"It is very important to involve family, especially for mother because baby and mother somewhat close together."

A qualitative interview study focusing on Vietnamese parents experienced role in the physical therapy treatment for their child with congenital muscular torticollis

"Det är viktigt att involvera familjen, framförallt mamman, eftersom barnet och mamman har ett speciellt band"

En kvalitativ intervjustudie om vietnamesiska föräldrar upplevda roll i den fysioterapeutiska behandlingen för deras barn diagnostiserade med kongenital muskulär torticollis

Authors
Laitinen, Jenny
Sjösten, Fanny

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Mentor
Lena Zetterberg
Lic. Physical Therapist
PhD
Department of Neuroscience,
Physical Therapy
ABSTRACT

Introduction
The parents involvement in the physical therapy treatment of their child diagnosed with congenital muscular torticollis is crucial for a positive outcome. The parents’ role has been mentioned as valuable in many studies, but there is a lack of studies that solely focus on the parents.

Purpose
The purpose was to interview Vietnamese parents at Ho Chi Minh City Children's Hospital in Vietnam, focusing on what the parents believe to be their role in the treatment of their child with congenital muscular torticollis.

Design and method
This study had a qualitative and exploratory research design with eight semi-structured interviews. To process the data a qualitative inductive content analysis were used.

Results
There were a will from the participants to be involved in the physical therapy treatment but there were also a need and desire for more knowledge. The participants experienced role in the treatment were regarding knowledge, trust, support and involvement.

Conclusion
All of the participants saw their importance to the treatment and wanted to be involved in the intervention. Despite the will to be involved there are a need of more support from the hospital.

Key words: Physical therapy, Congenital muscular torticollis, parents, experienced role, involvement.
SAMMANFATTNING

Bakgrund
I den fysioterapeutiska behandlingen för barn med kongenital muskulär torticollis är det viktigt att föräldrarna involveras. Föräldrarnas delaktighet i behandlingen är avgörande för att uppnå positiv effekt. I ett flertal studier tas föräldrarnas roll i behandlingen upp som viktig, trots detta finns det i nuläget ingen studie som enbart ser till föräldrarnas roll.

Syfte
Syftet med studien var att intervjuar vietnamesiska föräldrar på Ho Chi Minh Children’s Hospital i Vietnam angående deras upplevda roll i behandlingen som deras barn med kongenital muskulär torticollis genomgår.

Design
Studien hade en kvalitativ explorativ forskningsdesign med 8 semistrukturerade intervjuer. I analysprocessen användes en kvalitativ induktiv innehållsanalys.

Resultat
Resultatet delades in i 4 kategorier och 14 subkategorier. Resultatet visade att det fanns en vilja från deltagarnas sida att vara involverad i den fysioterapeutiska behandlingen men det fanns också ett behov och en önskan av att få en ökad kunskap.

Konklusion
Alla deltagarna såg sig själva som en viktig del i behandlingen och ville vara involverade. Trots viljan att vara delaktig så finns det ett behov av ökat stöd från sjukhuset.

Key words: Physical therapy, Congenital muscular torticollis, parents, experienced role, involvement.
BACKGROUND

Physical therapy is a profession found world wide and the international cooperation is crucial for growth and evidence based practice within the profession (1). One main benefit with Minor Field Studies and Vietnam as the chosen country for the study, is the possibility to develop a future international cooperation and exchange of knowledge between Sweden and Vietnam regarding physical therapy. Therefore this bachelor thesis was written within the framework of Minor Fields Studies and took place in Vietnam at Ho Chi Minh City Children’s Hospital.

Congenital muscular torticollis

The name torticollis comes from the Latin word “torus” which means twisted and “collum” which means neck (2). Characteristic for torticollis is shortening and thickening of the sternocleidomastoid muscle (SCMM) which causes an abnormal posturing of the head and neck. This abnormal posturing is seen as a lateral flexion of the neck towards the affected side and a rotation of the neck to the opposite side (2–6). Congenital muscular torticollis (CMT) is the third most common congenital musculoskeletal disorder in pediatrics worldwide (3,7). The prevalence is ranging from 0.3% up to 2% in newborns (2,4,5,8), but has been reported as high as 16% (4,5,9). The condition is slightly more frequently among males than females (5,7). It has not been confirmed which side of the neck, right or left, that is more common to be affected. Bilateral involvement of the neck is unusual, but existent (2,7).

It is unknown what the etiology of CMT is, but evidence suggests that it is related to mainly two things. Firstly, the infant’s positioning in uterus. Breech birth might increase the risk of CMT. Secondly, trauma at birth, which also might increase the risk for the infant to develop CMT (2,4,5,7,10). In addition to this, one study (5) also suggests that infants that are larger in size and the use of forceps at delivery, might be related to the infant developing CMT (5).
CMT has been associated with five other disorders which are hip dysplasia, brachial plexus injury, craniofacial asymmetry, plagiocephaly and developing delay (2,5,7).

There is a 98% chance that a child at 2.5 months of age achieve near full ROM of the neck when implementing physical therapy treatment before 1 month of age. When implementing the treatment when the child is 6 month or older it can require 9 to 10 months of physical therapy and the chances of full recovery of the necks ROM is decreased (4). There are some rare cases of unresolved or recurring CMT in older children. Today we do not have enough knowledge to predict which child will resolve and which child will progress to more severe or persistent CMT (5).

**Physical therapy examination**

Torticollis is a well-known pediatric disorder among infants (4,9). It is important to implement an early screening process among infants in order to discover the disorder as early as possible. Early treated asymmetrics and dysfunction will decrease the length of the rehabilitation (2,4,5). The most common physical therapy assessment for CMT is to measure and observe passive and active range of motion (ROM) of the cervical spine. Rotation and lateral flexion of the cervical spine are the directions that are measured and documented (5,7–9). In a clinical guideline from 2013 by Kaplan et al. (5), a goniometer or an arthrodial protractor is recommended as a measuring instrument for ROM of the cervical spine. The arthrodial protractor is also being recommended as a measuring instrument for the cervical spine in the book with the swedish title “Fysioterapi för barn och ungdom: teori och tillämpning” written by Beckung et al. (9). Also included in the assessment are palpation and observation of the SCMM, observation of the child's spontaneous positioning of the head and asymmetrics of the skull and neck (5,9). Because of the correlation between CMT and other diagnoses, as mentioned before, it is also preferable to screen the upper and lower extremities (5) as well as the child’s neuromotor development (7,9). It is important to exclude other differential diagnosis that may seem similar to CMT (2,9).
Physical therapy treatment

The aim of the treatment is to achieve full passive range of motion of the cervical spine and a symmetric position of the head (5,9). The treatment for CMT is primarily conservative and is executed by a physical therapist. The average time of the intervention is five months with continuously follow ups (9). The physical therapy treatment for CMT includes passive stretching, facilitation of active movements of the affected SCMM (2,4,5,7,9), positioning and educating the parents or caregivers about CMT and the positive effects of physical therapy (2,4,5,7,9,11). In some severe cases when no progress is being made through a conservative approach an operation will be necessary, followed up by physical therapy (2,9).

