital Medical Center..... **22 (31.0%)**  
 b.) Location specific (workplace), not published..... **19 (26.8%)**  
 c.) Author(s) of book(s) on CMT (published)..... **14 (19.7%)**  
 d.) Instructor(s) from continuing education course(s) (not published)..... **8 (11.3%)**  
 e.) APTA Clinical Practice Guideline..... **4 (5.6%)**  
 f.) Authors of published primary research..... **2 (2.8%)**  
 g.) Hospital for Special Surgery..... **2 (2.8%)**  
**Total = 71 (100%)**

**42.** Please rank order the importance of the following five strategies for developing your treatment approach. (Please rate all five strategies, but you should only select one response per column.) My CMT treatment approach is developed by...

	Most Important	Very Important	Important	Somewhat Important	Least Important	Missing
a.) My own personal review of the literature. <b>N=220</b>	40 (18.2%)	<b>56</b> <b>(25.5%)</b>	36 (16.4%)	30 (13.6%)	17 (7.7%)	41 (18.6%)
b.) Lessons taught to me by colleague(s). <b>N=220</b>	31 (14.1%)	37 (16.8%)	<b>60</b> <b>(27.3%)</b>	35 (15.9%)	11 (5.0%)	46 (20.9%)
c.) Lessons taught at continuing	<b>55</b> <b>(25.0%)</b>	42 (19.1%)	39 (17.7%)	25 (11.4%)	18 (8.2%)	41 (18.6%)

education courses. <b>N=220</b>						
d.) A process or protocol developed at my workplace. <b>N=220</b>	22 (10.0%)	14 (6.3%)	16 (7.3%)	36 (16.4%)	<b>85 (38.6%)</b>	47 (21.4%)
e.) A published evidence-based guideline/ pathway/ protocol. <b>N=220</b>	32 (14.55%)	32 (14.55%)	31 (14.1%)	41 (18.6%)	<b>45 (20.5%)</b>	39 (17.7%)

**43.** What are the three most important factors that determine frequency of scheduled appointments (1x/week, 2x/week, 3x/week...) for a patient with CMT? Select three choices.

- ☐ Severity of head tilt..... **122/220** **(55.5%)**
- ☐ Severity of the limitation in cervical rotation... **99/220** **(45.0%)**
- ☐ PT perception of parent's ability to adhere to HEP.....  
..... **72/220** **(32.7%)**
- ☐ Age of the child..... **70/220** **(31.8%)**
- ☐ Parent's comfort in their own ability to adhere to HEP.....  
..... **50/220** **(22.7%)**
- ☐ Presence of co-morbidities..... **42/220** **(19.1%)**
- ☐ Parental schedule..... **35/220** **(15.9%)**
- ☐ Number of visits authorized by insurance... **27/220** **(12.3%)**
- ☐ Type of CMT..... **26/220** **(11.8%)**
- ☐ Following a guideline/ pathway/ protocol... **18/220** **(8.2%)**
- ☐ Availability of PT appointments..... **15/220** **(6.8%)**
- ☐ Distance that family travels to PT..... **9/220** **(4.1%)**
- ☐ Parent request..... **8/220** **(3.6%)**
- ☐ Doctor request..... **8/220** **(3.6%)**
- ☐ Other: EIP (Early Intervention Program) guideline.....  
..... **4/220** **(1.8%)**

**44.** What is the typical frequency of PT visits that you recommend in the first four weeks of treatment for an infant who shows a postural preference (no muscle tightness nor mass), and who is...

	1x/week	2x/week	3x/week	4x/week	5x/week	1x /month	2x /month	Missing
0-3 months old <b>N=220</b>	<b>94 (42.7%)</b>	15 (6.8%)	3 (1.4%)	0 (0.0%)	0 (0.0%)	17 (7.7%)	52 (23.6%)	39 (17.7%)
4-6 months old <b>N=220</b>	<b>117 (53.2%)</b>	25 (11.4%)	2 (0.9%)	0 (0.0%)	0 (0.0%)	8 (3.6%)	29 (13.2%)	39 (17.7%)
7+ months old <b>N=220</b>	<b>99 (45.0%)</b>	40 (18.2%)	3 (1.4%)	0 (0.0%)	0 (0.0%)	11 (5.0%)	26 (11.8%)	41 (18.6%)

**45.** What is the typical frequency of PT visits that you recommend in the first four weeks of treatment for an infant who shows a muscular torticollis (muscle tightness but no mass), and who is...

	1x/week	2x/week	3x/week	4x/week	5x/week	1x /month	2x /month	Missing
0-3 months old <b>N=220</b>	<b>112 (50.9%)</b>	33 (15.0%)	6 (2.7%)	0 (0.0%)	0 (0.0%)	5 (2.3%)	27 (12.3%)	37 (16.8%)
4-6 months old <b>N=220</b>	<b>111 (50.5%)</b>	55 (25.0%)	6 (2.7%)	0 (0.0%)	0 (0.0%)	1 (0.5%)	10 (4.5%)	37 (16.8%)
7+ months old <b>N=220</b>	<b>100 (45.5%)</b>	62 (28.2%)	8 (3.6%)	0 (0.0%)	0 (0.0%)	4 (1.8%)	8 (3.6%)	38 (17.3%)

**46.** What is the typical frequency of PT visits that you recommend in the first four weeks of treatment for an infant who shows a sternomastoid tumor (palpable mass in SCM), and who is...

