Walking with cerebral palsy

Task-specific strength training and reflections on daily walking in adults with cerebral palsy

Beate Eltarvåg Gjesdal

Thesis for the degree of Philosophiae Doctor (PhD)
University of Bergen, Norway
2022

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Date of defense: 10.06.2022

Year: 2022

Title: Walking with cerebral palsy

Name: Beate Eltarvåg Gjesdal

Print: Skipnes Kommunikasjon / University of Bergen

Scientific Environment

The work presented in this thesis has been conducted at the Western Norway University of Applied Sciences (HVL). The thesis was carried out within the institutional framework of the doctoral programme at the Faculty of Medicine, Department of Global Public Health and Primary Care, University of Bergen (UiB). The PhD project is anchored in the Multidisciplinary Research Group on Health, Sports, and Function (HVL). I also participated in the Research School in Public Health and Primary Care (UiB).

My principal supervisor was Silje Mæland, PhD (UiB), while Kristoffer Toldnes Cumming, PhD, Østfold University College, Cecilie Brekke Rygh, PhD (HVL) and Mona Kristin Aaslund, PhD (HVL) were cosupervisors.

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Preface

After completing a master's degree at the Norwegian School of Sport Science, I started working in the motion analysis lab at Sunnaas Hospital HF. Being part of their interdisciplinary lab team was rewarding and educational. I was particularly intrigued by the different motion analysis applications in sports performance and physical rehabilitation. For example, for adults with cerebral palsy, the recommendations were either surgery, botulinum toxin, or orthoses. Focused training to improve walking was not included in the recommendations. In contrast, athletes use motion analysis primarily to enhance performance through focused training.

This thesis is anchored in an interdisciplinary team consisting of physiotherapists, sports scientists, and physiologists. We targeted walking in adults with an interdisciplinary approach and discussed whether improving walking with strength training was realistic in adults with cerebral palsy. To approach the problem, we needed to know 'which' strength training to do, 'how' to perform it, and the rationale of 'why' we would do it. With my background as a movement scientist and teacher, it is common to set a goal and define a path to reach this goal and this way of thinking has become a part of my constitution. Further, the user perspective was thought to be essential for setting reachable goals and deciding the level of performance. Lastly, the complexity of walking might challenge our ability to generalize training since 'one-size-fits no one', but I wonder if there is a least common multiple.

Bergen 2022,

Beate Eltarvåg Gjesdal

Acknowledgements

Many people have contributed to completing this thesis, and they all deserve a warm thank you. First and foremost, I would like to express my sincere gratitude to all the participants that gave their time and effort when conducting the studies.

This thesis would not have been possible without my highly competent and committed supervisors. I am forever grateful for the wisdom you have shared and for everything I have learned from you. I hope that our friendship and collaboration will continue to grow in the future. Associate Professor Silje Mæland, thank you from the bottom of my heart for being the supervisor and person you are. Your ability to balance autonomy support with critical feedback has been encouraging, and thank you for not letting me drown in the learning pit. Associate Professor Cecilie Brekke Rygh, thank you for your valuable inputs on biomedical imaging, discussions, support, and guidance. Associate Professor Kristoffer Toldnes Cumming, thank you for your guidance and discussions on sports science and the most appreciated Friday coffee breaks. Associate Professor Mona Kristin Aaslund, thank you for the valuable clinical contribution to the interdisciplinary discussions and support. I would also like to thank the committee for their helpful revision feedback and the opportunity to work on the synopsis, which, in my opinion, improved it.

In addition, I thank the Western Norway University College (HVL) for employing me and the University of Bergen (UiB) for granting me entry into the Faculty of Medicine's PhD programme. A warm thank you to all the participants in my research group at HVL, the *Multidisciplinary research group on health, sports, and function,* for their excellent contributions throughout this project. Interdisciplinary collaboration occurs in this group. Like Elisabeth Ersvær and Line Wergeland, your enthusiasm encourages how to bring about interdisciplinary work. Also, a special thanks to my academic writing mentor, Bård Bogen. You have the ability to inspire when words become demanding. Thank you, Lars Peder Vatshelle Bovim, for your input, for discussing lab work, for your collaboration and support. Thank you for your statistical guidance, Professor Roy Miodini Nilsen. And a warm thank you for reading and commenting on my final (final) draft of my synopsis, Maria Nordheim Alme.

This PhD involved two master's students. Thank you for your effort and sincere interest, Vilde Cathrine Nesse and Silje Marie Rydningen Torberntsson in data collection and analysis. And also, a deep gratitude to all of the bachelor students who took part; Vegard Flister, Peter Husby, Ingvild Frostad Gulichsen, Martin Eidissen, Aleksander Solberg, Jonas Lund and John Bjørlo.

Many people have contributed, and my previous colleagues at Sunnaas Hospital HF have inspired me with the project and interdisciplinary work: Arve Opheim, Nana Lise Broch, Petra Ahlvin Nordby, and Linda Rennie. Professor Reidun Jahnsen, thank you for your contribution and your willingness to share your expertise. Thank you to all the BARN network members, in particular Teresa Brnic Gote, Katrine Jansen, and Merete Malt, for protocol guidance, and Kamilla Arnevik at Turbo for collaboration and discussions. Thank you for inviting us to your facilitation in Melbourne, Professor Gavin Williams. Your interdisciplinary team, which included physiotherapists and exercise physiologists, was remarkable. Thank you for the introductory guidance with the ultrasound equipment, Professor Olivier Seynnes, at the Norwegian School of Sports Science.

Thank you for writing the Python script on filtering data, Elise Klæbo Vonstad. Being part of your digital shut-up-and-write sessions with Gunhild Marie Lundberg and Madeleine Lorås, kept me going during a mostly locked-down PhD period. You are knowledgeable, structured, and great people, and the academic writing workshops were really appreciated. You motivated me to complete the thesis!

My dearest colleagues from HVL and fellow PhD candidates, thank you for being such wonderful and inspiring people: Ingvild Hernar, Lene Kristiansen, Unni Moen, Elisabeth Søiland, Trine-Lise D. Steinskog, Tonje Teigland, Silje Blindheim, Silwia

Kolasa, Anne Kristin Snibsøer, Kristine Berg Titlestad, and Thomas Potrebny. Merete Salveson Engeset and Susanne Grødem Johnsson, it was a pleasure to travel and write with you! And finally, my lovely PhD person from day 1 as a PhD student, Eline Skirnisdottir Vik, for your friendship, generosity, and wisdom. Furthermore, I would like to thank my bachelor programme in radiography colleagues, Head of Section Eli Eikefjord and Head of Department Bjørg Hafslund, for providing an inspirational work environment.

Thank you, NLA Høgskolen and Amund Langøy, for facilitating the completion of the thesis. Runar Eikhaug, Sigrun Norhagen Lindaas, Per Ivar Kjærgård and all my new colleagues, thank you for the inspirational work environment and your encouraging comments during the completion.

My daily 'sense of coherence persons' were Madeleine Tychesen Aksdal, Anne Lene Bakke Toppe, Aina Valdersnes, Silje Myking, and Gunnhild Nyhammer. Weekly runs, mountain hiking, and glasses of wine were particularly appreciated during the home-office pandemic. And to my girls from 'home' who cheered throughout, you know who you are – it meant a lot.

Above all, I thank my kind and supporting family. My parents for always believing in me and my grandparents for their unending love. Katrine and Anders Christensen, you are the brightest and kindest people, and I am fortunate to have you as friends and family. Thank you, Stella, and Bo, for not caring at all about what a PhD is. My parents' in-laws for kindness, babysitting, and support, and my closest in-laws' neighbours for helping hands. Most especially, thank you, dearest Vidar, for taking care of the family when I was only physically present and for the much-appreciated morning coffee in bed. I could never have done this without your support, for which I am forever grateful. Emma, it is time for shopping and Brage, let us catch some Pokémon.

Vidar, Guro, Halvor, Emma and Brage – you rock my world ♥

Abstract

Background: Adults with cerebral palsy (CP) have impaired walking, affecting their activity and participation in social life. Still, little is known about how walking is experienced as adults. Effective strength training to improve walking in CP is not established. Ballistic plantar flexor exercises are suggested as task-specific in strength training to improve walking but have not been studied in adults with CP. **Aims**: The main goal of this thesis was to explore walking in adults with CP, and the secondary goals were A) To explore daily walking in adults with CP from a subjective perspective and B) To explore whether ballistic strength training is feasible and improves walking and potential muscle adaptations. **Methods**: Subjective perspective of daily walking was explored with semi-structured interviews and analysed with systematic text condensation. The feasibility of eight weeks of supervised ballistic strength training of ankle plantar flexors was investigated with semi-structured interviews, physical performance, and self-reported outcome measures. Walking kinematics was assessed with three-dimensional gait analysis (3DGA), and muscle adaptations were evaluated with ultrasound and a dynamometer. **Results:** Intrinsic factors, such as reduced functional capacity and reduced balance and extrinsic environmental factors, such as walking anomalies attracting onlookers' attention and seasonal changes, were associated with daily walking. The participants could perform ballistic exercises on ankle plantar flexors after four weeks. Preferred walking speed increased in two of eight participants, decreased in one, and stayed unchanged for five participants. Five of six participants improved muscle strength, but muscle architecture remained unchanged. **Conclusion:** Daily walking was influenced by intrinsic embodied, and extrinsic environmental factors, and walking changes through adulthood calls for lifelong follow-up. Ballistic strength training of ankle plantar flexors was feasible and improved muscle strength in most participants, but walking kinematics and performance mainly remained unchanged. Ballistic strength training and physiological adaptation in spastic muscles need further investigation before the effects on walking can be determined. This conclusion is based on findings from underpowered studies.

Norwegian Summary

Bakgrunn: Voksne med cerebral parese (CP) har redusert gangfunksjon, som påvirker aktivitet og deltakelse. Likevel vet man lite om hvordan daglig gange og utfordringer knyttet til dette, oppleves som voksen. Til tross for redusert gangfunksjon er det ikke en etablert en treningsform som forbedrer gange. Oppgavespesifikk styrketrening av plantarfleksorene, f.eks. ballistiske øvelser, trener muskelen slik den brukes når man går, men er ikke undersøkt hos voksne med CP. **Hensikt:** Hovedmålet med denne doktorgraden var å utforske gangfunksjon hos voksne med CP, operasjonalisert i to undermål; A) Undersøke daglig gange hos voksne med CP fra et subjektivt perspektiv og B) Undersøke om ballistisk styrketrening er gjennomførbar, forbedrer gangfunksjon og potensiell muskulær adaptasjon. **Metode:** Subjektivt perspektiv på daglig gange ble undersøkt med semi-strukturerte intervjuer. Gjennomførbarheten av åtte uker med veiledet oppgave-spesifikk styrketrening ble undersøkt med semi-strukturerte intervjuer, fysiske og selvrapporterte utfallsmål. Gangkinematikk ble vurdert med tredimensjonal ganganalyse (3DGA), og potensiell muskel adaptasjon ble evaluert med ultralyd og dynamometer. **Resultater:** Selvopplevd gangfunksjon var påvirket av iboende faktorer, som redusert funksjonell kapasitet og forverret balanse. Ytre faktorer påvirket også, som at gangmønsteret tiltrekkes oppmerksomhet av forbipasserende, og ulike årstider kunne utfordre gangfunksjon. Den oppgavespesifikke treningen, de ballistiske øvelsene, kunne deltakerne utføre etter fire uker. Foretrukket ganghastighet økte hos to av åtte deltakere, reduserte hos én og var uendret for fem deltakere. Fem av seks deltakere forbedret muskelstyrken, men muskelarkitekturen forble uendret. **Konklusjon:** Daglig gange ble påvirket av iboende, og ytre faktorer hos voksne med CP, voksenlivet krever livslang oppfølging. Ballistisk styrketrening av ankel plantar fleksorer var gjennomførbart og forbedret muskelstyrken hos de fleste deltakerne, men gangkinematikk og fysiske utfallsmål forble hovedsakelig uendret. Fysiologisk tilpasning til ballistisk styrketrening i spastiske muskler trenger ytterligere undersøkelser før effekten på gange kan fastslås. Denne konklusjonen er basert på funn med lav statistisk styrke, og kan ikke si noe om effekt av treningen.

List of Publications

Gjesdal BE, Jahnsen R, Morgan P, Opheim A, Mæland S. Walking through life with cerebral palsy: reflections on daily walking by adults with cerebral palsy. International Journal of Qualitative Studies on Health and Well-being. 2020;15(1):1746577-1746577. doi:10.1080/17482631.2020.1746577

Gjesdal BE, Mæland S, Williams G, Aaslund MK, Rygh CB, Cumming KT. Can adults with cerebral palsy perform and benefit from ballistic strength training to improve walking outcomes? A mixed methods feasibility study. BMC Sports Science, Medicine and Rehabilitation. 2021;13(1). doi:10.1186/s13102-021-00382-1

Gjesdal, B.E., Mæland, S., Bogen, B., Cumming, K.T., Nesse, V.C., Torberntsson, S.M.R., and Rygh, C.B. Ballistic strength training in adults with cerebral palsy may increase rate of force development in plantar flexors, but transition to walking remains unclear.
(In second-round review for publication in BMC Sports Science, Medicine and Rehabilitation)

Contents

Abbreviations

3DGA	Three-dimensional gait analysis
CBR	Cecilie Brekke Rygh
CNS	Central nervous system
CoM	Centre of mass
CP	Cerebral palsy
FISSA	Fatigue Impact and Severity Self-Assessment
FL	Fascicle length
FunCap-CP	Functional capacity training for walking in adults with CP
HiMAT	High-Level Mobility Assessment Tool
ICF	International Classification of Functioning
MG	Medial gastrocnemius
MT	Muscle thickness
NPRS	Numeric Pain Rating Scale
PA	Pennation angle
PGIC	Patient global impression of change
REC West	Western Norway Regional Committees for Medical and Health Research Ethics
RFD	Rate of force development
RFD_{PF}	Plantar flexor rate of force development
RM	Repetition maximum
RTF	Rate of torque development
SI	International System of Units
SM	Silje Mæland
TD	Typical development
US	Ultrasound
$VO2_{max}$	Maximal oxygen consumption

Definition of Concepts

Ambulation	Synonym of 'walking'.
Ballistic exercise	Explosive movements that enable acceleration throughout the full range of motion.
Centre of mass	A hypothetical point where the mass of a body that moves in the same way that a particle subject to the same external forces would move (1).
Disability	An umbrella term for impairments, activity limitations, and participation restrictions (2).
Explosive strength	'Explosive' muscle strength or contractile rate of force development (RFD) is a term to describe the ability to rapidly develop muscular force (3).
Force	A vector quantity that describes the action of one body on another. The action may be direct, such as the foot pressing on the floor, or indirect, like the gravitational attraction between the body and the earth. Force can never be measured directly. It is always estimated, for example, by measuring the deflection of a spring under the action of a force (International System of Units (SI) – newton; N) (1).
Gait	Manner or style of walking.
Joule	SI unit of work for energy.
Locomotion	Movement or the ability to move from one place or another. It can refer to humans, vertebrates or invertebrate animals, and microorganisms.
Mobility	The ability to move oneself, either independently or using assistive devices.
Moment	The turning effect produced by force. Calculated as the product of the force and the perpendicular distance between the point of application of the force and the axis of rotation (SI unit: newton metres; Nm) (1).
Newton meter	NM; SI unit for moment/torque of force.

Plyometric	Explosive form of exercise with an eccentric phase before a concentric phase.
Power	The rate of doing work; is equal to the work done divided by the time during which the work is being done (SI unit: watt; W) (1).
Skill	The ability to do something well; expertise.
Stiffness	The ratio of stress to strain at any point in the elastic region of deformation. A higher modulus indicates stiffer material (1).
Strength training	All training to develop or sustain the ability to create most force at different muscle contraction speeds.
Strength training specificity	Physiological adaptations to strength training are determined by various factors, including muscle actions, speed of movement, range of motion, muscle groups trained, energy systems involved, intensity and volume of training (4).
The principle of ‘specificity’	In motor performance, ‘greatest improvements are observed when strength training programs are prescribed that are specific to the task or the activity’ (4).
Walking	An activity in which the body advances at a slow to moderate pace by moving the feet in a coordinated fashion. This includes recreational walking, walking for fitness, and competitive race-walking (MeSH).
Walking ability	The ability to walk.
Walking deterioration	The self-reported worsening of walking ability.
Walking function	A broader term than walking ability; encapsulates more of the participation goal achieved with the walking.
Work	Work is done when a force moves an object through a distance ($W = F \times d$). The definition of work is independent of time (SI unit – joule; J) (1).

Appendices

Papers I–III with supplementary files.

1. Digital meeting invitation for conceptualising the project
2. Information letter to participants – Study A
3. Information letter to participants – Study B
4. Interview guide – Study A
5. Interview guide – Study B
6. Monitor scheme – Study B
7. Training diary – Study B
8. REK approval – Study A
9. REK approval – Study B

1 Background

1.1 Cerebral Palsy

Cerebral palsy (CP) is a collective term for an injury to the immature brain, regardless of the size and localisation. CP covers disabilities associated with movement and posture and is defined as:

> CP describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to nonprogressive disturbances that occurred in the developing fetal or infant brain. The motor disorder of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour; by epilepsy, and by secondary musculoskeletal problems (5, p. 9).

This definition illustrates a diversity within the CP population. The causes and risk factors are multifactorial, and the damage can occur before, during or after birth. Prenatal or perinatal risks, such as very low birth weight, gestational age, infections, and genetic factors, are reported (6). Although more seldom, the damage to the central nervous system (CNS) can occur postnatally, then other factors are responsible, such as brain trauma (7). Therefore, in contrast to other neurological deficits occurring in adulthood, like multiple sclerosis, the injury to the immature brain in CP results in developmental disorders. The yearly incidence of CP is 2.5 per 1,000 live births in Norway (8), and adults mildly affected have a near-average life expectancy (9).

1.1.1 Classification of Cerebral Palsy

There are several ways of classifying CP, and the following subgroups of CP are spastic, dyskinetic, ataxic, and unclassifiable (Figure 1). The subgroup classification relates to the injury location in the CNS. The CNS injury can affect one or both sides of the body, referred to as unilateral/hemiplegic or bilateral/diplegic. Most persons with CP are classified as spastic, and common MRI findings of perinatal unilateral spastic CP is grey matter injury, while bilateral CP often is white matter injury (10). The motor disorders of CP are frequently accompanied by disturbances of sensation, perception, cognition, communication, behaviour, epilepsy, and secondary musculoskeletal problems (5). Even though the brain damage is static, the secondary outcomes change throughout life and affect living and function (11).

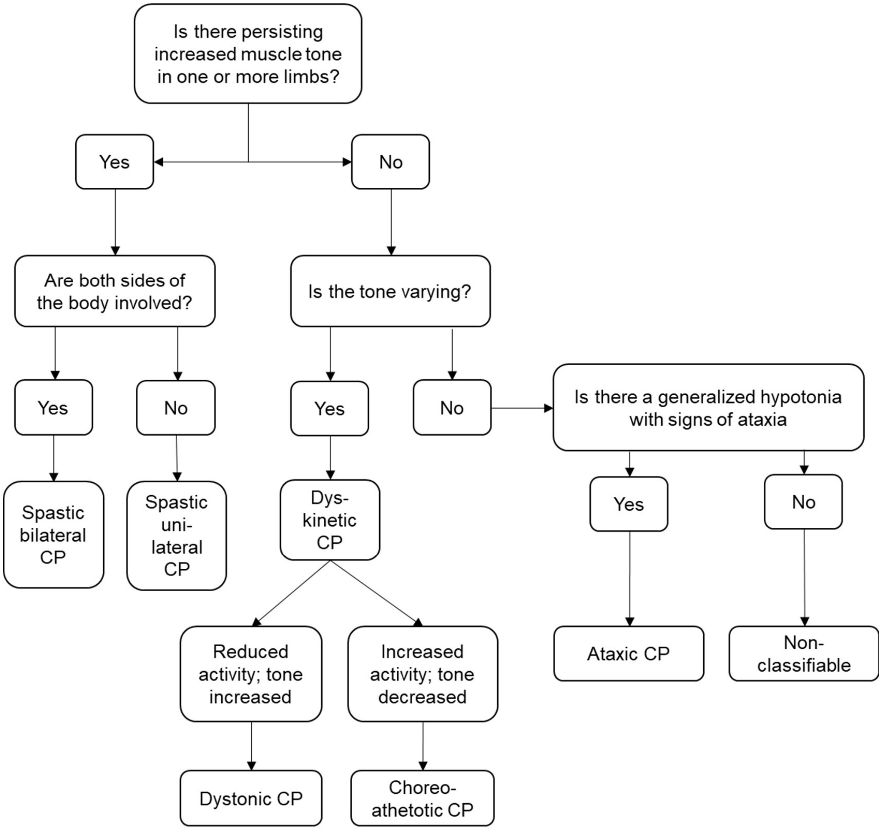

Figure 1. Classification tree for subtypes of cerebral palsy. Reproduced from Cans et al. (12, p.821) with permission from John Wiley and Sons.

1.1.2 Gross Motor Function Classification System

The motor function of persons with CP is commonly classified with the gross motor function classification system (GMFCS), which ranges from level I–V (Figure 2) (13). This range includes a broad spectrum of movement impairments. GMFCS levels I–III describe the highest motor function where levels I and II can walk independently, and persons on level III can walk with aids. Level IV describes those using wheelchairs for mobility, and level V describes the most severe CP form with the need for care. GMFCS is extended and revised for five age spans to account for natural maturing, from ‘Before 2nd birthday’ to ‘Between 12th and 18th birthday’. The distribution of motor classification across adults with CP is unknown. However, since adults with CP are assumed to have an average life expectancy, one can expect an equal distribution of motor classification as in children.

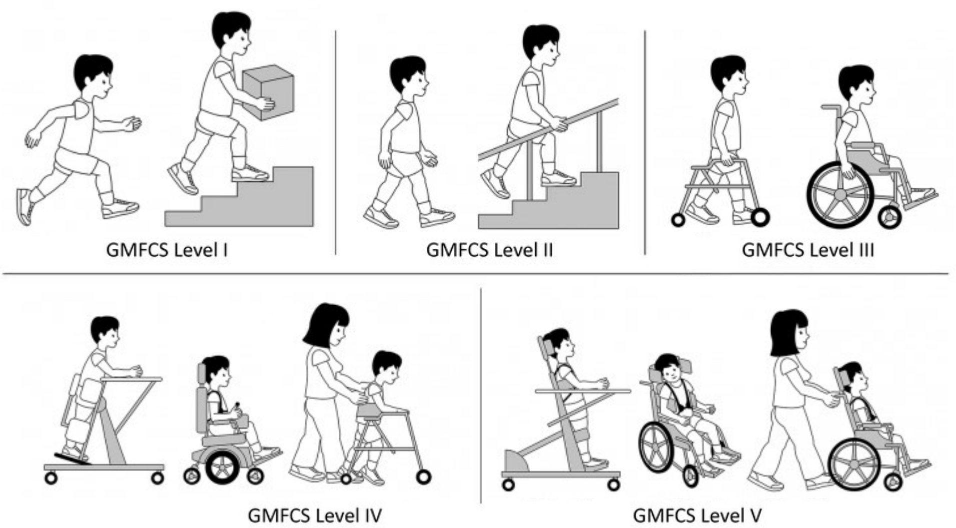

Figure 2. The Gross Motor Function Classification System (GMFCS) of children and young people with cerebral palsy can be categorised into five levels. Adapted, with permission (14), from resources at The Royal Children's Hospital, Melbourne, Australia https://www.rch.org.au/clinicalguide

1.1.3 Cerebral Palsy and International Classification of Functioning

The International Classification of Functioning, Disability and Health (ICF) is the standard language and framework of the World Health Organization (WHO) for the description of health and health-related states (2). In a medical model, the persons’ disability should be intervened, in contrast to the social model, where the disability is viewed as a socially created problem (2). The ICF framework includes the biological, individual, and social perspectives on health, promoted as a bio-psycho-social model (Figure 4) (2). ICF is a valuable tool for several areas of use; for example, in assessing at the individual level, policy development in sectors that need information on people's functional status, and research framework (2), which makes ICF relevant in the context of this thesis.

Disability "is the umbrella term for impairments, activity limitations and participation restrictions" (2, p.4). Disability is a natural part of the human condition, and nearly all people will be impaired, either temporarily or permanently, during livelihood (2). From a global perspective, the WHO reports that over a billion people, about 15% from children to adults, live with disabilities (2) which challenges walking for many. It is well known that persons with CP have problems in body function or structure that affects walking. ICF emphasises the relational understanding of the complexity of *health conditions* and *contextual factors*. Health conditions include body structures and functioning, activity and participation. Contextual factors include environmental and personal factors (2). Therefore, impaired walking may affect involvement in life situations, and the physical, social, and attitudinal environment might affect the walking impairment. Hence, walking with CP can be described within the bio-psycho-social model (Figure 4) (2).

Table 1. The formal definitions of ICF components are inserted in a table, as defined in the glossary by WHO (2, p.301-307).

Component	Definition
Body functions	The ICF classifies body functions under several areas including mental functions, sensory functions and pain, voice and speech functions, and neuromusculoskeletal and movement-related functions.
Body structures	In the ICF the structural or anatomical parts of the body such as organs, limbs, and their components classified according to body systems.
Activity	In the ICF, the execution of a task or action by an individual. It represents the individual perspective of functioning.
Participation	In the ICF, a person's involvement in a life situation, representing the societal perspective of functioning.
Contextual factors	Factors that together constitute the complete context of an individual's life, and in particular the background against which health states are classified in the ICF. There are two components of contextual factors: environmental factors and personal factors.

1.2 Walking

There is evidence that the daily amount of walking (distance, number of steps, speed) is associated with better health and lower cardiovascular and all-cause mortality (15-19), and 'walkability' is emphasised as an important public health measure in infrastructure planning (20, 21). Moreover, walking speed is suggested as 'the 6th vital sign' (22). Walking is an activity optimised for energy conservation due to the body's centre of mass (CoM) pattern of mechanical shifts of potential and kinetic energy (23). The CoM is a hypothetical point on the body that best represents the weight of all body segments for a given movement or position. The CoM is usually positioned near the midriff and slightly in front of the body during standing, depending on body shape. The CoM follows a sinusoidal pattern in healthy walking (Figure 3). The potential and kinetic energy of CoM are cyclically out of phase along this path; thus, the most gravitational potential energy coincides with the least kinetic energy when CoM is at its highest point (midstance). The shift between potential and kinetic energy of the walking limb is described as a pendulum (23). Therefore, the inverted pendulum mechanism (Figure 3) is a mechanical analogy often used when describing walking (24, 25).

