Survey of Parents Participating in an Infant Toddler Screening Program: Identification and Education Regarding Torticollis

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SURVEY OF PARENTS PARTICIPATING IN AN INFANT TODDLER SCREENING PROGRAM: IDENTIFICATION AND EDUCATION REGARDING TORTICOLLIS

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A Scholarly Project
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Department of Physical Therapy
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in partial fulfillment of the requirements
for the degree of
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This Scholarly Project, submitted by Amanda Carlson, Brianna Mayo, and Satyasharan Patel 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 Chairperson of Physical Therapy under whom the work has been done and is hereby approved.

(Graduate School Advisor)

(Chairperson, Physical Therapy)
PERMISSION

Title
Survey of Parents Participating in an Infant Toddler Screening Program: Identification and Education Regarding Torticollis

Department
Physical Therapy

Degree
Doctor of Physical Therapy

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Date 12/13/06
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ABSTRACT

Background and Purpose: Since 1992 there has been an increased number of children diagnosed with congenital muscular torticollis (CMT), which is a condition that affects the position and shape of the head. This study was designed to find out from parents involved in an infant toddler screening program about the information they have received regarding torticollis and if they feel it has been satisfactory. Subjects: A survey of 150 parents with children who participated in an infant toddler screening program were initially included in a randomized sample for this study. Fifty-four surveys were returned to the researchers, of which 4 were from parents of children with torticollis. Method: The survey was designed to assess the knowledge and satisfaction of information received by parents in reference to CMT. Survey items also addressed the time children were placed on their stomachs or in supportive positioning devices (car seats, swings, etc.), or on their backs for sleep as these factors were aspects which influenced the incidence of torticollis. Results: Thirty-nine percent of respondents indicated that their children slept on their back. Twenty-one percent of parents placed their child on their stomach for 0-9 minutes per day. Thirty-one percent of respondents indicated that they placed their child in a car seat for 30-39 minutes daily. Sixty-four percent responded that they
placed their child in a swing for 0-9 minutes per day. **Discussion and Conclusion:** Based on our findings from this study it is suggested that parents increase the amount of time their child spends on their tummy while awake and decrease the amount of time their child is in a car seat and, or swing through early education provided by healthcare professionals. Due to the small return rate from parents whose children have torticollis (n=4) it was not possible to determine the significance of these results. The overall conclusion from comments made by parents of children with torticollis was that early education for parents and communication between all healthcare providers is important to best serve all parents and their children.
CHAPTER I

INTRODUCTION

Congenital muscular torticollis is a condition in which there is shortening of the sternocleidomastoid on one side of the neck that causes the head to tilt towards and rotate away from the affected side.\textsuperscript{1} This condition predominantly affects children from the age of 0-3 months.\textsuperscript{2} Because it affects children so early in life it can cause delays in developmental milestones such as crawling, rolling, and standing.\textsuperscript{3} This condition is easily preventable when detected early in the infant’s development.\textsuperscript{4} Physical therapy has an important role in the treatment of torticollis and has been shown to be very effective in restoring cervical mobility.\textsuperscript{2,5}

For this study, an infant toddler screening program was utilized as a population base. The infant toddler screening program is a free service for any parent who would like to have their infant ages 0-3 years old screened for any health concerns. The study was done to determine the adequacy and satisfaction of parent education about torticollis.

PROBLEM STATEMENT

There is a lot of information and education currently available regarding torticollis. However, the problem is that it is not known how this information is (or is not) being presented to the families within this infant toddler screening program or if recipients perceive the information as adequate.
PURPOSE OF STUDY

To determine what information the parents receiving services from a specific infant toddler screening program (a) have received about torticollis, (b) how it was delivered, (c) if they felt the information was adequate and (d) treatments that their child may have received for torticollis.

SIGNIFICANCE OF STUDY

The Back to Sleep Program was created in 1992 to decrease the occurrence of Sudden Infant Death Syndrome (SIDS) and it accomplished that.\(^6\) Due to the reluctance of parents to place their children on their stomachs for play, there has been an increase of plagiocephaly (flat spots on the head) that may result in torticollis.\(^7,8\) This study was initiated in response to the concern for early identification and proper education of torticollis through the infant screening program. Most cases of torticollis can be corrected with a simple stretching program and supervised awake tummy time initiated at birth. This study is designed to gather information regarding whether parents are receiving proper and timely information and/or treatment of torticollis, which is necessary to prevent developmental delays in children. With an increased general awareness, proper prevention, and physical therapy intervention for torticollis can prevent the development or progression of torticollis.\(^2,9,10\)
RESEARCH QUESTIONS

1) Are parents receiving adequate information regarding positioning recommendations and tummy time for their child concerning torticollis and are they satisfied with the information they received?

