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Criteria Used for Identification of Torticollis by Professionals Providing Developmental Screenings

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Criteria Used for Identification of Torticollis
By Professionals Providing Developmental Screenings

by

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Doctor of Physical Therapy
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This Scholarly Project, submitted by Amanda Van Hatten and Lacey Jenson in partial fulfillment of the requirements for the Degree of Doctor of Physical Therapy from the University of North Dakota, has been read by the Advisor and Chair person of Physical Therapy under whom the work has been down and is hereby approved.

Peggy Mahr

(Graduate School Advisor)

Thomas Mohr

(Chairperson, Physical Therapy)

PERMISSION

Title	Criteria Used for Identification of Torticollis By Professionals Providing Developmental Screenings
Department	Physical Therapy
Degree	Doctor of Physical Therapy

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ABSTRACT

Purpose: The main objective of this study was to gather data from development screeners providing infant/toddler developmental screening regarding the criteria used to identify torticollis, information about referral practices when torticollis is suspected, and the information being provided to parents regarding torticollis.

Subjects: Subjects were recruited through a midwestern developmental screening organization. All developmental screeners were invited to participate in this study and inclusion criteria consisted of participants that currently were completing developmental screenings in the selected regional area.

Procedures: Focused interviews along with pre-questionnaires were utilized to gather the data. The pre-questionnaire which was distrusted first, included questions regarding demographics and current professional practice. Two interviews were held simultaneously. Each interview was recorded through the use of a note taker and DVD recording. The interview consisted of a total of seven questions overall and lasted about 45 minutes.

Data Analysis: For statistical analysis, a triangulation approach was utilized. Common themes and denominators along with memorable quotes from the screeners were compiled. Descriptive statistics were also utilized for the nominal data.

Results: The turn out rate for the focus interview was seven out of twelve developmental screeners (58.39%). The results of the pre-questionnaire indicated that developmental screeners utilized the following as criteria to identify torticollis to be head tilt, flattened head shape, and restricted neck (cervical) motion. The results of the focused interview process identified head/neck asymmetry, family self-identification and the child's ability to complete midline tracking as the criteria used most often for torticollis identification. The results of this study also indicated that the screeners considered plagiocephaly and club foot to be the most commonly identified associated conditions with torticollis.

Conclusions and Clinical Application: The results of this study indicated further research is needed to determine the criteria commonly used to identify torticollis, along with its associated conditions. In addition, education regarding the used of comprehensive and consistent criteria for the identification of torticollis is recommended to prevent failure to identify this condition or associated pathologies.

CHAPTER I

INTRODUCTION

The results of recent studies[1-3] have documented an increase in the incidence of torticollis over the last 10 years. Torticollis is a condition that presents with a unilateral shortening of the sternocleidomastiod (SCM) muscle.[1-6] This unilateral shortening results in lower positioning of the ear on the same side of the shortened SCM muscle (lateral flexion) with rotation of the head away from the side of the shortened SCM muscle, so the face is pointed away from the shortened muscle.[1, 3-4, 7]

Some studies[8-11] have made a link between the increase of torticollis and the "Back to Sleep" campaign that was developed in 1992. This program promoted the positioning of infants on their backs for sleep, but on their stomachs for play. The authors of these studies have proposed that a consequence of the relationship between the "Back to Sleep" program and the increased incidence of torticollis has resulted from the fact that parents have neglected the "tummy for play" portion of the campaign.[8-11]

Problem Statement

It is unknown why the incidence of torticollis is rising. In the literature review for this study, no research was found that specifically addressed professionals' awareness of torticollis or the criteria used for identification when completing developmental screenings. Therefore, there appears to be a lack of consistent, standardized criteria for torticollis that could be used in developmental screening.

Significance and Purpose of Study

The purpose of the study is to gather data from professionals providing infant/toddler developmental screening services regarding (a) if diagnostic criteria have been observed during developmental screenings, (b) what criteria has been used to identify torticollis, and (c) what associated conditions are being identified during screenings. Data generated through this study may be used to develop educational materials for professionals and family members regarding the early identification and prevention of torticollis.

Research Questions

1: When conducting a regional developmental screening, are professionals observing for diagnostic criteria of torticollis?

2: What diagnostic criteria are professionals who conduct regional developmental screenings using to identify torticollis?

3: When screening a child with suspected torticollis, what associated conditions are professionals looking for?

Hypotheses

The null hypothesis was that professionals completing developmental screenings for infant/toddler were not using a specific list of criteria to identify torticollis and were not identifying associated conditions. The alternative hypothesis was that professionals completing developmental screenings for infant/toddler were using a specific list of criteria to identify torticollis and were not identifying associated conditions.

CHAPTER II

LITERATURE REVIEW

Congenital muscular torticollis (CMT) is also known as "Twisted Neck" or "Wry Neck".[1, 4] CMT is a nonossuous form of torticollis as opposed to osseous torticollis (bony malformation) or a neurogenic torticollis (Sandifer syndrome, or tumors of the posterior fossa).[2] This condition involves a unilateral shortening of the sternocleidomastoid (SCM) muscle.[1-6] This neck muscle is made up of four bands. The cleidomastoid portion which is the deep band, originates from the medial third portion of the clavicle to insert onto the mastoid process. The cleido-occipital portion is one of three superficial bands that form an "N" over the cleidomastoid band. This superficial band shares the same origin site as the deep band but inserts on to the occiput, specifically the lateral portion of the superior nuchal line. The other two superficial bands, sterno-occipital and sternomastoid, also share the same origin point which is on the common tendon that is located on the superior sternum. However, the sterno-occipital band inserts with the cleido-occipital band onto the superior nuchal line and the sternomastoid band inserts onto the anterior and superior portion of the mastoid. All of the bands are interconnected either at the originating points or the insertion points leading to all four bands being affected one way or another by CMT.[7-8]

When a muscle shortens it contracts which results in an action. When the SCM muscle is shortened on one side it will pull the ear down toward the shoulder on that same side (lateral flexion) and then rotate the head to the opposite side, so the face is pointed away from the shortened muscle.[1-3, 7] The infant/toddler may also exhibit asymmetry with neck extension that can cause a forward head posture.[2,9] Depending on the etiology of CMT, the shoulder muscles, specifically the upper trapezius which shares the same nerve innervation as the SCM,[7] may also be involved.