	1x/week	2x/week	3x/week	4x/week	5x/week	1x /month	2x /month	Missing
0-3 months old <b>N=220</b>	<b>93 (42.3%)</b>	53 (24.1%)	8 (3.6%)	0 (0.0%)	0 (0.0%)	3 (1.4%)	13 (5.9%)	50 (22.7%)
4-6 months old <b>N=220</b>	<b>86 (39.1%)</b>	65 (29.5%)	10 (4.5%)	0 (0.0%)	0 (0.0%)	1 (0.5%)	7 (3.2%)	51 (23.2%)
7+ months old	<b>77 (35.0%)</b>	66 (30.0%)	15 (6.8%)	0 (0.0%)	0 (0.0%)	2 (0.9%)	7 (3.2%)	53 (24.1%)

<b>N=220</b>								
--------------	--	--	--	--	--	--	--	--

**47.** What factor most often causes you to increase the scheduled frequency?

- \_\_\_\_\_
- ☐ No change/ Lack of progress..... **104/220** **(47.3%)**
  - ☐ Caretaker not adhering properly to HEP..... **58/220** **(26.4%)**
  - ☐ Severity of head tilt or ROM restriction..... **27/220** **(12.3%)**
  - ☐ Co-morbidities..... **20/220** **(9.1%)**
  - ☐ Infant approaching a new age or skill..... **11/220** **(5.0%)**
  - ☐ Parent request..... **6/220** **(2.7%)**
  - ☐ Presence of tumor/mass..... **6/220** **(2.7%)**
  - ☐ Plagiocephaly..... **5/220** **(2.3%)**
  - ☐ Pain..... **3/220** **(1.4%)**
  - ☐ Patient cooperation/ Ability to tolerate handling..... **3/220** **(1.4%)**
  - ☐ Parental availability..... **2/220** **(0.9%)**
  - ☐ Visual concerns..... **2/220** **(0.9%)**

**48.** What factor most often causes you to decrease the scheduled frequency? \_\_\_\_\_

- ☐ Parental adherence to HEP..... **98/220** **(44.5%)**
- ☐ Steady Progress/ Resolution of symptoms... **69/220** **(31.4%)**
- ☐ Improved ROM..... **61/220** **(27.7%)**
- ☐ Improved head posture..... **36/220** **(16.4%)**
- ☐ Age appropriate motor skills..... **32/220** **(14.5%)**
- ☐ Familial request..... **11/220** **(5.0%)**
- ☐ Improved strength..... **9/220** **(4.1%)**
- ☐ Muscle softening..... **7/220** **(3.2%)**
- ☐ Improved anthropometric measurements..... **1/220** **(0.5%)**
- ☐ Number of visits authorized by insurance company..... **1/220** **(0.5%)**
- ☐ Transition to Early Intervention..... **1/220** **(0.5%)**
- ☐ Suspicion of underlying pathology..... **1/220** **(0.5%)**

**49.** How much time do you typically schedule for a treatment session of a patient with CMT?

- ☐ 1 hour..... **95** **(43.2%)**
- ☐ 45 minutes..... **56** **(25.4%)**
- ☐ 30 minutes..... **31** **(14.1%)**

<input type="radio"/> 15 minutes.....	<b>1</b>	<b>(0.45%)</b>
<input type="radio"/> 1.5 hours.....	<b>1</b>	<b>(0.45%)</b>
<input type="radio"/> 2 hours.....	<b>0</b>	<b>(0.0%)</b>
Missing.....	<b><u>36</u></b>	<b><u>(16.4%)</u></b>
<b>Total = 220</b>		<b>(100%)</b>

**50.** How often do you use each of the following interventions in the treatment of patients with CMT? (Please rate each intervention.)

