Master's thesis

NTNU
Norwegian University of Science and Technology
Faculty of Medicine and Health Sciences
Department of Neuromedicine and Movement Science

Kristin Lie

Experiences with the Use of Orthoses for Ambulant Children with Cerebral Palsy. A Qualitative Study

Master's thesis in Physical Activity and Health
Supervisor: Karin Roeleveld
Co-supervisor: Sylvia Söderström
May 2022

NTNU
Kunnskap for en bedre verden

Kristin Lie

Experiences with the Use of Orthoses for Ambulant Children with Cerebral Palsy. A Qualitative Study

Master's thesis in Physical Activity and Health
Supervisor: Karin Roeleveld
Co-supervisor: Sylvia Söderström
May 2022

Norwegian University of Science and Technology
Faculty of Medicine and Health Sciences
Department of Neuromedicine and Movement Science

NTNU
Kunnskap for en bedre verden

Infographic

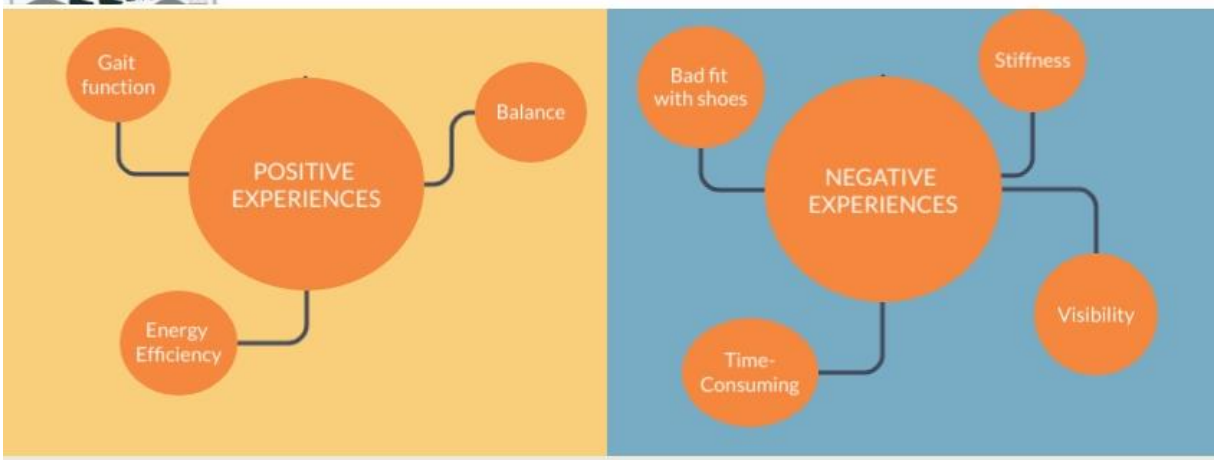
NTNU

EXPERIENCES WITH THE USE OF ORTHOSES

For Ambulant Children with CP

INFORMANTS

- Children (6-11 years old), hemiplegic CP, GMFCS I-II, using orthoses (n=8)
- One of the informants parents (n=8)



"I use the orthosis at school because it makes it easier to walk"

"His orthosis now does not work well enough in leisure time activities with his friends, for example, football. The foot gets too stiff if he uses the orthosis"

Activities with Orthoses

Activities without Orthoses

Made with VISME

Abstract

Background: two out of three children with cerebral palsy (CP) use orthoses to support the ankle joint, prevent secondary impairments, and improve gait function. Even though gait function is important, this may not be enough for children wanting to participate in activities with friends and peers. However, there is limited research on the functionality of the orthoses in different activities and if orthoses contribute to or inhibit activity and participation, which is essential for children's well-being. Hence, this project aims to answer the research question: How do children with cerebral palsy (CP) experience the use of orthoses in different activities and social situations?
Methods: in-depth interviews were used to address the experienced use of orthoses among eight children diagnosed with hemiplegic CP GMFCS level I-II, six- to eleven years old, living in Norway, and using ankle-foot orthosis (AFO) (n=4) or electrical orthoses (n=4) for ankle stability. Additionally, one of the children's parents was interviewed.
Findings: children experienced the orthoses as helpful in gait-related activities, such as school and hiking, due to improved gait function, balance, and energy efficiency. Furthermore, especially the AFOs were experienced as too stiff and too visible, resulting in decreased use of orthoses and poorer conditions to execute the same activities as friends and peers. However, this was not the case for children using electrical orthoses.
Conclusion: Orthoses were experienced as facilitators for activity and participation in gait-related activities due to improved bodily functions. However, AFOs are experienced to result in activity- and participation limitations in dynamic and social activities due to experienced stiffness and aesthetics. Findings indicate that children's expectations are difficult to fulfil with just one orthosis. Suggesting there is a need for different orthoses in different situations.

Sammendrag

Bakgrunn: to av tre barn med cerebral parese (CP) bruker ortoser for å støtte ankelleddet, forhindre sekundære skader og forbedre gangfunksjon. Selv om gangfunksjon er viktig kan målene med en ortose være utilstrekkelig for barn som ønsker å delta i aktivitet med venner. Per dags dato er det mangel på studier som evaluerer hvordan ortoser fungerer i forskjellige aktiviteter og om ortosene bidrar til eller hindrer barn i aktivitet og deltakelse. Derfor er forskningsspørsmålet til dette prosjektet: Hvordan opplever barn med CP bruk av ortoser i forskjellige aktiviteter og situasjoner?
Metode: dybdeintervju ble utført på åtte barn i alderen seks- til elleve år, med hemiplegisk CP (GMFCS I-II), bosatt i Norge, samt bruker ankel-fot ortose (AFO) (n=4) eller elektrisk ortose (n=4) på foten. I tillegg ble åtte foreldre intervjuet.
Funn: informantene opplevde ortosene som bidragsytere i aktiviteter der gangfunksjon er sentralt, som for eksempel på skolen og på gåtur, grunnet bedret gangfunksjon, balanse og energiforbruk (kroppslige funksjoner). På den andre siden opplevde noen informanter AFO som for stiv i noen aktiviteter og for synlig, som resulterer i mindre bruk av ortoser og dermed dårligere forutsetninger for å utøve samme aktiviteter som funksjonsfriske venner. Sammenlignet med AFO viste ikke elektrisk ortose de samme tendensene.
Konklusjon: ortoser ble opplevd som bidragsytere til økt aktivitet og deltakelse I aktiviteter som stiller krav til gangfunksjon, som et resultat av forbedret kroppslige funksjoner. Spesielt AFO ble opplevd som for stiv og for synlig, som fører til begrensninger i aktivitet- og deltakelses i aktiviteter med retningsforandringer samt sosiale situasjoner. Funn indikerer at barns forventninger og behov er vanskelig å oppnå med én ortose. Dette argumenterer for behovet av forskjellige ortoser til forskjellig bruk.

Acknowledgements

Firstly, I would like to direct a huge thank you to my main supervisor Karin Roeleveld for her exceptional guidance and sharing of her expertise in the field. I will also direct a huge thank you to my co-supervisor, Sylvia Søderstrøm, for her guidance and knowledge in qualitative research. It has been inspiring to work with both of you.

Further, I am grateful for the collaboration with fellow students. Therefore, I would thank Johan Gravdal for collaborating with me in the recruitment- and data collection process. And good luck with your thesis. Thank you to all my friends and fellow students who have helped me in this process by reading through my thesis, long sessions on campus, and joyful lunch breaks.

I owe thanks to Trøndelag Ortopediske Verksted for letting us perform data collection in their locals during opening hours. Thank you, Beitostølen Helsesportsenter; I am grateful for the opportunity to conduct pilot interviews before the data collection started; it was beneficial and instructive. At last, I would like to give a huge thank you to all children and parents who participated in this project. Thank you for making time to join in a hectic everyday life.

Abbreviations

AFO: Ankle-foot orthosis
BHSS: Beitostølen Helsesportsenter
CP: Cerebral palsy
GMFCS: Gross Motor Function Classification System
ICF: International Classification of Functioning, Disability and Health
NTNU: Norwegian University of Science and Technology
TOV: Trøndelag Ortopediske Verksted

Table of Content

1 Introduction

Middle childhood (6-10 years) and early adolescence (11-14 years) are important phases in children's development. An individual's identity, self-concept, social interaction, and ability to cooperate are compiled in these childhood phases (Eccles, 1999). For these children, participation in school- and leisure-time activities are proven crucial for the child`s development of self due to introduction to new social roles and social statuses. In addition, participating in school and leisure time activities contribute to a deeper understanding of society outside the safe environment within the family, resulting in increased autonomy (Eccles, 1999). Children not participating in these activities for different reasons are more likely to develop long-lasting intellectual, emotional, and interpersonal challenges (Erikson, 1668; Eccles, 1999). Furthermore, substantial evidence indicates participation is crucial for children's well-being, development, socialisation, and quality of life (King et al., 2006, Eccles, 1999). In comparison, the mentioned improvements are consequential with documented positive effects of participation in physical activity, including improved well-being, self-esteem, and happiness (Holder et al., 2009).

Furthermore, children with disabilities tend to participate less in physical activity, sports, and other leisure-time activities than typically developed children (Martin Ginis et al., 2016). In addition to lower engagement in activities, participation is also shown to decline more rapidly in disabled children as they get older than in peers (King et al., 2006). There are several types of disability, and an individual with disabilities is defined as "an individual with long term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (WHO, 2021). Importantly, cerebral palsy (CP) is the most common cause of physical disability among children and one of the largest groups of patients with paediatric services in high-income countries (Odding et al., 2006). Approximately 70% of children diagnosed with CP have gait function. However, the degree of gait function fluctuates among patients (Andersen et al., 2008). Additionally, children with CP have activity limitations due to primary- and secondary impairments (Morris, 2002).

To classify the different stages of CP, Gross Motor Function Classification System (GMFCS) is widely used (Baxter et al., 2007). This is a five-level classification system, where level I concerns patients with the least severe degree of disability, and level V (five) involves the most severe (Palisano et al., 1997). Level I-III patients have gait functions. However, some can walk without visible limitations, while some are dependent on assistive devices to maintain gait function (Palisano et al., 1997). Children diagnosed with CP use different assistive devices to handle everyday tasks and activities. As many as three out of four Norwegian children diagnosed with CP uses orthoses to improve gait function (Øien et al., 2016). The orthopaedic goal with orthoses is 1) to prevent misalignment, 2) to support the ankle joint, 3) to prevent contractures in muscles, and 4) to improve gait function (Totah et al., 2019, Øien et al., 2016).