Etiology

The cause is unclear, but there are four main theories that are being considered regarding the etiology of torticollis; (a) a possible lack of blood supply or trauma to the SCM muscle, (b) a mass or tumor in the belly of the SCM muscle that impairs the normal functional movement of the muscle, (c) a form of trauma at birth, and/or (d) intrauterine positioning. Authors[2, 7, 12] have indicated that these theories may overlap which results in controversy regarding why CMT occurs.

Several authors[2, 13-14] have concluded that a history of difficult or traumatic birth has occurred with 30%-60% of infants with CMT. It is thought a lesion of 1-3 cm of the SCM muscle, which results in bleeding, can occur during a difficult or traumatic birth. The SCM muscle is encased in fascial tissue (connective tissue) creating a compartment. When the SCM muscle bleeds an increase in pressure within the compartment occurs which may compromise the blood flow to an area of the muscle. The area that is commonly ischemic within the SCM is the inferior third portion. It is proposed that the ischemic area is replaced with fibrous tissue that results in muscle tightness and contracture of the muscle.

Another theory proposed is that intrauterine positioning or crowding may result in CMT. With intrauterine crowding, the mother's uterus is too small for the infant which results in malposition of the infant in the uterus. This malposition results in the SCM muscle being in a shortened position and the anterior chest and shoulder being compressed towards the infant's face. These mechanical forces alter the development of the otherwise normal muscle tissue of the SCM muscle leading to shortening. Therefore, the SCM and the shoulder muscles are involved.[1, 13-14] Both of the above theories can lead to a mass or tumor (1-3 cm) in the belly of the SCM, either from bleeding which results in a hematoma or swelling as a consequence of trauma.

CMT Subtypes

There are three subtypes of CMT; muscular torticollis (MT), sternomastiod tumor (SMT), and postural torticollis (POST). With MT, the SCM muscle on the affected side is simply tight or in a shortened position with no palpable mass.[1]

In SMT, a mass is present within the SCM muscle. This subtype is thought to be the most common presentation of CMT. This mass is generally present at birth and can be palpated. It will continue to develop over the next 2-3 months and finally disappear between 4-8 months. After the mass disappears it leaves the SCM muscle shortened which diminishes lateral flexion on the same side and results in head rotation away from the affected side. This contracture is thought to prevent the SCM muscle from growing at a normal rate with the rest of the neck and spine musculature.[4, 15-21]

The last subtype is known as POST and is considered to be the least common form of CMT. This type appears to have no unilateral SCM muscle tightness and no palpable mass. It is thought to result from other anomalies of the neck musculature that causes a postural dysfuntion.[9]

Incidence

The prevalence of CMT has been reported as 1 in every 250 births[1, 3] to 1 in every 300 births[2] according to the recent studies. The variability range of CMT among newborns is from 0.3% to as high as 2.0% and the condition has been found to be prevalent in boys and girls equally.[1,3,7] CMT is also the third most common musculoskeletal condition affecting infants/toddlers following hip dysplasia and club foot.[5] CMT is generally observed within the first 3 months of birth and commonly presents as a right-sided torticollis.[1, 8]

The incidence of CMT has increased over the last 10 years. This increase is thought to be directly related to the "Back to Sleep" campaign sponsored by the American Academy of Pediatrics (AAP) to help prevent Sudden Infant Death Syndrome (SIDS). SIDS was thought to be the results of infants sleeping on the belly. The AAP created a campaign to promote parents to place their infants in a supine position while sleeping to prevent SIDS. It was reported by the AAP in 1996, that approximately 76% of infants were in the supine position for sleep compared to 30% in 1992. Along with the "Back to Sleep" campaign there was a "Tummy for Play" campaign. Since 1995, there has been a dramatic increase in the prevalence of CMT and is thought to be related to infants not spending time in the prone position.[8-11]

Differential Diagnosis

CMT is found to be the most frequent cause of abnormal head posture (AHP).[19] However, there are other conditions which present like CMT and result in abnormal head posture. Some orthopedic conditions that present like CMT are; Klippel- Feil, which is a congenital condition where there is fusion of 1 or more cervical vertebrae, absence of the cervical transverse ligament, absence of cervical neck musculature, contracture(s) of other neck musculature besides the SCM muscle and/or brachial plexus injury from a difficult or traumatic birth. Also, it is recommended that a radiograph be taken to rule out spine abnormalities causing the AHP. [1, 3,8,19]

Non-orthopedic conditions that can present like CMT include ocular conditions. Due to involvement of the eye musculature, infants may use a head tilt or head rotation to compensate for the ocular abnormality. Examples of these ocular conditions include nystagmus, weak lateral rectus muscles, and superior oblique muscle palsy.[1, 3, 19]

Sandifer syndrome can also present like CMT. This syndrome is associated with gastroesophageal reflux (GERD) and hiatal hernias. With this syndrome the infant's head and neck posture is laterally flexed and rotated towards the opposite side secondarily to the pain from the GERD. The pain is intermittent, changes position and is not present while the infant is a sleep.[1, 3, 6-7, 19]

Neurological syndromes may also present as CMT such as central nervous system lesions that occupy space, posterior fossa masses/tumors, herniated cervical disc, and dystonia. Magnetic resonance imaging (MRI) may rule out these syndromes along with a specific neurological evaluation. Usually other symptoms present with these conditions besides the AHP such as headache, vomiting, ataxia and other neurological signs.[19]