2) Are parents incorporating sufficient “tummy time” into activities of daily life?

HYPOTHESES

Null hypothesis 1: Parents are not being educated properly on torticollis.

Alternate hypothesis 1: Parents are being properly educated on torticollis.

Null hypothesis 2: Parents are not incorporating sufficient “tummy time” daily into child’s routine.

Alternate hypothesis 2: Parents are incorporating sufficient “tummy time” daily into child’s routine.
LITERATURE REVIEW

The three main types of torticollis include sternomastoid tumor, congenital muscular torticollis (CMT), and postural torticollis. In this study we will be focusing on congenital muscular torticollis. CMT is a condition diagnosed within the first three months of life. It is characterized by tilting and rotation of the head and a large fibrous mass within the sternocleidomastoid (SCM) muscle that may or may not be present. The SCM is located on the lateral sides of the neck and it is attached to the mastoid process, the clavicle and the sternum. It is innervated by the spinal accessory nerve and dorsal rami C2-C3. The main function of the SCM is to flex the neck bilaterally, rotate contralaterally and tilt ipsilaterally.

The cause of CMT is currently unknown, however, several theories exist. Such theories include birth trauma, lack of blood supply to the SCM, and abnormal positioning within the uterus. Risk factors associated with CMT include multiple birth babies, breech positioning, vacuum and/or forceps extraction, and large birth weight. These risk factors have been shown to increase the incidence of CMT. Some associated impairments of CMT are plagiocephaly (flat spots on the head) and hip dysplasia (abnormal formation of the hip joint). There is a current controversy as to whether plagiocephaly is a result or a cause of CMT.

There are many tools that professionals use to help diagnose CMT. As with all patients, a thorough history, examination, and evaluation are necessary. Some topics that may be addressed in the history include: prenatal history, birth history, family history of torticollis, past medical history, caregiver interview, sex
of infant, age at diagnosis, side of SCM involved, other congenital abnormalities, previous lab work, medications and difficulty with feeding. Other issues that may need to be discussed are sleeping position, time on back versus stomach, time spent in car seats, swing, and infant positional devices.\textsuperscript{1,3,5,14} 

It is also recommended that the healthcare professional's examination of the infant include an evaluation of cranial and facial abnormalities. Some of these abnormalities could include head tilt, facial asymmetry, ear displacement, palpable mass in the neck, shortening of the SCM, plagiocephaly, neck skin creases, and eye misalignment.\textsuperscript{3,5} 

If torticollis is untreated, it can lead to atypical motor milestones such as inability to cross midline, purposeful asymmetric motor movements of the head, asymmetric posture, delayed rolling, and delayed righting reactions. The child does not develop normal milestones, because the torticollis alters their ability to interact with the environment.\textsuperscript{15} 

According to Campbell and Hedeken,\textsuperscript{16} to assess motor development the professional should look at muscle and soft tissue extensibility and strength, decreased oral skills due to neck and face muscle weakness, hip asymmetry such as leg length discrepancy, and skin fold. Campbell and Hedeken also stated that 8-20\% of children with CMT may also have associated hip dysplasia. The healthcare professional will also look for compensatory movement patterns, persistent asymmetric tonic neck reflex, windswept hips, visual and body neglect, as well as neurological deficits.\textsuperscript{3,16} According to Campbell and Hedeken,\textsuperscript{16} the Test of Infant Motor Performance (TIMP) has been clinically validated, to identify
movement impairments and is a good way to document the motor improvements of the infant. Another motor test that can be used is the sit up test, depicted by Caputo et al., it has been determined to be highly sensitive, reliable, and can be easily performed by non-experienced personnel. The sit-up test provides a reliable diagnosis for torticollis but is only useful for infants that have adequate range of motion.

Range of motion (ROM) will need to be assessed by the professional for an infant suspected of having CMT. The goniometer is a reliable tool in measuring ROM. According to Campbell et al., ROM should be assessed statically and dynamically while the infant is on their stomach. However, Livingston and Saluti disagree and suggest ROM can also be assessed on the infants back with the head supported off the plinth by the therapist.