The ankle-foot orthosis (AFO) is the most used orthosis for children with CP. AFO is a brace supporting the ankle joint by adjusting misalignment and improving functioning such as foot drop, imbalance, and prevention of contractures in muscles (Totah et al., 2019). Evidence supports high satisfaction among AFO users. 84% of Norwegian children using AFO experience improved functioning, especially in gait (Andersen et al., 2018). Similar numbers have been presented by other researchers, whereas 75% were satisfied and 25% reported dissatisfaction (Holtkamp et al., 2015). Even though high satisfaction is reported

regarding the use of AFO, the use is shown to decline after the child turns five years old (Wingstrand et al., 2014). The use of AFO is complex, and it is likely to think that several factors affect the actual use. Factors affecting the use of orthoses have been addressed in several studies. Visibility and aesthetics of the AFO are often experienced as a burden due to concerns of being noticeable and different from peers (Eddison et al., 2020). Additionally, personal factors, environmental factors, parents' perspectives, and device-related factors are shown to affect the use of orthoses (Huang et al., 2009). Moreover, most children using AFO do not use it when being home due to the home being free time and children have a more relaxed behaviour in their home environment (Huang et al., 2009).

Due to some critique towards the AFO in particular, electrical orthosis has proven to be a sufficient alternative to the AFO. Similarly, as with the AFO, the electrical orthoses improve gait function, gait velocity, energy efficiency, and balance (Bosch et al., 2014). In addition, electrical orthoses contribute to muscular activation resulting in dorsiflexion during the swing phase of gait (Ring et al., 2009; Bosch et al., 2014). Individuals using electrical orthoses are more satisfied with aesthetics than those using AFO. However, electrical orthoses are not proven to improve gait function better than AFOs (Bosch et al., 2014).

Firouzeh et al. (2021) conducted a scoping review investigating early AFO use, AFO patterns, and parent and clinician perspectives on AFO use among young children with CP. Results stated that most literature on AFO explores gait-related outcomes. None of the included studies examined how the use of AFO affects children with CP in activity and participation or children's experiences (Firouzeh et al., 2021). Despite this, Ireno et al. (2019) found that approximately 50% of included children experienced orthoses to inhibit participation in play. Additionally, there is a lack of research giving children the opportunity to speak for themselves. In particular, this means studies including children with CP, addressing how children experience the orthoses in activity and participation, and addressing barriers and motivations for using orthoses are needed. Furthermore, even though it is crucial to have the ability to walk, this may not be enough for children wanting to play and participate in sports with their friends. Such participation involves a wide range of movements, changes of direction, and speed. Therefore, it is important to understand how children experience the use of orthoses in different situations in their daily lives.

1.1 Research Aim

Therefore, this project aims to achieve knowledge on how children with CP experience the use of orthoses in different activities and situations and address if orthoses contribute to or inhibit activity and participation. This knowledge will be achieved by answering the research question: How do children with CP experience the use of orthoses in different activities and social situations?

2 Theoretical Framework

This project is anchored in two different theoretical frameworks, the International Classification of Functioning, Disability and Health (ICF) and Identity and the Body. The ICF model analyses findings by classifying how orthoses contribute to or inhibit activity and participation in different situations. Positive and more challenging experiences regarding the use of orthoses are divided into body functions and body structures, environmental factors, personal factors, and activity and participation. Further, the theory of Identity and the Body are used to discuss and explain the findings in the discussion section of the project. Firstly, a brief introduction of the theories is given. Then, the application of the theoretical framework in the current project is presented.

2.1 International Classification of Functioning, Disability and Health

ICF is defined as a framework and standard language for describing health and health-related states (WHO, 2007). The theory is used as a tool to classify an individual's health condition. The classification identifies the function and disability/limitations in body functions and body structures, activity and participation, environmental factors, and personal factors (WHO, 2007). Table 1 presents concepts of importance in ICF and the definitions.

Table 1. Overview of important definitions in the ICF model (WHO, 2007)

Concepts	Definition
Body Function	physiological functions of body systems, including psychological functions
Body Structures	anatomical parts of the body such as organs, limbs and their components
Activity	the execution of a task or action by an individual
Participation	involvement in a life situation
Environmental Factors	the physical, social and attitudinal environment in which people live and conduct their lives
Personal Factors	the particular background of an individual's life and living, and comprise features of the individual that are not part of a health condition or health state

The original ICF model is centred around the individual's health condition and impairment. Meaning the focus is on how the impairment affects and is affected by body functions and body structures, activity and participation, environmental factors, and personal factors (Rimmer, 2006). Figure 1 illustrates the ICF model.

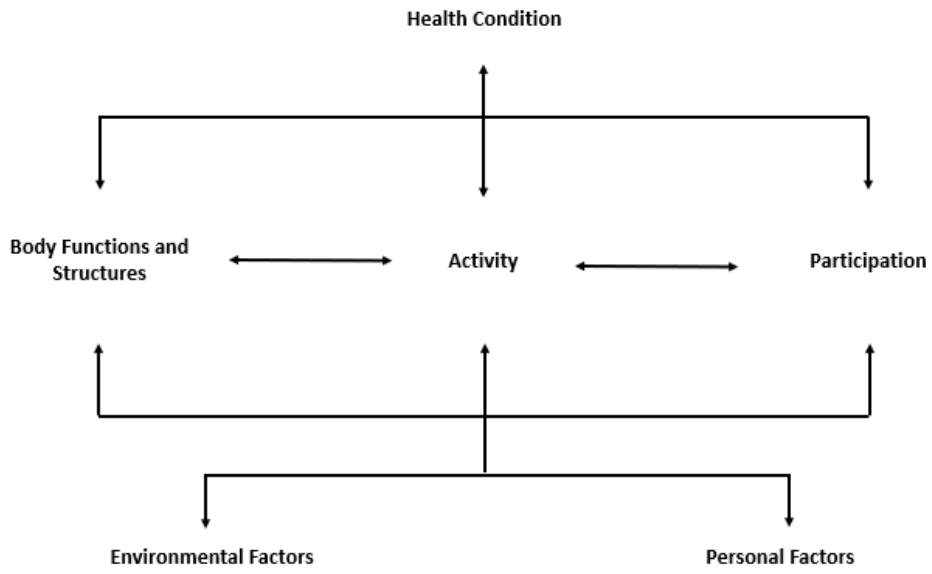


Figure 1. ICF model (WHO, 2007)

However, in this project, the ICF model is used to analyse if orthoses contribute to or inhibit children from participating in different activities and social situations. Meaning the focus that initially was on the health condition/impairment is in this project directed towards the use of orthoses. The adapted ICF model is presented in the following figure (figure 2).

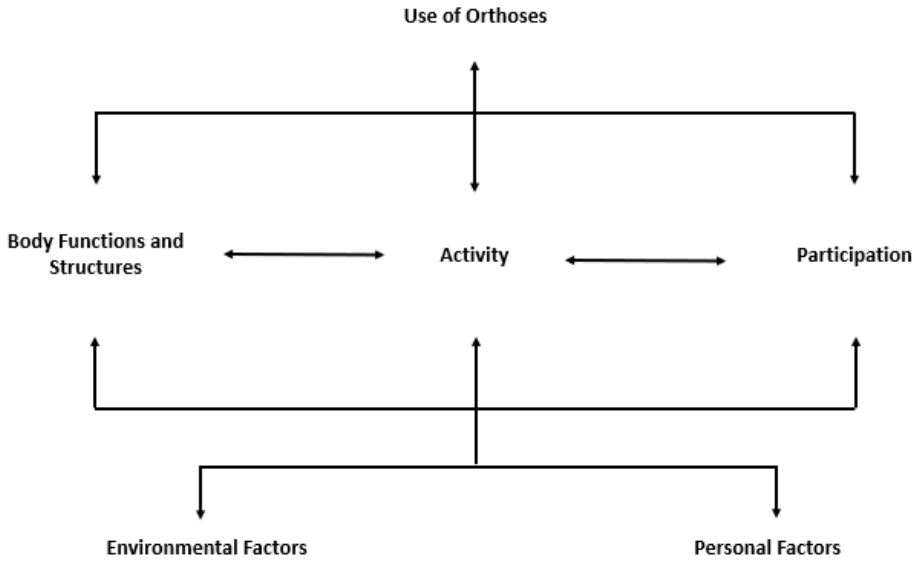


Figure 2. Adapted ICF model

Furthermore, children's experiences with the use of orthoses are presented (in findings) as 1) Body Functions and Body Structures, 2) Environmental Factors, 3) Personal Factors, and 4) Activity and Participation, which are central concepts in ICF. These experiences were analysed and categorised as positive experiences, meaning situations where orthoses contribute to increased activity and participation. Or challenging experiences, referred to as situations where orthoses restrict children's activity and participation. The application

of the ICF model is beneficial for this project by making it possible to enhance knowledge about if reasons for the non-use of orthoses are based on bodily restrictions or if it is a more complex theme. Even though the orthoses' impact on body functions and structures, environmental factors, personal factors, and activity and participation are essential, some of the revealed experiences needed to be analysed from another approach.

2.2 Identity and the Body

As mentioned in the introduction, children's identities are developed in early adolescence (Eccles, 1999). However, experiences of different embodied factors such as race, sex, and impairment are developed in childhood through interaction with other individuals. In addition, children in this developmental phase get more aware of themselves, which is important when creating a personal identity (Hart et al., 1987; Traustadóttir et al., 2015).

The relationship between disability and identity has been given significant attention in the last decades. Different researchers have investigated identity in disabled children, and several theories have been presented (Goffman, 1963, Ville, 2008, Gilson et al., 1997; Traustadóttir et al., 2015). However, this project is anchored in the Identity and the Body theory. This theory emphasises the importance of considering the body when investigating children's identity development, especially in disabled children (Traustadóttir et al., 2015). Considering the body is more relevant now than ever due to an increased focus on the body in modern society (Turner, 2001; Traustadóttir et al., 2015). In today's society, children are constantly exposed to a "perfect body appearance" through social media and culture (Grogan, 2007; Traustadóttir et al., 2015). When comparing bodies with each other, the comparison is often based on a "gold standard", which in this case is a non-disabled body. Therefore, due to the increased exposure to ideal bodies in social media, children with disabilities become more aware of their bodily differences (Traustadóttir et al., 2015).

For children with CP and GMFCS-level I or II, one of the most visible differences from peers is the use of orthoses. This theoretical framework is used to achieve a deeper understanding of the findings in the discussion. Identity and the Body is an advantageous theory to use in this project due to investigating if the informants are comfortable with identifying the orthoses as a part of their body or not. If informants are not comfortable identifying themselves with the orthosis, this may indicate the informants experience the orthoses as visible.