<b>N = 220</b>	Always	Usually	Sometimes	Rarely	Never	Don't Know this Tx	Missing
PROM exercises:	<b>114</b>	42	12	8	6	0	38
Stretching	<b>(51.8%)</b>	(19.1%)	(5.5%)	(3.6%)	(2.7%)	(0.0%)	(17.3%)
Positioning Program	<b>171</b>	12	1	0	0	0	36
	<b>(77.7%)</b>	(5.5%)	(0.4%)	(0.0%)	(0.0%)	(0.0%)	(16.4%)
AROM exercises	<b>163</b>	16	3	1	0	0	37
	<b>(74.1%)</b>	(7.3%)	(1.4%)	(0.4%)	(0.0%)	(0.0%)	(16.8%)
Strengthening: Head	<b>141</b>	38	5	1	0	0	35
Righting Reactions	<b>(64.1%)</b>	(17.3%)	(2.3%)	(0.4%)	(0.0%)	(0.0%)	(15.9%)
Strengthening: Trunk	<b>111</b>	55	17	0	1	0	36
Equilibrium Responses	<b>(50.5%)</b>	(25.0%)	(7.7%)	(0.0%)	(0.4%)	(0.0%)	(16.4%)
Developmental Exercises	<b>127</b>	42	14	0	0	1	36
	<b>(57.7%)</b>	(19.1%)	(6.4%)	(0.0%)	(0.0%)	(0.4%)	(16.4%)
Neurodevelopmental	53	40	<b>55</b>	17	10	6	39
Techniques	(24.1%)	(18.2%)	<b>(25.0%)</b>	(7.7%)	(4.5%)	(2.7%)	(17.7%)
Physioball	25	61	<b>73</b>	17	5	2	37
	(11.4%)	(27.7%)	<b>(33.2%)</b>	(7.7%)	(2.3%)	(0.9%)	(16.8%)
Bolster or Wedge	14	46	<b>79</b>	37	2	1	41
	(6.4%)	(20.9%)	<b>(35.9%)</b>	(16.8%)	(0.9%)	(0.5%)	(18.6%)
TAMO	4	2	10	9	44	<b>106</b>	45
	(1.8%)	(0.9%)	(4.5%)	(4.1%)	(20.0%)	<b>(48.2%)</b>	(20.5%)
Microcurrent	0	0	0	3	<b>100</b>	75	42
	(0.0%)	(0.0%)	(0.0%)	(1.4%)	<b>(45.4%)</b>	(34.1%)	(19.1%)
Total Motion Release	8	6	14	9	60	<b>83</b>	40
	(3.6%)	(2.7%)	(6.4%)	(4.1%)	(27.3%)	<b>(37.7%)</b>	(18.2%)
Myokinetic Stretching	0	4	7	6	53	<b>106</b>	44
	(0.0%)	(1.8%)	(3.2%)	(2.7%)	(24.1%)	<b>(48.2%)</b>	(20.0%)
Soft Tissue Massage	40	55	<b>65</b>	12	6	1	41
	(18.2%)	(25.0%)	<b>(29.5%)</b>	(5.5%)	(2.7%)	(0.5%)	(18.6%)
Kinesio® Tape	4	26	<b>92</b>	35	20	7	36
	(1.8%)	(11.8%)	<b>(41.8%)</b>	(15.9%)	(9.1%)	(3.2%)	(16.4%)
Tubular Orthosis for	1	4	50	<b>66</b>	50	13	36
Torticollis (TOT collar™)	(0.5%)	(1.8%)	(22.7%)	<b>(30.0%)</b>	(22.7%)	(5.9%)	(16.4%)
Parent Home Instruction	<b>182</b>	1	0	0	0	0	37
	<b>(82.7)</b>	(0.5%)	(0.0%)	(0.0%)	(0.0%)	(0.0%)	(16.8%)
*Other (Please specify): _____							

\*Other answers included the following interventions: Myofascial release (9); Craniosacral techniques (8); Muscle Energy Techniques (3); McConnell taping (1); Crosstape (1); Cranial banding (1); Turtle cap (1); Theratogs (1); Benik cap (1); Custom collar (1); Foam collar (1); AAROM (1); Cuevas MEDEK Exercise (1); Integrative Manual Therapy (1).

**51.** How often do you recommend the following equipment/ positioning devices (recognizing that some may require consultation with the referring MD)? Please rate each of the following options.

<b>N=220</b>	Always	Usually	Sometimes	Rarely	Never	Missing
Gel cushion head rest	0 (0.0%)	4 (1.8%)	36 (16.3%)	27 (12.3%)	<b>113</b> <b>(51.4%)</b>	40 (18.2%)

TOT collar™	0 (0.0%)	0 (0.0%)	<b>67</b> <b>(30.4%)</b>	64 (29.1%)	51 (23.2%)	38 (17.3%)
Foam Collar	0 (0.0%)	1 (0.5%)	22 (10.0%)	48 (21.8%)	<b>107</b> <b>(48.6%)</b>	42 (19.1%)
Kinesio® Tape	2 (0.9%)	25 (11.4%)	<b>103</b> <b>(46.8%)</b>	30 (13.6%)	20 (9.1%)	40 (18.2%)
Head positioner device	7 (3.2%)	22 (10.0%)	56 (25.5%)	35 (15.9%)	<b>61</b> <b>(27.7%)</b>	39 (17.7%)
Physioball	3 (1.4%)	40 (18.2%)	<b>80</b> <b>(36.4%)</b>	36 (16.4%)	21 (9.5%)	40 (18.2%)
Cranial orthosis or helmet	1 (0.5%)	20 (9.1%)	<b>136</b> <b>(61.8%)</b>	13 (5.9%)	12 (5.4%)	38 (17.3%)
*Other:						

\*Other answers included the following devices: Boppy Tummy Time (2); Noggin Nest (2); Snuggin-go (1); towels/washcloths (1); Foam head positioner (2); Plagiocradle/Turtle (2)

**52.** How often do you consult with the referring doctor to recommend the following specialists or procedures? Please rate each of the following options.