Passive stretching of the neck is the first-choice of intervention (5,6). Evidence today show no general recommendation when it comes to frequency, intensity and duration of passive stretching. Physical therapists should make an individual plan of care based on the child’s age and disabilities (9). Even if there are not any general recommendations, studies show that an increased frequency of the treatment is improving the outcome when it comes to achieving full ROM of the neck and decrease asymetrics (2,5,6). A prospective randomized controlled study from 2017 by He et al. (8) compared two different stretching treatments in children with CMT. One group did five sessions a day and the other group did ten sessions a day. The sessions contained of ten stretching exercises each held for ten to fifteen seconds with a resting period of ten seconds between each exercise. The conclusion was that the group who completed ten sessions a day got an improved outcome compared to the other group who did five sessions a day (8).

The parents role in the physical therapy treatment

The parents role in the treatment is not to be forgotten, since they as parents usually spend most of the time with the child they do have an important role in the following intervention. To achieve a positive effect of the treatment, the parents’ adherence to the plan of care play an important part (5). It is necessary for the parents’ to have belief in the physical therapy intervention and feel valued and involved in the process. The physical therapist should
provide strategies for the parents when it comes to positioning and handling of the child to make them involved in the treatment (5).

The parents are advised to keep the child laying on the tummy as much as possible when awake. This “tummy time” strengthens the neck muscles, relief the pressure on the back of the head and also stimulates the neuromotor development (5,9). They are also advised to be aware of the child's head position in the car, in the stroller, when carrying and during breast or bottle feeding (5,7,9). Parents also play an important role to encourage the child into active movements for example during playtime (2,5). The physical therapist and the parents should cooperate and keep a close contact during the whole intervention. It is also valuable for the physical therapist to be available and open to discuss the disorder with the parents (5).

To create adherence to the intervention it is important for the parents to make a behaviour change in their way to handle their child in relation to CMT and to uphold the strategies given by the physical therapist (12). For that to happen the physical therapist need a behavioural approach in the intervention. By using the theory of operant conditioning with reinforcement as a main tool the physical therapist increases the chances for the behaviour to uphold. The physical therapist can use reinforcement by having regular follow ups and validate the parents when they have maintained the treatment they have been instructed to do at home. Additional reinforcement for the parents is also when they see the progress their child is doing because of the treatment (13).

In a study done by Rabino et al. (11) they tried to identify factors that were related to parental adherence to the physical therapy treatment for CMT. They saw a correlation between parental adherence and perceived “disease treat”. No correlation was found between parental adherence and “communication, satisfaction with and trust in the physical therapist”, “expectations and beliefs in the treatment” or “preferences for an active role versus a passive role in health care” (11). In another study done by Lillo-Navarro et al. in 2015 (14) they tried to see parental adherence to a home exercise program subscribe by a physical therapist for young children with different physical disabilities. They found a correlation between parental
adherence and the characteristics of the home exercise program as well as the characteristics of the physical therapist’s teaching style (14). A recent study, also done by Lillo-Navarro et al (12), about parental adherence showed that parents with low perception of barriers and high self-efficacy had a higher adherence to do a home exercise program for their child with a physical disability. The study also showed that the behaviour were influenced by health professionals. The key to adherence was information from the physical therapist, explain the usefulness of the treatment, use the child as a model to instruct and satisfaction with the physical therapist. It was also important for the physical therapist to ask about adherence at follow-ups and let the parents explain difficulties and receive support from the physical therapist (12).

**Ho Chi Minh City Children’s Hospital in Vietnam**

The Ho Chi Minh City Children's Hospital is the third children’s hospital established in the southern hub of Vietnam. The construction started in 2014 and the hospital officially opened in January 2017. It is located in the Binh Chanh District and is today consider to be the most modern children's hospital in Vietnam. With thirty-nine clinical and subclinical departments the hospital receive between one and two thousand patients a day (15). According to physical therapist Dao, head of the physiotherapy department at the Ho Chi Minh City Children's Hospital, there are 21 physical therapists at her department. None of the physical therapists are specialized in CMT but all of them are expected to be able to treat children with CMT. The average number of CMT-patients who are examined and treated are approximately ten per day. The age of these patients varies from two weeks to ten years. The doctor is the one to diagnose the child and to decide if the child is in need of physical therapy treatment and for how long. During the physical therapy treatment the child goes to continuously follow-ups at the doctor.

Physical therapist Dao and her colleagues use the following treatment for CMT; stretching the muscle as well as the body, positioning of the neck and neck exercises with stimulation by sound and light. Physical therapist Dao also mention that to educate and instruct the parents is a part of the intervention in the aim for them to proceed the treatment at home. The
parents are supposed to do the treatment 20-30 minutes per session, several times a day. They are to come to the hospital preferable three times a week but this varies depend on how far they live and how many other patients are treated at the physical therapy department at the same time.

According to physical therapist Dao, there are few studies done regarding physical therapy and CMT in Vietnam. CMT and physical therapy is a new research topic in Vietnam and surely this results in a lack of focus on parent’s involvement overall. Physical therapist Dao expresses that there is a need for this kind of studies in Vietnam. Especially when many families live in rural areas and do not have the possibility to travel to a hospital in the city for a daily or weekly treatment. Therefore the parents need to be able to execute a frequent treatment at home, which make them an important part of the treatment.