There are assessment tools outside the scope of physical therapy that healthcare professionals may use for diagnosis of CMT, such as: radiography, computerized tomography (CT), magnetic resonance imaging (MRI) and ultrasonography. Livingston and Saluti stated that "no treatment should begin until a radiograph of cervical spine is taken and the etiology is determined." Lawrence et al., and Brendencamp et al., contend that CT is the best test to depict soft tissues of the neck, and this method allows easier positioning of infants than other radiology tests. However, Hayashi S et al., stated that proton density weighted images, such as those used in MRI's, identify CMT in the SCM, by detecting inflammation in the early stages. Ultrasonography is another method of detecting SCM tumor in patients with CMT.
According to Karmel-Ross, it is important to complete a thorough evaluation of an infant suspected of having CMT because other conditions may present in a similar manner. Some other conditions that present similarly to CMT include: benign paroxysmal torticollis, ocular torticollis, sandifer syndrome, Grisel’s syndrome, CNS lesions, rheumatoid arthritis, tuberculosis, tonsillitis, and pharyngitis, fractures to the cervical region among others.

There are many conservative treatment options available for children diagnosed with CMT. The most common, safe, and successful treatment for CMT has been shown in research to be manual stretching of the affected muscles at an early age. It is important for healthcare professionals to identify and treat the CMT before the age of one to two to have the most effective treatment. According to Sonmez K et al, it is also important to make an early diagnosis of CMT so that treatment intervention is not delayed. Possible complications could result in the development of irreversible deformities in the spine and lower extremities.

For each patient the success of conservative treatment is dependent upon the age in which they began exercises. Cheng et al, concludes that when manual stretching exercises are initiated by a healthcare professional before the age of one, 95% of children receiving this treatment have a resolution of their symptoms. Manual stretching can also prevent the progression of torticollis to a level in which surgery would be necessary.

For manual stretching there is little agreement on common frequency and repetitions in the literature. One successful example of treatment is a study of
torticollis completed by Cheng et al.,\textsuperscript{10} where manual stretching was performed 3 times a week by a trained and experienced physical therapy. For each child, three repetitions of fifteen manual stretches of the involved sternocleidomastoid muscle were performed and a rest period of ten seconds was given between each stretch during each treatment session. These parameters were found to be successful within this study.\textsuperscript{10}

One possible complication of manual therapy for CMT is sudden muscular giving-away or snapping of the SCM muscle.\textsuperscript{10,25} Cheng\textsuperscript{10} found this complication in eight percent of the patients in the study with no negative effects.

According to the American Academy of Pediatrics (AAP),\textsuperscript{6} parent education is a very important part of the “back to sleep, tummy to play” program and parents should be instructed on current recommendations from the AAP. This is especially important because Mildred et al.,\textsuperscript{26} found that because of the back to sleep program parents are fearful of placing their child on their stomach during supervised play. One recommendation from the AAP is observed tummy time while awake in order to assist in the development of upper shoulder girdle strength and the prevention of occipital plagiocephaly and in turn torticollis. Another recommendation includes having the child alter their supine head position during sleep. The parent should place the infant to sleep with their head facing to the right side for one week and then alternating sides the next week.

In a case study by Rahlin,\textsuperscript{27} Tscharnuter Akademie for Motor Organization (TAMO) therapy was performed along with soft tissue mobilization on a child with torticollis. The principles of this type of therapy are based on
dynamic theory concepts designed to address the “goals of developing the child’s abilities to spontaneously adapt motor behaviors to a variety of natural situations, actively select task specific information, and synchronize his or her actions with the perceived information.” In the case study, the child improved within nine treatment sessions using this therapy, which is well within the Guide to Physical Therapy Practice estimated number of visits. Through this literature review there was minimal research found on the outcomes of this therapy on children with congenital muscular torticollis, so further studies on a larger scale need to be done in order to validate the use of the TAMO therapy.

According to Cheng et al,10 surgical treatment is advocated for torticollis when conservative treatment is unable to resolve the dysfunction. There is also an increased chance of surgery when a torticollis diagnosis is not made until later in life and treatment is delayed.24 Cheng et al,10 determined that, “if following conservative treatment of at least six months there continues to be head tilting, limited passive rotation and lateral bending of the neck of greater than 15 degrees, tightness in the muscle, and poor results on their special assessment chart, then surgery would be indicated.”