<b>N=220</b>	Always	Usually	Sometimes	Rarely	Never	Missing
Cranial Orthotist	15 (6.8%)	32 (14.5%)	<b>106</b> <b>(48.2%)</b>	18 (8.2%)	13 (5.9%)	36 (16.4%)
Orthopedist	11 (5.0%)	9 (4.1%)	<b>85</b> <b>(38.6%)</b>	60 (27.3%)	19 (8.6%)	36 (16.4%)
Neurologist	9 (4.1%)	8 (3.6%)	<b>98</b> <b>(44.5%)</b>	59 (26.8%)	10 (4.5%)	36 (16.4%)
Ophthalmologist	10 (4.5%)	10 (4.5%)	<b>100</b> <b>(45.5%)</b>	49 (22.3%)	15 (6.8%)	36 (16.4%)
Cervical X-ray	14 (6.36%)	14 (6.36%)	<b>73</b> <b>(33.2%)</b>	60 (27.3%)	23 (10.4%)	36 (16.36%)
Ultrasound	9 (4.1%)	5 (2.3%)	42 (19.1%)	57 (25.9%)	<b>70</b> <b>(31.8%)</b>	37 (16.8%)
For Botox	8 (3.6%)	2 (0.9%)	18 (8.2%)	66 (30.0%)	<b>89</b> <b>(40.5%)</b>	37 (16.8%)
For Surgery	8 (3.6%)	0 (0.0%)	15 (6.8%)	67 (30.4%)	<b>91</b> <b>(41.4%)</b>	39 (17.7%)
*Other:						

\*Other answers included the following specialists: Gastroenterologist (1); Neurosurgeon (1); Plastic Surgeon (1); Pulmonologist (1); Allergist (1); Genetics (1); Developmental optometrist (1); Behavioral optometrist (1).

**53.** Given your best estimate, how many treatment sessions does a patient with CMT typically receive for an episode of care (initial exam to discharge)?

☐ 11-15 sessions..... **47** **(21.4%)**



<input type="radio"/> 16-20 sessions.....	37	(16.8%)
<input type="radio"/> 6-10 sessions.....	30	(13.6%)
<input type="radio"/> 21-25 sessions.....	26	(11.8%)
<input type="radio"/> 26-30 sessions.....	19	(8.6%)
<input type="radio"/> More than 30 sessions.....	14	(6.4%)
<input type="radio"/> *Other (Please specify): _____	8	(3.6%)
<input type="radio"/> 5 sessions.....	5	(2.3%)
Missing.....	34	(15.5%)
<b>Total =</b>	<b>220</b>	<b>(100%)</b>

\*Other answers included: Varies (5); Seen longer term through EIP (3)

**54.** Given your best estimate, what is the typical duration for an episode of care (initial exam to discharge) of a patient with CMT?

<input type="radio"/> More than 3 months – up to 6 months.....	88	(40.0%)
<input type="radio"/> More than 6 months – up to 9 months.....	50	(22.7%)
<input type="radio"/> More than 1 month – up to 3 months.....	20	(9.1%)
<input type="radio"/> More than 9 months – up to 1 year.....	19	(8.6%)
<input type="radio"/> *Other (Please specify): _____	5	(2.3%)
<input type="radio"/> More than one year.....	2	(0.9%)
<input type="radio"/> One month or less.....	2	(0.9%)
Missing.....	34	(15.5%)
<b>Total =</b>	<b>220</b>	<b>(100%)</b>

\*Other answers included: Until they are walking (3); Varies (1); Intermittent follow-up through grade school (1).

#### **SECTION 4: Discharge/ Discontinuation**

This section of questions will be used to determine the patterns of discharge or discontinuation of physical therapy for patients with CMT, as described by physical therapists in the USA.

**55.** In your best estimate, are the majority of your patients with CMT...

- ☐ Discharged from PT by you based on your clinical decision.... **166 (75.5%)**
- ☐ Discontinued from PT for reasons not based on your clinical decision  
..... **13 (5.9%)**
- Missing..... **41 (18.6%)**
- Total = 220 (100%)**

**56.** How important are the following criteria in determining discharge of patients with CMT?

(N=220 for all)	Most Important	Very Important	Important	Somewhat Important	Least Important	Not at all Important	Missing
a.) Straight Head Posture	75 (34.1%)	<b>84</b> <b>(38.2%)</b>	11 (5.0%)	3 (1.3%)	0 (0.0%)	0 (0.0%)	47 (21.4%)
b.) Full Passive Cervical Lateral Flexion	67 (30.5%)	<b>87</b> <b>(39.5%)</b>	16 (7.3%)	7 (3.2%)	1 (0.4%)	0 (0.0%)	42 (19.1%)
c.) Full Passive Cervical Rotation	69 (31.4%)	<b>81</b> <b>(36.8%)</b>	22 (10.0%)	7 (3.2%)	1 (0.4%)	0 (0.0%)	40 (18.2%)
d.) Within 5 degrees of Full PROM	46 (20.9%)	<b>86</b> <b>(39.1%)</b>	28 (12.7%)	10 (4.5%)	1 (0.5%)	2 (0.9%)	47 (21.4%)
e.) Full Active Cervical Lateral Flexion	51 (23.2%)	<b>90</b> <b>(40.9%)</b>	30 (13.6%)	9 (4.1%)	0 (0.0%)	0 (0.0%)	40 (18.2%)
f.) Full Active Cervical Rotation	58 (26.4%)	<b>86</b> <b>(39.1%)</b>	30 (13.6%)	6 (2.7%)	0 (0.0%)	0 (0.0%)	40 (18.2%)
g.) Within 5 degrees of Full AROM	50 (22.7%)	<b>86</b> <b>(39.1%)</b>	26 (11.8%)	11 (5.0%)	0 (0.0%)	2 (0.9%)	45 (20.5%)
h.) Achieving Developmental Milestones	<b>96</b> <b>(43.6%)</b>	62 (28.2%)	14 (6.4%)	3 (1.4%)	3 (1.4%)	1 (0.4%)	41 (18.6%)
i.) Age of the Child	11 (5.0%)	32 (14.5%)	33 (15.0%)	35 (15.9%)	<b>40</b> <b>(18.2%)</b>	24 (10.9%)	45 (20.5%)
j.) Symmetrical Righting Reactions	54 (24.5%)	<b>79</b> <b>(35.9%)</b>	34 (15.5%)	11 (5.0%)	2 (0.9%)	0 (0.0%)	40 (18.2%)
k.) Parental Compliance with HEP	59 (26.8%)	<b>77</b> <b>(35.0%)</b>	25 (11.4%)	9 (4.1%)	5 (2.3%)	1 (0.4%)	44 (20.0%)
l.) Parental Satisfaction	49 (22.3%)	<b>86</b> <b>(39.1%)</b>	32 (14.5%)	10 (4.5%)	0 (0.0%)	0 (0.0%)	43 (19.5%)