**Sustainable development goals and World Confederation of Physical Therapy**

This bachelor thesis is based upon United Nations Development Programme's sustainable development goal number three: Good health and well-being (16) and the World Confederation of Physical Therapy’s (WCPT) strategic plan for 2017-2021 for the development of WCPT and the profession (17). “A global community of physical therapists, where everyone feels connected”, is something that the WCPT has mention as one of their strategic plan outcomes to achieve by 2021 (17). By doing this bachelor thesis in Vietnam it contributes to an international development in physical therapy between Sweden and Vietnam. An international cooperation is important for the profession to grow and evolve by learning from each other.

**PROBLEM STATEMENT**

CMT is the third most common congenital musculoskeletal disorder in pediatrics worldwide (3,7). The prevalence is ranging from 0.3% up to 2% in newborns (2,4,5,8), but has been reported as high as 16% (4,5,9). Studies have shown that discovering CMT by early screening and fast implemented treatment have a good effect on the outcome of the intervention (2,4,5). Alongside the physical therapist, the parents play an important role in the
intervention. The parents’ adherence is crucial to the frequency of the treatment since they, as parents, usually spend most of the time with their child (5,11). Therefore it is necessary for the parents to have belief in the physical therapy intervention and feel valued and involved in the process. Even if the parents’ role has been mentioned as valuable in many studies (4,5,7,9–11), there is a lack of studies that solely focus on the parents.

CMT and physical therapy is a new research topic in Vietnam and surely this results in a lack of focus on Vietnamese parent’s involvement in the physical therapy treatment. Physical therapist Dao expresses that there is a need for this kind of study in Vietnam. Knowledge about parents’ view of the intervention done for their child are of great importance along with the role they themselves have in the intervention. If we do have this knowledge as physical therapists, we can make the treatment for CMT more efficient. As a physical therapist, it is valuable to understand the parents when implementing a behavioural change. This behavioural change can increase the chance of their adherence in the intervention for their child (13).

**PURPOSE**

The purpose of this study was to describe and explore what Vietnamese parents believe to be their role in the treatment of their child, diagnosed with congenital muscular torticollis, at Ho Chi Minh City Children's Hospital in Vietnam.

**RESEARCH QUESTION**

- How do Vietnamese parents consider their role in the physical therapy intervention that their child, diagnosed with congenital muscular torticollis, is going through?
METHOD

Design

The study is based on a qualitative and exploratory research design. A qualitative design was chosen because the authors aimed to get a better understanding of the participants’ view of the subject through interviews (18). Because of the lack of previous studies in this subject and with the aim not to get a final and conclusive answer an exploratory approach was suitable (19).

Selection

The participants in the study were selected through purposive sampling (18). With the help of physical therapist Dao the participants were selected to meet the authors criterias. The first nine participants who came to the hospital whom met the inclusion criterias and said yes to participating were interviewed. Eight of the nine interviews were included in the study. Seven of the interviewed were women and in one interview both the mother and the father were interviewed together.

Inclusion criteria: Participants in this study were Vietnamese parents who had their child from an age of 0 to 3 years old enrolled in an ongoing treatment for CMT at the Ho Chi Minh City Children's Hospital in Vietnam.

Exclusion criteria: Children diagnosed with CMT accompanied with a tumor.

Data collection

Data was collected through semi-structured interviews recorded with a cellphone. The semi-structured interview allowed the authors to ask individual follow up questions if needed (18). Two of the physical therapists at the department were interpreters for the interviews. The first interview was a pilot-interview and was not included in the study. After the
pilot-interview the authors made changes to the pre-written interview guide (appendix 1). Since the participants did not speak English the authors were dependent on the interpreters. The pre-written interview guide (appendix 1) was too difficult for both the participants and the interpreters to understand and translate. Therefore a new interview guide (appendix 2) was designed with questions that were simplified and more close-ended questions were used for the sake of both participants and interpreters.

**Execution**

The authors wrote an information letter in English (appendix 3) about the study that later on got translated into Vietnamese (appendix 4). The Vietnamese version was handed out by physical therapist Dao in January 2019. The parents who were interested in participating in the study announced that to physical therapist Dao. When the authors arrived at the hospital in Vietnam two physical therapists at the department helped the authors to capture potential participants when they arrived at the hospital for treatment. Both Dao and the two physical therapists did sign a written consent of professional secrecy (appendix 5).

Before commencing the interview all participants signed a written consent (appendix 6). The written consent was translated to Vietnamese (appendix 7). The interviews took place in February/March 2019. All interviews were held at the hospital in associating with the physical therapy treatment for the participant’s child. The length of the interviews varied from 10 to 15 minutes and was recorded with a password protected cellphone. When all transcriptions were done, the audio files on the cellphone were deleted. The authors took turns in leading the interviews and the one who did not lead, was sitting in the room as an assessor. The assessor was allowed to fill in with follow up questions if needed.

**Data processing**

When processing the data, the authors used a qualitative inductive content analysis. Both the manifest and the latent content were analyzed but because of shortage of data, the study is mostly based on the manifest content (20). Transcription of the interviews were made by both authors. The transcription was literal and sounds as sighs, hummings, laughter etc. was not
included. The transcriptions were read individually by the authors where they were seeking to find patterns and important parts or quotes that were of value for the following progression of the process. When the transcripted interviews were read individually, the authors compared their findings to seek for similarities and differences. The content analytical units were based on parts of the interviews that were of value for the research question and the purpose of the study. Together the authors condensed the content analytical units to different codes, that later on in the process were divided into subcategories and categories. The codes were used to ease the process of finding subcategories and categories (20). The findings of subcategories and categories were made by the authors individually. To come to an agreement of the subcategories and categories, there was a discussion between the authors. To increase the trustworthiness triangulation between the authors and the mentor was done. Example of the analytical process can be seen below (chart 1).

**Chart 1.** Example of the analytical process.

<table>
<thead>
<tr>
<th>Content analytical unit</th>
<th>Condensed content analytical unit</th>
<th>Code</th>
<th>Subcategory</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Yes very much. She say that the wrist and back hurts when she lift the head and do exercise. She say that she loves the baby very much and she see herself very important to do the exercise. Because her house is very far from here she say that she does it every day. So that is the reason she think that she is very important to the baby.”</td>
<td>“She say that she loves her baby very much and she see herself very important to do the exercise. Because her house is very far from here she say that she does it every day. So that is the reason she think that she is very important to the baby.”</td>
<td>Confident to be part of the treatment and see the importance of involvement.</td>
<td>Important to involve the parents.</td>
<td>Be involved in the physical therapy treatment.</td>
</tr>
</tbody>
</table>
Ethical considerations

When potential participants arrived at the hospital for treatment, they were given the option to participate in the study by a physical therapist at the hospital. The potential participants were given both written (appendix 4) and verbal information about the study. If they decided to participate in the study, they signed a written consent (appendix 7). The participants had the right to withdraw at any time during the interview and were also guaranteed confidentiality when presenting the results of the study.