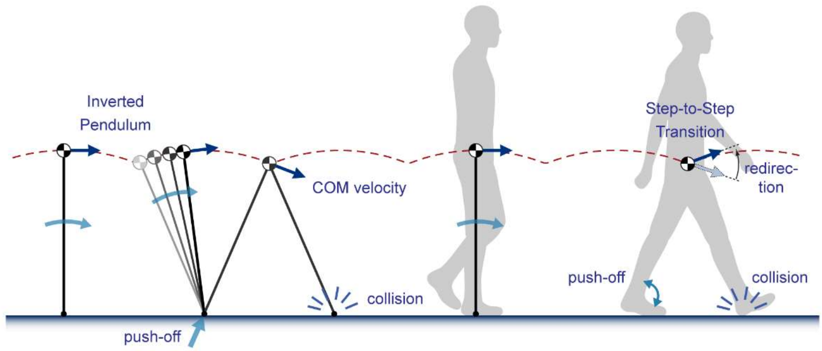

Figure 3. The mechanical analogy of the inverted pendulum of the lower leg and centre of mass in walking. Reprinted from Collins et al. (26, p.2) (CC BY-NC 4.0).

In walking, one foot is always in contact with the ground (single support), and when shifting weight from one leg to the other, both feet are on the ground (double support). One stance phase and one swing phase on each leg constitute a gait cycle, which is also called a stride and typically lasts around one second in healthy adults (27). The cyclic walking pattern is subdivided into phases, allowing a more precise description of walking that is of interest.

In the pre-swing phase, the leg prepares to push off the ground, the knee unlocks and flexes, and the hip flexes from an extended position. Simultaneously the ankle joint moves from dorsiflexion to plantarflexion at a velocity of 300°/sec at a walking speed of 1.3 m/s (28). The speed at which a force is produced is referred to as power. In walking, the hip, knee, and ankle power contributions are relatively similar across walking speeds (29). Furthermore, the magnitude of plantar flexor power is closer to three times that of other joints, and the largest power burst occurs in late stance (30). This large power burst of the ankle plantar flexors coincides with the ankle joint velocity of 300°/sec, at a walking speed of 1.3 m/s (28). Plantar flexors are important in forwarding propulsion (31) and are simulated as the main contributor to propulsion (32).

In a study comparing CoM trajectory in walking between CP children and healthy controls, the researchers found CP walking was less pendular due to the less effective exchange between potential and kinetic energy (33). The less efficient mechanical representation of walking is also determined by increased energy consumption. Typically developing persons are measured at walking intensities around 23% of VO_{2max} (maximal oxygen consumption), in contrast to persons with CP, who walk with higher energy demand, as high as 54% of VO_{2max} (34) and in another study measured to close to or above their anaerobic threshold (35).

1.2.1 Walking with Cerebral Palsy

Walking with cerebral palsy can be described in the ICF`s integrative model of functioning, disability and health (2). In the following sections, walking with CP is presented according to the ICF framework; contextual factors, activities and participation, and body structure and functioning (Figure 4).

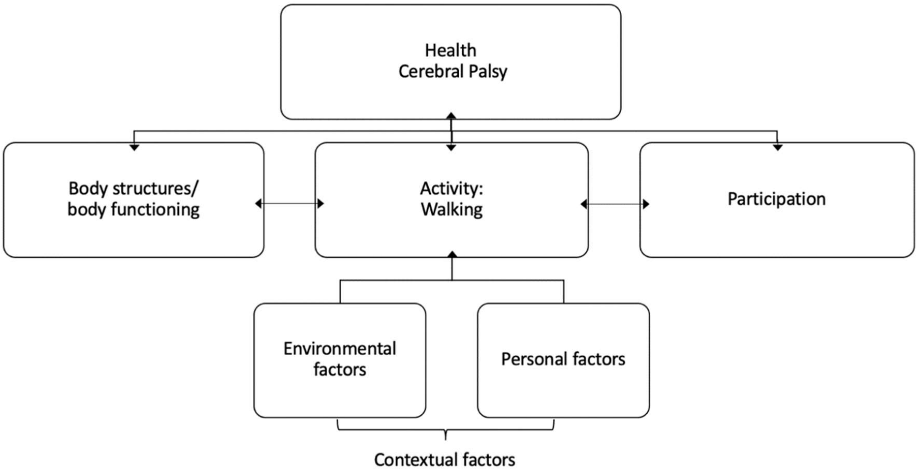

Figure 4. Walking and cerebral palsy in the International Classification of Functioning, Disability and Health (ICF) model. Reproduced from Kostanjsek (36, p.3) (CC BY-NC 2.0).

1.2.2 Contextual Factors

Domestic life and work are considered necessary although problematic for adults with CP (37), emphasising that the environmental factors in which people conduct their lives may not be well facilitated. Adults with CP report lower well-being and health status, particularly regarding physical health (38), partly because various barriers deprive them of partaking in health promotion activities (39). Consequently, awareness, acceptance, and action are themes that illuminate coping strategies of adults growing older with CP (40).

Many children with CP find walking problematic, and consequently, walking is targeted in rehabilitation (41, 42). As these children grow into adulthood, walking deterioration is a well-known phenomenon (43, 44), but not much is known about how walking is experienced in adults. The personal factors associated with adult walking are necessary to understand the health-related situational context. Although personal factors are not classified in the ICF, it is characterised as follows: "A component of contextual factors within the ICF that relate to the individual – for example, age, gender, social status, and life experiences" (2, p. 307). Although personal factors vary, insight into how these factors affect daily walking can help achieve the goal of increased accuracy in healthcare. Therefore, it is recommended to include user experiences in developing health services (45). More knowledge on personal factors potentially improves interventions and services in populations with disabilities (46).

1.2.3 The Activity of Walking

Due to the importance of walking in assessing health and functioning, there has been a substantial increase in research on walking over the last decades. Even though adults outnumber children with CP, most scientific literature on walking relates to children. For example, a PubMed search (29.07.21) of 'cerebral palsy' and 'walking' showed 1,999 results; when adding adults, the results dropped to 367. Approximately 70% of those diagnosed with CP are independent walkers without severe cognitive impairment (47), classified as GMFCS I–II (numbers from 2002–2015) (48). Maintaining the ability to walk efficiently and safely is a premise for partaking in social activities, enhancing the quality of life, and maintaining independence for adults with CP (49, 50). The change in walking performance from children to adulthood varies the most for intermediate walkers (51). Those mildly affected (GMFCS levels I–II) remain mainly at the same level during their first 21 years. Those severely affected (levels IV–V) are more prone to losing function in childhood (52). Further, when reaching 25 years of age, a decline in mobility is more likely to occur, except for those climbing stairs without support, who appear to maintain their function for another 15 years (53).

It is well documented that secondary conditions and mobility levels worsen in adults with CP (25–58% of 18–76-year-olds) (44, 54, 55). Walking deterioration of adults with CP is described as the self-reported worsening of walking function (43). On average, such deterioration occurs around 35 years of age in persons with spastic bilateral CP and at around 52 years in persons with spastic unilateral CP (56). Typical onset of age-related changes in gait is reported in the decade from 60 to 70 years (30). The literature suggests lifespan follow-up of adults to better understand the mobility decline, how these factors develop in adulthood, and how they are connected (11, 47).

1.2.4 Body Structure and Function

The manner of walking is defined as gait. Three prerequisites are used to simplify the understanding of the control of gait; progression (moving the body in the desired direction), postural control (body systems achieve orientation and stability), and adaptation (the environment we walk in is constantly changing) (57, loc. 11408). These tasks are solved almost automatically in a coordinated and efficient manner in typically developing (58). This is in contrast to persons with CP, where energy consumption in walking is increased and related to a higher GMFCS score, a more impaired person walks with higher metabolic cost (59). However, although the body consists of numerous limbs, joints, muscles, and tissues that must be coordinated for this smooth trajectory to occur, muscles are the only tissue with force-producing ability. Hence muscle strength is required to walk (60, 61).

Although walking does not require maximal strength, it is evidence of a nonlinear relationship between leg strength and gait speed (62). The impact of the muscular weakness on gait can be predicted using data simulation. The plantar flexors, hip abductors, and hip flexors were found to have the largest impact on TD gait. Furthermore, plantar flexor weakness primarily increased the walking cost (63). In the muscle-tendon complex, the muscles produce force, and the tendon stores energy and transfers the force to the bone. Depending on tendon stiffness, the soft tissue can save up to 14% of total positive power per stride in walking (64). The Achilles' energy storage and return enhance the efficiency of the ankle muscle-tendon in walking. The energy storage and release interaction are referred to as mechanical analogies both as a spring (65) and a catapult mechanism (66). This emphasises the importance of the calf muscle-tendon complex in walking as energy-conservative locomotion. The inverted pendulum model of the stance leg does not include compliant leg behaviour; hence, a simple bipedal spring-mass model is suggested as an improved mechanical analogy (67).

Body structures and functions explain how the body parts work. On a structural level, the spastic muscle volume is reduced compared to healthy peers (68) and of another composition; that is, containing more collagen (69), prolonged sarcomere length (70), and impaired ability to generate force rapidly (71). Altered muscle morphology can be explained by the paresis in CP (72) but could also be due to a lower concentration of satellite cells. Satellite cells are myogenic stem cells essential for muscle growth and repair (73). Due to structural changes, the ankle range of motion is reduced and has greater ankle stiffness than healthy controls (74). In addition, the CNS injury results in loss of selective motor control, abnormal muscle tone, and power imbalance between muscle agonist and antagonist (75, loc. 478). This can be explained by impaired spinal neuronal networks such as inhibition and post-activation depression (76). The functional outcome is the impaired ability to walk efficiently in persons with CP.

Other factors associated with impaired gait function are increased pain, physical fatigue, changes in muscle tone (for example, spasticity), reduced balance, and motor control (56, 77, 78). There are indications of an association between walking deterioration and pain (43). Studies from the USA (79) and Norway (56) reported more chronic pain in adults with CP than the general population, most frequently reported in the lower back, hips, and legs.

Chronic fatigue is another impairment of body structure level reported to be significantly higher in adults with CP than in the general population in Norway (43). Fatigue can be defined as “a sense of physical tiredness and lack of energy, distinct from sadness or weakness” (80, p. 435). Adults with CP report a higher level of fatigue than healthy controls (81). In one study, increased fatigue correlated with increased body mass index (BMI), waist circumference and age in adults with CP (82). These factors vary between individuals. Hence persons with CP constitute a heterogenous and complex population.

1.3 Interventions to Improve Walking in Cerebral Palsy

Mobility, walking, and muscle strength are targeted in the rehabilitation of adults with CP (83-85). Although it is reported a relationship between lower limb muscle strength and walking capacity in neurological diseases (86), the efficacy of conservative interventions, such as strength training, is not established in this population. Muscle strength is one factor required for walking (60, 61, 87), and with the reduced muscle strength in persons with CP (88), one could assume that strength training improves walking function. Improving muscle strength has improved gait speed in mobility-limited older adults (<0.9 m/s) (89) and muscle strength is related to walking capacity in other neurology deficits such as stroke (86). However, this is not supported in the current literature on CP like strength training aiming to enhance walking in adults with CP improves muscle strength but fails to improve walking (83, 90-93).

In a focused review, Williams et al. (94) critique the strength exercises for not being task-specific for walking propulsion in neurological rehabilitation and suggest that the power events responsible for forwarding propulsion should be targeted; ankle plantar flexor power generation at push-off, hip extensor power generation in the early stance phase, and hip flexor power generation in the terminal stance and early swing phase. Accordingly, Williams et al. (94) concluded that this lack of specificity might explain the missing carryover of strength training effect to improved walking.

1.3.1 Task-Specific Strength Training

ACSM guidelines for healthy adults state that the foremost principles for progression in strength training are *progressive overload, variation,* and *specificity* (4). Regarding the latter, the muscles adapt specifically to the exposed training stimuli. Therefore the muscles involved, speed of movement, and range of motion (among other factors) should be considered in specific training goals (4). Task-specific strength training implies that the muscles' involvement in accomplishing the task, in this case, walking, should be replicated. In this context, it is defined as: "In relation to strength

training and walking in people with neurologic conditions, task specificity relates to how well the exercises target the primary muscle groups responsible for propulsive strength during walking" (94, p. 512). Therefore, strength training may improve performance when it is performed specifically to the task of the activity.
The ankle plantar flexor's role in normal walking is substantial (95), and ankle power is reduced in both children and adults with CP compared to healthy peers, and as a consequence, other joints must compensate (96). Due to its relevance in walking, a recent review targeted plantar flexors interventions, such as ankle-foot orthoses, functional electrical stimulation, botulinum toxin, surgery and physical therapy, to impact walking in children and young adults with CP (97). Although targeting the ankle positively affected walking ability, the lack of powered studies could not determine the effect (97).

To target the average ankle joint velocity (300 °/s) at push-off in walking (28), high-velocity exercises are required. One group of such exercises are ballistic exercises. Ballistic exercises allow acceleration throughout the movement because there is no deceleration phase. The discharge rates of the motor units are greater in ballistic exercises than in slow contractions (98). The exercises aim to improve the rate of force production and, thereby, muscle power (99). Power is the rate of doing work, and terms such as 'ballistic', 'plyometric', and 'power training' are used interchangeably in the literature. In common, they all involve faster muscle contractions. A common measure of ballistic strength is the muscles' rate of force development (RFD), which is reduced in spastic muscles (71). Geertsen et al. (100) found an association between a reduction in ankle push-off velocity and reduction of plantar flexor RFD, supporting the need to further investigate the ability of the muscles to produce force at higher velocities when incorporated into strength training programmes for persons with CP. As Geertsen et al. (100) report an association, further investigation is needed before a causal relationship can be established.

Most strength training to improve gait in persons with CP does not focus on contraction velocity in the strengthening exercises for the lower limb (83, 90).

However, some studies do, like the article by Moreau et al. (101), where youth with CP performed high-velocity exercises (progression up to 120 °/sec) in a stationary dynamometer, resulting in increased fascicle length and more effective power outcomes compared to the group that performed traditional strength training. Rapid force generation might be superior to maximal strength in walking (71). Therefore, Moreau et al. (101) concluded that more focus on higher training velocities should be given in clinical practice, since

Williams et al. (102) published a theoretical framework for exercise prescription using knowledge of the biomechanics of walking and the ACSM guidelines for strength training developed for healthy adults (4). Although ballistic strength training is feasible in neurological population, with promising results in mobility and muscle strength and power (103), its feasibility is not examined in adults with CP. As concluded in the Cochrane review of exercise interventions for CP, specifically examining the effectiveness of muscle strengthening, current exercise guidelines for the general population must be investigated to see if they are effective and feasible for people with CP (85).

1.3.2 Spastic Muscles and Strength Training

The literature lacks evidence on how power training affects spastic muscle architecture in CP. Strength training is a relatively young discipline in CP, as it was believed to worsen spasticity. However, scientific research on upper-motor neuron syndrome has shown that strength training does not aggravate spasticity (104), and it has been widely accepted in therapy. Although muscle architecture is different in persons with CP (70), muscles get stronger (84) and muscle volume increases (105) with strength training. Still, muscle adaptation to strength training in this population is sparsely reported in the literature (106). Therefore, future strengthening interventions are suggested to include outcome measures on muscle morphology to better understand muscle response to training in this population (106). Examples of muscle adaptation to strength training could be increased muscle size, increased muscle strength, and improved muscle endurance or muscle power (4).

1.4 Rationale for the Thesis

According to ICF terminology, walking is defined as an activity. The complexity of walking in adults with CP is related to body structures and functions, participation, and contextual factors. First-person reflections on the meaning of walking in adults with CP are sparse. Therefore, we were interested in how adults with CP experienced walking. Gait is the manner of walking, and gait analysis and simulation have demonstrated that ankle plantar flexors produce the most power in forwarding propulsion (31, 32) but are reduced in individuals with CP when walking (107). Conservative interventions to improve walking is not established (83), and muscles responsible for walking propulsion are not specifically targeted (94). Therefore, we wanted to investigate whether task-specific strength training of the plantar flexor muscles through ballistic exercises is feasible when using guidelines developed for a population without neuromuscular deficits.

2 Aims

The main goal of this thesis was to explore walking in adults with CP. This is a broad goal, and two secondary goals were defined to operationalize the main goal.

A. To explore daily walking in adults with CP from a subjective perspective.
B. To explore whether ballistic strength training is feasible and whether it improves walking and potential muscle adaptation.

Three papers with specific aims were designed to answer the main goal and secondary goals:

Paper I: To explore personal reflections on daily walking by adults with CP.

Paper II: To investigate if adults with CP can perform and benefit from ballistic strength training of the ankle plantar flexors to improve walking; evaluated through physical measures, self-reported measures, and interviews.

Paper III: To investigate whether eight-week ballistic strength training of the ankle plantar flexors could improve muscle strength, muscle architecture and walking function in adults with CP.

3 Methods

3.1 Scientific Perspective

In the scientific context, I position myself in the pragmatic paradigm. As a pragmatic researcher, the studies are planned according to the best answers to the research question (108), and the knowledge brought forward can infer from separate paradigms or mixing them (109). This reflects the composition of the interdisciplinary team: Functional capacity for walking in adults with CP (FunCap-CP).

3.2 Design and User Participation

We identified a *knowledge gap* in strength training literature to improve walking in adults with CP and invited central organisations to a digital meeting to discuss training interventions further (May 2015: CP association, NTNU, NIH, Beitostølen, Turbo, Sunnaas HF and HIB; Appendix 1). Because persons with CP may have different experiences and perspectives about successful treatment than the healthcare professionals and researchers, we performed group conversations in Bergen and Oslo (May 2015), inviting adults with CP to truly capture the user perspective. These conversations partly revealed that their training motivation was motor control and daily independence, emphasising the relevance of the user perspective in the experimental training study.

The person-centred perspective is a core factor in evidence-based healthcare. It is recommended in all stages of science recommended by the Norwegian Ministry of Health and Care Services to improve efficacy (45). Therefore, we emphasised the user's perspective throughout the project. For example, we had email correspondence with user participants with CP to clarify any wording we used in the recruiting text. They also shared an important input regarding barriers in recruiting mildly affected participants since young adults might not acknowledge their disability. Hence, we made an informational film about the project, and we were conscious of including a mildly affected person to reach the target audience.

The knowledge gap we identified in the literature and the input we received from user organisations, user participants, clinicians, and researchers formed the knowledge base when conceptually defining the project proposal for the functional capacity for walking in adults with CP; FunCap-CP. In designing the studies, we used a diverse approach to answer the overall aim of the thesis (Figure 5). Paper I, alternatively referred to as *the reflections paper*, is derived from the qualitative Study A. Paper II, alternatively referred to as *the task-specific strength training* paper, and Paper III, alternatively referred to as *the training response paper*, derived from the quasi-experimental Study B. In addition, some unpublished results (bachelor's degrees, master's degrees, and one medical education assignment at the master's thesis level) were part of the project, but all were not part of the thesis.

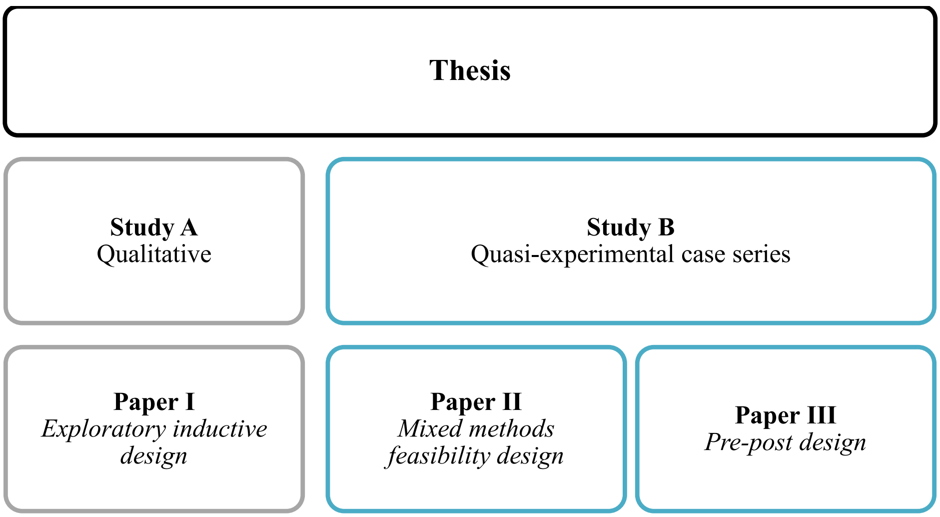

Figure 5. The thesis' studies, papers, and methods.

3.3 Instrumentation and Analyses

Regarding the biological, individual, and social perspectives on walking with CP, we chose outcome measures to cover the components of ICF (Figure 4). The measurement tools are not established; therefore, when deciding on which outcome measures to use, we searched for those that are valid and reliable in adults with CP. These are described in more detail in the following sections on Study A and B.

Table 2. The outcome measures are sorted according to the ICF components and associate codes. The relevant paper(s) is (are) specified with a number in parentheses.

Functioning and Disability			Contextual Factors	
Body functions	Body structures	Activity	Participation	Environmental and personal factors
b280 Sensation of pain (II) b4552 Fatiguability (II) b7303 Power of muscles in the lower half of the body (III) b770 Gait pattern functions (III) b7601 Control of complex voluntary movements (II) b235 Vestibular functions (II)	s75022 Muscles of ankle and foot (III)	d450 Walking (I, II, III) d1559 Acquiring skills (II) d4 Mobility (II)	d460 Moving around in different locations (I) d465 Moving around using equipment (I)	e225 Climate (I) e345 Strangers (I)

3.3.1 The Qualitative Study A

Participants and Recruitment

Study information was emailed to adult members of the local CP association, and information was posted on social media. Inclusion criteria for Study A (Paper I) were adults with CP eager to share their experiences on daily walking, classified as GMFCS Level I–III and that had completed secondary school and could partake in conversation. Persons of interest got in touch and received the information letter

(Appendix 2). Totally eight ambulatory adults (26–60 years old; four women and four men) provided informed consent and were included in the study.

In qualitative studies, the sample size is not determined by power calculations, which is more common in quantitative research (110, loc. 2551). The most used strategy to determine sample size in qualitative research is *saturation,* which "in purposive sampling is reached when the addition of more cases does not produce new information that can be used in theme and theory" (111, p. 166). Concerning saturation, there can be several reasons why the researchers cannot find new information in subsequential interviews, such as insufficient interview technique, lack of experience within the field, or when funding for conducting research is running out (112, p. 65). Since Paper I is explorative, the aim was not to describe walking entirely but to learn something new about the phenomena of walking in adults with CP. Therefore, we found *information power*, a pragmatic model of guiding sample size, more appropriate. This model discusses the study aim, sample specificity, theory, quality of dialogue, and analysis strategy (113). Determining the sample size in dialogue with experienced qualitative researchers was a valuable experience since guiding sample size in qualitative research was a new experience. We set the initial approximation to a sample size of 8–10 participants based on these considerations.

Interviews

Although focus group interviews have the potential to inspire participants (112, p. 138), these interviews may reflect what is widely thought and accepted rather than what people do and think (110). The paper's aim was personal experiences. Therefore, individual interviews were chosen. The interview guide (Appendix 4) was constructed based on the focus group conversations in Bergen and Oslo and iteratively with the four co-authors (SM, RJ, PM, BEG). Before data collection, I wrote down expectations about potential findings and maintained a reflexive log for discussion with SM. This log also contributed to transparency about the process and analysis decision trail.

Each interview was arranged to occur and conducted at a location chosen by the participant. When meeting, I introduced the project and presented my background, since this could affect how the participants worded themselves (114). It was emphasized that no right or wrong answers existed. Some preliminary questions were used to initiate the conversation before the main question: “Can you share your experience on how it is to walk with CP?”. The dialogue evolved reflections on the importance of daily walking and keywords, including reflections on the following topics: a typical day, falling, the wish/need to do exercises targeting walking, overuse injuries, energy consumption, changes experienced in adulthood, fatigue, and inpatient rehabilitation as adults. When performing the interviews, I intentionally used a critical incident technique, inviting participants to share their experiences on specific behavioural descriptions of defined situations (115), which potentially strengthened the constructed material for analysis. With dialogical validation, I repeated what the interviewees said in a manner with my own words to make sure we understood each other (112, p. 193). The participants were interrupted mainly when clarification or elaboration was needed. The interviews lasted from 28 to 68 minutes (mean 50 minutes), a good margin within the recommended length of 90 minutes (116). Interviews were transcribed verbatim, giving a total of 135 pages.

Analyses

Data materials were analysed using systematic text condensation (STC), a four-step thematic cross-case analysis that offers a framework befitting the explorative aim of the study (117). Similarities, differences, and variations in experiences, feelings, or attitudes from several participants are analysed in a cross-case analysis (112, p. 93). A stepwise analysis is performed at each level but is iterative, allowing for increased understanding at one level to cause a step back in another level (Figure 6) (117). The academic physiotherapists (RJ, AO, PM) were part of the iterative process, going back and forth throughout the analytical process.

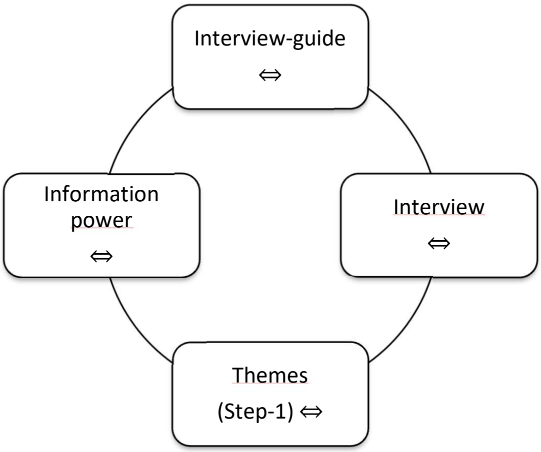

Figure 6. The levels of the iterative analysis (indicated with the arrows) of systematic text condensation.

Step 1: Total impression (117). After three interviews, we (SM, BEG) read the data material to gain an overall impression, striving to bracket the preconceptions and theoretical frame (112). We used two researchers to establish a more expansive analytic space (112). We identified preliminary themes that we discussed, hence bringing together those about the same thing ("walking to be able to participate" (BEG) and "crucial for participation/an active life/to fit in" (SM)). Additionally, 'seasonal change' was included following interviews 1–3, as themes on climate emerged from the material.