3 Methods

This thesis was a part of a more significant project by the Norwegian University of Science and Technology (NTNU), consisting of one qualitative and one quantitative project, resulting in two Master theses. The two projects collaborated on recruitment and data collection. However, only the qualitative project will be presented in this thesis.

3.1 Study Design

An exploratory qualitative study design was used to achieve knowledge of how children experience the use of orthoses in different situations. The qualitative study design was considered beneficial for answering the research question due to its focus on exploring subjective experiences and understanding the informants through open dialogues (Tjora, 2018). The exploratory approach allows a broader perspective, which is necessary due to the lack of research in this field. Therefore, the qualitative study design was chosen over a quantitative approach. Further, the stepwise deductive inductive analysis method by Axel Tjora (2018) was used to analyse the interviews.

3.2 Informants

Informants were recruited through the registry at Trøndelag Ortopediske Verksted (TOV). Informants included in this project were Norwegian children in primary school (six- to twelve years old), diagnosed with hemiplegic CP, GMFCS level I or II, and using AFO (n=4) or electrical orthoses (n=4) on their foot. Only children with approximately equal to normal cognitive function were included. Meaning they were able to receive and understand instructions and conduct an interview. Children in primary school were the age group of interest due to the documented high dropout rate regarding the use of orthoses in this age group (Wingstrand et al., 2014). Additionally, one of each children's parents was interviewed.

Eight children and eight parents were included in the project, giving a total of sixteen interviews. The children are referred to as C1-C8 and the parents as P1-P8. Informant characteristics are presented in Table 2.

Table 2. Characteristics of informants

INFORMANTS (CHILDREN)	GENDER (M/F)	AGE	AFO	ELECTRIC ORTHOSIS	GENDER OF PARENT (M/F)
C1	F	11	X	X	F
C2	M	8	X		M
C3	M	11	X		F
C4	M	8	X	X	M
C5	F	10	X		M
C6	M	7	X	X	M
C7	F	11	X	X	M
C8	M	10	X		F
	M: male, F: female X: current orthosis X: previous used orthosis				

In this sample, 50% (n=4) currently use AFO, while 50% (n=4) currently use electrical orthoses. However, all informants use or have used an AFO.

3.3 Recruitment of Informants

The snowball sampling method was used to reach saturation. First, as many informants as possible were recruited in Trondheim due to both time- and cost restrictions. Further, informants were recruited in Ålesund and Bergen.

Children fitting the inclusion criteria in Trondheim and Ålesund were found by using the registry at TOV, while children in Bergen were recruited from the registry at Drevelin. Further, families with children fitting the inclusion criteria received two letters of information, one for the children and one for the parents. After approximately a week, a text message was sent to one of the children's parents. They got two options: 1) reply "ok" if they wanted more information about the project, or 2) not reply if they were not interested in participating. The parents interested in more information were contacted with a phone call to receive comprehensive information. In addition, inclusion criteria were repeated to ensure correct inclusion. A suitable time to participate was agreed upon for families wanting to participate. Furthermore, a poster with information about the project and contact information was hung up in several locations and posted on the Facebook page of CP-Foreningen Trøndelag. The recruitment resulted in eighteen informants. However, one recruitment error was made due to misunderstandings resulting from language challenges. Therefore, one child and one parent were excluded from the project.

3.4 Data Collection Method

Individual in-depth interviews were used as the data collection method for this project. The goal of in-depth interviews is to "create a situation in which a relatively free conversation encompasses some specific topics pre-determined by the researcher" (Tjora, 2018, p. 93). To create a situation with a free conversation, making the informant feel safe is of great importance. In-depth interviews are used to study opinions, attitudes, and experiences. Additionally, in-depth interviews seek to understand the informant's "life world", which is the world seen from the informant's perspective (Kvale, 1996; Tjora, 2018). Due to the current project investigating children's experiences with the use of orthoses, in-depth interviews were a suitable data collection method for this project.

Two interview guides were developed, one for the children and one for the parents. Interview guides used in this project are attached as Appendix 1 (children) and Appendix 2 (parents). The children's interview guide mainly consisted of questions regarding the experienced use of orthoses. The interview guide for the children was divided into three phases: the warm-up phase, the reflection phase, and the winding-up phase (Tjora, 2018). The warm-up phase consisted of a presentation of the researcher and the informant and open questions about what the children like to do in their leisure time and other things of their interest. The warm-up phase belays the interview situation and creates the foundation for the rest of the interview. Questions about how the children experience orthoses in different situations were asked in the reflection phase. Lastly, in the winding-up phase, the children were allowed to talk about and share information not discussed in the interview guide. This was done to create an open dialogue to end the interview.

Further, in addition to questions regarding the experienced use of orthoses, questions about motivation and received information about the use of orthoses were included in the parent's interview guide. The interview guide for the parents was likewise divided into the warm-up, reflection, and winding-up phases. However, the warm-up phase was not seen as quite crucial for the parents compared to the children, leading to less attention to this part of the interview. Moreover, the children's interviews lasted for approximately ten- to fifteen minutes, and the parent's interviews for twenty- to thirty minutes.

In total, sixteen interviews were conducted between October (21) and January (22). Twelve informants were recruited in Trondheim, two in Ålesund, and two in Bergen. Fourteen of the interviews were conducted with a physical presence. At the same time, two interviews were conducted digitally via Zoom due to the Covid-19 pandemic. All interviews were recorded with a Dictaphone borrowed from NTNU. Furthermore, the recorded interviews were transcribed consecutively. In addition, three pilot interviews were conducted at Beitostølen Helsesportsenter (BHSS) in September 2021. These interviews were not recorded or included in the project.

3.4.1 Protocol: Individual In-Depth Interviews

Due to this project being a part of two Master theses, children performed physical tests (quantitative project) in addition to interviews. The tests and the interviews were conducted on the same day to be time-efficient. As an introduction and warm-up session, the child was asked some questions regarding the type of orthosis and which foot the orthosis was used on. Height and weight were additionally measured. The children performed the interview as the first part of the protocol for several reasons. Firstly, to ensure answers were based on their daily lives with orthoses and not the performance from the tests. Secondly, due to the assumption of a somewhat limited range of concentration. The interviews were held in a private room to avoid disturbances. Furthermore, interviews were conducted without the parents being in the same room due to the presumption that parents' presence affects children's behaviour, which could harm the interview.

After finishing the interview, the child completed the physical tests while the parent performed the interview. The interviews with the parents were likewise conducted in the same private room to avoid disturbances. After finishing the interviews and test protocol, the children got a small gift as a thank you for participating.

3.5 Analysis

After all recorded interviews were transcribed, it resulted in 56 pages of transcribed material. Further, the stepwise-deductive inductive method by Axel Tjora was used to analyse the data material. The deductive approach sees the data material from theoretical to empirical. Meanwhile, the inductive approach works with the material from raw data to theory. The main goal of the stepwise-deductive inductive analysis is to compile theories or concepts from raw data (Tjora, 2018). The stepwise-deductive inductive method was chosen due to its focus on staying close to the informants, which is advantageous in in-depth interviews as well.

The analysis consisted of six steps: 1) data were collected and transcribed, 2) irrelevant data were excluded from the analysis, 3) relevant data were coded, and quotes were addressed, 4) similar codes were group coded, 5) categories/concepts were identified, and 6) final categories were seen form two appropriate theories (Tjora, 2018). Due to children's experiences with orthoses being the main focus of this project, the parent's interviews were used to substantiate the children's experiences. Thus, even though the parents shared important information, some information was excluded due to not being relevant for this project.

The analysis resulted in four main categories: 1) Body Function and Body Structure, 2) Environmental Factors, 3) Personal Factors, and 4) Activity and Participation. Table 3 illustrates an example of the analysis.

Table 3. Example of how the data material has been analysed with the stepwise-deductive inductive method by Axel Tjora (2018).

Preliminary theme	Code	Quote	Category
Activities without AFO	Stiffness of the AFO	"His orthosis now does not work well enough in leisure time activities with his friends, for example, football. The foot gets too stiff if he uses the orthosis."	Environmental Factors
Activities with AFO	Improved balance	"If she doesn't use the orthosis, she falls very quickly because she has no balance (…) So if she doesn't use the orthosis, she falls very quickly when walking uphill and downhill."	Body Functions and Body Structures

3.6 Ethical Considerations

All informants received a letter of information for children (Appendix 3) and parents (Appendix 4). Parents were asked to thoroughly go through the letter of information with their child to ensure informed consent and understanding. Signed informed consent was necessary to participate in the project. Due to children being seen as a vulnerable group in science, parents were required to sign the consent. Participation in the project was voluntary, and the consent could be withdrawn at any point without consequences. Furthermore, the interviews were confidential, and data material was anonymised. Additionally, the project was approved by the Regional Ethical Committee (REK #283727).

4 Findings

Sixteen in-depth interviews were conducted, identifying several both positive and challenging experiences with the use of orthoses. The main findings from the interviews are presented as follows: 1) Body Functions and Body Structures, 2) Environmental Factors, 3) Personal Factors, and 4) Activity and Participation. Due to some children using AFO and some using electrical orthoses, it will be made accountable for which type of orthoses is being discussed. Findings mainly call attention to experiences and themes being addressed by children, and interviews with the parents are used to emphasise the children's statements. Therefore, the children will be referred to as informants.

4.1 Body Functions and Body Structures

Informants reported several positive experiences with orthoses, including AFO and electrical orthoses. Most of the positive experiences were improved gross motor skills, such as enhanced gait function, balance, and energy efficiency. The first quote is one of the parents talking about how orthoses make it easier for the child to walk in hilly terrain due to improved balance:

> *If she doesn't use the orthosis, she falls very quickly because she has no balance (…) So if she doesn't use the orthosis, she falls very quickly when walking uphill and downhill (P7).*

The fact that the daughter (C7) falls quickly when walking in challenging terrain without the orthosis indicates that orthoses improve balance. Mastering walking in hilly terrain is essential for children to keep up with their friends when hiking at school, which is of great importance. The orthoses' positive impact on balance contributes to increased activity and participation in situations where gross motor skills such as gait and balance are challenged, for instance, when walking in hilly terrain. Furthermore, improved balance is highly related to enhanced gait function, which was another positive experience with the use of orthoses. The following quote is one of the informants talking about how it is to walk with orthoses:

> *It becomes a bit easier to walk with the orthosis. Or it is better to walk with it (C8)*

Here, an informant talks about how orthoses make it easier to walk. All informants reported orthoses to improve gait function, respectively, for AFO and electrical orthoses. Even though some experience the AFO as somewhat stiff, the stiffness contributes to improved ankle joint support, adjustment of misalignment, and foot drop. This means the orthoses contribute to improved body functions and body structures, resulting in balance and gait function improvements. The experienced bodily enhancements apply to both AFO and electrical orthoses.