One risk of this study was that the participants might have felt obligated to participate in the study in order to get a good treatment for their child. There might have been a fear that not participating in the study would affect the child’s plan of care negative. Therefore it was important to explain the authors’ purpose of the study and that their choice of involvement would not affect the treatment of their child. To decrease the chances of cultural differences affecting the study negatively the authors discussed the interview guide with the interpreter.

The benefits of the study were to get knowledge about what the parents believed to be their role in the intervention of their child. Through this knowledge, physical therapists can understand the parents better and involve them in the intervention in the best way possible. This will result in a more efficient intervention. Therefore the authors believe that the benefits of the study outweighs the risks.

RESULTS

Description of the participants

The age of the participants ranged from 22 to 32 years old. Nine female and one male participated in the study. The children's age ranged from 22 days to 8 months. Eight of the children were first borns and one was the second born child. One of the participants had a previous child diagnosed with congenital muscular torticollis. The amount of time the participants visited the hospital for treatment, ranged from once a month up to eight times a
month. Three of the children had their first time of physical therapy treatment at the hospital, three of the children had had physical therapy for two weeks, one of the children had had physical therapy for one month and one of the children had had physical therapy for eight months.

**Chart 2.** Description of the participants of the study.

<table>
<thead>
<tr>
<th>Age</th>
<th>28</th>
<th>25</th>
<th>29</th>
<th>32</th>
<th>22</th>
<th>29</th>
<th>27</th>
<th>30</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>female</td>
<td>female</td>
<td>female</td>
<td>female</td>
<td>female</td>
<td>female</td>
<td>female</td>
<td>male and female*</td>
</tr>
<tr>
<td>First child</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>second</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
</tr>
<tr>
<td>Age of the child</td>
<td>4 month</td>
<td>1 month 17 days</td>
<td>8 month</td>
<td>3 month</td>
<td>2 month</td>
<td>22 days</td>
<td>1 month 25 days</td>
<td>2 month</td>
</tr>
<tr>
<td>First child diagnosed with CMT**</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>no</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
</tr>
<tr>
<td>Side of the torticollis</td>
<td>right</td>
<td>right</td>
<td>right</td>
<td>right</td>
<td>right</td>
<td>right</td>
<td>left</td>
<td>left</td>
</tr>
<tr>
<td>Physical therapy treatment for how long</td>
<td>two weeks</td>
<td>First time today</td>
<td>8 month</td>
<td>First time today (at this hospital)</td>
<td>two weeks</td>
<td>First time today</td>
<td>two weeks</td>
<td>1 month</td>
</tr>
<tr>
<td>Amount hospital visits per month</td>
<td>4 times</td>
<td>8 times</td>
<td>2 times</td>
<td>2 times</td>
<td>4 times</td>
<td>8 times</td>
<td>1 time</td>
<td>2 times</td>
</tr>
</tbody>
</table>

*Age of the female unknown.

** Congenital muscular torticollis.
After finishing the analytic process the content of the interviews were divided into four categories with associated subcategories, which are presented in chart 3. Below chart 3, each category and subcategories are described. The quotes in the subcategories will be in cursive script and are the participants answers through the interpreter.

**Chart 3. Overview of categories and subcategories.**

<table>
<thead>
<tr>
<th>Categories</th>
<th>Subcategories</th>
</tr>
</thead>
<tbody>
<tr>
<td>In need of knowledge about CMT</td>
<td>Previous knowledge</td>
</tr>
<tr>
<td></td>
<td>Desire to learn more about the diagnose</td>
</tr>
<tr>
<td></td>
<td>Length of the treatment</td>
</tr>
<tr>
<td></td>
<td>Dosage and frequency</td>
</tr>
<tr>
<td></td>
<td>Wonders about operation</td>
</tr>
<tr>
<td></td>
<td>Possible relapse of disease</td>
</tr>
<tr>
<td>Trust in the treatment and the medical staff</td>
<td>Believe in physical therapy as a treatment for CMT</td>
</tr>
<tr>
<td></td>
<td>Follow instructions from the medical staff</td>
</tr>
<tr>
<td></td>
<td>Satisfied with the given information</td>
</tr>
<tr>
<td>In need of support from the hospital</td>
<td>Desire for more hospital visits</td>
</tr>
<tr>
<td>Be involved in the physical therapy treatment</td>
<td>Important to involve the parents</td>
</tr>
<tr>
<td></td>
<td>Confident to be a part of the treatment</td>
</tr>
<tr>
<td></td>
<td>Easy parts in the treatment as a parent</td>
</tr>
<tr>
<td></td>
<td>Difficulties in the treatment as a parent</td>
</tr>
</tbody>
</table>

**In need of knowledge about CMT**

The category *In need of knowledge about CMT* describes both the participants will to learn more about the diagnosis and treatment, but also their questions.

**Previous knowledge**

This subcategory is about the parents previous knowledge about CMT so to say before their child got the diagnose. The analysis showed that all, but one, did not have any previous knowledge about CMT. Most of the participants got knowledge about CMT after their baby
was diagnosed. “She say she does not have knowledge about torticollis. But after her baby has she know”.

Desire to learn more about the diagnose
The analysis showed a will from the participants to learn more about their child’s diagnose. Most of the participants did research on the internet to get more knowledge about the diagnose. “She say before she does not have baby she does not have knowledge, but when the baby had problems she find knowledge on the internet”. Other participants turned specifically to the Children's Hospital 2 in Ho Chi Minh City to get more knowledge about the diagnose. “She say she does not know if the exercises right or wrong and she want to this hospital to have more knowledge about torticollis”.

Length of the treatment
A common question the participants had was about the length of the treatment. The participants had wonders about when their child could feel better and when they could stop doing the exercises. “She wonder how long the baby will be better, how can finish do exercise”.

Dosage and frequency
This subcategory is about the participants questions about dosage and frequency regarding the home exercises. The wonders were regarding how many times per day they should do the home exercises as well as how many repetitions and sets to do per exercise. “She want to have how many times do exercises at home...”.