Observable Signs

Signs of CMT may present as early as 1 month of age. Neck motion asymmetry or abnormal posture may be the most obvious signs of CMT. This results in range of motion (ROM) limitations for the infant that involve the neck and upper extremity. Neck ROM limitations include decreased lateral flexion on the unaffected side, decrease in rotation from the unaffected side to the affected side and may involve cervical flexion and extension. Weakness and elongation of the SCM muscle on the unaffected side and a tight rectus splenius capitis on the unaffected side (secondary to the constant rotation away from the affected side) may also result. Upper extremity ROM limitations result from the body compensating for the asymmetric neck posture, commonly the upper trapezius being elevated on the affected side.[1-8, 22-23]

Cranio-facial changes may also take place and become noticeable after a month of age. Asymmetry of the facial structures may occur. Therefore, it is recommended that the involved side of the face be compared to the uninvolved side. These changes can include different positioning of the ear, a smaller eye shape, deviation of the chin point, a recessed eyebrow, diminished fullness of the cheek, under developed jaw, deviation of the nasal tip, and reduced angle of the mouth. Another observable sign is the mastoid may be larger with hypertrophy at the muscle insertion on the involved side resulting in the pull of the shortened SCM muscle.[2, 7, 11-14]

Skull shape changes also can be noticeable at birth and commonly by one month of age. The skull changes are known as plagiocephaly. The skull may be asymmetric and flattened on the unaffected side resulting in an abnormal head shape. Also, areas of hair loss may be observable. These changes are due to the prolonged head position, and the imbalance of muscle growth.[2, 7, 10-11, 14, 23]

Associated Conditions

There are many other developmental conditions that are associated with CMT. Plagiocephaly is the most common (90% occurrence rate with CMT) followed by hip dysplasia, club foot deformity, cervical scoliosis, bowed legs, visual disturbances, unlevel pelvis and retained primitive reflexes.[1, 3-5, 7-8] Plagiocephaly refers to a unilateral flattened occiput, limited neck mobility, ear malalignment, facial asymmetry, forehead protrusion, and bald spot which generally result from prolonged external pressures on the skull. As with CMT, plagiocephaly may arise from intrauterine malpositioning. Also a five fold increase in the incidence of plagiocephaly has occurred since the "Back to Sleep" campaign 1992, secondary to the excessive supine positioning of infants.[2, 8-9, 10-11, 24-26]

Developmental hip dysplasia (DDH) is where there is a dislocation of one hip. DDH is commonly seen in girls with a family history of DDH and has prevalence among newborns of 1%. Like CMT, the etiology is unknown but thought to be related to intrauterine positioning and/or a traumatic or difficult birth experience. DDH has a varied coexistence rate with CMT of 0-20% and is also observed with plagiocephaly. It is unknown which condition was present first (CMT or DDH). This condition is more common with females than males (a ratio of 4:1); however, males are more likely to have a co-diagnosis of CMT with DDH. General characteristics of DDH include leg length discrepancies and pain which commonly result in abnormal fussing with diaper changes.[24, 27-30]

Evaluation/Diagnosis

An extensive evaluation is necessary to determine if CMT is present in an infant/toddler. Recommendations are that the evaluation should include a detailed history of the infant/toddler including birth details related to the delivery, any instrumentation and/or resulting trauma to the child. The examination should also include screening for associated conditions, a thorough neurological screen and an upper/lower extremity evaluation. If possible, a postural assessment should be conducted. Observation of the performance of age appropriate motor skills, skin condition, head and face shape, ROM of the head and neck (can be assessed through visual field tracking), and palpation of the SCM muscles should be completed, along with diagnostic imaging.[1-2, 5, 11, 22, 30, 31-34] It is also recommended that the infant/toddler should be re-evaluated every 3 months.[1]

Radiographs are used to rule out any structural deformities or fractures that may have occurred to the cervical area. MRIs may also be used to assess the soft tissue in the cervical area and ultrasonography has been successful in aiding in the identification of CMT and identification of masses located within the belly of the muscle. This imaging allows the clinician to rule out whether or not the CMT is related to posture and/or POST.[1]

Treatment/Outcomes

Early identification and prevention of the consequences of CMT is the best treatment, however CMT is not always identified right away. Treatment involves physical and occupational therapy along with parent education and a home exercise program. Surgical intervention is generally recommended after six months of conservative treatment without complete resolution or if the child is at a significantly older age where conservative treatment is not an option.[36]

Therapy is generally comprised of stretching and strengthening exercises for the infant/toddler. Manual stretching techniques have been shown to be 95% effective in infants that are seen before the age of 1 year. Stretching involves passive SCM muscle stretches of the involved muscle and active ROM exercises completed through play. These techniques are designed to lengthen the shortened SCM muscle and are completed twice a day for five repetitions while holding each stretch for ten seconds. Cheng et. al[13] found that 86% of children with SMT in this study had an excellent outcome, 93% of children with MT had an excellent outcome with no further consequence and of those children with POST, 99% had an excellent outcome with no further consequences. It is also recommended that treatment should include a home exercise program that can be followed by the parents and/or caretakers. Treatment duration typically involves 3-12 months before complete neck mobility has been restored. The most predictive factor of the outcome of intervention is the age of the infant/toddler at the initiation of intervention.[13, 36-37]

It is also recommended that education be provided to parents regarding proper positioning. Caregivers of infant/toddlers should be aware of proper handling techniques that will be utilized during daily activities such as carrying, feeding and sleeping. Positioning recommendations are to encourage midline orientation and gain postural control of the head to prevent progression of the torticollis or plagiocephaly, positioning that encourages the use of the weakened muscles and placing the infant on his/her stomach for play as an alternative position. With the use of positioning equipment such as swings or high chairs, it is recommended that the child's head and lower extremities be stabilized in proper midline alignment. Rotation of the head to the involved side may be encouraged by alternating the position of the head when placing the child in the crib and encouraging the child to look at individuals as they enter the room.[7, 22, 36-37]

Botulinum toxin (BOTOX) is also being used as an intervention to assist with stretching of the tight SCM muscle. If there is no response to stretching over a month or 2 months then BOTOX is considered an option for intervention. BOTOX is injected into the affected muscle to decrease tone or relax the muscle and facilitate stretching. While effective, the effects of BOTOX are temporary and it is imperative that an efficient stretching program is implemented to take advantage of the effects from the injection.[38-40]

Timing of intervention is shown to play a very important role in the outcome of prognosis. It has been found that early intervention is crucial to an excellent outcome. Infants that received conservative treatment were more likely to have a full recovery. The potential to have a positive effect with early intervention is related to the rapid growth rate that a newborn experiences. Brain growth rate does not begin to slow down until the infant is 5-6 months of age and 80% of the skull growth occurs before 12 months of age.[41] Celayier[41] concluded that infants over the age of 18 months who had undergone at least 6 months of conservative intervention with no improvement would require surgery.