Step 2: Identifying and sorting meaning units (117). The transcripts were coded for reflections on walking in adulthood with meaning units. Coding at this stage was based on the themes in Step 1 but focused on transcending previous preconceptions (117). An overview of themes and content that we (SM and BEG) discussed was used as a decision trail if we needed to go back and identify what we assessed during the analysis (117). Before the next step, we revised the meaning units to target the study's aim with a more specific view. For example, if the interviewees were talking about pain but in a manner not related to walking, we omitted the meaning unit. The themes that emerged in the preliminary analysis are illustrated in Table 5.

Table 5. Preliminary themes from the iterative analysis process.

Code Groups	Subgroup	Meaning Units (Number)
Walking experiences	Walking as a conscious movement	36
	When tired, still going on	12
	Training for walking	5
Changes	Insidious vs abrupt changes	7
	What you cannot do anymore	7
	Pain	11
No heading yet	Winter/Summer	13
	Falling	17
	Walking aids	30

Step 3: Condensation (117). The content in each code group is considered an analytical unit and was further abstracted by condensing the content (117). The meaning units from the subgroup 'Daily walking as energy-demanding but chosen activity' were amalgamated and intentionally summarised the essence in first-person format. This is an example of what it looked like (my English translation):

> When walking with my sweetheart, I want her to enjoy herself, so I strive for her. It is no trouble keeping up with her, so I walk and walk. Usually, I do not notice I am tired early enough, and in the light of hindsight, I realise I should not have pushed myself the last half hour, while other times, I get short-winded 10 m on an uphill stretch. I do what I should until I almost cringe. I rebuild with a night's sleep, almost living the life of an athlete. This is what I am used to; this is my normal. And then it strikes me, do I have to push myself this way? If I had been kind to myself, I would have thrown in the towel earlier. But still, something about the will and stubbornness is part of me. I managed so far – this is my normal: as long as I can keep up, it will be OK.

Step 4: Synthesising (117). I took the role of a re-narrator and wrote the material in the third person (133), and the text was translated into English. This step aimed for a multivocal outcome of stories synthesised through cross-case analysis. An illustrative quote from the subgroup was chosen and used in its original form to elucidate the findings (117).

The example in the Step 3 condensate was synthesised in Step 4 into the following text:

Daily walking as an energy-demanding but chosen activity.

Participants described a range of experiences associated with maintaining walking ability. Some participants reported that to minimize the negative impact on social activities, they would proceed with the task as planned, even though it was a physically challenging one. One participant justified the strenuous effort of walking alongside the partner on a hike or when shopping because it was important to their relationship – even though they eventually ending up walking behind the partner. For some participants, a good night`s sleep was enough to reenergise for the next day. One young participant compared living with CP to 'living like an athlete', always pushing their body to the limit. Still, many participants felt being stubborn and having a 'strong will' as beneficial and essential in order to maintain their walking ability for as long as possible. One participant described the importance of walking as:

> Since my whole life is based on my ability to walk, then I am free to do what I want without significant help from others. It is important to have a minimum of a walking function that can take me places that are not accessible (with mobility aids) (Participant 5).

The category headings (e.g. "Daily walking as an energy-demanding but chosen activity") were expressive statements of the most significant interpretations. We worked through the material several times, and from the code groups and subgroups in Step 2 (Table 3), we ended up with a results section of two codes with three subgroups each (Paper I).

3.3.2 The Quasi-Experimental Study B

Participants and Recruitment

Study B (Paper IIs + III) contained information about the project and a short promotional video (described in Section 3.2) was posted on the local CP Association´s Facebook homepage. Written information about the project was also made available at a University Hospital and a local training centre for persons with neurological conditions. Those interested in the study contacted us via email or phone calls and received written (Appendix 3) and oral information about the project. Inclusion criteria were adults aged 18–60 years with CP GMFCS level I–II and confirmed spastic unilateral or bilateral CP diagnosis. Exclusion criteria were lower limb surgery during the last year, not completing primary school or any injury or similar that could limit participation. The participants provided written informed consent.

Intervention

The instructors met the participants in the rehabilitation laboratory at the University College for the training sessions. In the lab training sessions, the ballistic exercises targeted the plantar flexors. The full description of the training programme can be found in Hendrey et al. (118); a short version is summarised in Table 7. All training sessions started with a general warm-up of either indoor cycling or treadmill walking and were followed by three exercises on an inclined glideboard (Total Gym RS Encompass PowerTower®) see Table 7: (a) jump squats, (b) single-leg hopping on the paretic, leg and (c) bounding on alternating legs.

The recommended resistance in lower leg power exercises is 0–60% of the corresponding repetition maximum (RM) (4). 1RM is the maximal weight a person can lift once for a given exercise. We could not determine 1RM because the participants had difficulties performing the exercises. Training instructors were helping with the exercise for those who could not perform the exercise. With the glideboard, we determined resistance at the level at which participants could achieve the flight phase; the glideboard incline was set at 0–60% of body weight (which is not the same as 0–60% of RM). In contrast to the ACSM guidelines that recommend one to three sets per exercise with moderate loading (0–60% RM lower leg) with three to six repetitions for increasing muscular power (4). In the study by Hendrey et al. (118), each exercise had a time limit of five minutes, and rest periods were initiated by the participant, or the instructor based on the performance. The glideboard incline, number of sets, repetitions, and type of assistance were recorded for each session. In addition, other exercise activities besides the intervention were reported each time the participant came to the laboratory, such as delayed onset muscle soreness, adverse events, or other symptoms limiting exercise conduction (Appendix 6).

Table 7. Ballistic exercise prescriptions. Appendix adapted by Hendrey et al. (119, p.11-12) with permission from Elsevier.

a) Jump squats on glideboard (120) Aim: To target ankle plantar flexor and hip extensor power via a focus on speed and height of the jump.	
Supine on leg sled with hips at 30 º flexion and feet on the footplate Leg sled resistance is determined by the level at which participant can achieve bilateral ankle plantar flexion and inner range knee extension on push-off while maintaining ankle alignment +/- researcher facilitation to prevent excessive ankle inversion or knee hyperextension.	Instruction to research assistant: ○ Manual support at the ankle to provide mediolateral stability and/or support at the knee to present hyperextension is allowed. Instruction to participant: ○ Imagine you are jumping on the spot. Push through your toes and straighten your knees to jump and land back on your toes again. Do this as quickly as you can, jumping as high as you can. Rest whenever necessary.
b) Single leg hopping on the paretic leg (121) Aim: To isolate plantar flexors power via focus on speed and jump height.	
Either both feet on the footplate with hips and knees extended, or if able, paretic leg in contact with the footplate with the nonparetic leg bent up on the platform Determining initial load or starting position: ○ Leg sled resistance determined by the level at which participant can achieve flight phase ideally through his or her paretic leg only	Instruction to research assistant: ○ Ensure activity is isolated to the calf by ensuring the hip and knee are extended. ○ Manual support at the ankle to provide mediolateral stability and/or support at the knee to present hyperextension is allowed. Instruction to participant: ○ Hop on your toes, keeping your knee straight. Hop as high and as quickly as possible.
c) Bounding on alternating legs (122) Aim: To target the coordination and power production of alternating hip flexion, hip extension, and ankle planarflexion via quick and fast jogging.	
Hips bent to 30º ○ One leg in contact with the footplate, the other held in hip flexion Determining initial load or starting position: ○ Leg sled resistance determined by the level at which participant can achieve flight phase bilaterally with good control and coordination	Instruction to research assistant: ○ Manual support at the ankle to provide mediolateral stability is allowed. Instruction to participant: ○ Imagine you are jogging on the spot. Try and land lightly on your toes and aim to jog as quickly as you can.
Progression:	
The following rules should be adopted: ○ Skill acquisition rules as per intensity. ○ Increase speed once skill acquired. ○ Progressively increase resistance where rules 1 and 2 have been achieved.	

We introduced an extra training session midway through the intervention to address the progressive overload principle. Since walking was the target, we included home exercises for the hip flexor power generation (98) relevant for walking. Participants were given a demonstration and provided with videos explaining the home exercises. The participants chose exercises from a progressive list – for example, knee lift, claw, or triplings (wrist jog) – and were instructed to perform three sets of 12 repetitions once per week and report them in a training diary (Appendix 7).

Methods and Instrumentation

Most of the data were collected before and after the 8-week intervention, and some were also collected during the intervention. Figure 7 gives an overview of methods and instrumentation used in Study B and their distribution between Paper II and Paper III.

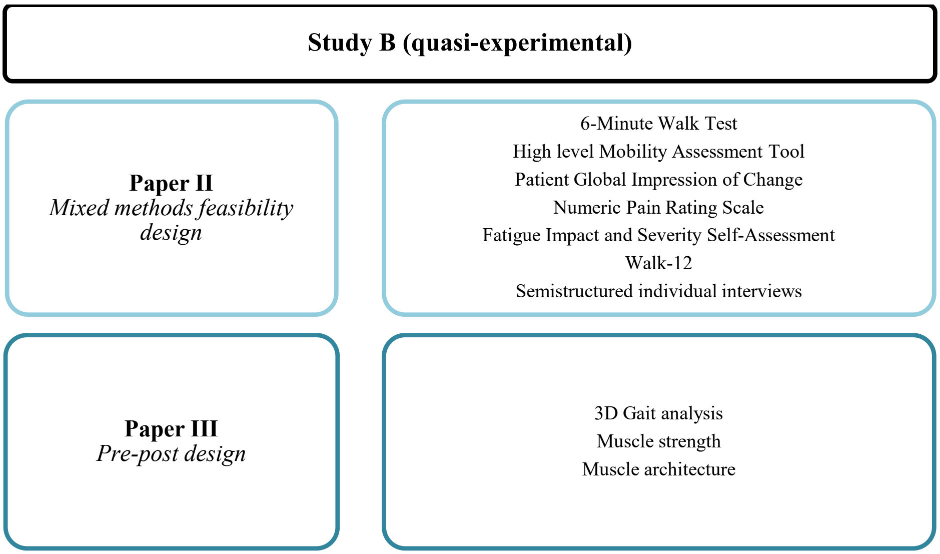

Figure 7. Methods and instrumentation in Study B and their distribution in Papers II and III.

The participants came to the lab for testing before and after the intervention. A test protocol was prepared, and a trained person oversaw the testing. We sought the same person to conduct the pre-and post-test but did not succeed for all. The testing took about four hours and was arranged in a circuit, starting with ultrasound and patient-reported outcome measures, before three-dimensional gait analysis (3DGA) and muscle strength measured with a dynamometer, and finally, the 6-Minute Walk Test (6MWT) and High-Mobility Assessment Tool (HiMAT).

Sample Size in Underpowered Studies

Since, to our knowledge, there have been no studies on ballistic strength training in adults with CP, we designed a quasi-experimental case series study composed of Paper II, with a mixed methods feasibility design, and Paper III, with a pre-post design. In contrast to studies using power calculation to justify sample size (123, 124), the sample size in feasibility studies varies (125). The ideal sample size is an estimation, not an absolute truth (123). A pragmatic strategy uses the largest feasible sample size (126) while considering ethics and costs (124). The consequence of fewer participants is that the selected sample will not represent the population; hence, the results cannot be generalised to the population (124). Case series are reported with a median sample number of seven (127). We aimed for ten subjects, the number of subjects enrolled in the study. One participant withdrew before baseline tests, and one participant had to withdraw due to bursitis in the foot. A total of eight participants completed the study.

3.3.3 Paper II Outcome Measures

The outcome measures in Paper II were chosen to assess the feasibility and walking from various perspectives. The physical outcome measures were chosen to measure walking objectively. The self-reported measures included how they experienced their walking and monitored whether the training triggered pain or fatigue. The interviews to include the participants' voices on their experiences with the training and any walking alterations. We searched for valid and reliable measurement tools for adults with CP but were not able to find them for all. Table 4 summarizes Paper II's physical and self-reported outcome measures, their validity, reliability, and relevant change.

Table 4. Summary of validity and reliability and relevant change of outcome measures in Paper II.

Measurement Tool	Valid	Reliable	Relevant Change
6MWT	In CP (128)	In CP (128)	CSC in CP (128): o 40 m with practice test o 56 m without a practice test
Eight-item HiMAT	In NP (129)		MDC in neurology (130): o 2 points
PGIC			Measures besides 'unchanged'
PainNRS	In CP (131)		CC in low back patients (132): o 2 points
FISSA	In CP (133)	In CP (133)	
Walk-12	In MS (134)	In MS (134)	CSC in MS (134): o 22 points (53%)

Abbreviations: 6MWT: 6-minute walk test; HiMAT: high mobility assessment tool; PGIC: patient global impression of change; PainNRS: pain numeric rating scale; FISSA: fatigue impact and severity self-assessment; MS: multiple sclerosis; CSC: clinically significant change; MDC: minimal detectable change; CC: clinical change.

There is no single, universally accepted outcome measure of walking in CP (135). We chose 6MWT as the main outcome measure as it is a reliable measurement tool for walking in CP (128). HiMAT is an assessment tool for high-level motor performance and is valid in the neurological population (129). It was chosen since greater functional mobility is associated with higher participation and better quality of life (136). The measurement tool assesses vestibular and functional mobility, such as changing body position by transferring from one place to another when walking, running, jumping, balancing, hopping and skipping (129).

Self-reported measures were Patient Global Impression of Change (PGIC) that measures current self-experienced walking function compared to before the intervention. Any pain was measured with the NPRS (125); before, Wk3, Wk6, and after intervention) on a scale ranging from '0 = no pain' to '10 = worst possible pain'. Fatigue was measured with FISSA (before and after intervention), a tool created for persons with CP (133) validated across GMFCS levels for fatigue in CP (82). A higher score indicates more fatigue. Perceived walking difficulties related to diagnosis were measured with Walk-12 (134) (before and after intervention). Walk-12 is a generic version of the Multiple Sclerosis Walking Scale (137).

Experiences with ballistic strength training and any impact on walking were explored with semi-structured interviews (by me or SM). The overarching question was, "What are your experiences with the training performed?". The qualitative data aimed to converge the quantitative outcome measures with follow-up questions from the interview guide (Appendix 5), such as, "Do you feel your gait has changed, either way?". As described in Paper I, we strived for the interviewees to freely describe what they experienced important (108) using a critical incident technique (115).

Paper II Data Analysis

Post-intervention results were analysed to baseline measurements and compared with the relevant change of either clinically significant change (CSC), minimal detectable change (MDC), or clinical change (CC). The semi-structured interviews were analysed with STC, following the previously described analyses in Study A. Integration is when qualitative findings interface with quantitative results and vary between mixed methods design (138, p. 220). The convergent design merged the quantitative and qualitative data to develop an expanded understanding of the feasibility of the task-specific (ballistic) strength training and walking. This analysis aims to answer to what extent the quantitative and qualitative results converge or diverge (138, p. 221). For example, adherence to home training was 38%, which is low compared to the lab training (95%). The qualitative findings of '*Addressing closer follow up to the home training*' converges the quantitative data in the interpretation by providing insight into how participants could not perform the exercises.

3.3.4 Paper III Outcome measures

Walking is a broad term and a challenge when comparing studies in the scientific literature with different descriptions and measurement outcomes, for example, mobility, locomotion, and function (47). The ballistic training intervention aimed to improve the velocity of force production when walking; therefore, 3DGA was chosen as the best way to study gait. This gives detailed information about kinematics (e.g. joint angle velocity) when walking. To measure any physiological changes in muscle adaptation, we used a dynamometer to measure strength and ultrasound to measure architecture.

Gait Analysis

There are several ways of performing a gait analysis, such as footfall analysis using gait mats, accelerometers worn on the body (139), three-dimensional gait analysis using cameras that capture infrared light, and markers on the body (three-dimensional gait analysis; 3DGA). The latter method has the advantage of enabling segmental analysis with relative ease. In gait analysis, kinetics at the joint level concerns moments (also called torque) and power. 3DGA is considered the 'gold standard' for gait analysis and was chosen for measuring gait kinematics. Analysing the data collected in a 3DGA is time-consuming and gives valuable information on the quality of gait used in, for example, surgical recommendations (140).

Gait analysis was measured with three-dimensional gait analysis (3DGA) in the rehabilitation lab to explore potential ankle angle push-off velocity changes. Passive reflective markers (12.5 mm) were attached with wig tape according to the plug-in-gait marker set, with additionally markers on the iliac crest for those with wobbling mass that could camouflage the marker from the set-up.

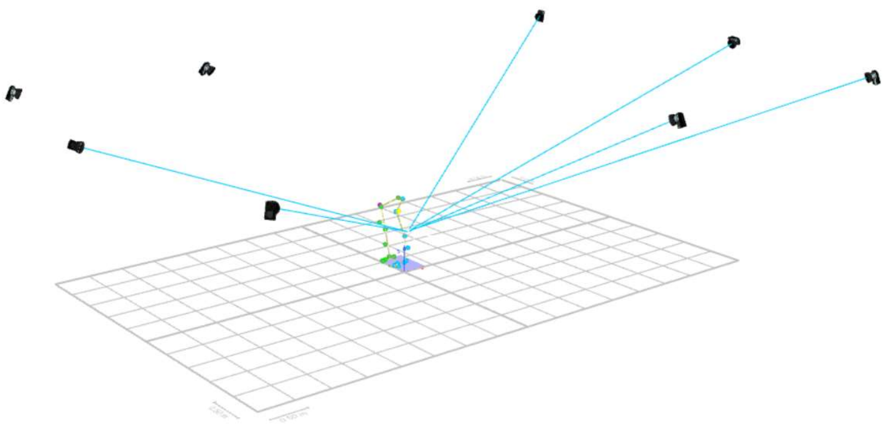

Figure 8. The reflective markers captured by infrared cameras in the lab to estimate coordinates (screenshot).

The participants walked barefoot on a 7 m overground pathway surrounded by eight synchronised Oqus cameras (Qualisys, Gothenburg, Sweden) with a force plate (Kistler Nordic AB, Jonsered, Sweden) mounted halfway (Figure 8). The participants were asked to walk at their preferred walking speed. Three walking trails, with the whole foot within the force plate of the left and right foot, were used for further analyses. Trials were processed in Qualisys Track Manager, including the gait cycle from the middle of the pathway. Those markers at the anterior superior iliac spine with longer gaps than 20 frames were filled manually. For those gaps exceeding 20 gaps due to wobbling mass, we used the trajectory of the 'help marker'. When processed, trials were exported to Visual 3D (C-Motion Inc., Rockville, MD, USA) with the project automated framework (PAF-module) gait module that includes the biomechanical model, spatiotemporal parameters, kinematics and kinetics (Figure 9). The force plate signal was used to detect initial contact and toe-off events, and kinematic gait pattern recognition was used in the other trials. The trials were manually checked regarding events to ensure accuracy in gait pattern recognition. Spatiotemporal parameters, like self-selected walking speed, were computed from 12 gait cycles. Ankle joint velocity at push-off and ankle range of motion was computed from the affected side or most affected side in those bilaterally affected for six gait cycles.

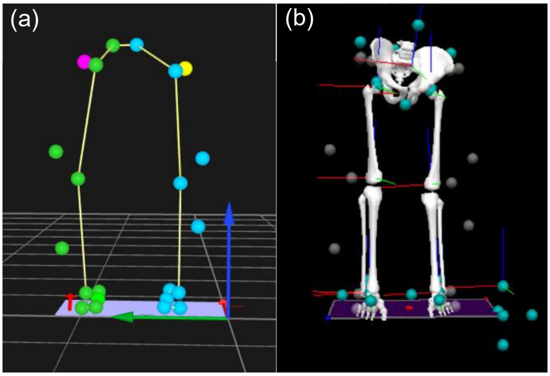

Figure 9. (a) Markers captured by the infrared cameras (QTM) were exported to (b) Visual3D, where the biomechanical model was built (screenshots).

Measuring Muscle Strength

The muscle strength of the plantar flexors was measured in a stationary dynamometer (CON-TREX®MJ ConTrex). The maximal voluntary contraction (MVC) of the plantar flexors was measured. MVC was isometrically measured in a seated position with the back reclined to approximately 30° and the knee extended (Figure 10a). The tester counted down and instructed the participants to perform the contraction 'as quickly and forcefully as possible and hold the contraction for 5 seconds while verbally encouraging the participants to perform optimally during the test. In all cases, three trials were given, but an extra try was given if a participant could not perform appropriately.

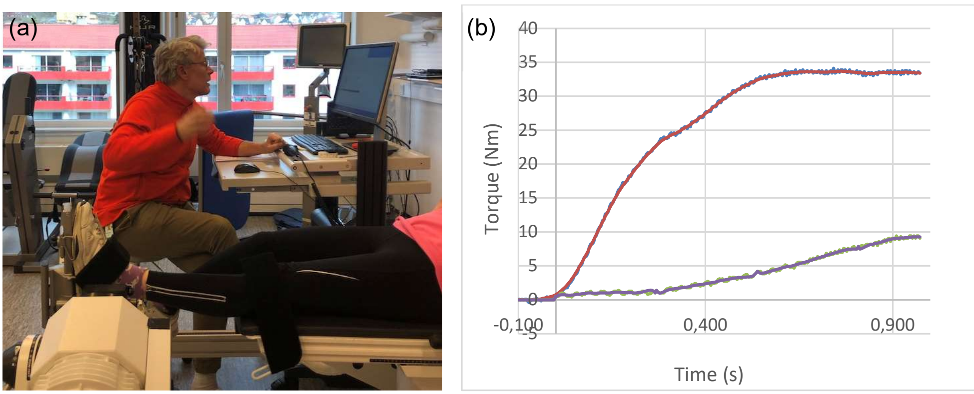

Figure 10. Testing of the ankle plantar flexors in the (a) ConTrex and (b) force curves (raw and smoothed) of one participant affected (purple) and non-affected (red) limb.

Data were imported offline to Microsoft Excel (Figure 10b), a torque plot was created for each trial, and measurements with countermovement and spikes were excluded. The trial that produced the highest MVC was used to further analyse the plantar flexor RFD (RFD_{pf}) in the early contraction phase at 50, 100, and 200 ms. The metric of RFD was Nm/s and derived from the force-time curve with Δforce/Δtime (141). The force curves were filtered with a fourth-order 15 Hz Butterworth low pass filter in Python. The onset of contraction was defined as baseline torque in the 500 ms preceding contraction plus three standard deviations.

Measuring Muscle Architecture

Magnetic resonance (MR) imaging is the ‘gold standard’ approach for assessing muscle size (142). Due to the costs, time and availability of MR scanners (143), ultrasound is a more available imaging method for muscle characteristics. Although ultrasound has been debated for clinical practice, it is suggested to be a reliable tool for monitoring MT after strength training (144). Muscle architecture of the medial gastrocnemius (MG) muscle was measured with 2D mode ultrasound (GE Logiq S8 Ultrasound, Milwaukee, Wisconsin, USA Korea, Ltd. 9, Sunhwan-ro 214Beon-gi 1, Jungwon-gu, Seongnam-si, Gyeonggi-do, KOREA) using an MLG-15-D probe, which is a high-frequency linear array ultrasound transducer.

Depth scanning was optimized to the participants’ anatomy, the gain was set to 50, and focus points were evenly distributed in-depth to ensure optimal imaging of each subject. Muscle thickness (MT), fascicle length (FL), and pennation angle (PA) were scanned when the participants lay relaxed in a prone position. The positioning of the test person was standardized to ensure a similar position of the leg for each scan session. The resting knee and ankle joints positions were measured according to Mohaheghi et al. (72); the resting ankle angle was measured with the fibular head and one arm aligned with the hindfoot along the calcaneal border, and the resting knee joint angle was measured laterally with one goniometer arm aligned with greater trochanter and the other aligned with the lateral malleolus. The probe placement, anatomic landmarks, and participant-specific features such as scars, moles, and vessels were marked on acetate paper to ensure similar probe placement across baseline and post scans of the MG. Ultrasound scans for MT were obtained by keeping the probe orientation transverse, and for FL and PA, the probe orientation was longitudinal.

Water-soluble ultrasound gel was applied to the probe to eliminate pressure on the skin to avoid compression of the area of interest (Figure 11). Five images were saved as digital imaging and communications in medicine (DICOM) files for each probe position and used for further image analyses.

Image analysis of MG examined MT, FL and PA. MT was defined as the distance between the deep and superficial aponeuroses (145). FL was measured from the superficial aponeurosis along the fascicle to the deep aponeurosis (146). If the total length of the fascicle was not visible, the remainder was estimated as a linear continuation of the fascicle and aponeuroses in the proximal direction: fascicle length = visible fascicle + h/sin PA (147). PA was defined as the angle between the identified fascicles and the deep aponeurosis described elsewhere (145).

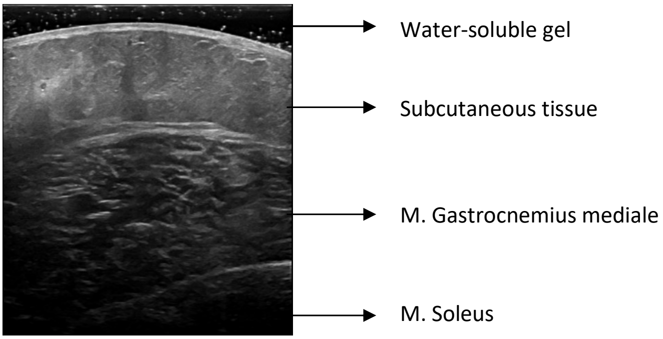

Figure 11. Ultrasound scan of muscle gastrocnemius muscle thickness with water-soluble gel to eliminate pressure on the skin to avoid compression of the area of interest.

Paper III Data Analyses and Statistics

Data were tested for normal distribution before statistical analysis. Results are presented individually for the participants with mean and standard deviation. In addition, when data are presented for the, they are presented as medians and interquartile ranges. Group changes were analysed using the Wilcoxon signed-rank test, GraphPad Prism 9.1.0 (GraphPad Software, San Diego, California, USA). P-values equal to 0.05 or lower were considered statistically significant.

3.4 Ethics

This thesis was conducted by the WMA Declaration of Helsinki Principles for Medical Research in Human Subjects (https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/). The participants signed informed consent before entering the study, and information was given both verbally and written that they could withdraw from the study at any time without giving any reason. Information and rights about data protection were given in the information letters (Appendix 2 and 3). The Regional Committee for Medical Research Ethics in Western Norway approved the research protocol for Paper I (REK-No. 2018-349) (Appendix 8) and Papers II and III (REK-No. 2018-2390) (Appendix 9).

4 Results

The main goal of this thesis was to explore walking in adults with CP. The secondary goals were defined to operationalize the main goal and divided into Study A and B.

4.1 The Qualitative Study A

Paper I was designed to answer the secondary goal A: To explore daily walking in adults with CP from a subjective perspective.