Wonders about operation
Some of the participants talked about a potential operation if the baby did not get better when doing the home exercises. These participants had questions regarding the effect of a potential operation and if an operation was the best option for the child. “She just had problem about when finish the operation the baby better or the torticollis can come again”.

Possible relapse of disease
Some of the participants expressed worries about a potential relapse of CMT after the
treatment was finished. They wondered if the treatment their child was given was enough or if there was a possibility for CMT to come back later in life. “She want to know about the torticollis is that come again?...”.

Trust in the treatment and the medical staff
This category is about the participants perceived thoughts about physical therapy and the medical staff who were involved in the treatment.

Believe in physical therapy as a treatment for CMT
This subcategory is about the participants thoughts about the treatment and shows that there was a belief about physical therapy as a treatment. The participants thought physical therapy would help the child to get better. “She want the baby will be better when involved in the physical therapy at the hospital”. The participants saw the importance of physical therapy and believed it to be necessary for the child. ”She think about physical therapy treatment is very necessary”.

Follow instructions from the medical staff
The analysis showed that the participants listened carefully to instructions given from both the doctor and the physical therapist. The participants received documents from the physical therapist about exercises to do at home, which the participants followed. Miss NN is, in the following quote, referring to a physical therapist at the hospital. ”...miss NN already sending the documents and we follow it”. The doctor at the hospital met the parents to set the diagnose and to give information about the diagnosis and treatment. The doctor told the parents about the importance of physical therapy in order for the child to get better. The analysis showed that the participants had trust in the doctor’s knowledge about the diagnose and listened to their instructions. ”The doctor say to parent the baby had torticollis so they must do exercise”. A lot of of the participants lived far away from the hospital and did not visit the hospital for treatment that often. This required them to do the exercises at home between the hospital visits. ”The doctor, miss NN, say that you can train at home”.
**Satisfied with the given information**

A few participants thought that they had gotten all the information they desired. The participants experience was that the physical therapist gave a lot of information about the diagnose and the treatment and therefore the participants were satisfied. “She say that the physical therapist tell a lot of information so she thinks it is enough”. If the participants later on desired more information or had any questions, they would turn to the physical therapist. "She say that she is not missing. She come here and ask physical therapist if she is missing”.

**In need of support from the hospital**

This category is about the participants thoughts about the amount of hospital visits with their child and how the distance to the hospital plays a part to the treatment.

**Desire for more hospital visits**

The analysis showed that the participants would like to come to the hospital more often than they did at the moment. After analyzing the data there were two practical reasons why it was not possible for them to come more often. Firstly it was because of the participants not having a lot of time. “She wants more, but she does not have the time”. Secondly, since most of the participants lived far away from the hospital, it was time-consuming to travel to the hospital. “She wants more but she do not have a lot of time and she live so far”.

**Be involved in the physical therapy treatment**

This category is about the participants thoughts about being involved in the treatment.

**Important to involve the parents**

The analysis showed that all of the participants in some way saw the importance of parents involvement in the treatment. The analysis also showed that there was a will among the participants to be involved in the treatment and to be an asset for their child. “She say that she loves her baby very much and she see herself very important to do the exercise. Because her house is very far from here she say that she does it every day. So that is the reason she think that she is very important to the baby”. Some participants talked about the fact that the child was dependent on the parents and therefore the parents were important in the treatment.
“She say the parent is very important because the can not do exercises himself...”. The bound between a mother and her child was strong and created a will to be involved in the treatment. “It is very important to involve family, especially for mother because mother and baby someway close together”.

Confident to be a part of the treatment
Some of the participants expressed a feeling of calm and confidence about their involvement in the treatment. “She believes she can do exercise for her baby”.

Easy parts in the treatment as a parent
The participants thought that the exercises were easier to do when the child was asleep. “When the baby sleeps she can put the baby in the good position”. One of the participants expressed that she found it easier when she, as a mother, and the child were doing the exercises together. “Easy when the baby and the mother do exercise”.

Difficulties in the treatment as a parent
The participants found it difficult to do the exercises when the child was sick or crying. “The hard when the baby is sick or the baby cry”. They also expressed that it was difficult when the baby was awake. “She must choose the time when the baby sleep”. Sometimes the participants found difficulties in not knowing if their execution of the exercises were right or wrong. “...she do exercise very slowly and does not know if that is right or wrong”.

DISCUSSION

Summary of the results
The result were divided into 4 categories and 14 subcategories. After analysing the participants experienced role in the treatment, the authors found that there was a will from the participants to be involved in the physical therapy treatment but there were also a need and desire for more knowledge about the diagnose and the treatment. All but one participant had no previous knowledge about CMT. This lack of previous knowledge resulted in the participants having similar questions about the diagnose and the treatment. Despite their
questions about the diagnose and the treatment there was a belief to physical therapy as a treatment. There was a diversity in the amount of hospital visits per month among the participants. Almost all of the participants lived far away from the hospital, which made it very time consuming to travel to the hospital for treatment.

Discussion of the results

Even though CMT is the third most common congenital musculoskeletal disorder in pediatrics worldwide (3,7), all, but one, participant had no previous knowledge about the diagnose. When the diagnosis is set the parents receive both written and verbal information about CMT and the following treatment. The information is given by both the physician and the physical therapist. According to several studies educating the parents about CMT and the effects of physical therapy treatment, is an important part in the intervention (2,4,5,7,9,11). The first physical therapy session at the hospital is about 30 minutes and contains information about CMT, as well as demonstration of the home exercises. The main focus in the first session is to give information to the parents regarding CMT and the following treatment. It is a lot of information at the same time and the authors thought that it seemed quite difficult for the parents to assimilate and understand all of the given information. The focus in the following physical therapy sessions is mainly passive treatment by the physical therapist.

