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Report of a Child with Severe Fibrosis and Problems after Surgery both as an Infant and at Preschool Age

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ABSTRACT

A case report describing a child with severe left-sided congenital muscular torticollis (CMT). Physical therapy (PT) had no effect before surgery was performed. The first surgery was performed at 13 months of age and in the beginning post-surgery results were good. However, reoccurrence of fibrosis tissue occurred soon with a contracture in the sternocleidomastoid muscle (SCM), with a rather mild head tilt and elevated shoulder on the affected left side. Due to the COVID-19 pandemic, re-surgery was delayed for about two years. During that time the problems increased; the elevated shoulder got more prominent and a lump developed in the left-side upper trapezius muscle. Re-surgery was performed at pre-school age. Rehabilitation after re-surgery was challenging and took a long time. Early in treatment he achieved good passive range of motion (PROM) in the cervical spine but there were substantial problems with the elevated left shoulder and lump in the same shoulder, unusual problems at this young age.

Key words: Congenital muscular torticollis; Reoccurrence; Surgery; Lump; Elevated shoulder; Physical therapy.

ABBREVIATIONS

AROM Active range of motion CMT Congenital muscular torticollis
PROM Passive range of motion SCM Sternocleidomastoid MFS Muscle Function scale
KT Kinesiology taping PT Physical therapy

INTRODUCTION

CMT is a common musculoskeletal problem among infants [1]. The reported incidence varies from 0.4%-2.0% to 16% of newborns [2,3]. Typically, the head is titled toward the affected SCM muscle and rotated toward the opposite side. PT usually gives good or excellent results for 90-95% of infants with CMT. A sternomastoid tumor (SMT) can appear

two to four weeks after birth and in about 10-20 % of these infants there will be remaining contracture giving limited passive range of motion (PROM) in the cervical spine that does not respond to PT [4]. Remaining limited PROM and a tight band or tumor in the SCM muscle that tilts the head are indications for surgery [5]. About 5% of infants with CMT require surgery [2,6].

At an older age surgery is more often required. Due to remaining scar tissue, the problem may escalate with skeletal growth. The SCM muscle grows from 4 cm in infanthood to 14 cm at 13 years of age [7]. After surgery some individuals get new scar tissue and need a second round of surgery [8]. CMT with poor posture can give excessive muscle tension or strain resulting in muscle knots. When muscles are chronically tense or strained, these knots can lead to a lump between the neck and shoulder [9].

CMT mostly includes an imbalance in muscle function/strength in the lateral flexors of the neck; lateral head righting on the contralateral side is weakened compared with the affected side [10-14]. This imbalance has not been found in healthy control subjects [15].

The imbalance can be estimated and scored on the muscle function scale (MFS) [16]. PROM in cervical rotation and lateral flexion can be measured using a big protractor [6,17].

To assess the clinical and subjective outcomes of CMT before and after surgery, Cheng and Tang´s scoring system can be used [6,17,18]. The scoring system includes: rotational deficits (degrees), side flexion deficits (degrees), craniofacial asymmetry, residual band, head tilt, and subjective assessment (cosmetic and functional). After surgery scoring also includes scar tissue. The levels are excellent, good, fair, and poor [6] **(Table 1)**.

Table I. Levels and scores using Cheng and Tang´s scoring system to assess the clinical and subjective outcomes of CMT. Scores after surgery also include scar tissue and therefore have a higher range.

Level	Scores before surgery	Scores after surgery
Excellent	16-18	17-21
Good	12-15	12-16
Fair	6-11	7-11
Poor	<6	<7

Evidence-based clinical practice guidelines from the section on pediatrics of the American physical therapy association including classification grades and a decision tree for CMT were first published in 2013 [19]. The guidelines were updated in 2018 and 2024 and in the current guidelines, the grades of severity of CMT range from 1-8, from early mild to very late [20].

When surgery is performed in early infanthood a brace is not always used after surgery. For ages above 1-2 years a brace is usually applied directly after surgery and worn 24 hours a day, only being taken off for training and showering. In the early postoperative period repetitive cervical AROM and PROM training is important [21]. This includes treatment by a physical therapist three times a week [22], and a home program carried out several times each day. Stretching and exercises to reestablish perception of midline through integration of visual, vestibular, and proprioceptive systems [23] are also important. PT is continued as long as needed [22]. The affected side is mostly stronger also after surgery and strengthening the opposite side is necessary [17]. In adolescents and adults with neglected CMT, it is not unusual to have an elevated shoulder on the affected side [8,24].

CASE

An infant of 4.5 months of age with severe CMT came to the clinic for a second opinion in January 2019. On the left side there was a head tilt and an SMT. The muscle was contracted with clearly limited PROM in both rotation and lateral flexion. During the first visit he was tense and unwilling to cooperate in an examination. Both his first physician and physical therapist had limited experience of CMT, and therefore treatment had not been optimal. He was not referred for surgery when treatment didn't work. An ultrasound examination was performed before he came for a second opinion and the size of the SMT was 3x2 cm in October 2018. The same size was recorded in February 2019 when a new ultrasound examination was performed. PROM in rotation on the left side was estimated on photos to be 45° **(Figure 1)** and 90° on the right side. At that time measuring with a protractor was not doable as it was difficult to get him relaxed enough in a measuring situation. It was easier to have him in the physical therapist's lap and perform rotation.

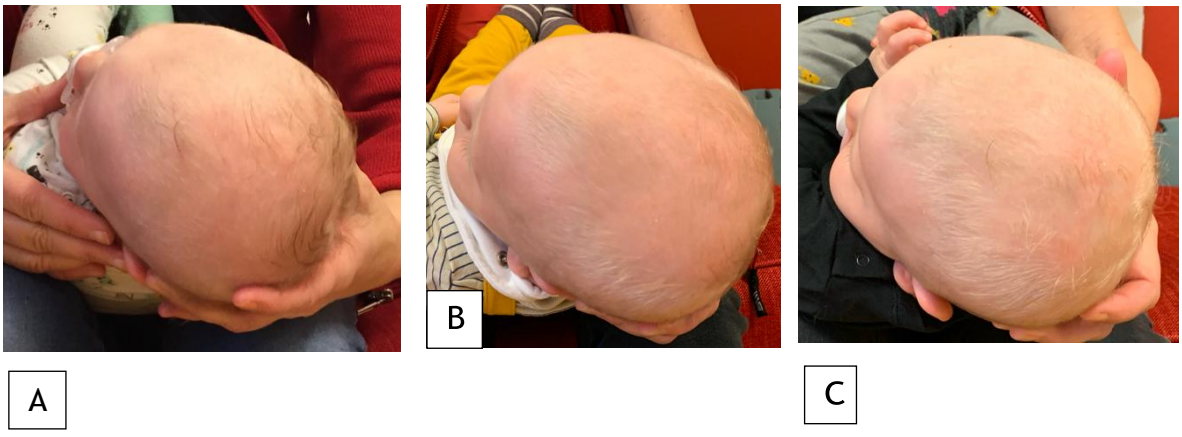

Figure 1. A January **B** February and **C** March, there is no progress in PROM in rotation

There were also obvious differences in PROM in lateral flexion **(Figure 2)**. Estimates here also had to be made using photos, as it was difficult to get him relaxed enough in the measuring situation. Holding him in a side position when examining lateral flexion worked.

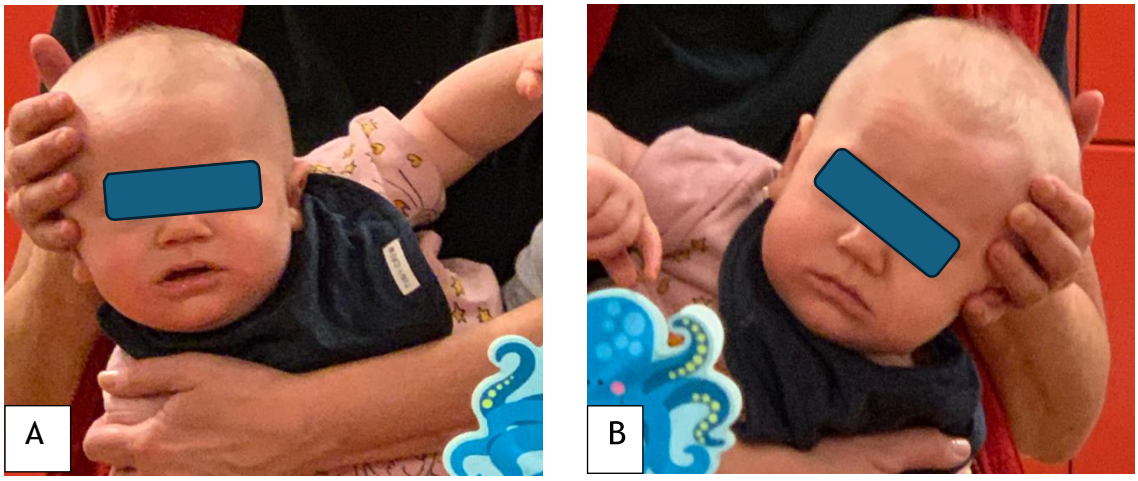

Figure 2. PROM lateral flexion in the cervical spine, clearly more PROM in lateral flexion toward the left side as ROM toward the right is restricted by a contracted muscle on the left.

