Sit-to-Stand Exercise Programs for Children with Cerebral Palsy

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List of Abbreviations

CP……Cerebral Palsy

GMFCS…….……..…. Gross Motor Functional Classification System

ICF-CY……. International classification of functioning, disability and health: children and youth version

WeeFIM……. Functional Independence Measure for Children

FTSST……. Five Times Sit-to-Stand Test

MCSI…….……..... Modified Caregiver Strain Index

PRISMA .....… Preferred Reporting Items for Systematic Reviews and Meta-Analyses

COREQ……... COnsolidated criteria for REporting Qualitative research

CONSORT……. CONsolidated Standards of Reporting Trials

PROSPERO……... International Prospective Registry of Systematic Reviews

TIDieR…….…Template for Intervention Description and Replication

SRQR……..... Standards for Reporting Qualitative Research

Exp…….....……Experimental group

Exp-STS……..…Experimental sit-to-stand group

Con…….……. Control group

Acknowledgements

Firstly, I am deeply grateful to my amazing supervisors Professor Nicholas Taylor and Professor Karen Dodd for your support, lots of encouragement and guidance, and belief that I can complete this thesis under many challenges along the way. However, with those challenges, there have been successes that I had never encountered before and would not have been able to accomplish without both of you. Thank you for sharing your time, your knowledge, your expertise, your meticulous approach to reviewing my work, and your equanimity for trying to explain to me in every issue. Thank you for understanding my situation; both being homesick when I first arrived in Melbourne, my situation in Thailand, and unable to travel back to Melbourne due to the travel restriction from the coronavirus situation. Thank you for always helping to find a suitable solution in every situation, setting reasonable timeframes that enabled and supported me to progress constantly. I want to tell you both that this was the most memorable moment of my life. Thank you for giving me the opportunity to work with you. It has been an absolute privilege to have this opportunity.

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Summary

Children with cerebral palsy and moderately severe mobility limitation typically cannot sit-to-stand safely, efficiently, and independently. This thesis hypothesised that improved sit-to-stand ability may be associated with better performance of other tasks requiring part or full sit-to-stand movement such as transferring from chair to toilet, lifting buttocks off a chair to put pants on, and moving to stand and commencing upright mobility. The thesis comprised four studies investigating the effects of task-specific sit-to-stand exercise training on mobility and self-care in these children.

A systematic review with meta-analysis (8 trials) found moderate-quality evidence that sit-to-stand exercise improved sit-to-stand performance (daily sit-to-stand repetitions, speed, sit-to-stand functional strength) in people with health conditions; but no evidence other outcomes such as mobility improved. Participants in included trials typically had mild mobility limitation.

A mixed methods study (25 caregivers; 25 children aged 4 to 12 years, Gross Motor Function Classification System (GMFCS) III-IV) using caregiver interviews and WeeFIM to observe the children's mobility and self-care independence concluded caregivers perceived the ability to sit-to-stand was important for upright mobility and some self-care tasks.

A randomised controlled trial (independent sample of n=38 children aged 4 to 12 years, GMFCS III-IV) found task-specific sit-to-stand training improved sit-to-stand performance, improved self-care by 2.2 units (95%CI 1.3 to 3.1) and mobility by 2.2 units (95%CI 1.4 to 3.0) compared to the control group, and reduced caregiver strain. The program had high adherence levels with no serious adverse events. Interviews with the caregivers of the children who completed training found the home-based component was

feasible. They perceived positive changes in their child and increased hope their child could continue to develop.

A targeted task-specific sit-to-stand exercise program could be a useful intervention for children with moderately severe cerebral palsy when aiming to improve their independence in self-care and mobility.

Statement of Authorship

This thesis includes work by the author that has been published and prepared for publication. Except where reference is made in the text of the thesis, this thesis contains no other material published elsewhere or extracted in whole or in part from a thesis submitted for the award of any other degree or diploma. No other person's work has been used without due acknowledgement in the main text of this thesis. This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

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Signed:

Sirawee Chaovalit

Date: 25 June 2021

Preface

This thesis comprises a series of six chapters that may be read independently. Chapter 2 is presented in published format with permission from *Disability and Rehabilitation*. Chapter 4 has been accepted for publication in *Developmental Medicine & Child Neurology* and is presented in the pre-publication format as the author accepted version in accordance with copyright agreements with this journal. Chapters 3 and 5 are presented in the format prepared for submission to *Developmental Neurorehabilitation* and *Pediatric Physical Therapy*, respectively. All chapters use the referencing and citation style of the particular journal in which they were published or prepared for submission.

Each paper presented within this thesis was designed, executed and written by the authors listed. The contribution of the PhD candidate, Sirawee Chaovalit, towards each paper is described in the publication statements (Appendix 2). Co-authors who contributed to published articles have signed publication statements confirming that the PhD candidate made a significant and leading contribution to the research design, conception, data collection, analysis and interpretation of findings, writing of the manuscript and the reviewing process.

Research procedures reported in this thesis that involved the recruitment of participants were approved by the La Trobe University and Health Service Human Research Ethics Committees (Appendix 1). The remaining chapters, Chapter 1 (Introduction) and Chapter 6 (Grand Discussion and Conclusions) conform to an author-date style of referencing and citation and are written in Australian English. A combined reference list for both chapters appear at the end of this thesis.

List of Publications

Chapter 2

Chaovalit S, Taylor NF, Dodd KJ. Sit-to-stand exercise programs improve sit-to-stand performance in people with physical impairments due to health conditions: a systematic review and meta-analysis. *Disability and Rehabilitation*. 2020;42(9):1202-11.

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Chapter 4

Chaovalit S, Dodd KJ, Taylor NF. (in press). Sit-to-stand training for self-care and mobility in children with cerebral palsy: a randomized controlled trial. *Developmental Medicine & Child Neurology* (accepted 2 June 2021).

List of Conference Presentations

Chaovalit S, Dodd KJ, Taylor NF. A sit-to-stand exercise program for children with moderately severe cerebral palsy: a randomized controlled trial. The American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) 75th Annual Meeting, Quebec, Canada, October 9, 2021 (Oral presentation).

Chapter 1 Introduction

1.1 Problem statement

Cerebral palsy is characterised by abnormal development of movements and posture due to a non-progressive brain lesion. These abnormalities can impair development of anti-gravity motor skills, such as the ability to independently sit-to-stand. Poor sit-to-stand function is common in children with cerebral palsy who have moderate to severe motor dysfunction classified at Gross Motor Function Classification System (GMFCS) levels III and IV. These children can walk using assistive devices but typically spend much of their time in sitting because movement against gravity is difficult. The ability to independently sit-to-stand is an important skill needed for many activities of daily living such as the ability to independently achieve upright mobility. Therefore, it seems reasonable to hypothesise that if sit-to-stand activity is improved, these children may increase their independence in being able to complete mobility and self-care tasks that have an upright standing component. To improve the ability to sit-to-stand, therapists may prescribe exercise programs incorporating repetitive practice, using the principles of task-specific training. To ensure that these children are offered optimal therapy, the effectiveness of these exercise programs need to be investigated. Accordingly, this thesis examines the effect of sit-to-stand exercise training on independent upright mobility and self-care function in children with cerebral palsy with moderate to severe motor dysfunction. Caregivers' perceptions about the outcomes and feasibility of a sit-to-stand home-based exercise program on themselves and their children are also explored.

1.2 Setting/context

The studies reported in this thesis were conducted in Thailand. Specifically, in southern Thailand at the Songklanagarind hospital, which is the largest tertiary general hospital in

the region. This hospital provides medical and allied health services for children with disabilities up to 300 km away and is also associated with the Prince of Songkla University. Most children with disability in the region receive treatment at Songklanagarind hospital before being referred onto their nearest local hospital or therapy service for ongoing management. The hospital has a specialist multi-disciplinary rehabilitation team that includes rehabilitation physicians, paediatricians, neurologists, orthopaedists, physiotherapists, occupational therapists, speech and language therapists, orthotic technicians, social workers, psychologists, and educators who work together to support these children. This team also provides ongoing consultant services to a special education school and to a centre providing services to children with intellectual disability located in the region.

The government in Thailand funds all medical and associated treatment for children registered with disabilities. Up to 15 years of age, children with cerebral palsy are eligible to access publicly funded physiotherapy services twice each week. However, the frequency of this service often reduces as children enter school and early adolescence. Physiotherapy services over time also often transitions from a focus on improvement of the child's independent movement, posture and physical skills to more provision of assistive technology or environment modification in order to encourage the school aged children to better access education and participation in age-appropriate environments. (such as the provision of equipment and/or modification of the child's environment).

1.3 Cerebral palsy

Worldwide, cerebral palsy is the most common physical disability in children, with a prevalence of around 2.11 per 1000 live births (95% CI 1.98 to 2.25) (Oskoui et al., 2013). Although it is known that the prevalence of cerebral palsy is lower in Asian compared with European populations (Lang et al., 2012), in Thailand cerebral palsy is

still the most common disability in children (National Statistical Office, 2012), with a prevalence of around 0.61 to 1.00 per 1,000 live births (Lang et al., 2012; Chueluecha et al., 2020).

Cerebral palsy is characterised by disorders of abnormal movements and posture (Krigger, 2006; Rosenbaum et al., 2007) and is caused by a non-progressive lesion to the immature brain (Garfunkel, Kaczorowski, and Christy, 2007). Children with cerebral palsy can have a range of impairments such as muscle stiffness and spasticity, impaired communication, impaired cognition, behavioural problems, seizures as well as deficits in sensory systems (e.g. visual, auditory, and tactile). All of these impairments contribute to the motor performance deficits and activity limitations observed in children with cerebral palsy (Rosenbaum et al., 2007). These impairments, together with adaptive changes that occur over time at neural and musculoskeletal levels, often lead to difficulty developing anti-gravity motor skills, such as the ability to move and transfer independently. Children with cerebral palsy who have more severe motor disabilities often achieve independent sit-to-stand transfer at a later age than children without disability, and the way they move is commonly slower, less efficient and less safe (Hanna et al., 2009; Hennington et al., 2004).

1.3.1 GMFCS III and IV

The Gross Motor Function Classification System (GMFCS) (Palisano et al., 1997) is widely used to classify the motor functioning of children with cerebral palsy. Using this system, the severity of functional disability is classified into 5 levels: from level 1, independent ambulation without restriction, to level V, limited self-mobility. Children with a disability classified at GMFCS level III have some mobility difficulties and they typically use hand-held devices such as crutches or a walker frame for ambulation over short distances and they use wheeled mobility when travelling long distances. Children

with a disability classified at GMFCS level IV use methods of mobility that require physical assistance in most settings, and they typically use powered mobility devices such as a motorised wheelchair when travelling longer distances (Palisano et al., 2008). Children with moderate to severe motor disability (classified at level III and IV) typically spend much of their time in sitting because they have difficulty moving against gravity.

Although the GMFCS levels are described by the resultant motor dysfunction, GMFCS levels are associated with other impairments that might affect function. For example, about 30% of the children classified as GMFCS III have a severe intellectual disability (IQ<50) (Carlsson, Hagberg, and Olsson, 2003), about 20% have a severe visual impairment (Stiers et al., 2002) and about 25% have epilepsy (Novak et al., 2017; Carlsson, Hagberg, and Olsson, 2003). Around 25% of the children classified as GMFCS IV have a severe intellectual disability, about 25% to 37% have a severe visual impairment, about 50% have epilepsy, about 45% have hip displacement requiring surgery and about 11% use a feeding tube (Cans, 2000; Stiers et al., 2002; Carlsson, Hagberg, and Olsson, 2003). Therefore, although the GMFCS levels directly describe motor function impairments, GMFCS levels III and IV are characterised by moderate (GMFCS III) to severe (GMFCS IV) overall disability, not just moderate to severe motor disability. Accordingly, throughout this thesis, children classified as GMFCS III and IV will be described as having moderately severe cerebral palsy.

1.3.2 Impaired sit-to-stand is a common problem for children classified at GMFCS levels III and IV

1.3.2.1 The biomechanics of sit-to-stand

The ability to independently sit-to-stand is an important skill needed to independently achieve upright mobility and perform many activities of daily living (Chou et al., 2003). Sit-to-stand is a transitional movement used to achieve upright standing posture that

requires movement of the centre of mass from a stable position to a less stable position over extended lower extremities (Vander Linden, Brunt, and McCulloch, 1994). Moving upright from sitting on a chair requires moving the body's centre of mass forward and upward to transfer the body's weight over the feet with sufficient equilibrium and balance (Riley et al., 1991). Not only are joint displacements required in the movement, but also the ground reaction force must be controlled by muscles and ligaments so that balance is maintained (Schultz, Alexander, and Ashton-Miller, 1992).

Sit-to-stand also can be described using kinematic and kinetic variables, with definitions supplied for phases and events during this movement (Kralj, Jaeger, and Munih, 1990; Schenkman et al., 1990; Kotake et al., 1993). Four phases of motion are often used to describe the sit-to-stand movement (Schenkman et al., 1990). Phase I (flexion-momentum phase) starts with initiation of the movement, it includes anterior rotation of the trunk and pelvis, and ends just before the buttocks are lifted from the seat of the chair. Phase II (momentum-transfer phase) starts when the buttocks are lifted off the seat of the chair and ends when maximal ankle dorsiflexion is achieved. During this phase, forward momentum of the trunk is transferred as the body moves in an upward and forward motion. Phase III (extension phase) is initiated just after maximum ankle dorsiflexion and ends with hip extension, including leg and trunk extension. Phase IV (stabilisation phase) begins after hip extension is reached and ends when all motion associated with stabilisation is completed, including anterior and posterior sway in standing after rising (Schenkman et al., 1990).

Muscle strength and coordination are important to control movement during the four phases of sit-to-stand. Normative data in adults suggests key roles for the gluteal, quadriceps and hamstring muscles during sit-to stand (Roebroeck et al., 1994). At phase I the tibialis anterior muscle is active. At phase II of the movement (seat off), the gluteals

and hamstrings show moderate increases in activity, with the largest increase in activity observed in the knee extensors (reaching 50 to 80% of the maximal standard contraction). In addition, co-contraction of the bi-articular hamstrings and rectus femoris occurs during transition in sit-to-stand (Roebroeck et al., 1994; Millington et al., 1992).

Sit-to-stand movement for children is similar to adults but does demonstrate some differences. Young children show more variability of movement during sit-to-stand, and they appear to have difficulty controlling horizontal momentum of the centre of mass, finding it difficult to end the movement in quiet standing (stabilisation phase) (Cahill, Carr, and Adams, 1999). In typically developing children, since the base of support is reduced when moving from sit-to-stand to a small area limited by the feet, and body balance and equilibrium reactions are developing, the developing central nervous system is challenged to control whole-body movement and stability (Seven, Akalan, and Yucesoy, 2008). A systematic review investigated sit-to-stand movement in children (including typically developing children and children with disabilities such as cerebral palsy) (da Costa, Savelsbergh, and Rocha, 2010). The review included 11 studies and it aimed to determine the intrinsic and extrinsic factors influencing the sit-to-stand movement of children. The biomechanics of the sit-to-stand movement in all children were influenced by the following intrinsic factors: type of development (typical or atypical), the child's age, skill level, body structure (e.g. obesity), and function (limited or full function); and by the following extrinsic factors: the chair characteristics (e.g. height from the ground, amount of seat padding), adding weight to the trunk, adding prosthetic and orthotic devices, and the environment in the room (e.g. visual scenes, noise). In children with disabilities, sit-to-stand was affected by additional factors associated with the child's disability: such as the use of ankle-foot orthoses, and the presence of associated motor and sensory dysfunction. For children with cerebral palsy, sit-to-stand

movement can be especially difficult due a loss of motor control from muscle weakness, and lack of joint range of motion due to muscle spasticity, muscle tightness and contractures (da Costa, Savelsbergh, and Rocha, 2010). Previous studies found that children with cerebral palsy have difficulty controlling horizontal momentum of the centre of mass (Thanapan, 2013), which is an essential parameter for achieving sit-to-stand function in children (Prasertsukdee, 2002).

A separate systematic review aimed to evaluate sit-to-stand movement specifically in children with cerebral palsy (dos Santos, Pavao, and Rocha, 2011). The review, which included 9 studies, concluded that performing the sit-to-stand movement in children with cerebral palsy was often difficult. They showed variability in sit-to-stand movement performance due to intrinsic factors such as the child's age, the type of cerebral palsy, level of GMFCS, degree of muscle weakness, severity of spasticity, and severity of impaired postural control and balance (dos Santos, Pavao, and Rocha, 2011). Two of the included studies found that spasticity of the lower limb muscles impacted sit-to-stand ability and that increased spasticity led to a slower speed of sit-to stand (Park et al., 2003; Park et al., 2006). Muscle weakness also appeared to be associated with the poor postural control and balance observed during sit-to-stand in children with cerebral palsy (dos Santos, Pavao, and Rocha, 2011). Three included studies found that compared to their typically developing peers, children with cerebral palsy moved from sit-to-stand significantly slower, and showed more anterior pelvic tilt, and earlier knee extension (Hennington et al., 2004; Park et al., 2003; Wilson et al., 1997). The extension phase of sit-to-stand was also significantly longer in duration for children with cerebral palsy than for children without disabilities (Hennington et al., 2004; Park et al., 2003; Wilson et al., 1997). Moreover, the maximum extensor power generation of the hip and knee joints

were significantly reduced in children with cerebral palsy (Hennington et al., 2004; Park et al., 2003; Wilson et al., 1997).

When analysing the extrinsic factors influencing the adaptive sit-to-stand movement patterns seen in children with cerebral palsy, two of the included studies found an increase speed of sit-to-stand movement when children used hinged ankle-foot orthoses (AFO) (Park et al., 2003; Wilson et al., 1997). With regards to the chair seat height, one included study found that standing from low seat heights increased the extension phase duration; however, these children were able to modify their movement strategies to complete sit-to-stand movement from both low and high seats (Hennington et al., 2004).

In summary, compared to typically developing peers, during sit-to-stand children with cerebral palsy usually move more slowly, less efficiently and smoothly, and they fall more often (Hanna et al., 2009; Hennington et al., 2004; Park et al., 2003). This is a particular problem in children with moderately severe disabilities (GMFCS level III and IV) because of the severity of their abnormal movements and postures.

1.3.2.2 Sit-to-stand: terminology and the ICF-CY

According to the International Classification of Functioning, Disability and Health for Child and Youth (ICF-CY) (World Health Organization, 2007), it is important to focus not only on impairment or diseases but also on functional characteristics. The relationship between sit-to-stand movement and function (that is, the effect of limitations in sit-to stand on other activities such as self-care and mobility) has not previously been reported and this has been identified as an important gap in the literature (dos Santos, Pavao, and Rocha, 2011).

According to the ICY-CY, sit-to-stand fits within the activities and participation component of functioning and disability. Within the ICF-CY an activity is defined as the execution of a task or action by an individual, while participation is defined as a person's

ability to be involved in a life situation. The task of transferring from sitting to standing is classified within the domain of mobility, specifically within 'changing basic body position' (ICF-CY classification code d410).

Apart from changing and maintaining body position (which includes the sit-to-stand task) the ICF-CY domain of mobility also includes: carrying moving and handling objects (d430-d449), walking and moving, and moving around using transportation. For children with cerebral palsy classified as GMFCS III and IV walking (d450) and moving around in different locations (d460) can be difficult. Children classified as GMFCS III and IV, especially within the house, often move around by means other than walking (d455), such as by crawling.

The ICF-CY domain of self-care is concerned with tasks related to caring for oneself including washing (d510), caring for body parts (d520), toileting (d530), dressing (d540), eating (d550) and drinking (d560) (WHO 2007). Many of these self-care tasks typically involve being able to perform tasks or parts of tasks classified under mobility in ICF-CY. For example, the self-care task of toileting (d530), requires the person to be able to complete the mobility task of changing a body position (d410) to safely transfer oneself. Also, the self-care task of dressing (d540) some items such as pants, requires the person to be able to maintain a body position (d415) that could comprise at least part of the sit-to-stand movement.

Therefore, being able to transfer from sitting to standing, can be an important prerequisite for both mobility and some aspects of self-care. For the purposes of this thesis the term 'upright mobility' will be used to describe activities across both the mobility and self-care domains of the ICF-CY that could include walking, moving from one place to another and maintaining an upright posture to enable the performance of some self-care tasks.

Because children with cerebral palsy classified as GMFCS III and IV spend much of their time in sitting (Hanna et al., 2009; Park et al., 2003) their functional mobility and independence in self-care tasks related to sit-to-stand may be limited, and so they may need some assistance from caregivers to complete many activities of daily living. It is hypothesised that therefore, if these children can improve sit-to-stand, they may increase their independence in mobility and relevant self-care tasks related to sit-to-stand and in turn reduce the burden of care on caregivers.

1.4 Task-specific training in cerebral palsy

Task-specific training is a term that has evolved from the movement science literature (Schmidt et al., 2018), and incorporates the principles of motor learning with components including context, practice, and dose (Carr and Shepherd, 2010; Schmidt et al., 2018; Hubbard et al., 2009). Task-specific training involves practising a context-specific task, where the intervention focuses on improving the motor skill(s) needed to accomplish a task (Hubbard et al., 2009). Task-specific training can include the isolated practice of an impaired essential movement (that is, practice of part of the task) if the whole task cannot be completed adequately. For example, this could include practicing phase I (flexion-momentum phase) of sit-to-stand with initiation of the movement including anterior rotation of the trunk until just before the buttocks are lifted from the seat of the chair. Task-specific training also involves practice under different conditions or environments to encourage transfer of the task to other related tasks (Hubbard et al., 2009). Other motor learning strategies such as feedback, task modification, positive motivation and practice of the task in treatment environments that mirror the usual home or community environment can be applied to optimise task-specific training and to enhance motor learning (Hubbard et al., 2009). Repetitive task training is combined with tasks that are meaningful to the person to enhance cognitive involvement to result in improved motor

learning (Bayona et al., 2005). For example, for a child this could involve reaching for a favourite toy after completion of sit-to-stand. Therefore, task-specific training involves the repetitive practice of specific motor tasks, which can be whole task, or a part of a task with the inclusion of feedback modified to suit a child's abilities. To enhance activity in children with cerebral palsy, task-specific training can be applied as a treatment option in physiotherapy.

Task-specific training for children with cerebral palsy can be viewed as an example of the application of a systems model theory of movement (Bernstein, 1967). A systems model suggests that synchronising the interaction of multiple relevant systems such as a person's muscle strength, coordination, cognition, and automatic function can improve motor impairments in children with neurological conditions such as cerebral palsy (Bernstein, 1967). To improve impaired movement in these children, therapeutic programs need to provide sufficient repetitions to stimulate motor learning to produce a successful movement strategy, and must practice that movement in the child's natural environment such as the child's home (Bernstein, 1967; Muratori et al., 2013).

A systematic review has been conducted to evaluate and synthesise evidence about the effectiveness of task-specific training in ambulant children with cerebral palsy (aged 4 to 18 years), and to identify the motor learning strategies reported within task-specific training programs (Toovey et al., 2017). The review included 13 studies (including 8 randomised controlled trials) with 405 participants. The included children were classified as GMFCS levels I-III. The effects of task-specific training were evaluated for tasks such as throwing, swimming, sit-to-stand, and overground walking.

Only one study in the systematic review (Toovey et al., 2017) reported effects of task specific training on sit-to-stand (Kumban et al., 2013). That study evaluated the effects of sit-to-stand task-specific training on children with mild to moderate cerebral palsy (the

majority of participants GMFCS level I and II) and found that a program of repetitive sit-to-stand practice had no significant between-group effects on any activity outcomes such as balance, and the Motor Assessment Scale, which includes movement out of supine, sit-to-stand and walking (Kumban et al., 2013). It is not known why this program proved ineffective, however, close examination of the program showed that children in this study typically only performed 30-60 repetitions of sit to stand each week and so it might be because the training dose was not adequate for task-specific training to improve gross motor functions. Or it could be because most of the children in this study had only mild to moderate disability (GMFCS level I and II), and so could already complete the activity of sit-to stand with little difficulty. Hence, they might not be expected to have gained further benefits from training of sit-to-stand due to ceiling effects (Kumban et al., 2013).

The systematic review (Toovey et al., 2017) concluded that evidence was inconclusive about whether task-specific training was effective in improving specific skill performance, activity including gross motor function, and participation-related outcomes in ambulant school-aged children with cerebral palsy. The reporting of dose in studies included in this review was variable (ranging from 3 to 90 hours over durations from 10 days to 6 months), but typically was 30 to 45 minutes per day/ 2 to 3 days per week for 3 to 6 weeks. Further, any positive effects in outcomes were only identified immediately following task-specific training, and so evidence about the retention of outcomes over longer periods is lacking.

Another systematic review and meta-analysis investigated the effects of intensive training of motor function and functional skills in young children with cerebral palsy aged from 4 to12 years (Myrhaug et al., 2014). The review included 38 studies (including 29 randomised controlled trials) with 1,407 children. Children with all levels of GMFCS were included in the review. Twenty-three of the studies investigated the effect of task-

specific training on hand function, most commonly constraint induced therapy (17 studies). Sixteen studies reported outcomes on gross motor skills, with training involving a number of named intensive approaches including Vojta training, intensive physiotherapy, and goal-directed functional training. The outcomes and interventions in these 16 studies were considered by the authors as too heterogeneous to be pooled in meta-analyses, but only two single studies found that intensive interventions prescribed over 3 to 7 sessions per week led to higher scores on the Gross Motor Function Measure 88 (Stiller, Marcoux, and Olson, 2003; Choi, Lee, and Ro, 2011). It is possible that gross motor skill training was not consistent with the principles of task-specific training and not sufficiently intense to lead to changes in the other studies. The reporting of the intensity in this systematic review for training of gross motor function and functional skills was quite variable, ranging from 2 to 7 exercise sessions per week for around 5 to 12 weeks. Also, gross motor skill training was not incorporated into the child's natural environment. Therefore, the optimal intensity of the interventions that target gross motor function and functional skills with the child's natural contextual environments where the child would normally want or need to use the skills requires further investigation. To enable the high repetitions that are a requirement of task-specific training, home-based training was often applied. To enhance adherence, parents or caregivers should receive adequate education about home-based training, and receive adequate support (e.g. video records of training) to achieve the training goals (Novak, Cusick, and Lannin, 2009; Novak, 2011). However, the impact of home-based training as part of task-specific training on caregivers remains to be resolved.

A small case series has reported that more than 750 sit-to-stand repetitions throughout the intervention period may be required to achieve independence in sit-to-stand and carry over to improvements in walking speed in adults with chronic stroke. Although it remains

unknown if this finding can be generalised to other populations such as children with neurological conditions such as cerebral palsy (Boyne, Israel, and Dunning, 2011), this finding does suggest that completing a large number of sit-to-stand repetitions, might be required to learn new skills and improve activity.

Task-specific training is an approach with a sound theoretical basis that may be useful in improving a gross motor skill such as sit-to-stand in children with cerebral palsy. However, despite this theoretical basis, the evidence base in support of intensive training that is inherent in task-specific training is greater for attainment of hand function than for attainment of gross motor skills, and to date there is little evidence about the application of task-specific training to improving sit-to-stand. A second key issue is training dose. While there remains uncertainty about optimal training parameters for task-specific training, it appears high training doses involving caregivers and home-based training are likely to be required.

1.5 Thesis aim

The overall aim of this thesis was to investigate the effects of a task-specific sit-to-stand exercise training program on self-care and upright mobility for children with cerebral palsy with moderate to severe motor dysfunction. The secondary aims were to explore caregivers' perceptions about the outcomes and feasibility of a sit-to-stand home-based exercise program on themselves and their children with moderately severe cerebral palsy.

1.6 Thesis plan

To address these aims, this thesis comprises four studies presented as a series of manuscripts prepared for publication (Chapter 2 to 5). Each chapter is presented in the format that it was published or in format prepared for submission.

Chapter 2 is a systematic review and meta-analysis of the literature to synthesise evidence and identify gaps in knowledge from the available published literature about the effects of sit-to-stand exercise programs on people with physical impairments due to health conditions. This chapter was published in *Disability and Rehabilitation*. The study is presented in published format.

Chapter 3 is a mixed methods analysis conducted to investigate whether impaired sit-to-stand is perceived by the primary caregivers of children with moderately severe cerebral palsy to impact mobility and self-care in their children. This chapter is presented in the format required for submission to *Neurodevelopmental Rehabilitation*.

Chapter 4 is a randomised controlled trial conducted to investigate whether sit-to-stand training for children with moderately severe cerebral palsy can improve self-care and mobility and to evaluate the effect of training on caregiver burden. This chapter has been accepted for publication in *Developmental Medicine & Child Neurology*; and is presented in the author accepted version.

Chapter 5 is a qualitative analysis exploring caregivers' perceptions of a sit-to-stand exercise program for children with moderately severe cerebral palsy. This chapter is presented in the format required for submission to *Pediatric Physical Therapy*.

Chapter 6 contains the grand discussion and conclusions of this thesis. It provides a summary of the main findings of each of the studies reported in this thesis; key issues and implications of the findings are discussed, the strengths and limitations of this series of studies and of each study are identified, and implications for future research are identified and conclusions are made.

Chapter 2: Sit-to-stand exercise programs improve sit-to-stand performance in people with physical impairments due to health conditions: a systematic review and meta-analysis.

2.1 Introduction

Difficulty in performing sit-to-stand is common in people with physical impairments due to both neurological and musculoskeletal health conditions. The ability to sit-to-stand is an important component of many functional activities. Hence, an impaired ability to sit-to-stand may make it difficult for people with health conditions to independently perform many activities of daily living, such as transferring, dressing and toileting. To improve the ability to sit-to-stand, therapists may use the principles of motor learning and the principles of task-specific training and prescribe repetitive practice of sit-to-stand as an exercise program. Although repetitive sit-to-stand exercise programs are prescribed in therapeutic practice, to our knowledge, there have been no previous published systematic reviews investigating the effects of these programs.

Therefore, a systematic review was conducted to examine the current evidence on the effects of sit-to-stand exercise programs on patient-related outcomes in people with physical impairments due to health conditions. Chapter 2 presents the systematic review and meta-analysis.

2.2 Study One

Chapter 2 is presented in its published format (Chaovalit et al., 2020):

Chaovalit S, Taylor NF, Dodd KJ. Sit-to-stand exercise programs improve sit-to-stand performance in people with physical impairments due to health conditions: a systematic review and meta-analysis. *Disability and Rehabilitation*. 2020;42(9):1202-11.

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REVIEW

Sit-to-stand exercise programs improve sit-to-stand performance in people with physical impairments due to health conditions: a systematic review and meta-analysis

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ABSTRACT

Purpose: To determine the effects of sit-to-stand exercise programs on patient-related outcomes in people with physical impairments due to health conditions.

Methods: This review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines and was registered prospectively. Seven electronic databases were systematically searched for relevant articles. Inclusion and exclusion criteria were used to screen the titles and abstracts of articles identified using the key search terms of sit-to-stand and exercise. Only randomized controlled trials were included. The methodological quality of papers was assessed using the Cochrane risk of bias tool.

Results: A total of eight trials were included. A meta-analysis was conducted using four of the trials that focused on patients with neurological conditions. There was moderate-quality evidence that sit-to-stand exercise programs improve sit-to-stand performance, but no evidence from another meta-analysis that sit-to-stand training improved balance for patients with neurological conditions. There was also no evidence from individual trials that positive changes occurred in the outcomes of gait speed and distance, lower limb muscle strength, falls, or participation.

Conclusions: Sit-to-stand training could be a useful intervention when patients have limited sit-to-stand function and the aim of treatment is to improve this performance.

➤ IMPLICATIONS FOR REHABILITATION

- Sit-to-stand training could be a useful intervention for patients when the aim is to improve sit-to-stand performance.
- Sit-to-stand training may not be a useful intervention when the aim is to improve other functions such as balance.

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KEYWORDS
Sit-to-stand; chair rising; exercise therapy; task-specific training; rehabilitation; sit-to-stand performance; systematic review

Introduction

The ability to sit-to-stand is an important component of many functional activities of daily living, such as standing up to prepare for walking, and completing self-care activities such as dressing and toileting [1–3]. Difficulty in being able to sit-to-stand is common in people with physical impairments due to neurological conditions such as stroke and cerebral palsy, or due to musculoskeletal conditions such as osteoarthritis. Because a limited ability to sit-to-stand can impact on mobility and self-care activities, improving sit-to-stand is an important therapeutic goal for many of these people.

To improve sit-to-stand function, therapists commonly use the principles of motor learning [4] and prescribe repetitive practice of sit-to-stand as an exercise program. This functional task-specific training may include repetition of part of the sit-to-stand movement or repetition of all of the sit-to-stand movement along with feedback. While the focus of this training is usually to improve a person's ability to independently sit to stand, it is reasonable to hypothesize that practice of this sort might lead to improvements in other associated outcomes such as increased lower limb muscle strength, improved sitting and standing balance, greater independent mobility, and increased ability to perform functional activities.

Although repetitive sit-to-stand exercise programs are prescribed in therapeutic practice, to our knowledge there have been no published systematic reviews investigating the effects of these programs. Accordingly, this systematic review aimed to determine the effects of therapeutically prescribed sit-to-stand exercise programs on patient-related outcomes in people with physical impairments due to health conditions.

Methods

This review was conducted and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [5,6]. The review methods were registered prospectively with the International Prospective Register of Systematic Reviews (PROSPERO; http://www.crd.york. ac.uk/prospero/, reference CRD42017067780).

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Supplemental data for this article can be accessed here.

Table 1. Inclusion and exclusion criteria.

Categories	Inclusion	Exclusion
Population	• People with any health conditions associated with physical impairment from any source, of any severity, a chronic or acute condition • Any age, any sex	• People with psychological impairments only
Intervention	• Sit-to-stand exercise program prescribed by a health professional • Prescribed exercise implemented at home, school, hospital or anywhere else • Program prescription is for at least 3 weeks, 2 times/week • Starting position from a sitting position on the ground, chair, bench, or other surface to standing • Sit-to-stand exercise was the main intervention in the study (more than 75% of the program)	• Exercise prescribed by a non-health professional e.g., fitness trainer • Squat exercise (e.g., starting and returning from a starting position of standing) • For recreational purpose • For the sole purpose of increasing fitness
Outcome	• Any patient related outcomes: Impairments (e.g., strength, spasticity, balance, weight bearing) Activities (e.g., gait, sit to stand, functional reach) Participation (e.g., home, sporting, work, school, social)	• Effect on other people (e.g., parent, caregiver, teacher) • Service level outcomes (e.g., length of stay, cost)
Type of studies	• Randomized controlled trials • Full text	• Case studies • Qualitative studies • Paper with abstracts only • Individual opinions and editorials • Thesis

Search strategy

The following electronic bibliographic databases were searched from the earliest available time to August 2018: MEDLINE, EMBASE, CINAHL, AMED, ERIC, SPORTDiscus, and, Ausport-Med. Keywords and synonyms for each of the concepts of sit-to-stand and exercise were combined with the OR operator. The concepts of sit-to-stand, exercise, and a filter for randomized controlled trial based on the Cochrane Highly Sensitive Search Strategy [7] for identifying randomized trials were combined with the AND operator (see Supplementary Table S1 for the full search strategy).

Study selection

Inclusion and exclusion criteria were used to screen the titles and abstracts of all articles identified in this search (Table 1). Studies involving sit-to-stand exercise programs in patients with an acute or chronic health condition associated with a physical impairment from any source and of any severity were included. The sit-to-stand intervention needed to be prescribed at least two times each week, for at least three weeks. Studies were excluded if sit-to-stand exercise was not the main intervention, or if the study was not a randomized controlled trial. Titles and abstracts of studies retrieved were screened independently by two reviewers (SC, NT or KD) to identify studies that potentially met the inclusion criteria. The full text of these studies was assessed by two reviewers (SC, NT or KD) independently. Any disagreements were resolved through discussion with a third reviewer. Cohen's Kappa (κ) with 95% confidence levels was calculated to measure agreement between reviewers; $\kappa > 0.6$ was regarded as substantial agreement [8]. Reference lists of all selected studies were searched for any additional relevant studies.

Data extraction

Extracted information included: full reference details; study objective; study design; subject details; description of the intervention both in the experimental group and the control group according to the template for intervention description and replication (TIDieR) checklist [9]; outcome measures used and results. One of the reviewers extracted data (SC), which were checked for accuracy by a second reviewer (KD).

Risk of bias assessment

Risk of bias within studies was assessed using the Cochrane risk of bias tool [10]. Two reviewers (SC, NT) independently assessed the following domains: (1) adequate sequence generation (selection bias); (2) allocation concealment (selection bias); (3) blinding of participants and personnel (performance bias); (4) blinding of outcome assessment (detection bias); (5) incomplete outcome data (attrition bias); (6) selective outcome reporting (reporting bias); and, (7) other sources of bias. Disagreements between the reviewers were resolved by discussion until consensus was reached. No studies were excluded in this step, but the percentage of studies achieving each Cochrane domain was calculated. The completeness of description of the intervention in the experimental and in the control groups was assessed using the TIDieR checklist [9] by two reviewers (SC, KD) independently. Cohen's Kappa was calculated to measure agreement between reviewers using the Cochrane risk of bias tool and the TIDieR checklist. Risk of bias between studies was assessed by applying the Grading of Recommendations Assessment, Development and Evaluation (GRADE) criteria [11,12] to completed meta-analyses. The initial quality of evidence was deemed high because one of the inclusion criteria for this review specified that only randomized controlled trials would be included. The quality was downgraded from high to moderate if: (1) at least one of the studies in the meta-analysis did not provide allocation concealment or blinded outcome assessment, (2) there was greater than low levels of statistical heterogeneity between trials ($I^2 > 50\%$), or, (3) there were large confidence intervals (defined as >0.8 for standardized mean differences). If two or more of these criteria were not fulfilled, then quality was double downgraded from high to low. A footnote was used to explain the reasons for downgrading each meta-analysis.

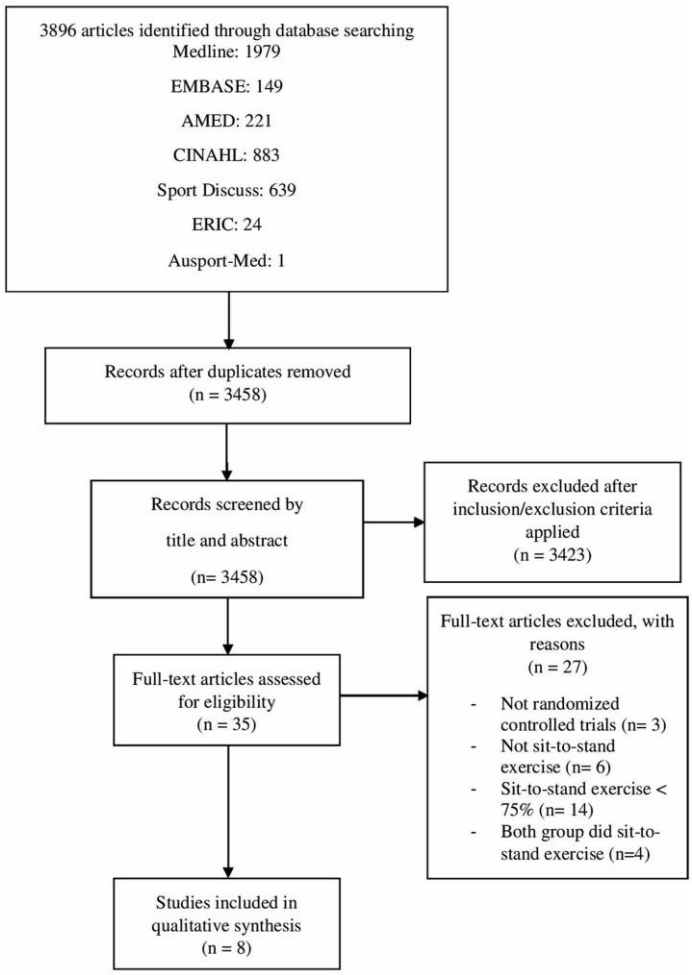

Figure 1. Flow diagram of study selection.

Data analysis

Intervention effects for each trial were estimated by the calculation of risk ratios (for dichotomous outcomes) or standardized mean differences (for continuous outcomes), with standardized mean difference calculated using Hedges' *g* from post-intervention means and standard deviations [13]. Standardized mean differences (SMD) and 95% confidence intervals (CI) of outcomes from individual studies were displayed in a forest plot. Meta-analysis was performed using Review Manager (RevMan) version 5.3 [14], when at least three trials were clinically homogeneous with a similar population, intervention and comparator, and outcome measure. Meta-analyses were completed using a random-effects model, with standardized mean differences for continuous outcomes and risk ratios for dichotomous outcomes. Positive standardized mean differences (effect sizes) values indicated that the result favored the group receiving the sit-to-stand intervention; effect sizes of <0.20 were considered small, 0.50 considered moderate, and >0.80 considered large [15].

Results

The initial search strategy yielded 3896 articles (including duplicates). After applying inclusion and exclusion criteria to the title and abstract, 35 articles were retrieved for full-text review. After full-text review, 27 articles were excluded because: three were not randomized controlled trials; 20 did not focus on sit-to-stand exercise; and four included sit-to-stand exercise in both the experimental and control groups (see Supplementary Table S2 for the detail of the papers excluded after full text review). In total, eight articles reporting the results of eight trials were included in the final review (Figure 1).

Table 2. Risk of bias summary.

	Adequate sequence generation	Allocation concealment	Blinding participants and personnel	Blinding outcome assessment	Incomplete outcome data	Selective outcome reporting	Other sources of bias
Barreca et al. [23]	L	U	H	L	L	L	H
Bhatt et al. [22]	U	H	H	H	H	U	H
Tung et al. [19]	L	L	H	L	L	L	H
Liao et al. [16]	U	H	H	L	L	L	L
Matsufuji et al. [20]	L	L	H	H	U	L	H
Rose and Taylor [18]	L	U	H	L	L	L	L
Yamashita et al. [21]	H	H	H	H	U	U	L
Kumban et al. [17]	L	H	H	L	L	U	L

L: low risk of bias; H: high risk of bias; U: unclear risk of bias.

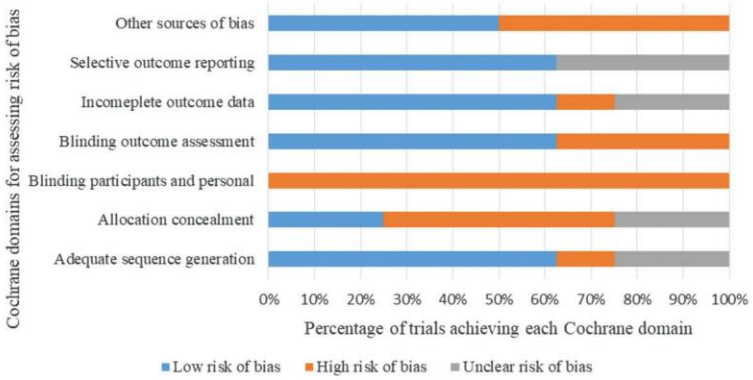

Figure 2. Risk of bias of trials included in the systematic review.

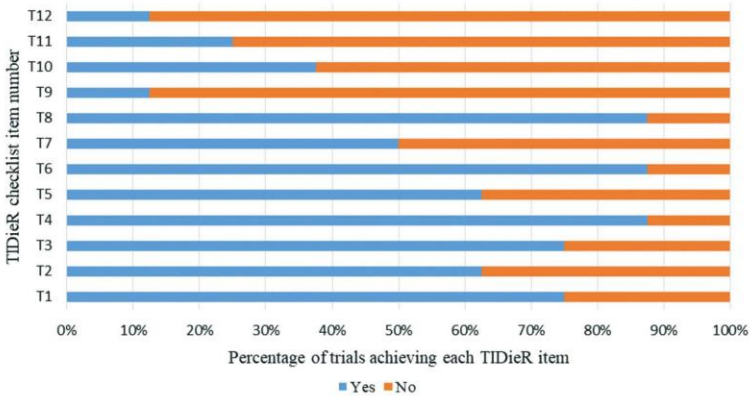

Figure 3. Percentage of included trials achieving each TIDieR item of the experimental group.

Risk of bias

Overall, quality of the trials was low to moderate (Table 2, Figure 2). All of the trials showed a high risk of performance bias with no studies blinding participants or therapists. Five of the eight trials reported all results, demonstrating a low risk of reporting bias. Five of the trials demonstrated a low risk of bias of reporting incomplete outcome data, blinding outcome assessment, and adequate sequence generation. There was substantial agreement between researchers ($\kappa = 0.64$, 95% CI 0.44–0.84).

Completeness of reporting

Overall, information about the modes of delivery for the intervention group (TIDieR item 6, T6) was the most satisfactorily reported. Information about how the intervention was personalized (T9) and whether the exercise was delivered as planned (T12) were two of the least satisfactorily reported items (see Supplementary Table S3 for the TIDier table). The experimental group interventions were more completely reported than the control group (Figures 3 and 4); the percentage of trials satisfying each TIDieR item ranged from 0 to 88% for the experimental group, compared

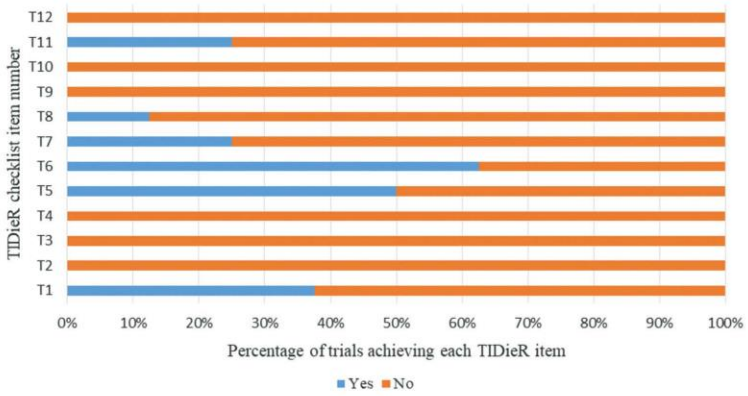

Figure 4. Percentage of included trials achieving each TIDieR item of the control group.

to 0 to 63% for the control group. Adequate detail about the exercise program (T8) for the experimental group was satisfied in more than 80% of trials, whereas for the control group this was less than 20%. Only in the experimental group was information reported about the rationale of the intervention (T2), materials (T3) and procedures (T4) used in the intervention, how the intervention was personalized (T9) and modified (T10), and whether the exercise was delivered as planned (T12). There was substantial agreement between researchers (κ = 0.72, 95% CI 0.62–0.82).

Trial characteristics

Five of the eight trials investigated patients with neurological impairment (Table 3). Six of the eight trials investigated older adults (mean age >50 years), and two trials investigated children [16,17]. Sample sizes were small with no study allocating more than 33 participants. Typically, training was conducted three times a week for six weeks. Most sit-to-stand training sessions comprised three sets of 10 repetitions. Six of the sit-to-stand training programs were supervised by a physiotherapist [17–22], one by a caregiver [16], and one by a nurse [23]. Three studies described the progression of the intervention. Of these, one increased the amount of resistance [16]; one increased the number of repetitions [18]; and one increased the difficulty of the task by changing the floor conditions and the degree of knee flexion [19]. For the control group, four trials implemented a general physical therapy program [16,17,19,23]. Another three trials used specific exercises such as a low-intensity knee extension exercise using adjustable ankle cuff weight, a stretching exercise, and a one-leg standing exercise [18,20,21]. In one trial, the control group had no intervention (Table 3) [22].

Effect of sit-to-stand exercise on sit-to-stand performance

Meta-analysis of four trials [16,17,19,23] that included a total of 112 participants with neurological conditions, provided moderate-quality evidence that sit-to-stand exercise compared with a general physical therapy program was effective for improving sit-to-stand performance such as mean daily independent sit-to-stand repetitions [23], increasing speed as assessed by time taken to complete independent sit-to-stand [17,19], and increasing sit-to-stand functional strength as assessed by one repetition maximum sit-to-stand [16] (SMD = 0.52, 95% CI 0.14–0.90) (Figure 5). Two other trials that measured sit-to-stand performance in other populations could not be included in this meta-analysis [18,21]. Both these trials observed positive SMDs favoring sit-to-stand training that did not reach statistical significance (Figure 6) [18,21].

Effect of sit-to-stand exercise on balance

Meta-analysis of three trials [17,19,22] that included a total of 65 participants with neurological conditions, provided moderate-quality evidence that sit-to-stand exercise compared with a general physical therapy program did not improve balance outcomes, such as increasing balance score from Berg Balance Scale [19] and Pediatric Balance Scale [17] on patients with neurological conditions [SMD = 0.18 (95% CI −0.39–0.76), I^2 = 22%]. Two other trials that measured balance in other populations could not be included in this meta-analysis [18,21]. Neither of these trials found statistically significant differences between sit-to-stand training and the comparison, although one observed a moderate effect size in favor of sit-to-stand training (Figure 6) [21].

Effect of sit-to-stand exercise on other outcomes

Due to the heterogeneity in the populations and outcomes, meta-analysis could not be completed on the other outcomes investigated in the various individual trials: gait speed and gait distance, falls, other functional activities assessed by specific measures such as the Gross Motor Function Measure or the Functional Independence Measure, lower limb muscle strength, and societal participation. In 39 of 40 comparisons, the 95% confidence interval of effect (standardized mean difference) crossed or included zero, so it could not be concluded that sit-to-stand exercise had any significant effects on any of these other outcomes (Figure 6). In a single study of 17 participants with hemodialysis, significant effects were found suggesting that the group that completed sit-to-stand exercise had *reduced* isometric knee extensor strength compared to the comparison group who did stretching exercise [20].

Discussion

The result of this systematic review suggests that therapeutically prescribed sit-to-stand exercise programs can improve sit-to-stand performance in people with physical impairments due to health

Table 3. Characteristics of included studies.

Study	Diagnosis	Group (I/C)	Sample size, sex	Age (Y) (Mean ± SD)	Intervention	Program details (I/C)					
						Training duration (wk)	Frequency of the training	Session length (min)	Total sessions	Intensity and Volume	Resting time (Second)
Load/Progression											
Barreca et al. [23]	Stroke	I	25; 17 M, 8 F	67.0 ± 11.9	General physical therapy program and STS exercise	4–8	3/week	45	12–24	3 sets / session 5 STS repetitions/ set Body weight/ NR	NR
		C	23; 14 M, 9 F	70.0 ± 10.4	General physical therapy program	5–10	3/week	45	15–30	NR NR	NR
Tung et al. [19]	Stroke	I	16; 9 M, 7 F	51.0 ± 12.1	General physical therapy program and STS exercise	4	3/week	45	12	6 different STS tasks (Task A – Task F) Body weight/Base, completed time each task (When reached the target time of each task, progressed to the next task)	NR
		C	16; 11 M, 5 F	52.7 ± 14.1	General physical therapy program	4	3/week	30	12	NR NR	NR
Bhatt et al. [22]	Parkinson's disease	I	13; 10 M,3 F	63.7 ± 8.9	Audiovisually cued STS exercise	4	3/week	20	12	3 sets/session 20–30 repetitions/ set NR	30 between task
		C	8; 5 M, 3 F	65.5 ± 6.2	No intervention	N/A	N/A	N/A	N/A	N/A	N/A
Matsufuji et al. [20]	Hemodialysis	I	6; 3 M, 3 F	68.8 ± 8.1	Regular hemodialysis sessions and STS exercise	12	3/week	15	36	5 sets/ session Repeated base on individually predefined duration Body weight/ NR	4 short breaks/session
		C	11; 9 M, 2 F	70.3 ± 4.4	Regular hemodialysis sessions and Stretch exercise	12	1/week	15	12	NR NR	NR
Rose and Talor [18]	Mobility-limited adults over 80 years of age	I	33; 10 M,23 F	85.2 ± 3.2	Repeated STS exercise by GrandStand System™	6	Daily	NR	42	1 set/session 10 repetitions/set Body weight/↑ repetitions by 5 a day or as they were able to a maximum of 50 sit-to-stands a day	NR
		C	33; 9 M,24 F	85.1 ± 4.0	Low-intensity knee extension exercises (adjustable ankle cuff weights)	6	Daily	NR	42	1 set/session 10 repetitions/set No weight/↑ load and repetitions as they were able, to a maximum of 2 sets of 10 repetitions and 4 kg in weight	NR
Yamashita et al. [21]	Locomotive disorders: osteoarthritis or spondylosis	I	15; 0 M, F 15	66.3 ± 6.4	STS exercise	20	3/week	30	60	3 sets/ day 10 repetitions/set Body weight/ NR	NR
		C	15; 1 M, 14 F	66.9 ± 6.6	One-leg standing exercise	20	3/week	30	60	3 sets in each leg/ day 1 min/ each set NR	NR

(*continued*)

Table 3. Continued.

Study	Diagnosis	Group (I/C)	Sample size, sex	Age (Y) (Mean ± SD)	Intervention	Program details (I/C)					
						Training duration (wk)	Frequency of the training	Session length (min)	Total sessions	Intensity and Volume	Resting time (Second)
Liao et al. [16]	Cerebral palsy	I	10; 7 M, 3 F	7.1 ± 1.7	General physical therapy program and Loaded STS exercise	6	3/week	20–30	18	3 sets/ day - 10 repetitions with a body vest at 20% of 1-RM STS load and 50% of 1-RM STS repeatedly without stopping until fatigue -10 repetitions with a body vest at 20% of 1-RM STS load 50% of 1-RM STS/ ↑ load every 2weeks	120–180
		C	10; 5 M, 5 F	7.6 ± 1.5	General physical therapy program	6	3/week	NR	18	NR NR	NR
Kumban et al. [17]	Cerebral palsy	I	10; 5 M, 5 F	12.3 ± 2.6	General physical therapy program and STS task training	6	3/week	20	18	As many times as possible within 20 min NR	NR
		C	11; 5 M, 6 F	12.4 ± 2.4	General physical therapy program	6	1/week	NR	6	NR NR	NR

I: intervention group; C: control group; NR: not reported; N/A: not available; STS: sit-to-stand; 1-RM: 1 repetitions maximum; M: male; F: female; ↑: increase.

conditions. Improvements were found in increased functional independence as assessed by the mean number of daily independent sit-to-stand repetitions, increased speed as assessed by time taken to complete independent sit-to-stand and increased strength as assessed by the ability to perform sit-to-stand against increasing resistance. However, there was no evidence from a meta-analysis that sit-to-stand training improved balance for patients with neurological conditions, and there was also no evidence from individual trials that sit-to-stand exercise programs improved the quality of life, general health status, cognitive function, increased gait speed or distance, increased individual lower limb muscle strength, improved any other functional activity or reduced falls.

Our finding of improved performance of the task that was repeated, suggests that improvements may be due to repetitive practice, consistent with the principles of motor learning [4] and task-specific training [24]. Task-specific training is commonly incorporated in therapy. It involves the repetitive practice of a whole task or a part of a task (i.e., part practice) often modified to suit a patient's abilities, and practiced under different conditions consistent with the context under which the task will be performed in daily activities, such as taking account of bed height and whether or not hands are used to assist sit-to stand [4,24–27]. As part of the training, the therapist commonly incorporates feedback. The therapist commonly assesses the specific deficits in functional performance, e.g., the speed of sit-to-stand is assessed as slow, and this specific element is practiced in the prescribed exercise program.

Even though the prescribed exercise programs involved repetitive practice, dosages were typically those associated with progressive resistance training regimens (i.e., three sets of 10 repetitions, three times a week for six weeks, with some progression of resistance). Despite this we found no evidence that individual lower limb muscle strength improved. It is possible that the exercise prescription did not provide the optimal dose parameters, particularly adequate progression of resistance to improve muscle strength. Positive changes did not occur in other outcomes such as balance and independent function. This is likely because these outcomes are not sufficiently similar to the sit-to-stand task, and the protocol used was not consistent with the principles of motor learning and task-specific training to improve these other outcomes. Another possible explanation for the lack of changes in other outcomes is that the dose was inadequate for motor learning. A small case series has reported that more than 750 sit-to-stand repetitions throughout the intervention may be required to achieve independence in sit-to-stand function and improvement in walking speed for people with chronic stroke [28]. Inspection of Table 3 suggests participants in most studies in our review would not have completed that number of sit-to-stand repetitions. Despite this the randomized controlled trials in our review did provide a sufficient dose to obtain improvements in sit-to-stand performance.

A sit-to-stand exercise program could be a useful treatment to improve sit-to-stand performance if difficulties with sit-to-stand are identified on assessment. However, if the therapeutic aim is to positively affect other functions that are less similar to the sit-to-stand function, such as balance and mobility, a sit-to-stand exercise program would not be expected to have any effect. It is possible that the functional outcome measures in the trials in this review did not include tasks that were closely enough associated with the task of sit-to-stand. Thus, future studies could investigate other outcomes that are more closely associated with the

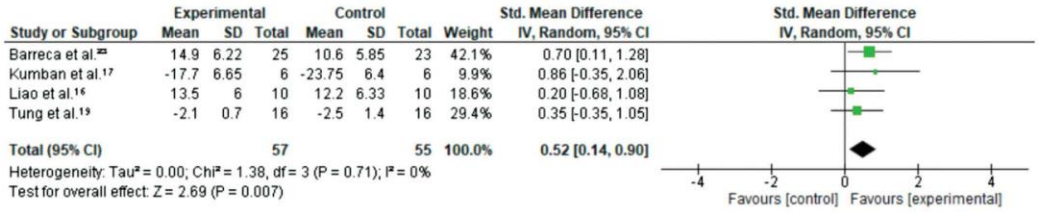

Figure 5. Forest plot: effect of sit-to-stand exercise on sit-to-stand performance by pooling data from four trials. Reason for GRADE downgrade: Three trials did not conceal allocation.

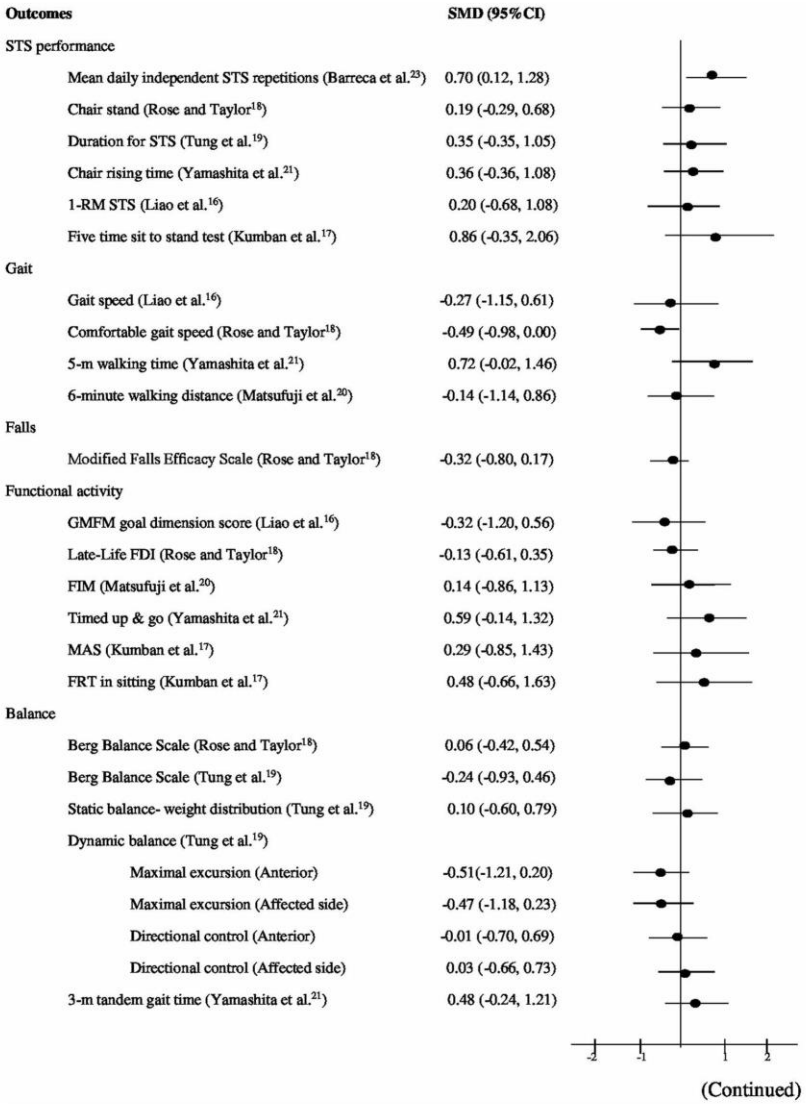

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Figure 6. Forest plot of the standardized mean difference (SMD) by outcomes. STS: sit-to-stand; 1-RM: 1 repetitions maximum; GMFM: Gross Motor Function Measure; FDI: Function and Disability Instrument; FIM: Functional Independence Measure; MAS: Motor Assessment Scale; FRT: Functional Reach Test; COM: center of mas; SO: seat-off; MT: movement termination; BLOB: backwards loss of balance; FLOB: forward loss of balance; PBS: Pediatric Balance Scale; COOP: Dartmouth Primary Care Cooperative Information Project; SF-36v2: Health-related quality of life measured by the three component version of SF-36; 3MS: modified Mini-Mental State.

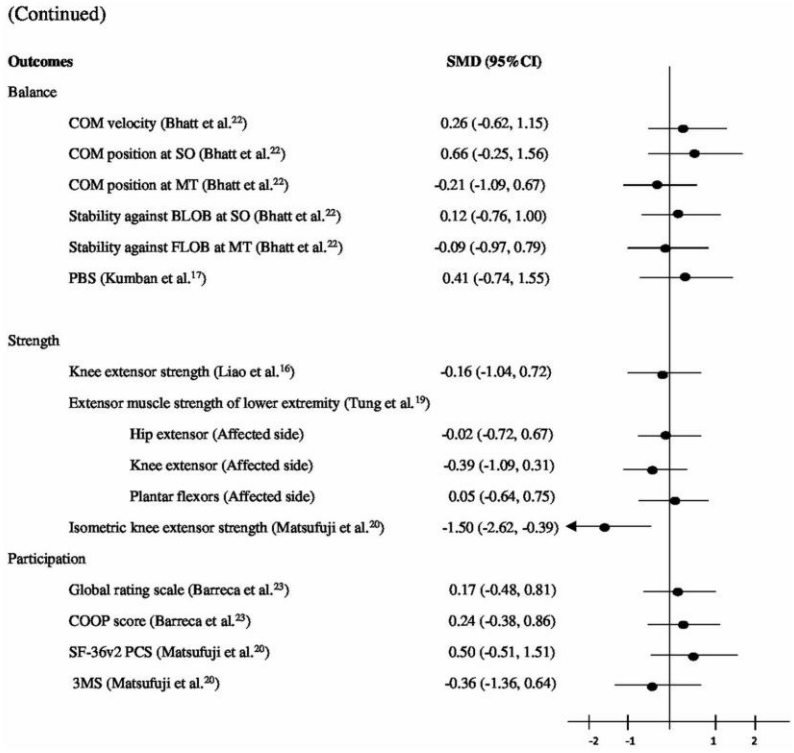

Figure 6. Continued.

sit-to-stand function, such as transferring, chair rising, and other self-care activities.

This study was the first systematic review investigating the effect of a sit-to-stand exercise programs on patient-related outcomes in people with physical impairments due to health conditions. A possible limitation of this review is that the meta-analysis on sit-to-stand performance used various measures of performance which may lead to concerns about the homogeneity of the outcome measures for this analysis. However, we considered that the speed, strength, and strength of completing the sit-to-stand task were all part of the construct of "performance". In addition, the I^2 value of 0% suggested that there were low levels of statistical heterogeneity in this meta-analysis. Meta-analyses could not be completed on some outcomes investigated in the various individual trials: gait speed and gait distance, falls, other functional activities assessed by specific measures such as the Gross Motor Function Measure or the Functional Independence Measure, and lower limb muscle strength, which may lead to concerns about the conclusion that there was no evidence that sit-to-stand exercise programs improved these outcomes. However, the 95% confidence interval of effect (SMD) of these outcomes of individual trials crossed or included zero, so this current review provided preliminary evidence that it could not be concluded that sit-to-stand exercise had any significant effects on these outcomes (Figure 6). A strength of this review is that it closely followed the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines. In addition, all trials were assessed for completeness of reporting using the TIDieR checklist and the GRADE approach was applied to determine the level of evidence of the results between trials as expressed in a meta-analysis. However, because of the methodologic-limitations of the published literature, the results should be considered with some caution. Limitations in the trials included: small sample sizes and the selection of outcomes not closely associated with the training intervention [20]. In individual trials, some authors reported significant results that did not correspond with the results from our analysis; this is possibly because we used the method of using post-intervention values to estimate standardized mean differences, as recommended [10].

Conclusion

There is moderate-quality evidence from four randomized controlled trials that therapeutically prescribed sit-to-stand exercise improves sit-to-stand performance, and no evidence that sit-to-stand exercise can result in positive changes in other outcomes. Sit-to-stand training could be a useful intervention when the aim is to improve sit-to-stand performance.

Disclosure statement

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Chapter 3: Impaired sit-to-stand is perceived by caregivers to affect mobility and self-care in children with cerebral palsy who had moderate to severe mobility limitations: a mixed methods analysis

3.1 Introduction

The systematic review and meta-analysis presented in Chapter 2 examined the current evidence about the effects of sit-to-stand exercise programs on patient-related outcomes in people with physical impairments due to health conditions. That review found moderate-quality evidence demonstrating that sit-to-stand training can be a useful intervention when patients have limited sit-to-stand activity, and the aim of treatment is to improve sit-to-stand performance.

Children with moderate to severe disability (Gross Motor Function Classification System (GMFCS) level III and IV) due to cerebral palsy often show difficulty in anti-gravity motor development, such as the ability to independently sit-to-stand. To better understand the effects of limited ability to sit-to-stand on upright mobility and self-care in children with cerebral palsy and how this may affect their caregivers, a mixed-methods analysis was completed. Chapter 3 presents the mixed-methods analysis.

3.2 Study two

Chapter 3 is presented in the format required for submission to *Neurodevelopmental Rehabilitation*.

Impaired sit-to-stand is perceived by caregivers to affect mobility and self-care in children with cerebral palsy who had moderate to severe mobility limitations: a mixed methods analysis

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Declaration of interest

The first author (SC) is a PhD student who is funded by Faculty of Medicine, Prince of Songkla University, Thailand. The authors report no conflicts of interest.

Impaired sit-to-stand is perceived by caregivers to affect mobility and self-care in children with cerebral palsy who had moderate to severe mobility limitations: a mixed methods analysis

Abstract

Objective: To explore the effects of impaired ability to sit-to-stand on upright mobility and self-care

Methods: A mixed methods research design was conducted with 25 children with cerebral palsy and moderate to high mobility limitations (GMFCS levels III and IV) and their caregivers. Caregivers were interviewed and each child's activities rated using mobility and self-care domains of the Functional Independence Measure for Children (WeeFIM).

Results: Difficulty in sit-to-stand was perceived by caregivers to reduce their child's ability to independently perform mobility and some self-care tasks; and negatively impacted the caregivers physically and psychologically. WeeFIM scores showed that self-care tasks involving sit-to-stand (toileting and bathing) required more assistance than those not expected to involve sit-to-stand (eating and grooming). Qualitative and quantitative findings were convergent.

Conclusions: The ability to sit-to-stand independently may be an important precursor skill for independence in upright mobility and self-care for children with moderate to severe mobility limitations.

Keywords: Children with cerebral palsy; Caregiver; Sit-to-stand; Mobility; Self-care function

Impaired sit-to-stand is perceived by caregivers to affect mobility and self-care in children with cerebral palsy who had moderate to severe mobility limitations: a mixed methods analysis

Introduction

Children with moderate to severe mobility limitations (Gross Motor Function Classification System (GMFCS) level III and IV) due to cerebral palsy often show delayed or abnormal development of antigravity motor activities such as sit-to-stand function. Compared to typically developing peers, during sit-to-stand these children usually move more slowly, less efficiently and smoothly, and they fall more often.[1-3]

The ability to independently sit-to-stand is an important skill needed for many activities of daily living such as the ability to independently stand and walk.[4] Children with cerebral palsy classified at Gross Motor Function Classification System (GMFCS) level III use wheeled mobility when travelling long distances and children classified at level IV use a manual wheelchair or powered mobility in the community. Therefore, these children often spend much of their time in sitting.[2,5] This suggests that in these children mobility and some self-care tasks related to sit-to-stand such as toileting might be limited; and that these children may need some assistance from caregivers to complete these types of activities of daily living.

Little has been documented directly about how impaired sit-to-stand affects daily tasks such as mobility and self-care in these children. It has been demonstrated that GMFCS level has a strong association with gross motor activity including mobility.[6] The association between GMFCS and self-care tasks is weaker, but children with cerebral palsy classified as GMFCS IV were reported as having less ability to complete self-care tasks (personal care activity) than children with mild mobility limitation (GMFCS I).[6]

Although summary scales are useful as a way of evaluating between-group differences, they do not provide information about limitations with specific mobility and self-care tasks. Nor do they enable direct exploration of whether limitations in the ability to transfer from sitting to standing impact on specific everyday activities that are important for a child's independence. This type of more specific information is important to therapists planning treatment for children with cerebral palsy

Therefore, we aimed to use a mixed methods research design to explore caregivers' perceptions about the impacts that an impaired ability to sit-to-stand might have on their child's mobility and self-care, and how in turn this may affect the caregivers. All of the children had cerebral palsy and moderate to severe mobility limitations.

Method

A parallel mixed methods research design was used.[7] The first part of the study used qualitative methods. Semi-structured interviews were conducted using an interpretive description methodological framework. This framework was used to better understand the views of caregivers which could then be used to generate knowledge to inform clinical practice.[8] The primary caregivers of a child with cerebral palsy were individually interviewed about how their child's difficulty in moving from sit-to-stand impacted on their child's upright mobility (i.e. standing and walking) and their ability to look after themselves. The second part of the study used quantitative methods to summarise independence in mobility and self-care tasks across GMFCS levels III and IV, and to identify if tasks that require the ability to sit-to-stand (e.g. toileting) were more difficult to complete independently than tasks that would be not be expected to be affected by a limited ability to sit-to-stand (e.g. eating). The child with cerebral palsy was observed using the Functional Independence Measure for Children (WeeFIM).[9-12] Qualitative data

were reported according to the consolidated criteria for reporting qualitative studies (COREQ) checklist[13] (See Supplementary Table S1). Ethical approval was obtained from the relevant university and health service Human Research Ethics committees.

Participants

Participants were recruited purposively through a large metropolitan rehabilitation centre that provides specialist outpatient and inpatient services for children with cerebral palsy, and through the physiotherapy unit of the largest hospital in southern Thailand. After initially sending expression of interest forms to caregivers of children who received therapy at the rehabilitation centre or at the physiotherapy unit, the researcher (SC) met with caregivers who wanted to find out more about the study, to provide more information and an opportunity to ask questions. Prior to participating, the children with cerebral palsy were invited to provide their own verbal assent, in addition to their caregivers' providing written informed consent.

To be eligible, the children of caregivers had to have a diagnosis of cerebral palsy (any type), be classified as level III or IV on the GMFCS[5] and be aged from 4 to 12 years, inclusive. Caregivers were included if they were the primary caregivers for the child, and they spoke Thai fluently.

Qualitative interview

A face-to-face in-depth semi-structured interview was conducted with each caregiver, individually. Semi-structured interviews used a pre-determined interview guide of questions and prompts. The interview guide was developed by one member (SC) of the research team to address the research aims. The research team (SC, NT, KD) then finalized the interview guide and developed prompts through discussion. Each caregiver was asked a series of open-ended questions about their child's upright mobility and self-

care functions. The interview started with a general question: 'Can you tell me about any difficulty that your child has in transferring from sitting to standing?' The interview continued with more specific questions: (1) "How difficult is it for you when your child cannot sit-to-stand independently?", (2) "What concerns you most about your child's difficulty in being able to transfer from sitting to standing?", (3) "Can you describe mobility tasks (e.g., walking, running or going up stairs) that are difficult for your child because they cannot sit-to-stand easily?", (4) "Can you describe self-care tasks that are hard for your child that result from difficulty in being able to sit-to-stand?" The participants were encouraged to discuss any additional relevant issues that arose during the interview. All interviews were conducted by a female physiotherapy researcher (SC) who was not previously known to the caregivers. The interviewer received one-on-one training from experienced qualitative researchers in the research team (KD, NT).

Quantitative measure

Immediately after the interview the independence of each child's activities of daily living was rated using the self-care and mobility domains of the Functional Independence Measure for Children (WeeFIM) by an accredited assessor (SC). WeeFIM has demonstrated evidence of reliability[14] and concurrent validity,[10] with measurement properties maintained when used to measure the functional status of Thai children with disabilities.[11-12] These domains rate a total of 11 items: eating, grooming, dressing of the upper body, dressing of the lower body, toileting, bathing, ability to get in and out of chairs, on or off toilets, in and out of bathtubs or shower stalls, walking in a standing position or using a wheelchair, and upstairs or downstairs. WeeFIM scoring is based on a seven-level ordinal scale ranging from total assistance required to complete all of the task components with the assistance of another person (score of 1), to complete independence

with the child able to complete all components of the task without assistance or supervision in a safe and timely manner (score of 7).[10-12,14]

Data analysis

The sample size was determined by the qualitative analysis, with recruitment stopped once no further themes were emerging from the interviews. Consistent with an interpretive description approach, inductive, thematic analysis was used to identify key concepts from the qualitative data, which were clustered to create themes.[15] Each interview was audio-recorded and transcribed verbatim to Thai language first. To increase trustworthiness of the data, the researcher provided participants with a written copy of their transcript to check that it was an accurate representation of their thoughts and to see if they wanted to add any other comments. No participant made any corrections or additions. Thai transcripts were translated into English (by an English expert from a university International Affairs Office). The bilingual researcher (SC) further checked the translated English transcripts to ensure they accurately represented the participants statements. All interview transcripts in English were coded by two investigators (SC, NT) and read by a third investigator (KD), independently. After initial coding, the researchers (SC, NT) compared codes, organised them into categories, clustered these categories to create themes. The researchers (SC, NT, KD) discussed the themes and any differences until consensus was reached. If consensus could not be reached a third coder (KD) was consulted. The researchers were physiotherapists; SC had 10 years of clinical experience in pediatric physiotherapy, NT was active in clinical research, and had experience in qualitative research, and KD was involved in academic management and had experience in community-based pediatric qualitative research.

Quantitative analysis of the WeeFIM data was performed using the Statistical Package for Social Sciences software version 25.0 (SPSS). Descriptive statistics (mean,

standard deviation, range of scores) were determined. Before completing statistical tests normality tests (Shapiro-Wilks) were applied to WeeFIM self-care and mobility tests. As the assumption of normality could not be rejected ($p > .05$), we proceeded with parametric analyses. To determine if children required more assistance with some daily tasks than others, a repeated measures ANOVA with pairwise comparisons was conducted to determine if there were differences in item scores within the domains of self-care and mobility. To compare GMFCS level III and IV across the mobility and self-care domains of WeeFIM, independent t-tests were completed. Qualitative data were triangulated with the quantitative data to determine if there was convergence or divergence of these data.[7]

Results

Participant Characteristics

All caregivers approached agreed to participate. A total of 25 caregivers and their children were recruited. At this stage it was deemed that saturation had been achieved in the qualitative analysis, so recruitment stopped. Eleven boys and 14 girls with cerebral palsy (mean age of 8.2 years; SD 2.9 years) participated. Most of the children had spastic diplegia and 18 of 25 had a GMFCS-rated disability of level IV (Table 1). Most (19 of 25) of the children also had speech, vison or intellectual disabilities in addition to their mobility limitations. Thirteen of 18 children classified as GMFCS IV, and 2 of 7 children classified as GMFCS III had an intellectual disability. Primary caregivers ranged in age from 32 to 54 years, with a mean age of 44.4 years (SD 6.6). Most of the primary caregivers were women who described their occupation as home duties.

[Table 1 near here]

Qualitative thematic analysis

Theme 1: Difficulty in sit-to-stand impacts children's mobility and self-care tasks

All caregivers reported that it was difficult for their children to transfer from sit-to-stand independently without holding furniture or a walker. Most said their child could only transfer from sit-to-stand with physical support, that they transferred very slowly, their child's legs and feet adopted abnormal postures and movement patterns, and that their child often fell.

"My son always has difficulties in transferring from sitting to standing…. he spends a long time trying to transfer from sitting to standing…he has to pull bars or other objects to help pull himself up…and during pulling, his legs and feet (are) always more straight than usual." (ID 1, GMFCS IV)

"He cannot sit-to-stand independently; he has to hold some furniture such as a sofa or table to pull himself up to upright. Even if he has some furniture for holding, he still falls many times." (ID 5, GMFCS IV)

Some caregivers said that their child did not sit-to-stand independently because they lacked confidence in doing this task.

"If lacking something for holding, she's quite worried about falling and not confident to do it." (ID 15, GMFCS III)

- ***Impact on the child's mobility***

Many caregivers reported that difficulty in transferring from sit-to-stand directly impacted their child's independent mobility. Because they couldn't move from sit-to-stand independently some children preferred to crawl inside for mobility rather than walk. For convenience and safety when going longer distances or when outdoors, their child used a wheelchair.

"She falls many times when she tries to transfer from sitting to standing, so she prefers to crawl." (ID 21, GMFCS IV)

"For my daughter right now, as she cannot sit-to-stand independently, so she always crawls instead of walking. And for longer distances outdoors, she can propel a wheelchair." (ID 7, GMFCS IV)

Many of the children with moderate physical mobility limitations (GMFCS level III) could walk with a high-top shoe or ankle-foot orthosis and with an assistive mobility device such as a walker. However, the difficulties in being able to sit-to-stand still impacted their walking.

"She cannot transfer independently and safely from sitting to standing, so when she wants to walk with her walker, she needs a lot of help from me for standing up and also support while walking. She told me she is not confident to do it and is afraid of falling." (ID 8, GMFCS III)

- ***Impact on the child's self-care***

Most caregivers reported they always did everything for their child when toileting and bathing. This was because hygiene was important, and it was safer and quicker for the caregivers to do these things rather than encouraging their child to do these tasks independently. Many children also found it difficult to dress independently. Caregivers particularly reported their child commonly had difficulty putting on pants, socks and shoes (i.e. dressing their lower body). Due to difficulty in transferring from sit-to-stand, many of the children spent large amounts of time sitting. Therefore, most of the children could independently complete self-care activities such as eating and self-grooming tasks that typically are easily completed in sitting (e.g. brushing hair, brushing teeth, and

washing their hands). However, some children required verbal supervision, and a small number of children still needed some physical help to complete these tasks.

"I usually do everything for her for hygiene, safety, and timesaving, especially toileting and bathing. I prefer to do it all for her." (ID 12, GMFCS IV)

"She always does some self-care task such as eating and grooming in sitting position under my supervision. For other more difficult self-care tasks, I do all for her for safety and timesaving, especially toileting and bathing." (ID 3, GMFCS IV)

"She can eat by herself in sitting position on the floor without any help from me. I just prepare the meals for her. For other self-care tasks that are more difficult than eating such as dressing and grooming, I still have to help her. For toileting and bathing, I always do it for her for hygiene and safety. As she still falls when she tries to stand up, so I am happy to do for her to avoid falling." (ID 6, GMFCS IV)

It appeared that few caregivers tried to teach independence in self-care tasks. They often did everything for their child, even if the child appeared capable of doing certain tasks. One parent stated, *"I forgot to notice that she really can do these tasks; I never let her try alone or try to train her." (ID 7, GMFCS IV)* Another parent stated, *"Because I do everything for her, so I am not quite sure about her real ability in self-care tasks." (ID 12, GMFCS IV)*

Theme 2: Difficulty in sit-to-stand impacts caregiver today and tomorrow

Caregivers said that not only did their child's inability to sit-to-stand reduce their child's physical functioning and independence, but it also impacted directly on them as caregivers.

- ***Impact today***

One impact on caregivers was that they more closely supervised their child at all times. This was to do activities for the child or to provide standby assistance. Caregivers said this took a lot of time each day. They also often had to modify their home environment to accommodate their child's needs.

"Even though I have set some furniture to support him, he still falls, so I have to take care of him closely and keep an eye on him all the time." (ID 25, GMFCS IV)

"He always falls when he tries to transfer from sitting to standing, so I have covered the room's floor with a mattress to prevent injuries from falling." (ID 5, GMFCS IV)

- ***Impact tomorrow***

Caregivers also said they were worried about their child's future. They said they didn't know when and if their child would be able to sit-to-stand safely and independently and so be able to be more independent in mobility and some self-care tasks. They were worried about what their child would do if they weren't there to assist. Some caregivers said they thought that their child could be more independent, but that they knew that they had not encouraged this. Some parents said that in the future they would let their children try to do as much as they could independently so that they would know more about their child's true ability.

"The most important concern I have is how my child will take care of himself without me." (ID 1, GMFCS IV)

"Um the most worrying thing now is the progression of the next step of development. Because now he is still stuck in the sitting position and it seems quite hard to progress to more difficult stages such as walking." (ID 14, GMFCS IV)

"I have forgotten to pay attention to her self-care tasks, I just do everything for her like a routine for safety and to save time. She may actually be able to do something more that I never knew before." (ID 2, GMFCS IV)

Caregivers also said one of their greatest concerns was how their child could be independent in the community and at school. Caregivers expressed hope that in the future their children would be able to progress developmentally.

"I hope one day he can progress to sit-to-stand independently and have a chance to develop to walk and then he can go anywhere that he wants." (ID 13, GMFCS IV)

Quantitative data

The mean scores for the mobility and self-care domains of the WeeFIM were 15.6/35 and 19.0/42, respectively, indicating that, on average, children required moderate assistance with these tasks (Table 2). Children classified as level III were more independent in mobility (Mean Difference (MD) 14.3 units, 95%CI 8.6. to 20.0) and self-care tasks (MD 10.4 units, 95%CI 1.9 to 14.3) than children classified as GMFCS IV. There was a significant difference within items of the mobility domain ($F(4,96)=4.09$, $p=.004$). Pairwise comparisons indicated that negotiating stairs required more assistance than transferring. There was a significant difference within items of the self-care domain of the WeeFIM ($F(5,120)=31.9$, $p<.001$). Pairwise comparisons indicated that toileting and bathing required more assistance than eating and grooming. The themes identified in the qualitative data converged with quantitative data (Table 3).

[Table 2 and Table 3 near here]

Discussion

The findings of this study support the view[4,16] that children with cerebral palsy and moderate to severe mobility limitations often have difficulty moving from sit to stand

efficiently, safely and independently. Self-care tasks requiring the ability to sit-to-stand to complete independently (toileting and bathing) needed more assistance than tasks that would not be expected to be affected by an ability to sit-to-stand independently (eating and grooming). Further, our findings suggest that the ability to independently and safely sit-to-stand was perceived by caregivers to be an important precursor skill needed to perform many activities of daily living such as the ability to independently achieve upright mobility (i.e. stand and walk) and complete important everyday self-care tasks, especially toileting and bathing. This reduced functional independence, in turn, meant that their caregivers needed to modify their homes and spend more time and physical energy everyday caring for their child. Further, they worried about their child's ability to function and be independent without them, especially outside the home, now and into the future.

Since an ability to sit-to-stand safely was perceived by caregivers to be a precursor skill for many everyday functional activities, this leads to the hypothesis that training sit-to-stand could be a focus of therapy in children with cerebral palsy and moderately severe mobility limitations. It is important to remember that the hypothesis that training sit-to-stand could improve mobility and self-care is based on a perceived association, which would need to be tested. In support of the hypothesis, results of a recent randomised controlled trial found a 6-week task specific sit-to-stand training program led to small increases in independence in mobility and self-care in children with cerebral palsy classified GMFCS III and IV.[17]

The results of the current study highlight the physical and psychological impact on people caring for a child with moderate to severe mobility limitations. The caregiver interviews support the importance of educating and helping caregivers to optimise their child's functional and emotional independence as much as possible. It could be argued that the importance of optimising and maximising this independence early becomes even

more important as the child grows taller and heavier and so becomes more physically challenging for caregivers to provide care for them. Provision of support and education for caregivers on how to maximise their child's potential for independence should be viewed as an important part of therapy.[18-21] There is also a need for therapists to provide psychological support for caregivers expressing deep concern for their child's future. Consistent with the principles of family centered practice,[22-24] these findings suggest that the therapy team needs to holistically address the issues affecting the family, in addition to addressing the specific activity limitations of the child.

A strength of this study was the use a combination of qualitative and quantitative approaches to explore the impacts of an impaired ability to sit-to-stand on mobility and self-care functioning. Employing a mixed-methods design allowed triangulation of results, and this increases the validity and the levels of trustworthiness and rigour.[25] The children in our study all had moderate to severe mobility limitations which meant that exploring the perception of association between sit-to-stand and the ability to do everyday tasks was very relevant for this group. Another strength is that data were reported according to the consolidated criteria for reporting qualitative studies (COREQ) checklist[13] (see Supplementary Table S1).

Despite these strengths there were some limitations. Interviews were conducted and recorded in Thai, and then recordings were transcribed into English. This meant there was the potential that the nuance of thoughts expressed in Thai by caregivers may have been lost when analysed in translated English. However, the translation and verification processes used in this study increase our confidence in the accuracy of the analysis. The descriptions of the children's ability to complete activities, and the link between sit-to-stand and activities was based on caregiver perceptions. Therefore, the belief of caregivers that sit-to-stand is an important precursor activity for children with cerebral

palsy and moderate to severe mobility limitations needs to be confirmed quantitatively.[17] Another limitation was that the way the questions were worded may have invoked negative responses by focusing on limitations of sit-to-stand, self-care and mobility. Finally, the generalisability of the findings to other settings needs to be considered. While children with cerebral palsy who have moderately severe mobility limitations in other countries might be expected to find similar difficulties in completing activities, it is possible there may be specific and unique factors operating in Thailand such as religion, family attitudes, and cultural beliefs that may have affected the impact that this had on the children and caregivers recruited to this study. For example, a previous study found that in Thailand societal and family attitudes to disability and the limited health and education resources available to some people may result in people with disabilities not reaching their highest potential.[18]

Conclusion

Impaired ability to sit-to-stand in children with cerebral palsy was perceived by caregivers to impact children's ability to independently perform mobility and some self-care tasks; and that these limitations negatively impacted the caregivers physically and psychologically. These results suggest that the ability to sit-to-stand independently may be an important precursor skill for development of independence in mobility and some self-care tasks for children with moderate to severe mobility limitations.

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Table 1 Characteristics of children with cerebral palsy and their primary caregivers

	Children (n=25)	**Primary caregivers (n=25)**
Mean age (SD), y	8.2 (2.9)	44.4 (6.6)
Gender, n (%)	Boys 11(44)/ Girls 14 (56)	Male 2 (8) / Female 23 (92)
GMFCS levels, n (%)		
III	7 (28)	
IV	18 (72)	
Type of CP, n (%)		
Spastic diplegia	14 (56)	
Spastic hemiplegia	3 (12)	
Spastic triplegia	3 (12)	
Spastic quadriplegia	2 (8)	
Dyskinetic	1 (4)	
Ataxia	1 (4)	
Mixed	1 (4)	
Associated disabilities, n (%)		
Speech Issues	15 (60)	
Intellectual Disability	13 (52)	
Vision Impairment	8 (32)	
Hearing Impairing	2 (8)	
Other	-	
Education, n (%)		
High school		6 (24)
Diploma		4 (16)
Bachelor's degree		12 (48)
Master's degree		3 (12)
Doctoral or profession degree		-
Occupation, n (%)		
Home duties		17 (68)
Farmer		2 (8)
Childcare worker		3 (12)
Hospital staff		1 (4)
Other (Own business, Retired government staff)		2 (8)

Table 2 WeeFIM scores of motor items in children with cerebral palsy classified with GMFCS

WeeFIM subset scores	GMFCS III (n=7)		GMFCS IV (n=18)		Total (n=25)	
	Range	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)
Self-care						
- Eating	4-6	5.6 (0.8)	2-6	3.7 (1.4)	2-6	4.2 (1.5)
- Grooming	3-6	4.0 (0.6)	1-5	2.9 (1.3)	1-6	3.2 (1.2)
- Bathing	3-5	3.9 (0.9)	1-3	2.4 (1.1)	1-5	2.8 (1.2)
- Dressing-upper body	3-6	4.0 (1.0)	1-4	2.6 (0.9)	1-6	3.0 (1.1)
- Dressing-lower body	3-5	4.0 (1.0)	1-3	2.6 (0.9)	1-6	3.0 (1.1)
- Toileting	3-5	3.9 (0.9)	1-3	2.3 (1.1)	1-5	2.8 (1.2)
Total self-care score (6 to 42)		25.4 (4.9)		16.6 (6.3)		19.0 (7.0)
Mobility						
Transfers						
- Bed/chair, wheelchair	4-6	5.4 (0.8)	2-4	3.2 (0.9)	2-6	3.8 (1.3)
- Toilet	4-6	5.1 (0.7)	1-4	2.4 (1.0)	1-6	3.2 (1.6)
- Tub	4-6	5.1 (0.7)	1-4	2.4 (1.0)	1-6	3.2 (1.6)
Locomotion						
- Walk/wheelchair	4-6	5.7(0.5)	2-3	3.1 (0.8)	2-5	3.8(1.4)
- Stairs	2-3	2.3 (0.5)	1-2	1.3 (0.5)	1-3	1.6 (0.7)
Total mobility score (5 to 35)		23.7 (2.7)		12.5 (3.7)		15.6 (6.1)
Total motor item score (77)		**49.0 (6.3)**		**29.1 (9.5)**		**34.6 (12.6)**

Table 3. Triangulation of qualitative and quantitative data.

THEME/ SUBTHEME	Qualitative finding	Quantitative finding	Triangulation
Difficulty in sit-to-stand impacts children's mobility and self-care tasks.			
- Impacts on the children's mobility	Many children have difficulty in walking independently and Children with GMFCS III show more independence in mobility tasks than children with GMFCS IV	Low score from WeeFIM in mobility domain, need moderate assistance to complete task mobility tasks (mobility score = 15.6/35). Higher score from WeeFIM in mobility domain in GMFCS III = 23.7(2.7) than GMFCS IV = 12.5(3.7).	Convergent
- Impacts on the children's self-care tasks	Children need assistance to complete self - care tasks, especially toileting and bathing.	Need moderate assistance to complete self-care tasks (self-care score = 19.0/42)	Convergent
Difficulty in sit-to-stand impacts caregivers today and tomorrow.			
- Impacts today	Many children fell and weren't safe.	Many items from WeeFIM indicate children require close supervision/ standby assistance	Convergent
- Impacts tomorrow	Worried about their children's future (life without caregivers)	Many items from WeeFIM indicate children require total assistance.	Convergent

Supplementary Material

Supplementary Table S1. Consolidated criteria for reporting qualitative research (COREQ) checklist

Domain 1: Research team and reflexivity		
Personal characteristics		
1. Interviewer	Primary author SC	Secondary author NT
2. Credentials	PhD Scholar, Physiotherapy	PhD
3. Occupation	PhD Scholar, Physiotherapy	Academic, Allied Health
4. Gender	Female	Male
5. Experience & training	Training in qualitative research methods and WeeFIM assessment	Experience in qualitative research
Relationship with participants		
6. Relationship established prior to study commencement	No	No
7. Participant knowledge of the interviewer	Participants were provided with an information sheet and consent form which outlined the aim of the study.	NA
8. Interviewer characteristics	Participants knew the researcher was a physiotherapy and PhD scholar with an interest in children with disability.	NA
Domain 2: Study design		
Theoretical framework		
9. Methodological orientation and Theory	Thematic analysis	
Participant selection		
10. Sampling	Convenience sampling of children and caregivers meeting inclusion criteria	
11. Method of approach	Face-to-face interview	
12. Sample size	25	
13. Non-participation	Did not arise	

14. Setting of data collection	Physical therapy unit room of Songklanagarind hospital, Thailand
15. Presence of non-participants	No
16. Description of sample	Diagnosis, age, level of severity (GMFCS)
Data collection	
17. Interview guide	Interview questions guide table and prompts guides provided by the authors.
18. Repeat interviews	No
19. Audio/visual recording	Interviews were audio-recorded
20. Field notes	Field notes taken after interviews
21. Duration	Approximately 30 minutes
22. Data saturation	Sampling continued until data saturation
23. Transcripts returned	Yes
Domain 3: analysis and findings	
Data analysis	
24. Number of data coders	Two
25. Description of the coding tree	Codes recorded by each coder
26. Derivation of themes	Themes were derived from the data by thematic content analysis.
27. Software	Manual coding line by line
28. Participant checking	Yes
Reporting	
29. Quotations presented	Yes
30. Data and findings consistent	Yes
31. Clarity of major themes	Yes
32. Clarity of minor themes	Yes

Chapter 4: Sit-to-stand training for self-care and mobility in children with cerebral palsy: a randomized controlled trial

4.1 Introduction

In Chapter 3 it was reported that impaired ability to sit-to-stand in children with cerebral palsy with moderate to high disability was perceived to impact children's ability to independently perform mobility and self-care tasks, and negatively impacted caregivers physically and psychologically. These results suggest that the ability to sit-to-stand independently may be an important precursor skill for developing independence in self-care and upright mobility tasks for children with moderate to severe disability.

Therefore, the study presented in Chapter 4 aimed to investigate the effects of sit-to-stand exercise training on self-care and upright mobility for children with cerebral palsy with moderate to severe motor dysfunction; and evaluate the effects of the training on speed of sit-to-stand performance and caregiver strain on an independent sample of children from those who participated in Chapter 3.

4.2 Study three

Chapter 4 has been accepted for publication by the journal *Developmental Medicine & Child Neurology*. It is presented in its format (single-spaced) accepted for publication.

Chaovalit S, Dodd KJ, Taylor NF. (in press). Sit-to-stand training for self-care and mobility in children with cerebral palsy: a randomized controlled trial. *Developmental Medicine & Child Neurology* (accepted 2 June 2021).

Sit-to-stand training for self-care and mobility in children with cerebral palsy: a randomized controlled trial

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Declaration of interest

The first author (SC) is a PhD student funded by Faculty of Medicine, Prince of Songkla University, Thailand. The authors report no conflicts of interest.

Sit-to-stand training for self-care and mobility in children with cerebral palsy: a randomized controlled trial

Abstract

AIM To investigate if a sit-to-stand exercise programme for children with cerebral palsy improved self-care and mobility.
METHOD Thirty-eight children with CP (19 males, 19 females; mean age 8y 0mo; SD 2y 4mo, age range 4y 0mo to 12y 4mo) classified as level III or IV on the Gross Motor Classification System and their caregivers were randomly allocated to sit-to-stand training plus routine physiotherapy (balance and gait training) or routine physiotherapy control. Task-specific sit-to-stand training was completed five times a week for 6 weeks under physiotherapist (twice weekly) and caregiver (three times weekly) supervision. Blinded outcome assessments at week 7 were the self-care and mobility domains of the Functional Independence Measure for Children (WeeFIM), Five Times Sit-to-Stand Test (FTSST) and the Modified Caregiver Strain Index (MCSI).
RESULTS Sit-to-stand group self-care increased by 2.2 units (95%CI 1.3 to 3.1) and mobility increased 2.2 units (95%CI 1.4 to 3.0) compared to the control group. Sit-to-stand group FTSST reduced 4.0 seconds (95% CI 3.2 to 4.7) and MCSI reduced 0.8 units (95% CI 0.4 to1.2) compared to the control group.
INTERPRETATION A sit-to-stand exercise programme for children with moderately severe cerebral palsy improved sit-to-stand performance and resulted in small improvements in self-care and mobility, while reducing caregiver strain.

Running footer: Sit-to-stand exercise for children with CP

What this paper adds

- Sit-to-stand training improved independence in self-care and mobility for children with cerebral palsy (CP).
- Home-based sit-to-stand training programmes for children with CP can reduce the burden on supervising caregivers.

Sit-to-stand training for self-care and mobility in children with cerebral palsy: a randomized controlled trial

Children with cerebral palsy and moderate to severe disability (Gross Motor Function Classification System (GMFCS) level III and IV) often have difficulty changing body position by transferring from sit to stand efficiently, safely, and independently.[1-2] This is a concern because being able to sit-to-stand is an important component of many everyday activities such as standing up to prepare for walking, and for completing self-care activities such as dressing, washing oneself and toileting.[1-3] Therefore improvements in sit-to-stand might lead to greater independence for the child and in turn may reduce caregiver strain by reducing level of assistance required for self-care and mobility. For these reasons, optimizing the ability to sit-to-stand for these children may be a focus of therapy.

One systematic review[3] of 8 randomized controlled trials has investigated the effects of sit-to-stand exercise training programmes on children and adults with physical impairments. Two of the trials included children with cerebral palsy.[4-5] A meta-analysis within the review suggested there was moderate-quality evidence that sit-to-stand exercise programmes can improve sit-to-stand performance. This improvement was likely to be due to repetitive practice, consistent with the principles of motor learning[6] and task-specific training,[7] whereby a systems approach involves adaptation of the brain to solve movement problems.[6] Therapy for children with cerebral palsy commonly incorporates task-specific training. Consistent with criteria for functional therapy,[8] this involves the goal-directed, repetitive practice of a whole task or a part of a task often modified to suit a child's abilities, and practiced under different conditions consistent with the context under which the task will be performed in daily activities.[4-7, 9]

Although repetitive practice improved sit-to-stand performance, a further meta-analysis in the review[3] found no evidence that sit-to-stand exercise programmes improved other functional activities, including mobility. A possible reason for changes not being detected in other outcomes was that the prescribed exercise dose may have been inadequate for motor learning. Exercise dosages were typically similar to those associated with progressive resistance training regimens (i.e. 3 sets of 10 repetitions, 3 times a week for 6 weeks, with some progression of resistance/intensity). While progressive resistance exercise increases muscle strength in people with cerebral palsy, there is evidence that increases in strength do not carry over into increased activity.[10-11]A small case series has reported that more than 750 sit-to-stand repetitions throughout the intervention may be required to achieve independence in sit-to-stand and carry over to improvement in walking for people with chronic stroke.[12] Most trials in the systematic review, including the 2 trials that focused on children with cerebral palsy[4-5], did not complete that number of sit-to-stand repetitions. So it remains possible that implementation of programmes for children with cerebral palsy that are more consistent with the principles of motor learning and task-specific training may improve not only sit-to-stand performance but also carry over to improvements in mobility and self-care functions that are typically performed in upright stance.

Inspection of the 2 trials that included children with cerebral palsy[4-5] also shows that the effects of sit-to-stand exercise programmes for children with moderately severe disabilities who, by definition of their disability, have quite severe difficulty moving from sit-to-stand independently, remains unknown. This is because both previous trials recruited children with relatively mild disability (GMFCS level I, II with only a few level III) who typically have little difficulty moving from sit-to-stand independently. It is

assumed that relatively close caregiver supervision of the children would be required for completion of a sufficient number of sit-to-stand repetitions for effective task-specific training. The amount of supervision required plus changes in the interaction between the parent and the child during training could lead to increased caregiver strain, particularly with a demanding programme.[13-14]

Accordingly, our primary aim was to investigate the effects of sit-to-stand exercise training on self-care function and independent upright mobility for children with cerebral palsy with moderate to severe motor dysfunction. The secondary aims were to evaluate the effects of the training on sit-to-stand performance and caregiver strain.

METHOD

Design

A single-blind, randomized controlled trial was conducted using two parallel groups with one-to one allocation. This trial was conducted at a rehabilitation centre and physiotherapy unit in Thailand from November 2019 to March 2020 with a home exercise component included. Ethical approval was obtained from La Trobe University and Health Service Human Research Ethics committees. Children with cerebral palsy were invited to provide their own verbal assent in addition to their caregivers' providing written consent for themselves and their child to participate. The study was registered prospectively with the Australian New Zealand Clinical Trials Registry (ACTRN12619001525178) and reported consistent with the CONSORT checklist.[15]

An independent researcher prepared the random allocation sequence using permuted blocks, with children stratified by GMFCS level. Allocations were placed in consecutively numbered sealed opaque envelopes. After written informed consent had been obtained and baseline testing was completed, the trial coordinator allocated the children by opening the next sealed envelope.

Participants

Children were included if they had any type of cerebral palsy (e.g. spastic, athetoid, ataxic) classified as level III to IV on the GMFCS; were aged 4 to12 years (inclusive), were able to sit-to-stand with or without the assistance of caregiver or furniture without falling, and were able to follow simple verbal instruction such as, 'stand up, please'. Children were excluded if they had undergone an orthopedic intervention, selective dorsal rhizotomy, or botulinum toxin injection to the lower limbs within the previous 6 months or had any orthopaedic problems or medical conditions such as osteogenesis imperfecta, arthrogryposis multiplex congenita, or spinal muscular atrophy that prevented participation in intensive exercise training. The primary caregivers of these children were included if they spoke Thai fluently.

Intervention

Both groups received routine physiotherapy for 30 minutes, 5 times a week for 6 weeks. Two of these sessions were conducted in a quiet private training room and were supervised by one of two registered physiotherapists and 3 sessions were conducted at home and supervised by the child's primary caregiver. The routine physiotherapy program consisted of balance training and gait training with the assistive device orthosis that the child normally wore. In addition, at each exercise session the experimental group received 30 minutes of a sit-to-stand training program following the principles of task-

specific training focusing on three phases: repetition of part of the sit-to-stand task (e.g. foot placement, forward weight shift); repetition of all the sit-to-stand movement along with feedback; and repetition of the sit-to-stand movement applied within the context of self-care tasks (e.g. standing and reaching for a toy) (Fig. 1). The training duration of 6 weeks was chosen to ensure an adequate number of repetitions of sit-to-stand could be completed to transfer to improved activity,[12] while taking account of the need to optimise adherence. To control for this additional time, the control group participants received 30 minutes of hot pack application and lower limb stretching. A full description of the interventions, according to template for intervention description and replication (TIDieR)[16], can be viewed in Table 1 and 2**.**

Outcome measures

All outcomes were measured at week 0 and week 7 by an accredited assessor blinded to group allocation.

The primary outcome measures were the 11 items of the self-care and mobility domains of the Functional Independence Measure for Children (WeeFIM).[17] There are 6 items for self-care and 5 items for mobility. The WeeFIM assesses the amount of assistance required from a helper to complete all of the task components; a score of 1 is defined as total assistance, and 7 is defined as complete independence with scores summed for each domain.[17] The minimum clinically important differences for children classified as GMFCS III are 3.3 units for WeeFIM self-care and 2.7 units for mobility.[18] The minimum clinically important differences for large effects are 5.2 units for self-care and 4.3 units for mobility.[18]

Secondary outcomes were sit-to-stand performance assessed using the time taken to stand up and sit down from a chair five times as quickly as possible (Five Times Sit-to-Stand Test:FTSST)[19]; and the 13-item Modified Caregiver Strain Index (MCSI),[20] with caregiver responses on a 0-2 scale summed to provide a score out of 26, with higher scores being indicative of higher levels of strain associated with caregiving. The minimum clinical important difference for FTSST and MCSI were based on 0.5 of the baseline standard deviation (SD) of the control group.[21] Attendance at training sessions, adherence to training protocols during sessions, and adverse events for both home sessions and rehabilitation centre sessions were recorded. The results of a qualitative analysis of caregiver perceptions of the sit-to-stand training programme will be reported elsewhere.

Data analysis

A sample size of 42 participants (21 in each group) was required to detect a large clinically important difference (d=0.8) in the self-care (5.2 units/42) and mobility (4.3 units/35) domains of WeeFIM[18] at a type I error rate of 0.05 and power (1 – type II error rate) of 0.7.

Descriptive statistics were used to describe the demographic characteristic of participants (Table 3). Analysis of covariance was used to compare the main outcomes of the primary and secondary continuous outcomes between control and experimental groups at week 7 using the baseline value as the covariate. Inspection of data and Shapiro–Wilks tests (p>0.05) confirmed that the distributions did not violate the assumption of normality. Analysis of covariance is robust to violations of the assumption of normality.[22] Consistent with the principle of intention to treat, all available data were analysed according to group allocation, without adjusting for the level of adherence. Between-group differences were reported as mean differences with 95% confidence intervals (CIs). Statistical significance

was set at α=0.05. Data analysis was completed using SPSS v25.0 (IBM Corp., Armonk, NY, USA).

Attendance was expressed as the percentage of sessions attended (ratio of the number of training sessions attend to the total number of sessions prescribed, multiplied by 100); reasons for non-attendance were also recorded. Adherence to exercise prescription within sessions was calculated as the number of repetitions of sit-to-stand completed in each session as a proportion of the number prescribed by the physiotherapist. Adverse events were categorized as serious or non-serious. Non-serious events were defined as those not needing medical attention and that did not cause children to miss exercise sessions. Serious adverse events were defined as events (such as a serious fall) that resulted in injury and resulted in missed training sessions.

RESULTS

Participants Characteristics

Forty children with CP and their caregivers were identified for possible participation. Two children were excluded because they had received botulinum neurotoxin A injections to their lower limbs within the previous 6 months. Therefore, 38 children with CP (19 males, 19 females; mean age 8y 0mo; SD 2y 4mo; age range 4y 0mo to 12y 4mo) classified in GMFCS levels III and IV and their caregivers were included (Table 3 and Fig. S1, online supporting information). No one dropped out and everyone completed the follow-up assessment at week 7 (Fig. S1). The two groups were similar in age, sex, and distribution of GMFCS levels.

Primary outcomes: Self-care and mobility domain of the Functional Independence Measure for Children (WeeFIM)

The sit-to-stand group improved self-care by a mean of 2.2 units (95% CI 1.3–3.1) and improved mobility by a mean of 2.2 units (95% CI 1.4–3.0) compared to the control group (Table 4). The upper band of the 95% CI for self-care (3.1 units) was close to but still less than the minimum clinically significant difference of 3.3 units. The upper band of the 95% CI for mobility (3.0 units) exceeded the minimum clinically significant difference of 2.7 units.

Secondary outcomes: Five Times Sit-to-Stand Test (FTSST), and Modified Caregiver Strain Index (MCSI)

The sit-to-stand group reduced their FTSST by a mean of 4.0 seconds (95% CI −4.7 to −3.2) and reduced their MCSI by a mean of 0.8 units (95% CI −1.2 to −0.4) compared to the control group (Table 4). The upper band of the 95% CI of the FTSST (4.7s) exceeded the minimum clinically significant difference of 4.2 seconds. The upper band of the 95% CI of the MCSI (1.2 units) was less than the minimum clinically significant difference (1.8 units) (Table 4).

Attendance was excellent in both groups: 93% (mean 27.8/30 sessions) for the experimental group and 90% (mean 26.9/30 sessions) for the control group. There was 100% attendance at the scheduled 12 sessions supervised by the physiotherapists in both groups, but children in the control group missed more scheduled home-based sessions (P = 0.033). The caregiver being busy was the main reason for missed sessions, both in the control (32 sessions) and the experimental group (40 sessions). Other reasons for non-attendance were: illness (experimental n=3 sessions, control n=2), the child refusing to participate due to boredom or fatigue (experimental n=2 sessions, control n=12); and clashes with other appointments (experimental n=4 sessions, control n=5). The mean

number of sit-to-stand repetitions completed within each session in the experimental group was 65.7 (SD 2.5). The average number of repetitions of sit-to-stand completed when the session was supervised by a physiotherapist was 67.8 (SD 2.3), compared with an average of 64.1 (SD 2.8) when the session was supervised by the caregiver. The mean number of sit-to-stand repetitions completed over the 6-week program was 1960.3 (SD 76.1).

No serious adverse events, such as falls, were reported in either group. Only non-serious adverse events were reported in a mean of 13.1 sessions/30 for the experimental group and 10.1/30 sessions for the control group. The most common non-serious event reported was fatigue.

DISCUSSION

This trial has demonstrated that a 6-week sit-to-stand exercise programme led to small improvements in the independence of self-care and mobility of children with moderately severe cerebral palsy and increased sit-to-stand performance. The training program was safe, adhered to by children and their caregivers and was associated with small reductions in caregiver strain. Consistent with previous trials we found that repetitive and intensive practice of a skill such as sit-to-stand can improve sit-to-stand performance.[5, 23] In contrast to other trials, our findings show that such a training programme can also lead to small improvements in self-care and mobility.

One explanation for the positive results of our trial compared to previous trials was that we targeted our intervention at those who were most likely to benefit, those classified as GMFCS level III and IV. Most of the participants of previous trials were children with cerebral palsy who had mild to moderate disability. These children could already independently sit-to-stand with little difficulty, so further training might reasonably not be expected to improve their abilities. In addition to targeting children who were most likely to benefit from the sit-to-stand training, we prescribed a training dose consistent with the principles of task-specific training. The training dose of previous trials may not have been adequate for task-specific training to improve gross motor functions and learning to develop skill in children with cerebral palsy.[4-5] Participants in our trial programme completed an average of almost 2,000 repetitions of sit-to-stand, a number shown to be sufficient to train a task.[12]

Despite the statistically significant results favouring the sit-to-stand group, the size of the effect on self-care and mobility was relatively small. Based on the confidence bands around the between-group mean differences relative to the minimum clinically important differences, our results suggest that the observed change in self-care was not clinically significant, while the changes in mobility may be clinically significant. Therefore, our results only partially support the view that training sit-to-stand may be important for children with moderate to severe disability. It is possible that sit-to-stand training may be more relevant for mobility in this group as the ability to get to and maintain an upright position is fundamental to upright gait.[24] In contrast, many self-care activities such as those completed in sitting (e.g. feeding) are not dependent on the ability to transfer safely and independently from sit-to-stand.

Despite the potential additional strain of supervising the sit-to-stand programme three times a week for 6 weeks, there were small reductions in the strain experienced by caregivers. Consistent with the results of the primary outcome, it suggests that the children may have improved enough in their self-care and mobility to reduce the physical strain of caring on caregivers. It is also possible that being actively involved in their

child's therapy may have reduced the emotional strain contributing to caregiver burden. This is a positive finding for therapists as it provides reassurance that prescribed exercise programmes can be implemented at home without risk of increasing caregiver strain.

Strengths of this trial included its randomized design that was conducted and reported according to the Consolidated Standards of Reporting Trials (CONSORT) guidelines. Our trial was a single-blind randomized controlled trial, with an accredited assessor blinded to group allocations. Additionally, the exercise training programmes had excellent compliance and there was no loss to follow up. However, there were limitations. First, we only examined the impacts after a relatively short programme on outcomes and it remains unknown if larger improvements may have been found after a longer training programme or if benefits are retained after training stops. Second, while we found attendance and adherence to the programme was excellent in this group of Thai participants the generalizability to other cultures remains unknown. To optimize attendance and adherence a number of features were incorporated into the programme such as the use of an exercise diary and individualized video records of the sit-to-stand program and weekly physiotherapist review.[25] In Thai culture children are expected to do as their parents and those in authority instruct without choice.[26] Therefore, the generalizability of the findings to other cultures where compliance with medical and therapeutic advice might not be embraced so willingly by the caregivers, and where children might be less willing to comply to directions, certainly over so many sessions, is unknown.

CONCLUSION

A relatively short 6-week sit-to-stand exercise programme led to small improvements in children's ability to complete mobility and self-care tasks, which may be clinically relevant for mobility; and can improve sit-to-stand performance, without increasing caregiver strain. Our results provide partial support for the importance of sit-to-stand as a precursor skill for developing safe and independent mobility for these children. Training sit-to-stand could be a useful focus of therapy in children with moderate and severe cerebral palsy.

Table 1: Intervention: experimental group

TIDieR criteria	Experimental group
Name	Sit-to-stand exercise programme.
Why	Improving mobility and self-care functions.
What	Children received 1 hour of physiotherapy: 30 minutes of routine physiotherapy: 15 minutes of balance training in sitting and standing with progressions including changing the base of support, increasing the time maintained, and superimposing movement while maintaining balance; 15 minutes of overground walking training with the assistive device orthosis that the child usually uses. Progressions included increasing distance and walking with reduced support. 30 minutes of sit-to-stand training (three phrases): (1) repetition of part of the sit-to-stand task (e.g. foot placement, forward weight shift); (2) repetition of all the sit-to-stand movement along with feedback; (3) progression: repetition of all the sit-to-stand movement applied within the context of self-care tasks (e.g. sit-to-stand with reaching for a toy).
Who provided it	Two physiotherapists experienced in working with children with cerebral palsy for more than 10 years at the unit where the study was conducted; child's caregiver for the home programme.
How	Individually, face to face, one physiotherapist per one child; individually, face to face, one caregiver per one child.
Where	Two days a week in a quiet private training room located in the physiotherapy unit in Thailand; 3 days a week at the child's home.
When and how much	Training duration: 6 weeks; Frequency of training: five times per week; One hour per day, 2 days a week for the hospital-based sessions; One hour per day, 3 days a week (on days not training with the physiotherapist) for the home-based programme; Session length, 60 minutes (30 minutes of regular physiotherapy and 30 minutes of sit-to-stand training); Total number of sessions: 30 sessions; Intensity and volume: Phase 1: practised until part-task completed; Phase 2: three sets of 25 repetitions of sit-to-stand, resting 2–3 minutes between each set; Phase 3: individualized according to ability.
Tailoring	Details of the balance and walking training were individualized depending on each child's abilities; the progression of the sit-to-stand task from phases 1 to 3 with increasing difficulty was implemented according to each child's ability.
Modifications	The intervention was not modified during the study.
How well	An independent physiotherapist monitored treatment once weekly to ensure that treatment was implemented as planned; an exercise diary was provided to therapists and caregivers to record data about: total number of sessions, reasons for any non-attendance, occurrence of any adverse events, number of repetitions of sit-to-stand completed in phase 2 in each exercise session. An updated video recording of the sit-to-stand home programme was provided to the caregiver once each week.

TIDieR, template for intervention description and replication.

Table 2: Intervention: control group

TIDieR criteria	Control group
Name	Routine physiotherapy programme.
Why	Improving mobility and self-care functions.
What	Children received 1 hour of physiotherapy: 30 minutes of routine physiotherapy: 15 minutes of balance training in sitting and standing. with progressions including changing the base of support, increasing time maintained, and superimposing movement while maintaining balance; 15 minutes of walking training with the assistive device orthosis that the individual child usually uses. Progressions included increasing distance and walking with reduced support. In addition, to account for the time receiving the intervention in the experimental group children received: 15 minutes of a hot pack applied to both lower limbs; 15 minutes of stretching to both lower limbs.
Who provided it	Two physiotherapists experienced in working with children with cerebral palsy for more than 10 years at the unit where the study was conducted; child's caregiver for the home programme.
How	Individually, face to face, one physiotherapist per one child; individually, face to face, one caregiver per one child.
Where	Two days a week in a quiet private training room located in the physiotherapy unit in Thailand; 3 days a week at the child's home.
When and how much	Training duration: 6 weeks; Frequency of training: five times per week; One hour per day, 2 days a week for the hospital-based sessions; One hour per day, 3 days a week (on days not training with the physiotherapist) for the home-based programme; Session length: 60 minutes (30 minutes of regular physiotherapy and 30 minutes of hot pack and stretching); Total number of sessions: 30.
Tailoring	Details of the balance training and walking training were individualized dependent on each child's abilities.
Modifications	The intervention was not modified during the study.
How well	An independent physiotherapist monitored treatment once weekly to ensure that treatment was implemented as planned; An exercise diary was provided to the therapists and the caregivers to record data about: the total number of sessions, the reasons for any non-attendance, occurrence of any adverse events.

TIDieR, template for intervention description and replication.

Table 3: Baseline demographic characteristics of participants

Characteristic	Randomized and completed the study (*n*=38)	
	Exp-STS (*n*=19)	Controls (*n*=19)
Children (*n*=38)		
Mean age (SD), y:mo	7:2 (2:1)	8:8 (2:5)
Sex, male	10 (53)	9 (47)
GMFCS level (III/IV), *n*	8/11	8/11
Type of CP		
Unilateral spastic CP	1 (5)	2 (11)
Bilateral spastic CP	17 (90)	15 (79)
Ataxic	0 (0)	1 (5)
Dyskinetic	1 (5)	0 (0)
Mixed	0 (0)	1 (5)
Primary caregivers (*n*=38)		
Mean age (SD), y:mo	39:6 (8:4)	40:3 (8:1)
Sex, female	17 (90)	18 (95)
Education		
High school	4 (21)	4 (21)
Diploma	5 (26)	6 (32)
Bachelor's degree	10 (53)	9 (48)
Master's degree	–	–
Doctoral or professional degree	–	–
Occupation		
Home duties	12 (63)	10 (53)
Farmer	4 (21)	5 (27)
Childcare worker	–	2 (11)
Other (self-employed, retired government staff)	3 (16)	2 (11)

Data are *n* (%) unless otherwise stated. Exp-STS, experimental sit-to-stand group; GMFCS, Gross Motor Function Classification System; CP, cerebral palsy.

Table 4: Mean (SD) of groups, mean (SD) difference within groups, and mean (95% CI) between-group difference

Outcomes	Groups				Difference within groups		Difference between groups
	Week 0		Week 7		Week 7 minus week 0		Week 7 minus week 0
	Exp (*n*=19)	Controls (*n*=19)	Exp (*n*=19)	Controls (*n*=19)	Exp	Controls	Exp minus controls
WeeFIM self-care (6–42)	18.5 (4.7)	17.3 (4.4)	21.0 (5.0)	17.7 (4.3)	2.5 (1.9)	0.4 (0.6)	2.2 (1.3–3.1)
WeeFIM mobility (5–35)	14.4 (4.5)	14.3 (4.8)	17.1 (5.0)	14.7 (4.8)	2.6 (1.4)	0.4 (1.0)	2.2 (1.4–3.0)
Total WeeFIM (11–77)	32.9 (8.5)	31.6 (8.9)	38.1 (9.5)	33.0 (8.9)	5.2 (2.5)	1.3 (2.6)	3.8 (2.1–5.5)
FTSST (s)	32.0 (7.4)	36.9 (8.5)	28.9 (7.7)	38.0 (9.2)	−3.2 (1.1)	1.1 (1.2)	−4.0 (−4.7 to −3.2)
MCSI (0–26)	11.84(3.0)	14.11 (3.7)	11.0 (2.9)	14.1 (3.5)	−0.9 (0.5)	−0.1 (0.5)	−0.8 (−1.2 to −0.4)

CI, confidence interval; Exp, experimental group; WeeFIM, Functional Independence Measure for Children; FTSST, Five Time Sit-to-Stand Test; MCSI, Modified Caregiver Strain Index.

(A) (B)

Figure 1: Examples of the sit-to-stand training. (A) Phase 1 repetition of part of the sit-to-stand task: forward weight shift. (B) Phase 2 repetition of all the sit-to-stand movement along with feedback.

Supporting information

The following additional material may be found online:

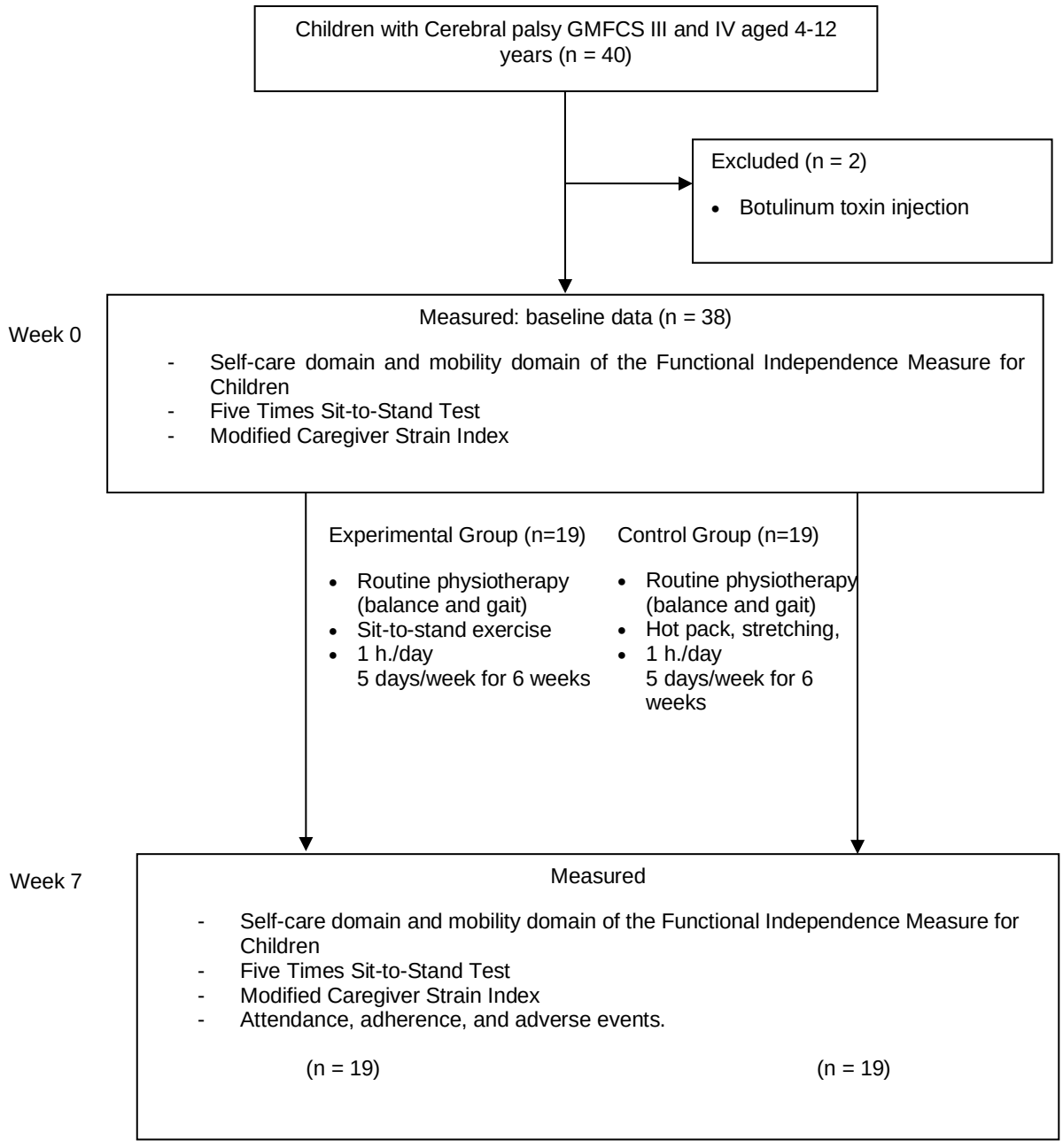

Figure S1: Design and flow of participants through the trial.

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Chapter 5: Caregivers' perceptions of a sit-to-stand exercise program for children with moderately severe cerebral palsy

5.1 Introduction

In Chapter 4 it was reported that a sit-to-stand exercise program for children with moderately severe cerebral palsy improved sit-to-stand performance and resulted in small improvements in self-care and mobility, while reducing caregiver strain. To explore the caregivers' perceptions about any outcomes from the exercise program for their child or themselves and their views about the feasibility of supervising an intensive home-based training program, a qualitative study was conducted with the children's caregivers. The themes emerging from this analysis were then triangulated with quantitative outcomes. Chapter 5 contains that study.

5.2 Study four

Chapter 5 is presented in the format prepared for submission to *Pediatric Physical Therapy*.

Caregivers' perceptions of a sit-to-stand exercise program for children with moderately severe cerebral palsy

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Caregivers' perceptions of a sit-to-stand exercise program for children with moderately severe cerebral palsy

Abstract

Purpose: To explore caregiver perceptions about the outcomes and feasibility of a sit-to-stand home-based exercise program on themselves and their children with moderately severe cerebral palsy.

Method: Face-to-face semi-structured interviews were conducted with the caregivers of 19 children with moderately severe cerebral palsy (Gross Motor Function Classification System level III-IV) who had completed a 6-week sit-to-stand exercise program. Each week a physical therapist supervised the program twice and caregivers three times. Interviews were transcribed verbatim, analyzed thematically, and triangulated with quantitative outcomes.

Results: Themes were: (1) caregivers saw positive changes in their children from completing the program, (2) the program was feasible to complete, (3) seeing change gave caregivers hope that their child could develop with further training. Qualitative and quantitative findings converged.

Conclusions: Caregivers perceived positive changes in their children and increased hope for their future after a sit-to-stand exercise program, suggesting the program is feasible with caregiver supervision.

Key words: children with cerebral palsy, caregiver, sit-to-stand exercise, qualitative.

Running footer: Sit-to-stand exercise for children with CP

Caregivers' perceptions of a sit-to-stand exercise program for children with moderately severe cerebral palsy

INTRODUCTION

Children with moderately severe cerebral palsy (i.e. level III-IV on the Gross Motor Function Classification System)[1] often have difficulty moving from sit-to-stand independently, efficiently and safely. Therefore, they are more sedentary than their typically developing peers[1, 2] which can impact their general strength and aerobic fitness[3] and they often require more assistance to complete everyday functional activities such as dressing, washing and toileting.[4, 5] For this reason, sit-to-stand exercise programs may be a useful addition to physical therapy interventions.

While there is some evidence that sit-to-stand exercise programs can improve sit-to-stand performance,[6] less is known about the effects on other outcomes. It seems reasonable to hypothesise that if a child learns to sit-to-stand independently they can move to standing and then practice walking, or they can stand to adjust clothing when dressing, or more efficiently transfer on and off a toilet or move into and out of a bath. Therefore, a sit-to-stand exercise program might lead to improved physical skills such as upright mobility and self-care. Quantitative methods such as randomized controlled trials are well placed to test these specific hypotheses. However, it is possible that exercise programs might lead to other less expected outcomes for the children doing the programs and the caregivers who support them. For example, learning a new motor skill requires repetitive practice of the motor skill over many sessions and in authentic environments; [7, 8] therefore, exercise programs for children with cerebral palsy often incorporate home-based sessions. Children with moderately severe disabilities have difficulty moving independently from sit-to-stand and so each home-based exercise session must be closely supervised by their caregiver(s) who are often inexperienced in implementing exercise

programs. This means that home-based sessions might prove to be ineffective and so no changes occur in outcomes for the children, and/or the program could place an unreasonable strain on caregivers, which could lead to negative outcomes for the child, their caregivers or even their families.

Qualitative methods can be used to better document all outcomes, and to explore depth of understanding about the reasons for success or failure of the exercise program or to identify strategies for facilitating implementation of such a program. Accordingly, the aim of this study was to explore caregivers' perceptions about the positive and negative outcomes of a sit-to-stand exercise program on themselves and their child with moderately severe cerebral palsy, and to explore the feasibility of conducting such a program, particularly a program that included home-based sessions.

METHOD

Qualitative research methods using in-depth semi-structured interviews explored caregiver perceptions of their child's participation in a sit-to-stand exercise program. An interpretive descriptive methodological framework was used to better understand the outcomes of the exercise program and to generate new knowledge that could be used by therapists when prescribing home-based physical therapy interventions for children with moderately severe cerebral palsy.[9, 10] To enable triangulation of qualitative data, data were concurrently collected on the child's functional independence in mobility and self-care tasks (WeeFIM),[11] on caregiver strain (Modified Caregiver Strain Index),[12] and on program attendance. This study is reported according to the Standards for Reporting Qualitative Research (SRQR).[13] Ethical approval was obtained from the relevant University and Health Service Human Research Ethics committees. Written informed consent was obtained from all participants prior to their participation. The study was conducted in a large rehabilitation center and surrounding community in Thailand.

Participants

Participants were included if they spoke Thai fluently and they were the primary caregivers of children with cerebral palsy who had completed a 6-week sit-to-stand exercise intervention as a part of a randomized controlled trial. The results of the trial are reported elsewhere.[14] The caregivers were interviewed because their perceptions were thought to be important as there were home-based components of the intervention. The children were aged from 4 to 12 years old and were classified as level III or IV on the Gross Motor Function Classification System (GMFCS)[1]. The children were recruited from a large metropolitan rehabilitation center that provides specialist outpatient and inpatient services for children with cerebral palsy, and the physical therapy unit of the largest hospital in southern Thailand. Potential children and their caregivers were first identified by perusing client lists at the physical therapy center. Then, potentially suitable clients were approached by an independent clinician to see if they were interested in taking part in the study. After potential clients provided permission, the researcher (SC) spoke to the family, answered any questions, and proceeded with consent procedures. Participants were recruited consecutively until the sample size required for a quantitative analysis that will be reported elsewhere was achieved. It was expected that the sample obtained for the intervention arm of the quantitative analysis (n=19) would be sufficient to achieve data saturation for qualitative analysis.

Intervention

The 6-week exercise program comprised 5 training sessions each week (total of 30 exercise sessions). Each child trained individually twice a week under the supervision of a physical therapist in the quiet private training room in the rehabilitation center, and three times each week under the supervision of the caregiver at home. In each session, the child completed 30 minutes of task-specific sit-to-stand training based on three phases: practice

of part of the task (e.g. weight shift, lean forward); completion of the whole sit-to stand task aiming for 75 repetitions in each session; and practice incorporating sit-to-stand into a functional task (e.g. stand from sitting and reach for a toy). After sit-to-stand training, in each session the child then completed 30 minutes of balance and walking practice. In an attempt to improve adherence and effectiveness of the prescribed exercises, an exercise diary, an individualized video recording of the sit-to-stand program and weekly physical therapist review was provided to the caregiver.

Interviews

Semi-structured in-depth interviews were conducted individually with each of the caregivers in a quiet private training room in the rehabilitation center. The interviews were conducted in week 7 immediately after the child completed the program. Each interview went for approximately 20 minutes and was audio-recorded. A researcher experienced in conducting semi-structured interviews (SC) used a pre-determined interview guide of questions and prompts (Table 1). This researcher also took notes to record emergent themes during each interview.

Trustworthiness and rigour

Credibility was ensured by conducting multiple interviews, by triangulation of data between the qualitative and quantitative data, and by involving multiple researchers in the analysis and peer review of data. The researchers all had degrees in physical therapy; SC had 10 years of experience in pediatric physical therapy, NT was active in clinical research, which included experience in qualitative research, and KD was involved in academic management and had experience in community-based pediatric qualitative research. To enhance credibility the transcript of their interview (in Thai language) was sent to the participants for validation (i.e. member checking) and they were asked for their feedback on whether the transcript reflected their thoughts and they were given the

opportunity to add any further ideas. Transferability was enhanced through description of the participants involved. Dependability was achieved through detailing the processes of data collection, analysis, and interpretation, and by peer-review of data analysis at multiple stages of the analysis by two members of the research team (SC, NT). Confirmability was achieved through discussion of the data at each stage of analysis by the research team.

Data analysis

Each audio-recorded interview was first transcribed verbatim to Thai language. Then, the transcript was translated into English (by an English expert from a University International Affairs Office). The English transcripts were then checked by the bilingual researcher (SC) to determine if they accurately recorded the participant's responses. Data were analyzed using a process of inductive thematic analysis, whereby data were coded independently, line-by-line, by two researchers (SC, NT), and then initial codes from each interview were identified and grouped. Following this, the researchers (SC, NT) discussed the first stage of coding and from these discussions the overall themes emerged. The researchers discussed interpretation of the data until consensus was reached. Transcriptions were re-read, to ensure no data had been overlooked. There was ongoing dialogue throughout the process, to ensure themes were not missed. Qualitative data were triangulated with within-group changes in the WeeFIM mobility and self-care scales and the Modified Caregiver Strain index, as well as percentage of sessions attended. Within-group changes were analyzed with paired *t*-tests and expressed as mean differences and 95% confidence intervals.

RESULTS

Nineteen caregivers were recruited: 8 caregivers had children who were classified as level III on the Gross Motor Classification System (GMFCS) and 11 had children who were

classified as level IV on the Gross Motor Classification System (GMFCS). Participant characteristics are shown in Table 2. Caregivers were aged from 26 to 53 years, with a mean age of 39y 6mo (SD 8y 4mo). Most caregivers were female who described their occupation as home duties. The sit-to stand training program was completed with high adherence rates, with 93% of scheduled sessions completed and an average of 65.7 (SD 2.5) repetitions of sit-to stand completed in each session. No additional comments or thoughts were received from caregivers through the member checking process. [Table 2 near here]

Qualitative thematic analysis

Theme 1: All caregivers saw positive changes in their children

All caregivers reported that overall their children appeared more confident, and they transferred and moved more independently around the home after completing the exercise program. Most said their child could move more easily and faster from sit-to-stand by themselves, and they appeared to have more confidence to stand. There were no negative outcomes reported by caregivers.

"It's very useful for my child. I can see that she can do sit-to-stand movement faster and easier than before, looks more confident and safer." (ID 006, GMFCS III)

"He is more courageous and more confident in transferring from chair to bed, from chair to walker, from walker to bed, and not stuck in lying position as before." (ID 013, GMFCS IV)

"He can move from living room to bedroom with his walker with more independence and confidence. Normally, he always needs someone to guide direction and stay with him, but now he is more confident to do by himself." (ID 015, GMFCS III)

Many caregivers said that although some self-care activities such as eating did not change, other self-care tasks such as dressing, especially dressing their lower body, improved and their child became more independent.

"Doesn't change so much for eating because normally he does this task quite well under my supervision without assistance from me. For dressing, it seems like he can put on his pants faster than before under my supervision" (ID 014, GMFCS III)

Many caregivers reported they typically did everything for their child, especially toileting and bathing. This was because the caregivers believed hygiene was important and simply doing the task for the child was thought to be safer and quicker than training and encouraging their child to do the task independently. Therefore, few changes were found in the children's ability to bath and toilet independently.

"He doesn't change so much for these tasks (bathing and toileting). Because I always do these for him to save time, and for hygiene and safety. So, I haven't seen any changes" (ID 011, GMFCS IV)

Even if their child was not independent in bathing and toileting, some caregivers noticed that their child was more confident and more independent when being bathed and during toileting.

"I still need to help her to complete these 2 tasks (bathing and toileting) for hygiene and safety. But still noticed that she can move and change positions easily and quickly and stand up faster while bathing and toileting so that it is easy for me to clean him." (ID 003, GMFCS IV)

Theme 2: The sit-to-stand exercise program was feasible to complete at home

Most caregivers reported the program was feasible to do at home. They particularly noted how useful the physical therapist's video recording of their child doing the exercises was

as a reminder of how to do the exercises correctly and the value of the exercise diary was as a way of monitoring progress over time. When asked what helped them to do the program at home one participant responded:

"The exercise diary and video recording when the physiotherapist explained and demonstrated the home program each week"." (ID 014, GMFCS III)

Some children found it hard to complete all parts of the program, especially completing the prescribed 75 repetitions of sit-to-stand.

"Actually, it's not too hard. But part 2 which are many repetitions per set were quite hard for my son. He is always a lazy boy. Many repetitions in phase 2 quite hard to control for my son. Sometimes, I have to put on a cartoon on the TV while exercising to draw his attention." (ID 008, GMFCS III)

When asked how the exercise program could be improved a few caregivers suggested it was important to have a physical therapist overseeing the program. Also, some caregivers wanted to have more progression in the exercise program *"to apply this exercise program with more difficult tasks" (ID 008, GMFCS III)*; while a couple of caregivers suggested that strategies to maintain their child's interest were helpful.

"For me and my son, phase 3 progression phase quite hard to practice at home. How to make it easier for him to practice this step? Even though a physiotherapist tries to teach us every week, I still can't get as good as her." (ID 007, GMFCS IV)

"Maybe add some techniques to attract attention from the children. But when my son trained this exercise with his physiotherapist, he can do it very well and always completed the goal 60 or 70 repetitions, that is different from training with me." (ID 006, GMFCS IV)

Theme 3: Seeing positive changes gave caregivers hope that their child could develop with further training

One of the most positive outcomes reported by the caregivers was that they themselves had seen positive changes in their child and this had given them hope that their child could, with further training, become more independent.

"I think this exercise has made me more interested in changing my child's development. Just only 6 weeks of training gave her more confidence in doing various activities at home such as transfer, eating, and other self-care tasks." (ID 006, GMFCS III)

"Yes, I am very happy to see him more active, more confidence in movement. If he continued to practice, he would have more progression. I think." (ID 013, GMFCS IV)

As summed up by one caregiver:

"I like it because it's easy to do at home. And these exercises are similar to a real-life task and practical. I see a positive change in my son's development." (ID 002, GMFCS III)

Triangulation

The three main themes identified in the qualitative data from this study converged with quantitative data of increased independence in mobility and safe-care tasks, and reduced caregiver strain (Table 3).

DISCUSSION

After finishing a 6-week sit-to-stand exercise program in children with moderately severe cerebral palsy, all caregivers saw positive changes in their child. The children moved more around the home; they were more confident when transferring and were more independent and safe when performing some self-care tasks such as dressing. All caregivers reported the program was feasible to complete at home with help from the

video recording of the program and the exercise diary supplied by the physical therapist. Seeing change in their child from practicing tasks gave caregivers hope and greater confidence that their child could develop with further training. Qualitative findings converged with the quantitative findings of increased independence in mobility and self-care tasks as measured by the WeeFIM, and reduced caregiver strain, as measured by the Modified Caregiver Strain Index. Collectively these results reinforce the idea that improving the ability to sit-to-stand may be an important precursor skill for upright mobility and self-care in children who find it difficult to sit-to stand independently.

These qualitative results suggest that a relatively intensive program comprising a high number of repetitions of a task to be completed 5 times each week could be feasibly implemented. A concern was whether the caregivers might find supervising the program three times each week too much of a strain, or that the child might find the amount of repetition required too onerous. However, despite this being a concern for a few caregivers, the program was completed with high rates of adherence, and the caregivers reported that supervising the program and seeing positive changes gave them more confidence and hope their child could improve. This finding adds to the literature supporting the feasibility of incorporating home-based training for children with cerebral palsy[15] with a training dose consistent with the principles of task-specific training.[8]

Use of an exercise diary and individualized video-recordings of the sit-to-stand program and the supervision of a physical therapist were noted by caregivers as important to optimize attendance and adherence to training and made it feasible to complete at home. This finding was similar to a previous study[16] which also found that provision of an exercise diary, individualized video records of the program given to caregivers and supervision by a physical therapist were the main factors that improved effectiveness and adherence.

An important finding to emerge was the view of caregivers that seeing positive changes in their child gave them hope for the future. Caring for a child with cerebral palsy can be complex, and it commonly involves increased stress and demands on the caregivers, often including a heightened concern about the future for their child.[17] It has been proposed that the bio-ecological model of human development can help understanding of the process of adaptation of caregivers of children with cerebral palsy.[18] According to this model, and consistent with the findings of our study, at the level of microsystem, problem-solving strategies to address physical limitations may be expected to be more effective than emotion-focused strategies in helping caregivers cope.[19] This finding, provides another positive reason to involve caregivers in home-based task specific training such as a sit-to-stand exercise program.

A strength of this study was that it was conducted and reported according to the Standards for Reporting Qualitative Research (SRQR).[13] A range of measures was used to enhance the credibility of the findings, including having two researchers independently code, analyze and interpret data, member checking of transcripts, and triangulation of qualitative data with quantitative data. The use of inductive qualitative methods revealed insights such as participation in the program providing caregivers with hope for the future of their child that would not have been detected with deductive quantitative methods. A limitation was that only the experiences of caregivers were explored and so the thoughts of the children and even the physical therapists supervising the sessions remain unknown. Further, the outcomes of the sit-to-stand training were only identified immediately after completing the program, and so the retention of outcomes over longer periods remains unknown. The generalizability of the emerging themes to other cultures also remains unknown. According to Thai cultural beliefs, children are expected to be obedient with parents or caregivers' instructions[20] and this might help at least partially explain the high

attendance and adherence to the prescribed program. In other cultures and settings where compliance with medical and therapeutic advice might not be embraced so willingly by the caregiver and where children might be less willing to comply with directions, it is uncertain if caregivers' views about exercise program feasibility would be the same.

CONCLUSION

Caregivers reported that a sit-to-stand exercise program with a home-based component was feasible to conduct for children with moderately severe cerebral palsy and that the program could lead to improvements in their children's mobility and self-care. The positive perceptions of the exercise program provided caregivers with hope that their children could continue to develop their physical abilities with further therapy.

WHAT THIS ADDS TO THE EVIDENCE

- A task-specific sit-to-stand exercise program for children with moderately severe cerebral palsy was perceived by caregivers to improve their children's ability to complete self-care and mobility tasks.
- A sit-to-stand exercise program with three home-based sessions each week was perceived to be feasible by the caregiver.
- Caregivers reported that seeing positive changes in their children gave them hope that therapy could help with their development in the future.

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Table 1 Semi-structured interview guide.

Topic	**Participant questions and prompts**
Start more specific questions	(1) Overall what do you think about the sit-to-stand exercise program? What parts were the hardest to do? What parts were easy? How could the exercise program be improved? What would make it easier to do? Do you think the exercise program was useful or not? *Prompts*: tell me more…, tell me why….
Positive effects	(2) Can you tell me about any positive benefits or positive changes you have seen from completing this training program? *Prompts*: tell me more about… (3) Tell me more about any change you have seen when your child performs mobility? *Prompts*: Could you explain more… (4) Tell me more about any change you have seen when your child performs self-care task? *Prompts*: Could you explain more, which task, tell me more about this task
Negative effects	(5) Can you tell me about any negative outcomes from doing this program of this training? *Prompts*: Could you explain more, how it happened, have there been any incidents such as a fall
Any concern Worried about their child's future	(6) Can you tell me how doing the sit-to-stand training has made you think about your child's development? What parts are you most concerned about? Tell me more about any concerns about your child's future? *Prompts*: tell me more…, tell me why…
Feasibility for home-program	(7) How easy or hard was it for you and your child to do this program at home? What helped you and your child do the program at home? How could the home program be improved? *Prompts*: tell me more…, tell me why…
Satisfaction	(8) Did you like the program and would you want to continue this training? Why? (9) Would you recommend this exercise program to other parents of children with cerebral palsy?
Further questions	Is there anything else you would like to add?

Table 2 Characteristics of children with cerebral palsy and their primary caregivers

	Children (n=19)	**Primary caregivers (n=19)**
Mean age (SD), y	7y 2mo (2y 1mo)	39y 6mo (8y 4mo)
Gender, n female (%)	9 (47)	17 (90)
GMFCS level (III/IV), n	8/11	
Type of CP, n (%)		
Spastic diplegia	14 (74)	
Spastic hemiplegia	1 (5)	
Spastic quadriplegia	2 (11)	
Spastic triplegia	1 (5)	
Ataxia	0 (0)	
Dyskinetic	1 (5)	
Mixed	0 (0)	
Education, n (%)		
High school		4 (21)
Diploma		5 (26.)
Bachelor's degree		10 (53)
Master's degree		-
Doctoral or profession degree		-
Occupation, n (%)		
Home duties		12 (63)
Farmer		4 (21)
Childcare worker		-
Other (Own business, Retired government staff)		3 (16)

CP cerebral palsy; GMFCS Gross Motor Function Classification System

Table 3. Triangulation of the results between qualitative and quantitative data.

THEME/ SUBTHEME	Qualitative finding	Quantitative finding	Triangulation
Theme 1: All caregivers saw positive changes in their children			
- The children's confidence and movement increased around the home.	Children show more confidence and independence with safety in transferring. They can move from one place to another within the house easier and faster than before.	Improved mobility score WeeFIM a mean of 2.6 units (95%CI 1.9 to 3.3)	Convergent
- Changes in the children's self-care tasks	Many caregivers found that there were fewer changes in self-care activities such as eating, but their child tried to help more in dressing tasks.	Improved self-care score WeeFIM a mean of 2.5 units (95%CI 1.6 to 3.3)	Convergent
Theme 2: The sit-to-stand exercise program was feasible to complete at home.	Most caregivers reported the home-based training was not too hard to do at home, but the video record from the physical therapist and the exercise diary helped them to follow the instructions.	Attendance was excellent: 93% (mean 27.8/30 sessions)	Convergent
Theme 3: Seeing change from practicing tasks gave caregivers hope that their child could develop with further training.	The greatest impact on the caregivers was that they had greater hope that their child could develop further and become more independent.	Reduced primary caregivers' MCSI a mean of 0.8 units (95%CI 0.6 to 1.1)	Convergent

MCSI: Modified Caregiver Strain Index

Chapter 6: Grand discussion and conclusions

The overall aim of this thesis was to investigate the effectiveness of a sit-to-stand exercise program for children with moderately severe cerebral palsy. In this grand discussion, the key findings of the studies conducted in pursuit of this aim are summarised and discussed with reference to the findings of relevant literature, and key issues including explanations for the observed findings and implications for practice are identified. Finally, the strengths and limitations of this research are highlighted, and directions are proposed for further research.

6.1 Summary of findings

The background evidence for the research program was examined in a systematic review and meta-analysis of the effects of sit-to-stand exercise programs on patient-related outcomes in people with physical impairments due to a health condition (Chapter 2). Eight randomised controlled trials were included. Five of these trials recruited people with neurological conditions, including two that recruited children with cerebral palsy. A meta-analysis was conducted using four of the trials that recruited patients with neurological conditions. Evidence of moderate quality suggested that prescribed sit-to-stand exercise programs can improve sit-to-stand performance (mean daily number of independent sit-to-stand repetitions, speed of sit-to-stand, and the amount of weight that could be added to complete a single repetition of sit-to-stand), but there was no evidence that they improved other outcomes such as balance or walking. Therefore, it was concluded that sit-to-stand training could be a useful intervention when the aim of treatment was to improve sit-to-stand performance. One limitation identified in the systematic review was that few of the included trials recruited participants who had difficulty completing the sit-to-stand task, and so few participants were included who might be expected to benefit most from training.

The aim of the next study was to obtain a greater understanding of how limited sit-to-stand performance affects daily tasks such as upright mobility and self-care in children with moderately severe cerebral palsy, and in turn how this may affect their caregivers (Chapter 3). The study used a mixed methods design. Twenty-five children aged from 4 to 12 years who had moderately severe cerebral palsy (GMFCS levels III and IV) and their caregivers were recruited. Children with moderate to high disability were selected because they were more likely to have limited sit-to-stand. The mixed methods involved using in-depth semi-structured interviews with caregivers and using the WeeFIM to observe the children's independence in mobility and self-care tasks. Caregivers perceived that an ability to independently, safely, and efficiently moving from sit-to-stand was important and that this was associated with independence in upright mobility and in performing some self-care activities in these children. The quantitative results from the WeeFIM confirmed the children required moderate assistance to complete many mobility and self-care tasks involving sit-to-stand. Collectively these results provided support for the hypothesis that the ability to sit-to-stand may be an important precursor skill for upright mobility and some self-care tasks in children with moderately severe cerebral palsy.

To test the hypothesis a randomised controlled trial was conducted (Chapter 4). A total of 38 children aged a mean of 8 years (SD 2y 5mo) with cerebral palsy classified as GMFCS level III-IV and their caregivers were randomly allocated to a task-specific sit-to-stand training plus routine physiotherapy (balance and gait training) experimental group (n = 19), or a routine physiotherapy (balance and gait training) control group (n = 19). The sample of children participating in the randomised controlled trial were independent of those who participated in the mixed methods study reported in Chapter 3. The primary outcome was independence in mobility and self-care as assessed with the WeeFIM at

week 0 (before training started) and at week 7 (after training finished). Secondary outcomes were sit-to-stand performance assessed by the time taken to complete five repetitions of sit-to-stand (FTSST), and caregiver strain, assessed with the Modified Caregiver Strain Index (MCSI). The results showed that the sit-to-stand group increased self-care by 2.2 units (95%CI 1.3 to 3.1) and mobility by 2.2 units (95%CI 1.4 to 3.0) compared to the control group. The sit-to-stand group's FTSST reduced a mean of 4.0 s (95% CI 3.2 to 4.7) and the MCSI reduced 0.8 units (95% CI 0.4 to1.2) compared to the control group. The results suggested that sit-to-stand task-specific training in children with moderately severe cerebral palsy improved mobility, self-care and performance of sit-to-stand, and also reduced caregiver strain. However, the size of improvements favouring the sit-to-stand training group, while statistically significant, were small, so that the clinical significance of these results was uncertain. Therefore, the results provided partial support for the hypothesis that sit-to-stand is an important precursor skill for developing safe and independent mobility and self-care for these children.

Finally, to gain an understanding of the caregiver perceptions about the outcomes of the training program and the feasibility of the sit-to-stand home-based exercise program on themselves and their child, a qualitative study was conducted and triangulated with relevant quantitative outcomes (Chapter 5). Nineteen caregivers of the children with moderately severe cerebral palsy (Gross Motor Function Classification System level III-IV) who participated in the sit-to-stand training program reported in Chapter 4 were interviewed. The qualitative analysis showed that the home-based component of training (three times each week for 6 weeks supervised by the caregiver) was viewed positively by caregivers. The program was completed with high adherence rates, and the caregivers reported that supervising the program and seeing positive changes in their child gave them more confidence and hope their child could improve with therapy in the future.

The evidence from these studies has provided new information about the role of sit-to-stand exercise programs for children with cerebral palsy. In contrast to previous studies (Kumban et al., 2013; Liao et al., 2007), the findings showed that a sit-to-stand training program can not only improve the actual performance of sit-to-stand, but can also lead to small improvements in upright mobility and in some self-care activities. This might be because in the current thesis an appropriate group of participants were recruited. That is, participants with moderate to severe mobility disability who were most likely to benefit from this training. In addition, the prescribed training dose was consistent with task-specific training and motor learning principles. In contrast, previous studies prescribed training doses more consistent with the aims of increasing muscle strength (Liao et al., 2007), rather than an adequate training dose for task-specific training to improve gross motor function and learning to develop skill in these children (Kumban et al., 2013).

Finally, the studies presented in this thesis provided important information confirming the feasibility of conducting a high-dose task-specific program that included a substantial home-based component. The home-based component was necessary so that participants completed a sufficient dose of training and so that training was conducted in authentic environments to facilitate carryover into everyday activities (Hubbard et al., 2009). However, requiring the caregivers to supervise more than half of the exercise program sessions, without direct supervision of a therapist at each session, raised concerns at the outset. There were concerns that this type of program could increase caregiver strain given the burden on families of caring for young children with disability (O'Neil et al., 2009) and so might not be effective or might not be tolerated. Contrary to these concerns it was found both quantitatively and qualitatively that caregiver supervision of the home-based component of the program was highly acceptable and, in fact, caregiver

participation reduced their perceptions of strain. This adds to the literature on caregiver strain for parents of young children with disability (Beckers et al., 2020).

6.2 Key issues and Implications

6.2.1 Sit-to-stand is an important precursor skill for upright mobility and some self-care tasks in children with moderately severe cerebral palsy

The findings of this research support the view that sit-to-stand may be an important precursor skill for developing independent mobility and improvement in those self-care tasks that require control of upright posture for children with moderately severe cerebral palsy. Functional improvement after a 6-week sit-to-stand exercise program was shown in the small improvements in mobility and self-care and also in sit-to-stand performance. The sit-to-stand exercise program implemented in this series of studies was developed to be consistent with a systems theory of motor control (Muratori et al., 2013; Bernstein, 1967).

A systems model suggests that motor impairments in people with neurological conditions can be improved by synchronising the interaction of multiple systems. Systems can be internal such as a person's muscle strength, coordination, cognition and automatic function or can be external such as the environment the person operates in (Bernstein, 1967). To successfully complete a physical task, relevant systems must work together to produce a movement strategy (Bernstein, 1967; Muratori et al., 2013). The systems model of development suggests that the development of physical skills in children occur as they learn to coordinate their developing nervous and musculoskeletal systems, and as they repetitively practice the requirements of physical tasks within the various prevailing environmental constraints (Shumway-Cook and Woollacott, 1995; Shumway-Cook and Woollacott, 2017). Therefore, a systems model suggests that therapeutic programs to improve impaired movement in children with neurological problems such as cerebral

palsy need to provide sufficient repetitions (dose) of a physical task for motor learning to occur. The child must practice the real task, which sometimes can be broken down into smaller components (part practice) if the whole task is too difficult to begin with, and practice of the task must occur in real-world authentic environments such as in the child's home, at their school, in their local neighborhood. In the sit-to-stand program described in Chapter 4 there was repetitive practice of part of the task of sit-to-stand (phase 1 of training), practice of the whole task (phase 2 of training) and practice incorporating the task into the context of daily living such as standing and reaching for a toy (phase 3 of training). Repetitions of the sit-to-stand task may have led to learning and coordination of the child's central nervous system and the musculoskeletal system leading to the development of improved sit-to-stand performance.

An important goal of motor learning is to ensure the skill learnt has been acquired, retained and transferred (Magill and Anderson, 2014). The progression of participants through the program phases across the 6 weeks of the program suggested the sit-to-stand skill was acquired. The children's improved performance of the task in the FSST at the week 7 assessment also suggested the task of sit-to-stand was retained. Training the task in the different contexts in which the task typically takes place can be used to transfer and improve other related tasks (Magill and Anderson, 2014). Central to this thesis is the idea that transfer of skills can occur between actions that share similar biomechanical characteristics such as the many self-care and transfer tasks that involve an initial horizontal momentum as body weight is shifted forward over the feet with flexion at hips followed by extension and maintenance of balance in standing, such as dressing and transfer while toileting and bathing (Carr and Shepherd, 2003). In terms of transference of skill, small improvements in mobility and self-care tasks requiring upright mobility were found, and this is consistent with the idea that there was at least partial transfer of learning

into related skills and then into important everyday contexts. Therefore, it is possible that there was some transfer from practice from one action (in this case sit-to-stand) to another (mobility and some aspects of self-care).

Feedback is another important feature of motor learning and necessary for the acquisition of a motor skill. Feedback can be internal, with information gained through the sensory experience of completing the task of sit-to-stand. Feedback can also be external. This is often referred to as augmented feedback. In the sit-to-stand program described in this thesis augmented feedback was provided by demonstration in the form of the individualised video of the training program prepared by the physiotherapist. Verbal feedback in the form of encouragement was also provided by the physiotherapist in the centre-based sessions and by the caregivers in the home-based sessions. Verbal feedback provided information to the child about how successful their sit-to-stand performance was, and/or provided prescriptive information about how to improve the task, such as suggesting solutions about foot position prior to sit-to-stand and/or how far to move their body weight forward over their feet (Magill and Anderson, 2014; Schmidt et al., 2018).

Task-specific training typically focuses on performance of functional tasks that are meaningful to the individual. It could be argued that according to the principles of specificity of training (Carr and Shepherd, 2010) that if the aim was to improve upright mobility and self-care tasks, then perhaps the focus of the task-specific training program should have been on these tasks. For example, if the aim of therapy was to improve independent mobility, the training program could have started in standing with appropriate supports and included phases of part and whole practice of walking. However, if a child with cerebral palsy with moderately severe mobility limitation cannot attain the position of upright posture safely, independently, and efficiently in the first place, it questions the usefulness of such training. The approach taken was to consider sit-

to-stand as an ‘impaired essential movement’(Carr and Shepherd, 2010). That is, sit-to-stand can be considered as an important precursor skill for the attainment of independent upright mobility and self-care in children with moderately severe cerebral palsy.

Therefore, the approach taken in this thesis is consistent with a systems approach with key elements incorporated in therapy to help solve problems of movement including task repetition and feedback in an appropriate context leading to skill acquisition and transfer to related independent function.

6.2.2 The provision of intensive physiotherapy for children with moderately severe cerebral palsy

In theory, providing intensive therapy may help young children with cerebral palsy develop solutions to impaired motor skills before they have developed compensatory strategies. It is argued that therapy should be more intensive for younger children (Moseley et al., 2002) because they are likely to benefit the most from motor learning and task-specific training. The reason for this is because if they can improve motor skills such as independent mobility and self-care it will have significant impacts on their future by increasing their overall independence and social participation (Palisano, Snider, and Orlin, 2004; Chiarello and Effgen, 2006).

However, resources, such as therapy services, are limited. This is a primary reason for why, as children with cerebral palsy get older, there is a tendency for less therapy to be provided (Chiarello et al., 2005) with more focus on provision of assistive technology or environment modification instead of training specific tasks. For example, instead of providing therapy to improve independent walking an older child might be provided with a wheelchair to support their mobility limitations (Moseley et al., 2002). Consistent with this, in Thailand where the studies in this thesis were conducted, more intensive therapy is typically provided for very young children with cerebral palsy than for older children.

Although children with cerebral palsy in Thailand up until the age of 15 years are eligible to receive publicly funded physiotherapy up to twice a week, it is observed that commonly school-age children receive less therapy than this, and the focus of physiotherapy indeed tends to focus on compensatory strategies.

Systems theory and practice both reinforce the idea that intensive therapy such as the task-specific intervention described in this thesis is more likely to be applied to young children with cerebral palsy. However, the evidence in support of this practice is uncertain (Myrhaug et al., 2014). For example, Sorensen et al. (2020) found an intensive motor learning therapy program for children with cerebral palsy aged 2 to 5 years, while effective for children classified GMFCS I and II, led to no changes in children classified GMFCS III and IV. It could be speculated that children with less disability had impairments that had less impact on their systems and therefore these children had more potential movement solutions to achieve the desired mobility or self-care outcome. It remains unknown why the intervention was not effective for children with moderately severe cerebral palsy. However, as the intervention program was play-based perhaps it was difficult to achieve the dose or specificity required for motor learning in the children with more severe disability. Furthermore, the authors suggested it might be possible that in the families' everyday life, training time spent on practical activities such as dressing, eating, or personal hygiene was not prioritised; the caregivers usually did these tasks for their child instead of getting the child to practise them (Sørensen et al., 2020).

The sit-to-stand program evaluated in this thesis demonstrates that positive changes in independent function can be obtained by children in the middle years of childhood (age 4 to 12 years). Despite theoretical concerns that compensatory and possibly inefficient movement patterns may have become established and be difficult to unlearn, children completing the sit-to-stand program demonstrated improvements in their ability to move

from sit-to-stand and in their independent mobility and self-care. A key factor that perhaps contributed to these positive findings were that the children were old enough, with supervision, to repeat the repetitive tasks required for training. That is, the children were old enough to be able to complete prescribed exercise rather than have potentially less specific and less intensive play-based therapy.

The findings of this thesis may provide some initial evidence supporting intensive therapy for children of the middle years, providing hope for therapists, families, and the children themselves that functional improvements are still possible. The results of this thesis may also challenge the practice of providing less therapy as children get older and the practice of focusing on supporting compensation rather than independent motor learning. The approach taken in this thesis has been to implement intensive therapy to try to improve an underlying skill: the ability to move from sit to stand. The positive results found in the randomised controlled trial suggest there is still a role for intensive therapy and a capacity for improvement in motor control in school-aged children with moderately severe cerebral palsy (Meehan et al., 2016; Palisano et al., 2012).

Another important finding was that sit-to-stand training also helped the caregiver of the child with moderately severe cerebral palsy by giving them confidence and hope. Caregivers reported that seeing positive changes in their children gave them hope for the future and so gave them confidence to continue participating in and completing the exercise program. Caregiver participation in training also seemed in some cases to increase their interest in training other motor skills and transferring what they had learnt to other skills. The results of the studies reported in this thesis suggest it is worth continuing intensive training for this group in older school-aged children and that investing therapeutic resources can make a positive difference to the children and their families.

6.2.3 Authentic environments: home-based training

Incorporating a large home-based component to the training program had practical and theoretical advantages. Practical advantages included increasing the feasibility of the program by enabling a sufficient dose of task-specific sit-to stand training to be completed. Theoretical advantages included training in the authentic environment of the home, consistent with motor skill learning theory, and involvement of caregivers in provision of the program, consistent with family centred therapy. The practical and theoretical advantages of including a large home-based component may have contributed to its effectiveness (Chapter 4).

The sit-to-stand training program was developed based on the findings of previous training programs that suggested it was necessary to provide intensive training to effect changes. The program aimed to have children repeating sit-to-stand 75 times each session, 5 times a week for 6 weeks. Due to this high dose, it was deemed to be not feasible to be supervised by physiotherapists alone. Therefore, the program incorporated a large element of home-based training supervised by the children's caregivers. Feasibility domains of home-based training that can be considered include implementation and acceptability (Bowen et al., 2009).

The home program component of the sit-to-stand exercise program reported in this thesis was implemented with high degrees of adherence. Children and their caregivers completed 15.8 of the 18 (88%) scheduled sessions at home. They also completed a mean of 64.1 of 75 repetitions of sit-to-stand each session, indicating a high degree of within-session adherence. These results are consistent with the findings of a large systematic review of 92 records (61 studies, 31 conference presentations) which concluded that home-based exercise programs for young people with cerebral palsy can be implemented with high rates of adherence, ranging from 56% to 99% (Beckers et al., 2020). Also,

consistent with the qualitative findings of this thesis (Chapter 5) most of the studies in the systematic review of Beckers et al (2020), reported that the home-based exercise interventions were acceptable; they were easy to carry out and parents valued seeing improvement in their children. These positive findings of implementation and acceptability along with the findings of reduced caregiver strain (Chapter 4) provide strong support for the feasibility of incorporating a large home-based component into therapy programs for children with cerebral palsy.

A key consideration in the implementation of the training program were factors that supported caregivers to supervise the home-based component of the program. The interviews with caregivers showed that many caregivers thought the physiotherapist's role was very important to the success of the program and one that promoted adherence. The physiotherapist progressed the dose of the exercise program every week, monitored the performance of the child and created individualised video-recordings of the sit-to-stand program for the caregiver. The physiotherapist also provided information, emotional support and encouragement to the children and their caregiver.

The use of an exercise diary to record information about the exercise was also used to increase motivation and improve adherence to the exercise program by providing the number of repetitions from the previous session completed, target to be achieved and any adverse events, and progression from everyday session. Therefore, use of an exercise diary and individualised video-recordings of the program and the support and supervision of a physical therapist were important factors to optimise adherence to training and made it feasible to complete at home (Novak and Berry, 2014).

Another advantage of including a large home-based component is that it could be considered consistent with the principles of family centred therapy. Family centred therapy recognises the importance of changing the focus of providing health care for

children with disability from health professionals deciding what care is needed, to recognising that the parents of young children with a disability are experts and should be central to the process of therapy provision (King, Rosenbaum, and King, 1997; Winton and Bailey, 1997). Family centred therapy is widely recognised and recommended and has been claimed to improve health outcomes (Rosenbaum et al., 1998).

A model of home programs for children with cerebral palsy incorporating the principles of family centred practice has been proposed. The five components of the model are to: 1. Develop a collaborative relationship; 2. Set mutually agreed goals; 3. Select therapeutic activities; 4. Support implementation; and, 5. Evaluate outcomes (Novak and Cusick, 2006). The sit-to-stand training program in this thesis could be considered to partly meet this model. From the interviews it was clear that the physiotherapists developed a strong relationship with the caregivers and there were clear goals with the training program, but it appeared the relationship between the physiotherapists and caregivers may have been a more traditional directive relationship rather than a collaborative one. The physiotherapists also provided strong support for implementation, as described above, and evaluation of outcomes was an important part of the program. Therefore, a theoretical benefit of the training program was that it involved caregivers in supervising therapy and thus being involved directly in their children's care. A consideration for future studies would be the use of greater acknowledgment of the caregivers as experts in developing mutually agreed training goals and therapeutic activities. Co-design principles could be used to provide a framework for the process of enhancing the collaborative relationship and development of therapy goals (Westerveld, 2018). In the future an evidenced-based intervention such as sit-to stand program could be one of the therapy strategies to discuss with parents.

A further theoretical advantage of the home-based component of the training program was that it enabled training to be completed in the authentic environment of the home. By improving the ability of children to increase independent mobility and self-care in their home environment where they spend much of their time, it enabled them to practice a skill where they needed to use that skill in everyday activities (Tieman et al., 2004). Conversely, if training is limited only to the clinic there may not be transfer of the skill to the home environment where they have to use the skill. Therefore, incorporation of the home-based component of the program is consistent with the principles of motor skill learning and transfer of training to other tasks (Schmidt et al., 2018).

The practical and theoretical advantages of incorporating a home-based component to training may have contributed to the quantitative and qualitative effectiveness of the program (Chapters 4 and 5). These findings are consistent with a previous review about the effectiveness evidence of home program intervention (Novak and Berry, 2014). They found high quality evidence that home program interventions with task-specific training are effective in improving motor outcomes in children with cerebral palsy (Novak, Cusick, and Lannin, 2009; Katz-Leurer et al., 2009). For example, Katz-Leurer et al. (2009) found intensive home-based task-specific training programs led to improved balance performance in children with spastic cerebral palsy or severe traumatic brain injury. Key features of successful home programs are that the content of the program needs to be well thought out, based on theory and evidence, implemented as intended, and combined with parent preferences (Novak, Cusick, and Lannin, 2009; Novak, 2011). Therefore, a task-specific sit-to-stand exercise program with three home-based sessions each week as reported in this thesis was feasible and effective for children with moderately severe cerebral palsy and their caregivers.

6.3 Strengths and limitations

A strength of this thesis is that it includes a range of study designs, including a systematic review with meta-analysis, mixed-method analysis, randomised controlled trial, and qualitative analysis to investigate sit-to-stand exercise training for children with moderately severe cerebral palsy. The thesis also considered the view of the family by exploring caregiver perceptions about the outcomes and feasibility of the exercise program on themselves and their child. To further explore the feasibility of conducting such a program, particularly a program that included home-based sessions, the contextual factors that could affect implementation and adherence to the intervention were considered and any adverse events associated with training were described.

The reporting of the research within this thesis is of a high standard. It complies with recommended protocol guidelines, and the systematic review and randomised controlled trial were registered prospectively. The systematic review in Chapter 2 was reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines and registered prospectively on the International Prospective Registry of Systematic Reviews (PROSPERO). The qualitative data in Chapter 3 were reported according to the consolidated criteria for reporting qualitative studies (COREQ) checklist. The randomised controlled trial in Chapter 4 was conducted and reported according to the Consolidated Standards of Reporting Trials (CONSORT) guidelines and registered prospectively on the Australian and New Zealand Clinical Trials Registry. A full description of interventions in the trial were reported according to the Template for Intervention Description and Replication (TIDieR) checklist and guide. The qualitative study in Chapter 5 was conducted and reported according to the Standards for Reporting Qualitative Research (SRQR).

The trial conducted as the main part of this thesis was a single-blind randomised controlled trial, with an assessor blinded to group allocation. Other trial features that reduced risk of bias were that random allocation was concealed, the groups were similar at baseline, and there was no loss to follow-up so that data were analysed according to intention to treat. According to the PEDro scale (Moseley et al., 2002) for evaluating methodological quality, the trial reported in Chapter 4 would be assigned a score of 8 out of 10. The PEDro items not fulfilled were that neither therapists nor participants remained blind to group allocation, as is often the case in exercise-based trials.

Additionally, the study participants demonstrated excellent adherence to the sit-to-stand training program. The high levels of training adherence likely resulted from several features incorporated into the program, such as the use of an exercise diary, individualised video records of the sit-to-stand program prepared by the physiotherapist, and the support and monitoring provided by the weekly physiotherapist review. The techniques used to promote adherence were consistent with behavior change techniques of feedback, goal setting and monitoring (Michie et al., 2011).

Qualitative analyses in this thesis were conducted and triangulated with quantitative outcomes. This increases the validity and levels of trustworthiness and rigour of the qualitative analyses. In addition, two researchers independently coded, analysed, and interpreted data and member checking of transcripts was completed.

There are some limitations to the research conducted in this thesis. For the randomised controlled trial, impacts on outcomes were only examined after a relatively short program (6-weeks of training), and it remains unknown if larger, clinically significant improvements in mobility and self-care may have been found after a more extended training program or after a program that incorporated booster sessions. The outcomes in the randomised controlled trial were also only measured immediately after the program,

so it remains unknown how long changes in sit-to-stand performance and functional independence were retained and incorporated into daily life after the program was completed.

For the qualitative trials, interviews were conducted and recorded in Thai, and then recordings were transcribed into English. This meant there was the potential that the nuance of thoughts expressed in Thai by caregivers may have been lost when analysed in translated English. However, the translation and verification processes used increases confidence in the accuracy of the analysis.

6.4 Areas for further research

This series of studies has contributed to the literature and provided useful information particularly for therapists designing and implementing therapeutic exercise-based interventions for children with cerebral palsy. However, the studies also point towards possible directions for future research.

First, the generalisability of the findings of this thesis to other cultures remains unknown. Each of the studies were conducted with children and their caregivers receiving therapy services from a southern rehabilitation centre, and physiotherapy unit in Thailand. Since the prescribed exercise program was intensive in nature, requiring the children to practice a difficult and, arguably, somewhat boring activity repeatedly and in authentic contexts, including their own home, it required a high level of ongoing adherence from the children, and from their caregivers. Caregivers were required, in the home-based part of the program, to oversee the quality and number of repetitions completed. It is possible this type of program might be less successfully completed in cultures where children are not generally as obedient to caregivers and therapist's directions and where caregivers themselves are likely to be less adherent with therapy prescription, especially over extended periods of weeks. Therefore, future research using the same techniques for

optimising compliance, but in other cultural settings might be useful to better understand if sit-to-stand training exercise programs and other task-specific training programs are as successfully implemented in other cultures.

The optimal prescription dose parameters of therapy also remain unknown. A small case series that informed the design of the trial in this thesis reported that more than 750 sit-to-stand repetitions throughout the intervention period may be required to achieve independence in sit-to-stand and carry over to improvements in walking speed in adults with chronic stroke (Boyne et al., 2011). Participants in the trial reported in Chapter 4 exceeded this number of repetitions completing an average of more than 2,000 repetitions across the 6-week intervention. However, optimal training parameters of training frequency and duration are not known. While the results from the randomised controlled trial showed small positive changes in self-care and mobility, further research examining different lengths of training and different numbers of training sessions per week could be conducted. In addition, further research could be conducted to determine the optimal mix of home-based (caregiver supervised) versus rehabilitation centre-based (physiotherapist supervised) therapy.

Further research should be done to determine how long positive changes are maintained, and if the training needs to be repeated at certain intervals to retain positive outcomes. As part of any such study it would be important to determine not only if positive changes are maintained but if they increase once habitually incorporated into daily activities, thereby providing evidence of skill transference (Magill and Anderson, 2014).

The experiences and thoughts of caregivers were prioritised in this series of studies. This was because they were considered central to the implementation of any successful program. It was thought important to know their thoughts as they were required to supervise a large number of home-based sessions and were also required to take their

child to rehabilitation centre-based sessions. Also, there was a potential risk that the program might put unreasonable strain on caregivers, and this might have ended up being a key factor that could have affected program feasibility. To complement the experiences of caregivers, the thoughts and perceptions of the children themselves and the therapists supervising the programs should also be considered in a future study.

Finally, it remains unknown whether the task-specific high-dose training principles applied to sit-to-stand in the current series of studies could be applied directly to upright mobility and self-care tasks. For example, as expressed by a couple of caregivers during their interviews, a future study may be able to progress the principles to more directly address and improve upright mobility in children with cerebral palsy.

6.5 Conclusion

A targeted task-specific sit-to-stand exercise program based on the principles of motor learning is feasible and can help improve mobility and some self-care tasks in children with cerebral palsy and moderately severe mobility limitation.

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Appendix 1: Ethics Approval Statements

Chapter 3

Study 2: Limitations in sit-to-stand activity are perceived to affect mobility and self-care in children with cerebral palsy with moderate to high disability: a mixed-methods analysis

La Trobe University	HEC18299
Prince of Songkla University	Approved

Chapter 4 and Chapter 5

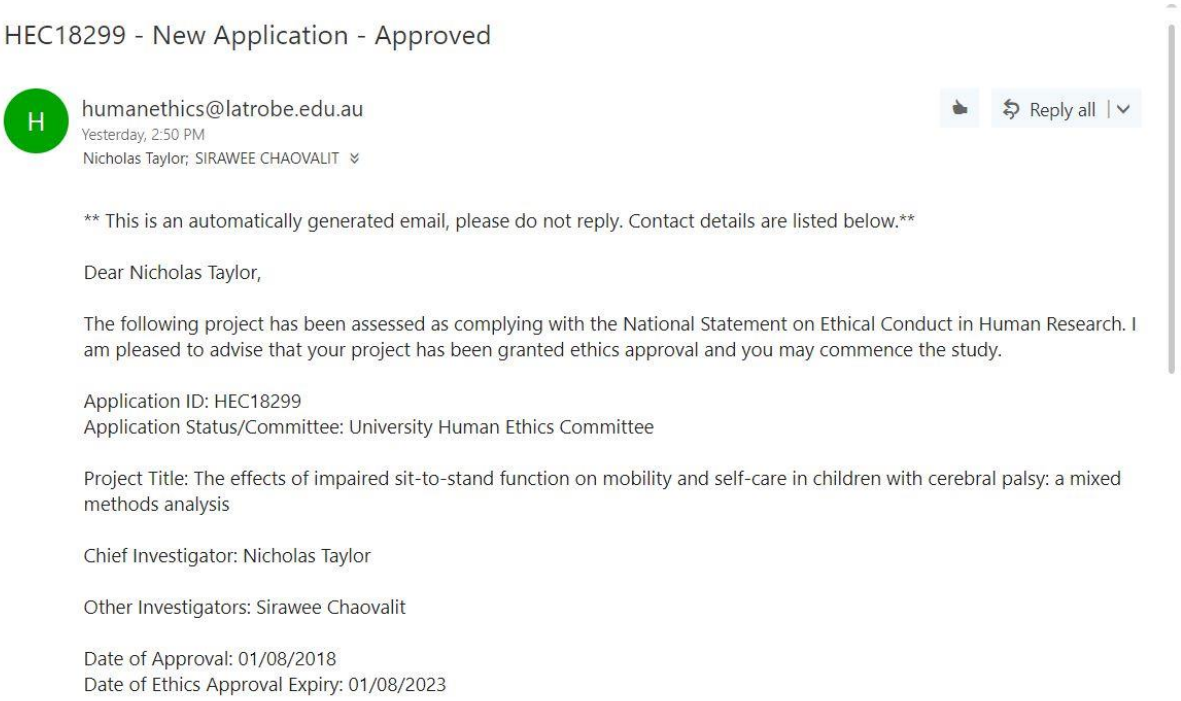
Study 3: A sit-to-stand exercise programme for children with moderately severe cerebral palsy resulted in small improvements in self-care and mobility: a randomized controlled trial

La Trobe University	HEC19389
Prince of Songkla University	Approved

Study 4: Caregivers' perceptions of a sit-to-stand exercise program for children with moderately severe cerebral palsy

La Trobe University	HEC19389
Prince of Songkla University	Approved

Chapter 3



HEC18299 - New Application - Approved

H humanethics@latrobe.edu.au
Yesterday, 2:50 PM
Nicholas Taylor; SIRAWEE CHAOVALIT

Reply all

** This is an automatically generated email, please do not reply. Contact details are listed below.**

Dear Nicholas Taylor,

The following project has been assessed as complying with the National Statement on Ethical Conduct in Human Research. I am pleased to advise that your project has been granted ethics approval and you may commence the study.

Application ID: HEC18299
Application Status/Committee: University Human Ethics Committee

Project Title: The effects of impaired sit-to-stand function on mobility and self-care in children with cerebral palsy: a mixed methods analysis

Chief Investigator: Nicholas Taylor

Other Investigators: Sirawee Chaovalit

Date of Approval: 01/08/2018
Date of Ethics Approval Expiry: 01/08/2023

Department of Physical Therapy, Faculty of Medicine,

Prince of Songkhla University, Thailand

Tel. (6674)45-1627

Fax. (6674)45-1627

June 12, 2018

To whom it may concern,

Approval from External Institution for the Use of Location

This is to certify that Ms. Sirawee Chaovalit, a Ph.D. student in Physical Therapy at the LaTrobe University, Australia, was given a permission to collect the data for her research in the topic of 'The Effects of Impaired Sit-to-Stand Function on Mobility and Self - Care in Children with Cerebral Palsy : a Mixed Methods Analysis' at the Department of Physical Therapy, Faculty of Medicine, Prince of Songkhla University from August 2018 to September 2018.

Sincerely yours,

(Ms. Pornnit Wattanapisitkul)

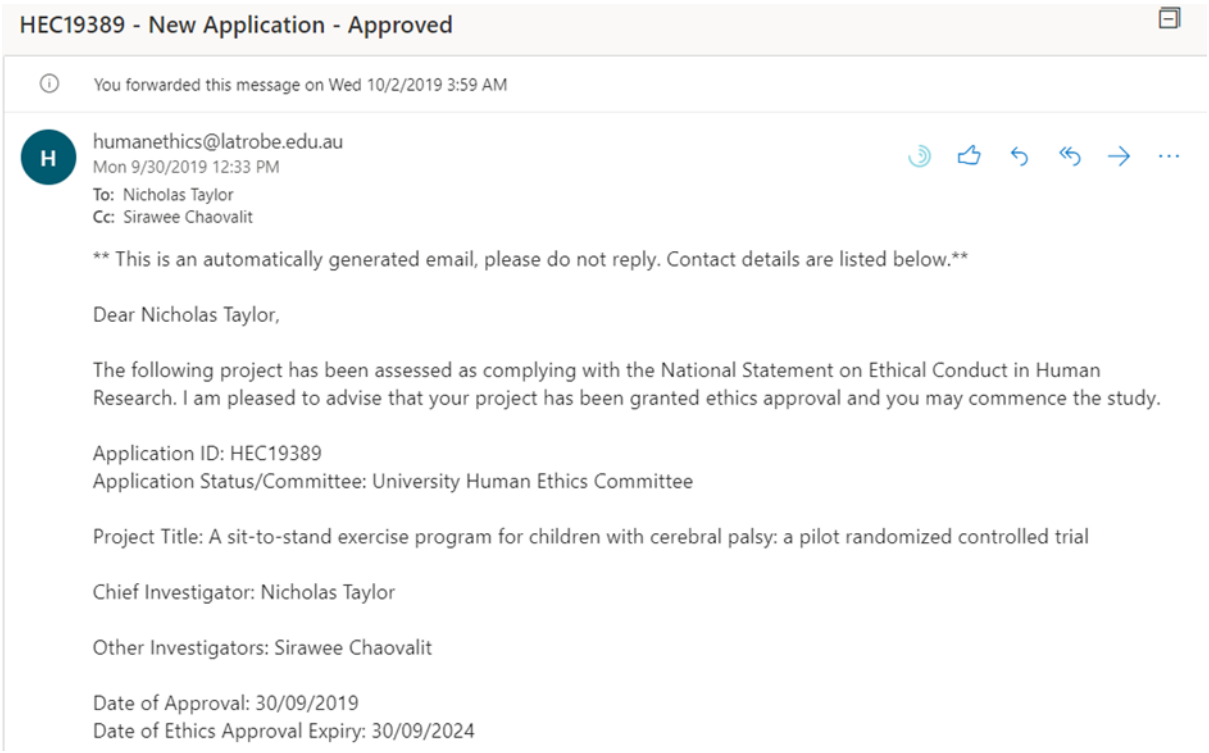
Head of Department of Physical Therapy

Faculty of Medicine

Prince of Songkhla University

Thailand

Chapter 4 and Chapter 5



HEC19389 - New Application - Approved

You forwarded this message on Wed 10/2/2019 3:59 AM

H

humanethics@latrobe.edu.au
Mon 9/30/2019 12:33 PM
To: Nicholas Taylor
Cc: Sirawee Chaovalit

** This is an automatically generated email, please do not reply. Contact details are listed below.**

Dear Nicholas Taylor,

The following project has been assessed as complying with the National Statement on Ethical Conduct in Human Research. I am pleased to advise that your project has been granted ethics approval and you may commence the study.

Application ID: HEC19389
Application Status/Committee: University Human Ethics Committee

Project Title: A sit-to-stand exercise program for children with cerebral palsy: a pilot randomized controlled trial

Chief Investigator: Nicholas Taylor

Other Investigators: Sirawee Chaovalit

Date of Approval: 30/09/2019
Date of Ethics Approval Expiry: 30/09/2024

Department of Physical Therapy, Faculty of Medicine,

Prince of Songkhla University, Thailand

Tel. (6674)45-1627

Fax. (6674)45-1628

August 8, 2019

To whom it may concern,

Approval from External Institution for Use of location

This is to certify Ms. Sirawee Chaovalit, a Ph.D. student in Physical Therapy at the LaTrobe University, Australia, was given a permission to collect the data for her research in the topic of "A sit-to-stand exercise program for children with cerebral palsy: a pilot randomized controlled trial" at the Department of Physical Therapy, Faculty of Medicine, Prince of Songkhla University from September 2019 to December 2019.

Sincerely yours,

(Mrs.Theardkhwan Plukwongchuen)

Head of Department of Physical Therapy

Faculty of Medicine

Prince of Songkhla University

Thailand

บันทึกข้อความ

ส่วนงาน ภาควิชากายภาพบำบัด คณะแพทยศาสตร์ โทร. 161131

ที่ มอ 376/63-00141 **วันที่** 17 ธันวาคม 2562

เรื่อง ขอความอนุเคราะห์เก็บข้อมูลและใช้สถานที่เพื่อเตรียมการทำงานวิจัย

เรียน รักษาการในตำแหน่งหัวหน้าภาควิชากายภาพบำบัด

ด้วยข้าพเจ้า นางสาวศิรวีร์ เชาวลิต อาจารย์ประจำภาควิชากายภาพบำบัด คณะแพทยศาสตร์ กำลังศึกษาปริญญาเอกหลักสูตร Ph.D in Physiotherapy(Physiotherapy) ณ La Trobe University, Melbourne, Victoria, ประเทศออสเตรเลีย และกำลังเตรียมการทำงานวิจัย เรื่อง "โปรแกรมการออกกำลังกายลุกขึ้นยืนสำหรับเด็กสมองพิการ : การทดลองนำร่องแบบสุ่มและมีกลุ่มควบคุม" (A sit-to-stand exercise program for children with cerebral palsy : a pilot randomized controlled trial)

ในการนี้ ข้าพเจ้าใคร่ขอความอนุเคราะห์สำรวจข้อมูลเพื่อเตรียมการทำงานวิจัยในเรื่องดังกล่าว โดยการประเมินและฝึกฝนโปรแกรมการการออกกำลังกายนี้ ณ หน่วยกายภาพบำบัด และหน่วยกิจกรรมบำบัด ระหว่างวันที่ 23 ธันวาคม 2562 - 31 มกราคม 2563 เวลา 08.30 - 16.30 น.

จึงเรียนมาเพื่อโปรดพิจารณาและขอความอนุเคราะห์ใช้สถานที่ จะเป็นพระคุณยิ่ง

(นางสาวศิรวีร์ เชาวลิต)
อาจารย์ภาควิชากายภาพบำบัด

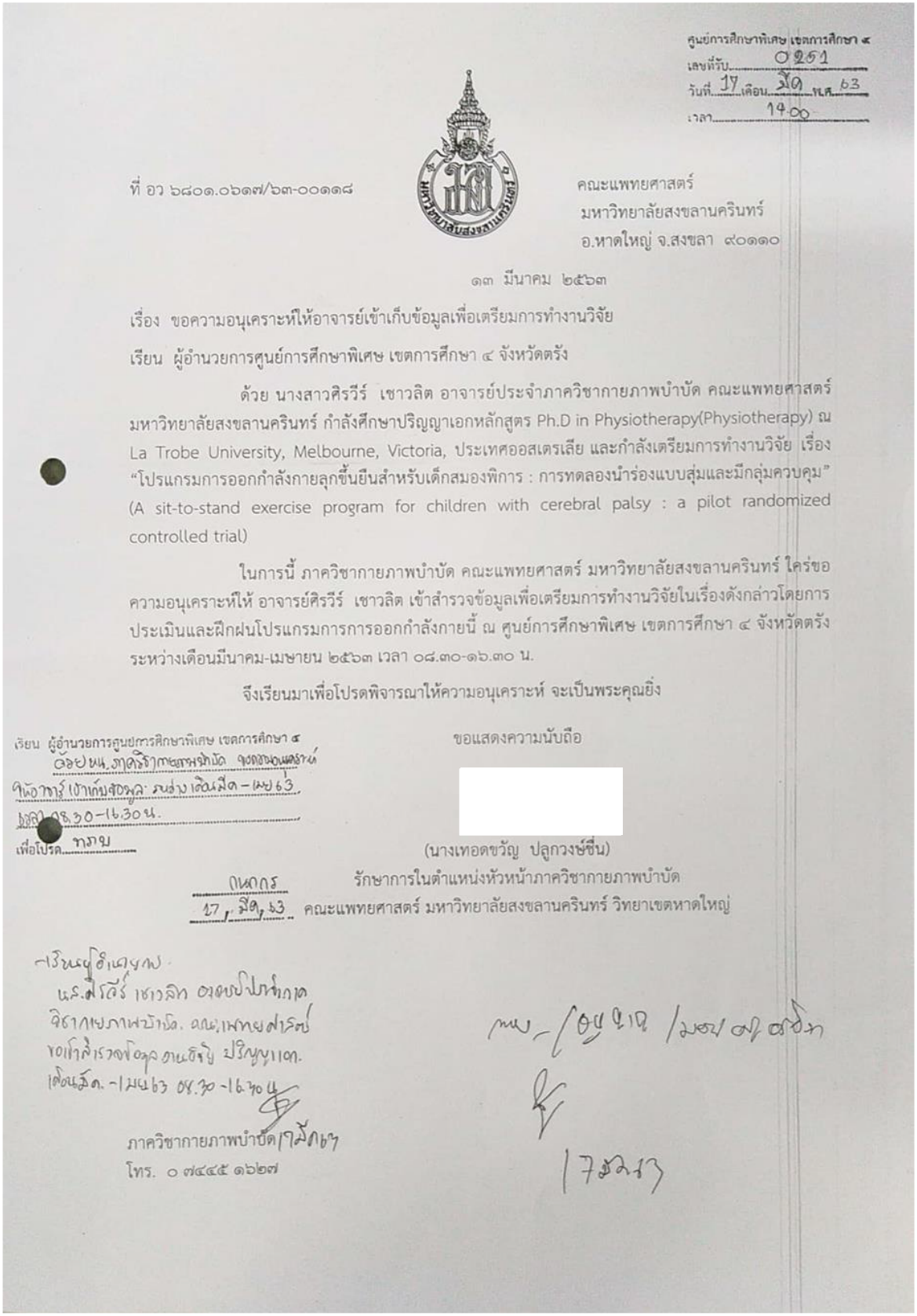
เรียน รักษาการในตำแหน่งหัวหน้าภาควิชาออร์โธปิดิกส์และเวชศาสตร์ฟื้นฟู

เพื่อพิจารณาให้ความอนุเคราะห์ อาจารย์ศิรวีร์ เชาวลิต สำรวจข้อมูลเพื่อเตรียมการทำงานวิจัยขณะศึกษาต่อปริญญาเอก ณ หน่วยกายภาพบำบัดและหน่วยกิจกรรมบำบัด ระหว่างวันที่ 23 ธันวาคม 2562 - 31 มกราคม 2563 เวลา 08.30 - 16.30 น.

(นางเทอดชวัญ ปลูกวงษ์ชัน)
รักษาการในตำแหน่งหัวหน้าภาควิชากายภาพบำบัด

สำเนาเรียน : หัวหน้าหน่วยกายภาพบำบัด
หัวหน้าหน่วยกิจกรรมบำบัด

Approval letter from special education center



ศูนย์การศึกษาพิเศษ เขตการศึกษา ๔
เลขที่รับ 0251
วันที่ 17 เดือน มี.ค. พ.ศ. 63
เวลา 14.00

ที่ อว ๖๘๐๑.๐๖๑๗/๖๓-๐๐๑๘

คณะแพทยศาสตร์
มหาวิทยาลัยสงขลานครินทร์
อ.หาดใหญ่ จ.สงขลา ๙๐๑๑๐

๑๓ มีนาคม ๒๕๖๓

เรื่อง ขอความอนุเคราะห์ให้อาจารย์เข้าเก็บข้อมูลเพื่อเตรียมการทำงานวิจัย

เรียน ผู้อำนวยการศูนย์การศึกษาพิเศษ เขตการศึกษา ๔ จังหวัดตรัง

ด้วย นางสาวศิรวีร์ เชาวลิต อาจารย์ประจำภาควิชากายภาพบำบัด คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์ กำลังศึกษาปริญญาเอกหลักสูตร Ph.D in Physiotherapy(Physiotherapy) ณ La Trobe University, Melbourne, Victoria, ประเทศออสเตรเลีย และกำลังเตรียมการทำงานวิจัย เรื่อง "โปรแกรมการออกกำลังกายลุกขึ้นยืนสำหรับเด็กสมองพิการ : การทดลองนำร่องแบบสุ่มและมีกลุ่มควบคุม" (A sit-to-stand exercise program for children with cerebral palsy : a pilot randomized controlled trial)

ในการนี้ ภาควิชากายภาพบำบัด คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์ ใคร่ขอความอนุเคราะห์ให้ อาจารย์ศิรวีร์ เชาวลิต เข้าสำรวจข้อมูลเพื่อเตรียมการทำงานวิจัยในเรื่องดังกล่าวโดยการประเมินและฝึกฝนโปรแกรมการการออกกำลังกายนี้ ณ ศูนย์การศึกษาพิเศษ เขตการศึกษา ๔ จังหวัดตรัง ระหว่างเดือนมีนาคม-เมษายน ๒๕๖๓ เวลา ๐๘.๓๐-๑๖.๓๐ น.

จึงเรียนมาเพื่อโปรดพิจารณาให้ความอนุเคราะห์ จะเป็นพระคุณยิ่ง

ขอแสดงความนับถือ

(นางเทอดขวัญ ปลูกวงษ์ชื่น)
รักษาการในตำแหน่งหัวหน้าภาควิชากายภาพบำบัด
คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์ วิทยาเขตหาดใหญ่

เรียน ผู้อำนวยการศูนย์การศึกษาพิเศษ เขตการศึกษา ๔
ด้วย น.ส. ศิรวีร์ เชาวลิต อาจารย์ภาควิชากายภาพบำบัด
ขอเข้าสำรวจข้อมูลเพื่อเตรียมการทำงานวิจัย
ในเรื่อง โปรแกรมการออกกำลังกายลุกขึ้นยืนสำหรับเด็กสมองพิการ : การทดลองนำร่องแบบสุ่มและมีกลุ่มควบคุม
ระหว่างเดือน มี.ค.-เม.ย. 63 เวลา 08.30-16.30 น.
เพื่อโปรด ทราบ
17 มี.ค. 63

ภาควิชากายภาพบำบัด โทร. ๐ ๗๔๔๕ ๑๖๒๗

17 มี.ค. 63

Appendix 2: Publication Statements

Chapter 2

Statement from the co-authors confirming contribution of the PhD candidate:

As co-authors of the paper, "Sit-to-stand exercise programs improve sit-to-stand performance in people with physical impairments due to health conditions: a systematic review and meta-analysis," we confirm that Sirawee Chaovalit has made the following contributions:

- Conception and design of the research
- Collection of data
- Analysis and interpretation of the findings
- Writing the paper
- Critical appraisal of the content, and
- Response to reviewers

Professor Nicholas Taylor Date: 11th June 2021

Professor Karen Dodd Date: 11th June 2021

Chapter 3

Statement from the co-authors confirming contribution of the PhD candidate:

As co-authors of the paper, "Impaired sit-to-stand is perceived by caregivers to affect mobility and self-care in children with cerebral palsy who had moderate to severe mobility limitations: a mixed methods analysis," we confirm that Sirawee Chaovalit has made the following contributions:

- Conception and design of the research
- Collection of data
- Analysis and interpretation of the findings
- Writing the paper
- Critical appraisal of the content, and
- Response to reviewers

Professor Nicholas Taylor Date: 11th June 2021

Professor Karen Dodd Date: 11th June 2021

Chapter 4

Statement from the co-authors confirming contribution of the PhD candidate:

As co-authors of the paper, "Sit-to-stand training for self-care and mobility in children with cerebral palsy: a randomized controlled trial," we confirm that Sirawee Chaovalit has made the following contributions:

- Conception and design of the research
- Collection of data
- Analysis and interpretation of the findings
- Writing the paper
- Critical appraisal of the content, and
- Response to reviewers

Professor Nicholas Taylor 11th June 2021

Professor Karen Dodd 11th June 2021

Chapter 5

Statement from the co-authors confirming contribution of the PhD candidate:

As co-authors of the paper, "Caregivers' perceptions of a sit-to-stand exercise program for children with moderately severe cerebral palsy," we confirm that Sirawee Chaovalit has made the following contributions:

- Conception and design of the research
- Collection of data
- Analysis and interpretation of the findings
- Writing the paper
- Critical appraisal of the content, and
- Response to reviewers

Professor Nicholas Taylor Date: 11th June 2021

Professor Karen Dodd Date: 11th June 2021

Appendix 3: Permissions

Inclusion of Chapter 2 in PDF format with thanks to *Taylor and Francis* and

> *Disability and Rehabilitation.* Permissions statement available at: https://authorservices.taylorandfrancis.com/publishing-your-research/moving-through-production/copyright-for-journal-authors/, retrieved 11st June 2021"

Inclusion of Chapter 4 in pre-submission format with thanks to

> *Developmental Medicine & Child Neurology.* Permissions statement available at: https://onlinelibrary.wiley.com/page/journal/14698749/homepage/ForAuthors.html, retrieved 11st June 2021"