Even though information was a part of the treatment, the same questions about the diagnose and the treatment were recurrent from the participants during the interviews. The authors could not find an answer to why these particular questions were recurrent from the participants. Although the authors do have some thoughts about why these questions were recurrent. A possible reason might be that the participants do receive information, but the amount of information is too much to assimilate at one session. Another possible reason might be that the participants do not receive any information about the specific questions or that the information is abstruse. The authors can not come to a final conclusion regarding this matter. The main questions were about length of the treatment, dosage and duration, wonders about operation and possible relapse of disease. According to physical therapist Dao the length of the treatment varies from child to child and therefore she can
not say an average time for the treatment. According to the book with the Swedish title “Fysioterapi för barn och ungdom: teori och tillämpning” the average treatment time for CMT is 5 months (9). Regarding dosage and frequency there are no general recommendations, but an increased frequency of the treatment show an improvement to the outcome (2,5,6). Physical therapists should make an individual plan of care based on the child’s age and disabilities (9). Some of the participants had questions whether an operation would be the best option for their child. According to one study (2) and one book (9) an operation is only an option in severe cases when no progress is being made through a conservative approach (2,9).

The interviews showed that there was a desire from the participants to learn more about the diagnose and the treatment. It is important to make use of the participants desire to learn more and encourage them to ask questions or discuss the diagnose if this is required. The physical therapy sessions should contain information and education through the hole intervention. At the follow-ups at the hospital, potential questions from the parents should be discussed. A study has shown that it is important that the physical therapist is open to discuss CMT and the treatment with the parents (5).

There was a desire from the participants regarding more hospital visits per month. Because of the distance most of the participants had to the hospital, more hospital visits per month was at the moment not an option. The distance made it very time-consuming for the participants to travel to the hospital. A long distance to a hospital is something that will always be a factor in health care world wide. In the interviews the participants had only spoken of their wish to come to the hospital more often, but after analyzing the interviews the authors interpret this as a wish for more support from the hospital. The words “more support” were not something that was outspoken by the participants and therefore the authors can not make a final conclusion about what kind of support the participants would need/like. Even if the authors can not make a final conclusion regarding the matter, they think that it is of value that the physical therapist and the parents keep an open discussion and brings up potential questions from the parents before ending every session. It may also be of value for the parents to monitor their behaviour.
regarding their involvement in the intervention through a journal. A previous study (5) shows the importance of cooperation between the physical therapist and the parent and that keeping a close contact throughout the intervention is positive. The study, also shows the importance of strategies given by the physical therapist (5). As mentioned before, it is crucial for the physical therapist to form an individual plan of care for each child (9).

All participants saw the importance of the parents involvement in the physical therapy treatment. There was also a will among the participants to be involved in the treatment and to be an asset for their child. Many previous studies have also brought up the importance of the parents involvement in the physical therapy treatment of their child (2,5,11,12,14). A study has mentioned the importance of the parents to have belief in the treatment and feel appreciated in the process (5).

To have a positive effect of the outcome of the treatment it is crucial to create parental adherence (5,11,12,14). Most of the participants lived far away from the hospital, which makes it even more important to create parental adherence. According to a recent study from 2019 (12) there are a correlation between parental adherence and low perception of barriers, high self efficacy and parents satisfaction with the physical therapist (12). One participant expressed a confidence of doing the home exercises for her child. The participants did believe in the medical staff and that they had knowledge about the diagnose and the capability of treating their child. During the interviews the authors did not perceive the participants to question the capability of the medical staff. The participants listened to the medical staff and followed their given instructions, which furthermore shows on the participants trust in the medical staff. According to another study there are a correlation between parental adherence and the characteristics of the home exercise program, as well as the physical therapists teaching style (14). There are separate conclusions regarding the physical therapists influence on the parental adherence. A study done by Rabino et al. (11) made the conclusion that the physical therapist do not have an impact on the parental adherence. The only correlation seen in the study, was the correlation between parental adherence and “disease-threat” (11). The authors did sense an underlying feeling of “disease-threat” among the participants during the
interviews. Even if this study did not specifically investigate parental adherence the authors do believe that the physical therapist plays an important role in creating parental adherence.

The participants expressed both easy parts and difficult parts regarding the home exercises. The participants express that it was difficult to do the exercises when the baby was crying, sick or was awake. There was an uncertainty among the participants regarding if their execution of the exercises were right or wrong. According to a recent study the physical therapist should use the child as a model when instructing the exercises, especially the exercises that are difficult. During follow-ups the physical therapist should let the parents explain difficulties in the treatment and then give the parents support (12).

**Discussion of the method**

The purpose of this study was to make a research about parents experienced role in the physical therapy treatment for their child diagnosed with CMT at Ho Chi Minh City Children's Hospital in Vietnam. Therefore a qualitative and exploratory research design with semi-structured interviews were chosen (18, 19).

The participants, who were included in the study, were asked to participate in the study by a physical therapist when arriving at the hospital for treatment. Since it was the physical therapist who treated their child who asked about their participation, they themselves might have felt pressured to say yes to participate. There could have been a fear of that their child's plan of care might be affected if they said no to participate. Since the physical therapist is the one with knowledge about CMT and is responsible for the treatment of their child the participants are in dependency to the physical therapist which could also create a pressure for the participants to say yes.

The first interview guide (appendix 1) contained open questions to get a wider and deeper answer from the participants. During the pilot-interview the authors realised that the pre-written interview guide needed a change. Neither the participant nor the interpreter understood the questions because of confusion of languages. The pilot-interview was therefore not included in the study and changes were made to the interview guide. The new
interview guide (appendix 2) contained less open questions and an easier, more understandable language. Before commencing the second interview, the authors sat down with the two interpreters to discuss the content of the new interview guide. The discussion led to no changes and therefore the new interview guide was the one used in the rest of the interviews. Because of confusion of languages it was difficult to ask any follow-up questions. This, together with the changes of the interview guide, could possibly have affected the answers from the participants and the final content from the interviews. It also made it difficult for the authors to get as wide and deep answers as desired.

Before arriving in Vietnam the authors believed it was a professional interpreter who would attend the interviews. When the authors arrived at the hospital it was not a professional interpreter, instead it was two physical therapist who worked at the hospital. The two physical therapist who interpreted were also involved in the child's treatment. This was not preferable because of ethical considerations. Since there were no other interpreters available, this was the only option. This could have resulted in the participants not expressing their exact thoughts and instead answering what they thought the physical therapist wanted to hear. This could have affected the results of the study.

It was a benefit that both authors were present during the interviews. Because of the confusion of languages some parts of the participants answers were difficult to understand and therefore also difficult to interpret in the following data processing. Some of the quotes were difficult to interpret and divide into subcategories because of the confusion of language. It was an advantage to have both authors in the room during the interviews. This made it possible for the authors to later on have a discussion about the parts that were difficult to interpret.