**57.** In your best estimate, when physical therapy for a patient with CMT has been discontinued, what is typically the reason for discontinuation? Please rate each potential reason separately. Physical Therapy is discontinued because:

	Always	Usually	Sometimes	Rarely	Never	Missing
a.) There is a health insurance limitation on visits or payment	5 (2.3%)	16 (7.3%)	<b>76</b> <b>(34.5%)</b>	55 (25.0%)	25 (11.4%)	43 (19.5%)

for services. (N=220)						
b.) The parent decided that the patient no longer needs PT. (N=220)	2 (0.9%)	32 (14.5%)	<b>100</b> <b>(45.5%)</b>	43 (19.5%)	2 (0.9%)	41 (18.6%)
c.) The physician decided that the patient no longer needs PT. (N=220)	0 (0.0%)	6 (2.7%)	49 (22.3%)	<b>78</b> <b>(35.5%)</b>	45 (20.4%)	42 (19.1%)
d.) The parent/ caretaker no longer shows up for appointments. (N=220)	3 (1.3%)	14 (6.4%)	<b>91</b> <b>(41.4%)</b>	62 (28.2%)	8 (3.6%)	42 (19.1%)
e.) The patient is referred for surgery. (N=220)	0 (0.0%)	1 (0.4%)	8 (3.6%)	78 (35.5%)	<b>89</b> <b>(40.5%)</b>	44 (20.0%)

**58.** Given your best estimate, what percentage of your patients with CMT are discharged from PT with full resolution? (Full resolution defined as: full PROM, full AROM, midline head position, and symmetrical righting reactions)

**Mean = 75.7%, N= 176, Range = 0-100%, Std Dev = 21.6%**

**59.** At time of discharge, when do you typically schedule a follow-up PT visit for your patients with CMT:

- ☐ I don't typically schedule a follow-up visit but recommend parents call if problem occurs..... **123 (55.9%)**
- ☐ 1 month after discharge..... **27 (12.3%)**
- ☐ 3 months after discharge..... **19 (8.6%)**
- ☐ 6 months after discharge..... **6 (2.7%)**
- ☐ I don't typically schedule a follow-up visit nor recommend it ..... **1 (0.5%)**
- ☐ One year after discharge..... **0 (0.0%)**
- Missing..... **44 (20.0%)**
- Total = 220 (100%)**

**60.** In your best estimate, what percentage of patients with CMT return after they were discharged for a second episode of care?

**Mean = 10.3%, N= 172, Range = 0-90%, Std Dev = 16.0%**

## **SECTION 5: Outcomes**

This section of questions will be used to determine the patterns of physical therapy outcomes for patients with CMT, as described by physical therapists in the USA.

**61.** What group data on CMT are being collected and analyzed by you or your facility to improve outcomes of patient care? (Circle all that apply.)  
(N=173 respondents)

- ☐ No group data on the management of CMT is being analyzed at my Workplace.....**109/173 (63.0%)**
- ☐ Achievement of patient goals (posture, head tilt, ROM).....**48/173 (27.7%)**
- ☐ Number of visits to complete episode of care...**36/173 (20.8%)**
- ☐ Parental satisfaction.....**33/173 (19.1%)**
- ☐ Use of standardized measures in documentation...**26/173 (15.0%)**
- ☐ Change in scores on standardized measures **16/173 (9.2%)**
- ☐ Referral sources.....**13/173 (7.5%)**
- ☐ Comparison of interventions.....**11/173 (6.4%)**
- ☐ Cost of services.....**8/173 (4.6%)**
- ☐ Assessment of pain.....**6/173 (3.5%)**
- ☐ Reasons for payment denial.....**4/173 (2.3%)**

**62.** If group data is collected and analyzed, with whom are outcomes shared?  
Circle all that apply. (N=56 respondents)

- ☐ Staff.....**50/56 (89.3%)**
- ☐ Administration.....**30/56 (53.6%)**
- ☐ Third party payors.....**6/56 (10.7%)**
- ☐ Consumers.....**6/56 (10.7%)**
- ☐ Professional publications.....**5/56 (8.9%)**
- ☐ Promotional materials.....**3/56 (5.4%)**
- ☐ Other (Referring Physicians).....**1/56 (1.8%)**