Even though the stiffness of the AFO contributes to improved gait function and balance, several informants experienced some challenges regarding the stiffness. The following quote is one of the parents talking about how the stiffness of the AFO affects his child in activities with friends:

> *His current orthosis does not work well enough in leisure time activities with his friends, for example, football. The foot gets too stiff if he uses the orthosis (P2).*

P2 explains that the AFO becomes an obstacle for the child due to being too stiff. The stiffness leads to decreased range of motion in the ankle joint, making it difficult for the child to manoeuvre the ball with the ankle. Even though the stiffness leads to improved gait function and balance, experienced bodily restrictions are more significant than the

experienced improvements. Meaning the stiffness of the AFO is experienced as positive in gait-related activities and harmful in movements demanding transitional movements.

Even though body functions and structures are of great value, several factors affect the use of orthoses. For instance, it is essential to know how orthoses are experienced in their surroundings. Hence, the following part presents how informants experience the use of orthoses regarding environmental factors.

4.2 Environmental Factors

Most of the experienced challenges regarding orthoses were environmental challenges. Challenges such as the AFO not fitting in football shoes, difficulties with shin guards, and time-consuming taking on and off were addressed. Respectively, these challenges were primarily directed toward the AFOs. One of the informants addresses that AFO is impossible to use when playing football due to not fitting in the football shoes:

> *The orthosis doesn't fit in the football shoes, making it more difficult to run (C3).*

Several reported similar challenges with the football shoes and the AFO, meaning this is a problem of importance. This may result in decreased conditions for C3 to play football due to poorer balance and gait function when not using the AFO. C3 additionally mentioned that he experiences the AFO as challenging to use when running. Despite the issues regarding AFOs and football shoes, shin guards have also been experienced as challenging to match with AFOs. One of the parents talks about difficulties with using shin guards and AFOs at the same time:

> *And I think it's about this orthosis is placed on the front of the leg, and he must wear shin guards, so it became difficult. So, I think it's mainly about that (P3).*

The quote suggests that the child mainly does not use AFO when playing football because he needs to wear shin guards. The shin guards and the not fitting football shoes may indicate that practical challenges are just as big a problem as the physical restrictions. These challenges do not affect the body function directly; however, it leads to poorer conditions to execute the same activities as his friends. Moreover, one of the informants shared that she experienced issues with the orthosis falling off. However, this was an AFO attached to the shoe instead of the foot.

AFO was experienced as time-consuming by the informants. This was most problematic in social settings and at school due to not being able to keep up with friends. Children using AFO tend to be the last ones out in the recess, which was a considerable barrier. One of the informants talked about an incident at school where the entire recess was used to put on the AFO:

> *Or once I did not get recess because I had such tight boots that it took so long to put on the orthosis. (C6).*
>
> *I think he sees it as an obstacle. And especially when he gets dressed at school. The fact that it takes a long time and that he gets last out in his recess at school is a huge barrier for him (P6).*

Additionally, P6 has observed AFO being time-consuming and experienced as a huge obstacle for his son. Being the last person out in the recess made C6 feel different from his friends, contributing to decreased use of AFO or reduced participation in the break. In addition, using more extended time than his friends to get dressed for recess may contribute to unwanted attention and comments from others. The following theme of

personal factors explains how this unwanted attention affects the informants and the use of orthoses.

4.3 Personal Factors

The most experienced personal factor was the visibility of the orthoses, especially the AFO. One of the parents talks about how the AFO was experienced as too visible for their child:

> *We think it's mainly because it is very visible, but she won't talk about that (…). It was a coincidence that I noticed that she didn't want to use the AFO because when I was picking her up from school, I saw that the AFO was on the shelf and had been there for a long time. So, I think it became a bit too visible for her (P1)*

In this case, the visibility of the AFO resulted in C1 replacing the AFO with an electrical orthosis, which is less visible. Negative experiences regarding the visibility of AFO were a recurring problem, especially among the informants who already had replaced the AFO with electrical orthoses. Further, visibility contributing to unwanted attention was mentioned as a challenge, resulting in less use of orthoses or/and a change of orthosis. Children constantly comparing themselves with friends, classmates, or other peers may lead to children using orthoses feeling different from their friends. Furthermore, the unwanted attention may amplify the feeling of being different and make the informants more aware of their physical and opportunity differences than friends and peers. According to P1, the visibility and the attention that comes with it decreased the use of AFO for the child. This drop in use negatively affects the ability to perform and participate in several situations. In comparison, the visibility does not negatively affect all the informants. The following quote is from one of the children answering why he would like to continue to use his current AFO:

> *I don't know, but I like the football print (C2).*

In contrast to those experiencing the AFO as too visible, C2 seems to experience the co-determination of print on the AFO as a motivation. Being allowed to determine the print on the AFO makes the orthosis more personal. Some think the AFO is too visible, while others like the visibility and attention. Consequently, if the informants like or dislike the aesthetics of the AFO are individual.

Moreover, the following part of the findings will present how informants experience the use of orthoses in different activities and situations and in which activities they prefer and do not prefer to use orthoses.

4.4 Activity and Participation

Informants reported both activities where informants preferred to use orthoses and activities where it was preferred not to use orthoses. Figure 3 shows in which activities the informants uses the orthoses. Additionally, table 3 gives an overview of which leisure-time activities the informants mentioned participating in in the interviews and whether the orthoses are being used. Table 4 provides an overview of which informants using the orthoses at home, in school, and social situations. Both table 3 and 4 shows if the informants use AFOs or electrical orthoses. As shown in Figure 3, Table 4, and Table 5, school and hiking are where most informants use orthoses.

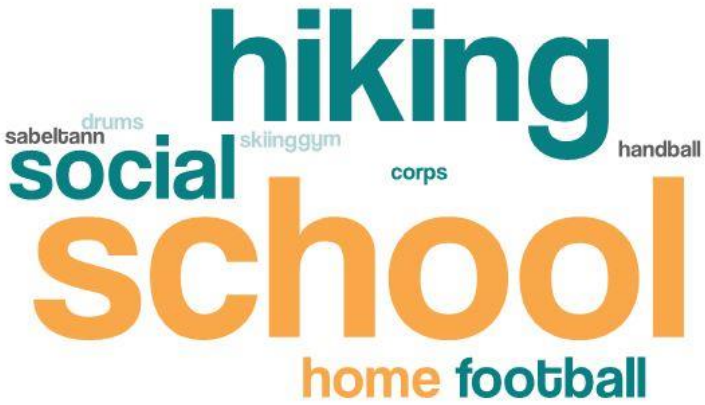


Figure 3. Word cloud presenting in which activities informants prefer to use orthoses. The activities with largest text are the most frequently answered activity

Table 4. Overview of leisure-time activities the informants have mentioned in the interviews, which activity each informant performs, and if they perform the activity with AFO, electrical orthoses, or without orthoses. C1-C8 are each of the informants (children)

	Football	***Swimming***	***Handball***	***Climbing***	***Taekw.***	***Skiing***	***Hiking***	***Gymnastics***
C1				O		X	X	
C2	O						X	
C3	O						X	
C4	X	O			O		X	
C5	O	O	X				X	O
C6	X						X	
C7					O		X	
C8							X	O
	Red text: electric orthosis		X: activities with orthoses					
	Black text: AFO		O: activities without orthoses					

Table 5. Overview of the use of orthoses at home, in school, and social situations, and which orthoses the informants use. C1-C8 are each of the informants (children)

	Home	***School***	***Social***
C1	O	X	O
C2	O	X	O
C3	O	X	X
C4	O	X	X
C5	O	X	O
C6	O	X	O
C7	O	O	O
C8	X	X	X
	Red text: electric orthosis	X: activities with orthoses	
	Black text: AFO	O: activities without orthoses	

School is the most frequently answered activity where orthoses are experienced as sufficient (Figure 3). One of the informants talks about why he uses orthosis at school:

> *I use the orthosis at school because it is easier to walk with the orthosis (C3)*

C3 uses orthosis at school since it makes walking easier, resulting in increased activity and participation in school. This quote is consistent with the rest of the informant's experiences. As many as seven out of eight experience using orthoses at school as helpful. And explained the desired use by 1) the use of orthoses makes it easier to walk, and 2) informants reported more walking at school than in other situations. As shown in Table 4, all children preferred to use orthoses when hiking. These results are consistent with findings presented under Body Functions and Body Structures, suggesting that orthoses improve gait function, balance, and energy expenditure. This indicates that orthoses contribute to increased participation at school and when hiking. Furthermore, one of the children mentioned that she use the AFO when skiing (cross-country skiing):

> *We use to go skiing quite often. And I use the orthosis when skiing so that my foot gets straight (…). I think it is nice to use orthosis when skiing. It makes me faster (C1).*

Here, one of the informants talks about her experience using AFO as beneficial when skiing due to straightening her foot. Indicating AFO contributes to increased activity and participation in skiing due to supporting the ankle joint and adjusting misalignment. In addition, C1 experienced improvements contributing to increased motivation for use due to making her "faster", suggesting experienced positive effects leading to improved participation in activities, resulting in increased application of AFO.

Several informants have experienced activity and participation limitations due to using orthoses in vigorous activities and sports, especially with the AFO, resulting in less use of

Figure 4. Activities where informants do not use orthoses. The activities with largest text are the most frequently answered activity.

AFO in several activities. These activities are presented in Figure 4, a word cloud consisting of activities where the informants do not prefer to use orthoses.

Home is where most informants do not use orthoses due to less walking, not wearing shoes inside, and due to the home being seen as "free time" where they are supposed to relax. However, this is for more practical reasons, not affecting performance or participation.

As shown in Figure 4, vigorous activities and sports are highly represented in activities performed without orthoses. The majority of informants reported AFOs to be experienced more as a burden than a facilitator for participation in football. One of the children and the parent talk about experiences with the use of AFO in football like this:

> *I think it is easier to play football without orthosis (C2)*
>
> *His orthosis now does not work well enough in leisure time activities with his friends, for example, football. The foot gets too stiff if he uses the orthosis (P2).*

C2 experienced the AFO as challenging to use when playing football and therefore prefers not to use it. In addition, he states that it is "easier" to play football without the AFO, indicating the use of AFO in football leads to activity and participation limitations. Challenges regarding the AFO not fitting in the football shoes affect the children's football involvement. Hence, this leads to two possible solutions for the informants. They can either use other types of shoes where the AFO fits. This would decrease performance, negatively affecting participation and motivation to participate due to feeling different. Or use the football shoes without the AFO, resulting in reduced gait function and balance and increased energy efficiency. Either way, none of these options are optimal.