4.1.1 Paper I

Research aim: To explore personal reflections on daily walking by adults with CP.

Results

Intrinsic and extrinsic factors were associated with daily walking in adults with CP. Intrinsic factors (reduced functional capacity and reduced balance) provoked rest during the day because walking was an energy-demanding activity, albeit a chosen one. For many, freedom and independence came with walking ability, and falling outdoor was a considerable risk some were willing to take. Extrinsic factors (walking anomaly, attracting onlookers' attention, and seasonal changes) influenced participation, and a seasonal icy ground could challenge an intrinsic factor such as balance. Accepting walking aids was potentially helpful when coping with intrinsic and extrinsic factors. The importance of maintaining walking ability was emphasised (nearly all had experienced walking deterioration), but scepticism towards the possibility of walking improvements after training was expressed.

4.2 The Quasi-Experimental Study B

Paper II and III were designed to answer the secondary goal B: To explore whether ballistic strength training is feasible, improves walking and potential muscle adaptation.

4.2.1 Paper II

Research aim: To investigate if adults with CP can perform and benefit from ballistic strength training of the ankle plantar flexors to improve walking; evaluated through physical measures, self-reported measures, and interviews.

Results

The participants from Paper I expressed scepticism that improving walking in adulthood was possible; hence, the participant's experiences were incorporated in Paper II when investigating the feasibility of task-specific strength training to improve walking in a neurologic population. This intervention has not previously been explored scientifically in adults with CP. This paper demonstrated that adults with CP could perform ballistic exercises when familiarised with them and provided with instructions, evaluated through physical measures, patient-reported outcome measures, and interviews. One person withdrew because of bursitis in the foot. Most reported better balance and walking control after the intervention. Most participants reported self-experienced improvements of walking, but there were no clinically relevant improvements in the physical performance measures (6MWT and HiMAT) that supported the self-reported measures. A longer intervention timeframe may be required before determining if improved walking could achieve physical or functional benefits. The participants described better balance and walking control after the intervention. Therefore, gait kinematics and muscle strength were investigated further in Paper III.

4.2.2 Paper III

Research aim: To investigate whether eight-week ballistic strength training of the ankle plantar flexors could improve muscle strength, muscle architecture and walking function in adults with CP.

Results

In Paper III, we wanted to explore further if any structural changes or gait pattern could explain their experienced improvement in walking. Objective measures of walking revealed improved preferred walking speed by more than 0.1 m/s in two participants, decreased in one and stayed unchanged for the remaining five. Five of six participants improved muscle strength of ankle plantar flexor RFD and MVC (missing data for two participants), but muscle architecture scanned with ultrasound was unchanged. Preferred walking speed (3DGA) increased in two of eight participants, decreased in one, and stayed unchanged for the remaining five. Although walking speed depends on ankle joint velocity at push-off, there was no systematic covariation in how the participants changed regarding angular velocity and walking speed. Ballistic strength training targeting ankle plantar flexors may be a potential training approach to improve RFD in adults with CP, but this needs further exploration. Furthermore, assessing whether increasing RFD might transition to walking function will require more extensive studies to reach more definitive conclusions.

5 Discussion

The knowledge basis of walking in adults with CP is sparse. Therefore, the overall aim of this thesis was to gain knowledge on the meaning and experiences of walking and to study whether task-specific (ballistic) strength training is feasible in adults with CP and evaluate potential muscle adaptation to this training.

In the following section, the methodological considerations about the internal and external validity of the results are discussed (5.1), followed by a general discussion (5.2).

5.1 Methodological Considerations

This section elaborates on considerations and critically reflects on the techniques and methodological choices to answer the research questions. Firstly, I discuss the following regarding the validity of the included studies: 5.1.1, to what degree the results are true (internal validity) and 5.1.2, to whom the results may be relevant (external validity). Secondly, in 5.1.3, I will discuss the position I, as a researcher, might have influenced the analyses of the findings.

5.1.1 Internal Validity

Factors such as study design, choice of participants, and outcome measures can influence the study's results, and *internal validity* considers whether the results are valid (110, loc. 1395).

Method Triangulation

Triangulation is a research strategy used to increase the validity and reliability of research findings (148). Therefore, this thesis consists of quantitative and qualitative studies. Paper I searched knowledge on daily walking in adults with CP. Hence, a qualitative study investigated human qualities such as experiences, thoughts, expectations, and attitudes (112). Paper II investigated whether adults with CP could perform and benefit from ballistic strength training of the ankle plantar flexors to improve walking using both qualitative and quantitative measures. Paper III quantitatively investigated whether 8-week ballistic strength training of the ankle plantar flexors improved gait kinematics in adults with CP and potential muscle adaptation of the MG. A quasi-experimental design evaluates intervention without including randomisation (149). Using this design, we had to admit the methodological limitation of not including a control group but still acknowledging the report as the first step in this field of investigation (150).

Method triangulation may enhance the rigour of studies and promote a more comprehensive understanding of the given phenomenon. However, there are several criticisms of triangulation in research (151). When method triangulation is used, one must be careful when comparing and weighing results and be aware of study biases related to each method used (151). Further, the broad definition of triangulation may be an argument for replacing the term *triangulation* with *mixed methods* (151).

Addressing Feasibility With Mixed Methods Design

The training intervention was intentionally designed as a cohort study. Due to limited evidence of ballistic strength training in adults with CP, a feasibility study may be recommended (152). However, randomised controlled trials (RCT) are often the best way to evaluate the effectiveness of an intervention in evidence-based medicine, a pilot or feasibility study conducted before an RCT is recommended to improve internal validity in this type of research design (153). A pilot is a scaled-down version of the study, whereas a feasibility study is done before the main study to estimate key parameters (154). The guidelines for ballistic exercise description are based on healthy adults. According to Ryan et al. (85), we used a feasibility study in Paper II, as this might be the place to start when using exercise guidelines developed for the general population in persons with CP.

Including several methods in a single study is considered a strength when investigating feasibility (152). *The task-specific strength training paper* used a mixed methods convergent design. A mixed method convergent design concurrently collects qualitative and quantitative data (138) and is appropriate because the qualitative interpretations may converge with the quantitative findings. Paper II included quantitative (whether walking was affected) and qualitative (personal experience of walking after intervention and for a detailed understanding of how adults with CP experienced task-specific training) research methods.

Several published articles guide focus areas for feasibility studies (152, 153). Orsmond and Cohn (155) compiled seven such articles on guiding feasibility into five overarching questions (Table 3), offering a broader perspective than a single study might provide. As with any research, one should identify an area that best fits the study's requirements (152). Paper II investigated if adults with CP could perform and benefit from ballistic strength training of the ankle plantar flexors to improve walking and focused on three of the suggested objectives (Objective 2, 3 and 5) (Table 3) (155). By choosing this area of focus, we missed the clinicians' perspective (Objective 4) on how they experienced the ballistic training by the participants and whether they experienced being properly trained. As a result, it can be considered a weakness that only the participant's perspective is included in Paper II.

Table 3. Orsmond and Cohns' (155) five feasibility objectives lined up in a table with its associated main question.

Objective	Main question
1 Evaluation of recruitment capability and resulting sample characteristics	*Can we recruit appropriate participants?*
2 Evaluation and refinement of data collection procedures and outcome measures	*How appropriate are the data collection procedures and outcome measures for the intended population and purpose of the study?*
3 Evaluation of acceptability and suitability of intervention and study procedures	*Are study procedures and intervention suitable for and acceptable to participants?*
4 Evaluation of resources and ability to manage and implement the study and interventions	*Does the research team have the resources and ability to manage the study and intervention?*
5 Preliminary evaluation of participant response to intervention	*Does the intervention show promise of being successful with the intended population?*

Since validity threats vary among designs, the convergent threats are listed, such as "not using parallel concepts in data collection for both the quantitative and qualitative databases, having unequal quantitative and qualitative sample sizes, keeping results from the different databases separate, failing to resolve disconfirming results" (138, p. 251). We followed the recommended strategies by Creswell to minimise validity threats of the convergent design (138). For example, we addressed the same concept in the qualitative and quantitative data and used the same sample in the quantitative and qualitative data collection. The integration of data analysis involved comparing quantitative and qualitative data.

Selection Bias

A selection bias occurs when the study sample is systematically different from the population of interest (110, loc. 1397). The population of interest in this thesis was adults with CP. Study A (Paper I) aimed to investigate walking in adults with CP. Purposive sampling included participants with relevant experiences of the phenomena we explored (walking;) (138). Study B (Paper II and III) searched for persons who wanted to participate in an intervention aiming to improve walking and included participants who could walk; hence, the sample relates to the walking part of the population of adults with CP. We included both genders with an age span of 32 years (range 24-56); some of the participants had experienced walking deterioration, while others had not, and there was a wide span of BMI (18–38). Despite all having CP, this diverse group reflects the study sample.

Information Bias

Information bias, also called measurement bias, is any systematic or nonrandom error in data collection (110, loc. 1395).

Interview

The reflections paper and *the task-specific strength training paper* used semi-structured interviews, making the researcher an instrument (112, p. 41). As a 'measurement tool', my background (teacher and movement scientist) impacted me, and a reflexive log was kept during data collection (112, p. 53). The focus group conversation was a helpful preparation for the interview setting. Additionally, the semi-structured interview technique was rehearsed with the supervisor. Mock interviews are suggested by Wahyuni (116) to rehearse expressions and words before the interviews, and prepared me as the measurement tool.

Familiarization with Outcome Measures

The testing took about four hours. Due to the time spent, the logistics of testing personnel, and the time burden for the participant, we did not take the time to perform a familiarization test of the measurement tools. This is likely to have influenced the findings since a pre-test familiarizes the participant with the test's content (156, p. 274). In retrospect, a familiarisation test with the primary outcome measures: 6MWT and MVC/RFD in the ConTrex should have been conducted.

Muscle Strength

Muscle strength of the ankle plantar flexors was measured in a stationary dynamometer (ConTrex). Due to actin and myosin crossing, the participant's ankle joint was positioned at 0°, as recommended for force production in TD people (157). However, the muscle torque-angle relationship may not be the same in CP as in healthy adults since a more plantarflexed position is suggested to be more powerful in adults with CP (158). Therefore, testing force in several positions or customising it to each person could affect the force signal and might have influenced the results. The most appropriate should be used in further studies.

In accordance with the literature, the trial with the highest MVC was used for further analysis of RFD, and those signals with a countermovement were excluded (141). As seen in Figure 12a, all pre-test signals have a countermovement; hence, they are excluded for RFD analysis. We should have plotted the force signal during testing to ensure each participant had trials without countermovement. Still, it is noteworthy how the shape of the force signal differs between pre-and post-test, and if this is due to the training or familiarization with the testing is unclear.

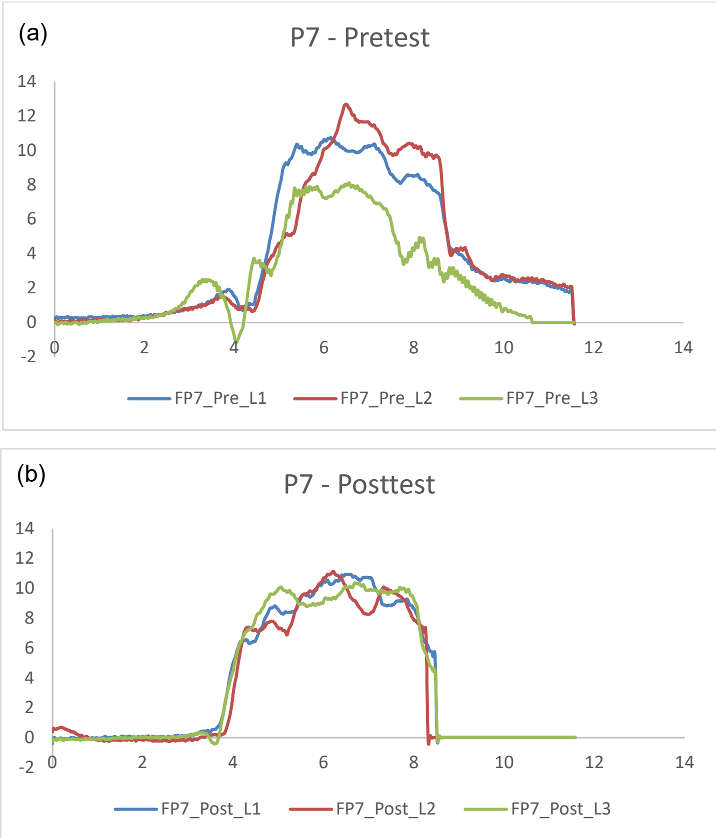

Figure 12. (a) Pre-test (b) Post-test of isometric ankle plantar flexors of participant 7.

Furthermore, because some participants' MVC did not occur until five seconds, it may not be appropriate to use the trial with the greatest MVC to analyse RFD in CP, as proposed for TD (141). Therefore, one suggestion is to use the trial with the highest MVC within the first 500 ms. We used guidelines for analysing data in healthy persons (141), which may have been insufficiently accurate for this sample.

Muscle Architecture

Measuring muscle architecture with ultrasound is debated and lacks agreement in terminology, disciplines, clinical practice, and research (159). There are two sources of variation for biomedical images: scanning and imaging analysis. Before the start-up of Study B, we initiated a bachelor project to familiarize ourselves with measurement outcome variations and image procedures and prepared a standard operating procedure. Before the analysis, image data analyses criteria were defined. The criteria were to ensure consistent image data analyses between participants and between scans and to minimise reader variability. According to defined image standards, the two images with the highest image quality were selected for further analysis; the image contained region and characteristics of interest and no motion artefacts or blurriness due to motion of probe or tester. Pre-and post-images were blinded before image analysis. To minimise reader bias, two researchers (Vilde Cathrine Nesse and BEG) analysed the data with a professional experienced with biomedical images (CBR) of analysing biomedical images, which strengthens the validity of the image analysis.

Response Bias

Self-reported instruments are threatened by bias that may result from social desirability or recall period (160). Validation of the instrument is the most important approach for avoiding social desirability (160), which we aimed for in the used instruments. FISSA and NPRS are validated in adults with CP, Walk-12 is valid in another neurologic population (multiple sclerosis), and PGIC has not been validated in CP. Validating the instrument would have been a comprehensive process (160), but that would have strengthened the validity.

Recall bias is related to several factors, such as length of recall period and sample characteristics, which should be reflected when deciding recall period (160). PGIC was the instrument with the longest recall period of eight weeks, as the question was ‘How is your walking function now compared to before the intervention started?’. Walk-12 has a recall period of two weeks, seven days for the FISSA scheme, and one day for the numeric pain rating scale (PainNRS). Also, partaking in an intervention aiming to improve walking might enhance the placebo (161). Therefore, the recall of how the diagnosis of CP has affected walking during the last two weeks may be prone to the placebo effect.

The PainNRS score is a total pain score that does not distinguish between pain sites. The most frequently reported pain is in the lower back, hips and feet (56, 79). We do not know where the participants experienced pain due to the measurement tool we used. Rather than a single number representing the entire body, we should have used a scheme that identifies pain sites, such as reporting pain in checkboxes for eight body parts and pain frequency (43).

5.1.2 External Validity

This section discusses external validity, which asks to whom the study's conclusions or findings apply beyond the study participants; across populations, settings, time, outcomes, and treatment variations (156, p. 278). External validity is probable the most well-known term, yet, nomenclature varies by research genres, such as *transferability* in qualitative studies (116) and *inference transferability* in mixed methods studies (138, p. 280).

In *the reflections paper*, we used a qualitative design, and transferability considers to whom the findings can be relevant in other contexts than the one in which the project was conducted (112). A purposive sample of eight persons may not be reproducible, but the research findings might be transferred to others (116). Our participants' age range (26–60) and the GMFCS I–III from Norway are consistent with the findings in the United States among participants with CP (18–65 years) and GMFCS I–III on the use of strategies in their daily lives to cope with age-related changes (162). Hence, whether the findings are transferable is judged by the consumer of research rather than the researcher (138, p. 33).

We used both qualitative and quantitative methods in *the task-specific strength training paper*. When merging the results, the inference transferability "is the degree to which research conclusion can be applied by other similar settings, people, time periods, contexts, and theoretical representation (…)" (111, p. 297). We cannot generalize our results to all adults with CP. However, we included the participants' voices in the feasibility design, which is important to the chosen outcome measures.

Furthermore, patients may have other thoughts about the intervention than therapists and scientists. Therefore user involvement is a priority in healthcare science (45), and the inference of this study might be transferred to other studies investigating innovative interventions in neurological populations.

In *the training response paper,* we used a pre-post design without a control group, which is a limitation to external validity, as we cannot infer treatment effects (163). Despite this limitation, we chose this design because we wanted to investigate if any structural changes could explain the functional outcome measures in the task-specific strength training paper. Even though the data are not externally valid, we believe they may be helpful to researchers planning studies in this or other neurological groups.

5.1.3 Reflexivity

Reflexivity is an active attitude (112) on how the researcher self-reflects on potential biases and predispositions (156, p. 284). Knowledge is the product of human perception, interpretation, and interaction; therefore, the scientist will affect the process and its results (112). Being a novice interviewer, a reflexive log helped me reflect upon my scientific role. After each interview, I had a peer debrief with my principal supervisor, who asked questions about the interviews that made an important area for reflection on how to be a friendly professional without being personally involved and to stay in the role.

Furthermore, my scientific position as a researcher has changed during this PhD period. I entered with a purely quantitative background, more in line with the positivistic paradigm. I considered RCT not only to be on top of the evidence-based scientific pyramid but also to be the only ‘real science’. As a PhD student, I learned that RCTs are not the only study design that can provide useful information on treatment effects; well-designed observational studies can also do that (163). Today, I position myself in the pragmatic paradigm, which allows for inductive and deductive analysis. I had to let go of the deductive mindset and make room for an explorative, inductive mindset. It was a difficult shift. Despite all my newfound knowledge, the experience prompted me to rethink who I am as a researcher. As a result, I agree with Murad et al. (164) that the evidence-based pyramid must be modified to better visualize how the designs are not necessarily hierarchical but may have a smoother transition upwards (164).

Although feasibility and pilot studies are important for research, observational studies may be challenging to get published (165). Which made me reflect upon the question, when is the science of value? If these studies are not published, the clinician might not find all the relevant information observational designs can provide (166). Not only in journals that are predisposed to the strength of scientific methodology but also in meeting with other scientists or scientific environment. Some have condescending attitudes to qualitative science that shine through (167), and it is also in the encounter with these I meet my 'old' self. Learning a completely new research method has been demanding. I have gone a few rounds with myself and developed the research perspective. It has not been easy, but that transformation has reshaped me as a researcher, allowing me to approach new projects more openly.

5.2 General Discussion

Daily walking in adults with CP was affected by reduced functional capacity, reduced balance, walking anomaly, attracting onlookers' attention, and seasonal changes. Still, the walking ability was important to maintain for as long as possible (Paper I). Ballistic strength training of the ankle plantar flexors is considered task-specific training for walking, and adults with CP could perform the ballistic exercises when familiarised. The participants' self-reported improvements were not confirmed with the physical outcome measures (Paper II) or gait kinematics (Paper III). However, the muscle strength increased, although no change in muscle architecture was detected (Paper III). The nature of the study is of necessity, explorative, since there is very little research in this area. Therefore, the results discussed in this section should be considered in light of the methodological discussion.

5.2.1 Personal and Environmental Factors Affected Daily Walking

Adults with CP reported how crowded places like shopping malls were avoided, as walking required more space (Paper I). This is in accordance with others, as functional mobility is reported to be problematic in young adults with CP (37). Other environmental factors, such as climate, differ according to latitude. Nordic countries, for example, have four seasons with variable weather. TD might walk a little more carefully during winter with snow-covered surfaces. For adults with CP, cold weather made it more energy-demanding to walk and initiated a planning-ahead phase (Paper I). This is by others reported as coping strategies of growing older with CP (40). Walking is, therefore, not an unconscious activity in adults with CP.

Adults with CP were aware of their walking anomaly, confirmed by onlookers' attention and comments (Paper I). The movement pattern of walking with CP is easily detected, as the vertical oscillation of CoM is on another path than typically developing (33). It was reported 'easier' to cope with and accept onlookers in adulthood (Paper I). They are simultaneously saying, although indirectly, that it was harder to accept onlookers at a younger age. Mental health in children and youth are reported with experiences of bullying from peers at school and longing to be 'normal' (168). Therefore, childhood experiences of walking with CP might affect how they experience their adulthood walking, and a walking variation might come with a history.

Reduced balance forced participants to ask themselves whether it was time for a walking aid. Some preferred wheelchairs, even though they could walk. It was considered a safe choice because reduced balance and falling outside were risky (Paper I). Hence, factors that make up the physical environment might not be well organised. Along with a declining function came sorrows of being unable to continue as before. Personal factors are not classified in the ICF but are suggested to be important because personal factors can influence functioning and disability (46). Despite an increased risk of falling outside when walking, some prioritised it since freedom and independence came with the walking ability (Paper I). This reveals something about their attitude toward an important function that changes in adulthood.

Maintaining walking ability was necessary for independence and participation but being independent came with a price (Paper I). From the literature, late effects of CP and walking deterioration are frequently described (11, 37, 43, 44), and nearly all Paper I participants had the same experience. Walking deterioration is reported in varying age ranges during life, from 32 in bilateral to 50 in unilateral (43). Consequently, impossible to participate at the same pace as in younger days. Reduced walking and limitation of daily life are also described by Morgan et al. (169). Hence, walking is a chosen conscious activity that made them reflect upon the smartest thing to do. The follow-up is widely variable in adults with CP (170-172), and these results reveal a transition in adulthood that addresses the need for lifelong follow-up.

5.2.2 Task-Specific Strength Training to Improve Walking

Participants from *the reflections paper* were sceptical about whether their walking (activity) could be improved with training. Still, they expressed hope and optimism that exercises could maintain their walking ability.

Walking

Six of eight participants experienced walking improvement (PGIC) after the intervention; however, these experienced changes were not reflected in the physical outcome measures of 6MWT, HiMAT (Paper II) or walking speed (Paper III). The training mainly targeted the ankle plantar flexors, and it was suggested back in 1974 by Carlsöö et al. (173) how weak plantar flexors affected hemiparesis walking. Still, we could not find literature targeting this muscle with strength training in adults with CP. Study B participants were inexperienced with ankle plantar flexor training (Paper II). The inexperience of targeting ankle plantar flexors aligns with the critique by Williams et al. (94) on how relevant muscle groups for walking are not targeted in neurological populations. Furthermore, targeting only a single muscle function can still be a limitation, as walking relies on several muscles (174).

Ballistic StrengthTraining of Ankle Plantar Flexors

The exercises were ballistic to replicate walking and energy storage (102). The exercises were instructed to be performed with high velocity, and the participants shared frustration and struggled with the performance (Paper II). The rapid change from dorsal flexion to plantar flexion of 300 °/s in walking (28), was not easily adapted in the exercises. One explanation for the challenge of performing ballistic strength exercises is that their rapid force development is impaired, reported in thigh muscles (71) and ankle muscles (100). Fibre composition could give valuable insight into the muscles' micro-level to better understand force production and the physiological adaptation of strength training. However, the invasive outcome measures (for example, muscle biopsies) pose a burden to the participants and incur expenses but might give valuable information that should be included in further research on strength-training response.

About halfway (after four weeks) into the intervention, the participants improved in performing the exercises and needed less guidance. The prolonged familiarisation time could be explained because conducting the exercises was cognitively challenging (Paper II). In performing the exercises that targeted the ankle, the knee took control of the motion. It was challenging to 'downregulate' the knee and simultaneously 'turn on' the ankle muscles because participants did not know how to control this (Paper II). The participants reported that numerous repetitions 'forced' their brains to finally master the exercises. The stages of learning described by Fitts and Posner are divided into three stages: cognitive, associative, and autonomous (57, loc. 1568). Because the first step of skill acquisition, the 'cognitive stage', requires the most attention, the participants might be at the first motor skill stage of skill acquisition. In this stage, the problem is understanding what to do (57). Technically challenging skills in sports science are often divided into smaller part-exercises when the skill is too difficult to perform as a whole. To target, only one phase of walking can compare with part-exercises, which are perhaps more used in technically challenging sports exercises (175). Therefore, isolating the ankle plantar flexors before targeting them during walking could be a good place to start. Specificity and repetitions are also recommended by Kleim and Jones (176) regarding plasticity and motor skill acquisition. Based on the participants' descriptions, these results may suggest that the training was as much about motor control and motor skill acquisition as power training. Coordination training is suggested to be beneficial for children with CP to improve control distally in walking (107). The results from this thesis substantiate that it might be something even adults can benefit from.

The exercise performance required participants to lie supine on the glideboard, with the limb out of sight, which proved difficult for some. Wingert et al. (177) reported a significantly less accurate kinaesthetic position of the upper- and lower limb position when omitting vision, suggesting a proprioceptive deficit. Vision might also compensate for missing proprioceptive information in our participants, forcing them to use other feedback strategies. Some asked for a mirror to regain visual feedback from their leg (Paper II). Furthermore, verbal communication with the instructor or hands-on was described as crucial to controlling the ankle plantar flexors.

5.2.3 Structural and Functional Training Adaptation

The ankle plantar flexors produce less power when walking with CP, and the power production might not be targeted adequately when *walking*. Therefore, the reduced ankle power reported in CP walking was targeted with task-specific (ballistic) strength training. The desire of prescribing exercises to improve health and performance implies that our understanding of the adaptations evolves (178). Therefore the muscles involved, speed of movement, and range of motion (among other factors) should be considered in specific training goals (4). The potential muscle adaptation of the ankle plantar flexors and their contribution to gait is discussed in the following section.

Muscle adaptation

Progressive overload is essential for strength training progression and muscle adaptation (179), and strength training specificity lays the foundation for specific physiological adaptation. Power training recommendations by the American College of Sports Medicine (ACSM) are 1-3 sets per exercise (0–60% of 1 RM for lower body exercise) for 3-6 repetitions for power training (4). The participant's series (1–7) and total reps (60–428) varied during the intervention (Paper II) and differed considerably from the ACSM recommendations. Additionally, it was challenging to decide on resistance at the beginning of the intervention due to the participants' difficulties performing the exercises. Therefore, progression was based on a qualitative assessment of whether the exercises were done correctly. This approach can be prone to bias and may have led to, for example, slower progression than necessary. The training's potential muscle adaptation was evaluated with muscle strength and architecture.