**63.** Has service delivery changed as a result of the group data on outcomes?  
(N= 55 respondents)

- ☐ No.....**33/55 (60.0%)**
- ☐ Yes.....**22/55 (40.0%)**

**64.** How has service delivery changed as a result of the group data on outcomes? (Open ended)

**(N=20 respondents)**

Prognose - Adjusting plan of care/ frequency of treatments/ estimate duration of care .....	<b>5/20</b>	<b>(25.0%)</b>
Treatment - Shifted focus to treatments that provide best outcome.....	<b>5/20</b>	<b>(25.0%)</b>
Developed standardized pathway among clinicians...	<b>4/20</b>	<b>(20.0%)</b>
Referral - Enabled earlier referral to PT & a better understanding of what PT does/ Increased vigilance of inpatients in NICU/ Increased collaboration with physicians & staff.....	<b>4/20</b>	<b>(20.0%)</b>
Measurement - Selected the tool or technique for standardization of measurements across clinicians/clinic sites...	<b>3/20</b>	<b>(15.0%)</b>
Changes in handouts/ resources / evaluation form/ discharge letter with reasons for follow-up.....	<b>3/20</b>	<b>(15.0%)</b>
Developed a more standardized referral process for adjunct intervention (for helmets/ TOT collar/ Botox).....	<b>2/20</b>	<b>(10.0%)</b>
Expanded services: Developed craniofacial clinic at three more sites (staffed with PT, MD, orthotist).....	<b>1/20</b>	<b>(5.0%)</b>

**65.** In your opinion, how important are each of the following clinical attributes in predicting improvement for your patients with CMT?

<b>(N= 220 for all)</b>	<b>Most Important</b>	<b>Very Important</b>	<b>Important</b>	<b>Somewhat Important</b>	<b>Least Important</b>	<b>Missing</b>
a.) Ethnicity	0 (0.0%)	6 (2.7%)	7 (3.2%)	30 (13.6%)	<b>126 (57.3%)</b>	51 (23.2%)
b.) Gender	0 (0.0%)	3 (1.4%)	9 (4.1%)	39 (17.7%)	<b>120 (54.5%)</b>	49 (22.2%)
c.) Maternal Delivery (vaginal vs. C-Section)	5 (2.3%)	21 (9.5%)	37 (16.8%)	<b>56 (25.5%)</b>	52 (23.6%)	49 (22.2%)
d.) Length of baby at birth	2 (0.9%)	9 (4.1%)	21 (9.5%)	50 (22.7%)	<b>86 (39.1%)</b>	52 (23.6%)
e.) Position in utero (vertex vs. breech)	10 (4.5%)	40 (18.2%)	<b>59 (26.8%)</b>	43 (19.5%)	20 (9.1%)	48 (21.8%)
f.) Primiparity vs. multiple birth	14 (6.4%)	<b>53 (24.1%)</b>	45 (20.5%)	35 (15.9%)	24 (10.9%)	49 (22.2%)
g.) Birth Order (first vs. second born)	2 (0.9%)	16 (7.3%)	29 (13.2%)	46 (20.9%)	<b>77 (35.0%)</b>	50 (22.7%)
h.) Age at Presentation	<b>86 (39.1%)</b>	67 (30.5%)	21 (9.5%)	0 (0.0%)	0 (0.0%)	46 (20.9%)
i.) Initial degree of passive cervical rotation	<b>70 (31.8%)</b>	69 (31.4%)	25 (11.4%)	7 (3.2%)	0 (0.0%)	49 (22.2%)
j.) Type of CMT (tumor, postural, muscular)	<b>81 (36.8%)</b>	64 (29.1%)	24 (10.9%)	5 (2.3%)	1 (0.4%)	45 (20.5%)
k.) Degree of craniofacial asymmetry	54 (24.5%)	<b>77 (35.0%)</b>	31 (14.1%)	12 (5.5%)	0 (0.0%)	46 (20.9%)
l.) Presence of hip dysplasia	17 (7.7%)	<b>53 (24.1%)</b>	49 (22.3%)	40 (18.2%)	10 (4.5%)	51 (23.2%)
m.) Initial degree of head tilt	<b>82 (37.3%)</b>	69 (31.3%)	16 (7.3%)	7 (3.2%)	0 (0.0%)	46 (20.9%)
n.) Initial degree of active cervical rotation	66 (30.0%)	<b>71 (32.3%)</b>	30 (13.6%)	5 (2.3%)	0 (0.0%)	48 (21.8%)
o.) Parental adherence to treatment	<b>137 (62.3%)</b>	32 (14.5%)	5 (2.3%)	1 (0.4%)	0 (0.0%)	45 (20.5%)
p.) Presence of plagiocephaly	52 (23.6%)	<b>86 (39.1%)</b>	29 (13.2%)	8 (3.6%)	0 (0.0%)	45 (20.5%)



q.)Other co-morbidities	59 (26.8%)	<b>63</b> <b>(28.6%)</b>	32 (14.5%)	11 (5.0%)	2 (0.9%)	53 (24.1%)



ME – 5	MI – 1	MN – 8
MO – 1	MS – 3	MT – 1
NC – 4	ND – 1	NE – 2
NH – 5	NJ – 6	NM – 6
NY – 5	NV – 1	OH – 6
OK – 3	OR – 7	PA – 6
RI – 1	SC – 1	SD – 2
TN – 5	TX – 8	UT – 1
VA – 5	VT – 2	WA – 7
WI – 4	WV – 2	WY – 1

**69.** In your state, is CMT alone a “qualifying diagnosis” to be eligible for services through the Early Intervention Program?