CHAPTER III

METHODOLOGY

This research project used focused interviews to gather data from professionals providing infant/toddler developmental screening services. On May 15, 2006, an initial planning meeting with the study advisory committee occurred at the Department of Physical Therapy, University of North Dakota. At that meeting, it was determined that subjects for the focused interview would be recruited from professionals working at a midwestern developmental screening organization. Based on the recommendations of the committee, two different instruments were developed to gather the data; a pre-interview questionnaire which addressed demographic information and information regarding current professional practice, and a set of questions to be asked during the focused interview. It was determined that two or three smaller focused groups would be more beneficial than one large group. Each focus group would have a coordinator, interviewer, and recorder. It was also determined that the focused interview would take place on a weekday night, preferably at the University of North Dakota. The Institutional Review Board (IRB) at the University of North Dakota approved the study design on June 20, 2006. Each of the researchers, Lacey Jenson and Amanda Van Hatten, completed a focused interview and with collaborators serving as note takers.

Subject Selection

Subjects were recruited via a letter of invitation to the focused interviews which were scheduled during the organization's quarterly in June, 2006. The invitation described the study, the interview process and the measures that would implemented to protect confidentiality in accordance with the IRB requirements. (See Appendix A) The inclusion criteria to participate in the study required that (a) participants were currently completing developmental screenings and (b) were located in the regional area that was selected. Twelve subjects were invited to participate in this research study.

The subjects participating represented a variety of educational and professional backgrounds. Each subject indicated their willingness to participate in the study by completing the pre-interview questionnaire and attending the focused interview sessions.

Instrumentation

The questions for the focused interviews were kept to a total of seven to allow adequate time for discussion. (Appendix B) A pre-interview questionnaire was developed which addressed demographic information, years completing developmental screens, amount of screens completed per month and general information regarding torticollis. (Appendix C)

Each subject was greeted as they arrived at the designated interview location. An introduction was provided by the agency coordinator. It was stressed to the screeners that there responses would not be considered as right or wrong answers during the interview. Ground rules were established for each interview group that established that only one person was to speak at a time to provide clarity of the recording and allow all comments to be heard.

Focused Interviews

The researchers followed the protocols outlined by R. Krueger for the focused interviewer and the recorder, copies of which are included as Appendices D and E. Prior to the focused interview, the recorders had received training regarding completion of the Focus Interview Analysis Worksheet. (Appendix F) Prior to the initiation of the focused interview, a copy of a memorandum describing the project was reviewed by the subjects. (Appendix G) Once subjects had agreed to participate, they were randomly divided into two groups and separated into two different rooms.

During the interview, as each of the seven questions were addressed, an opportunity was given to each subject to respond to the question. All seven questions were addressed separately, and data recorded and key points summarized by the recorders. Recorders were also instructed to listen for and record notable quotes that might illustrate an important concept or point of view. Prior to concluding the session, the recorder addressed the subjects' questions/responses to obtain any clarification that was required. The interview concluded with the interviewer expressing appreciation to the subjects for their willingness to participate. Each session was audio and video taped onto a DVD. Following the interviews, the recorders submitted the notes to the researchers for analysis. Confidentiality of the respondents was protected during the data review.

Data Analysis

The researchers reviewed the data and completed the analysis. Descriptive statistics were utilized for the nominal data. Phenomenology data analysis was implemented with triangulation to report common themes and denominators. Additionally, memorable quotes from the interventionists were compiled. (Appendix H)

CHAPTER IV

RESULTS

Pre-Interview Questionnaire

The pre-interview questionnaire was designed to address educational preparation and the variety of educational backgrounds, years worked in the specific field, amount of time employed at the developmental screening organization, the number of developmental screenings preformed on a monthly basis, the referral protocol, and general knowledge of torticollis. The questionnaire was composed of nine questions and was completed by seven subjects of the original twelve invited. (58.3% response rate). The results gathered from this question documented that 57.1 % of the respondents were speech language pathologists (SLP), and the remaining 42.9% of the subjects had credentials in early childhood development, social work, and education. The second question addressed years of practice in these fields with the average years worked within an individual's profession was 14.4 years, with the longest duration being 35 years as a SLP and the shortest being 6 years (SLP and social work). The average time spent working for the developmental screening organization was 68.1 months with the most amount of time being 276 months and the least amount of time being 3 months, both of these were SLP.

The average number of screenings being completed per month was 16.9, with the highest being 25 and the lowest 3. The varied range represented full and part time employees and new employees as well as experienced professionals. Five of the 7 participants reported that they had identified diagnostic criteria for torticollis. The most often used criteria identified by subjects included observation of tilting of the head, flattening of the head, and restricted neck (cervical) motions (69.2%). The following three signs of torticollis were not being utilized by the screeners; low birth weight, club foot and bowed legs (genu varum).

When asked if the subjects were making referrals for follow up evaluations or interventions, 71.4% indicated referrals had been made. Responses of the 7 participants indicated, 5 referrals were made to physicians, 3 to physical therapy and 2 to occupational therapy. Regarding providing parents with education on the identification and/or prevention of torticollis, 71.4% answered "no" to this question.

Focused Interviews

Research Question 1: When conducting a regional developmental screening, are professionals observing for diagnostic criteria of torticollis?