Within this literature review there was no research found regarding bracing for the treatment of torticollis. Studies may need to be completed in this area to enhance the overall treatment of children with torticollis.

Botulinum type A or B single injections are also used in the treatment of torticollis, both of which have been determined to be safe and effective measures of treatment.28,29 Type B was developed when patients became resistant to Type
A botulinum. Some adverse side effects associated with type A include dry mouth/sore throat, dysphagia, neck weakness, and voice changes/hoarseness which are dependent on the amount injected; and Type B botulinum side effects include difficulty swallowing and dry mouth.²⁸,²⁹

Prognosis for an infant with torticollis tend to be excellent following conservative therapy if a diagnosis is made before 6 weeks of age and the child has no palpable mass.¹⁷ In patients where a mass continues to be palpable past 6 weeks, there is a poorer prognosis, therefore torticollis needs to be effectively monitored and treated.¹⁷ Emery²³ reported that the average treatment for children with palpable mass took 6-7 months and for children without a palpable mass 3-4 months of conservative therapy. For those children with CMT the length of therapy required was directly related to restriction of neck rotation.¹⁰,²³

In a study conducted by Jennings et al,³⁰ it was found that the most effective way to communicate with parents about tummy time was by using a visit from the doctor and nurse complimented with a brochure.³⁰ It was found that the earlier the parents received this information, such as within days of the child's birth, the parents were more likely to follow the recommendations given to them by the nurse/physician and the child in turn tolerated the treatment better.³⁰ The study compared the children whose parents received information from nurse/doctor and a brochure from those children whose parents received only doctor directives, or only doctor and nurse visits, or doctor/nurse visit with a video.³⁰

Based on this literature review, the aim of this study is to determine what
information parents are receiving regarding torticollis, and if they are satisfied with this information in order to recognize if improved methods of education should be implemented for the welfare of the child. This study also wanted to verify if parents are following the recommendations for tummy time.
CHAPTER II
METHODOLOGY

SUBJECTS

The subject population included parents of children who have been participants in an early intervention infant screening program and whose children have received referrals for motor concerns as a result of an initial screening evaluation. Subjects were chosen randomly from this population and a total of 150 surveys were distributed to families. Consent to participate in this study was verified by the family returning the survey.

INSTRUMENTATION

A survey instrument (appendix A) was created in order to assess the knowledge and satisfaction of parents in reference to CMT. The questions were developed based upon a literature review using search engines such as PubMed, Cochrane, and CINAHL. Questions were developed using guidelines from Survey Research Methods 2nd ed.31

PROCEDURE

The study was approved by the IRB at the University of North Dakota on May 9, 2006. A survey questionnaire was mailed to family members who have participated in the early intervention infant screening program. Subjects were asked to respond to questions regarding: information received about torticollis,
signs of this condition, referrals made for torticollis and associated motor issues, interventions received and educational materials provided. The surveys were prepared for mailing by the researchers and were given to the director of the early intervention infant screening program, who applied the mailing address labels and deposited the letters for mailing at the campus postal service. The mailing envelopes were coded for purposes of mailing reminder notices. Following two weeks, a reminder letter and an additional survey were mailed to the families who had not responded.

Fifty-four surveys were returned, of those, four surveys were completed by parents of children with torticollis. All surveys were analyzed using SPSS software focusing on the descriptive statistics of each question.
CHAPTER III
RESULTS

In the survey instrument, subjects were asked to respond to the methods of delivery that applied to the birth of their child. Of the fifty-four respondents, 39 (26.5%) had full-term pregnancies, 37 (25.7%) reported vaginal deliveries, 31 (21%) reported that the child was positioned in a head-down position during the delivery, 13 (8.8%) reported premature birth, 14 (9.5%) reported a cesarean section, 1 (0.7%) reported a use of forceps, 10 (6.8%) reported use of suction, and 2 (1.4%) reported a breech delivery. These data are represented in Figure 1.

Figure 1: Delivery Method
A visual representation of the child’s diagnosis is illustrated in Figure 2. Subjects were asked to select all diagnoses that applied to their child. Of the fifty-four respondents only 7 reported a diagnosis for this question. Four (7.4%) respondents indicated a diagnosis of torticollis, 2 (3.7%) stated a diagnosis of plagiocephaly, 1 (1.9%) child was diagnosed with clubbed foot, and 2 (3.7%) children were diagnosed with a condition other than what was listed on the survey. This data is reflected below in Figure 2.