- ☐<sub>1</sub> Yes..... **54 (30.9%)**  
☐<sub>2</sub> No..... **70 (40.0%)**  
☐<sub>3</sub> Not Sure..... **51 (29.1%)**  
**175 responses**

**70.** How would you describe the location of your practice?

- ☐<sub>1</sub> Rural..... **31 (17.7%)**  
☐<sub>2</sub> Urban..... **65 (37.1%)**  
☐<sub>3</sub> Suburban..... **79 (45.1%)**  
**175 responses**

**71.** What is the typical distance that families travel to receive P.T. services?

- ☐<sub>1</sub> None, I travel to them..... **41 (23.3%)**  
☐<sub>2</sub> 1-5 miles..... **16 (9.1%)**  
☐<sub>3</sub> 6-10 miles..... **49 (27.8%)**  
☐<sub>4</sub> 11-20 miles..... **53 (30.1%)**  
☐<sub>5</sub> 21-30 miles..... **12 (6.8%)**  
☐<sub>6</sub> 31-40 miles..... **5 (2.8%)**  
☐<sub>7</sub> 40+ miles..... **0 (0.0%)**  
**176 responses**

**72.** Are you required to pass a competency exam before working with patients with CMT?

- ☐<sub>1</sub> Yes..... **21 (11.9%)**  
☐<sub>2</sub> No..... **156 (88.1%)**  
**177 responses**

**73.** Does your practice offer a torticollis clinic or group therapy for infants with CMT?

- |   |                      |                |
|---|----------------------|----------------|
| <input type="radio"/> <sub>1</sub> Yes..... | <b>10</b>            | <b>(5.6%)</b>  |
| <input type="radio"/> <sub>2</sub> No.....  | <b>167</b>           | <b>(94.4%)</b> |
|   | <b>177 responses</b> |                |

**74.** At your facility, do PTAs treat patients with CMT?

- |   |                      |                |
|---|----------------------|----------------|
| <input type="radio"/> <sub>1</sub> Yes..... | <b>26</b>            | <b>(15.0%)</b> |
| <input type="radio"/> <sub>2</sub> No.....  | <b>147</b>           | <b>(85.0%)</b> |
|   | <b>173 responses</b> |                |

**75.** Do you co-treat your patients with CMT with...?

- |   |                      |                |
|---|----------------------|----------------|
| a.) OTs.....                            | <b>43</b>            | <b>(24.3%)</b> |
| b.) SLPs.....                           | <b>18</b>            | <b>(10.2%)</b> |
| c.) PTAs.....                           | <b>5</b>             | <b>(2.8%)</b>  |
| d.) COTAs.....                          | <b>1</b>             | <b>(0.6%)</b>  |
| e.) Orthotists.....                     | <b>33</b>            | <b>(18.6%)</b> |
| f.) Educators.....                      | <b>11</b>            | <b>(6.2%)</b>  |
| g.) Early Intervention Specialists..... | <b>32</b>            | <b>(18.1%)</b> |
|   | <b>177 responses</b> |                |

## **SECTION 7: PROFESSIONAL DEVELOPMENT**

**76.** Are you a member of the APTA?

- ☐<sub>1</sub> Yes..... **138 (78.4%)**  
☐<sub>2</sub> No..... **38 (21.6%)**  
**176 responses**

**77.** Are you a member of the Section on Pediatrics?

- ☐<sub>1</sub> Yes..... **129 (73.7%)**  
☐<sub>2</sub> No..... **46 (26.3%)**  
**175 responses**

**78.** Are you an Board Certified Pediatric Clinical Specialist?

- ☐<sub>1</sub> Yes..... **47 (26.8%)**  
☐<sub>2</sub> No..... **128 (73.1%)**  
**175 responses**

**79.** Have you completed a Board Certified Clinical Residency in Pediatrics?

- ☐<sub>1</sub> Yes..... **5 (2.9%)**  
☐<sub>2</sub> No..... **169 (97.1%)**  
**174 responses**

**80.** Have you taken CEU courses on CMT?

- ☐<sub>1</sub> Yes..... **131 (74.4%)**  
☐<sub>2</sub> No..... **45 (25.6%)**  
**176 responses**

**81.** In your opinion, what training has been the most beneficial for your overall management of patients with CMT? (Check all that apply.)

- ☐<sub>1</sub> PT Education: Entry level school..... **18 (10.2%)**  
☐<sub>2</sub> APTA Certified Pediatric Residency Program..... **3 (1.7%)**  
☐<sub>3</sub> Post Professional Education/ Advanced Studies (MS, MA, tDPT, PhD)..... **15 (8.5%)**  
☐<sub>4</sub> Continuing Education Courses..... **118 (67.0%)**  
☐<sub>5</sub> Webinars..... **13 (7.4%)**  
☐<sub>6</sub> "On the Job" Training..... **107 (60.8%)**  
☐<sub>7</sub> Personal Review of the Literature..... **113 (64.2%)**  
☐<sub>8</sub> Participation in online PT community..... **33 (18.8%)**  
☐<sub>9</sub> Personal Experience..... **123 (69.9%)**  
☐<sub>10</sub> Other..... **13 (7.4%)**

**176 respondents**

**82.** If a standardized classification system were developed for the varying presentations of CMT, would you use it?

- ☐<sub>1</sub> Yes..... **162 (95.9%)**  
☐<sub>2</sub> No..... **7 (4.1%)**  
**169 responses**

**83.** If a standardized examination form were available, would you use it?

- ☐<sub>1</sub> Yes..... **148 (95.5%)**  
☐<sub>2</sub> No..... **7 (4.5%)**  
**155 responses**

**84.** How many years have you been practicing physical therapy?

**174 responses**

**Range = 1-49                      Mean = 17.89                      Std dev = 11.89**

**85.** How many years have you practiced in pediatrics?

**175 responses**

**Range = 1-45                      Mean = 15.87                      Std dev = 10.93**

**86.** How many years have you worked with infants with CMT?

**174 responses**

**Range = 1-42                      Mean = 11.43                      Std dev = 8.21**

**87.** What aspect of CMT management would you like to see additional guidance on? (open-ended)

- 
- 
- |   |           |                |
|---|-----------|----------------|
| a.) Epidemiology.....   | <b>1</b>  | <b>(0.5%)</b>  |
| b.) Education to PCPS & payors on importance of early referral...             | <b>9</b>  | <b>(5.4%)</b>  |
| c.) Differential Diagnosis.....   | <b>17</b> | <b>(10.2%)</b> |
| d.) Standardized Examination.....   | <b>19</b> | <b>(11.4%)</b> |
| e.) Standardization of Measurement .....                                      | <b>11</b> | <b>(6.6%)</b>  |
| f.) Classification System of Severity.....                                    | <b>11</b> | <b>(6.6%)</b>  |
| g.) Treatment Guidelines/ Frequency/ Algorithm.....                           | <b>13</b> | <b>(7.8%)</b>  |
| h.) Evidence based Treatment (Techniques with evidence for CMT)<br>.....      | <b>24</b> | <b>(14.4%)</b> |
| i.) Treatment techniques in need of evidence for infants with CMT...<br>..... | <b>15</b> | <b>(9.0%)</b>  |
| j.) Treatment of difficult cases.....   | <b>9</b>  | <b>(5.4%)</b>  |

k.) Parent Education.....	8	(4.8%)
l.) Outcomes Research.....	13	(7.8%)
m.) When to refer for helmet/TOT/surgery/ Botox.....	11	(6.6%)
n.) Guidelines for Discharge & Follow-Up.....	4	(2.4%)
o.) CPG with training.....	1	(0.5%)
p.) Pain.....	1	(0.5%)
	<b>167</b>	<b>responses</b>

**88.** If there were one resource/ document/ tool that might help to improve your practice, what would that be?

---



---

a.) Standard Measurement Tool.....	19	(18.6%)
b.) Standard Examination.....	23	(22.5%)
c.) Classification System.....	7	(6.9%)
d.) Treatment Algorithm/ Protocol.....	9	(8.8%)
e.) Chart to Track Changes.....	5	(4.9%)
f.) Clinical Practice Guidelines.....	12	(11.8%)
g.) Website for clinicians.....	3	(2.9%)
h.) Good compilation of handouts for parents.....	8	(7.8%)
i.) Other.....	9	(8.8%)
j.) Learning a new skill.....	3	(2.9%)
k.) Information that should be shared with MDS.....	4	(3.9%)
	<b>102</b>	<b>responses</b>

**89.** How did you access and complete this survey?

<input type="radio"/> <sub>1</sub> Accessed it from the web link posted in the e-newsletter from the Section on Pediatrics.....	85	(48.3%)
<input type="radio"/> <sub>2</sub> E-mailed <a href="mailto:headsupcmt@yahoo.com">headsupcmt@yahoo.com</a> as seen on Section on Education Listserv .....	4	(2.3%)
<input type="radio"/> <sub>3</sub> E-mailed <a href="mailto:headsupcmt@yahoo.com">headsupcmt@yahoo.com</a> as seen on Section on Pediatrics Listserv .....	7	(4.0%)
<input type="radio"/> <sub>4</sub> Received info from SOP State Rep & e-mailed <a href="mailto:headsupcmt@yahoo.com">headsupcmt@yahoo.com</a> .....	10	(5.7%)
<input type="radio"/> <sub>5</sub> Colleague sent me the e-mail address for <a href="mailto:headsupcmt@yahoo.com">headsupcmt@yahoo.com</a> .....	48	(27.3%)
<input type="radio"/> <sub>6</sub> Received request via phone call to my place of work...	5	(2.8%)
<input type="radio"/> <sub>7</sub> Melanie sent me an e-mail.....	17	(9.6%)
	<b>176</b>	<b>responses</b>

**COMMENTS** Please share your comments about any aspect of this survey OR on the management of CMT that may not have been addressed.

---

---

---

---

---

---

**THANK YOU!!! You have finished the survey! Please click “Submit” or return the survey in the envelope provided. Thank you!**