Focus interview question 1: *Have you observed or identified signs of Torticollis when completing screenings?* Six of the 7 participants indicated that they had assessed an infant/toddler with signs of torticollis.

Research Question 2: What diagnostic criteria are professionals who conduct regional developmental screenings using to identify torticollis?

Focus interview question 3: *Is it something you routinely see or have seen increase in the last two years?* Among the 6 respondents, the most common criteria used to identify torticollis included: head and neck asymmetry (3), tracking to midline (2), delayed motor milestones (2). In addition asymmetry in facial structures and cervical movement, muscular weakness, positional changes and head flattening were all mentioned by one of the respondents. (Table 1)

Table 1: Criteria used for the Identification of Torticollis

3	Head/Neck Asymmetry
2	Identification by Family
2	Tracking to Midline
2	Delayed Developmental Motor Milestones
1	Head Flattening
1	Positional Changes
1	Head/Neck Motion
1	Neck Muscular Weakness
1	Facial Asymmetry
1	Shoulder Asymmetry

Research Question 3: When screening a child with suspected torticollis, what associated conditions are professionals looking for?

Four subjects responded to the interview question 4: *When providing a screen for a child with suspected Torticollis, what else are you looking for?* Associated conditions that were identified included plagiocephaly (3), club foot (3), delayed milestones (1), limb involvement (1), weakness(1) and facial asymmetry (1). (Table 2)

Table 2: Other Findings Associated with Torticollis

3	Plagiocephaly
3	Club Foot
1	Delayed Developmental Motor Milestones
1	Limb Involvement
1	Neck Musculature Weakness
1	Facial Asymmetry

Focus interview question 5: *Is it something you routinely see or have seen increase in the last two years?* Six participants responded to the question all reported they have observed an increase incidence of torticollis within the last two to five years.

Focus interview question 5: *Have you received referrals for children who have signs of torticollis?* Participants were unable to answer this question directly due the organization's protocols for processing referrals which resulted in the coordinator receiving all referrals. Historically, within this organization, a referral for torticollis would generally go directly to a physical therapist/occupational therapist which are qualified in this field. No further information could be gathered regarding this question due to the fact that no physical therapists or occupational therapists participated in the focus interviews.

Focus interview question 6: *Who have you most frequently made referrals to for further evaluation of the risk of torticollis?* Six participants responded to this question. The most common response was that a referral would be made to a motor screener for further evaluation. Another common response was that parents were allowed to make the decision of either having a more detailed evaluation completed by a motor screener or a referral to the family's physician.

Focus interview question 7: *What type of educational materials and information do you feel should be provided to parents regarding the prevention of identification of torticollis?* As with the previous questions, six participants responded to this question and indicated that the developmental screeners do not make diagnoses. Instead, a developmental screening is completed, findings are documented and then further referrals are made as necessary to meet the needs of the child. However, the respondents all indicated that educational materials promoting tummy time, recommendations for activities and positioning which included switching sides with feeding and crib positioning would be made to the parents.

To conclude the focus interview, subjects were asked: *What would you like to see come from this research study?* All participants responded with suggestions that included a checklist for torticollis and associated diagnoses that could be taken with on a developmental screening, a reference tool that could be used by individuals from any professional background and a parent informative handout that could be left with the parents regarding recommendations made for torticollis prevention.

CHAPTER V

Discussion and Conclusion

The principle findings between the pre-questionnaire and the focus interview were consistent when addressing if the screeners were assessing torticollis and the criteria being used to assess torticollis. Both assessment tools found that 85.7% of the screeners in the study were assessing torticollis when completing a developmental screening. It was also consistent between the two assessment tools that criteria being observed consisted of head/neck asymmetry (also flat spots of the head), family identification (through photos or general observation), midline orientation, restricted cervical range of motion and delayed developmental milestones were equally observed and assessed among the screeners. The findings indicated that plagiocephaly and club foot were routinely assessed as associated conditions by the subjects; however, subjects expressed a lack of awareness of the fact that hip dysplasia was commonly associated with torticollis. [24, 27-30]

From the results of this study, it was concluded that further education regarding the identification of torticollis should be made available to professionals providing developmental screening services. Information specific to associated conditions and a standardized method of evaluating children for these conditions would be recommended.

Limitations

Seven subjects participated in the study and completed the pre-interview questionnaire and the focus interviews (58.3%). The low return rate could be attributed to the fact that there were a small number of subjects available within the region that the study targeted. Some subjects were required to travel to attend the interviews which may have been difficult. Some of the subjects were part-time employees and may have had other obligations limiting their participation. In the future, it is recommended that a larger geographic area be included for the subject selection criteria.

Another factor that may have affected the results was the fact that subjects were not required to be full time employees of the agency and many had additional full time employment. The variation in employment status would result in varied levels of preparation and continuing education opportunities that may have influenced the professionals' knowledge base regarding this condition.

Conclusion and Recommendations

This study proved the null hypothesis which was that professionals completing developmental screenings for infant/toddlers were not using a specific list of criteria to identify torticollis. The results from this study suggested that there is a need for training in this region regarding the assessment of children for torticollis.

It is recommended that future research be completed with a larger group of subjects drawn from a wider geographic area to identify additional training needs and current level of practice. An online survey may also assist in getting feedback from subjects who are located in very rural areas and have difficulty with travel requirements to attend a focused interview. It is also recommended that, following additional needs assessment research, a standardized protocol for screening children for torticollis be developed for use by professionals from varied backgrounds.

APPENDIX A

Assessment and Diagnostic Criteria of Torticollis Among Regional Professionals who Conduct Developmental Screenings Consent Form

You are invited to participate in a research study being done by Amanda VanHatten and Lacey Jenson under the supervision of our advisor, Peggy Mohr of the University of North Dakota (Physical Therapy). There has been an increase in the number of children with torticollis. We are conducting this study to see if this increase is due to professionals conducting regional developmental screenings are more aware of torticollis therefore screening for it more often or due to professionals not being aware of torticollis therefore missing the diagnosis.