To increase the trustworthiness of the study the authors did work both individually and together during the data processing. A triangulation with the tutor was also made to increase the trustworthiness of the study.
Clinical relevance and future research

Several studies write shortly about the importance of parental involvement in physical therapy treatment (2,5,11,12,14). The results from this study shows that the participants saw their involvement in the physical therapy treatment as important. The child is dependent on the parents since they are the one who spend most time with their child and therefore the participants saw their value to the treatment. Both the result of this study, and previous results of studies, show the importance of educating the parents and give them information about the diagnose and following treatment (2,4,5,7,9,11,12). The participants of this study get information about the diagnose and the treatment, but there are still recurrent questions from several of the participants. In order for the participants to feel comfortable and confident to be involved in the treatment, it is important for the participants and the physical therapist to have an open discussion about wonders and worries about the diagnose and the treatment.

The results also showed that there was a need of support from the hospital since most of the participants lived far away from the hospital. Even though the authors saw that there was a need of support from the hospital, the authors can not make a conclusion regarding exactly what kind of support is needed. Further research needs to be done regarding this matter. Also of value is more research regarding how and when the information about the diagnose and the treatment should be given to the participants to avoid these recurrent questions.

CONCLUSION

The result of this study showed that there was a will among the participants to be involved in the physical therapy treatment. The participants saw their role in the treatment as important and of value to their child. There was also a belief among the participants to physical therapy as a treatment for CMT. Despite the participants will to be involved in the treatment, there is a need of more support from the hospital for the participants to feel comfortable and confident in the treatment. The support might include that the physical therapist and the parents keep an open discussion and brings up potential questions. To create adherence and uphold a behaviour change among the parents a journal to monitor their behavior could be of value.
REFERENCE


Appendix

Interview guide

Before commencing the interview the participants will receive information about the study and thereafter sign the consent form. The interview will be recorded and will take 30-45 minutes. The study is confidential and optional, the participants have the right to withdraw their participation in the study whenever they like without any given reason. The interview is semi-structured which allow us to ask individual follow up questions if needed. The interview will begin with six background questions, followed by question number seven to sixteen which is the main part of the interview.

1. How old are you?
2. Is this your first born child?
3. How old is your child?
4. Is this child your first child diagnosed with congenital muscular torticollis?
5. How long has your child been given physical therapy treatment?
6. Did you have any previous knowledge about physical therapy treatment for congenital muscular torticollis?
   - If yes what knowledge did you have?
7. Which instructions has been given to you by the physical therapist regarding your part in the treatment?
8. What do you consider your role to be in the physical therapy treatment?
9. Do you see yourself important to the physical therapy treatment your child is given? If yes/no why?
10. How do you feel about being involved in the physical therapy treatment for your child?
11. What pros and cons do you see as a parent having an active versus a passive role in the physical therapy treatment?
    - Which role do you prefer to have? Why?
12. How do you experience the physical therapy treatment your child is being given?
13. What do you believe that the physical therapy treatment that your child is being given can lead to?
14. What do you think of physical therapy as the first-choice treatment for congenital muscular torticollis?
15. What do you believe to be the most important part of the physical therapy treatment to achieve a positive outcome?
16. Is there something else you would like add or clarify?
**Interview guide**

Before commencing the interview the participants will receive information about the study and thereafter sign the consent form. The interview will be recorded and will take 30-45 minutes. The study is confidential and optional, the participants have the right to withdraw their participation in the study whenever they like without any given reason. The interview is semi-structured which allow us to ask individual follow up questions if needed. The interview will begin with six background questions, followed by question number seven to twelve which is the main part of the interview.

1. How old are you?
2. Is this your first born child?
3. How old is your child?
4. Is this child your first child diagnosed with congenital muscular torticollis?
5. On which side is the congenital muscular torticollis?
6. How long has your child been given physical therapy treatment?

7. How often do you come to the hospital for physical therapy treatment?
   - Do you think that's enough or would you like to come more often?
8. Did you have any previous knowledge about physical therapy treatment for congenital muscular torticollis?
   - If yes what knowledge did you have?
9. What have you been told to do at home by the physical therapist?
10. Is there any information about the treatment that you're missing and want to have clarified by the physical therapist?
11. Do you see yourself important to the physical therapy treatment your child is given? If yes/no why?
12. What do you think about being involved in the physical therapy treatment for your child?
13. Is there anything in the treatment that you find easy to do as a parent?
14. Is there anything in the treatment that you find hard to do as a parent?
15. Before we end the interview, is there something else you would like add?
To whom it may concern that have their infant in an ongoing intervention for torticollis at the Ho Chi Minh City Children's Hospital.

Our names are Jenny Laitinen and Fanny Sjösten and we are two physical therapist students at Uppsala University in Sweden. We will be in Vietnam in the end of February of 2019, staying for eight weeks, to write our bachelor thesis. By this we hope to exchange knowledge and develop a future international cooperation between Sweden and Vietnam regarding physical therapy.

We would like to ask for your participation for our bachelor study “A qualitative interview study focusing on Vietnamese parents experienced role in the physical therapy intervention for their infant with congenital muscular torticollis”. In this document you will receive information regarding the study and what it contains.

Congenital muscular torticollis is the third most common congenital musculoskeletal disorder in pediatrics. One main part of the physical therapy treatment is to involve the parents by educating and instructing them. This is valuable for a positive outcome of the treatment. It is well researched about diagnostics and treatment for the disorder, but there are few studies done focusing on the parents. Therefore the purpose of our study is to better understand the parents’ belief to be their role in the treatment of their child.

Do you want to share your experience of the physical therapy treatment that your child is given as well as your view of the role you play in the plan of care?

By participating in this study you can contribute to increase knowledge about congenital muscular torticollis and how you, as a parent, experience the intervention.

If you do decide to participate in this study you will do an interview with us, either alone or together with your partner for 30-45 minutes. The interview will be done in Vietnamese and for us to understand we will use an interpreter. We will together decide on a time and place for the interview with help from physical therapist Dao. For us to be able to later analyze the content of the interview, it will be recorded. You have the right to withdraw from the interview at any time without any given reason. You also have the right to change or exclude parts of your own interview if you regret anything that you have said. It is also confidential, only the two of us and physical therapist Dao will know of your participation. Physical therapist Dao will sign a written consent of professional secrecy and will not participate in the interviews. For your confidentiality your interview will be coded with a number and all names will be excluded. Your answers will be presented as quotes and cannot be connected with you. Your child's plan of care will not be affected by your decision to not participate, withdraw from the study or what you say during the interview. The final result of the study will be presented in a bachelor thesis. The data will belong to the Physiotherapy Programme, Department of Neuroscience at Uppsala University.