Figure 2: Diagnosis

![Diagram of diagnosis responses]
The illustration of Figure 3 demonstrates the age of the respondent's child in months. At the time of survey completion, 24 (44%) children were between 0 and 9 months, 17 (39.1%) were between 10-19 months, 11 (20.4%) were between 20-29 months, 2 (3.7%) were between 30-39 months. See Figure 3 depicted below.

Figure 3: Age of children in months
Figure 4 represents the reported referral source from all fifty-four subjects. Twenty-seven (50%) referrals occurred from sources other than the patient's primary healthcare provider, 20 (37%) patient referrals were from a pediatrician, 7 (13%) referrals were from a family friend, and there were no reports of a referral from a website. See Figure 4 below.

Figure 4: Referral of children to infant toddler screening program
The responses from each parent about the child's preferred sleeping position is depicted below in Figure 5. Twenty-one (39%) respondents reported their child preferred to sleep on their back, 14 (26%) stated that their child preferred their tummy, 3 (6%) reported their child slept on their side and 16 (29%) reported their children slept in a variety of positions. See the illustration of Figure 5 below.

Figure 5: Children's preferred sleeping position
Figure 6 is an illustration of the responses about the amount of time infants spend on their tummy. Eight (21%) parents indicated that they placed their child on his or her tummy for 0-9 minutes per day. Seven (17.9%) respondents indicated that their child spent between 30 – 39 minutes, 7 (17.9%) respondents reported that their child spent greater than 100 minutes, about 4 (10.2%) stated that their child spent between 10-19 minutes, another 4 (10.2%) stated that their child spent 90-99 minutes, about 3 (7.6%) of the children spent between 20-29 minutes, another 3 (7.6%) spent between 60-69 minutes, 2 (5.1%) incorporated 70-79 minutes, and lastly 1 (2.5%) child spent 40-49 minutes on their tummy daily. There were no responses from parents about time their children spent between 50-59 minutes and 80-89 minutes on their tummy. See below for the depiction of Figure 6.

Figure 6: Reported minutes per day children spend in “Tummy Time”
Figure 7 illustrates the responses pertaining to the amount of time per day the children spent in a car seat. Seventeen (31%) parents indicated that they placed their child in a car seat for 30-39 minutes, 8 (18%) children spent 10-19 minutes, another 8 (18%) spent 20-29 minutes, 6 (13%) spent 60-69 minutes, 3 (7%) spent 0-9 minutes, 2 (4%) spent 90-99 minutes, and 1 (2%) reported that their child spent greater than 100 minutes in a car seat. There were no reports from parents of children who spent between 40-59 minutes and 70-89 minutes per day in a car seat. See Figure 7 below for the graphical illustration.

Figure 7: Reported minutes per day children spend in a car seat

![Bar chart showing the distribution of minutes spent in a car seat by children.](image-url)
Figure 8 gives a depiction of the number of minutes parents placed their child in a swing per day. Twenty-five (64%) parents indicated that they placed their children in a swing for 0-9 minutes per day. Four (10%) children spent 30-39 minutes, 3 (8%) spent 10-19 minutes, another 3 (8%) spent greater than 100 minutes, 2 (5%) children spent 90-99 minutes, 1 (3%) spent 20-29 minutes, and 1 (3%) reported that their child spent 60-69 minutes in a swing daily. See Figure 8 below for an illustration of this information.

Figure 8: Reported minutes per day children spend in a swing
CHAPTER IV
DISCUSSION

Research Question 1: Are parents receiving adequate information regarding positioning recommendations, and tummy time for their child concerning torticollis and are they satisfied with the information they do receive?

This study received only four surveys from parents of children diagnosed with torticollis. Due to the small number of responses from these parents, none of the results were statistically significant for this study. However, upon review of the responses from their surveys it was found that a discussion of their responses was important.

A few key concerns expressed by the parents include the pediatrician's lack of early action for a child with torticollis. One parent stated in their comments that their pediatrician “didn't seem too concerned.” This parent was also told to “stretch and wait for 2 months.”

Another concern of the parents was that education before child birth regarding head flattening would have been very helpful. This parent also stated that “none of her books, classes, doctors or nurses informed us ... until 2 months later.”