This study will help provide data on the awareness of torticollis among professionals conducting regional developmental screens, how often torticollis is being screened during these developmental screenings, the criteria being used to diagnosis torticollis and if torticollis is being screened for when they are accessing a child with associated disorders of torticollis. The expected duration of subject participation is from 5/15/05- 7/17/06. The project procedure involves a survey with questions directed to the screening and diagnostic criteria being used for torticollis.

There are no possible risks from this study. The benefits, which may result from this study, are having insight on the rising numbers of torticollis. Whether or not it is being assessed at regional developmental screens, allowing professionals that conduct these developmental screens to be aware of any changes, if any that need to be made to ensure screening of torticollis. Early diagnosis leads to early intervention that will provide a positive outcome for the patients that are being diagnosed. We cannot guarantee or promise that you will receive any benefits from this study.

If you choose to participate there will be no compensation for your time to be involved with the interview.

Coding will be used so no direct or indirect identifiers will be used. Any information from this study, that can be identified with you will remain confidential and will be disclosed only with your permission. All data and consent forms will be kept in separate locked cabinets for a minimum of 3 years after the completion of this study. Only the researcher, the adviser (*Peggy Mohr*) and people who audit IRB procedures will have access to the data (*Amanda VanHatten, and Lacey Jenson)*. After 3 years, the data will be shredded.

Participation is voluntary, and your decision whether or not to participate will not change your future relations with the Physical Therapy Departments at the University of North Dakota. If you decide to participate, you are free to leave the study at any time without penalty.

If you have questions about the research, you may call Peggy Mohr at 701-777-2831. If you have any other questions or concerns, please call the Research Development and Compliance office at 777-4279.

APPENDIX B

Focus Interview Questions

Question 1 Have you observed or identified signs of torticollis when completing screenings?

Question 2 Is it something you routinely see or have seen increase in the last two years?

Question 3 What do you consider the most useful diagnostic criteria for identifying risk of torticollis?

Question 4 When providing a screen for a child with suspected torticollis what else are you looking for?

Question 5 Have you received referrals for children who have signs of torticollis?

Question 6 Who have you most frequently made referrals to for further evaluation of the risk of torticollis?

Question 7 What type of educational materials and information do you feel should be provided to parents regarding the prevention or identification of torticollis?

APPENDIX C

Criteria Used for Identification of Torticollis By Professionals Providing Developmental Screenings

Pre-Questionnare for Focused Interview Participants

1. What is your educational background: (Check all that apply).
   - ☐ Occupational Therapist
   - ☐ Physical Therapist
   - ☐ Speech Language Pathologist
   - ☐ Nurse
   - ☐ Physician
   - ☐ Social Worker
   - ☐ Educator
   - ☐ Nurse Practitioner
   - ☐ Other: ____________________

2. How long have you practiced with young children and their families? (in years or less than one year) __________________________

3. How long have you been performing developmental screening procedures? ? (in years or less than one year) __________________________

4. How many developmental screenings do you average per month: ______________

5. Have you observed or identified signs of torticollis when completing developmental screenings during the last two years? ☐ Yes ☐ No

6. What diagnostic criteria have you used to identify or as a basis of a referral for torticollis? (Check all that apply)
   - ☐ Facial lop-sidedness
   - ☐ Tilting of the head
   - ☐ Flattening of the head
   - ☐ Restricted neck (cervical) motions
   - ☐ Limitation in upper extremity motion in any direction
   - ☐ Curve of the back to the left or right (scoliosis)
   - ☐ Low birth weight
   - ☐ Hip dysplasia
   - ☐ Club foot
   - ☐ Bowed legs (genu varum)
   - ☐ Other: ____________________

7. Are you making referrals for follow-up evaluation/intervention for torticollis?
☐ Yes ☐ No

8. If so, to whom are you making your referrals?

____

9. Are you providing educational materials to families that is specifically related to torticollis identification and/or prevention? ☐ Yes ☐ No

APPENDIX D

Setting up the Focus Group Interview

(Interviewer)

1. Assist in securing the names and addresses of parents from the parent coordinator.

2. Select the time and date for the meeting in collaboration with the Parent Coordinator. Make arrangements for the room, which will be utilized including coffee or soft drinks and cookies. We recommend that you do not use a school for the setting. Other possibilities are churches, banks, or Human Service Center.

3. Make arrangements to have another person attend the session with you to serve as the recorder.

4. Ask the parent coordinator to come to the session 30 minutes early to greet the parents as they arrive.

5. Items that will be needed for the session consist of:

   a. Tape recorder with a microphone and blank tape(s) for 90 minutes
   b. Name cards to set on the table in front of each parent, the interviewer, and the recorder.
   c. Wall chart, which has the questions, printed one question per sheet. In addition to providing visual input during the session, having the questions printed on separate sheets allows for recording the key concepts and issues generated by the parents. The visual cues provide an easy reference for the participants as the session progresses.
   d. A dry marker for writing on the wall chart.
   e. Refreshments and snacks: We would appreciate a simple snack (ex: cookies, doughnuts, etc.) and beverage.

APPENDIX E

Recording the Session

The note taker or assistant moderator is a critical role in the focus interview process. It is extremely important to have an accurate and comprehensive record of the participants responses. Points to consider prior to, and concurrent with, the session consist of:

1. Double check the tape recorder, microphone, and supply of tapes to ensure that the equipment is available and working. The tapes will provide a wonderful backup to your notes.

2. Arrange to arrive at the session 30 minutes early to assist the moderator in setting up the room and to sound test the equipment.

3. Refer to the attached handout(s) on tips for taking notes and serving as the assistant facilitator. Use the designated Analysis Worksheet Form for recording the content of the session.

4. Sit in a designated location outside the circle and opposite of the facilitator, closest to the door. Greet any parents that arrive late and find them a place to sit.