Muscle Strength

Based on the current research literature, power training studies in neurological populations are sparse but increasingly (101, 180, 181). Muscle power can be trained in several ways, and different terminology is used in the research literature: functional power training (182), explosive resistance training (180), high-velocity induced strength training (101), and ballistic strength training (102). One measure of the muscles' ability to produce force rapidly is RFD. The participant's RFD was less than typically developing (100) but increased after the intervention, although only at 100 ms (Paper III). In the research literature, the gastrocnemius fibre type-I and type-II are found in equal proportions (50/50) in TD (183). In contrast, spastic muscles in CP are measured with up to 90% of type-I fibres (184). Since fibre type-II is important for power, the muscle architecture could be a limiting factor for RFD in CP.

Muscle Architecture

The muscle architecture is one of the determinants of force production in the muscle, and MT is a good indicator of muscle strength and mass (185). After eight weeks of ballistic strength training, no structural changes in MT, FL, or PA were detected with ultrasound (Paper III). The measurements were performed when the muscles were at rest; dynamic ultrasound could give information about the actions of the muscles during movement (186) and could offer valuable information about, for example, the

PA throughout the gait cycle (187). Physiological adaptation of strength training (increased velocity) is reported in adults with CP after 8–10 weeks (101). In a systematic review, Verschuren et al. (188) recommend strength training periods between 12–16 weeks for individuals with CP. Improved muscle architecture is expected after 8–12 weeks of strength training in healthy people (178), but reported measured with ultrasound already after three weeks (189). Measurement tools and studies may have focused on different responses, therefore the widespread variation in time to muscle response. Nevertheless, the training period in our study may have been too short for adaptation to muscle architecture.

The median pre-test scans of MT were measured to 1.62 cm (Paper III). TD gastrocnemius MT of less than 1.5 cm is considered low muscle mass (190). Our findings are in corroboration with others that spastic muscles have lower muscle mass than healthy muscles (70). In TD individuals, the MT of the gastrocnemius is reported to decline with increasing age (40–79 years), and deterioration is reported earlier in men than women (191). MT is not reported with increasing age in adults with CP in the literature. The divergent results between the participants call for more research on muscle physiology to better understand how natural ageing and physiological strength training respond in adults with CP. Additionally, that might vary more than TD due to spasticity, load pattern, and activity. The physiological adaptation to power training is more than muscle adaptation, like better coordination between the nervous system and muscle-tendon complex (192).

Other Potential Physiological Adaptations

No measured changes in the muscle structures could explain the increased RFD (Paper III). This was also the result of a strength training study of healthy older adults with impaired plantar flexor torque (193). The authors' strength training intervention targeted plantar flexors. The participants were instructed to raise their heels as fast as possible from a standing position and lower them at moderate speed (194). Similar to our results (Paper III), the healthy older adults improved RFD without structural changes to their muscle architecture (194). Therefore, it is likely that other potential physiological adaptations could explain the increased RFD.

In addition to muscle factors, Fitts et al. (195) list neural determinants that affect the muscles' force and power output like "cortical drive, afferent inputs to the central nervous system and alpha motor neurone recruitment" (p.113). Increased RFD without any change of muscle architecture assumes neural factors are responsible (141). Neurological adaptation is a physiological adaptation to strength training (196), although muscle structure and function are most frequently used as outcome measures after such interventions. However, neural adaptation was superior to muscle hypertrophy after explosive strength training in older adults (197). Moreover, Holtermann et al. (198) reported changes in H-reflex after resistance training, suggesting that improved RFD is a reflex adaptation at a spinal level, in contrast to the recruitment of motor neurons, which occurs at a supraspinal level (198). We did not measure the H-reflex amplitude, but this should be measured in CP better to understand the neural activation in muscle force generation.

The presumed reduction of proprioceptive information might explain why participants found it challenging to perform the exercise rhythm since proprioceptive input from muscle spindles and Golgi tendon organs is central in rhythm-generating networks, at least in cats (199). The inhibitory pathway in motor control is of functional relevance. In healthy adults, an asymmetry has been found in the inhibitory reflex of triceps surae to tibialis anterior such that triceps surae receives a less inhibitory response from tibialis anterior than the other way around (200). The reflex behaviour of reciprocal excitation contrasts with reciprocal inhibition as a neuronal development error. This is found in the tibialis anterior and soleus both were activated (normally, the tibialis anterior is inhibited) with dorsal stretch in CP (201). The age-dependent suppression of reflex is not shown in children with CP (202); hence, the ability to suppress this reflex when moving is impaired (203). To better understand the ballistic strength training in adults with CP, the PA, MT, RFD, supraspinal drive, H-reflex, stiffness, ultrasound, and electromyography need to explain any changes.

The muscle action of the gastrocnemius is near isometric at push-off, whereas the tendon lengthens in stance and recoils at push-off in TD (66, 204). This contrasts what Kalsi et al. (186) measured in children with CP, where spastic muscle fascicles are found to elongate, and the tendon remains near static. A stiffer tendon means that more force is needed for the tendon-elongation and energy storage and might not, therefore, contribute to the 'catapult' mechanism at push-off. Knowledge about tendon stiffness could be valuable to understanding the dynamics of the muscle-tendon complex and can be measured relatively easily with hand-held devices (205).

Gait analysis

Self-experienced change of improved walking (Paper II) was not detected with gait analysis (Paper III). Opheim et al. (206) aimed to objectively identify with 3DGA those who reported walking deterioration but could not detect this self-experienced change quantitatively, which illuminates a challenge of measuring walking objectively regarding how the participants have a subjective experience.

The angular velocity at push-off varied with walking speed and between participants. For instance, the walking speed of Participant 2 was 1.1 m/s at pre-test and 1.4 m/s at post-test. However, some small studies in children have targeted ankle plantar flexor strength with promising results in spatiotemporal parameters (207) and ankle plantar flexor power (208). Despite this, angular velocity at push-off stayed constant at about 275 °/s. The contributions of the ankles, knees, and hips tend to be equal regardless of walking speed in TD individuals (29). However, earlier research has shown that children with CP tend to increase hip power and interpreted it as a compensating mechanism for decreased ankle power generation (107). This shift to hip power is also reported in healthy older adults (209). We did not investigate the hip-ankle power relationship in our sample, but this could have shed light on the findings.

6 Conclusion

How adults with CP experience walking are poorly understood. Therefore, we investigated daily walking reflections, whether task-specific training to improve walking is feasible, and potential muscle adaptation.

We found that daily walking was influenced by both intrinsic embodied and extrinsic environmental factors. Even though the participants in the reflections paper expressed scepticism about their ability to improve walking through training, they experienced exercises important to maintain walking as deemed important to preserve for as long as possible. Eight weeks of task-specific ballistic strength training of the plantar flexors was feasible for adults with CP.

Most participants subjectively reported improved balance (interview) and walking (PGIC). However, these changes could not be detected using standardized physical outcome measures (6MWT and HiMAT) or biomedical imaging (ultrasound). Nevertheless, a long familiarisation time potentially affected the results. Therefore, when implementing new task-specific strength training for this population, allowing for a long familiarisation time is recommended in the future. Although we did not find any architectural muscle adaptations, RFD increased in five of six participants, indicating a neuromuscular adaptation that should be explored further.

This thesis contributes to a sparse but growing body of empirical knowledge about adults with CP and strength training targeting walking. As their walking changes through adulthood, this skill is influenced by structure, function, participation, and contextual factors, calling for lifelong follow-up. Furthermore, task-specific strength training of the plantar flexors has not been targeted with ballistic exercises in this population before. These findings highlight that training interventions and physiological adaptation in spastic muscled need further investigation, before the effects of such strength training on walking can be determined.

7 Implications and Future Perspectives

7.1 Clinical Implications

Daily walking experienced by adults may provide valuable insight, as walking is targeted in childhood physiotherapy. The extrinsic contextual factors (walking anomaly, attracting onlookers' attention, and seasonal changes) identified in this thesis should be noted by clinicians. Nevertheless, it is essential to understand contextual factors as barriers to daily walking in persons with CP to better control their life situation and participation. The studies constituting this thesis were not designed to evaluate the effect; therefore, clinical implications are unclear. However, our study findings have contributed to the knowledge of walking in adults with CP from different perspectives.

7.2 Future Research

Based on the results from this thesis, new questions for future research emerged. Today, we have limited knowledge of daily walking, the physiological adaptation to strength training and if strength training improves walking in adults with CP. Some of the unanswered questions that need to be addressed are suggested in this section.

Intrinsic factors (reduced functional capacity and reduced balance) were reported to change in adulthood, calling for lifelong healthcare follow-up. Therefore, future studies targeting cardiorespiratory, muscular and coordination in the ageing population with CP could be designed with longitudinal and cross-sectional studies to increase knowledge and awareness of ageing in CP.

Ballistic strength training is suggested as task-specific for walking (102). Although participants in our study intentionally performed ballistic strength exercises, we did not measure the velocity of the performed exercises. Additionally, the interviews revealed how challenging it was to master the exercise and control the ankle motion. Therefore, future studies should control for exercise velocity. This is of particular interest since training adaptation is specified to the stimulus applied (some examples: muscle actions involved, speed of movement, range of motion, intensity, and training volume) (4).

When designing strength training programmes for adults with CP, most of the basis for recommendation constitutes individual studies. This contrasts with the ACSM guidelines "Progression models in resistance training for healthy adults" (4). Guidelines for strength training in adults with CP need to be established. Therefore, the basal science of neuromuscular adaptation to strength training should be further investigated in adults with CP. Hence the basic understanding of force production (like Henneman's size principle and the Hill curve) would help understand the physiological adaptation to strength training.

Five of six participants improved muscle RFD after the intervention, but muscle architecture was not detected. Since RFD may be influenced by the degree of neural activation, muscle size and muscle fibre-type composition (210), these should be included in future studies when investigating the muscles' RFD to ensure if other parameters are responsible for the RFD results. Also, RFD is estimated from MVC force curves, and typically the trial with the highest MVC is used for further analysis (211). We noted that persons with CP used a long time to generate peak force. Hence further studies of the relationship between MVC and RFD in CP are needed.

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Paper I

INTERNATIONAL JOURNAL OF QUALITATIVE STUDIES ON HEALTH AND WELL-BEING
2020, VOL. 15, 1746577
https://doi.org/10.1080/17482631.2020.1746577

Walking through life with cerebral palsy: reflections on daily walking by adults with cerebral palsy

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ABSTRACT

Purpose: Walking is a major target in childhood physiotherapy for children with cerebral palsy (CP). Little information exists on the importance or value of walking when these children grow up. The aim of this study was to explore personal reflections on daily walking by adults with CP.

Method: Semi-structured individual interviews were conducted and analysed with systematic text condensation, a four-step thematic cross-case analysis.

Results: Eight ambulatory adults (26–60 years, four women and four men) with CP were interviewed. Almost all had experienced deteriorated walking ability in adulthood and reported that walking was restricted and affected by intrinsic features, such as pain, fatigue, reduced balance and fear of falling. Extrinsic features such as being looked at due to walking abnormality and environmental factors, such as seasonal changes affected their free walking and was common. Some had accepted using mobility aids for energy conservation.

Conclusions: Both intrinsic and extrinsic factors influence walking in adults with CP. Reflections by the adults with CP suggest these features may reduce participation in public spaces and potentially increase acceptance and use of mobility aids.

ARTICLE HISTORY
Accepted 14 March 2020

KEYWORDS
Adults; cerebral palsy; walking; gait; reflections; interview

Introduction

Walking is an important activity for health and well-being (Nordh et al., 2017; Stamatakis et al., 2018) and slow walking speed greatly increases the risk for social participation limitations in older adults (Warren et al., 2016). Several populations with neurological conditions are known to demonstrate impaired walking due to factors, such as reduced muscle strength, joint range of motion, coordination and motor control, leading to increased spatiotemporal asymmetry or unsteadiness (Mahlknecht et al., 2013). Such impairments, may in turn, restrict mobility by limiting walking distance, walking speed or the ability to manoeuvre in various environments and contexts. Cerebral palsy (CP) is one such condition that is associated with impaired walking. CP is caused by non-progressive brain damage acquired early in life, but living with CP is not viewed as being in a static condition (Mutch et al., 1992; Rosenbaum et al., 2007). Motor function in persons with CP is highly variable. It has been reported that 70% of those diagnosed with CP will learn to walk, although later than typically developing children (Andersen et al., 2008).

Many children with CP undergo extensive rehabilitation during their childhood aimed at acquiring functional abilities (Moll & Cott, 2013). Being able to walk might contribute to independence in daily activities (Andersson & Mattsson, 2001), and has been described as an important rehabilitation domain both by parents of children with CP and health care professionals (Bottos et al., 2001; Vargus-Adams & Martin, 2011). Despite extensive rehabilitation, including training of motor functions during childhood, persons with CP have reported negative musculoskeletal changes and subsequent reduction in functional status (Turk, 2009). This has been described as a "general slowing down" (Moll & Cott, 2013), and adults with CP have reported twice as much pain, and significantly more fatigue than the general population (Jahnsen, Villien, Aamodt et al., 2004; Jahnsen et al., 2003). Recent studies found that adults (18–-30 years of age) with CP are approximately seven times more likely to have musculoskeletal morbidities, such as osteopenia, osteoporosis, osteoarthritis and rheumatoid arthritis compared to typically developing young adults (D. Whitney et al., 2018), high risk of

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musculoskeletal morbidities is also reported across all age groups (D. G. Whitney et al., 2018). These and other impairments suggest the need for continuous healthcare into and throughout adulthood. However, regular follow-up and access to rehabilitation may be experienced as difficult to access or even absent by adults with CP (Morgan et al., 2014).

Studies have shown that 25–58% of adults with CP experience decline in mobility (Bottos et al., 2001; Himuro et al., 2018; Morgan & McGinley, 2013). Deterioration of walking ability has been described as early as mid-`30 s and `40 s (Moll & Cott, 2013; Opheim et al., 2013) in contrast to typically developing persons who report deterioration after age 75 years. In CP, those with worse initial walking ability, being bilaterally affected, and reporting higher levels of fatigue experience greater deterioration (Morgan & McGinley, 2013). Furthermore, deteriorated walking ability has also been found to be associated with more pain and self-reported reduced balance (Opheim et al., 2009). The perception of deteriorated walking is subjective (Opheim et al., 2012, 2013), however a Kaplan-Meier estimate including 105 adults with CP illustrated a marked decline evident around the age of 35 years (Opheim et al., 2009). To date, we have little knowledge about how walking deterioration influences the day-to-day lives of an adult with CP, suggesting a need to explore this in more detail using qualitative methodology (Opheim et al., 2013).

This study aimed to explore personal reflections on daily walking by adults with cerebral palsy.

Materials and methods

Based on the paucity of first-person reflections on daily walking in adults with CP, we designed an exploratory, inductive qualitative study using semi-structured individual interviews.

Participants

Ambulant adults with CP (>18 years) living in the community, of any CP subtype, with GMFCS Level I–III (Livingston et al., 2007), who had completed secondary school, able to partake in a conversation and provide informed consent, were invited to participate. Information about the study was sent to the Secretary General of the Norwegian CP-association, who forwarded the email to adult members of the regional CP-association. Information was also posted on the Norwegian CP-association and Western Norway University of Applied Sciences Facebook page with encouragement for others to share using snowball sampling to maximize the spread of information to a population who were challenging to reach (Sedgwick, 2013). Further, written information regarding the study was made available at a Norwegian training centre for adults with CP and the regional hospital. Those interested in participating contacted the first author, and after confirming inclusion criteria, an interview appointment was scheduled.

Eight adults with spastic CP, four men and four women, aged 26–60 years, who had completed secondary school, were included in the study. Six participants were students and/or were employed, and two were receiving disability benefits. All participants resided in South-Western Norway. A written consent form with information about the study was distributed by email. None of the participants had met or had contact with the interviewer in any rehabilitation or treatment setting previously.

Ethics

Ethical approval was granted by Regional Committees for Medical and Health Research Ethics (REC West Norway) (2018/349).

Data collection

The individual interviews were semi-structured and took place at a mutually convenient location. The interviews lasted from 28 to 68 minutes (mean 50 minutes). Consent to audiotaping and verbatim transcription was given before the interview commencement. It was emphasized to the participants that no right or wrong answers existed, and the best information they could give was sharing their reflections regarding daily walking. The first author conducted the interviews starting with an overarching question "Can you share your experience on how it is to walk with CP?" The dialogue evolved reflections on the importance of being able to walk on a daily basis, and keywords that formed the interview guide were based on the research question: a normal day, falling, the wish/need to do exercises targeting walking, overuse injuries, energy consumption, changes experienced in adulthood, fatigue, inpatient rehabilitation as adults, and additionally seasonal changes was included following interviews 1–3 (Figure 1). The interviewees were only interrupted when a clarification was needed.

We included only current walkers (GMFCS level I–III) and therefore gained a sample with specific and recent experiences of daily walking to share. We explored reflections regarding walking in persons with CP in adulthood and assessed the quality of the dialogue to be particularly strong in seven out of eight interviews (Malterud et al., 2015). Questions such as *"What are your thoughts about this?"* were asked to encourage further reflections. The data collection process was an iterative process involving all authors at different steps described in Figure 1. Traditionally *saturation* is used to describe when

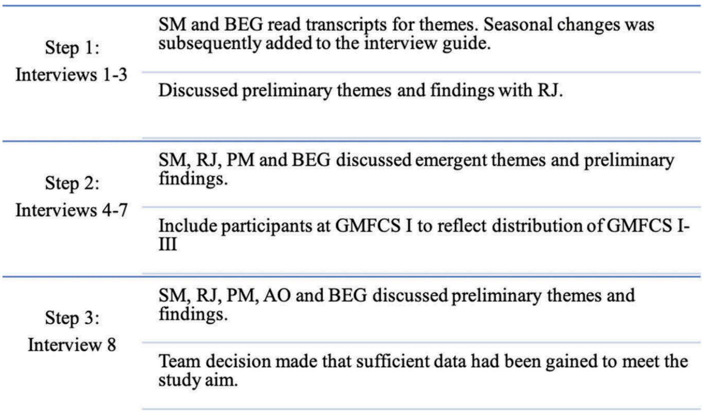

Figure 1. Data analysis flow chart. Step 1: After three interviews SM and BEG read transcripts for themes and discussed them with RJ. Step 2: After seven interviews SM, BEG, RJ and PM found it necessary based on themes and findings to include GMFCS I. Step 3: The team concluded that information power was reached for the material.

further empirical data does not add more to the data (Malterud, 2012), however in this exploratory study we used *information power* to guide our data collection. Our ambition was not to cover the whole range of the phenomena (walking), but rather to present new insights into daily walking and identify emerging information relevant to the study aim) (Malterud et al., 2015). In the iterative process we discussed the study aim, sample specificity, use of established theory, quality of dialogue and analysis strategy that all influenced the strength of the data and hence information power (Malterud et al., 2015). Through this ongoing evaluation we identified that we had sufficient data to answer the research question after eight interviews.

Data analysis

Data were analysed with systematic text condensation (STC), a four-step thematic cross-case analysis that offers a framework befitting the explorative aim of the study (Malterud, 2012). The first (BEG) and last author (SM) conducted the first three steps of STC, reading the data material to gain an overall impression, coding meaning units that represented reflections on walking in adulthood and amalgamating the content from meaning units. In the first steps, we received input in the analysis process from RJ and AO. In the last step, when the material was written in third-person format, we translated the text to English, and all authors worked together in an iterative analytical process. A more detailed description of STC can be found elsewhere (Malterud, 2012).

Results

Both intrinsic and extrinsic factors influenced reflections on daily walking. Three types of intrinsic factors were described: reduced functional capacity, daily walking as energy-demanding, but chosen activity and reduced balance hinder free walking. The extrinsic factors influencing daily walking were: attracting attention from onlookers due to walking variation, seasonal changes challenging walking and mobility, and accepting walking aids.

Intrinsic factors and their influence on walking

Reduced functional capacity influenced walking

Many participants had experienced adverse physical changes in adulthood and pondered whether these changes came about because they had used their body in an "unsound manner" for years, without preventive measures. Several participants described pain as a factor that influenced their current walking ability negatively. One person described how walking resulted in increasing back pain and subsequent reduced the capacity to walk. A participant in the 30 s, regularly working long hours, was reluctant to realize that reduction in walking ability could happen, although acknowledging a strong message from a physiotherapist to "stop working so much in order preserve current walking ability". Some participants reported that bodily changes and subsequent mobility restrictions were insidious and slowly emerging in onset. In contrast, others described that changes in mobility came suddenly like "an avalanche", exemplified by a participant who recalled the time when the ability to step up onto a curb without support was lost. Alterations, such as reduced muscle strength and joint flexibility may have led to mobility restrictions, which in next turn may lead to further functional decline in a vicious circle. Also, when bodily changes forced the participants to inactivity, this could lead to a feeling of "not being good enough". One participant described how the enforced inactivity had resulted in having to cope with the subsequent feeling of being "lazy".

Most participants described restrictions in more complex walking tasks, like during uphill or prolonged walking distances, resulting in reduced walking speed. One young participant described that spasms and foot muscle soreness increased when walking long distances and increased limping was associated with tiredness. A dilemma mentioned by several participants was that the "less affected" body side got tired when trying to offload the "more affected" side. Another participant described having to stop going to concerts due to the burden of prolonged standing. Even though trying to adapt to the situation by leaning towards a wall, it became too strenuous, and it felt like the inability to offload body weight interrupted the concert experience. Other participants described difficulties with, and some subsequent cessation of different activities, such as swimming, riding a bike, and domestic activities like vacuuming and picking up objects from the floor. Some participants chose to remain very active by doing activities, such as hiking and walking the dog despite increasing aches and pain. One of the participants shared strategies to continue with daily tasks when the pain set in:

> "I sit down as soon as I can and work primarily in sitting. I do this because the back gets me, and my feet are in constant tension (…). I actually feel my back now after this marginal amount of walking. So, I take a lot of paracetamol. Yes, this is a great burden" (Participant 2).

Daily walking as an energy-demanding, but chosen activity

Participants described a range of experiences associated with maintaining walking ability. Some participants reported that to minimize the negative impact on social activities, they would proceed with the task as planned, although it was a physically challenging one. One participant justified the strenuous effort of walking alongside the partner on a hike or when shopping, because it was important to their relationship—even though eventually ending up walking behind the partner. For some participants, a good night`s sleep was enough to re-energize for the next day. One young participant compared living with CP to "living like an athlete", always pushing their body to the limit. Still, many participants felt being stubborn and having a "strong will" as beneficial and essential in order to maintain their walking ability for as long as possible. One participant described the importance of walking as:

> "My whole life is based on my ability to walk, then I am free to do what I want without significant help from others. It is important to have a minimum of walking function that can take me places that are not accessible (with mobility aids)" (Participant 5).

Walking, training/exercising, studying and working were all mentioned as energy-consuming activities that made them reflect upon the question "what is the smartest thing to do?" Increased energy expenditure during daily activities directed them to choose the least energy-consuming alternative. One participant described choosing the elevator instead of the stairs from the parking lot, in order not to arrive at the office in a sweat. Another participant told about sometimes having to push oneself beyond the limits in order to keep up, for instance, being able to attend afternoon soccer training with the children. Other strategies that were used to cope with the limited energy could be locating a car park within a short walking distance to the target destination, and also always looking for a chair or bench when walking. The participants found that the need for energy conservation took time to accept and planning for having sufficient energy for the whole day was a concern for all of them.

Reduced balance restricted free walking

The participants generally experienced that their balance had become reduced and that this was strongly connected to how they walked. All of the participants had fallen previously, and the reduced balance limited them with regards to walking distance and also a greater need for taking breaks and sitting down. Many participants reported that their balance had become worse in adulthood. The problems became evident in daily activities, and they described activities like ascending and descending stairs, jogging, dancing and walking in shops and malls, as problematic. They also found it more embarrassing and "scarier" to fall with increasing age. A younger participant reflected that this might be the case because it felt more "natural" to fall as a child or youth. Although some participants fell infrequently, one person described the feeling of always being nervous when walking downhill. Another was nervous about being unsteady when walking on stones and pebbles. On occasions, failing to consider fatigue, a grass tussock was enough to provoke a fall. The same participant also reported that trying to hide the walking difficulty while walking alongside someone, would almost certainly lead to a fall.

Several participants reported that at home there was always something to grab hold of when getting up after falling, in contrast to outdoors. Falls were, therefore, easier to cope with at home.

Walking up or down stairs could be challenging, and one participant reported fear of being unsteady, and thus consequently did not carry anything when descending stairs. Crowded places, like shopping malls, were avoided by many participants, since they needed more space to move freely. One participant described a sense of being "carefree" when walking in the mountains or in the woods. When being outdoors, some participants reported that they could not get up without help from others after falling and therefore were reluctant to go out. This is how one participant described the change in adult life:

> "Before, I used the crutches to get up after falling, but that is too difficult now, and I cannot manage to get back on my feet, and that makes it scarier to fall. Indoors, I can climb up against something, but outside I'm just lying there like a seal in need of help. That was how I was forced to recognize that I cannot walk that much anymore. Because if I walk, then I fall, and this made it easier to accept using the wheelchair. I could not stand having it like that, I could not stand falling all the time" (Participant 1).

All these intrinsic factors precipitated the need for contact with health care professionals, as they were not prepared for these changes even though some had received information about the late effects of CP from older friends with CP and health care professionals. While some participants, in the beginning, struggled to manage these changes, others felt that an awareness of the late effects allowed them to accept the bodily changes and reduced functional capacity more smoothly. In contrast, one participant felt that his/her walking ability had been stable and even improved since childhood and had not noticed any deterioration.

Extrinsic factors and their influence on walking

Attracting attention from onlookers due to walking variation

The independent walkers (n = 6) experienced walking as "natural" despite their CP; however, the visual influence of their abnormal walking pattern on onlookers remained a source of concern. Many participants described distress when onlookers commented on the appearance of their walking, although they reported that these comments affected them more when they were younger. One young participant talked about the self-induced reduction in running speed when passing others because the movement anomaly was more visible when running faster. Another young participant described a mismatch between own walking self-confidence and the visual impact of the walking pattern on others, reporting that onlookers were "terrified" when watching the participant descending stairs, a task that was felt confident by the participant. One participant shared the emotions that people's looks provoked:

> "When hiking or walking downstairs I slow down, and the feeling of people looking at me being different hits me. Meeting new people is always challenging, as I fear them judging me on my walking handicap. I wish they could see «me» and not the other (CP)" (Participant 8).

Seasonal changes challenges walking and mobility

Walking on icy surfaces made them use more energy and time to ensure safe footing, and as a result, they had to add extra time to get to appointments in time. One participant who resides near a bus stop, still chose to use the car on icy days despite additional expenses with tolls and parking fees, because of fear of slipping and falling. Another participant reported a preference for in-patient rehabilitation stays during winter because being away from home for a couple of weeks, meant not having to worry about going outside for grocery shopping and other errands. Participants who occasionally used a wheelchair felt frustrated regarding inadequate wheelchair design for winter conditions, leaving them feeling unsafe and restricted in their mobility. Therefore, summertime was preferable for many participants.

> "On cold days I can go as far as usual, but I can stumble more because I do not lift my legs properly and then there is a big chance that I fall or slip. There have been some falls on the ice to say the least" (Participant 6).

Accepting walking aids

This theme overlaps the prior intrinsic themes of balance, falling and energy-saving strategies, as it describes how accepting walking aids can be helpful when coping with these issues. Walking aids, like a crutch or stick, was perceived as helpful by those reporting to be unsafe when walking. Some participants kept a crutch in the car and thought of it as an assistance in balance function, rather than an aid to increase walking distance. Some felt insecure, even when using a crutch. Big and heavy customized shoes were mentioned as a contributing factor to increased falls risk when walking. This footwear could be challenging during summer as foot sweat and sand between toes could be enough to disturb free walking. One participant described how the partner persuaded to get a disability access-parking permit in order to increase community access and mobility. After the initial reluctance, the participant admitted that this was beneficial for increasing social participation. Several others also had experience with the time-demanding processes of accepting the use of various types of mobility aids and special disability permits. This process of acceptance often started when activities of daily living suddenly became more challenging with increasing age, and the technical aids enabled them to pursue their activities. Some participants used the aids both as an energy saving strategy and to prevent falling. One young participant reported that it was important to keep the walking function "as good as possible for as long as possible", and therefore used the wheelchair at times in order to save energy during parts of the day. Many of those who started using a walking aid, found it better than first assumed and expected, because suddenly they had more energy to "do other things". However, the experience of accepting walking aids was described like this by one participant:

> "This is how I was forced to figure out I could not walk as much anymore, as I get tired and start falling. I could not bear to have it this way, and this made it easier for me to accept the wheelchair, I did not want to constantly fall" (Participant 1).

Nearly all participants described deterioration in walking ability associated with increasing age, and that it was easier to speak up and inform those around them about their mobility limitations when they became older. Exercises to maintain walking ability was experienced as important for them, although most participants expressed scepticism as to whether they could improve their walking function. Still, they emphasized the importance of maintaining some form of walking function for as long as possible.

Discussion

This qualitative study provides reflections regarding daily walking and changes in walking ability in adulthoods from a sample of ambulant persons with CP. The main findings were that adverse bodily changes, such as increased pain and enforced energy-saving strategies, were together with reduced balance, reported to affect daily walking performance. These intrinsic factors, along with extrinsic factors, such as seasonal challenges, may restrict daily free walking. Consequently, mobility aids might be more willingly accepted and used in adulthood in order to save energy for social participation. Lastly, walking "differently" may force those with CP to accept being stared at when walking in public spaces.

Intrinsic factors

Although it is well known that 25–58% of adults with CP experience walking decline (Morgan & McGinley, 2013), this study revealed not all felt prepared for these changes. Some had incidentally "heard" of such decline through friends or health care professionals and interpreted this as a result of having used their body in an "unsound" manner over time. This variation in knowledge and awareness may come as a result of lack of access to health care professionals with knowledge about adult CP disability (Andersson & Mattsson, 2001). Patient education program is used in the computing context may increase knowledge about future disability and increase autonomy in treatment decisions as seen in patients with multiple sclerosis (Köpke et al., 2009) however one may argue that increasing disability and increasing fear of the future may result in self-restriction of activities as described in older adults with CP (Morgan & McGinley, 2018).

Our findings about how pain and fatigue restricted the ability to participate in activities of daily living, has previously been found in cross-sectional studies (Jahnsen, Villien, Aamodt et al., 2004; Jahnsen et al., 2003; Opheim et al., 2009). However, in this study we got in-depth descriptions and reflections on how this impacts their lives and the range of decisions and dilemmas they had to face during activities that able-bodied persons do not have a conscious adherence to. The current study found that management strategies, such as planning ahead and activity modification helped them to cope with pain and fatigue and this is in line with a previous study (Brunton, 2018). This may potentially empower them to keep walking and hence remain socially active and participating.

All participants in this study had experienced falling when walking and felt more embarrassed with falling as they grew older. Falls are common in adults with CP across all GMFCS levels (Morgan & McGinley, 2013). Several participants described being nervous about falling, supporting previous research reporting a greater fear of falling in adults with CP than among older people without disabilities (Morgan & McGinley, 2013). Results from the current study indicate that adults with CP may refrain from going out due to fear of falling. Both falling, and the fear of not being able to get up again, may have negative impact on independence and participation. Negative changes in balance function may seem to have the same negative effect as participants shared stories and reflections about them reducing or stopping activities. These findings shed light and depth to previous findings from quantitative research (Jahnsen, Villien, Egeland et al., 2004; Opheim et al., 2012), supporting the need for life-long follow-up regarding balance and mobility. Our results may assist clinicians become aware of which walking activities adults with CP sacrifice, enabling a person-centred approach to tailoring follow-up interventions.

Extrinsic factors

Adults with CP reported experiencing unsolicited attention and comments about the appearance of their walking, but such comments had usually affected them more at a younger age. It has previously been reported that youth with CP have experienced stress, depression and anxiety related to bullying from peers at school or social isolation linked to the bodily differences (Lindsay, 2016). As a youth, they "longed" to be "normal" and were frustrated with having to cope with bodily differences resulting in isolation from peers (Lindsay, 2016). The results from this qualitative study support this premise with acknowledgement of "being different" but suggest some decline in the impact of such adverse comments as individuals with CP age.

Physical environmental factors, like cold weather and icy ground, were reported to make it more energy-demanding to walk, also they felt that their muscles got stiffer. Winter conditions are a common environmental factor for Norway and many other northern hemisphere countries, with cold winters influencing walking negatively. The frustration with continually having to plan ahead in order to go to different places, has been expressed in youth with CP (Palisano et al., 2009) and was reinforced during winter conditions by participants in this study. Both independent and community-based strategies to facilitate safe access outside the home during adverse weather conditions should be explored further.

Concurrent with an awareness of adverse bodily changes, some participants reported having to accept mobility aids to assist with balance, prevent falling and save energy. The process of acceptance of these aids often started when daily activities suddenly became more challenging with increasing age, and mobility aids enabled them to pursue their activities—albeit some required significant persuasion from the family. Some participants in this study used a wheelchair as an energy-saving strategy, similarly reported by participants in a study of Stewart et al. (2012) who explained how such choices often were guided by weighing the trade-offs inherent in their social participation. However, these participants were representative of all GMFCS levels. The use of assistive devices has also been linked to stigma threatening adults with CP's ability to maintain a feeling of being "normal" (Lindsay, 2016). This premise was echoed by some participants in this study.

Strengths and limitations

A qualitative design was considered the most appropriate approach to explore reflections of daily walking in adults with CP, as this research method is suitable when exploring human experiences (Malterud, 2001). The interviewer and respondents had never met before, and this might have strengthened the confirmability in how the respondent was not eager to please the interviewer in any health-related issues (Richards & Emslie, 2000). BEG and SM wrote down their expectations about potential findings before data collection and BEG kept a reflexive log that she discussed with SM in the process. Two authors (BEG and SM) took part in all steps of the analysis and focused on distinguishing between what we thought we would find and what was found, to commit to reflexivity (Malterud, 2001).The focus on walking in everyday life and the wide age distribution of our purposive sample is considered a strength as previous research has shown that changes may occur both in early and late adulthood. This range is used in previous research on adults with CP (Bottos et al., 2001; Himuro et al., 2018; Morgan & McGinley, 2013) thus strengthening the transferability of the results. Finally, commonality of experience in walking decline and managing walking whilst ageing was reflected across gross motor function levels (GMFCS Levels I–III), rather than reflective of a single GMFCS Level (e.g., Level III). This may be an area for greater exploration. As this study is based on the reports of eight adults with CP, it does not permit any conclusions or generalization however about the impact of age, gender, living situation or GMFCS level on walking ability. A final point is that results may need to be considered in the context of Norwegian healthcare, geography and climate.

Conclusion

Reflections from adults with CP shed light on how both intrinsic and extrinsic factors affected their daily walking. Whereas intrinsic factors, such as pain, reduced capacity and fear of falling resulted in reduced participation in public spaces and encouraged the use of walking aids. Extrinsic factors such as being a target for curious onlookers' and challenges of a harsh winter season challenges balance and free daily walking more than usual. These factors aid our understanding of how walking ability influences daily life of adults with CP and emphasize the need for lifelong follow-up by healthcare.

Acknowledgments

The authors wish to thank the participants in this study sharing their reflections on daily walking, and also Associate Professor Bård Bogen for valuable inputs.

Disclosure statement

No potential conflict of interest was reported by the authors.

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Paper II

Gjesdal *et al.*
BMC Sports Science, Medicine and Rehabilitation (2021) 13:160
https://doi.org/10.1186/s13102-021-00382-1

BMC Sports Science, Medicine and Rehabilitation

RESEARCH

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Can adults with cerebral palsy perform and benefit from ballistic strength training to improve walking outcomes? A mixed methods feasibility study

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Abstract

Background: Power bursts of hips and ankle plantar flexors are prerequisites to walking propulsion. However, these power bursts are reduced during gait for persons with cerebral palsy (CP) and mainly in the ankle plantar flexors. Hence, task specific training, such as ballistic strength training, is suggested to increase muscle power in walking but not investigated in adults with CP. Therefore, the aim was to investigate if adults with CP could perform and benefit from ballistic strength training to improve walking, evaluated through physical measures and self-reported measures and interviews.

Methods: In this mixed methods feasibility study, eight ambulatory adults (aged 24–56) with spastic CP conducted ballistic strength training on a glideboard targeting the ankle plantarflexors two times a week for eight weeks. The feasibility of the training was assessed through objectives described by Orsmond and Cohn. Before and after the intervention, physical measures (6-Minute Walk Test and the eight-item High-level Mobility Assessment Tool) and self-reported measures (Patient Global Impression of Change, Numeric Pain Rating Scale, Fatigue Impact and Severity Self-Assessment, and Walk-12) were collected. After the intervention, semi-structured interviews explored experiences of this training.

Results: The participants experienced training the ankle plantar flexor as relevant but reported it took about four weeks to coordinate the exercises successfully. Although we observed no changes in the physical performance measures, most participants reported improvements; some felt steadier when standing, walking, and hopping.

Conclusion: This study demonstrated that ballistic strength training was feasible and suitable in adults with CP. However, guidance and a long (4 weeks) familiarization time were reported necessary to master the exercises. Most participants reported self-experienced improvements, although no physical performance measures improved. Thus, prolonged intervention may be required for perceived physical improvements to emerge. Also, other outcome measures sensitive to power output remains to be investigated.

Keywords: Gait, Ankle plantarflexors, Resistance training, Interview, Patient reported outcome

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Background

Walking onset is postponed in children with cerebral palsy (CP) due to an injury of the immature brain which may prevent healthy development [1]. There is vast variation in function, from independent individuals to those in need of total care. Hence CP is referred to as an 'umbrella term' for all of these individuals [2]. Limited coordination and motor control are often accompanied by disturbances of sensation, perception, cognition, and secondary musculoskeletal problems (like muscle shortening and weakness) [3]. Self-reported factors such as pain, fatigue and joint contracture have been associated with a decline in mobility and balance [3]. Adults with CP report walking deterioration earlier than their peers and the more severely affected report deterioration at the youngest age [4].

Muscle weakness affects joint control during gait [5], and although resistance training improves muscle weakness in CP, walking has not been shown to improved [6]. In a focused review, Williams et al. [7] highlighted that strength training to improve walking should be task-specific to the propulsive power bursts in gait (hip flexors, hip extensors and ankle plantar flexors). However, few neurologic rehabilitation studies target these muscles [7]. Therefore, a theoretical framework suggests ballistic strength training as task specific to increase muscle power relevant for walking in neurologic rehabilitation [8]. Ballistic strength training is a type of power training aiming to increase the rate of force production, and preferable since these exercises eliminates the deceleration phase due to its jumping nature. Muscular power is the scalar product of force generation and movement velocity. Hence both traditional strength training and power training has the potential to increase muscular power [9], but light resistance and rapid excursions are suggested preferable when increasing power [9].

Recent literature reveals a growing interest in power training for improving walking in youths and adults with CP, but different terminology and various muscles are targeted. Moreau et al. [10] reported beneficial results of walking speed in youths with CP after high-velocity strength training compared to traditional training targeting knee extensors. Kirk et al. [11] found increased toe-lift in the late swing after explosive resistance training of the ankle dorsiflexors in adults with CP. These studies suggest that focus on power could benefit walking in this population. However, to our knowledge, ballistic strength training of calf muscles (ankle plantar flexors) has not been studied in adults with CP.

All power bursts relevant for walking are reduced in persons with spastic CP, and mainly ankle power [12]. This could be explained by reduced muscle volume [13], plantarflexor weakness [14] and impaired rapid force generation capacity [15, 16]. Two of the neuromuscular contributors to maximal power are the maximal rate of force development (RFD) and coordination [9]. Ankle plantar flexor RFD has been associated with impaired gait function in adults with CP [16]. Ankle plantar flexor ballistic strength training (power training) focus on angular velocity, is suggested to be task-specific to walking [8], and safe and feasible for adults after traumatic brain injury [17], and in children with CP [18]. However, it is unknown whether this training is feasible, or if it improves walking and how it is experienced by adults with CP.

The purpose of this study was to investigate if adults with CP can perform and benefit from ballistic strength training of the ankle plantar flexors to improve walking. This was evaluated through physical measures, self-reported measures, and interviews.

Methods

Design

A mixed methods feasibility design yields a broad perspective when exploring a new intervention in adults with CP. Combining qualitative and quantitative data provide the potential for a better understanding of the research problems [19], and including participants' voices is requested by The Norwegian Ministry of Health and Care Services [20]. Qualitative and quantitative data were rigorously collected and analysed following the convergent design. Further, we compared each individual's qualitative and quantitative data to obtain a thorough understanding, and the results were mixed in the discussion [19].

In line with the goal of a feasibility study, we aimed to answer the question, "Can it (ballistic strength training) work (for adults with CP)?". Several single studies are published to guide authors in conducting a feasibility study. Therefore Orsmond and Cohn [21] synthesised recommendations from seven published articles into five overarching objectives for a feasibility study: "(1) *Evaluation of recruitment capability and resulting sample characteristics,* (2) *Evaluation and refinement of data collection procedures and outcome measures,* (3) *Evaluation of acceptability and suitability of intervention and study procedures,* (4) *Evaluation of resources and ability to manage and implement the study and intervention,* (5) *Preliminary evaluation of participant responses to intervention*". Since this study investigated whether they could perform and benefit from the ballistic training, objectives 2–3–5 [21] are used in this study design and structure of this article's discussion.

Recruiting and inclusion and exclusion criteria

Information about the study was sent to the regional CP Association, which forwarded it to their adult members. Information was also posted on social media with encouragement for others to share, through posters in training centres and at the Regional Hospital. Inclusion criteria were adults with spastic CP, gross motor function classification system (GMFCS) level I–II. The participants also had to complete primary school to make sure they understood the instructions. The key exclusion criterion was lower limb surgery during the last year before the study intervention. We invited potential participants that met all the criteria to visit the laboratory for an information meeting about the study to ask questions prior to start-up.

Participants

Ten adults with independent walking function enrolled in the study. One withdrew before commencing because participation was too burdensome. Nine participants came to the pre-test, seven of whom were classified as hemiplegic and GMFCS I, and two of whom were classified as diplegic and GMFCS II (Table 1). None of the participants had previous experience with ballistic training.

Ethical approval was granted by the Regional Committees for Medical and Health Research Ethics of West Norway (REK-No. 2018-2390) and all volunteers signed a written informed consent before the study intervention. The study was carried out according to the latest revision of the declaration of Helsinki.

Intervention

The participants conducted three ballistic exercises targeting ankle plantarflexors twice a week for eight weeks in the rehabilitation laboratory at the University College. An additional home exercises was introduced in week five. Optimal dosage is not established in adults with CP, however frequency (2–3 times per week) and duration (8–10 weeks) is suggested as guidelines when improving muscle power in young adults with CP [10]. All supervised training in the lab started with a general warm-up of either indoor cycling or treadmill walking. Three exercises were performed lying on an inclined glideboard supervised by trained personnel (Total Gym RS Encompass PowerTower®): (a) jump squats, (b) single leg hopping on the paretic leg and (c) bounding on alternating legs. We aimed to incorporate task specific training by closely monitoring exercise performance in each training session with a prioritised list of progression rules of skill acquisition, speed, and the range of motion. After midstance, the ankle moves from dorsiflexion (10°) to plantarflexion (20°) [22]. The load was increased once these performance criteria were met. Participants were encouraged to complete as many repetitions as possible within five minutes. If the exercises were not performed with quality, the load was considered too high. A quality check of muscle activation was to palpate the gastrocnemius muscle during the exercise. This is relevant since a commonly observed challenge was that the knee-extensors compensated for the weak ankle plantarflexors. This was a bigger problem at the beginning of the intervention when the participants needed much more feedback. Therefore, breaks were initiated either by the participant or researcher/training supervisor if ankle plantarflexor technique and or coordination deteriorated. The glideboard incline and number of repetitions, and type of assistance for each session, were recorded. For a detailed description of the exercises, see Appendix 2 in Hendrey et al. [17].

At week five a home exercise was introduced to the participants. The exercises targeted the hip flexor power generation, the second most important muscle group for power-burst in forward propulsion relevant for walking [8]. Demonstration of the home exercises and videos explaining the performance were provided to the participants. Moreover, they were asked to report the home training in a training diary. Three exercises were chosen from a progressive list, e.g., knee lift, claw or triplings,

Table 1 Participant characteristics

Case	Sex	Age	BMI	Subtype	GMFCS	Lab exercise completed (total 16)	Home exercise completed (total 4)
P1	F	27	18	Uni	I	15	2
P2	F	51	23	Uni	I	15	3
P3	F	28	27	Uni	I	16	0
P4	M	53	30	Bilat	II	15	1
P5	M	34	28	Bilat	II	13	2
P6	F	24	24	Uni	I	16	2
P7	F	30	38	Uni	I	16	0
P8	M	56	28	Uni	I	16	2

BMI body mass index, *GMFCS* gross motor function classification scale and were instructed to perform three sets of 12 repetitions and report them in the training diary. Although the hip, knee and ankle power contributions are relatively similar across walking speeds [23], hip flexor weakness is found to impact gait [24] and this is why we chose to target these. The home exercises were inspired by athlete exercises task-specific to develop hip flexor power in running, with focus on rapid excursions. Which is why we chose to target these. The home exercises were inspired by athlete exercises task-specific to develop hip flexor power in running, focusing rapid excursions.

Demonstration to the home exercises and videos explaining the performance were provided to the participants. Moreover, they were asked to report the home training in a training diary. Three exercises were chosen from a progressive list, e.g., knee lift, claw or triplings, and were instructed to perform three sets of 12 repetitions and report them in the training diary. Although the hip, knee and ankle power contribution are relatively similar across walking speeds [23]; hip flexor weakness is found to impact gait [24] and this is why we chose to target these. The home exercises were inspired by athlete exercises task-specific to develop hip flexor power in running, with focus on rapid excursions.

Other exercise activities besides the intervention, delayed onset muscle soreness, adverse events or other symptoms limiting participation in the exercise were recorded by the personnel each time the participant came to the laboratory. All subjects were asked to continue their regular training routines (Additional file 1: Home-based training and other training).

Outcome measures

Physical measures

Physical measures were performed before and after the intervention.

The *six-minute walk test (6MWT)* measured changes in walking capacity. Participants walked along a 30-m-long circuit and every minute, a standard set phrase was given by the investigator. Heart rate (HR) was measured using a waist belt and HR monitor (Polar, M400) and a perceived exertion scale (Borg 1–20) was registered immediately after the test. The 6MWT is reliable in adults with CP; an increase in walking distance of 40 m is considered clinically significant when a practice test is conducted and 56 m when not conducted [25].

The eight-item version of the *High-level Mobility Assessment Tool (HiMAT)* measured high-level mobility (run, hop and skip). HiMAT has been validated for individuals with neurological conditions [26] and the eight-item HiMAT score was used in the analysis [27]. The maximum score is 32 points, with a higher score indicating better performance. Minimal Detectable Change (MDC) is two points [27].

Self-reported measures

The *patient global impression of change (PGIC)* scale was used four times during the intervention (weeks 2, 4, 6 and post-test) to rate participants' current walking function compared to how it was prior to intervention, on a 7-point scale from 'Very much better' to 'Very much worse'. Any measure other than 'Unchanged' is meaningful in PGIC.

The *Numeric Pain Rating Scale (NPRS)* was used to report pain intensity four times (pre-test, week 3, week 6 and post-test) on a scale from '0 = no pain' to '10 = worst possible pain'. The NPRS is valid in adults with CP [28] and a clinical change of two points has been reported in patients with low back pain [29].

The *Fatigue Impact and Severity Self-Assessment (FISSA)* instrument measured experienced fatigue related to CP twice during the last week (pre-and post-test). The FISSA is validated and reliable for individuals with CP [30]. The minimum score is 31 and the maximum score is 137, with a higher score indicating greater fatigue.

The *Walk-12* instrument was used to investigate any self-perceived change in walking difficulties related to diagnosis after ballistic strength training. Walk-12 is a generic version of the Multiple Sclerosis Walking Scale-12. The Multiple Sclerosis Walking Scale has the potential to evaluate the neurologic conditions impact on walking, monitor change in walking over time and evaluate therapeutic effectiveness [31]. Holland et al. [32] concluded that this version might be suitable for other neurologically disabled persons [32]. Walk-12 was measured two times (pre-and post-test). The maximum score was 60 points, and the minimum score was 12 points; fewer points indicate fewer perceived walking difficulties. Scores were converted to percentages when presenting data. Walk-12 has the potential to give valuable information on how neurologic disease is related to walking difficulties. No validation has been done for this modified version among adults with CP, but among adults with Multiple Sclerosis, a clinically significant change is 22 points, or 53% [33].

Qualitative interviews

Semi-structured individual interviews were conducted at post-test. Interviews were related to experiences with ballistic training and the overarching question was 'What are your experiences with the training performed?', with the specification that we were interested in both positive and negative experiences. The first and second authors conducted the interviews. The interview guide is given in Additional file 1: Interview guide.

Analysis

Descriptive statistics were used to describe physical performance and self-reported measures. Results were compared to measures of clinical change to determine the necessary change on an outcome measure to exceed variation and errors in the measurement. Adherence was reported as percentage of the prescribed exercise sessions attended.

The interviews were transcribed verbatim and analysed with systematic text condensation (STC), a four-step thematic cross-case analysis approach [34]. The first and second authors conducted the first three steps of STC, reading the data material to gain an overall impression, coding meaning units that represented experiences with the training performed and amalgamating the content from meaning units. In the last step, all authors worked together in an iterative analytical process.

Results

Feasibility

Participant characteristics are described in Table 1. The ability to perform the training varied among the participants. One participant withdrew before the pre-test because of time constraints and P9 withdrew due to a bursitis in the foot after seven training sessions (this participants outcome measures are not included). For the included participants that completed the study, the adherence to the exercises with guidance was 95% and 38% for home exercises. After pre-test P8 felt sore in the gluteus medius muscle and did not perform the first session strictly to the plan but had no trouble in the remaining sessions.

Physical measures

Two participants (P6, P8) increased their eight-item HiMAT score and one participant (P2) decreased by more than two points. None of the participants had a clinically important change for the 6MWT (Table 2).

Self-reported measures

Four of eight participants reported their walking function to be 'much better' at post-test, two 'minimally better' and two 'unchanged' (Table 3). The self-reported measure of perceived walking difficulties related to diagnosis was

Table 3 Patient global impression of change compared to before intervention

Patient global impression of change				
	Week 2	**Week 4**	**Week 6**	**Post**
P1	Unchanged	Unchanged	Unchanged	Unchanged
P2	Minimally better	Much better	Much better	Much better
P3	Unchanged	Unchanged	Unchanged	Unchanged
P4	Unchanged	Minimally better	Minimally better	Minimally better
P5	Minimally better	Much better	Much better	Much better
P6	Minimally better	Much better	Much better	Much better
P7	Minimally better	Minimally better	Much better	Much better
P8	Minimally better	Much better	Much better	Much better

Table 2 6MWT distance, heart rate and perceived exertion after testing and eight-item HiMAT

	6MWT						**Eight-item HiMAT**	
	Distance (m)		**Heart rate (BPM)**		**Perceived exertion (Borg)**		**Score (pts)**	
	Pre	**Post**	**Pre**	**Post**	**Pre**	**Post**	**Pre**	**Post**
P1	560	607	169	184	12	14	13	13
P2	505	495	124	121	9	9	13	10*
P3	600	582	150	157	11	11	10	11
P4	425	415	165	149	16	14	4	4
P5	491	500	195	194	14	19	12	11
P6	664	678	184	193	12	12	11	17*
P7	520	520	145	138	13	13	13	13
P8	642	661	177	175	15	17	11	17*

These were conducted at pre- and post-test

*Indicate clinical change between measurement points

6MWT six-minute walk test, *HiMAT* high-level mobility assessment tool

Table 4 NPRS during and at post-test and Walk-12 and FISSA scores measured at pre- and post-test

	NPRS				Walk-12	FISSA
	Pre	Week 3	Week 6	Post	Pre–post	Pre–post
P1	0	0	0	0	32–35	71–74
P2	2	0	1	1	20–32	31–41
P3	1	0	1	1	27–22	44–51
P4	5	0	7*	3*	68–68	110–111
P5	3	4	3	3	40–58	75–103
P6	0	1	0	1	33–28	64–45
P7	0	1	1	1	38–42	MI
P8	2,5	0	0*	5*	53–47	126–114

MI missing item, *NPRS* numeric pain rating scale, *FISSA* fatigue impact and severity self-assessment

*Indicate clinical change between measurement points

increased in four and decreased in three participants, and unchanged in one participant (Table 4). Three participants reported more fatigue at post-test, two reported less fatigue, two were unchanged and one had missing data (Table 4). Pain varied amongst measurement times. Pain scores equal to or above 3 were only reported by the oldest participant (P8) and those with bilateral CP (P4 and P5) (Table 4).

Qualitative interviews

It was time-consuming to master the ballistic exercises and control the ankle

Ballistic training was new to all participants, and controlling the ankle joint in a limb with movement disorder was challenging. Training the affected side was experienced very differently for those with unilateral CP than training the unaffected side. For example, coordinating the calf muscle contraction and timing the movement was complicated. In the first part of the intervention, the active knee extensor muscles indicated incorrect exercise performance, which reminded them to reduce the compensating muscles and use the calf muscles more. This training demanded concentration. Sometimes they became tired and lost focus; hence, ballistic strength training was multi-tasking, controlling and strengthening the limb. Although, the number of repetitions forced their mind to control the motion in a completely new way. They shared a common frustration of not mastering the technique, reflecting upon 'what am I actually doing in this exercise' and how they planned the ankle motion attempting to activate it:

> *You need to try to connect it [the ankle flexors] and disconnect the others [the knee extensors], and how are you able to do that, right, it is this connection that is difficult because there is nothing natural to it…When I tell my right foot to do it, there is nothing automatic going on; I have kind of learned it in a way. (P8)*

All participants reported that it was particularly difficult to find the rhythm of the exercise. However, after about four weeks of training they reported 'mastering' the exercise to a certain extent. Therefore, some provided feedback that more focus should be prioritized to perform the movement. The importance of having guidance from a trainer was the basis of perceived success. The glideboard did not challenge balance, which they felt gave more focus to the movement. When they mastered it in the final part of the later weeks, the training apparatus gave a particular rhythmic sound. This connection between muscles and rhythm of the exercise was described as hard to control. Therefore, they wished the study could be prolonged when the rhythmic sound became more automatic. Towards the end of the intervention, all reported greater awareness of the calf muscles during training. It had been a struggle, but with all the repetitions completed during the training session, they eventually got used to it:

> *I think there has been some progress that let me feel that I mastered it more at the end than in the beginning, but still, sometimes I got it and sometimes not…sometimes it's just right I think, and suddenly I can't do it again. (P1)*

Various training responses and walking awareness

The participant's bodies responded differently throughout the period. On some days the leg muscles felt more tired than others, but they were unable to detect any pattern to how long the feeling lasted after the workout, whereas others did not feel anything at all. The knee extensors felt sorer in the first half of the intervention, explained by the long learning phase to master the exercises. They felt steadier during standing and walking with ballistic training and explained this as more muscle control, more focus on how the heels touched the ground and less stumbling when tired. One participant was able to jump after the intervention, something they had never managed before.

> *I feel a lot more support, you know a lot more, I have kind of more support around the ankle in the foot, so when walking I can feel that the foot isn't that loose anymore, it became firmer, I am more determined in gait when walking. I notice. And I also feel that I have become much stronger. (P7)*

Overall, they did not feel that walking speed had improved, but that their legs contributed more evenly to gait. They reported that the unaffected leg began to compensate less and the affected leg felt more involved. This raised hope that it was possible to achieve more balance between the sides. When the affected leg was in swing, they had to think 'heel first, then toe' before the foot hit the ground. Those with unilateral CP compared sides of the body, with one describing how the sound of the unaffected leg in a pedestrian tunnel helped control 'proper' heel-toe walking by matching the echo to the affected leg. The unaffected leg was considered dominant and they reported this side needed to be disconnected, and simultaneously the affected leg reconnected, to control push-off; something they found harder when tired. One participant expressed fascination on how little training was needed to improve walking and noticed a huge difference, by experiencing that the foot did not collapse during walking. In contrast, two participants described that they could not feel any changes due to the training. However, neither experienced their gait to be problematic. One described the conscious feeling of controlling the affected side:

> *I actually think more, yes, I have tried to walk, mmh, walk more properly then, and trying consciously to use the left foot like I think we are supposed to use the feet in a kind of way, yes, I actually try that, hoping this will be more automatic… (P2)*

Addressing closer follow-up to home exercises

The participants experienced the ballistic exercises on the glideboard in the rehabilitation laboratory as a good supplement to their usual workout. However, all the participants found it hard to perform the home exercise targeting the hip muscles. Even though the exercises were available by video from a website, some found it hard to know if they had performed them correctly. Some used family members to help with a quality check. At least half conducted some of the home exercise sessions, even though not strictly to the plan. They called for closer follow-up when home exercises should be part of the training, especially when an exercise targeted muscles other than the calf muscles. One participant also suggested that the exercise could have been part of the ballistic warm-up routine to ensure it was done correctly. One described it like this:

> *It was exhausting, especially the running, or running in quotes, with hips high up, because that is a muscle I practically never needed. So, that was heavy, but I will continue doing that because I felt it gave results. (P6)*

Discussion

This study demonstrates that ballistic strength training is feasible for and well accepted by adults with CP. Both ballistic training and targeting the ankle were new to the participants, who reported a familiarization phase of about four weeks. There was no change in physical performance tested by 6MWT and HiMAT, although self-reported measures and findings from the qualitative interviews indicated otherwise.

Evaluation of acceptability and suitability of intervention and study procedures

The most effective dose in ballistic training for people with CP is currently unknown [6]. With a different muscle morphology in spastic muscles [13], it is uncertain if the same recommendations as for healthy adults should be applied. Vershuren et al. [35] have published guidelines to increase muscle strength in CP. They suggest that once force has been developed in simple tasks more complex exercise activities could be added. In accordance with their suggestions, it is rationally to target the calf with ballistic strength training, before introducing functional power training in whole-body motions as suggested by Van Vulpen et al. [36]. Moreau et al. [10] suggested from their strength study with higher velocity movements in youth with CP that eight to 10 weeks and two to three times per week are effective at improving muscle power. Our study follows these recommendations for frequency and duration. The studies we found in the literature, including exercises performed with high velocity, are single-joint only, via an isokinetic dynamometer [10, 11, 37]. Our participants targeted the ankle plantarflexors by lying on a glideboard and simultaneously controlling the hip and knee beside the ankle push-off. They found it challenging to perform ballistic strength exercises and our study exercises might require greater motor control, since the motion was not facilitated by the equipment. Another plausible explanation for this might be an impaired RFD that has previously been found in the thigh [15] and ankle muscles [16]. These suggestions may explain why a long familiarization time was reported.

Coordination training targeting the ankle has been recommended to improve the walking pattern in children with CP [12]. Without coordination, the controlled application of force is compromised. Based on our qualitative results and the fact that the CP lesion is located in the brain [1], we argue that the participants also indirectly performed coordination training. For each laboratory session, three exercises with as many repetitions as possible within five minutes were performed (Additional file 1: Training log). We could argue that this amount is more to increase local muscular endurance, but there is no established optimum for ballistic strength training. Rest periods are vital to ensure correct quality [9] and should have been included more structurally. Our participants did not have adequate control over the ankle and reported that all repetitions forced them to control the motion. When strength exercises set requirements for coordination, it is possible that basic motor control strategies should be integrated with basic strength training principles of progressive overload, specificity and variation [38] for a more holistic approach in this population. Intervention time is therefore an area for further exploration when targeting any muscle group. Our participants reported that exercises targeting the ankle plantarflexors were relevant, which was supported by the high adherence (95%) to the supervised laboratory exercises targeting the ankle. Our study has demonstrated that ballistic strength training targeting the ankle plantarflexor muscle is acceptable in a sample that never had trained the ankle plantarflexors ballistically before.

Adults with CP report more pain [39] and fatigue [40] than the general population. In this study, participants with bilateral CP and older participants reported higher pain levels [4]. Importantly, the perception of pain did not seem to increase during or after an eight-week ballistic training period. Three participants experienced a greater amount of fatigue at post-test, whereas two participants experienced less fatigue. From the interviews, some reported how periods with exams, or full-time and part-time work, led to an accumulated feeling of life becoming too hectic to proceed with the training intensity. An increase in total burden of activities to fit into a week potentially increased the FISSA scores for some participants. Factors affecting pain and fatigue should be considered in each individual prior to further training studies, including whether participants have enough time and capacity to complete the training intervention, although on their own they may not be barriers.

One participant withdrew from the study after seven training sessions because of a bursitis under the toes in the affected foot. The motion of the exercise was new to all participants; however, the load was less than body weight (from 15 to 60% of bodyweight). With an exploratory approach, we targeted the plantarflexors twice per week to account for enough restitution. Even though pain was monitored twice a week, this was not captured by the screening. It is possible that questions targeting the specific area could give better monitoring than just asking for pain in general. However, there is always a risk of injury in strength training and close monitoring is recommended.

Evaluation and refinement of data collection procedures and outcome measures

In total, the participants attended 95% of the laboratory-based exercises. In these sessions the participants were monitored closely and guided with feedback, which was crucial to understanding the exercise criteria. This may explain the high adherence to the laboratory-based sessions. Experiences from the home exercises stated that they were cognitively challenging and were met with low (38%) adherence. Exercises to be performed at home should have followed the content in the laboratory-based exercises. Participants suggested this could be part of the warm-up routine of the laboratory-based sessions in the first weeks, to learn the motion before doing it independently.

After the ballistic intervention, participants' perceived walking difficulties related to their diagnosis increased in P2 and P6 (Table 4), in contrast to walking ability that P2 rated as 'much better' after the intervention (Table 3). P2 also explained how walking became a more conscious activity when trying to walk better and use the affected side more. Even though these results seem conflicting, their perception might differ from the outcome measures, and both could be right.

Walking speed, walking endurance, gross motor function, spatiotemporal data, kinematics and kinetics have all been used as outcome measures to evaluate intervention efficacy in adults with CP [41, 42]. Walking is a complex motion that requires both RFD/power and motor control. Improvements in complex movements takes time and in our study, the eight-week intervention did not seem to produce a change in the desired outcome for walking (6MWT). We targeted ankle plantarflexors as the 'bottle-neck' of reduced forward propulsion and any change in muscle capacity should also have been investigated.

Preliminary evaluation of participant responses to intervention

Six participants reported improvement in walking (PGIC), but the results from the walk test (6MWT) and gross motor function (HiMAT) did not confirm this perceived improvement. In a qualitative study, both intrinsic and extrinsic factors have been shown to influence daily walking in adults with CP [43]. The comprehension of the exercise is necessary for walking function and balance makes the perception that the exercise works important. Individual feedback on performance and progression was highlighted as crucial for progression by the participants. However, as training interventions for adults with CP have been few in Norway, this opportunity to receive training aiming to improve walking could trigger the placebo effect and might explain the discrepancy between the positive subjective reports and the lack of improvement in the objective measures.

A subjective feeling that the affected leg contributed more evenly to gait was reported from the interviews. We did not measure symmetry, and this might have improved with no change to walking speed. However, ballistic strength training can increase RFD, but it does not appear to have improved sufficiently to translate into improved 6MWT and HiMAT scores. Still, we believe that increasing the functional capacity for the muscles' ability to generate force will also improve walking distance, but the motion must firstly be consolidated in a more prolonged intervention phase.

There is limited evidence in the literature supporting aerobic or strength training to improve motor function or increase gait speed on a group level in people with CP [6]. We have a small sample size with GMFCS I-II, but as a group, they are heterogeneous. With a small population and large variation, we need to properly understand the muscular physiological adaptation to ballistic strength training before including a more extensive study sample.

Limitations

This study includes data on a small convenience sample and may not be representative of a general CP population. This study investigated only one of the three muscle groups responsible for propulsion during walking with ballistic strength training. Still, the calf muscles contribute the most in forwarding propulsion. Independent evaluators should have conducted the interviews, but we did not have the resources to employ them. The home exercises should have been closer monitored and controlled in order to gain effect. The reliability and validity of Walk-12 in CP are yet to be determined, but we used because it is a good measure for self-rated walking ability in other neurological conditions.

Conclusion

This study demonstrated that ballistic strength training was feasible and suitable in adults with CP. However, guidance and a long (four weeks) familiarization time were reported necessary to master the exercises. Most participants reported self-experienced improvements, although no physical performance measures improved. Thus, prolonged intervention may be required for perceived physical improvements to emerge. Also, other outcome measures sensitive to power output remains to be investigated.

Abbreviations

CP: Cerebral palsy; 6MWT: Six-minute walk test; HiMAT: High-level mobility assessment tool; PGIC: Patient global impression of change; NPRS: Numeric pain rating scale; FISSA: Fatigue impact and severity self-assessment; STC: Systematic text condensation.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s13102-021-00382-1.

Additional file 1. Interview guide, Training log, Home-based training and other training.

Acknowledgements

We thank in particular the participants in this study, the J. L. Mowinckels Foundation for supporting training equipment and Vegard Flister, Peter Husby, Ingvild Frostad Gulichsen, Silje Marie Rydningen Torberntson, Martin Eidissen and Aleksander Solberg for their contribution in the laboratory. We thank the anonymous reviewers whose comments helped improve and clarify this manuscript.

Authors' contributions

BEG: The primary author was in charge of writing both quantitative and qualitative part, recruitment of participants, conducting the study, data collection and analyses. SM: Contributor of manuscript writing, study design, conducting the study and qualitative analyses. GW: Contributor of manuscript writing, study design. MKAa: Contributor of manuscript writing, study design. CBR: Contributor of manuscript writing, study design and conducting the study. KTC: Contributor of manuscript writing, study design. All authors read and approved the final manuscript.

Funding

The J. L. Mowinckels Foundation funded the glideboard, but had no role in the study.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The study was carried out according to the latest revision of the declaration of Helsinki. Ethical approval was granted by the Regional Committees for Medical and Health Research Ethics of West Norway (REK-No. 2018-2390) and all volunteers signed a written informed consent before the study intervention and were informed of their rights to withdraw from the study at any time without having to provide a reason.

Consent for publication
Not applicable.

Competing interests
The authors declare that they have no competing interests.

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Received: 16 May 2021 Accepted: 18 November 2021
Published online: 18 December 2021

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Interview guide

The purpose of this qualitative part of the study is to map your experience of having participated and whether participation has led to changes in daily life that we are unable to capture any other way. The guide serves more as support for structure rather than a compulsory checklist for interviews.

- Short introduction to the interviewer and study background
- As you have read and signed, the interview is recorded but will be deleted
- You will be made anonymous in our further work with the interviews
- You can withdraw anytime during the interview without having to give any reason

Can you start by describing some specific experience that you have had as a participant during the intervention? Whether it is a positive or negative experience.
Based on your experiences of the supervised training program for the last eight weeks, what do you think of:

- The amount of training
- The training intensity
- The guidance
- How it was to learn these exercises (how long it took, what feedback you needed, what you did to succeed)
- Did the workout affect any of your daily activities?
- Do you feel your gait has changed, either way?

Training log

Registered mean incline on glideboard, sets and mean repetitions for each set during the sessions in the lab. Care should be taken with this overview, since counting reps and registering at the same time with guidance. In some sessions there were two instructors.

	Participant 1								
	Jump squats			Single leg jumping			Jogging		
	Inc	Set	Rep	Inc	Set	Rep	Inc	Set	Rep
S1	7	3	20	NR	NR	NR	NR	NR	NR
S2	8	3	23	8	3	31	7	3	122
S3	11	6	27	9	6	38	NR	NR	NR
S4	12	7	21	9	1	40	12	4	100
S5	12	6	25	9	5	68	12	4	100
S6	12	4	63	7	3	90	12	6	65
S7	12	4	51	6	3	128	12	3	170
S8	12	4	48	8	4	60	12	5	100
S9	12	4	57	6	5	82	10	2	238
S10	13	3	73	4	6	59	10	3	132
S11	12	4	59	5	4	101	10	2	133
S12	12	4	53	5	6	46	9	5	50
S13	10	6	42	7	5	81	9	1	240
S14	11	3	83	6	5	71	9	3	122
S15	12	3	67	5	4	77	10	5	54
S16	-	-	-	-	-	-	-	-	-

	Participant 2								
	Jump squats			Single leg jumping			Jogging		
	Inc	Set	Rep	Inc	Set	Rep	Inc	Set	Rep
S1	8	1	92	10	1	139	4	1	99
S2	9	4	36	9	3	45	9	6	59
S3	10	5	44	8	6	35	9	4	76
S4	11	3	90	8	5	39	NP	NP	NP
S5	11	3	57	8	5	34	9	6	32
S6	11	5	32	8	6	42	9	5	46
S7	11	3	52	8	4	50	11	3	86
S8	11	3	78	8	3	91	11	4	76
S9	11	2	142	10	3	131	11	3	144
S10	11	4	51	8	5	44	11	5	66
S11	12	3	91	8	2	159	11	2	216
S12	12	4	66	8	2	151	11	4	108
S13	12	3	97	9	3	100	11	3	144
S14	12	5	67	8	3	91	11	4	126
S15	12	4	60	8	5	49	11	4	95
S16	-	-	-	-	-	-	-	-	-

	Participant 3								
	Jump squats			Single leg jumping			Jogging		
	Inc	Set	Rep	Inc	Set	Rep	Inc	Set	Rep
S1	8	4	59	4	9	35	4	4	52
S2	12	4	35	11	6	31	14	5	66
S3	13	5	39	10	5	43	14	6	56
S4	13	4	55	10	5	51	14	4	101
S5	13	4	38	11	5	50	NR	7	54
S6	13	5	42	11	7	33	14	6	58
S7	14	4	49	11	7	25	14	6	57
S8	14	2	100	11	5	51	14	5	59
S9	14	4	55	11	4	58	14	6	51
S10	14	4	57	10	4	62	14	5	74
S11	14	4	50	10	2	149	14	3	125
S12	14	4	50	10	5	50	14	4	65
S13	14	4	44	10	5	44	14	5	52
S14	14	5	48	10	4	69	14	4	90
S15	14	4	48	10	5	54	14	6	54
S16	14	2	150	10	4	76	14	4	109

	Participant 4											
	Jump squats			Single leg jumping (R)			Single leg jumping (L)			Jogging		
	Inc	Set	Rep	Inc	Set	Rep	Inc	Set	Rep	Inc	Set	Rep
S1	11	4	22	8	3	49	9	5	34	NR	NR	NR
S2	11	5	34	8	4	43	8	4	65	13	6	53
S3	11	5	29	8	2	162	8	4	71	14	5	94
S4	13	4	60	8	3	99	8	3	100	14	4	134
S5	13	4	50	9	4	69	8	5	46	15	4	105
S6	13	4	50	9	4	65	7	5	71	15	6	75
S7	13	3	83	7	4	62	7	4	91	14	2	219
S8	13	4	52	6	3	74	6	4	58	12	5	79
S9	13	4	56	6	3	98	6	3	74	13	2	241
S10	13	2	132	5	3	99	5	3	80	13	2	234
S11	13	2	117	5	2	141	5	6	44	12	3	140
S12	13	5	39	5	3	78	5	4	50	11	4	79
S13	13	5	46	5	2	159	5	2	166	11	3	141
S14	13	4	55	5	4	70	5	4	57	11	3	118
S15	NP	NP	NP	5	4	54	5	3	50	9	3	143
S16	-	-	-	-	-	-	-	-	-	-	-	-

	Participant 5											
	Jump squats			Single leg jumping (R)			Single leg jumping (L)			Jogging		
	Inc	Set	Rep	Inc	Set	Rep	Inc	Set	Rep	Inc	Set	Rep
S1	7	3	30	6	5	40	8	4	55	6	5	41
S2	10	6	21	7	6	31	-	-	-	10	4	53
S3	9	5	17	7	4	41	7	5	38	10	3	64
S4	11	3	63	8	4	56	6	5	34	11	2	156
S5	12	4	35	8	5	39	-	-	-	11	3	87
S6	12	4	35	8	5	45	-	-	-	11	4	50
S7	12	4	46	8	4	75	-	-	-	11	3	97
S8	12	4	45	12	4	62	-	-	-	11	4	63
S9	12	3	66	8	2	173	-	-	-	11	3	91
S10	12	2	118	8	4	72	-	-	-	11	2	150
S11	12	3	80	7	5	47	5	5	39	11	4	75
S12	12	3	80	7	2	157	5	3	53	11	3	100
S13	NP	NP	NP	7	2	155	5	4	46	11	3	100
S14	-	-	-	-	-	-	-	-	-	-	-	-
S15	-	-	-	-	-	-	-	-	-	-	-	-
S16	-	-	-	-	-	-	-	-	-	-	-	-

	Participant 6								
	Jump squats			Single leg jumping			Jogging		
	Inc	Set	Rep	Inc	Set	Rep	Inc	Set	Rep
S1	7	5	22	6	4	43	6	2	50
S2	9	5	20	7	6	34	11	5	52
S3	9	5	42	7	4	51	12	4	66
S4	9	3	93	7	3	95	13	3	144
S5	9	6	25	7	4	63	13	4	83
S6	10	5	28	7	4	61	13	3	117
S7	10	3	60	7	3	110	13	2	188
S8	11	4	38	7	4	60	13	4	85
S9	10	3	66	8	2	171	13	2	213
S10	11	4	43	8	5	60	13	4	83
S11	12	3	73	8	1	364	14	2	185
S12	12	3	73	8	2	149	15	2	190
S13	13	3	74	9	4	73	15	1	400
S14	13	2	123	9	3	95	15	1	424
S15	14	4	50	NR	4	55	16	1	428
S16	14	3	95	10	4	96	16	1	431

	Participant 7								
	Jump squats			Single leg jumping			Jogging		
	Inc	Set	Rep	Inc	Set	Rep	Inc	Set	Rep
S1	12	5	22	8	4	48	NR	NR	NR
S2	13	4	36	10	4	56	14	4	56
S3	10	4	50	11	4	63	15	4	91
S4	15	6	28	11	2	125	13	4	85
S5	16	5	39	11	4	63	13	5	64
S6	16	4	50	11	5	50	13	7	47
S7	16	4	50	11	5	49	13	7	46
S8	16	4	42	11	4	70	13	4	78
S9	15	4	51	11	2	156	13	3	127
S10	15	4	76	11	2	179	13	3	119
S11	15	3	89	12	2	151	13	3	124
S12	15	4	50	13	5	47	13	6	45
S13	15	4	42	13	4	50	13	5	53
S14	15	4	50	11	5	50	13	4	50
S15	15	4	41	11	5	46	13	5	54
S16	15	5	51	11	5	58	13	5	64

	Participant 8								
	Jump squats			Single leg jumping			Jogging		
	Inc	Set	Rep	Inc	Set	Rep	Inc	Set	Rep
S1	NP	NP	NP	NP	NP	NP	NP	NP	NP
S2	9	4	43	6	5	91	11	4	108
S3	10	4	62	5	4	49	11	3	195
S4	11	3	77	6	4	67	12	3	132
S5	11	6	25	NR	NR	NR	NP	NP	NP
S6	11	5	44	6	4	63	12	6	53
S7	11	2	124	6	1	348	12	3	135
S8	11	3	77	5	3	103	7	4	70
S9	11	3	90	4	3	94	7	3	144
S10	11	4	60	4	5	47	7	4	100
S11	11	2	136	4	1	311	7	3	158
S12	9	4	63	5	3	90	7	5	68
S13	8	2	112	5	2	155	7	3	147
S14	7	2	100	5	2	151	7	3	123
S15	7	3	80	5	3	100	8	4	90
S16	8	2	122	5	2	176	8	3	176

NP = not performed, NR = not reported.

Home-based training and other training

The participants reported other training when they came to the laboratory sessions. Fitness class includes bootcamp, Zumba, basisball, step/strength etc.

	Participant1		**Participant2**	
	Home-based training	Other training	Home-based training	Other training
w1		None		2 x Fitness class
w2		Walk		Indoor rowing + strength
w3		Bike + 16 km mountain hike		2 x Fitness class
w4		None		3 x Fitness class
w5	None	None	Home-based training	3 sessions
w6	Home-based training	None	Home-based training	2 x Fitness class
w7	Home-based training	None	Home-based training	Swimming + fitness class
w8	None	None	Home-based training in water	Swimming
	Participant3		**Participant5**	
	Home-based training	Other training	Home-based training	Other training
w1		Treadmill running		None
w2		40 min indoor rowing		None
w3		2 x run + 3h mountain hike		None
w4		40 min ellipse/strength, 55 min run, 1,5 h skiing		None
w5	None	Walk	None	Pool rehab
w6	None	Ellipse	None	None
w7	None	1,5 h run	None	Pool rehab
w8	None	Mountain hiking + 1 h run	Home-based training in water	Pool rehab
	Participant6		**Participant7**	
	Home-based training	Other training	Home-based training	Other training
w1		Physio		MI
w2		None		2 x run + 2 x mountain hike
w3		Physio		2 workout sessions
w4		2h walk + Walk		Run + Fitness class
w5	4 x Home-based training	None	None	None
w6	4 x Home-based training	None	None	None
w7	None	None	2 x Home-based training	None
w8	None	None	Home-based training	Run + Mountain hike
	Participant9		**Participant10**	
	Home-based training	Other training	Home-based training	Other training
w1		None		Walk
w2		None		2 x 1,5 h mountain hike
w3		1,5 h mountain hike		None
w4		Walk + mountainike		None
w5	None	Swimming + Fitness class	None	None
w6	None	3 x Fitness class	None	None
w7	Home-based training	Swimming + 2 x Fitness class	None	Mountain hike
w8	Home-based training	Mountain hike + 2 x Fitness class	None	None

MI = missing item

Appendices

1. Digital meeting invitation for conceptualising the project
2. Information letter to participants – Study A
3. Information letter to participants – Study B
4. Interview guide – Study A
5. Interview guide – Study B
6. Monitor scheme – Study B
7. Training diary – Study B
8. REK approval – Study A
9. REK approval – Study B

Sunnaas sykehus HF

FUNCAP CP

FUNCTIONAL CAPACITY TRAINING FOR WALKING IN ADULTS WITH CEREBRAL PALSY

You receive this document as an invitation to participate in the development of a comprehensive project with the aim to enhance gait function for people with cerebral palsy.

We would like to invite you to a meeting to discuss a possible research project on March 20th 2015, 13.00-15.00 at Sunnaas sykehus HF, Nesodden. You can join either directly at meeting room PV04 (A187), or using a videoconference system or use Lync.

Thank you for taking your time to read and consider your participation in this project.

Sincerely,

Petra A. Nordby MSc, Beate E. Gjesdal MSc and Arve Opheim PhD

Please, do not hesitate to contact us if you have any questions:

Arve Opheim	Sunnaas HF/Göteborgs Universitet	Arve.Opheim@Sunnaas.no
Petra A. Nordby	Sunnaas HF	Petra.Ahlvin@Sunnaas.no
Beate E. Gjesdal	Sunnaas HF/Høgskolen i Bergen	Beatee@Sunnaas.no

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

PERSONER MED CEREBRAL PARESE SINE ERFARINGER MED Å GÅ

Dette er en forespørsel til deg om å delta i et forskningsprosjekt der formålet er å undersøke hvilken betydning gangfunksjon har for voksne personer med cerebral parese (CP). Forespørselen rettes til deg fordi du er voksen i yrkesaktiv alder (trenger ikke å være i arbeid), og har CP. Du må ha fullført grunnskole for å kunne delta. Studien er en del av et doktorgradsprosjekt ved Universitetet i Bergen og Høgskulen på Vestlandet (HVL).

HVA INNEBÆRER PROSJEKTET?

Deltakelse i studien innebærer en samtale som varer maksimalt i 1 time, den vil bli tatt opp med lydopptaker. Temaet for samtalen vil i hovedsak være dine opplevelser og erfaringer med gangfunksjon. Doktorgradsstipendiat Beate Eltarvåg Gjesdal ringer deg og avtaler tid og sted for intervju. Sted for gjennomføring av intervju kan være hjemme hos deg eller i nærheten av der du bor, på Kronstad (HVL) eller et annet sted du foretrekker. Det er prosjektleder, fysioterapeut og forsker Silje Mæland og/eller doktorgradsstipendiat Beate Eltarvåg Gjesdal som gjennomfører intervjuet.

MULIGE FORDELER OG ULEMPER

Det forventes ikke å være noen fordeler, ulemper eller ubehag med å delta i studien.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du informert samtykkeerklæring på siste side. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet innsamlede opplysninger. Dersom du har spørsmål til prosjektet, kan du kontakte doktorgradsstipendiat Beate Eltarvåg Gjesdal, mobil 95 27 28 94, beate.eltarvag.gjesdal@hvl.no.

HVA SKJER MED INFORMASJONEN OM DEG?

Alle personopplysninger vil behandles konfidensielt. I prosjektet vil vi innhente og registrere opplysninger om deg. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil. All informasjon vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. Lydbånd og personidentifiserende materiale vil bli oppbevart innelåst i arkivskap på Høgskulen på Vestlandet, campus Bergen. En kode knytter deg til dine opplysninger gjennom en navneliste og denne vil bli oppbevart adskilt fra de transkriberte samtalene. Det er kun prosjektleder og doktorgradsstipendiat knyttet til prosjektet som har tilgang til navnelisten og som kan finne tilbake til deg.

Prosjektet skal etter planen avsluttes 31.12.2021. Ved prosjektslutt vil transkriberte intervjuer anonymiseres og lydopptak slettes. I tillegg vil anonymiserte intervjuer, i tråd med Nasjonal strategi for tilgjengeliggjøring og deling av forskningsdata, bli offentlig tilgjengeliggjort i et egnet forskningsdataarkiv. Gjenbruk av forskningsdata bidrar til vitenskapelige fremskritt, økt etterprøvbarhet og bedre kvalitetssikring av tidligere forskningsfunn.

Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte.

OPPFØLGINGSPROSJEKT

Det er planlagt en treningsstudie med fokus på gange etter dette prosjektet er ferdig. Det kan være aktuelt å ta kontakt med deg for å høre om du ønsker å være deltaker i kommende prosjekt hvis du samtykker til dette. Se siste side.

ØKONOMI

Reisegodtgjørelse med billigste kollektivtransport blir refundert.

GODKJENNING

Prosjektet er godkjent av Regional komite for medisinsk og helsefaglig forskningsetikk, 2018/349/REK vest (23.02/2018).

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELE MINE ERFARINGER MED Å GÅ

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

Deltakers mobilnummer

Deltakers e-post

OPPFØLGINGSPROSJEKT

Huk av her hvis det er aktuelt at vi kontakter deg i forbindelse med treningsstudien med planlagt oppstart i 2019:

☐ Ja, jeg ønsker å bli kontaktet for forespørsel om å delta i studie om trening av gangfunksjon

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

TRENING MED MÅL OM Å FORBEDRE GANGFUNKSJON HOS PERSONER MED CEREBRAL PARESE

Dette er en forespørsel til deg om å delta i et forskningsprosjekt der formålet er å undersøke om det er mulig å trene kraftutvikling i leggmuskulaturen som er relevant for fremdrift i gange. Forespørselen rettes til deg fordi du er voksen i yrkesaktiv alder (trenger ikke å være i arbeid), og har cerebral parese (CP). Du må ha fullført grunnskole for å kunne delta. Studien er en del av et doktorgradsprosjekt ved Universitetet i Bergen og Høgskulen på Vestlandet (HVL).

HVA INNEBÆRER PROSJEKTET?

Som deltager i denne treningsstudien vil du trene styrketrening i en periode som går over åtte uker. Det blir gjennomført tester før, undervegs og etter treningsperioden for å undersøke om treningen forbedrer gangfunksjonen din.

Når du er inkludert i studien vil du i en ukes tid før prosjektet starter gå med aktivitetsmåler. Dette er sensor som registrerer bevegelse. Denne sensoren skal du gå med en uke i strekk før, under og etter treningsperioden. I uken før treningsperioden starter skal du også gjennom omfattende testing som varer i ca. fire timer, testene utføres på Kronstad, Høgskulen på Vestlandet. Disse testene kartlegger en rekke fysiske parametere i muskelen som påvirkes med trening. Alle testene gjennomføres før og etter treningen, mens noen tester også vil bli brukt undervegs. Testene har til hensikt å undersøke egenskaper ved muskulaturen og bruk av muskulatur under gange og det blir brukt utstyr som ultralyd, tredimensjonal ganganalyse, elektromyografi og utstyr for å måle kraftutvikling.

Ballistisk styrketrening er trening med hurtig kraftutvikling som har til hensikt å bedre kraftutvikling under gange. For å undersøke at muskelen tåler denne typen trening vil vi etter første styrkeøkt ta blodprøver 30 min før økt, og 5 min, 1 time, 2 timer, 3 timer, 24 timer og 48 timer etter økten. Dette gjør vi for å se at muskulaturen tåler denne typen trening og når den er restituert til å tåle ny trening. Det blir også analysert hematologisk og immulogiske parametre og blodcelle status. Videre måles kraftutvikling. Dette blir bare gjort etter første økt. I tillegg til fysiske tester og selvrapporterte spørreskjema vil vi også intervjue deg etter treningsperioden for dine erfaringer tilknyttet deltakelse.

De første fire ukene trener du to ganger i uken, og det økes til tre ganger i uken fra uke fem, eller individuelt tilpasset progresjon. To ganger i uken må du til Kronstad, Høgskulen på Vestlandet, for å trene. Estimert tidsbruk til hver økt er satt til 30 min.

MULIGE FORDELER OG ULEMPER

Deltakelse i prosjektet vil kreve tid og oppmerksomhet, og det kreves at du som deltager er tilstede på treninger og testdager. Vi har lagt opp disse dagene slik at de er tidseffektive og vil derfor ikke ta mer tid enn nødvendig.

Treningene er harde og kan oppleves ubehagelige. Det er alltid en viss sjanse for skader og overbelastning i forbindelse med styrketrening. For å forsikre oss om at treningen ikke fører til unødvendig skaderisiko vil den gradvis økes i belastning og mengde. Du kan oppleve forbigående muskelstølhet i etterkant av treningen.

De fysiske testene som utføres vil kreve maksimal innsats, og vil oppleves anstrengende. Dette kan oppleves som ubehagelig for noen, og det vil alltid være en viss risiko for skade under testen og følelse av stølhet i muskulaturen kan forekomme i etterkant.

I dette prosjektet vil det blir tatt blodprøve. Det er vanligvis ikke forbundet med smerte, men det kan oppleves ubehagelig. Du kan oppleve en lett til moderat ømhet i området hvor prøven er tatt, men dette vil kun vare 1-2 døgn og vil ikke hindre deg i å bevege eller bruke armen som før.

Om du skulle oppleve ubehag eller andre ting som du tror kan ha sammenheng med studien, kan du når som helst nå oss på telefon (telefonnummer finnes under).

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du informert samtykkeerklæring på siste side. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet innsamlede opplysninger. Dersom du har spørsmål til prosjektet, kan du kontakte doktorgradsstipendiat Beate Eltarvåg Gjesdal, mobil 95 27 28 94, begj@hvl.no.

HVA SKJER MED INFORMASJONEN OG PRØVENE SOM BLIR TATT AV DEG?

Dataene og informasjonen som registres under testingen, skal brukes i henhold til formålet og hensikten med studien. Alle opplysningene vil bli behandlet uten direkte gjenkjennende opplysninger, som navn og fødselsnummer. Du vil ved forsøksstart få utdelt et forsøkspersonnummer (ID-nummer) som skal brukes under studien og det er bare dette nummeret som vil være tilknyttet til dine data. Det betyr at alle data vil bli behandlet konfidensielt og det vil ikke være mulig å identifisere deg i resultatene. Blodprøvene som tas av deg skal oppbevares i en forskningsbiobank lokalisert i Bergen. En generell forskningsbiobank skal lagre biologisk materiale til fremtidig forskning innenfor et gitt forskningstema. Ansvarshavende for biobanken (*Idrett, Helse og Funksjon: Biomarkører, ref. 2016/787*) er Elisabeth Ersvær.

Underveis i forsøket vil vi oppbevare en kodeliste med navn og forsøkspersonnummer. Denne kodelisten vil fysisk være låst inne, slik at det er kun forskerne tilknyttet studien som har adgang til den. Alle som får innsyn i informasjon om deg har taushetsplikt. Kodelisten lagres i 5 år etter prosjektslutt, og destrueres etter dette.

Dine rettigheter
Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rettet personopplysninger om deg,
- få slettet personopplysninger om deg,
- få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?
Vi behandler opplysninger om deg basert på ditt samtykke.

Prosjektet skal etter planen avsluttes 31.12.2023. Ved prosjektslutt vil transkriberte intervjuer anonymiseres og lydopptak slettes. I tillegg vil anonymiserte intervjuer, i tråd med Nasjonal strategi for tilgjengeliggjøring og deling av forskningsdata, bli offentlig tilgjengeliggjort i et egnet forskningsdataarkiv. Gjenbruk av forskningsdata bidrar til vitenskapelige fremskritt, økt etterprøvbarhet og bedre kvalitetssikring av tidligere forskningsfunn.

Prosjektleder, Silje Mæland, har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte. Personvernombudet ved HVL er Halfdan Mellbye, personvernombud@hvl.no. Tlf. 55 30 10 31.

ØKONOMI

Reisegodtgjørelse med billigste kollektivtransport blir refundert.

GODKJENNING

Regional komité for medisinsk og helsefaglig forskningsetikk har vurdert prosjektet, og har gitt forhåndsgodkjenning (REK Vest 2018/2390-05)

Etter ny personopplysningslov har dataansvarlig, prorektor for forskning ved HVL Gro Anita Fonnes Flaten og prosjektleder Silje Mæland et selvstendig ansvar for å sikre at behandlingen av dine opplysninger har et lovlig grunnlag. Dette prosjektet har rettslig grunnlag i EUs personvernforordning artikkel 6a og artikkel 9 nr. 2 og ditt samtykke.

Du har rett til å klage på behandlingen av dine opplysninger til Datatilsynet.

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

Hvis du har lest informasjonsskrivet og ønsker å være med som forsøksperson i prosjektet, ber vi deg undertegne nedenfor, og returnere skjemaet til en av personene oppgitt nedenfor. Du bekrefter samtidig at du har fått kopi av og lest denne informasjonen.

Det er frivillig å delta og du kan når som helst trekke deg fra prosjektet uten videre begrunnelse. Alle data vil, som nevnt ovenfor, bli avidentifisert før de blir lagt inn i en database, og senere anonymisert.

Med vennlig hilsen,

Beate Eltarvåg Gjesdal, PhD student, begj@hvl.no (mob. 95 27 28 94)

Silje Mæland, Førsteamanuensis, prosjektleder, smel@hvl.no (mob. 92 40 33 14)

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

Deltakers mobilnummer

Deltakers e-post

Intervjuguide

Intro: Jeg kommer til å styre samtalen, det er ingen riktige svar, det jeg får mest ut av er at du svarer så ærlig du kan. *Det er veldig fint hvis du klarer å belyse dine erfaringer med konkrete hendelser, som f.eks. når du går på et kjøpesenter eller når du går til jobb.*	*Critical incident technique – invitere deltakeren til å dele sine erfaringer i form av konkrete hendelser, som leder til en opplevd historie som hadde en spesiell betydning angående en bestemt sak* Åpne oppfølgingsspørsmål

Kort om hvorfor jeg forsker på dette.
 	
Spørreskjemaet
 	
Hvordan er det å gå med CP?
Betydning/tanker rundt det å gå?
 	
Stikkord:
- En vanlig dag
- Fall og redsel for å falle?
- Når begynte du å gå?
- Følelser, tanker, holdninger, identitet som funksjonshemmet eller passere som ikke funksjonshemmet?
- Gange – mål – familie – fysio
- Ungdom vs voksen
- Er det ønskelig å trene gangfunksjon?
- Evt. hvordan?
- Var det noen som snakket om
    o Belastningsskader
    o Energiforbruk
    o Vekselbruk med rullestor
- Har funksjonen endret seg – (kanskje ikke dårligere, men mer sliten, det koster mer??
- Treningsopphold?
- Fatigue
- Årstider (for eksempel snø)	

Erfaringer med treningsintervensjonen i prosjektet ”FUNCAP-CP” - en kvalitativ studie

Intervjuguide

Formålet med denne kvalitative delstudien er å kartlegge din opplevelse av å ha deltatt samt om deltagelse har ført til endringer i dagliglivet som vi ikke klarer å fange opp på annen måte.

Guiden fungerer mer som støtte for struktur fremfor en tvangsmessig sjekkliste for intervjuer.

Stikkord til innledning:

- Kort presentasjon: fysioterapeut og forsker
- Som du har lest og skrevet under på – tas opp på lydbånd, men slettes i etterkant
- Du vil være anonym når jeg jobber videre med materialet fra intervjuene
- Du kan når som helst trekke deg i løpet av intervjuet uten å måtte gi noen grunn for det

Kan du begynne med å beskrive noen konkrete opplevelse som du har hatt som deltaker i prosjektet? Om det er en positiv eller negativ opplevelse, er det samme.

Basert på at du nå ha vært gjennom et veiledet treningsopplegg i xx uker. Hva tenker du om

- Treningsmengden
- Treningsintensiteten
- Veiledningen

Har treningen påvirket noen av dine aktiviteter i dagliglivet?

- Opplever du gangen din som endret?

Post-testing:

- Kan du si noe om hvordan det var å lære disse øvelsene?
  (hvor lang tid brukte du, hvilken type feedback trenger du, hva gjorde du for å klare det etc.)

FUNCAP–CP

UTFYLLINGSSKJEMA UNDER TRENING

FP________ Dag: ________ Dato: ________ Tid: ________ Trener: ________ Økt: ______

Trening siden sist økt:	*Eventuell kommentar*
Oppvarming:	

Øvelse1: Jump Squats	
Helning på sleden: / / / / / / / / *Antall reps:* / / / / / / / /	*Assistanse:*
Kommentar:	

Øvelse 2: Singel leg jumping on paretic leg	
Høyre	**Venstre**
Helning på sleden: / / / / / / / / *Antall reps:* / / / / / / / /	*Helning på sleden (grader)* / / / / / / / / *Antall reps:* / / / / / / / /
Assistanse: *Kommentar:*	*Assistanse:* *Kommentar:*
Etter øvelse 2: Borg (legg):	*Etter øvelse 2: Borg (legg):*

Øvelse 3: Jogging on alternating legs	
Helning på sleden: / / / / / / / / *Antall reps:* / / / / / / / /	*Assistanse:* *Kommentar:*
Etter øvelse 3: Borg (hele kroppen/legg):	

FUNCAP-CP

Egentrening

FP:________ Dag:________ Dato:____________

http://kvardagsatleten.no/egentrening/index.html

Øvelse	Repetisjoner	Gjennomført
Koordinasjon	12 repetisjoner 3 ganger	
Gående kneløft	12 repetisjoner 3 ganger	
Hjulet (claw)	12 repetisjoner (på hvert bein) 3 ganger	
Hinkende kneløft	12 repetisjoner 3 ganger	

http://kvardagsatleten.no/egentrening/triplings.html

Øvelse	Repetisjoner	Gjennomført
Stående triplings	12 repetisjoner 3 ganger	
Triplings	12 repetisjoner 3 ganger	
Triplings tempo	12 repetisjoner (på hvert bein) 3 ganger	

http://kvardagsatleten.no/egentrening/hofte-3.html

Øvelse	Repetisjoner	Gjennomført
Hofte 1	12 repetisjoner (på hvert bein) 3 ganger	
Hofte 2	12 repetisjoner 3 ganger	
Hofte 3	12 repetisjoner 3 ganger	

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK vest	Camilla Gjerstad	55978499	23.03.2018	2018/349/REK vest
			Deres dato:	**Deres referanse:**
			13.02.2018	

Vår referanse må oppgis ved alle henvendelser

Silje Mæland
Avdeling for helse og sosialfag

2018/349 Personer med cerebral parese sine erfaringer med å gå

Forskningsansvarlig: Høgskulen på Vestlandet
Prosjektleder: Silje Mæland

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK vest) i møtet 07.03.2018. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10.

Prosjektomtale
Økt brukermedvirkning er ett av ti satsingsområder i den nasjonale forsknings- og innovasjonsstrategien for helse og omsorg, HelseOmsorg21. De fleste personer med cerebral parese (CP) har mye fokus på gangtrening i rehabiliteringen/treningen. Det er lite litteratur som til nå sier noe om hvor viktig gangfunksjon faktisk er for personer med CP. Med økt kunnskap om brukernes erfaringer og synspunkter rundt gange kan utforming av helsetjenester for denne populasjonen bidra til økt «treffsikkerhet» av eksisterende tilbud. Formålet med studien er å undersøke hvilken betydning gangfunksjon har for voksne personer med CP. Det vil bli brukt kvalitativ metode med semistrukturert individualintervju. Datamaterialet vil bli analysert med systematisk tekstkondensering. Dette er første delstudie i en doktorgrad, viser til vedlagt prosjektbeskrivelse for "Functional capacity for walking in adults with Cerebral Palsy" (FUNCAP-CP).

Vurdering
Studiepopulasjon
Deltakerne er voksne personer med mild til moderat CP. 10 deltakere vil bli inkludert.

Forsvarlighet
Studien tar sikte på ny innsikt i hvilken betydning gangfunksjon har for voksne med CP. Prosjektet vil, gjennom brukermedvirkning, undersøke deltakerne sine erfaringer med å gå. Komiteen har ingen merknader til intervjudelen og vurderer prosjektet som forsvarlig å gjennomføre for deltakerne. Det er en kvalitativ studie som er den første av tre delstudier i et PhD-løp. De to neste delstudiene er kvantitative og vil bli søkt om senere. Det synes ikke klart fra søknaden om resultatene av den første delstudien vil bli brukt videre i de neste studiene. Komiteen vil peke på at det vil være nyttig å gjøre en kvalitativ oppsummering av den første delstudien før de neste studiene gjennomføres.

Rekruttering
Informasjon om studien legges ut på sosiale medier og ved oppslagstavler ved legekontor, sykehus og treningssenter. Potensielle deltakere vil så kunne ta kontakt. Komiteen har ingen merknader til rekrutteringsprosedyrene.

Informasjonsskriv
Samtykke til deltakelse i forskning skal være en aktiv viljeserklæring. Samtykkealternativet *«Nei, jeg ønsker ikke å bli kontaktet»* bør derfor utgå. REK vest har ellers ingen merknader.

Prosjektslutt
REK vest forstår søknaden slik at opplysningene blir anonymisert ved prosjektslutt 31.12.2021. En har ingen merknader til dette.

Vedtak
REK vest godkjenner prosjektet i samsvar med forelagt søknad.

Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding til REK vest på eget skjema senest 30.06.2022, jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK vest dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Marit Grønning
dr.med. professor
komitéleder

Camilla Gjerstad
rådgiver

Kopi til: post@hvl.no

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK vest	Jessica Svärd	55978497	04.02.2019	2018/2390/REK vest
			Deres dato:	Deres referanse:
			11.12.2018	

Vår referanse må oppgis ved alle henvendelser

Silje Mæland
Fakultet for helse- og sosialvitskap

2018/2390 Trening av funksjonell kapasitet for gange hos voksne med cerebral parese

Forskningsansvarlig: Høgskulen på Vestlandet
Prosjektleder: Silje Mæland

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK vest) i møtet 16.01.2019. Vurderingen er gjort med hjemmel i helseforskningsloven (hforsknl) § 10.

Prosjektomtale
De fleste personer med cerebral parese (CP) har i oppveksten hatt mye fysioterapi med fokus på gangtrening. Ingen studier har til nå vist å kunne anbefale en treningsintervensjon over en annen for å påvirke gangfunksjonen. En kritisk review av Williams et al. (2014) poengterer at trening for å påvirke gange hos neurologiske pasienter ikke er oppgavespesifikk. Flere studier har vist at eksentrisk styrketrening påvirker muskelens kapasitet for hurtig kraftutvikling, ballistisk styrketrening er oppgavespesifikk for hurtig kraftutvikling. I denne studien vil halvparten av deltakerne trene eksentrisk styrketrening og den andre halvparten trene ballistisk styrketrening. Vi vil måle endring basalt, funksjonelt og selvopplevd.

Vurdering

Forsvarlighet
Studien har liten risiko med potensiell nytte for deltakerne. Prosjektet har beredskap slik at treningen ikke blir for hard. Komiteen diskuterte om studien kan klare å se forskjeller på to typer trening med få deltakere som kan ha store forskjeller i motorisk funksjonsnivå. Komiteen finner dog at studien har liten risiko og at den er forsvarlig å gjennomføre.

Forskningsansvarlig institusjon
Komiteen diskuterte om UiB også burde være forskningsansvarlig institusjon ettersom prosjektet er del av en doktorgrad ved UiB. Hvis UiB skal være forskningsansvarlig institusjon så må det søkes om i en prosjektendring.

Humant biologisk materiale og biobank
Fullblod skal tas og serum og plasma skal lagres i en tidligere godkjent generell forskningsbiobank Navn på biobanken: Idrett, Helse og Funksjon: Biomarkører, ref. 2016/787. Navn på ansvarshavende: Elisabeth Ersvær, HVL. Det må informeres om at prøvene lagres i en generell biobank også i informasjonsskrivet om studien.

Deltakere og rekruttering
Prosjektet skal rekruttere 10 personer, 18-70 år, med spastisk cerebral parese og høyt motorisk funksjonsnivå (GMFCS I-II). Deltakerne skal rekrutteres gjennom at informasjon om prosjektet legges ut på hvl.no, på sosiale medier som CP-foreningen sine nettsider, relevante Facebook-grupper, Instagram, Twitter osv. Det vil også bli hengt opp informasjon om studien ved legekontor, sykehus, treningssenter etc. Personer som er interessert vil inviteres til en kartleggingssamtale for å se om de innfrir inklusjonskriteriene. Her får de potensielle deltagerne ytterligere informasjon om prosjektet. Skriftlig informert samtykke signeres ved inklusjon. REK vest har ingen merknader.

Informasjonsskriv og samtykkeskjema
Det vedlagte informasjonsskrivet er relativt godt, men det er ikke brukt mal for infoskriv, dermed mangler informasjon om behandlingsgrunnlag for helseopplysninger og klagerett og annet.

Det står ikke noe om generell biobank i skrivet. Dette må legges til. Informasjon om destruksjon av prøver 5 år etter prosjektslutt må tas ut ettersom det skal benyttes en generell biobank.

Informasjonsskrivet har logo for HVL og for UiB. Dette signaliserer til deltakerne at UiB også er forskningsansvarlige. Hvis UiB skal være forskningsansvarlig institusjon må dette søker om i en prosjektendring, hvis ikke så må logo til UiB fjernes fra informasjonsskrivet.

Det står at «Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte.», men det er ikke oppgitt hvem som er prosjektleder for studien. Man må gjette at det er Silje Mæland, førsteamanuensis, som er prosjektleder.

Det står «Hvis du har lest informasjonsskrivet og ønsker å være med som forsøksperson i prosjektet, ber vi deg undertegne nedenfor, og returnere skjemaet til en av personene oppgitt nedenfor.», men det er ikke oppgitt adresse til personene, kun telefonnummer.

Prosjektleder har lagt ved informasjonsskrivet til den generelle biobanken i epost. Dette ser bra ut, men det må likevel stå noe i informasjonsskrivet for studien om biobank istedenfor det som står der nå om destruksjon 5 år etter prosjektslutt.

Informasjonsskrivet må revideres etter ovennevnte merknader og sendes til post@helseforskning.no med REK vest og referansenummer i emnefeltet.

Samarbeid med utlandet
Prosjektet samarbeider med forskere i Australia, men det er ikke oppgitt om data skal utleveres til disse. Det står ikke noe i informasjonsskriv om utlevering av data så REK vest forutsetter at ingen helseopplysninger skal leveres ut til Australia.

Prosjektslutt og behandling av data
Prosjektslutt er 31.12.2023. Data lagres avidentifisert med koblingsnøkkel på Høgskolen på Vestlandet (HVL) sin forskningsserver. Data vil bli anonymisert (kodeliste destrueres) fem år etter prosjektavslutning. REK vest gjør oppmerksom på at prosjektleder må sikre at data er reelt anonyme når koblingsnøkkelen er destruert.

Vi gjør samtidig oppmerksom på at det kreves et juridisk grunnlag for å behandle personopplysninger. Nytt av 20. juli 2018 er at REKs godkjenning ikke lenger gir et juridisk grunnlag for å behandle personopplysninger. Nå må denne behandlingen også oppfylle krav i personvernforordningen. Fortsatt skal alle forskningsprosjekter som omfattes av helseforskningsloven forhåndgodkjennes av REK, men egen institusjon har ansvar for at behandlingen av personopplysninger er i henhold til personvernforordningen.

Vilkår
Informasjonsskrivet må revideres etter ovennevnte merknader og sendes til post@helseforskning.no med REK vest og referansenummer i emnefeltet.

Vedtak
REK vest har gjort en helhetlig forskningsetisk vurdering av alle prosjektets sider. Prosjektet godkjennes med hjemmel i helseforskningsloven § 10 i på betingelse av at ovennevnte vilkår tas til følge.

Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding til REK vest på eget skjema senest 30.06.2024, jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK vest dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

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Med vennlig hilsen

Marit Grønning
dr.med.
Avdelingsdirektør, professor

Jessica Svärd
rådgiver

Kopi til: post@hvl.no

Graphic design: Communication Division, UIB / Print: Skipnes Kommunikasjon AS

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ISBN: 9788230859094 (print)
9788230843161 (PDF)