The father (P2) talks about how AFO in football results in stiffness in the ankle joint, making it more challenging to play. Several children experienced the AFO as too stiff, not fitting in the football shoes, and placed on the same leg area as the shin guard. Even though some of the children stated that they found it easier to run and play football without the AFO, it may decrease their ability to perform their best due to reduced balance and extended energy consumption when not using AFO. In contrast, this was not the case for children using electrical orthoses. Here, father and son talk about how they experienced the use of electrical orthoses in football:

> *I tend to use the electric orthosis when playing football because my dad says it makes it easier to play (C6)*
>
> *He mentioned yesterday that he wanted to use the electric orthosis when playing football because it makes him better (P6)*

C6 uses orthoses when playing football because his father says it would be helpful regarding improved performance. Therefore, this may indicate that C6 does not notice much difference with or without orthoses. Either way, both children using electrical orthoses and playing football prefer to use orthosis in the activity (Table 4). In summary, electrical orthoses seem to be more satisfying when playing football and align for increased participation in football compared to AFOs.

Both electric orthoses and AFOs are not used in swimming since the water would ruin the orthoses. In taekwondo, the main reason for not using orthosis was that it could get broken. The non-use in gymnastics was mainly because of not wearing shoes and climbing due to a too lousy range of motion. One mother talks about her son not using orthoses in all activities:

He participates in gymnastics in his leisure time, and he does not use orthosis in gymnastics, which works fine. So, not all activities require the use of orthoses (P8).

The non-use of orthoses in these activities does not result in activity or participation limitations due to evident and natural reasons. Importantly, not all activities have physical demands making it necessary to use orthoses.

Although orthoses are being used in social situations by most informants, several reasons for not using orthoses in social settings were addressed. Some experience the AFO as too visible and experience the attention they get from others regarding the AFO as unpleasant. Further, some experienced the AFO as too time-consuming, resulting in not being able to keep up with their peers. These challenges result in decreased use of orthoses and possibly reduced participation due to gait function, balance and energy expenditure being negatively affected. Indeed, the visibility creates unwanted attention and an increased focus on orthoses. Several children mentioned that attention and questions about the orthosis were experienced as unpleasant and somewhat dreadful. This leads to reduced use of orthoses in social situations, which negatively affects participation. Unwanted and increased attention regarding orthoses contributes to children being more conscious of how they appear to their friends. Hence, visibility may become a barrier to using orthoses in social situations. Respectively this mainly regards the AFO.

5 Discussion

This project aimed to achieve knowledge on how children with CP experience the use of orthoses in different activities and situations and address if orthoses contribute to or inhibit activity and participation. This knowledge was achieved by answering the research question: How do children with CP experience the use of orthoses in different activities and social situations?

Findings from the current study indicate that informants experience orthoses to contribute to activity and participation in gait-related activities. This is mainly due to improved gait function, balance, and energy efficiency when walking. Furthermore, informants experienced AFO respectively to inhibit activity and participation in activities demanding transitional movements, for instance, when playing football. In contrast, this was not the case for electrical orthoses. Additionally, the orthoses visibility was experienced as a barrier for several informants, leading to less use of orthoses.

5.1 Orthoses in Activity and Participation

Orthoses were experienced contributing to activity and participation in gait-related activities due to improved gait function, balance, and energy efficiency. Informants in the current study had a high frequency of orthosis use at school in total; seven out of eight used orthoses at school. The improved gait function was experienced as peculiarly helpful in school due to informants reported to be walking more at school than in other daily situations. The fact informants encounters the orthoses to be beneficial in school may indicate orthoses contribute to increased energy and concentration in learning activities, resulting in improved learning. This is only an assumption, and further research in the field is needed to conclude this assumption. However, findings showing a high frequency of assistive device use in school are consistent with previous research. Huang et al. (2009) stated that children desired to use devices at school to enable participation in school activities, keeping up with peers, and being independent (Huang et al., 2009). Findings from the current project and previous studies suggest that orthoses contribute to increased activity and participation in school and other gait-related activities due to improved bodily functions (gait function, balance, and energy efficiency). Lastly, the findings are consistent with previous research (Eddison et al., 2020, Firouzeh et al., 2021, Huang et al., 2009) and, therefore, not surprising.

AFOs were experienced as challenging to use in vigorous activities, resulting in activity and participation limitations due to the perception of stiffness and not fitting in football shoes and shin guards. Most of the experienced challenges regarding the use of AFOs are placed in the environmental aspect of the ICF model. Which respectively concern the practical issues with the AFO. In addition, AFO being experienced as challenging to match with different types of shoes is a known barrier and stated by several studies (Bulley et al., 2011; Ribeiro Volpini Lana, 2021). Moreover, the experienced stiffness affects the body function and body structure, resulting in decreased range of motion in the ankle joint.

The orthopaedic goals with orthoses are as mentioned 1) to prevent misalignment, 2) to support the ankle joint, 3) to prevent contractures in muscles, and 4) to improve gait function (Totah et al., 2019, Øien et al., 2016). The three first goals positively affect body functions and structures by preventing misalignment and contractures and supporting the ankle joint. Conversely, they additionally contribute to activity and participation limitations due to decreased range of motion in the ankle joint (Morris et al., 2002). This is consistent with findings from the current study, suggesting the AFO contributes to increased activity and participation in gait-related activities and inhibits activity and participation in vigorous

activities demanding transitional movements. Even though the prevention of secondary impairments and maintenance of gait function is of great importance, this may not be enough for children wanting to participate in activities with their friends. Additionally, a study conducted by Ireno et al. (2019) stated that 50% of the participants experienced orthoses to inhibit activity and participation in leisure time activities and play. Limited participation is shown to result in long-lasting intellectual, emotional, and interpersonal challenges (Eccles, 1999). Due to the documented importance of the involvement in childhood, previous studies, and findings from the current project, these findings should be of interest to orthopaedics making and prescribing orthoses (Eccles, 1999). Nonetheless, fulfilling all expectations a child may have to the orthoses seems somewhat difficult. Especially when one type of orthosis is supposed to work in all situations throughout the day. Resulting in less participation in vigorous activities or poorer conditions to execute the activities.

Informants in the current project experienced AFO as a burden in vigorous activities. In comparison, this was not the case for electrical orthoses, as they were preferred in such activities. These findings show a tendency of electrical orthoses to increase activity and participation in vigorous activities compared to the AFO. Previously research suggests electrical orthoses to improve gait velocity and energy efficiency and therefore is considered a good alternative to the use of AFOs (Laurent et al., 2009; Bosch et al., 2014). Nevertheless, electrical orthoses are not shown to advisably improve gait function compared to AFO (Bosch et al., 2014). Informants in this project preferred using electrical orthoses when playing football compared to those using AFO. This indicates a tendency of electrical orthoses to be more functional and contribute to increased participation and activity in vigorous activities compared to AFO. And it is likely to assume the increased range of motion in the ankle joint makes it easier to manoeuvre the ball with the electrical orthosis contra the AFO. However, this is only a tendency for this current study and more research on the orthoses functionality in activities and participation is needed.

5.2 Visibility and Identity

As mentioned earlier, the use and non-use of orthoses are likely to be affected by several reasons. Eccles (1999) stressed the importance of developmental changes occurring when the children are between six- and fourteen years old. Suggesting experiences in school and leisure-time activities significantly affect how identity, self-concept, and success are developed in this age group (Eccles, 1999). Additionally, Traustadóttir et al. (2015) emphasised the importance of the body when creating an identity, especially in disabled children. Increased focus on body appearance makes children with disabilities more aware of bodily deviations/differences from their friends and peers and other individual's perception of their body appearance (Traustadóttir et al., 2015). For children with CP and a low GMFCS level, one of the most visible differences is the use of orthoses, particularly the use of AFOs. Individuals using any type of assistive device usually identify the device as a part of themselves due to being attached directly to the body and often seen as an extended part of the body (Huang et al., 2009). Consequently, children with CP may identify themselves as different from their peers due to the use of a visible orthosis attached to their bodies.

Findings suggest AFO results in more activity and participation limitations than electrical orthoses due to aesthetics. The main reason for several informants to switch from using AFOs to electrical orthoses was based on dissatisfaction with the AFO's aesthetics and visibility. These findings were somewhat surprising. According to our knowledge, it was assumed that several of the informants would report pain and bodily limitations to be the

main reasons for switching from AFO to electrical orthoses. However, previous studies have stated that individuals using electrical orthoses are more satisfied with the aesthetics than those wearing AFOs (Bosch et al., 2014). Despite this, the visibility significantly impacted the total use of orthoses in informants in the current project. Children choosing to not use orthoses in activities due to the use contributing to activity- and participation limitations is somewhat natural. However, children choosing not to use orthoses due to aesthetics and visibility are findings of interest. Meaning children would rather have poorer conditions to perform activities than use a visible orthosis. These findings emphasise that orthoses contribute to children feeling different from their friends due to visible bodily differences.

Informants in the current study and other studies have reported that some experience the attention that comes with the use of orthoses to be unwanted and, in some cases, unpleasant (Traustadóttir et al., 2015). Increased attention to the orthoses can lead to children using orthoses to become more aware of their bodily differences, resulting in the feeling of being different. Previous studies have shown that even though the use of devices results in unwanted attention, it also enhances their performance, which was seen as preferable (Scherer, 2000; Huang et al., 2009). These findings are somewhat consistent with the current project. Several informants reported that they experienced questions about the orthoses as unwanted. On the other hand, this did not directly lead to non-use of orthoses but was experienced as a negative consequence due to the orthoses visibility.

5.3 Considerations

Even though there are limitations to this study, several strengths are additionally worth considering. As mentioned, Firouzeh et al., 2021 stated the need for qualitative research, including children. Consequently, the current project gives children with CP the chance to share their experiences with the use of orthoses in different situations. Receiving knowledge directly from children is advantageous since they have more information about the use of orthoses than parents and orthopaedics prescribing orthoses. Due to

from children using orthoses is advantageous since no one has the information and knowledge they have. In addition, the current project lets the children speak their minds and receive their experiences seriously. This information is essential for therapists and orthopaedics prescribing orthoses to understand children's needs better. Moreover, this project provides additional knowledge about the use of orthoses in activity and participation, which is vital due to the lack of research in this field (Firouzeh et al., 2021).

Children performing the interviews without their parents being present in the same room were experienced as positive and considered a strength of the project. Another strength to consider in this project is that the same person conducted all the interviews. This is a strength due to all interviews being conducted similarly, meaning the richness of the interviews was approximately the same.