5. Prepare a sequence of clarification questions as the session progresses. You will be asked at the end of the session whether or not you have anything you would like to add or any questions/responses that you would like to have clarified.

6. Arrange to spend 30 minutes with the facilitator immediately following the session. The debriefing session will be used to review the notes, prepare the diagram of seating arrangements, check the tape recordings, and label and file field notes, tapes, and other materials.

7. Within 24 hours of the session, submit the data to the Project Director. Make a back-up copy of the tape(s) and field notes before sending them in.

Note Taking

- **Note taking is a primary responsibility of the assistant moderator**
  The moderator should not be expected to take written notes during the discussion.

- **Clarity and consistency of note taking**
  Anticipate that others will use your field notes. Field notes sometimes are interpreted days or weeks following the focus group when memory has faded. Consistency and clarity are essential.

- **Field notes contain different types of information**
  It is essential that this information is easily identified and organized. Your field notes will contain:

  - **Quotes**
    Listen for notable quotes, the well said statements that illustrate an important point of view. Listen for sentences or phrases that are particularly enlightening or eloquently express a particular point of view. Place name or initials of speaker after the quotations. Usually, it is impossible to capture the entire quote. Capture as much as you can with attention to the key phrases. Use three periods ... to indicate that part of the quote was missing.

  - **Key points and themes for each question**
    Typically participants will talk about several key points in response to each question. These points are often identified by several different participants. Sometimes they are said only once but in a manner that deserves attention. At the end of the focus group the assistant moderator will share these themes with participants for confirmation.

  - **Follow-up questions that could be asked**
    Sometimes the moderator may not follow-up on an important point or seek an example of a vague but critical point. The assistant moderator may wish to follow-up with these questions at the end of the focus group.

  - **Big ideas, hunches, or thoughts of the recorder**
    Occasionally the assistant moderator will discover a new concept. A light will go on and something will make sense when before it did not. These insights are helpful in later analysis.

  - **Other factors**
    Make note of factors which might aid analysis such as passionate comments, body language, or non-verbal activity. Watch for head nods, physical excitement, eye contact between certain participants, or other clues that would indicate level of agreement, support, or interest.

- **Consider using a standardized recording form, such as the "Analysis Worksheet Form"**

Systematic Analysis Process

1. Start while still in the group
- Listen for inconsistent comments and probe for understanding
- Listen for vague or cryptic comments and probe for understanding
- Consider asking each participant a final preference question
- Offer a summary of key questions and seek confirmation

2. Immediately after the focus group
- Draw a diagram of seating arrangement
- Spot check tape recording to ensure proper operation
- Conduct moderator and assistant moderator debriefing
    - Note themes, hunches, interpretations, and ideas
    - Compare and contrast this focus group to other groups
- Label and file field notes, tapes and other materials

3. Soon after the focus group--within hours analyze individual focus group:
- Make back-up copy of tapes and send tape to transcriptionist for computer entry if transcript is wanted
- Analyst listens to tape, reviews field notes and reads transcript if available
- Prepare report of the individual focus group in a question-by-question format with amplifying quotes
- Share report for verification with other researchers who were present at the focus group

4. Later--within days analyze the series of focus groups:
- Compare and contrast results by categories of individual focus groups
- Look for emerging themes by question and then overall
- Construct typologies or diagram the analysis
- Describe findings and use quotes to illustrate

5. Finally, prepare the report
- Consider narrative style versus bulleted style
- Use a few quotes to illustrate
- Sequence could be question by question or by theme
- Share report for verification with other researchers
- Revise and finalize report

Transcribing Focus Group Interviews

◆ **Use quality play-back equipment**

The typist should avoid tape players with small speakers and awkward buttons. Ear phones might be considered. Focus group interview tapes always have background noise and participants will speak with different tones and voice levels--therefore these tapes will require concentration and the best quality play-back equipment that can be obtained. If possible, use equipment with a tape speed control and foot operated back space.

◆ **Minimize distractions**

Type transcripts in a place with minimal distractions or interruptions.

◆ **Identify moderator statements**

Place in bold print the statements and questions of the moderator. If possible, type the name of each speaker followed by their comment. Single space the comments and double space between speakers.

◆ **Type comments word for word**

In real life people do not talk in complete sentences and when typing the transcripts avoid the temptation to add or change the words, correct the grammar, etc. If some of the words are unintelligible then type three periods ... to indicate that words are missing from the transcript.

◆ **Note special or unusual sounds that could help analysis**

For example, if there is laughter, loud voices, shouting, etc. be sure that these are noted in the transcript in parenthesis. Make note if someone was interrupted.

◆ **Allow sufficient time**

Typically it takes about eight hours to type one hour of tape. But the time will vary with typist speed, the quality of the tape recording, the length of the session, the experience of the typist with focus groups, and the complexity of the topic.

Reporting Focus Group Results

◆ **Use a communications strategy**

Rather than thinking of "a report", think of what type of communication strategy is needed. A variety of reports might be used to keep people informed. Consider: e-mail messages, postcards, phone calls, bulleted summaries, selected quotes, moderator comments, mid-project or final project reports, personal visits by members of the research team, etc.

◆ **Use an appropriate reporting style that the client finds helpful and meets expectations.**

Ask users what kind of report would be helpful to them. What information are they looking for? What are the expectations and traditions of reports within the organization?

◆ **Strive for enlightenment**

Reports should raise the level of understanding of the client. The purpose is more to enlighten and convey new insights as opposed to repeating common knowledge which is already known by the sponsor of the study.

◆ **Make points memorable**

Help client remember the key points by limited the number of points you highlight. Too many points diminish overall impact. Begin with most important points and follow with lesser important points.

◆ **Use narrative or bulleted format**

Written reports can follow either a narrative format or a bulleted format. Don't surprise the client with a format different from what was expected.

◆ **Give thought to the oral report**

Oral reports should be brief, clear and concise. In addition, oral reports should allow opportunity for questions, indicate why the study is important and why the findings are meaningful, begin with the most important findings, and engage the listener in an active manner.

APPENDIX F

Focus Interview Questions

Question 1 Have you observed or identified signs of torticollis when completing screenings?

#1

Notable Quotes
#2

Notable Quotes
#3

Notable Quotes
#4

Notable Quotes
#5

Notable Quotes
#6

Notable Quotes
#7

Notable Quotes
#8

Notable Quotes

Focus Interview Questions

Question 2 Is it something you routinely see or have seen increase in the last two years?

#1

Notable Quotes
#2

Notable Quotes
#3

Notable Quotes
#4

Notable Quotes
#5

Notable Quotes
#6

Notable Quotes
#7

Notable Quotes
#8

Notable Quotes

Focus Interview Questions

Question 3 What do you consider the most useful diagnostic criteria for identifying risk of torticollis?

#1

Notable Quotes
#2

Notable Quotes
#3

Notable Quotes
#4

Notable Quotes
#5

Notable Quotes
#6

Notable Quotes
#7

Notable Quotes
#8

Notable Quotes

Focus Interview Questions

Question 4 When providing a screen for a child with suspected torticollis what else are you looking for?

#1

Notable Quotes
#2

Notable Quotes
#3

Notable Quotes
#4

Notable Quotes
#5

Notable Quotes
#6

Notable Quotes
#7

Notable Quotes
#8

Notable Quotes

Focus Interview Questions

Question 5 Have you received referrals for children who have signs of torticollis?

#1

Notable Quotes
#2

Notable Quotes
#3

Notable Quotes
#4

Notable Quotes
#5

Notable Quotes
#6

Notable Quotes
#7

Notable Quotes
#8

Notable Quotes

Focus Interview Questions

Question 6 Who have you most frequently made referrals to for further evaluation of the risk of torticollis?

#1

Notable Quotes

#2

Notable Quotes

#3

Notable Quotes

#4

Notable Quotes

#5

Notable Quotes

#6

Notable Quotes

#7

Notable Quotes

#8

Notable Quotes

Focus Interview Questions

Question 7 What type of educational materials and information do you feel should be provided to parents regarding the prevention or identification of torticollis?

#1

Notable Quotes
#2

Notable Quotes
#3

Notable Quotes
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Notable Quotes
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Notable Quotes
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Notable Quotes
#7

Notable Quotes
#8

Notable Quotes

APPENDIX G

UNIVERSITY OF UND NORTH DAKOTA

SCHOOL OF MEDICINE & HEALTH SCIENCES
DEPARTMENT OF PHYSICAL THERAPY
501 NORTH COLUMBIA ROAD
P.O. BOX 9037
GRAND FORKS, NORTH DAKOTA 58202-9037
(701) 777-2831
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Memorandum

To: Professionals Providing Developmental Screening Services for the F.I.T. Consulting, LLC Right Track Program

From: Lacey Jenson, Amanda VanHatten and Peggy Mohr, Ph.D., P,.T. (Advisor)

Lacey Jenson Amanda VanHatten Peggy Mohr

Date: May 22, 2006

Re: Focused Interview Research Project

We are students in the Doctor of Physical Therapy program at the University of North Dakota School of Medicine and Health Sciences. In fulfillment of our scholarly project requirements for this degree we are conducting a survey research project entitled: **Criteria Used for Identification of Torticollis By Professionals Providing Developmental Screenings.** We would like to invite you to participate in a focus interview, scheduled on Sept 9th, 2006. Participants in the focused interviews will be professionals conducting screenings for the F.I.T. Right Track program. Carol Johnson, program director, has agreed to assist us with the research project by distributing this invitation to professionals providing screenings.

The focused interview will be designed to gather data regarding the criteria used to identify torticollis in young children, information about referral practices when torticollis is suspected and the information being provided to parents regarding torticollis. Data generated through this process will be used to develop educational materials for professionals and family members regarding the early identification and prevention of torticollis.

The interview session will be informal and will be scheduled to last no more than one hour. Your input is critical to the research and we would appreciate your time and participation. Prior to the beginning of the interview process, you will be asked to complete a short questionnaire providing demographic information and your input regarding your current practice area. During the interview, the group will address a short number of questions. Responses will be recorded by a notetaker and audio tape for later analysis . All responses will be kept confidential and the results of the study will be reported in a manner that does not allow identification of the respondents. All data will be stored, apart from any identifying information in a secure location until shredded three years after the completion of the study. Audio tapes will be destroyed as soon as the data has been documented. Information resulting from this study will be available in the Harley French Library at the University of North Dakota School of Medicine and Health Sciences, Grand Forks, North Dakota.

Potential benefits of participation in the study include the opportunity to share your ideas and current practice with your peers, to provide input regarding the development of educational materials about toritcollis and the experience of participating in a research study. You will not be compensated for your participation in this study.

Risks or Discomforts to Participants: There are only minimal risks to participating in this project which could potentially include apprehension regarding participating in this type of group discussion. However, should you desire, you may decline to answer specific questions or terminate your participation at any time during the interview process.

Your attendance and participation in the interview session will be considered as consent to participate in this research project. Whether your participate or refuse to participate in this research will not affect your relationship with the F.I.T. Consulting Right Track program or the sponsors and/or researchers associated with this project.

If you have any questions regarding this research project, please contact Amanda Van Hatten at 701 740 1842 or the research project advisor, Peggy M. Mohr at 701 777 3689. If you have any other questions or concerns, please call Research Development and Compliance at 701 777 4279.

APPENDIX H

MEMORABLE QUOTES

"There isn't anything on a screening tool that identifies it (torticollis) for me."

"It would be nice if there was a checklist (for torticollis)."

"He doesn't like it." (When referring to the reason why parents avoid tummy time)

"Start for short periods of time and then increase it (tummy time) gradually."

"Must give parents a reason why for tummy time."

"Bring up to parent to look to see if positioning both ways." (Suggestion when screening)

"Primarily last 5 years seen more torticollis" (Referring to the increase in incidence)

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