According to CMT classification grades and the decision tree (2018), he had grade 3 i.e. early severe [25] when he was referred to the first physical therapist before three months of age. He had a mild plagiocephaly on the right side. On Cheng and Tang´s scoring system for the assessment of clinical and subjective outcomes he got zero scores before surgery, which is poor in all categories. He did not respond to stretching at all, and surgery was a prerequisite for PT to work. After some discussion with his physician, he was referred to a surgeon with experience of CMT and surgery. Surgery was decided in July 2019 but unfortunately it took until October the same year before surgery was performed as there was a discussion about the optimal time for surgery. This infant had severe discomfort caused by the fibrosis tissue and his dissatisfaction was exhausting for the parents. Early surgery would have been preferable. He was 13 months at the time of surgery and after surgery the parents said he was like a new child, more at ease. Together with the parents, stretching was carried out in an alternative way which was challenging but it worked. He was placed standing between the physical therapist's legs to stabilize his body, with his left side toward a mirror. His mother played with movable stickers on the mirror to distract him as the physical therapist stabilized the right shoulder and stretched his neck in rotation toward the left side. Lateral flexion was stretched when he was lying on his left side in the physical therapist's lap. Thanks to the mother's distracting play and some short breaks throughout the session, he cooperated well. He gained good PROM in rotation 90° to the left side and full PROM in lateral flexion i.e. ear to shoulder tested lying on the side. Three months after surgery he scored 12 on Cheng and Tang's scale, which is good. PROM was also good, but there was a reoccurrence of fibrosis in the SCM muscle, craniofacial asymmetry, and subjective assessment was only fair. We continued with stretching to try to keep the PROM at a satisfactory level. After a period of less training due to infections and colds there was a need for re-surgery which the surgeon was prepared to conduct if the parents consented. However, the COVID-19 pandemic had started at that time, and the parent's hesitation to visit a hospital was understandable. As the pandemic continued longer than expected, re-surgery was delayed for about two years. During these years, he had a longer break due to repeated colds and he returned with more fibrosis tissue on the left side that was impossible to stretch. His head tilt was minor but the left shoulder was

severely elevated **(Figure 3)** and there was limited PROM in both rotation and lateral flexion. PROM in rotation was measured with a protractor and was 70° on the left and 90° on the right, PROM in lateral flexion 65° on the left and 55° on the right.

Figure 3. Left shoulder severely elevated due to CMT on the left side.

The second surgery was performed in January 2023 at 4.5 years of age. After surgery he gained normal PROM in rotation and lateral flexion, and head in midline. But he still had a severely elevated shoulder on the left side and a lump in the trapezius muscle on the same side. This was probably caused by the tension of keeping an awkward position too long. Even though PROM in the left shoulder was good he spontaneously held his shoulder elevated, showing a high degree of asymmetry between shoulders **(Figure 4)**. He was not given a brace after surgery.

Figure 4. Post re-surgery, he had good PROM in his cervical spine and shoulder but kept his left shoulder elevated.

Stretching, massage with a small ball to make the lump go away and lots of active exercises were performed to accomplish symmetry between his shoulders. Kinesiology taping was used as a complement to correct the shoulder position **(Figure 5)**. This worked rather well for a while, but after some months the tape irritated his skin.

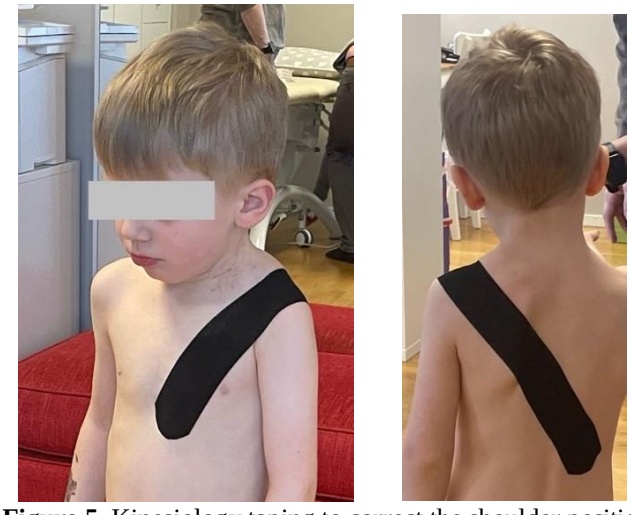

Figure 5. Kinesiology taping to correct the shoulder position.

The parents were very motivated and the home program worked well. A variety of exercises were used to keep it as playful as possible. A physical therapist specializing in shoulders was consulted about the shoulder and gave advice on the chosen exercises.

Due to an error in communication, PT was delayed and started three weeks after surgery, and no brace was applied. Treatment usually starts the day after surgery and a brace is worn directly after surgery. In addition, the physical therapist is usually informed in good time before surgery. According to the surgeon, a brace was not applied as the head was in midline. However, if communication had worked as it should have, a brace would have been recommended to keep the shoulder down. Parents had performed the active exercises they remembered from the first surgery, but stretching and other exercises were delayed. It took more than a year after re-surgery to reach a satisfactory result. The lump is gone and symmetry between the shoulders is mostly acceptable **(Figure 6)**.

Figure 6: A year after surgery, head in midline and shoulders show only a mild difference

DISCUSSION

This boy had severe CMT already as an infant and it was unfortunate that the professionals the family first met had limited experience of CMT. In fact, he was one of the physical therapist's first patients with CMT. In addition, the physician had a lack of experience of severe cases of CMT and therefore referral to the surgeon took much longer than necessary. Then the COVID-19 pandemic delayed the re-surgery and rehabilitation took a long time.

At follow-up in 2025, the results were good. Why he developed fibrosis tissue very soon after the first surgery is unknown. He may have been predisposed to developing fibrosis tissue or there might have been some fibrosis left after the first surgery.

This child and his parents spent considerable time on performing exercise programs. They should have a lot of credit for all the work they did together at home. The mother's work as a dancer and choreographer has given her great knowledge of the importance of training and therefore they were happy to be given a battery of exercises to choose from, with both parents ensuring training was playful for their son.

We can only speculate as to whether there would have been a substantial difference if treatment had not been delayed and a brace applied. However, delayed treatment is seldom beneficial. Kinesiology taping was chosen as a complement instead of putting on a brace several weeks after surgery. Applying a brace directly after muscle release often works well, however, it is not sure that a child would accept a brace several weeks after surgery. This child liked the taping, as he thought it looked like a police holster.

Another child with an elevated shoulder **(Figure 7)** and delayed surgery due to the COVID-19 pandemic, was given a brace directly after surgery. Good results were gained much more quickly. It was, however, this child's first surgery. There are similarities between these cases, both had left-sided CMT with limited ROM and an SMT on the left side at the start of treatment. They both had surgery at preschool age. However, the other child came to the clinic at a younger age and improved at an early stage thanks to stretching exercises.

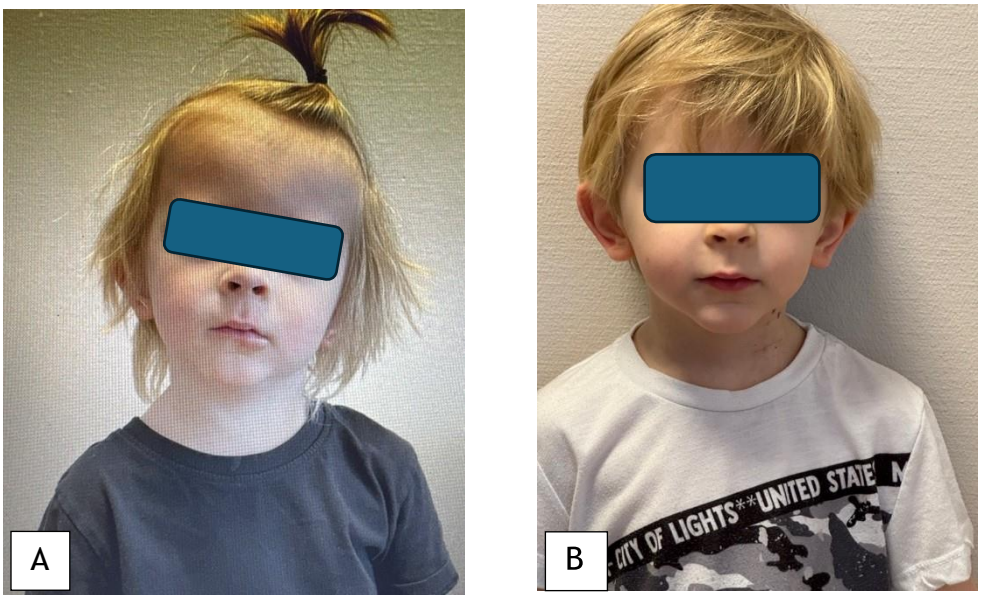

Figure 7. Another child before surgery (A) and after surgery (B) about the same age as the child in the case study, also with an elevated left shoulder. Surgery was also delayed for this child but not as much. This child got a brace directly after surgery in an attempt to avoid problems with the shoulder.

CONCLUSION

Some children seem to develop fibrosis tissue more easily than others and need re-surgery at an early stage. It is important to start PT directly after surgery and to use a brace to keep the head and shoulder in place.

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