One of the more considerable limitations of this project is the missing attention and questions regarding the electrical orthoses in the interviews. This skewed attention distribution happened because the project was planned to debate the use of AFOs respectively and not the electrical orthoses. Therefore, the interview guide was designed only to achieve knowledge of how the use of AFOs is experienced in different activities and situations. Further, it was shown challenging to recruit enough children through the recruitment process if inclusion criteria only allowed the present use of AFO. Mainly due to a limited time frame to conduct this project. Even though all included children presently- or previously used AFO, four out of eight had exchanged their AFO with electrical orthoses.

Hence, an interview guide involving questions about AFO and electrical orthoses would improve understanding of the use pattern.

Several researchers have discussed the sample size in qualitative studies. Factors such as 1) the aim of the project, 2) the specificity of the sample, 3) the theoretical background on the theme, 4) the quality of dialogue, and 5) the analysis strategy are factors to consider when determining desired sample size to reach saturation (Malterud et al., 2016; Sim et al., 2018). Due to the current project being a project with high specificity of the sample and in-depth interviews that contribute to rich and informal dialogues, the sample size (n=16) was considered to reach saturation. In addition, included sample size enables a thorough review of each interview, resulting in more attention directed towards each interview. Even though the first interviews were fairly characterised by missing experience with conducting interviews, all informants (both children and parents) answered all questions, and all interviews were rich enough to be included in the analysis and findings. Further, fourteen out of sixteen interviews were conducted physically. The two last interviews were conducted digitally over Zoom due to the Covid-19 pandemic. However, the quality of the interviews was not affected by the digital format.

Furthermore, the fact that children in the current project reported several experienced challenges regarding the use of orthoses than positive experiences could be explained by the children's GMFCS level. All children had GMFCS level I, which involves the less severe impairments. Meaning they can walk both inside and outside without huge complications (Palisano et al., 1997). The negative experiences may appear more noticeably than the positive due to these children's low magnitude of disabilities. Included children were able to perform leisure time activities such as football and handball, where respectively the AFO was experienced as too stiff and therefore inhibiting activity and participation. However, children with higher GMFCS levels and a higher magnitude of disabilities/impairments may find the orthoses more helpful than children in the current project.

6 Conclusion

Orthoses were experienced as facilitators for activity and participation in gait-related activities due to improved bodily functions. However, AFOs are experienced to result in activity- and participation limitations in vigorous activities with transitional movements and social activities due to experienced stiffness and aesthetics. Therefore, findings suggest that children's expectations are difficult to fulfil with just one orthosis, meaning there is a need for different orthoses in different situations.

6.2 Future Directions

Most existing literature investigating orthoses concerns the orthoses' impact on gait function and other gross motor functions (Firouzeh et al., 2021). However, research investigating the comparison of use patterns in AFOs and electrical orthoses is needed to achieve an improved understanding of how different types of orthoses work in different situations. Furthermore, studies on how orthoses are experienced in activity and participation in activities with higher demands are important. Increased knowledge in these fields establishes an improved base of evidence for therapists prescribing orthoses by contributing to an enhanced understanding of children's needs.

Reference List

Andersen, G. L., Hollung, S. J., Vik, T. (2018). Cerebral pareseregisteret i Norge - Årsrapport for 2018 med plan for forbedringstiltak. Retrieved from: https://oslo-universitetssykehus.no/seksjonavdeling/Documents/CPOP%20%C3%A5rsrapport%20med%20CPRN%202018.pdf

Andersen, G. L., Irgens, L. M., Haagaas, I., Skranes, J. S., Meberg, A. E., & Vik, T. (2008). Cerebral palsy in Norway: Prevalence, subtypes and severity. *European Journal of Paediatric Neurology, 12*(1), 4-13. doi:https://doi.org/10.1016/j.ejpn.2007.05.001

Baxter, P., Morris, C., Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., ... & Brien, G. O. (2007). The definition and classification of cerebral palsy. *Dev Med Child Neurol*, *49*(s109), 1-44. DOI: 10.1111/j.1469-8749.2007.00001.x

Bosch, P. R., Harris, J. E., & Wing, K. (2014). Review of therapeutic electrical stimulation for dorsiflexion assist and orthotic substitution from the American Congress of Rehabilitation Medicine stroke movement interventions subcommittee. *Archives of physical medicine and rehabilitation*, *95*(2), 390-396. https://doi.org/10.1016/j.apmr.2013.10.017

Eccles, J. S. (1999). The Development of Children Ages 6 to 14. *The Future of Children*, *9*(2), 30–44. https://doi.org/10.2307/1602703

Eddison, N., Healy, A., Chockalingam, N. (2020). Dose User Perception Affect Adherence when Wearing Biomechanically Optimised Ankle Foot Orthosis – Footwear Combinations: A Pilot Study. Foot (Edinb). Doi: 10.1016/j.foot.2019.101655

Firouzeh, P., Sonnenberg, L. K., Morris, C., & Pritchard-Wiart, L. (2021). Ankle foot orthoses for young children with cerebral palsy: a scoping review. *Disability and rehabilitation, 43*(5), 726-738. doi:10.1080/09638288.2019.1631394

Holder, M. D., Coleman, B., & Sehn, Z. L. (2009). The contribution of active and passive leisure to children's well-being. *Journal of health psychology*, *14*(3), 378-386.

Holtkamp, F. C., Wouters, E. J. M., van Hoof, J., van Zaalen, Y., Verkerk, M. J. (2015). Use of and Satisfaction with Ankle Foot Orthoses. Clinical Research on Foot & Ankle. 3:1. Doi:10.4172/2329.910X.1000167

Huang, I. C., Sugden, D., Beveridge, S. (2009). Assistive devices and cerebral palsy: factors influencing the use of assistive devices at home by children with cerebral palsy. Child: care, health and development, 35(1), 130-139.Doi:10.1111/j.1365-2214.2008.00898.

Huang, I. C., Sugden, D., & Beveridge, S. (2009). Assistive devices and cerebral palsy: the use of assistive devices at school by children with cerebral palsy. *Child: care, health and development*, *35*(5), 698-708. https://doi.org/10.1111/j.1365-2214.2009.00968.x

Ireno, J. M., Chen, N., Zafani, M. D., & Baleotti, L. R. (2019). The use of orthoses in children with cerebral palsy: perception of caregivers. *Cadernos Brasileiros de Terapia Ocupacional*, *27*, 35-44. https://doi.org/10.4322/2526-8910.ctoAO1612

Kathleen A. Martin Ginis, Jasmin K. Ma, Amy E. Latimer-Cheung & James H. Rimmer (2016) A systematic review of review articles addressing factors related to physical activity participation among children and adults with physical disabilities,

Health Psychology Review, 10:4, 478-494, DOI: 10.1080/17437199.2016.1198240

King, G., Law, M., Hanna, S., King, S., Hurley, P., Rosenbaum, P., ... & Petrenchik, T. (2006). Predictors of the leisure and recreation participation of children with physical disabilities: a structural equation modeling analysis. *Children's Health Care*, *35*(3), 209-234. https://doi.org/10.1207/s15326888chc3503_2

Morris, C. (2002). Orthotic management of children with cerebral palsy. *JPO: Journal of Prosthetics and Orthotics*, *14*(4), 150-158.

Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E., & Galuppi, B. (1997). Gross motor function classification system for cerebral palsy. Dev Med Child Neurol, 39(4), 214-23.

Ribeiro Volpini Lana, M., Pimenta Maia, J., Horta, A. A., Teixeira da Fonseca, S., & Guimaraes Assis, M. (2021). 'What if it were like this?'Perception of mothers of children with cerebral palsy about the ankle-foot orthosis of their children: A qualitative study. *Child: Care, Health and Development*, *47*(2), 252-260.

Rimmer, J. H. (2006). Use of the ICF in identifying factors that impact participation in physical activity/rehabilitation among people with disabilities. *Disability and rehabilitation*, *28*(17), 1087-1095. DOI: 10.1080/09638280500493860

Ring, H., Treger, I., Gruendlinger, L., & Hausdorff, J. M. (2009). Neuroprosthesis for footdrop compared with an ankle-foot orthosis: effects on postural control during walking. *Journal of stroke and cerebrovascular diseases*, *18*(1), 41-47.

Sim, J., Saunders, B., Waterfield, J., & Kingstone, T. (2018). Can sample size in qualitative research be determined a priori?. *International Journal of Social Research Methodology*, *21*(5), 619-634.

Shields, N., Synnot, A. Perceived barriers and facilitators to participation in physical activity for children with disability: a qualitative study. *BMC Pediatr* **16,** 9 (2016). https://doi.org/10.1186/s12887-016-0544-7

Tjora, A. (2018). Qualitative Research as Stepwise-Deductive Induction (1st ed.). Routledge. https://doi.org/10.4324/9780203730072

Totah, D., Menon, M., Jones- Hershinow, C., Barton, K., Gates, D. H. (2019). The Impact of Ankle-Foot Orthosis Stiffness on Gait: A Systematic Literature Review. Gait & Posture. 69:101- 111. Doi:10.1016/j-gaitpost.2019.01.020

Traustadóttir, R., Ytterhus, B., Egilson, S., & Berg, B. (Eds.). (2015). *Childhood and disability in the Nordic countries: Being, becoming, belonging*. Springer.

Wingstrand, M., Hägglund, G., Rodby-Bousquet, E. (2014). Ankle-foot orthoses in children with cerebral palsy: a cross sectional population based study of 2200 children. BMC Musculoskelet Disord, 15, 327, Doi:10.1186/1471-2474-15-327

World Health Organization. (2007). *International Classification of Functioning, Disability, and Health: Children & Youth Version: ICF-CY*. World Health Organization.

World Health Organization. (2021). WHO policy on disability.

Øien, I., Fallang, B., & Østensjø, S. (2016). Everyday use of assistive technology devices in school settings. *Disability and Rehabilitation: Assistive Technology*, *11*(8), 630-635.

Appendix 1 – Interview Guide Children

Starter med å bli litt kjent med barnet og forsikre meg om at han/hun skjønner hva vi skal gjøre sammen og hvorfor. Altså starter med å trygge barnet og å gjenta informasjon om prosjektet, og forklare gangen i intervjuet.

Kan du fortelle meg litt om hva du liker å gjøre en helt vanlig dag?
- Kan du fortelle litt om hva det er du liker med å gjøre dette?
- Bruker du skinnen din når du gjør dette?
- Hvordan er det for deg å bruke skinnen når du gjør dette?
- Er det noe du må gjøre sånn til vanlig som du ikke liker å gjøre?
- Kan du fortelle meg litt om det?
- Kan du fortelle meg litt om skinnen din? - Hvorfor må du bruke skinne på foten?
- Hva synes du om å bruke skinne på foten?

Bruker du skinnen din når du er på skolen?
- Kan du fortelle meg om hvordan det er?
- Liker du å bruke skinnen?
- Hva er det du liker og/eller ikke liker? -Kan du fortelle meg litt mer om det?
- Når bruker du skinnen? - Er dette ofte, eller bare av og til?
- Hvordan er det å bruke skinnen da/der? - Hva er det som er bra/ikke bra?

Bruker du skinnen din hjemme?
- Kan du fortelle meg om hvordan det er?
- Liker du å bruke skinnen?
- Hva er det du liker? /ikke liker? - Kan du fortelle meg litt mer om det?
- Når bruker du skinnen? - Er dette ofte, eller bare av og til?
- Hvordan er det å bruke skinnen da/der? - Hva er det som er bra/ikke bra?

Bruker du skinnen din når du er på fritidsaktiviteter?
- Kan du fortelle meg om hvordan det er?
- Liker du å bruke skinnen?
- Hva er det du liker/ ikke liker? - Kan du fortelle litt mer om det?
- Når bruker du skinnen din på fritiden? - Er dette ofte, eller bare av og til
- Hvordan er det å bruke skinnen når du gjør dette? - Hva er det som er bra/ikke bra?

Bruker du skinnen din når du er sammen med venner?
- Kan du fortelle meg om hvordan det er?
- Liker du å bruke skinnen?
- Hva er det du liker? /ikke liker? - Kan du fortelle meg litt mer om det?
- Når bruker du skinnen? - Er dette ofte, eller bare av og til?
- Hvordan er det å bruke skinnen da/der? - Hva er det som er bra/ikke bra?

Hvis du kunne bestemme helt selv;
- Når/i hvilke situasjoner hadde du brukt skinnen din?
- Ville du helst hatt den skinnen du har nå, en annen type skinne, eller ingen skinne i det hele tatt?
- Hva slags skinne og/eller sko ønsker du å ha?

Er det noe annet du har lyst å fortelle meg?
Er det noe du har lyst å spørre meg om?

Tusen takk for at du hadde muligheter til å delta og at jeg fikk snakke med deg om dette! 😉

Appendix 2 – Interview Guide Parents

Starter med å bli litt kjent, gi informasjonen om prosjektet, og forklarer gangen i intervjuet. Viktig å være sikker på at informantene forstår hva som skal foregå og hvorfor.

Kan du fortelle om informasjonen du har fått om bruk av ortoser?
-Hvordan synes du at denne informasjonen var? (Tilstrekkelig? Forståelig? Hensiktsmessig?)
-Husker du hvor og av hvem du først fikk denne informasjonen fra?
-Er det informasjon du/dere ønsker mer eller mindre av?
-Var informasjonen rettet mot dere som foreldre, eller også mot barnet?
-Hva synes du om det? -Hva kunne vært annerledes tenker du?
-Kom informasjonen på et passende tidspunkt? -Hva ville vært passende for dere?

Kan du fortelle noe om hvem som har bestemt at barnet skulle ha denne ortosen han/hun bruker?
-Har barnet hatt medbestemmelse?
-Har dere som foreldre hatt medbestemmelse?

Kan du fortelle noe om hvilke fysiske aktiviteter barnet gjør?
-Er det noe barnet strever spesielt med eller mestrer spesielt godt?
-Hva slags aktiviteter liker barnet å drive på med?
-Er det noe barnet skulle ønske han/hun kunne gjøre bedre?

Kan du fortelle litt om hvordan det er å motivere barnet ditt for å bruke ortosen?
-Er bruk av ortoser blitt en naturlig del av hverdagslivet? -Kan du fortelle om det?
-Hva tenker du bidrar til at det er blitt en naturlig del/ikke blitt en naturlig del av hverdagslivet?
-Hva er vanskeligst med bruken av ortoser, synes du?
-Hva tror du barnet ditt synes er det vanskeligste?
-Hva ser du at ortosene hjelper barnet ditt med? -Kan du fortelle litt hvordan dette skjer?

Kan du fortelle litt om hvordan du opplever det at barnet ditt må bruke ortoser?
-Synes du at det er til god hjelp for barnet ditt, i lek og aktivitet? -På hvilken måte?
-Synes du at det er til hinder for barnet ditt i lek og aktivitet? -På hvilken måte?
-Har du sett noen endring i barnets lek og aktivitet etter at han/hun begynte å bruke ortoser?
-På hvilken måte?

Kan du fortelle litt om hvordan du tror barnet ditt opplever å bruke ortoser?
-Hva tror du at barnet ditt forstår av hvorfor han/hun må bruke ortoser?
-Hvordan er dette blitt forklart for barnet?
-Hvordan tenker du at det best mulig kunne blitt forklart?
-Hva tror du er viktig for barnet ditt akkurat nå?

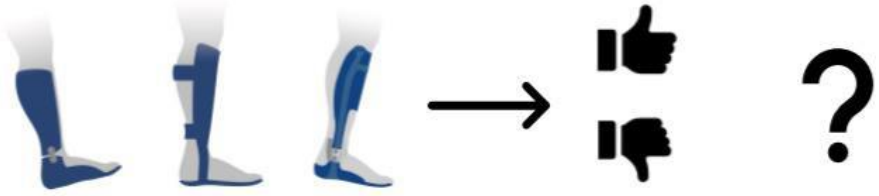
Er det noe annet du har lyst å fortelle meg?
Er det noe du har lyst å spørre meg om?

Tusen takk for at du hadde mulighet til å delta og at jeg fikk snakke med deg om dette! ☺

Appendix 3

Informasjonsskriv til barn

om deltakelse i et forskningsprosjekt til å finne ut:



Hvor bra fungerer dine ankelskinner i ulike aktiviteter?

Hensikten med prosjektet er å finne ut om ankelskinner gjør det lettere for deg å være med på hverdags- og fritidsaktiviteter, og sosiale aktiviteter sammen med vennene dine.

Hvorfor blir du spurt om å være med?

Du er barn i barneskolealder og har fått en ankelskinne på et ortopedisk verksted. Vi ønsker derfor å spørre deg litt om hvordan du synes det er å bruke skinnen, og å prøve ut noen fysiske tester med og uten skinne. Ved å delta i denne undersøkelsen, vil du være med å bidra til at andre barn som også bruker skinner skal kunne få skinner som fungerer bra og er bedre tilpasset aktiviteter som er viktige for den enkelte.

Hva vil skje dersom du deltar?

Dersom du ønsker å delta, vil du bli spurt om å gjennomføre åtte øvelser og ønsker vi å kunne spørre både deg og dine foreldre noen spørsmål rundt bruken av skinne.

- Du blir spurt om å gjennomføre åtte øvelser, som inkluderer gange, hopping, løping, bevege deg fra sittende til stående og gå i trapper.
- Disse øvelsene skal gjennomføres både med og uten skinne.
- Til sammen vil dette ta ca en halvtime.

- Vi ønsker å spørre både deg og dine foreldre noen spørsmål rundt bruken av skinne. Hvordan du bruker skinnen, og hvordan du opplever å bruke skinner i forskjellige situasjoner (som f.eks. hjemme, på skolen,på fritidsaktiviteter og blant venner).
- Intervjuet vil ta ca en halvtime og det er ønskelig at du gjennomfører intervjuet uten at dine foreldre er til stede.

Totalt vil fysiske tester og intervju med deg og intervju med dine foreldre ta maksimalt en og en halv time, medregnet pauser. Deltakelse i prosjektet er selvfølgelig frivillig, og du kan trekke deg fra studiet når som helst. Hvis du kun ønsker å delta på en av delene, er det også greit.

Om du er med i denne undersøkelsen, noterer vi oss om du bruker skinne på høyre eller venstre sideog om du har operert i foten eller fått sprøyte for spasmer.

Hva vil skje dersom du ikke deltar

Det er frivillig å delta i studiet. Dersom du ikke deltar, har det ingen konsekvenser for deg. Du får din vanlige time hos verkstedet og bruker din ortose som vanlig.

Dersom du ønsker å være med kan du og dine foreldre si ifra, så vil du få et brev med invitasjon til undersøkelsen. Om du sier ja til å delta nå, kan du når som helst senere ombestemme deg uten å angi noen grunn for det. Dersom du har spørsmål til studiet, kan du kontakte:

Kristin Lie, tlf.: 917 96 981, e-post: klie@ntnu.no

Johan Gravdal, tlf.: 995 68 671, e-post: johagra@ntnu.no

Karin Roeleveld, tlf.: 481 77 279, e-post: karin.roeleveld@ntnu.no

Appendix 4

Vil du delta i forskningsprosjektet

Ankel-fot ortoser for aktivitet og deltakelse hos barn med Cerebral Parese

Formålet med prosjektet og hvorfor du blir spurt

I samråd med deg og ortopeden har ditt barn fått henvisning for tilpasning av ankel-fot ortoser ved et ortopedisk verksted. Vi vil i den anledning spørre dere som foreldre om dere vil la barnet deres delta og vil delta selv i et forskningsprosjekt. Hensikten med prosjektet er 1) å finne ut om hvordan bruken av ortoser påvirker forskjellige fysiske aktiviteter, 2) undersøke opplevelsen barn og foreldre har av bruken av ortoser, og 3) å finne ut hvordan ortosen påvirker barnets aktivitet og deltakelse.

Til tross for at ortoser brukes av mange barn og unge med CP over hele landet er det mye vi ikke vet om effekten av bruken i aktivitet, annet enn observasjon av gange på klinikken. Siden aktivitet inkluderer andre bevegelser enn bare gange, ønsker vi å gjøre en vurdering av hvordan ortosene påvirker aktiviteter slik som løping, hopping, trappegåing og vendinger. Vi ønsker også å tilegne oss kunnskap om motiverende og begrensende faktorer for bruk av ortoser.

Ved å finne svar på spørsmålene vil det bli enklere for andre barn og unge å få tilpasset ortoser som fungerer vel og er bedre tilpasset aktiviteter som er viktig for den enkelte. Vi ønsker derfor å gjennomføre et forskningsprosjekt som skal finne svar på disse spørsmålene.

Hva innebærer prosjektet for dere?

Dersom dere er villig til å delta i forskningsprosjektet, avtaler vi et møte enten hjemme hos dere, på skolen eller en dag dere har en avtale på et ortopedisk verksted. Barnet vil bli spurt om å gjennomføre forskjellige øvelser og både foreldre og barnet blir spurt om å delta i et intervju.

De forskjellige øvelser (ca. åtte) inkluderer gange, hopping, sprint, løping med vendinger, bevege seg fra sittende til stående og trappegang. Disse øvelsene skal gjennomføres to ganger, både med og uten ortosen. Barnet vil få pauser imellom testene og du/dere kan være til stede hvis det er ønskelig. Dette vil det ta cirka 30 minutt.

I intervjudelen blir både barn
og foreldre intervjuet, og det er ønskelig at intervju med barna blir gjennomført uten at dere som foreldre er til stede. Dette for å unngå at deres tilstedeværelse påvirker barnas svar. Hvert av intervjuene vil vare cirka 30 minutt, og intervjuet med dere foreldre kan gjennomføres mens barnet gjennomfører testene. Dersom dere kun ønsker å delta på delen hvor barnet gjennomfører testene, er det også helt greit.

Alle testene samt intervjuene vil ta omtrent 1,5 timer til sammen. Deltakelse innebærer også at vi noterer kjønn og alder og henter opplysninger om og CP-diagnose og tidligere behandling fra pasientjournalen (kun informasjon om eventuelt botox injeksjoner og ortopedisk kirurgi i nedre ekstremiteter).

Selv om forskningsprosjektet består av både fysiske tester og intervju er det ikke gitt at alle skal delta på alt. Noen får tilbud om tester og intervju, mens andre får tilbud om kun tester. Dette fordi vi trenger færre deltakere på intervju-delen til å kunne få svar på spørsmålene.

Mulige fordeler og ulemper

Deltakelse vil innebære noe tidsbruk i forbindelse med undersøkelsene. Ingen av testene i studien vil være over normal fysisk påkjenning. Testene har blitt gjennomført på jevnaldrende barn tidligere. Dersom vi oppdager at det kan være aktuelt med en annen type AFO kan vi henvise deg til ortopedisk verksted eller til ortopeden på sykehuset for ny vurdering. Mindre justeringer kan vi gjøre mens dere er hos oss.

Frivillig deltakelse og mulighet for å trekke ditt samtykke

Det er frivillig å delta i prosjektet. Dersom dere ønsker å la barnet delta, undertegner dere samtykkeerklæringen på siste side. Dere kan når som helst og uten å oppgi noen grunn trekke deres samtykke. Dette vil ikke få konsekvenser videre. Dersom dere trekker tilbake samtykket, vil det ikke forskes videre på barnets helseopplysninger. Dere kan kreve innsyn i opplysningene som er lagret om barnet, og opplysningene vil da utleveres innen 30 dager. Dere kan også kreve at barnets helseopplysninger i prosjektet slettes. Adgangen til å kreve destruksjon, sletting eller utlevering gjelder ikke dersom opplysningene er anonymisert eller publisert. Denne adgangen kan også begrenses dersom opplysningene er inngått i utførte analyser.

Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte prosjektleder (se kontaktinformasjon på siste side).

Hva skjer med opplysningene om deg og barnet?

Opplysningene som registreres om barnet skal kun brukes slik som beskrevet under formålet med prosjektet, og planlegges brukt til 31.12.2023. Eventuelle utvidelser i bruk og oppbevaringstid kan kun skje etter godkjenning fra REK og andre relevante myndigheter. Dere har rett til innsyn i hvilke opplysninger som er registrert om barnet og rett til å få korrigert eventuelle feil i de opplysningene som er registrert. Dere har også rett til å få innsyn i sikkerhetstiltakene ved behandling av opplysningene. Dere kan klage på behandlingen av barnets opplysninger til Datatilsynet og institusjonen sitt personvernombud.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger (=kodede opplysninger). En kode knytter barnet til dets opplysninger gjennom en navneliste. Det er kun Kristin Lie, Johan Gravdal og Karin Roeleveld som har tilgang til denne listen.

Det vil ikke være mulig å identifisere deg eller barnet i resultatene av studien når disse publiseres. Publisering av resultater er en nødvendig del av forskningsprosessen. All publisering skal gjøres slik at individuelle deltakere ikke kan gjenkjennes.

Opplysningene om deg og barnet vil bli oppbevart i fem år etter prosjektslutt av kontrollhensyn. Opplysningene vil bli anonymisert eller slettet fem år etter prosjektslutt.

Deling av opplysninger og overføring til utlandet

Ved å delta i prosjektet, samtykker du også til at kodede opplysninger fra testene og sammendrag avintervju på engelsk kan overføres til utlandet (innenfor EU) som ledd i forskningssamarbeid og publisering i tråd med formålet angitt innledningsvis. Prosjektleder vil sikre at dine opplysninger blir ivaretatt. Koden som knytter deg til dine personidentifiserbare opplysninger vil ikke bli utlevert.

Forsikring

Deltakere er forsikret gjennom pasientskadeloven.

Smittevern

Vi forholder oss til smittevernstiltakene fra fhi som gjelder ved gitt tidspunkt for gjennomføring av prosjektet. Det vil kun være Kristin Lie og Johan Gravdal som er til stede ved datainnsamling. Vi påser at vi kan holde avstand og at desinfeksjon av hender og overflater vil bli gjennomført for å forhindre eventuell smittespredning. Dersom det er ønskelig, kan det avtales at vi bruker munnbind gjennom hele gjennomføringen og tar hurtigtest i forkant.

Økonomi

Det vil bli utbetalt 250 kr. som en kompensasjon for avsatt tid til deltakelse.

Godkjenninger

Regional komité for medisinsk og helsefaglig forskningsetikk har gjort en forskningsetisk vurdering og godkjent prosjektet (#283727).

NTNU og prosjektleder Karin Roeleveld er ansvarlig for personvernet i prosjektet.

Vi behandler opplysningene basert på rettslig grunnlag i EUs personvernforordning artikkel 6 nr. 1a og artikkel 9 nr. 2a og ditt samtykke. Du har rett til å klage på behandlingen av dine opplysninger til Datatilsynet.

Kontaktopplysninger

Dersom du har spørsmål til prosjektet eller ønsker å trekke deg fra deltakelse, kan du kontakte:

Kristin Lie, tlf.: 91796981, e-post: klie@ntnu.no

Johan Gravdal, tlf.: 99568671, e-post: johagra@ntnu.no

Karin Roeleveld, tlf.: 48177279, karin.roeleveld@ntnu.no

Dersom du har spørsmål om personvernet i prosjektet, kan du kontakte personvernombudet ved institusjonen, Thomas Helgesen, 93079038, thomas.helgesen@ntnu.no

SAMTYKKEERKLÆRING

Jeg har mottatt og forstått informasjon om prosjektet «Ankel-fot ortoser for aktivitet ogdeltakelse hos barn med cerebral parese >>, og har fått anledning til å stille spørsmål.

Som foresatte til_ _ _ _ _ _ _ _ _ _ _ _____(Fullt navn) samtykker vi til at hun/han kan
delta i prosjektet slik det er beskrevet i informasjonsskrivet

---

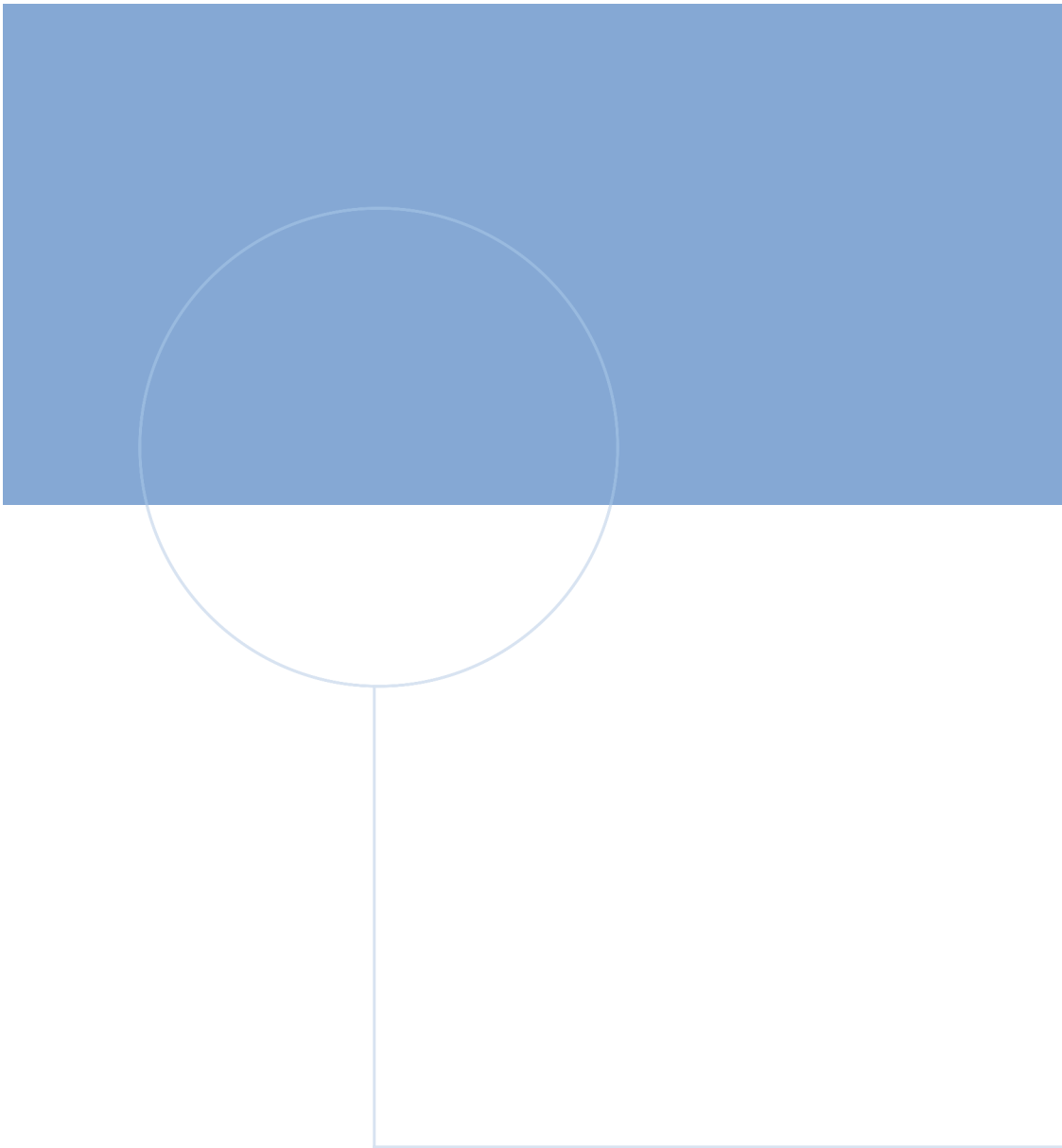
Sted og dato

Foresattes signatur

Foresattes navn med trykte bokstaver

Sted og dato

Foresattes signatur



NTNU

Kunnskap for en bedre verden