Parents also expressed that there seemed to be some confusion and inconsistency between healthcare providers. An inconsistency expressed by a parent through the survey was that the infant toddler screening program “referred (her child) to physical therapy even though (her) pediatrician was not concerned.” There are a few reasons why this could be occurring, one being that there was a
lack of communication between these two providers. It is important to keep good 
communication among all healthcare providers, especially because this study 
showed that parents are receiving their information from a wide variety of 
sources. Other reasons for the difference in opinion could be due to education 
on the part of the physical therapist or the pediatrician or possibly different 
experience levels between providers.

Based on the previous findings it is determined that there is a need for 
education and clear communication between all of the healthcare professionals 
and parents about torticollis. It is suggested that this be achieved through 
prenatal classes at the local community center or hospital, brochures handed to 
the parents after birth, continuing education of medical professionals stressing 
the importance of early education about torticollis, and by stressing 
improvements in communication between healthcare professionals.

It was found through this study that most parents participating in this study 
limited amount of time on their child’s stomach during play. As written above in 
the literature review, this could be caused by a possible fear the parents may 
have stemming from the “back to sleep” campaign. It is important to educate 
parents on the “tummy to play” portion of the campaign as well, to be sure that 
children are getting the proper tummy time for development.

Even with the recommendations set in the “back to sleep” campaign 
parents are still not consistent with their child’s sleeping position. The survey 
results from this study show that only 39% of parents placed their children on 
their backs to sleep. There is still a large population of the respondents that
either placed their child on their tummy (26%) or in a variety of positions (29%). This may be due to the lack of education overall on the “back to sleep, tummy to play” campaign. It is recommended in the future that further studies in this area question parents on their knowledge about the campaign from the American Academy of Pediatrics.

Overall satisfaction from parents was even, with two parents responding as very unsatisfied, one as satisfied, and one as extremely satisfied. Even with only four respondents for this question it is suggested that through the appropriate measures as mentioned previously it would be possible to improve satisfaction among those with lower satisfaction responses.

Research Question 2: Are parents incorporating sufficient “tummy time” into activities of daily life?

According to the American Academy of Pediatrics (AAP) tummy time is necessary while the child is awake to prevent plagiocephaly. As discussed previously in the literature review, torticollis may result from positioning influenced by plagiocephaly. According to the survey responses, thirty-one parents (80%) provided at least ten minutes of tummy time. Through this literature review, there was no set standard for the proper amount of time a child should spend on their stomach. Therefore, it cannot be suggested whether or not this is enough time. However, parents should be advised that the child should spend as much supervised time as possible on their tummy, based on AAP recommendations.
Time that a child spends in a car seat and swing has the potential to take time away from them spending time on their stomach. This study found that 48% of parents placed their children in car seats for at least 30 minutes or more per day. Even though time spent in a car seat may not always be prevented, due to the commute between work and home in rural areas, it is important to educate the parents on limiting the time a child spends in a car seat as much as possible. The parent should also be educated on proper positioning in a car seat, so the head is maintained in a neutral position. Also parents should monitor their child for signs of torticollis as mentioned above.

It appears from this study that 64% of these parents have been proactive in keeping their infant out of a swing for less than ten minutes per day. It is possible that the parents participating in this survey have received information about limiting time their child spends in a swing. It is important to maintain this trend via continuing education for the parents and caregivers.

Limitations

The greatest limitation to this study is the small return rate from parents whose children have torticollis. The small survey return rate may have been due to the population selected for the study, parent time restraints, and the possibility of decreased torticollis incidence in this area. Such a small population of torticollis (n = 4) does not allow the analysis of data to determine significance of results. In the future, studies should be focused on a larger and more specific population such as a statewide infant toddler screening program or children that
have been referred specifically for torticollis or plagiocephaly.

Additional limitations to this study include the confounding variables which do not allow statistical analysis of the data to form any correlations with torticollis to risk factors, tummy time, and other diagnoses and conditions such as clubbed foot and hip dysplasia. Future surveys should focus on limiting previously stated confounding variables.

Another limitation of this study is it’s reliance on the memory of the caregiver who completed the survey. For example, the average age of the participant’s children was 1 year and 9 months. The older the child, the less likely parents are able to recall the details of the birth and their referral source to the infant toddler screening program.

The final limitation for this study was that the survey did not require all parents to respond regarding the education that they received about torticollis and the satisfaction of the received information. In the future, it is recommended to ask this question of all respondents in order to acquire more significant results.
CHAPTER V

CONCLUSION

It was determined that further research should be completed with a larger sample size more specific to the target population (children with CMT). Even though there was a small sample of children diagnosed with torticollis, it is suggested that parents increase the amount of time their child spends on their tummy while awake and decrease the amount of time their child is in a car seat and, or swing through early education provided by healthcare professionals. Due to the small return rate from parents whose children have torticollis (n=4) it was not possible to determine the significance of these results. The overall conclusion from comments made by parents of children with torticollis was that early education for parents and communication between all healthcare providers is important to best serve all parents and their children.
Appendix A: Survey of Parents Participating In An Infant Toddler Screening Program: Identification and Education Regarding Torticollis

Our names are Amanda Carlson, Brianno Mayo, and Satyasharan Patel and we are students in the Doctor of Physical Therapy program at the University of North Dakota School of Medicine and Health Sciences. We are conducting a survey research project to learn what information parents of young children would find helpful regarding the early identification of torticollis (tilting of the head). It will take approximately five minutes to complete the survey. We would appreciate it if you could please complete and return the survey in the postage paid envelop by July 12, 2006.

1. Today's date?___________
2. Your child's current age in months: __________
3. Did anyone refer your child to the early intervention program? Check all that apply.
   - Pediatrician
   - Family Friend
   - Website
   - Other: __________
4. What is your child's preferred sleeping position?
   - Back
   - Tummy
   - Side
   - Mixed
5. On average how many minutes does your child-
   - Spend on his/her tummy per day? _______min/day
   - Spend in a car seat per day? _______min/day
   - Spend in an infant swing per day? _______min/day
6. During delivery, did you have any of the following? Check all that apply.
   - full-term pregnancy
   - premature pregnancy
   - cesarean vaginal delivery
   - forceps delivery
   - suction delivery
   - breech delivery
   - head down
   - single birth
   - multiple births
7. Has your child been diagnosed with any of the following conditions? Check all that apply
   - Tilting of the head (torticollis)
   - Hip instability (Hip Dysplasia)
   - Flattening of the head (Plagiocephaly)
   - Feet that are turned inward (Club Foot)
   - Curve of the back to the left or right (Scoliosis)
   - Bow-legged knees (Genu Varum)
   - Other: __________

If your child has been diagnosed with torticollis (tilting of the head) please continue on with the survey.

If your child has not been diagnosed with tilting of the head (Torticollis) the survey is complete. Please mail your survey in the enclosed addressed, postage-paid envelope. Thank you for your time.
8. Please indicate if you have received information regarding Torticollis (tilting of the head) and associated conditions from one of the following professionals. Check all that apply.
   - Physical Therapy
   - Occupational Therapy
   - Nursing
   - Social worker
   - Early interventionist
   - Pediatrician

9. In what form did you receive information about torticollis? Check all that apply.
   - Pamphlet
   - Video
   - Oral discussion by a professional
   - Website
   - Other: ___________

10. Regarding torticollis, what were you told to look for in your child? Check all that apply.
    - Facial lop-sidedness
    - Tilting of the head
    - Flattening of the head
    - Learning delays
    - Limitation in neck motion in any direction
    - Curve of the back to the left or right (scoliosis)
    - Low birth weight

11. Did you receive information about the following? Check all that apply.
    - Sleeping positions
    - Time spent in infant seats, swings, other supportive seating
    - Having your child spend supervised time playing on his/her stomach
    - Other specific recommendations:
    ____________________________

12. How satisfied were you with the information you received? Please check ONE.
    - Extremely satisfied
    - Very satisfied
    - Satisfied
    - Unsatisfied
    - Extremely unsatisfied

13. What is your most preferred method of receiving information?
    - Video
    - Pamphlet
    - Booklet
    - E-mail
    - Visit with healthcare professional
    - Other: ______________________

14. What treatments did your child receive? Check all that apply.
    - Stretching of the neck muscles
    - Helmet
    - Neck brace
    - Strengthening home exercises program
    - Positioning
    - Postural education
    - Surgery
    - Injections
    - Other: ______________________

15. What additional information about torticollis would be helpful to you?

Thank you for your time in completing this survey. Please return your survey by mailing it in the enclosed addressed, postage-paid envelope.
REFERENCES