If you are interested in participating in the study or have any questions, please contact us or physical therapist Dao.

Best regards,
Fanny Sjösten and Jenny Laitinen
Contact: sjosten.laitinen.uu@gmail.com

Mentor in Vietnam: Le Thi Dao, Head of physiotherapy department, Ho Chi Minh Children Hospital 2.
Mentor in Sweden: Lena Zetterberg, Lic. Physical Therapist PhD
Contact: Lena.Zetterberg@neuro.uu.se
Đánh cho những phụ huynh có con em được điều trị bệnh lý Vẹo cột tại Bệnh viện Nhi Đồng 2 Hồ Chí Minh.

Tên của chúng tôi là Jenny Laitinen và Fanny Sjösten, sinh viên ngành Vật lý trị liệu tại trường đại học Uppsala, Thụy Điển.

Chúng tôi sẽ đến Việt Nam vào cuối tháng 2 năm 2019, ở lại trong tám tuần, để viết luận án cử nhân. Chúng tôi hy vọng sẽ trao đổi kiến thức và phát triển một sự hợp tác quốc tế trong tương lai giữa Thụy Điển và Việt Nam về vật lý trị liệu.

Chúng tôi mong muốn xin sự đồng ý tham gia của quý vị vào chuỗi nghiên cứu của chúng tôi “Nghiên cứu phòng vận dilemma tập trung vào Cha mẹ có vài trò như thế nào trong việc can thiệp vật lý trị liệu cho trẻ bị bệnh lý vẹo cột bẩm sinh”. Trong tài liệu này, bạn sẽ nhận được thông tin liên quan đến nghiên cứu và những gì nó chứa.

Rói loan cơ bắp bẩm sinh là roi loan cơ xương bẩm sinh phổ biến thứ ba ở trẻ em. Một phần chính của điều trị vật lý trị liệu liên quan đến cha mẹ bằng cách giáo dục và hướng dẫn cha mẹ thực hành tại nhà. Điều này có ý nghĩa quan trọng đối với kết quả tích cực của việc điều trị. Dacija các nghiên cứu liên quan đến chăm sóc và điều trị cho roi loan cơ bắp bẩm sinh, nhưng có rất ít nghiên cứu được thực hiện tập trung vào cha mẹ. Do đó mục đích của nghiên cứu của chúng tôi là hiểu rõ hơn niềm tin của cha mẹ và vai trò của họ trong việc điều trị bệnh lý này.

Quý vị có muốn chia sẻ kinh nghiệm của quý vị về việc điều trị vật lý trị liệu mà con quý vị được cung cấp cũng như quan điểm về vai trò của quý vị trong kế hoạch chăm sóc? Bằng cách tham gia vào nghiên cứu này, quý vị có thể đóng góp để nâng cao kiến thức về vẹo cột bẩm sinh và làm thế nào quý vị, như một phụ huynh, cùng nhau can thiệp vào việc điều trị.

Nếu quý vị quyết định tham gia vào nghiên cứu này, chúng tôi sẽ làm một cuộc phỏng vấn với quý vị, một mình hoặc cùng với đối tác trong 30-45 phút. Cuộc phỏng vấn sẽ được thực hiện bằng tiếng Việt và để chúng tôi hiểu rằng chúng tôi sẽ sử dụng thông dịch viên. Ta sẽ cùng thống nhất về thời gian và địa điểm cho cuộc phỏng vấn với sự trợ giúp của cô Dao.


Nếu quý vị quan tâm đến việc tham gia nghiên cứu hoặc có bất kỳ câu hỏi nào, vui lòng liên hệ với chúng tôi hoặc cô Dao.
Trần trọng,
Fanny Sjösten và Jenny Laitinen

Liên hệ: sjosten.laitinen.uu@gmail.com

Cố vấn tại Việt Nam: Lê Thị Đào, Trưởng khoa vật lý trị liệu, Bệnh viện Nhi Đồng Hồ Chí Minh 2.

Cố vấn ở Thụy Điển: Lena Zetterberg, Lic. Tiễn sĩ vật lý trị liệu

Liên hệ: Lena.Zetterberg@neuro.uu.se
APPENDIX 5

Consent of professional secrecy

I do hereby acknowledge, consent and agree to all of the following terms and conditions:

- I will not speak of who have participated in the study.
- I will not speak of my involvement in the study with unauthorized personnel.
- I will not put any value in what is said during the interview and act as a neutral third part.

Date: ________________
Signature: __________________________________________________
Printed name: ________________________________________________
Consent form

I do hereby acknowledge, consent and agree to all of the following terms and conditions:

- I have the right to withdraw my participation in the study whenever I like without any given reason.
- I have the right to change or exclude parts of my own interview if I regret anything I have said.
- I have received information about the confidentiality of the study.
- The interview will be recorded.
- I have received information about how my data will be used.

Participant 1
Date: ________________
Signature: __________________________________________________
Printed name: ________________________________________________

Participant 2
Date: ________________
Signature: __________________________________________________
Printed name: ________________________________________________
Giấy chấp thuận
Tôi xác nhận, và đồng ý với tất cả các điều khoản và điều kiện sau đây:

- Tôi có quyền rút lại việc tham gia vào nghiên cứu bất cứ khi nào tôi thích mà không có lý do cụ thể nào.
- Tôi có quyền thay đổi hoặc loại trừ các phần trong cuộc phỏng vấn của tôi trong bất cứ điều gì tôi đã nói.
- Tôi đã nhận được thông tin về tính bảo mật của nghiên cứu.
- Cuộc phỏng vấn sẽ được ghi lại.
- Tôi đã nhận được thông tin về cách xử lý dữ liệu của tôi sẽ được sử dụng.

Người tham gia 1
Ngày: ________________
Chữ ký: __________________________________________________
Tên in: ________________________________________________

Người tham gia 2
Ngày: ________________
Chữ ký: __________________________________________________
Tên in: