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Relationship between habitual physical activity, gross motor function, community mobility and quality of life in 4-5 year old children with cerebral palsy

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Abstract

Background: Habitual physical activity (HPA) has many potential health benefits in children. Early childhood (0-6 years) is a critical period for carry-over of patterns of HPA into adulthood. Children with cerebral palsy (CP) have lower HPA compared to their peers with typical development. Studies of HPA in young children with CP under the age of 5 years are limited.

Aim: The broad aims of this research were to examine the relationships between HPA, time spent sedentary (TSS), gross motor function, community mobility and parent-reported quality of life in children with CP aged 4-5 years old across the full spectrum of functional severity according to the Gross Motor Function Classification System (GMFCS).

Design: Data were derived from two population-based cohort studies, the Queensland CP Child Study of Motor Function and Brain Development and the Queensland CP Chid Study of Growth, Nutrition and Physical Activity. Children with CP were invited to the former study and subsequently enter to the latter study. Participants aged 4-5 years were included in this study. This thesis comprises six reports including four published and two currently under peer-review: (1) a systematic review of the relationship between HPA and motor capacity in children with CP; (2) a validation study of accelerometer cut-points; (3) a cross-sectional study of HPA levels; (4) a relationship between HPA, TSS, motor capacity and capability; (5) a relationship between HPA and quality of life (QOL); and (6) a longitudinal study of HPA levels and TSS in preschool children with CP aged 18 months to 5 years across all GMFCS levels.

Participants: Queensland children diagnosed with CP who were born between 2006-2009 were eligible for inclusion. Children with progressive motor disorders were excluded and the analysis was restricted to participants 4-5 years corrected age. The longitudinal study included participants from both cohort studies aged 18 months to 5 years who had completed 3-day physical activity records.

Procedure: Participants were categorised for gross motor function using the GMFCS. Motor capacity was assessed using the 66-item gross motor function measure (GMFM-66). The ActiGraph® accelerometer was attached at participant's lower back to obtain measurements for HPA for all waking activities that were not water-based over a 3 days period. A corresponding activity diary, the Pediatric Evaluation of Disability Inventory (PEDI) functional skills of mobility domain (for assessing community mobility) and the parent proxy of the Cerebral Palsy Quality of Life questionnaire for Children (CP QOL-Child) were completed by parents of participants.

Results: The systematic review confirmed that motor capacity is directly related to HPA, and various subjective and objective measures of HPA were identified. There were limited studies using objective measures of HPA in young children with CP. The validation of accelerometer cut-points for sedentary time demonstrated that the previously established cut-point of 820 counts per minute for children with typical development was also valid in children with CP across all GMFCS levels. This cut-point was used to determine TSS for the cross-sectional studies.

The cross-sectional study of HPA showed that children with CP aged 4-5 years spent more than half of their day in sedentary time (58% in independently-ambulant group (GMFCS I-II), 74% in marginally-ambulant group (GMFCS III), and 93% in non-ambulant group (GMFCS IV-V)). Independently-ambulant children with CP (GMFCS I-II) had significantly higher HPA, lower TSS (p<0.001) and were more likely to meet the Australian Physical Activity Guidelines compared to those who were marginally-ambulant and non-ambulant (GMFCS III-V).

Examination of the relationships between the GMFM-66 and PEDI functional skills of mobility domain on HPA and TSS identified significantly positive associations with HPA (p<0.001) and significantly negative associations with TSS (p<0.001). After stratification for ambulatory status the significant associations were found in ambulant children with CP but not in non-ambulant children with CP.

Analysis of the relationship between HPA and QOL found that HPA was not associated with the parent-reported CP QOL-Child when controlling for motor capacity. The GMFM-66 explained 39% of variance in feelings about functioning, 27% of variance in emotional well-being and 18% of variance in access to services domain.

The longitudinal study of HPA and TSS in children aged 18 to 60 months showed that HPA levels were stable in GMFCS I-II and significantly increased in GMFCS III-V (p<0.001). Sedentary time significantly increased in all participants at aged 48 and 60 months (p<0.05). For every year increase in age, HPA decreased while TSS significantly increased 2.4% and 6.9% for GMFCS I-II and III-V, respectively (p<0.05).

Conclusions: This research shows that strategies to improve HPA and reduce TSS are needed in young children with CP from aged 36 months, especially for those who are marginally-ambulant and non-ambulant. Gross motor function is an important factor that is associated with HPA and TSS in this group of children, and is also associated with QOL domains of feelings about functioning, emotional well-being and self-esteem, and access to services.

Declaration by author

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Publications during candidature

Peer Reviewed Papers

1. Keawutan P, Bell K, Davies PS, Boyd RN. (2014). Systematic review of the relationship between habitual physical activity and motor capacity in children with cerebral palsy. *Research in Developmental Disabilities.* 35(6): 1301-9.
2. Keawutan P, Bell KL, Oftedal S, Davies PS, Boyd RN. (2016). Validation of accelerometer cut-points in children with cerebral palsy aged 4 to 5 years. *Pediatric Physical Therapy*. 28(4): 427-34.
3. Keawutan P, Bell KL, Oftedal S, Davies PS, Ware RS, Stevenson RD, Boyd RN. (2016). Habitual physical activity in children with cerebral palsy aged 4 to 5 years across all functional abilities. *Pediatric Physical Therapy*. 29(1): 8-14.
4. Keawutan P, Bell KL, Oftedal S, Ware RS, Stevenson RD, Davies PSW, Boyd RN. (2017). Longitudinal physical activity and sedentary behaviour in preschool aged children with CP across all functional levels. *Developmental Medicine & Child Neurology*. in press. date of acceptance 23rd February 2017.

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5. Keawutan P, Bell KL, Davies PS, Boyd RN. (2016). Relationship between habitual physical activity and quality of life in children with cerebral palsy at age 5 years. *Developmental Medicine and Child Neurology.* 58(S3): 7-8. Oral presentation: Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) Conference, April 2016, Adelaide, South Australia, Australia.
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Keywords

Habitual physical activity, sedentary behaviour, motor capacity, motor capability, performance, quality of life, children, cerebral palsy

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List of Abbreviations used in the thesis

BMI	Body Mass Index
CP	Cerebral Palsy
CP QOL-Child	Cerebral Palsy Quality of Life Questionnaire for children
CI	Confidence Interval
GMFCS	Gross Motor Function Classification System
GMFM-66	Gross Motor Function Measure 66 items
HPA	Habitual Physical Activity
MD	Mean Difference
MVPA	Moderate to vigorous physical activity
PEDI	Pediatric Evaluation of Disability Inventory
QOL	Quality of Life
SD	Standard deviation
TSS	Time Spent Sedentary
WHO	World Health Organization

Chapter 1: Introduction, Thesis Outline and Aims

1.1 Introduction

Physical activity has many health benefits in children, including improved cardiorespiratory, muscular fitness and bone health.[1, 2] Sedentary behaviour can lead to increased risk of non-communicable diseases such as cardiovascular disease and diabetes.[1] Functional limitations in children with physical disabilities may impact on their physical activity. Cerebral palsy (CP) is the most common physical disability in children.[3] A previous systematic review reported that children with CP had lower physical activity levels compared to their typically developing peers.[4] To date, studies of physical activity in children with CP have focused on ambulant children and adolescents with CP who require only minor or no mobility assistance, classified as levels I-III according to the Gross Motor Function Classification System (GMFCS). However, there are limited studies of younger children with CP under the age of 5 years and in non-ambulant children with CP who require mobility devices, classified as GMFCS IV-V.

1.1.1 Habitual physical activity

Habitual physical activity (HPA) has been defined as any bodily movement resulting in energy expenditure in daily life.[5] It contains four main components, mode (type), intensity, duration and frequency.[1] Physical activity levels have been categorised into four categories, sedentary, light, moderate and vigorous activities.[6] Each level is differentiated by the energy expenditure unit called metabolic equivalent (MET; 1 MET=3.5 mL O_2/kg^1/mim^1).[6] Table 1 provides the definition of activity levels.

Table 1 Definition of physical activity level

Activity level	Definition	Examples
Sedentary	≤ 1.5 METs	Sitting, reclining
Light	1.6-2.9 METs	Walking at 2mph, slow cycling, stretching
Moderate	3.0-5.9 METs	Walking at 3-4.5 mph, cycling at 5-9 mph
Vigorous	≥ 6.0 METs	Walking at ≥5.0 mph, jogging, cycling at ≥10 mph or uphill

Reproduced form Verschuren et al. (2014)[6]

Sedentary behaviour is any activity that uses ≤ 1.5 METs e.g. lying, sitting, and reclining.[7] Healthy people who have appropriate moderate to vigorous physical activity (MVPA) in their age range but are sedentary for the rest of the day, may experience

adverse effects of sedentary behaviour.[6, 8, 9] Previous studies reported an association between longer period of sedentary behaviour and high waist circumference, HDL-cholesterol, triglycerides, insulin, and C-reactive protein, which are risk factors for metabolic syndrome and cardiovascular disease.[8, 9] In addition, regular interruption of sedentary behaviour can reduce metabolic risk factors including adiposity and triglycerides.[8, 9] The effects of interruption of sedentary behaviour are independent of total sedentary time and MVPA time.[8, 9] As the effects on health associated with lack of sufficient MVPA and excess sedentary behaviour are different, increasing MVPA and reducing sedentary behaviour should both be encouraged.[6]

The World Health Organization (WHO) has developed the Global Recommendations on Physical Activity for Health from age 5 years throughout the life span.[1] Studies in physical activity of preschool children (aged 3-5 years) have increased due to the increased prevalence of obesity.[10-12] Furthermore, physical activity patterns and sedentary behaviour in childhood can persist into adulthood.[13-15] Many countries have developed physical activity and sedentary guidelines that include young children. The Australian Physical Activity Guidelines concur with those for Canada and the UK in recommending that children under age 5 years should be physically active for at least three hours a day and should not be sedentary for more than one hour at a time, with the exception of sleeping.[16-18]

1.1.2 Cerebral palsy

Cerebral palsy (CP) is the most common physical disability in children.[19] The prevalence of CP is 2.11 per 1000 live births.[19] Cerebral palsy is a group of permanent disorders, occurring in the developing fetal or infant brain that limit movement and activity.[3] Gross motor function of children with CP can be classified into five levels according to the Gross Motor Function Classification System (GMFCS).[20] The definition of GMFCS levels in children with CP aged 4 to 6 years are outlined in Table 2.

Table 2 The Gross Motor Function Classification System for children with CP aged 4-6 years.

Level	Definition
GMFCS I	Children walk indoors and outdoors and climb stairs. Emerging ability to run and jump.
GMFCS II	Children walk without need for any assistive mobility device indoors and for short distances on level surfaces outdoors. Children climb stairs holding onto a railing but are unable to run or jump.
GMFCS III	Children walk with an assistive mobility device on level surfaces and climb stairs with assistance from an adult. Children frequently are transported when travelling for long distances or outdoors on uneven terrain.
GMFCS IV	Children may at best walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces. Children are transported in the community. Children may achieve self-mobility using a power wheelchair.
GMFCS V	Self-mobility is severely limited even with the use of assistive technology.

Reproduced from Palisano et al. (1997)[20]

According to the International Classification of Functioning, Disability and Health Children and Youth (ICF-CY) framework, health conditions of children with CP results from the interaction of two components: functioning and disability (Body functions and structures, Activity, and Participation) and contextual factors (Environmental and Personal). (Figure 1)[21]

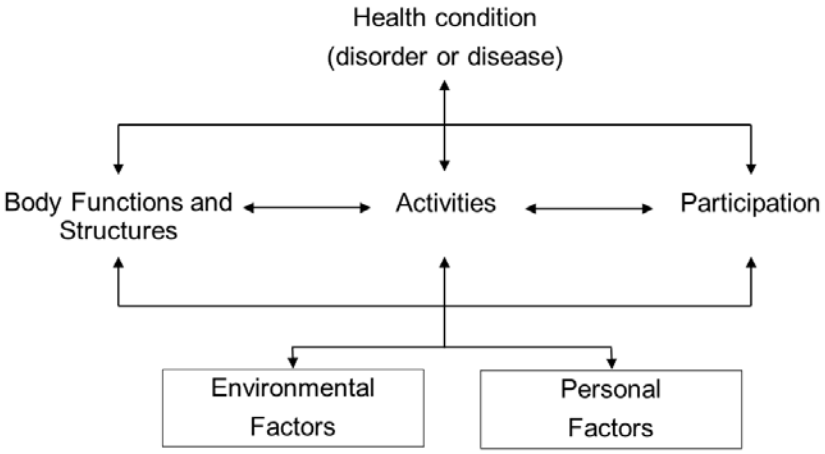

Figure 1 International Classification of Functioning, Disability and Health (ICF) Model; Reproduced from the World Health Organization[21]

Activity and participation are qualified by capacity and performance. Capacity is what a child can do in a standardised environment and performance is what a child does do in a naturalistic environment.[21] Motor capacity and performance of children with CP might be different and both likely influence their HPA.

1.1.3 Habitual physical activity measurements

HPA measurement tools that have been utilised in children with CP include subjective and objective measures. Subjective measurements may be easier to administer, although they are limited due to bias and recall errors.[22] Previous systematic reviews of physical activity measurements reported that the ActiGraph® accelerometers provide the most robust information on intensity, duration and frequency of a variety of physical activities including walking.[22-24] ActiGraph® accelerometers are widely used in children with typical development, and can be used in a wide range of settings, including free-living conditions.[25] The ActiGraph® has two models, the uniaxial model which measures acceleration of body movements in the vertical plane only, and the triaxial model, which measures acceleration in three planes, vertical (X), antero-posterior (Y) and mediolateral (Z) axes.[25] Activity counts per unit of time from triaxial accelerometers are combined into a vector magnitude, $VM = \sqrt{X^2+Y^2+Z^2}$. The ActiGraph® can measure physical activity intensity (sedentary, light, moderate to vigorous) by using an intensity cut-point. Physical activity intensity consists of resting and activity energy expenditure which are age-dependent parameters.[26] Then, an ActiGraph® intensity cut-point needs to be validated in specific age ranges and conditions.

1.1.4 Habitual physical activity in children with CP

Studies in HPA in children with CP have increased as rehabilitation in children with CP has shifted to health promotion and fitness.[6, 27] Lower HPA has been reported in children with bilateral CP aged 8-10 compared to their peer with typical development,[28] and a recent systematic review of children and adolescents with CP aged 5-18 years showed that HPA could be up to 53% lower compared to their typically developing peers.[4] In addition, the Gross Motor Function Measure (GMFM) dimension E (capacity of walking, running and jumping) was an important predictor of HPA in individuals with bilateral spastic CP aged 16-20 years.[29] Almost all studies using objective HPA measures were conducted in school aged and ambulant children with CP who met the criteria for GMFCS level I-III.[14, 28-34] Studies of HPA in young children with CP aged less than 5 years and non-ambulant children with CP are limited. To date, only one study examined HPA in children with CP aged 1.5-3 years across all GMFCS levels.[35] The current deficiency of HPA studies in young non-ambulant

children with CP may be due to insufficient data on activity intensity cut-points in this group of children.

A recent study of exercise and physical activity for people with CP recommended that individuals with CP should participate in MVPA for 60 minutes a day, more than 5 days a week and should be sedentary less than 2 hours a day or break up sitting for 2 minutes every 30-60 minutes.[36] However, there were no specific physical activity guidelines for young children with disabilities.

1.1.5 Community mobility

Community mobility may impact on HPA in children with CP due to their limitations of movement. This research program used the the Pediatric Evaluation of Disability Inventory (PEDI) functional skills of the mobility domain which refer to motor capability to assess community mobility. Capacity, capability and performance are different constructs.[37] Capacity is defined as what a child can do in a standardized, controlled environment.[21, 37] Capability is what a child can do in his/her daily environment.[37] The definition of performance is what a child actually does do in his/her daily environment.[21, 37] The activity and participation domains of the ICF framework refer to capacity and performance but not capability.[21] Previous studies suggest that contextual factors impact on the relationship between capacity, capability and performance (Table 3).[37] In addition, when one of the three constructs (capacity, capability, and performance) is improved, the other two constructs do not automatically change.[38]

Table 3 Constructs of capacity, capability, and performance in relation to contextual factors

Construct	Capacity	Capability	Performance
Description	Can do in a standardized, controlled environment	Cando in daily environment	Does do in daily environment
Physical environment factors	-	+	+
Social environment factors	-	-	+
Personal factors (motivation)	±	±	+

Reproduced from Holsbeeke et al (2009)[37]

Many factors, both personal and environmental, can be facilitators or barriers of HPA in children and adolescents with CP.[39] Facilitators of HPA include perception of relaxation as a benefit of exercise, desire to be active, parental and school awareness and encouragement of the benefits of physical activity, community access to physical activity or sport, and acceptance by peers. Barriers include low levels of energy or motivation of the child, parental non-acceptance of the extent of disability of the child, lack of opportunities, financial restrictions, and bullying.[39] Motor capacity in children with CP can be a major deterrent to participating in any physical activity. Furthermore, motor capability in children with CP might be different from motor capacity, and could be one of the most important factors that limit their HPA. The relationships between HPA, motor capacity and motor capability have not been examined in young children with CP aged 4-5 years. This research program was conducted to investigate these relationships using GMFM-66 to measure motor capacity, PEDI functional skills of mobility domain to measure capability and HPA to measure performance.

1.1.6 Quality of life

Quality of life (QOL) is one of the most important outcomes in children with CP, which may be improved by higher levels of HPA. There is moderate evidence that HPA has mental health benefit for example reduced depression and anxiety in children and adolescents with typical development.[2, 40] A study in the general population of adults found that higher physical activity levels are associated with better health related quality of life.[41] There are limited studies of associations between HPA and QOL in children and adolescents with CP[42-44] and no study in young children with CP.

Quality of life is multidimensional, and has been defined as “the individual’s perception of their position in life, in the context of value systems in which they live and in relation to their goals, expectations, standards and concerns”.[45] Individuals with severe disability can have an unexpectedly high QOL, referred to as the disability paradox.[46] Quality of life can be measured by two types of QOL questionnaires, generic and condition specific.[47] Generic questionnaires measures all aspects of health across a wide range of populations, and can be used to compare broad patient populations and treatment regimens, while condition specific questionnaires focus on a specific population.[47] The Cerebral Palsy Quality of Life questionnaire for children (CP QOL-Child) is a condition specific QOL tool designed for children with CP, which was developed to assess well-being across various broad domains.[48] The CP QOL-Child has two versions, parent proxy for children aged 4-12 years and self-report for children aged 9-12 years. Both versions had high reliability and

validity (internal consistency, Cronbach's α range from 0.74-0.92 for parent proxy and 0.80-0.80 for child self-report; test-retest reliability, ICC range from 0.76-0.89).[48] The CP QOL-Child parent proxy contains 7 subscales: social well-being and acceptance, feelings about functioning, participation and physical health, emotional well-being and self-esteem, access to services, pain and impact of disability, and family health. The CP QOL-Child self-report contains 5 subscales which are the same sub-scale as parent proxy with the exception of access to services and family health. The youngest age for valid self-report QOL is 9 years.[49] The parent proxy QOL is appropriate for young children with CP because clinical care is provided to a family unit. Therefore, the CP QOL-Child parent proxy version was chosen in this research program.

1.2 Thesis outline

To date there has been limited investigations of HPA and the relationships between HPA, sedentary behaviour, gross motor, community mobility and QOL in preschool children with CP aged 4-5 years using objective measures of physical activity. Knowledge of HPA patterns, sedentary behaviour, and their relationships with measures of motor function and QOL will contribute to the development of strategies to promote physical activity in children with CP. In this research program we investigated the relationship between HPA, time spent sedentary (TSS), gross motor function, community mobility and QOL in children with CP aged 4-5 years across the full spectrum of motor severity according to GMFCS levels in 6 sub-studies:

(1) Systematic review of the relationship between habitual physical activity and motor capacity in children with CP;
(2) Validation of accelerometer cut-points in children with CP aged 4-5 years;
(3) Habitual physical activity in children with CP aged 4-5 years across all functional abilities;
(4) Relationship between habitual physical activity, motor capacity and capability in children with CP aged 4-5 years across all functional abilities;
(5) Quality of life and habitual physical activity in children with CP aged 5 years: a cross-sectional study;
(6) Longitudinal physical activity and sedentary behaviour in preschool aged children with CP across all functional levels.

1.3 Aims and Hypotheses

The broad aim of this research was to describe the relationships between HPA, gross motor function, community mobility and parent-reported QOL in children with CP aged 4-5 years across the full spectrum of functional ability, according to the GMFCS levels I-V. The specific aims of each sub-study have been provided.

1.3.1 Sub-study 1: Systematic review of the relationship between HPA and motor capacity in children with CP.

Aim 1: To review the literature on the relationship between HPA and motor capacity in children with CP aged 3-12 years across all functional classifications (GMFCS I-V).

Hypothesis 1: Habitual physical activity will be directly related with motor capacity in children with CP.

1.3.2 Sub-study 2: Validation of accelerometer cut-points in children with CP aged 4-5 years.

Aim 2a: To derive the triaxial ActiGraph® (GT3X, GT3X+) accelerometer cut-point for sedentary time against direct observation in children with CP aged 4-5 years and validate the cut-points in an independent sample of children with CP.

Aim 2b: To validate previously established cut-points for sedentary time derived from children with typical development in a sample of children with CP, and compare their validity to the developed cut-points.

Hypothesis 2: Both the developed and the previously established cut-points for sedentary time will be valid for measuring sedentary time in children with CP aged 4-5 years across the spectrum of gross motor ability.

1.3.3 Sub-study 3: HPA in children with CP aged 4-5 years across all functional abilities.

Aim 3a: To describe HPA and sedentary behaviour in children with CP aged 4-5 years across all functional abilities.

Aim 3b: To compare HPA in children with CP aged 4-5 years to the Australian Physical Activity Guidelines.

Hypothesis 3a: Children with CP with higher functional capacity (GMFCS I-II) will have higher physical activity and lower TSS than children with lower functional capacity (GMFCS III-V).

Hypothesis 3b: Children with CP with higher functional capacity (GMFCS I-II) will be more likely to meet the Australian Physical Activity Guidelines than children with lower functional capacity (GMFCS III-V).

1.3.4 Sub-study 4: Relationship between HPA, motor capacity and capability in children with CP aged 4-5 years.

Aim 4: To investigate the relationship between HPA, time spent sedentary (TSS), motor capacity and capability in children with CP aged 4-5 year across all functional abilities.

Hypothesis 4: Motor capacity and capability will be associated with HPA and TSS.

1.3.5 Sub-study 5: Quality of life and HPA in children with CP aged 5 years: a cross-sectional study.

Aim 5a: To compare parent-reported QOL between ambulatory status in children with CP aged 5 years

Aim 5b: To investigate the relationship between HPA and parent-reported QOL in children with CP aged 5 years.

Hypothesis 5a: Parent-reported QOL between ambulant and non-ambulant children with CP will not be different in all domains.

Hypothesis 5b: Habitual physical activity will be positively associated with broad domains of parent-reported QOL in children with CP aged 5 years.

1.3.6 Sub-study 6: Longitudinal physical activity and sedentary behaviour in preschool aged children with CP across all functional level.

Aim 6: To investigate HPA levels and sedentary time in preschool aged children with CP from age 18 months to 5 years.

Hypothesis 6: Habitual physical activity levels and sedentary time of children with CP will be stable from 18 months to 5 years.

1.4 Format of Thesis

This thesis includes 6 papers (published or submitted to peer-reviewed journals). Chapter 2 is a published systematic review of the relationship between HPA and motor capacity in children with CP. Chapter 3 provides methods, outcome measures and procedures. Chapter 4 is the validation of accelerometer cut-points for sedentary time in children with CP aged 4-5 years. The cut-points that were validated in the validation study were used for the cross-sectional and longitudinal studies. Chapter 5 presents HPA levels and percentage of TSS in children with CP aged 4-5 years across all functional abilities. Comparison between active/sedentary time in children with CP and the Australian Physical Activity Guidelines were included in this chapter. Chapter 6 presents the relationships between HPA, motor capacity and capability in children with CP aged 4-5 years. Chapter 7 presents the relationships between HPA and parent-reported quality of life in children with CP at age 5 years, controlling for gross motor function. Chapter 8 presents the longitudinal study of HPA levels and sedentary time in children with CP from age 18 months to 5 years according to functional levels. Chapter 9 presents the grand discussion, implications and overall conclusions of this thesis. Chapter 10 presents references for the full thesis document. Additionally, the published and submitted papers (in chapter 2 and 4-9) contain references for individual papers which are formatted differently.

Chapter 2: Systematic review of the relationship between habitual physical activity and motor capacity in children with cerebral palsy

2.1 Introduction to Chapter 2

This chapter consists of the published manuscript entitled “Systematic review of the relationship between habitual physical activity and motor capacity in children with cerebral palsy”. This systematic review investigated the relationship between habitual physical activity and motor capacity in children with CP aged 3-12 years across all functional classifications. This study was conducted to identify and describe the relationship.

2.2 Paper 1: “Systematic review of the relationship between habitual physical activity and motor capacity in children with cerebral palsy”

This manuscript was published in Research in Developmental Disabilities on 11th March 2014.

Keawutan, P., Bell, K., Davies, P.S.W., Boyd, R.N. (2014) Systematic review of the relationship between habitual physical activity and motor capacity in children with cerebral palsy. *Research in Developmental Disabilities*. 35(6): 1301-9. DOI: 10.1016/j.ridd.2014.03.028.

This research was also presented as a scientific poster at the 7th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine, March 2014, Hunter Valley, NSW, Australia.

Keawutan P, Bell K, Davies PSW, Boyd RN. (2014) Systematic review of the relationship between habitual physical activity and motor capacity in children with cerebral palsy. Developmental Medicine & Child Neurology, 56(S2), 68-69.

Title: Systematic Review of the Relationship between Habitual Physical Activity and Motor Capacity in Children with Cerebral Palsy

Short title: Physical activity and motor capacity in cerebral palsy

Authors: Piyapa Keawutan, Kristie Bell, Peter SW Davies, Roslyn N Boyd

2.2.1. Abstract

Habitual physical activity (HPA) has many benefits for general health. Motor capacity in children with cerebral palsy (CP) can impact on their HPA. This study aimed to systematically review the available literature on the relationship between HPA and motor capacity in children with CP aged 3-12 years for all gross motor functional abilities (GMFCS I-V) compared to typically developing children. Five electronic databases (Pubmed, Cochrane, Embase, Cinahl and Web of Science from 1989 to July, 2013) were searched using keywords “children with cerebral palsy”, “physical activity”, “motor capacity” and “motor function” including their synonyms and MesH terms. Studies were included if they (i) were conducted in children with CP aged between 3-12 years, (ii) assessed HPA or time spent sedentary, (iii) assessed motor capacity in order to evaluate the relationship between HPA and motor capacity. All articles retrieved were reviewed by two independent reviewers and discussed until they reached consensus. Study quality of reporting was evaluated using the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) criteria. Search results identified 864 articles but after review of the title and abstract only 21 articles warranted closer consideration. Ten articles met the strict inclusion criteria as nine articles did not assess HPA and two were conference abstracts. Study quality assessment (STROBE) found nine articles were good quality (≥60%) and one was poor quality (55.9%). Participants were mean age 8.4 (SD=2.1) years (range 2-17 years) and included children at all GMFCS levels (3 studies), while seven studies only recruited GMFCS level I-III. HPA measurements were either subjective (Activity Scale for Kids, Dutch Questionnaire of Participation in physical activity and assessment of participation in physical education at school and regular physical activity in leisure time) or objective (StepWatch® and ActiGraph®7164). Nine studies found that motor capacity was directly associated with HPA, HPA in children with CP with high functional level (GMFCS I) was higher than those with lower functional levels (GMFCS III, IV and V); while one study reported no relationship between HPA and GMFCS level (HPA was measured by questionnaire, a potential limitation). Further studies are required to further elucidate HPA levels (active, sedentary behavior) according to objective motor capacity measures, age and gender to inform healthy lifestyle behavior (active/sedentary) in children with CP.

Key words: cerebral palsy, habitual physical activity, motor capacity, gross motor function

2.2.2. Introduction

Cerebral palsy (CP) is a group of non-progressive disorders caused by brain damage in early life, which leads to motor impairments (Rosenbaum et al., 2007). A meta-analysis has reported that overall prevalence of CP is 2.11 children per 1000 live births (Oskoui, Coutinho, Dykeman, Jette, & Pringsheim, 2013). Children with CP can be categorized using the Gross Motor Function Classification System (GMFCS) into five levels where level I is the highest mobility; “child walks without restriction: limitations in more advanced gross motor skills” to level V; “self-mobility is severely limited even with the use of assistive technology” (Palisano et al., 1997).

As might be expected, children with CP who have reduced movement capacity tend to have low levels of habitual physical activity (HPA) (Carlon, Taylor, Dodd, & Shields, 2012). Physical activity can be defined as “any bodily movement produced by skeletal muscles that results in energy expenditure” (Caspersen, Powell, & Christenson, 1985). There are four components of HPA i.e. mode, intensity, duration and frequency (Rhodes, Warburton, & Murray, 2009; U.S. Department of Health and Aging, 2008; WHO, 2010). The mode or type of physical activity has many forms including aerobic, strength, flexibility and balance (Rhodes et al., 2009; U.S. Department of Health and Aging, 2008; WHO, 2010). The intensity is usually divided into sedentary, light, moderate or vigorous intensity. The duration is generally expressed in minutes. Frequency refers to how often a person undertakes activities and is usually expressed as days per week.

Physical activity can be beneficial for health including bone health, cardiorespiratory and muscular fitness (U.S. Department of Health and Aging, 2008). Children with CP who are physically active can derive benefits to their general health including both their physical and psychosocial health throughout life (WHO, 2010). In addition, it is known that patterns of HPA in healthy preschool children (3-5 years) can persist into adulthood (Van Cauwenberghe, Jones, Hinkley, Crawford, & Okely, 2012; Zwier et al., 2010). Sedentary behavior may be stable over time from childhood until adulthood (Biddle, Pearson, Ross, & Braithwaite, 2010) which has implication for long term health. A previous systematic review has showed that children and adolescents with CP (aged 5-18 years) have 13 to 53 per cent less HPA than their typically developing peers (Carlon et al., 2012). There are many factors that can impact on HPA, for example, body functions, child-related factors, parental factors, opportunities for sport and physical activity, practical feasibility, social environment and facility/program factors (Vandenbroucke et al., 2009). A previous study has shown that families who focus on physical activity can improve habitual physical activity levels in their preschool aged typically developing children (O'Dwyer, Fairclough, Knowles, & Stratton,

2012). In children with CP, gross motor capacity can be one of the most important factors which can limit the level of HPA performance (Carlon et al., 2012). To date, there is limited knowledge on the relationship between gross motor capacity and HPA performance in children with CP. This review aimed to systematically examine the relationship between HPA and motor capacity in children with CP aged 3-12 years across all functional classifications (GMFCS I-V). The research question of this systematic review was: does motor capacity of children with CP impact on the level of physical activity?

2.2.3. Methods

Searching was conducted on electronic databases (Pubmed, Cochrane, Embase, Cinahl and Web of Science from 1989 to November, 2013; as the Gross Motor Function Measure (GMFM) has been available since 1989). The keywords for searching were “children with cerebral palsy”, “physical activity”, “motor capacity” and “motor function” including their synonyms and MeSH terms. Studies were included based on the following criteria: (i) participants were children with CP aged between 3-12 years; (ii) studies had HPA or time spent sedentary assessed; (iii) participants were assessed for motor capacity in order to evaluate the relationship between HPA and motor capacity; and (iv) articles were published in English. Studies were excluded if they were conducted in (i) adolescent and adults with CP (studies were accepted if participants were children with CP (3-12 years) ≥ 50% of all participants), (ii) did not report HPA and motor capacity, and (iii) were conference abstracts. Two independent reviewers assessed the titles and abstracts to determine if the articles met the inclusion criteria and the findings were discussed until consensus was reached. All studies that met the full inclusion criteria were assessed for study quality using the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) (Vandenbroucke et al., 2009). Articles were considered good quality if they received a STROBE score ≥ 60%. Data extraction was performed on all articles that met the inclusion criteria for (i) participant characteristics, (ii) measurement of HPA and motor function, and (iii) level of HPA and motor function.

2.2.4. Results

A total of 864 articles were identified by the initial search criteria (Figure 1). After review, 21 articles were selected for closer consideration. Following full examination of the 21 articles by two independent reviewers, 9 articles did not assess HPA and 2 articles were conference abstracts and were excluded from the review. There were 10 articles remaining that met the full inclusion criteria (Balemans et al., 2013; Bjornson, Belza, Kartin, Logsdon, & McLaughlin, 2007; Bjornson, Zhou, Stevenson, Christakis, & Song, 2013; Bjornson, Zhou, Stevenson, & Christakis, 2013a; Bjornson, Zhou, Stevenson, & Christakis, 2013b; Capio,

Sit, Abernethy, & Masters, 2012; Lauruschkus, Westbom, Hallstrom, Wagner, & Nordmark, 2013; Morris, Kurinczuk, Fitzpatrick, & Rosenbaum, 2006; van Wely, Becher, Balemans, & Dallmeijer, 2012; Zwier et al., 2010).

Participants characteristic

Participants characteristic are shown in Table 1. Two studies were secondary analysis from authors' previous studies (Bjornson et al., 2013; Bjornson et al., 2013a). Five of the included studies (Balemans et al., 2013; Bjornson et al., 2007; Bjornson et al., 2013; Capio et al., 2012; Zwier et al., 2010) compared the HPA levels of children with CP and typically developing children. Overall age range across all articles was 2-17 years, mean age (SD) 8.4(2.1) years in children with CP and 9.2(2.3) years in typically developing children. There were seven articles (Balemans et al., 2013; Bjornson et al., 2007; Bjornson et al., 2013; Bjornson et al., 2013a; Bjornson et al., 2013b; Capio et al., 2012; van Wely et al., 2012) that recruited children with CP who were able to walk (GMFCS level I-III) while the others (Lauruschkus et al., 2013; Morris et al., 2006; Zwier et al., 2010) included children across the full spectrum of functional severity (GMFCS level I-V; Table 1).

Qualitative analyses

After assessment, one article was rated as poor quality of reporting according to STROBE (STROBE score = 55.9%) (Capio et al., 2012) and the other 9 articles had good quality reporting (STROBE score ≥ 60%; Table 2). The mean STROBE score (±SD) of all articles was 72.3 (±7.5) percent.

Type of outcome measure

Studies included both subjective and objective measures of HPA (Table 3). The first subjective measure was the Activity Scale for Kids, performance version (ASKp) (Bjornson, Zhou, et al., 2013a; Morris et al., 2006). The ASKp measures physical performance of children (what a child usually does) over the past 7 days. It has reported validity, internal consistency (Cronbach's alpha 0.99), test-retest reliability (ICC 0.97) and inter-rater reliability (0.94) (Capio, Sit, Abernethy, & Rotor, 2010). The second subjective measure was a parent reported Dutch questionnaire (Zwier et al., 2010) about participation in physical activity (Zwier et al., 2010). The questionnaire reported intensity of physical activity (metabolic equivalent (METs) × hours per week) and duration of sport (hours per week) (Zwier et al., 2010). The last subjective measure identified in this review was assessments of frequency of participation in physical education (PE) at school and regular physical activity in leisure time (Lauruschkus et al., 2013). This assessment was conducted by physiotherapists who examined frequency of participation into ordinal scales; no participation; participation <1 time/week; 1-2 times/week and 3-5 times/week.

There were two objective measures identified in this review: the StepWatch® which counts steps and the ActiGraph®7164 which counts acceleration in 2D (Balemans et al., 2013; Bjornson et al., 2007; Bjornson et al., 2013; Bjornson et al., 2013b; Capio et al., 2012; van Wely et al., 2012). Four studies using the StepWatch® recorded steps during all waking hours, except for swimming and bathing for one week (Balemans et al., 2013; Bjornson et al., 2007; Bjornson et al., 2013b; van Wely et al., 2012). The StepWatch® was worn at lateral side of left ankle or the least affected ankle of the child. Another study that used the StepWatch® (Bjornson et al., 2013) was a secondary analysis from authors' previous cross-sectional studies (Bjornson et al., 2010; Bjornson et al., 2007; Bjornson et al., 2013b). The last study investigated HPA by using the ActiGraph® where the participants wore an accelerometer on their hip over one week (Capio et al., 2012).

Most papers used the GMFCS to classify the motor capacity of children with CP (Balemans et al., 2013; Bjornson et al., 2007; Bjornson et al., 2013; Bjornson et al., 2013b; Lauruschkus et al., 2013; Morris et al., 2006; van Wely et al., 2012; Zwier et al., 2010). The Gross Motor Function Measure-66-Item Set (GMFM-66-IS) was used in one recent paper (Bjornson et al., 2013a). The GMFM-66-IS was developed the item sets from the GMFM-66 and it has reported validity and excellent reliability (ICC 0.99) (Russell et al., 2010). Another paper used fundamental movement skills to assess motor capacity (Capio et al., 2012). The fundamental movement skills included five skills which were throwing, catching, kicking, running and jumping. Participants were assessed on five skills in quality of movement and outcome. The outcome of the fundamental movement skills were determined by accuracy of throwing and hitting a target, number of successful catches and kicks in 5 trials, distance of jumping and duration of running (Capio et al., 2012).

Relationship between physical activity and motor capacity

Nine studies reported a relationship between HPA intensity and motor function of children with CP (Table 3) (Balemans et al., 2013; Bjornson et al., 2007; Bjornson et al., 2013; Bjornson et al., 2013a; Bjornson et al., 2013b; Capio et al., 2012; Lauruschkus et al., 2013; Morris et al., 2006; van Wely et al., 2012). The study that examined an association between abilities of children with CP and their activities and participation showed a high negative correlation between the GMFCS and the ASKp score (Morris et al., 2006). Another study using the ASKp investigated associations between motor capacity (the GMFM-66-IS) and physical activity performance (the ASKp) (Bjornson et al., 2013a). This study reported a high correlation between the GMFM-66-IS and the ASKp (Bjornson et al., 2013a).

The study that used a subjective measure of frequency of participation in PE at school and physical activity in leisure time in children and adolescents with CP aged 7-17 years,

reported that participation in PE at school of children with low functional level (GMFCS V) had significantly lower odds than children with high functional level (GMFCS I) (Lauruschkus et al., 2013). Percentage of children and adolescents with CP who participated in PE at school were 94% in GMFCS I, 93% in GMFCS II, 86% in GMFCS III, 88% in GMFCS IV and 52% in GMFCS V. Percentages of active participation in PE 1-2 times weekly were 87% in GMFCS I, 75% in GMFCS II, 79% in GMFCS III, 68% in GMFCS IV and 35% in GMFCS V (Lauruschkus et al., 2013). Participation in regular physical activity in leisure time of GMFCS III had significantly lower odds than GMFCS I (Lauruschkus et al., 2013). Percentage of participation in regular physical activity in leisure time were 65% in GMFCS I, 59% in GMFCS II, 25% in GMFCS III, 36% in GMFCS IV and 21% in GMFCS V. Percentage of participation in regular physical activity in leisure time 1-2 times weekly were 37% in GMFCS I, 42% in GMFCS II, 11% in GMFCS III, 24% in GMFCS IV and 13% in GMFCS V (Lauruschkus et al., 2013).

There were six studies reporting the association between motor capacity and HPA that used objective HPA measures. Time spent sedentary (TSS) had negative correlations while time spent in moderate to vigorous physical activity (MVPA) had positive correlations with the quality of movement and outcome score measured by fundamental movement skills (throwing, catching, kicking, running and jumping) in children with CP, mean age (SD) 7.4(2.5) years (Capio et al., 2012). Furthermore, there were five studies that measured HPA by using the StepWatch® (Balemans et al., 2013; Bjornson et al., 2007; Bjornson et al., 2013; Bjornson et al., 2013b; van Wely et al., 2012). The study by Bjornson et al. (2007) reported that steps per day and percentage of time spent in MVPA in youth with CP with low functional level (GMFCS III) were significantly less than those at high functional levels (GMFCS I, II) (Bjornson et al., 2007). Similarly, the study by Van Welly et al. found that steps per day, percentage of time spent MVPA were associated with GMFCS levels (van Wely et al., 2012). A recent study reported that numbers of strides per day of children with CP aged 2-9 years were significantly decreased at lower functional levels (Bjornson et al., 2013b). The secondary analysis study in children with CP aged 2-13 years reported that time spent sedentary (TSS; minutes/day) significantly increased in those with lower functional level (GMFCS III) (Bjornson et al., 2013). Similarly, the study conducted in children with CP aged 7-14 years found that TSS (minutes/day) of children with CP with low functional level (GMFCS III) were significantly higher than those with high functional level (GMFCS I) (Balemans et al., 2013). All studies that compare HPA between children with CP and their typically developing peers reported that children with CP performed less HPA than typically developing peers (Balemans et al., 2013; Bjornson et al., 2007; Bjornson et al., 2013; Capio

et al., 2012; Zwier et al., 2010). Nevertheless, only one study has reported that there was no relationship between HPA (measuring by the Dutch questionnaire) and GMFCS levels in children with CP aged 5 and 7 years (Zwier et al., 2010) (Table 3).

2.2.5. Discussion

From this systematic review, our results have shown that almost all studies reported motor capacity was directly related to physical activity level in children with CP aged 2-17 years. Although all studies used different measures to investigate HPA intensity and motor capacity, the relationships were all positive (higher HPA levels were associated with higher motor capacity). In addition, a previous study conducted in adolescents with CP (11-17 years) has shown that physical activity levels were strongly associated with gross motor function (Maher, Williams, Olds, & Lane, 2007). On the other hand, one study found that motor capacity did not impact on physical activity levels (Zwier et al., 2010). This result might be due to the lack of validation of the questionnaire used for measuring HPA.

There are various HPA measures, both subjective and objective, used in children with CP. Subjective measures may be more convenient to collect data than objective measures, but, they can have bias and recall errors (Capio et al., 2010; Clanchy, Tweedy, & Boyd, 2011). From this review, there were three subjective measures: the ASKp (Bjornson 2013a; Morris et al., 2006), the Dutch questionnaire about participation in physical activity (Zwier et al., 2010) and the frequency of participation in PE at school and physical activity in leisure time (Lauruschkus et al., 2013). The ASKp was associated with motor capacity (GMFCS and GMFM-66-IS) and has excellent validity and reliability (Capio et al., 2010; Clanchy et al., 2011). The second subjective measure, the Dutch questionnaire, included questions regarding type of participation and duration in sports activity (Zwier et al., 2010). Types of participation in sports activities were converted into MET to determine the intensity of physical activity. Physical activity from the Dutch questionnaire (Zwier et al., 2010) had no significant relationship with GMFCS. It has been stated that a potential limitation in this study is that the validity and reliability of the Dutch questionnaire has not been investigated (Zwier et al., 2010). The conversion from type of activity to intensity (MET) in children with CP might not be the same as in typically developing children, as children with CP with low motor capacity might need more energy to complete the same task as healthy children. This could lead to an underestimate of the actual HPA performance in children with CP as measured on the Dutch questionnaire. The last subjective measure was frequency of participation in PE at school and physical activity in leisure time which was examined by physiotherapists (Lauruschkus et al., 2013). This study was conducted in a large number of participants (n=364) including a total population of children and adolescents with CP in Skåne region,

Sweden. The study investigated physical activity both at school and outside school. The study reported that HPA of children and adolescents with CP with high functional level (GMFCS I) was significantly higher than those with lower functional level (GMFCS III and V) (Lauruschkus et al., 2013).

Objective measures of HPA are more reliable than subjective measures (Capio et al., 2010; Clanchy et al., 2011). This review identified two objective measures, the StepWatch® and the ActiGraph®, that have excellent validity (Mitchell, Ziviani, Oftedal, & Boyd, 2013). From our results, there were five studies using the StepWatch® as HPA measure (Balemans et al., 2013; Bjornson et al., 2007; Bjornson et al., 2013; Bjornson et al., 2013b; van Wely et al., 2012). All studies reported that children with low functional level (GMFCS III) were associated with lower ambulatory activity and higher TSS (Balemans et al., 2013; Bjornson et al., 2007; Bjornson et al., 2013; Bjornson et al., 2013b; van Wely et al., 2012). The StepWatch® was designed to measure ambulatory activity, so only suitable for GMFCS I-III (Clanchy et al., 2011). Habitual physical activity levels from the ActiGraph® were associated with fundamental movement skills (Capio et al., 2012). The ActiGraph® is an accelerometer-based activity measure that detects acceleration of body movement and provides the most robust data of physical activity (duration, intensity and frequency) and it can be used in children with CP who are unable to walk. Nevertheless, the ActiGraph® is not suitable for water-based activities and cycling (Clanchy et al., 2011).

The measurement of motor function in this review found that most studies used the GMFCS to classify motor capacity (Balemans et al., 2013; Bjornson et al., 2007; Bjornson et al., 2013; Bjornson et al., 2013b; Lauruschkus et al., 2013; Morris et al., 2006; van Wely et al., 2012; Zwier et al., 2010). Furthermore, one study used functional movement skills (Capio et al., 2012) to determine physical activity patterns. There was one study using the GMFM-66-IS to investigate the relationship between HPA and motor capacity (Bjornson et al., 2013a). The GMFCS is an ordinal scale while the GMFM is a continuous variable (Palisano et al., 1997). It would be more precise to describe the relationship by using the GMFM as the motor capacity assessment.

Due to the variety of HPA and motor capacity used, data were not able to be combined in a meta-analysis. In addition, the articles identified in this review were conducted in wide age range (2-17 years), with most studies conducted in school aged children with CP (5-14 years). There are limited studies in young children with CP aged less than 5 years. Further studies should consider measurement of both HPA and motor capacity in order to describe more details of the relationship. Knowledge of the relationship would benefit to develop strategies to promote physical activity in children with CP.

2.2.6. Conclusion

Habitual physical activity is directly associated with motor capacity (higher HPA levels associated with higher motor capacity). Further studies are needed objectively examine the relationship between HPA and motor capacity in children with CP using valid and reliable measures.

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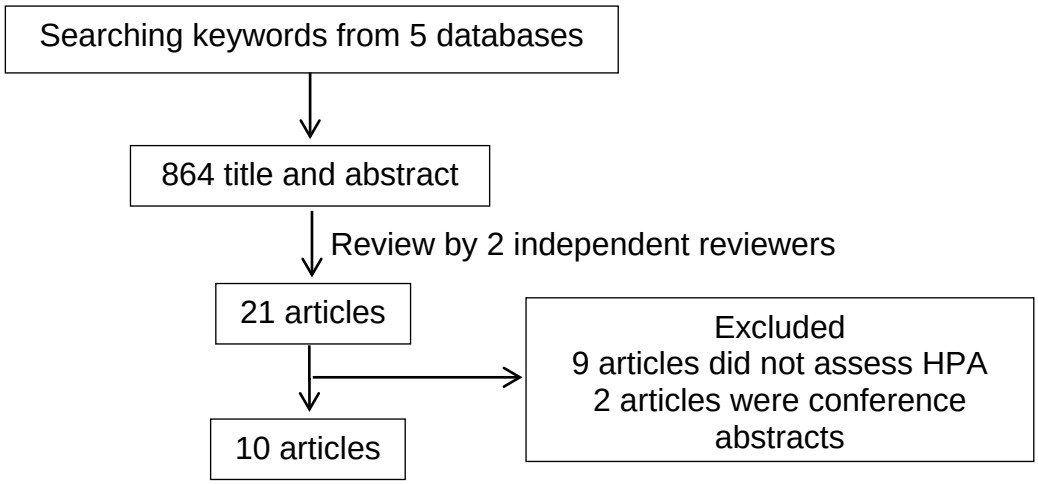

Figure 1 Flow chart of searching result of relationship between habitual physical activity and motor capacity in children with cerebral palsy.

Table 1 Summary of participants' characteristics.

Authors	Number of children		Sex n(%)		Age range (years)	Mean age(SD)		GMFCS level n(%)
	CP	TD	CP-male	TD-male		CP	TD	
Morris et al. (2006)	129	-	72(56)	-	6-12	9.9	1.9	I-V (N/A)
Bjornson et al. (2013a)*	128	-	76(59)	-	2-9	6.2(2.3)	-	I=44(35), II=54(42), III=30(23)
Zwier et al. (2010)	97	57	-	-	5 or 7	6.0	-	I=54(56), II=20(21), III=17(17), IV=6(6)
Lauruschkus et al. (2013)	364	-	220(60)	-	7-17	N/A		I=158(43), II=71(20), III=28(8) IV=59(16), V=48(13)
Capio et al. (2012)	31	31	-	-	-	7.4(2.5)	6.6(2.5)	I-III (N/A)
Bjornson et al. (2007)*	81	30	42(52)	-	10-12	11.8(1.9)	11.9(1.2)	I=31(38), II=30(37), III=20(25)
Van Wely et al. (2012)	62	-	39(63)	-	7-13	10.1(1.8)	-	I=37(60), II=16(26), III=9(15)
Bjornson et al. (2013b)*	128	-	76(59)	-	2-9	6.2(2.3)	-	I=44(35), II=54(42), III=30(23)
Bjornson et al. (2013)	209	368	117(56)	184(50)	2-13	8.3(3.4)	8.0(3.4)	I=75(36), II=84(40), III=50(24)
Balemans et al. (2013)	43	27	25(48)	11(41)	7-14	9.8(0.6)	10.1 (1.5)	I=23(53), II=12(28), III=8(19)
Total	1272	513			2-17	8.4(2.1)	9.2(2.3)	I=520(41), II=384(30), III=207(17), IV=79(6), V=71(6)

Key: CP, Cerebral Palsy; TD, Typical Development; GMFCS, Gross Motor Function Classification System; N/A, not applicable

* Participants were subset of Bjornson et al. (2013).

Table 2 Quality assessment for all articles met full inclusion criteria of relationship between habitual physical activity and motor capacity in children with cerebral palsy using modified STROBE guidelines.

Topic	items	Morris et al. (2006)	Bjornson et al. (2013a)	Zwiter et al. (2010)	Lauruskus et al. (2013)	Capio et al. (2012)	Bjornson et al. (2007)	Van Wely et al. (2012)	Bjornson et al. (2013b)	Bjornson et al. (2013)	Balemans et al. (2013)
Title and abstract	1a	0	1	0	1	0	1	0	1	1	0
	1b	1	1	1	1	1	1	1	1	1	1
Introduction											
Background/Rationale	2	1	1	1	1	1	1	1	1	1	1
Objective	3	1	1	1	1	1	1	1	1	1	1
Methods											
Study design	4	1	1	1	1	1	1	1	1	1	1
Setting	5	0	0	1	1	0	1	1	1	1	1
Participants	6a	1	1	1	1	1	1	1	1	1	1
	6b	1	1	1	0	1	1	0	0	1	0
Variables	7	0	0	1	1	1	1	1	1	1	1
Data sources/ measurement	8	1	1	1	1	1	1	1	1	1	1
Bias	9	1	1	0	0	1	1	1	0	0	0
Study size	10	1	1	1	1	1	1	1	1	1	1
Qualitative variables	11	1	1	1	1	1	1	1	1	1	1
Statistical methods	12a	1	0	1	1	1	1	1	1	1	1
	12b	1	1	1	1	1	1	1	1	1	1
	12c	1	0	1	0	1	1	1	0	0	0
	12d	0	1	0	0	0	1	0	0	0	1
	12e	0	0	0	0	0	0	0	0	0	0
Results											
Participants	13a	1	1	1	1	0	1	1	1	1	1
	13b	1	1	1	0	0	1	0	1	0	1
	13c	1	1	0	1	0	1	0	1	1	0
Descriptive data	14a	1	1	1	1	0	1	1	1	1	1
	14b	1	1	1	0	0	0	0	1	0	0
	14c	0	0	0	0	0	0	0	0	0	0
Outcome data	15	1	1	1	1	1	1	1	0	1	1

Table 2 (continued) Quality assessment for all articles met full inclusion criteria of relationship between habitual physical activity and motor capacity in children with cerebral palsy using modified STROBE guidelines.

Main results	16a	1	1	1	1	0	1	1	1	1	1
	16b	1	0	1	1	0	0	0	1	1	1
	16c	0	1	0	1	0	0	0	0	0	0
Other analysis	17	1	1	1	0	0	0	0	1	0	1
Discussion											
Key results	18	1	1	1	1	1	1	1	1	1	1
Limitations	19	1	1	1	1	1	1	1	1	1	0
Interpretation	20	1	1	1	1	1	1	1	1	1	1
Generalizability	21	1	1	1	1	0	1	1	1	1	1
Other information											
Funding	22	1	1	0	1	1	1	1	1	1	1
Total (34 score)		26	27	26	24	19	28	23	27	25	23
Percentage score		76.47	79.41	76.47	70.59	55.88	82.35	67.65	79.41	73.53	67.65

Table 3 Summary of the relationship between HPA and motor capacity in children with cerebral palsy.

HPA measure	Motor measure (n)	HPA Variables	GMFCS I	GMFCS II	GMFCS III	GMFCS IV	GMFCS V	Total CP	Comparison
ASKp (Morris et al., 2006)	GMFCS (N/A)	ASKp (mean(SD); score)	N/A	N/A	N/A	N/A	N/A	67 (46)	sig. correlation: ASKp & GMFCS, r = -0.9
ASKp (Bjornson et al., 2013a)	GMFM-66-IS (N/A)	ASKp (mean(SD); score)	N/A	N/A	N/A	N/A	N/A	N/A	sig. correlation: ASKp & GMFM-66-IS, r = 0.83
Dutch questionnaire (Zwier et al., 2010)	GMFCS (I =54, II=20, III=17, IV=6)	PA intensity (mean(SD); METs*h/wk)	N/A	N/A	N/A	N/A	N/A	18.1 (1.2)	no relationship: PA intensity & GMFCS
		sport duration (mean(SD); h/wk)	N/A	N/A	N/A	N/A	N/A	1.9 (5.8)	no relationship: sport duration & GMFCS
Frequency of participation (Lauruschkus et al., 2013)	GMFCS (I =158, II=71, III=28, IV=59, V=48)	PE at school (POR(95% CI))	reference	0.49 (0.21-1.12)	0.60 (0.20-1.81)	0.43 (0.15-1.19)	0.19 (0.06-0.65)	N/A	PE at school: GMFCS V < I (*p*=0.008)
		PA in leisure time (POR(95% CI))	reference	1.09 (0.60-1.97)	0.24 (0.09-0.62)	0.53 (0.23-1.22)	0.38 (0.12-1.17)	N/A	PA in leisure time: GMFCS III < I (*p*=0.003)
ActiGraph®7164 (Capio et al., 2012)	Fundamental movement skills: movement quality score (mean±SE) run=2.4±0.4, jump=2.2±0.4, kick=3.6±0.2, throw=3.2±0.2 catch=3.0±0.2 outcome score (mean±SE) run=4.7±0.5, jump=2.4±0.5, kick=2.1±0.2, throw=6.1±0.4 catch=2.8±0.2	TSS (mean; %)	N/A	N/A	N/A	N/A	N/A	57	sig. correlation: TSS & movement quality, r = 0.35-0.67; TSS & outcome, r = 0.32-0.51
		Time spent MVPA (mean; %)	N/A	N/A	N/A	N/A	N/A	7	sig. correlation: MVPA & movement quality, r = 0.41-0.72 MVPA & outcome, r = 0.33-0.65

Table 3 (continued) Summary of the relationship between HPA and motor capacity in children with cerebral palsy.

StepWatch® (Bjornson et al., 2007)	GMFCS (I=31, II=30, III=20)	PA intensity (mean(CI); steps/day)	N/A	N/A	N/A	N/A	N/A	4222 (3739-4749)	PA intensity: GMFCS I & II > III (p<0.001)
		time spent vigorous (mean(CI); %)	N/A	N/A	N/A	N/A	N/A	5.6 (4.7-6.5)	time spent vigorous: GMFCS I & II > III (p<0.001)
StepWatch® (Van Welly et al., 2012)	GMFCS (I=37, II=16, III=9)	PA intensity (mean(SD); steps/day)	5340 (1605)	4631 (1147)	2867 (1243)	N/A	N/A	4739 (1668)	PA intensity: GMFCS I & II > III (p<0.05)
		time spent MVPA (mean(SD), %)	16.4 (6.0)	15.3 (6.0)	8.8 (5.5)	N/A	N/A	15.0 (6.4)	time spent MVPA: GMFCS I & II > III (p<0.05)
		time spent vigorous (mean(SD), %)	6.4 (3.2)	5.6 (2.9)	3.2 (2.6)	N/A	N/A	5.7 (3.2)	time spent vigorous: GMFCS I > III (p<0.05)
									sig. correlation: those StepWatch® var. & GMFCS, r = -0.69
StepWatch® (Bjornson et al., 2013b)	GMFCS (I=44, II=54, III=30)	PA intensity (mean(SD); strides/day*)	6691 (2123)	5407 (2061)	1970 (1475)	N/A	N/A	N/A	PA intensity: GMFCS I > II GMFCS I & II > III (p<0.002)
StepWatch® (Bjornson et al., 2013)	GMFCS (I=75, II=84, III=50)	TSS (mean(SD); min/day)	1038.0 (96.0)	1073.0 (86.0)	1221.0 (89.0)	N/A	N/A	N/A	TSS: GMFCS I < II & III GMFCS II < III (p<0.001)
		time spent moderate (mean(SD); min/day)	48.0 (25.0)	48.0 (25.0)	11.0 (11.5)	N/A	N/A	N/A	N/A
		time spent vigorous (mean(SD), min/day)	4.0 (4.5)	3.0 (3.7)	0.5 (1.1)	N/A	N/A	N/A	N/A

Table 3 (continued) Summary of the relationship between HPA and motor capacity in children with cerebral palsy.

StepWatch® (Balemans et al., 2013)	GMFCS (I=23, II=12, III=8)	TSS (mean(SD); min/day)	317.0 (75.0)	375.0 (94.0)	400.0 (82.0)	N/A	N/A	N/A	TSS: GMFCS I < III (p<0.001)
		time spent moderate (mean(SD); min/day)	61.0 (22.7)	51.0 (24.4)	20.5 (21.1)	N/A	N/A	N/A	time spent moderate: GMFCS I > III (p<0.001)
		time spent vigorous (mean, min/day)	3.5	4.5	0	N/A	N/A	N/A	no sig. in time spent vigorous

Key: ASKp, Activity Scale for Kids performance version; CI, Confident Interval; CP, Cerebral Palsy; GMFCS, Gross Motor Function Classification System; GMFM-66-IS, Gross Motor Function Measure-66-Item Set; HPA, Habitual Physical Activity; MET, Metabolic Equivalent; MVPA, Moderate to Vigorous Physical Activity; N/A, not applicable; PA, Physical Activity; PE, Physical Education; POR, Proportional Odds Ratio; r, correlation coefficient; SD, Standard Deviation; sig., significant; TSS, Time Spent Sedentary; var., variables.

*Stride rate is counted on one leg while step rate is counted on two legs.

Supplementary Table 1 STROBE Statement—checklist of items that should be included in reports of observational studies.

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
Objectives	3	State specific objectives, including any prespecified hypotheses
Methods		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding
		(*b*) Describe any methods used to examine subgroups and interactions
		(*c*) Explain how missing data were addressed
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy
		(e) Describe any sensitivity analyses

Supplementary Table 1 (continued) STROBE Statement—checklist of items that should be included in reports of observational studies.

Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time
		Case-control study—Report numbers in each exposure category, or summary measures of exposure
		Cross-sectional study—Report numbers of outcome events or summary measures
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses
Discussion		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

A study of the relationship between HPA and motor capacity was published in 2014 after publication of the preceding systematic review. This study measured HPA using a uniaxial accelerometer, the ActivPAL™ in 45 adolescents and young adults with bilateral spastic CP classified as GMFCS II and III, aged 16-20 years.[29] The investigators found that the GMFM dimension E (walking/running/jumping) was the most important predictor of HPA, and the GMFM dimension D (standing) was also associated with HPA in young people with bilateral CP.[29]

2.3 Summary and conclusions

Our study confirmed that motor capacity was directly associated with HPA. The systematic review confirmed the need for a study examining the relationship between HPA and motor capacity in young children with CP. Specific findings are as follows:

i) Various habitual physical activity measures, both subjective and objective were used in previous studies. The subjective measures were the Activity Scale for Kids performance version (ASKp), questionnaires of physical activity participation, frequency of participation in physical education and regular physical activity in leisure time. The objective measures were the StepWatch® and the ActiGraph®.

ii) Previous reports of the relationship of HPA and motor capacity studies used a variety of motor capacity tests including the GMFCS, the GMFM and the Fundamental Movement Skills.

iii) Nine out of ten studies reported relationships between HPA and motor capacity. One study reported no relationship between HPA and the GMFCS; however, a potential limitation was that the HPA questionnaire had not been validated in children with CP.

iv) Our review identified very few studies in young children with CP aged less than 5 years (three studies) and these studies included only ambulant children with CP (GMFCS I-III).

Chapter 3: Material and Methods

This research program was completed as part of two population-based cohort studies: Queensland CP Child Study of Motor Function and Brain Development (National Health and Medical Research Council (NHMRC 465128) and Queensland CP Child Study of Growth, Nutrition and Physical Activity (NHMRC 569605).[50, 51] Eligible participants were asked to participate in the Queensland CP Child Study of Motor Function and Brain Development and were later invited to participate in the Queensland CP Child Study of Growth, Nutrition and Physical Activity. This study included data from these two cohort studies in children with CP at assessments conducted at 48 and 60 months of age.

3.1 Participants

3.1.1 Inclusion criteria

Children diagnosed with CP and born in Queensland, Australia from 1st September 2007 to 31st December 2009 were eligible for this study.

3.1.2 Exclusion criteria

Children with progressive brain disorders were excluded from this study.

The Queensland CP Child Study of Motor Function and Brain Development conducted assessments every 6 months from 18 months until 36 months of age, and at 48 months and 60 months corrected age.[50] The Queensland CP Child Study of Growth, Nutrition and Physical Activity assessed children at three time points (i) at 17 to 25 months (depending on study entry); (ii) 36±1 months; and (iii) 60±1 months corrected age. Children who are diagnosed after 25 months corrected age may enter the study at 30±1 or 36±1 months with additional assessments conducted at 48±1 months corrected age.[51]

Assessments were conducted at various health care providers across Queensland including the Royal Children's Hospital in Brisbane, regional hospitals in Cairns, Gold Coast, Mackay, Harvey Bay, Rockhampton, Mount Isa, Toowoomba, health care centres in Townsville, the Sunshine Coast, and Bundaberg, and in home visits by research physiotherapists and a research dieticians.

Figure 2 is a recruitment flow chart. Data on a total of 210 assessments at 48 and 60 months in 158 participants were available for analysis. Eighty-four participants were included in sub-study 2 (validation of accelerometer cut-points in children with CP aged 4-5 years), which were divided into calibration phase of analysis (n=55) and cross-validation phase (n=29). A total of 67 children with CP who had completed three-day activity monitoring at 48 and 60 months were allocated to sub-study 3 (HPA in children with CP aged 4-5 years across all functional abilities) and 4 (relationship between HPA, motor capacity and capability in children with CP aged 4-5 years across all functional abilities). Incomplete activity monitoring were due to refusal by children to wear the activity monitor, and difficulty by parents to attach the monitor to their child. A total of 132 participants were assessed at 60 months but only 58 participants provided sufficient activity monitoring for inclusion to sub-study 5 (QOL and HPA in children with CP aged 5 years: a cross-sectional study). For sub-study 6 (longitudinal physical activity in preschool aged children with CP across all functional levels), a total of 95 participants provided completed three-day activity monitoring, contributing 159 assessments.

3.1.3 Ethical consideration

All parents or legal guardians of participants signed informed consent before entry to the studies. Ethics have been approved by The University of Queensland Medical Research Ethics Committee (2008002260), The Children's Health Services District Ethics Committee (HREC/08/QRCH/122/AM01), The CP League of Queensland (CPQLD 2008/2010 1029), Gold Coast Health Service District Human Research Ethics Committee (HREC/09/QGC/88), The Townsville Health Services District Human Research Ethic Committee (HREC/09/QTHS/96), Rockhampton Health Services District Human Research Ethics Committee (HREC/08/QRCH/112), The Mater Health Services District Human Research Ethics Committee (1520EC). The Australia and New Zealand Clinical Trials Registry was ACTRN1261200169820 for the Queensland CP Child Study of Motor Function and Brain Development and ACTRN12611000616976 for the Queensland CP Child Study of Growth, Nutrition and Physical Activity.

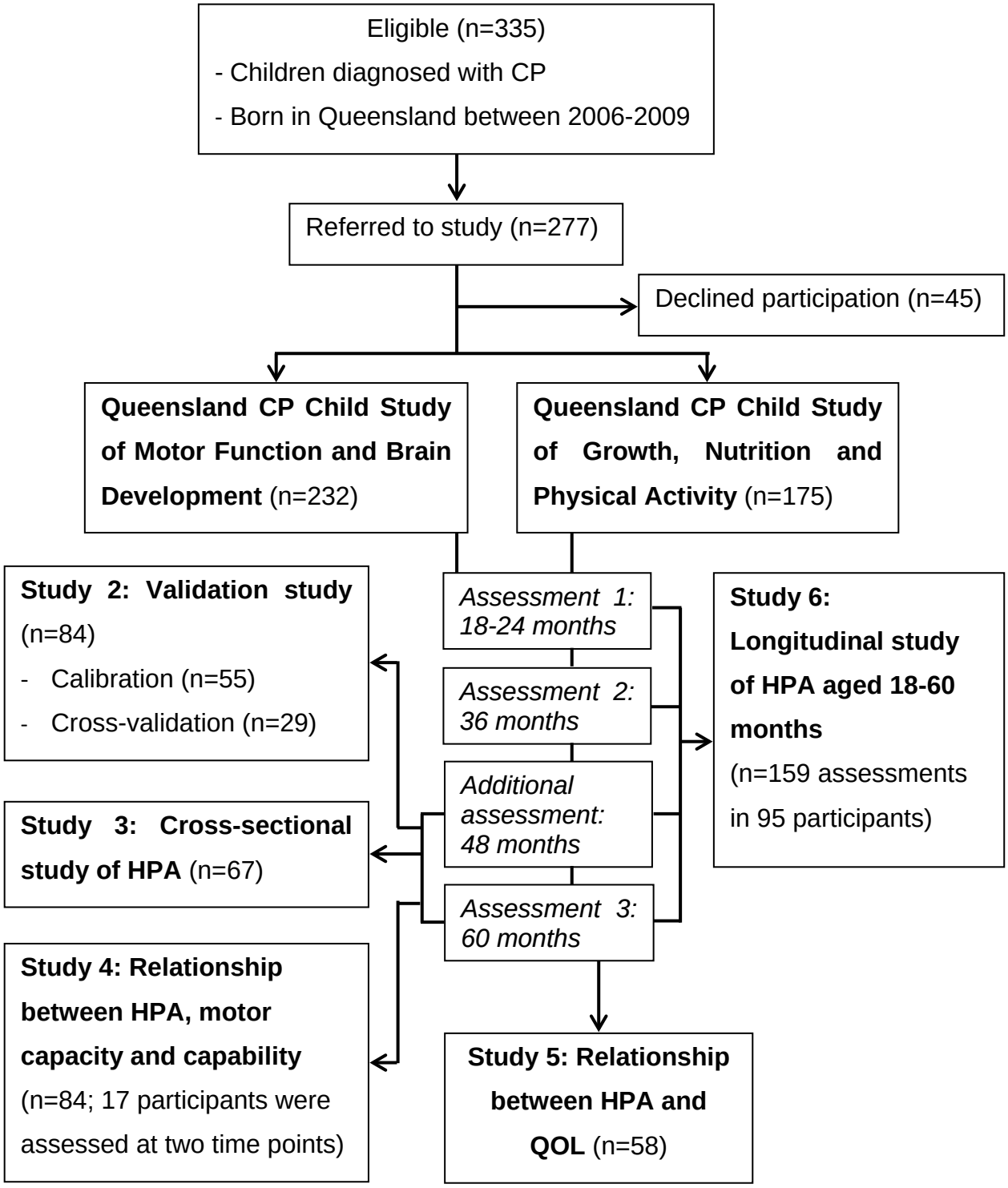

Figure 2 Recruitment flowchart

CP, cerebral palsy; HPA, habitual physical activity; QOL, Quality of life.

3.2 Outcome measures and procedures

Figure 3 shows a flow chart for outcome measures in each sub-study. The Gross Motor Function Classification System (GMFCS), motor type and distribution, and body mass index (BMI) were used in all sub-studies. Assessments were conducted at Royal Children's Hospital in Brisbane or home visits across Queensland. The Pediatric Evaluation of Disability Inventory (PEDI) functional skills of the mobility domain and the Cerebral Palsy Quality of Life questionnaire for Children (CP QOL-Child) were mailed to parents of participants one week prior to the assessment date. At each assessment visit, questionnaires were collected, and participants were assessed according to the 66-item Gross Motor Function Measure (GMFM-66). All assessments were videotaped for scoring. The GMFCS, motor type and distribution were used to classify children with CP. Height and weight were measured to calculate BMI (kg/m^2). Three-day activity monitoring and activity diary were explained to patents of participants for home activity. Prepaid parcel post was prepared for sending equipment from the home activity back to our research team.

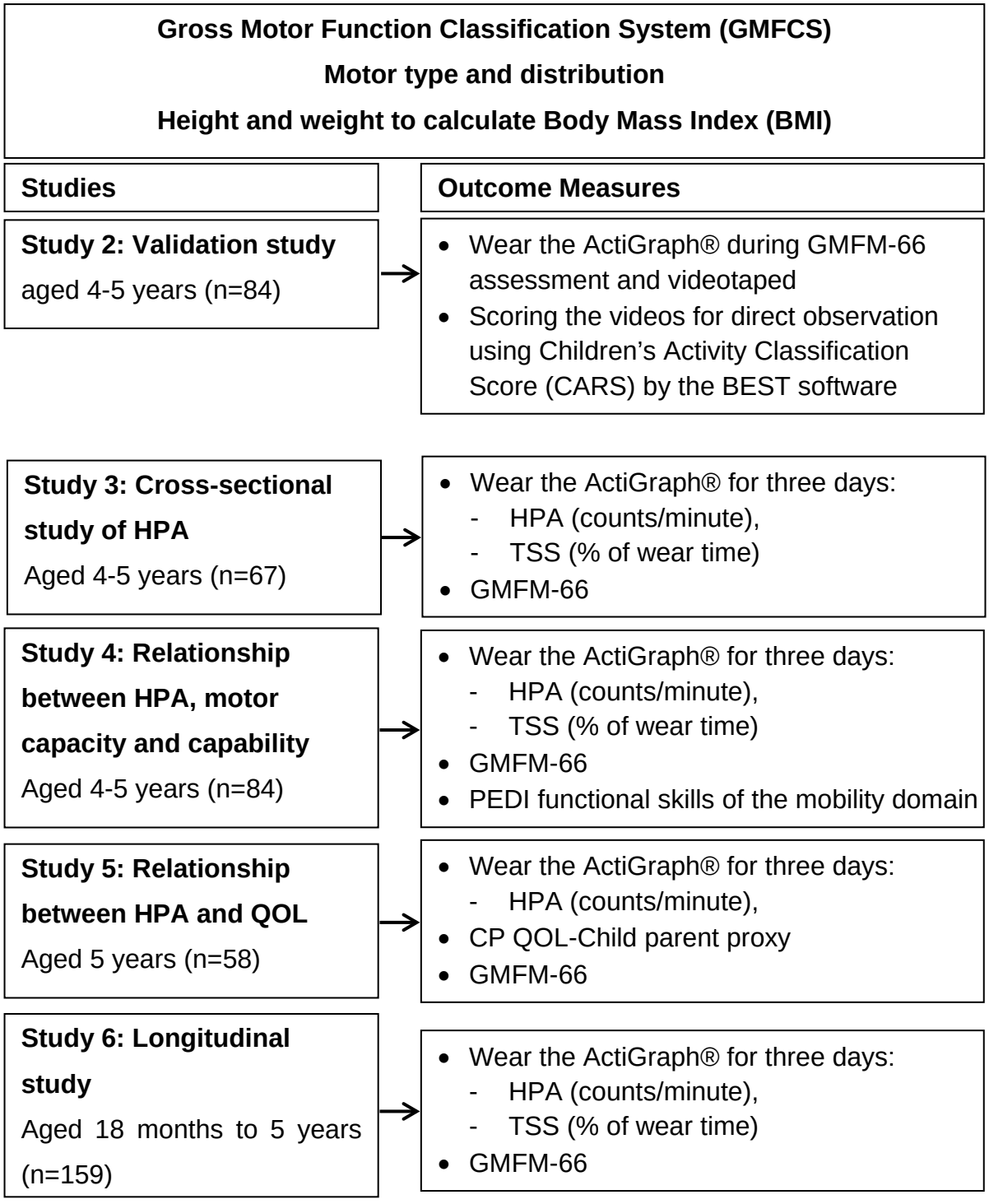

Figure 3 Outcome measures flow chart

HPA, habitual physical activity; TSS, time spent sedentary; GMFM-66, the 66-item Gross Motor Function Measure; PEDI, the Pediatric Evaluation of Disability Inventory; CP QOL-Child, the Cerebral Palsy Quality of Life questionnaire for Children.

3.2.1 Classification and description

All participants were classified using the GMFCS, motor type and distribution by two research physiotherapists at each time point of assessments without reference to the previous classification.

3.2.2 Motor Function Measures

The GMFM is a standard criterion-referenced measurement of gross motor capacity, and is the most widely accepted measurement system for assessment of gross motor function in children with CP, assessing 5 dimensions; lying/rolling, sitting, crawling/kneeling, standing and walking/running/jumping.[52] There are two main versions; the 88-item GMFM and the 66-item GMFM. The 66-item GMFM was developed by Rash analysis from the 88-item GMFM for optimising time of implementation, and improving scoring and interpretation. It has high validity and reliability (intraclass correlation coefficient=0.99).[53] Each item is scored on a 4-point ordinal scales (0 = does not initiate, 1 = initiates < 10% of activity, 2 = partially completes 10% to < 100% of activity, 3 = completes activity). The score is computed into interval scores by the Gross Motor Ability Estimator (GMAE) software. All participants were assessed the 66-item GMFM by two research physiotherapists and all assessments were videotaped. Additionally, the ActiGraph® accelerometers were attached to participants for the ActiGraph® cut-points validation study.

3.2.3 Community mobility measure

The Pediatric Evaluation of Disability Inventory (PEDI) functional skills of the mobility domain was used to determine community mobility in this study.[54] The PEDI has been developed for children with disability aged 6 months to 7.5 years. It evaluates functional skills across 3 domains, self-care, mobility and social function, which are scored as either unable (score 0) or capable (score 1). It has been reported to have good psychometric properties, no ceiling or floor effects, excellent internal consistency (Cronbach's $\alpha \geq 0.98$)[55] and excellent responsiveness (effect size=0.74, standard response mean=1.29 for the PEDI mobility).[56] The PEDI functional skills of the mobility domain was mailed to parents of participants and parents were asked to complete the PEDI before the assessments were conducted. The PEDI raw score was recoded to scale score form 0-100.[54]

3.2.4 Quality of Life

The Cerebral Palsy Quality of Life questionnaire for children (CP QOL-Child) is a condition specific measure of quality of life with high validity and reliability (Cronbach's α range from 0.74-0.92 for parent-report).[47, 48, 57] This questionnaire has two versions, parent proxy for children aged 4-12 years and self-reported for children aged 9-12 years. The parent proxy version of the CP QOL-Child[58] was therefore used in the current study. It has 7 subscales; social well-being and acceptance, functioning, participation and physical health, emotional well-being, access to service, pain and impact of disability, and family health. The parent-proxy CP QOL-Child was mailed to parents of participants and parents were asked to complete the CP QOL-Child before the assessments were conducted.

3.2.5 ActiGraph® validation study

The ActiGraph® validation study was conducted in two phases; the calibration phase and the cross-validation phase. Children were asked to wear the ActiGraph® accelerometer during the GMFM-66 testing session and the assessments were videotaped. The monitor was placed at the child's lower back close to the centre of mass of the body (L2) using a neoprene belt that did not hinder movement and allowed accurate measurement in children with an asymmetrical gait pattern. Acceleration output recorded at the lower back has been reported in ambulant wearers as the best predictor of energy expenditure compared to limb placements.[25] The accelerometer was set at 5-second epochs in order to detect short bursts of activity. Previous studies reported that physical activity in children is an intermittent burst and varying interval with the median duration of 6 seconds for low and moderate intensity activities.[59, 60]

The videotape of the GMFM-66 assessments were scored in real time using the computerized direct observational system Behavioral Evaluation Strategy and Taxonomy (BEST, Inc., FL, USA). Activities were categorized into two levels, sedentary or active, using modified Children's Activity Rating Scale (CARS). Previous studies have reported that the CARS has good validity and reliability in typically developing children aged 5-6 years.[61, 62] The sedentary behaviour were scored when a child was being stationary with or without limb movement. The active behaviour were scored when a child was moving their centre of gravity. If a child was moved by physiotherapist or parents or a child was moved out of video frame, those epochs were

excluded from the analysis. The real time CARS scores were calculated into 5-second epochs for comparison with accelerometer data.

3.2.6 Habitual physical activity

Habitual physical activity levels of children with CP were determined using the ActiGraph®. Participants were asked to wear the ActiGraph® at the lower back (L2) using a neoprene belt during all waking hours except for water-based activities, for a minimum of three days[63] (two mid-week days and one weekend day). Parents of participants were instructed to complete a corresponding diary which recorded when the monitor was put on and taken off, when the child woke up, slept, was being carried or pushed in pram. After the ActiGraph® and the activity diary were returned; the ActiGraph® data were downloaded and the wear time period was confirmed with the activity diary. Non-wear time periods were excluded from the analysis. All wear time data were imported to MATLAB® and converted to counts per minute. Time spent sedentary (TSS) compared to time spent active were determined by using the cut-points from the validation study. As wear time in each participants varied, the proportion of total wear time that contributed to TSS (%TSS) was calculated and used for analyses. The mean activity counts per minute and %TSS were estimated and compared between ambulatory status groups (GMFCS I-II, GMFCS III and GMFCS IV-V).

3.3 Statistical considerations

All statistical analyse were performed in Stata® version 13 with the threshold for significance set at $p<0.05$.

3.3.1 Sub-study 1: Systematic review of the relationship between HPA and motor capacity in children with CP

Data from the systematic review could not be meta-analysed because there were various HPA and motor capacity measurements.

3.3.2 Sub-study 2: Validation of accelerometer cut-points in children with CP aged 4-5 years

This sub-study has two phases of analysis, calibration (n=55) and cross-validation (n=29). Analysis for the calibration phase used a Receiver Operating Characteristic (ROC) curve and area under the curve to derive cut-points which

maximized sensitivity and specificity in each GMFCS level.[64] The cut-points that were derived from the calibration phase and the previously established cut-point for sedentary time of 820 counts per minute in children with typical development by the Butte et al[65] were applied in an independent sample for the cross-validation phase. A Bland-Altman analysis was performed in the cross-validation phase to calculate the bias and 95% limits of agreement for percentage of time spent sedentary between the direct observation and accelerometer cut-points.[66] The differences of time spent sedentary between the observation and cut-points were compared using paired t-tests.

3.3.3 Sub-study 3: Habitual physical activity in children with CP aged 4-5 years across all functional abilities

Differences of activity counts and %TSS according to ambulatory status in children with CP were analysed in 67 participants using linear regression. Participants were classified into three groups, independently-ambulant (GMFCS I-II, n=46), marginally-ambulant (GMFCS III, n=7) and non-ambulant (GMFCS IV-V, n=14) groups. Differences of number of participants who met the Australian Physical Activity Guidelines according to ambulatory status were analysed using logistic regression.

3.3.4 Sub-study 4: Relationship between HPA, motor capacity and capability in children with CP aged 4-5 years

The association between activity counts, %TSS, the GMFM-66 and the PEDI functional skills of the mobility domain were analysed in 84 assessments of 67 participants (17 participants completed data at two time points) using mixed-effect regression models, with the child included as a random effect. Activity counts and %TSS were dependent variables. The GMFM-66 and PEDI were independent variables.

3.3.5 Sub-study 5: QOL and HPA in children with CP aged 5 years: a cross-sectional study

The CP QOL-Child score in 58 participants were compared between ambulant children, including GMFCS I-III and non-ambulant children, including GMFCS IV-V using linear regression models. Relationships of activity counts on each domain of the CP QOL-Child were examined using multiple linear regression, with domains as

dependent variables, activity counts as independent variables, and GMFM-66 as a covariate.

3.3.6 Sub-study 6: Longitudinal physical activity in preschool aged children with cerebral palsy across all functional levels

Changes in activity counts and %TSS across the GMFCS levels were analysed in 159 assessments of 95 participants using mixed-effects regression models, with child included as a random effect. Mixed-effects regression models with age as a main effect were performed to examine rate of change in HPA and %TSS. Interaction effects were included in all models.

3.4 Overall sample size justification

A total 175 participants consented to participate in the CP Child Study of Growth, Nutrition and Physical Activity. The number of assessments are shown in Figure 4. The total completed 3-day physical activity monitoring were 159 assessments in 95 participants (43 participants completed at least two time points). There were many incomplete physical activity data so that attaching a monitor to a young child was a challenge. Reasons for non-wear of the activity monitor were refusal from the child and parental difficulty attaching the monitor to their child. Power calculations were performed in each sub-study using the G*Power program (Version 3.1.9.2). All sub-studies have sufficient power ≥ 0.95 (α=0.05). Additionally, the BMI was calculated to check differences between groups through all sub-studies as the BMI may impact on HPA. The results found that the BMI were not significantly different, then average BMI data were not reported.

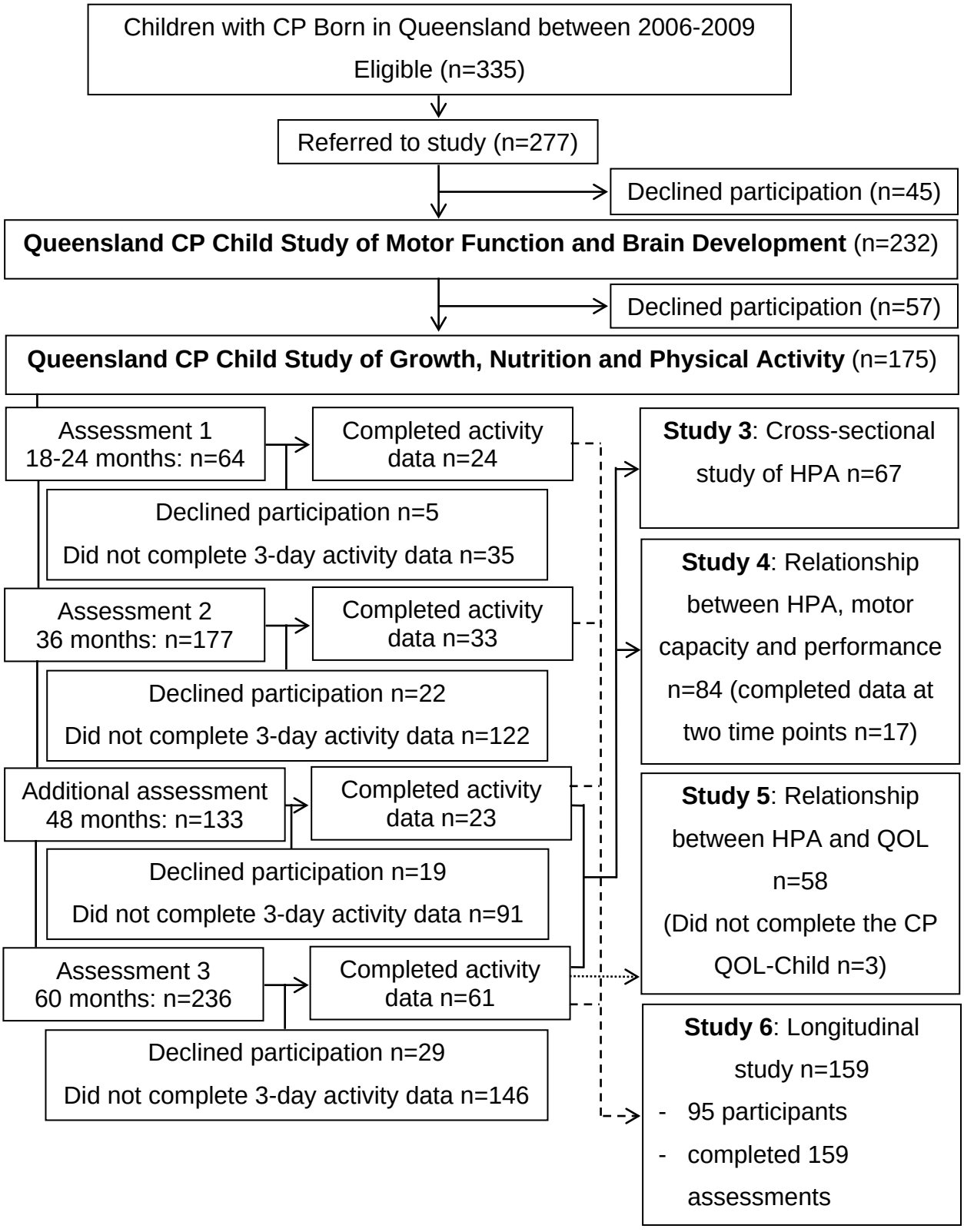

Figure 4 Overall number of assessments

CP, cerebral palsy; HPA, habitual physical activity; QOL, Quality of life.

Chapter 4: Validation of accelerometer cut-points

4.1 Introduction to Chapter 4

The validation study was conducted to derive and validate triaxial accelerometer cut-points for sedentary time in children with CP aged 4-5 years across all functional abilities and to compare these to previously established cut-points.[65] Data from the ActiGraph® accelerometer were compared with direct observation, a criterion measurement. The Receiver Operating Characteristic (ROC) curves were used to derive the cut-points and the Bland-Altman analyses were used for cross-validation.

4.2 Paper 2: Validation of accelerometer cut-points in children with cerebral palsy aged 4 to 5 years

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Title: Validation of accelerometer cut-points in children with cerebral palsy aged 4 to 5 years

Short title: Validation of accelerometer cut-points in CP 4-5 years

Authors: Piyapa Keawutan, Kristie L. Bell, Stina Oftedal, Peter S.W. Davies, Roslyn N. Boyd

4.2.1. Abstract

Purpose: To derive and validate triaxial accelerometer cut-points in children with cerebral palsy (CP) and compare these with previously established cut-points in children with typical development.

Methods: Eighty-four children with CP age 4 to 5 years wore the ActiGraph® during a play-based gross motor function measure assessment that was video-taped for direct observation. Receiver Operating Characteristic and Bland-Altman plots were used for analyses.

Results: The ActiGraph® had good classification accuracy in Gross Motor Function Classification System (GMFCS) levels III and V and fair classification accuracy in

GMFCS level I, II and IV. These results support the use of the previously established cut-points for sedentary time of 820 counts per minute in children with CP aged 4 to 5 years across all functional abilities.

Conclusions: The cut-point provides an objective measure of sedentary and active time in children with CP. The cut-point is applicable to group data but not for individual children.

Key words: cerebral palsy, children, gross motor function, measurement, physical activity, sedentary behavior, validation

4.2.2. Introduction

Physical activity is defined as “any bodily movement produced by skeletal muscles which results in energy expenditure” whereas habitual physical activity (HPA) is any physical activity in daily life.[1] Physical activity is associated with many health benefits in children, including improvements in bone health, cardiovascular and muscular fitness.[2, 3] Habitual physical activity can be determined using various measures, both subjective and objective.[4] Direct observation is a standard and practical assessment of physical activity based on definition.[5] Disadvantages of direct observation are high experimenter burden and reactivity of participants.[5] The ActiGraph® accelerometer is an objective HPA measure that has been widely used in children with typical development.[6] It can be used in free living conditions to measure activity intensity, duration and frequency.[6] There are two versions of the ActiGraph®, uniaxial and triaxial. The uniaxial accelerometer detects acceleration of body movement in vertical axis whereas the triaxial accelerometer detects movement in three dimensions, vertical (X), antero-posterior (Y) and mediolateral (Z) axes. The triaxial ActiGraph® calculates activity counts from three planes of movement into vector magnitude ($VM=\sqrt{X^2+Y^2+Z^2}$) whereas the uniaxial accelerometer uses the vertical axis to represent activity counts. Vector magnitude could better represent physical activity than the vertical axis alone as it combines movement from three planes. In addition, the triaxial ActiGraph® (GT3X) has been reported to have good/excellent reproducibility and good/fair concurrent validity compared with oxygen consumption (VO_2).[7]

Cerebral Palsy (CP) is an umbrella term for a non-progressive disorder of movement and posture.[8] Children with CP can be classified by gross motor capacity, using the Gross Motor Function Classification System (GMFCS) into five levels. Children with CP who can walk independently without restriction are classified as

GMFCS level I and those who can walk independently but have limitations when walking on uneven surfaces are classified as level II. GMFCS level III classifies children with CP who can walk with an assistive mobility device. For children with CP who rely on wheel chair, GMFCS level IV classifies those who can walk for short distances on a walker and level V classifies those who have severely limited self-mobility requiring a wheel chair to ambulate.[9] Movement limitations associated with CP can have a significant effect on HPA. A previous systematic review found that young people with CP aged 5 to 18 years across all levels of motor function performed 13% to 35% less HPA than their peers developing typically.[10] According to the International Classification of Functioning, Disability and Health (ICF), measurement of physical activity and sedentary behavior can be used as outcome measures in activity and participation domains.[11] The ActiGraph® accelerometer has been reported to be a valid measure HPA in children with CP and useful in clinical setting.[12] Wearing the ActiGraph® around the waist is feasible and unobtrusive in ambulatory and non-ambulatory children with CP.[13] As physical activity patterns in childhood can persist into adulthood, knowledge of physical activity levels and sedentary time in young children could provide valuable information for the development of better interventions in children with CP who may be inactive.

Physical activity data provided by the ActiGraph® includes activity counts (counts per epoch of time) which are accelerations of body movement. To determine a category of activity intensity (sedentary, light, moderate and vigorous) from activity counts, a cut-point for each intensity is required. In addition, validity of cut-points need to be established for children of specific age ranges and conditions. The ActiGraph® cut-points have been validated in toddlers with CP (18-36 months),[14] children and adolescents with CP (8-16 years)[15] and adults with CP.[16] The cut-points are yet to be validated in children with CP aged 4 to 7 years; however, the Evenson cut-points[17] in children with typical development aged 5 to 8 years have been used in many studies of school-aged children with CP.[13, 18, 19] A recent study by Butte et al.[20] established the triaxial ActiGraph® cut-points in preschool children with typical development (mean aged 4.5 years) against energy expenditure of 820, 3908, 6112 counts per minute for sedentary/light, light/moderate and moderate/vigorous physical activity. Studies of HPA in preschool children with CP (4-5 years) are limited possibly because of the lack of cut-points validity. The present study was designed to calibrate and validate cut-points in children with CP aged 4 to 5 years. The first aim of this study was to derive

the triaxial accelerometer cut-points against a criterion measurement (direct observation) in children with CP aged 4 to 5 years. The second aim of this study was to validate the developed cut-points in an independent sample of children with CP. The third aim of the study was to validate previously established cut-points for children developing typically by Butte et al.[20] in the present sample of children with CP, and compare their validity to newly the developed CP cut-points.

4.2.3. Methods

This study is incorporated two population based cohort studies.[21,22] Children born in the birth years 2006 to 2009 diagnosed with CP were eligible to be recruited. Participants were assessed every 6 months from 18 to 36 months and at 48 and 60 months' corrected age. Children were excluded if they were diagnosed with a progressive brain disorder. The assessments were conducted in many locations, including hospitals and home visits by a research physical therapist and a research dietician. All institutions where assessment were conducted approved the study. Informed consent was obtained for all participants from their parents or legal guardians.

Participants

Eighty-four children with CP across the spectrum of functional severity (GMFCS levels I-V) were recruited in this study. All participants were randomly divided into two groups according to the GMFCS to allow for the two phases of the study (calibration and subsequent validation of cut-points) at a 2:1 ratio. Fifty-five participants were allocated to the calibration group and 29 participants were allocated to the validation cut-points group. Characteristics of participants are shown in Table 1. There were no significant differences between samples for any variables.

Outcome measure and procedures

Participants wore the triaxial ActiGraph® accelerometer (GT3X and GT3X+, AtiGraph, Florida) during 66-item gross motor function measure (GMFM-66) assessments. The ActiGraph® records accelerations ranging in magnitude from 0.5 to 2.0 g and digitized by 12 bit analog to digital converter at rate of 30 Hz.[23] All assessments were videotaped and a digital watch was used to synchronized to the ActiGraph® with direct observation of the video. The GMFM-66 assessment is a gross motor function test based on typical development with a wide range of activities from floor activities to advanced activities.[24] The assessment was performed by a research physical therapist using play-based activities. The ActiGraph® was worn at a child's

lower back close to the center of mass of the body (L2) using a neoprene belt in order not to limit movement of the children. A study in children with typical development demonstrated that there were no significant differences of activity recording between wearing an accelerometer at lower back and hip.[6] Another reason to place the monitor at lower back is to limit the effect of asymmetrical gait patterns in children with CP.[25] Previous studies reported that physical activity in children is an intermittent burst and varying interval with the median duration of 6 seconds for low and moderate intensity activities.[26, 27] The accelerometers were set at 5-second epochs to detect short bursts of activity in children with CP. Vector magnitude (counts per 5 seconds) which is a combination of three planes of movement (vertical, anteroposterior and mediolateral planes) was used to compare with direct observation as the criterion measurement.

The videos of GMFM-66 assessments were scored in real time using the computerized direct observational system Behavioral Evaluation Strategy and Taxonomy (BEST, Inc., Florida). Children's activities were categorized into two activity intensities: sedentary and active. When a child was stationary with or without limb movement activity was scored as sedentary. Activity was scored as active when a child moved the center of mass. If a physical therapist or a parent moved a child or a child moved out of frame, the epochs were excluded from analysis. The real-time direct observation scores were calculated into 5-second epochs to match the accelerometer data. All videos were scored by one observer. The intrarater reliability for scoring was analyzed by double scoring of 20 videos (four children in each GMFCS level) two weeks apart. The agreement of 4934 epochs was 88.9% with 0.81 Kappa score (p<0.001), which was determined as excellent.[28]

Statistical analysis

Data were analyzed using SPSS version 22 statistical package. In the calibration phase, receiver operating characteristic (ROC) curve analyses were performed to derive cut-points for sedentary time that maximize sensitivity and specificity for each GMFCS level. The ROC curve is a plot of the true-positive fraction against false-positive fraction (inverse of the specificity) to determine diagnostic accuracy.[29] Each plot on the curve is the cut-point that provided individual sensitivity and specificity (Figure 1). The range of the sensitivity and specificity is between 0 and 1. The cut-points with maximum sensitivity and specificity were selected from each analysis. The vector magnitude (counts per 5 seconds) was used to determine the ROC curve at the test variable and the direct observation scoring was the state

variable, where 1=active and 0=sedentary. An area under the ROC curve was used to determine accuracy of the two measures. An area under the curve of 1 represents perfect accuracy while that of 0.5 represents a complete absence of accuracy. An area under the curve 0.9 or more was defined as excellent accuracy; 0.80 to 0.90 was good; 0.70 to 0.80 was fair; and less than 0.7 was poor.[29]

The cut-points for sedentary time from the calibration phase and the Butte cut-point of 68 counts per 5 seconds (820 counts per minute)[20] were validated using Bland-Altman analysis to calculate bias and 95% limits of agreement between two measures (the ActiGraph® cut-points and direct observation). As total valid time in each participant varied, a percentage of time spent sedentary of total valid time was used in the Bland-Altman analysis. A paired t-test was used to compare the differences between these two measurements with an α level of 0.05 to determine significance.

4.2.4. Results

Eighty-four children with CP including 48 males (mean age of 4 years 8 months [SD=6 months]; GMFCS level I=26, II=20, III=15, IV=12, V=11; unilateral spasticity=20, bilateral spasticity=55, dystonia=2, ataxia=5, hypotonia=1 and athetosis=1) were included. Average duration of the GMFM-66 assessments in calibration and validation sample was 19.1 and 19.6 minutes and average valid epochs (excluding the time when a child was moved by a therapist or the child moved out of the frame) for analysis were 16.1 minutes (192 epochs) and 16.9 minutes (203 epochs), respectively (see the Table).

Calibration phase

The ROC curve analyses for each GMFCS level are graphed in Figure 1. The selected cut-points for sedentary time were 100 counts per 5 seconds in the GMFCS I (74% sensitivity and 73% specificity), 93 counts per 5 seconds in the GMFCS II (73% sensitivity and 73% specificity), 63 counts per 5 seconds in the GMFCS III (74% sensitivity and 74% specificity), 60 counts per 5 seconds in the GMFCS IV (65% sensitivity and 63% specificity), and 16 counts per 5 seconds in the GMFCS V (81% sensitivity and 80% specificity). The area under the ROC curve (AUC) had good classification accuracy in the GMFCS III (AUC=0.81; 95% confidence interval [CI]=0.79-0.82) and V (AUC=0.84; 95%CI=0.78-0.89) and fair classification accuracy in GMFCS I (AUC=0.79; 95%CI=0.77-0.81), II (AUC=0.78; 95%CI=0.76-0.80) and IV (AUC=0.70; 95%CI=0.67-0.73).

Validation phase

The cut-points for sedentary time from the calibration phase and the Butte cut-point were applied to an independent sample of children with CP for the validation phase to determine time spent sedentary. The Bland-Altman plots are graphed in Figure 2. The Butte cut-point demonstrated lower bias in the GMFCS I, II, IV and V and narrower 95% limits of agreement in the GMFCS I, II, III and V. Comparing differences of percentage of time spent sedentary between the cut-points and the direct observation using a paired t test supports that the CP cut-point in GMFCS group I significantly overestimated time spent sedentary (p=0.037). The Butte cut-point overestimated time spent sedentary, but this difference was not statistically significant (p=0.091). In the other GMFCS groups no significant differences in time spent sedentary between observed and predicted values were found. In addition, the sensitivity and specificity for the validation group were calculated and are presented in a supplementary Table.

4.2.5. Discussion

In the calibration phase, good classification accuracy was found for the ActiGraph® cut-points for sedentary time in children with CP classified as GMFCS III and V and fair classification accuracy in children with CP classified as GMFCS I, II and IV (area under the ROC curve=0.79, 0.78 and 0.7, respectively). The ActiGraph® has some limitations in detecting body movement because of a stationary trunk for example standing. Children who are GMFCS IV have various positions on the floor such as crawling without reciprocal movement that the ActiGraph® might detect as sedentary activity. This may impact on the classification accuracy. The CP cut-points for sedentary time from this present study were different from the Butte cut-point.[20] A reason for these differences might be a difference in the criterion measurement. Our study used direct observation whereas the Butte study used energy expenditure (indirect calorimetry). Although direct observation and indirect calorimetry are both criterion standards of physical activity level, they are quite different. Energy expenditure is a physiologic consequence of physical activity as it refers to internal heat produced (basal metabolic rate and processing food for use and storage) and external work (physical activity). Direct observation is a gold standard for physical activity research.[5] Observation relies on an individual's judgment, but in this study interrater reliability of direct observation was excellent. Furthermore, direct observation method is more practical in young children with CP than indirect calorimetry.

In the validation phase, the CP cut-point in GMFCS group I significantly overestimated time spent sedentary, whereas there was no significant difference between observed and predicted time spent sedentary when using the Butte cut-points. In children classified as GMFCS II, IV and V, the Butte cut-point for sedentary time resulted in a smaller bias than the CP cut-point. The Butte cut-point also showed narrower 95% limits of agreement than the CP cut-point in GMFCS II, III and V. This suggests that the Butte cut-point of 68 counts per 5 seconds (820 counts per minute) for sedentary time from preschool children with typical development[20] can be used in children with CP aged 4 to 5 years across all GMFCS levels. There was small bias but wide 95% limits of agreement, which indicates that although the results were accurate on a group level, the difference between observed and predicted time spent sedentary for an individual child may be significant. It is recommended that time spent sedentary determined by the cut-point should only be compared on a group level. A previous study found that triaxial accelerometer cut-point for sedentary time in toddlers (18-36 months) with typical development and ambulatory toddlers with CP was 40 counts per 5 seconds and the cut-points in non-ambulatory toddlers with CP was 10 counts per 5 seconds.[14] The cut-points in toddlers are lower than in preschoolers. There are also different cut-points for sedentary time between ambulatory (GMFCS I-III) and non-ambulatory toddlers with CP (GMFCS IV-V). In contrast, the results of this study suggest that preschool children with CP can use the same cut-point for sedentary time regardless of the functional capacity.

According to the Australian physical activity guidelines, children aged 0-5 years should not be sedentary for more than one hour at a time, with the exception of sleeping, and should be physically active for at least three hours every day.[30] This study has validated cut-points for sedentary time which can be useful when assessing children with CP aged 4-5 years and determining whether they meet the physical activity guidelines. For the last two decades, improved HPA has focused on increasing moderate to vigorous physical activity. A recent study suggests that reducing sedentary behavior needs to be considered, as the effects of sedentary behavior are different from a lack of moderate to vigorous physical activity.[31] People who had moderate to vigorous physical activity for short periods and inactive the rest of the day are associated with high risk of chronic diseases.[31] In addition, sedentary behavior is the fourth leading risk factor for global mortality.[3] Previous studies using accelerometers measured sedentary time in children and youths with CP (GMFCS I-

III) found that children and youth with CP spend more time sedentary than their peers developing typically.[19, 32] The cut-points for sedentary time validated in this study could be used to assess efficacy of HPA interventions in preschool-aged children with CP (4-5 years) and allow longitudinal studies assessing the link between HPA and health outcomes. Increasing HPA has been reported to be associated with increased cardiorespiratory fitness, muscular strength, bone health and reduced metabolic disease risk factors, symptoms of anxiety and depression in children with typical development[3] but there are limited studies in children with disabilities.

The strengths of this study include having an independent validation sample; and including children with CP across all functional motor abilities. A potential limitation of this study is the small number of participants, which might impact the classification accuracy estimate of the cut-points. Further studies should provide additional validation data in participants at all GMFCS levels. In addition, the direct observation criterion measure does not differentiate between lying/sitting and standing. A recent study reported that standing posture in children with CP required energy expenditure more than 1.5 metabolic equivalents despite standing with support in children with GMFCS IV-V which is defined as non-sedentary activity.[33] The study suggests that children with CP should frequently change position to standing to reduce sedentary behavior.[31] Further cut-points studies should consider including the differentiation between lying/sitting and standing posture as standing posture is light activity.

4.2.6. Conclusion

ActiGraph® accelerometer cut-points are valid measures of sedentary and active time and these results support the use of the Butte cut-point of 68 counts per 5 seconds (820 counts per minute) for sedentary time in children with CP aged 4 to 5 years across all functional abilities. The cut-point for sedentary time can be used to determine time spent sedentary and active in this group of children providing an alternate objective outcome in addition to motor capacity. Time spent sedentary and active can be used to compare control and intervention groups, and also compare children's activity levels with the physical activity guidelines. In addition, physical activity levels can be a health indicator of change over time. It is important to note that the cut-point for the amount of sedentary time is recommended for use on a group basis not for individual children.

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Table 1 Characteristics of study participants (mean (SD)) whom were children with cerebral palsy aged 4 to 5 years.

	Calibration sample						Validation sample					
GMFCS	n	Age (years)	GMFM-66 (score)	GMFM-66 assessment duration (min)	Valid time* (min)	Valid epoch*	n	Age (years)	GMFM-66 (score)	GMFM-66 Assessment duration (min)	Valid time* (min)	Valid epoch*
I	17	4.6 (0.5)	76.1 (9.0)	17.3	16.0	191	9	4.7 (0.5)	76.2 (8.9)	16.1	15.0	179
II	13	4.9 (0.3)	62.0 (5.5)	19.7	16.0	192	7	4.6 (0.5)	62.1 (3.8)	22.3	21.5	257
III	10	4.6 (0.5)	52.3 (3.5)	21.8	20.1	241	5	4.6 (0.5)	49.9 (1.7)	26.5	22.6	271
IV	8	4.8 (0.5)	44.0 (9.9)	24.3	15.4	184	4	4.8 (0.5)	38.2 (4.3)	18.5	13.0	156
V	7	4.7 (0.5)	21.6 (4.6)	12.6	11.4	136	4	4.5 (0.6)	20.1 (2.9)	14.2	10.1	121

Key: GMFCS, Gross Motor Function Classification System; GMFM-66, 66-item Gross motor function measure; n, number of participant; SD, standard deviation; y, years; m, months; *excluding the time when a child was moved by a therapist or the child moved out of the frame; no significant differences between calibration and validation samples.

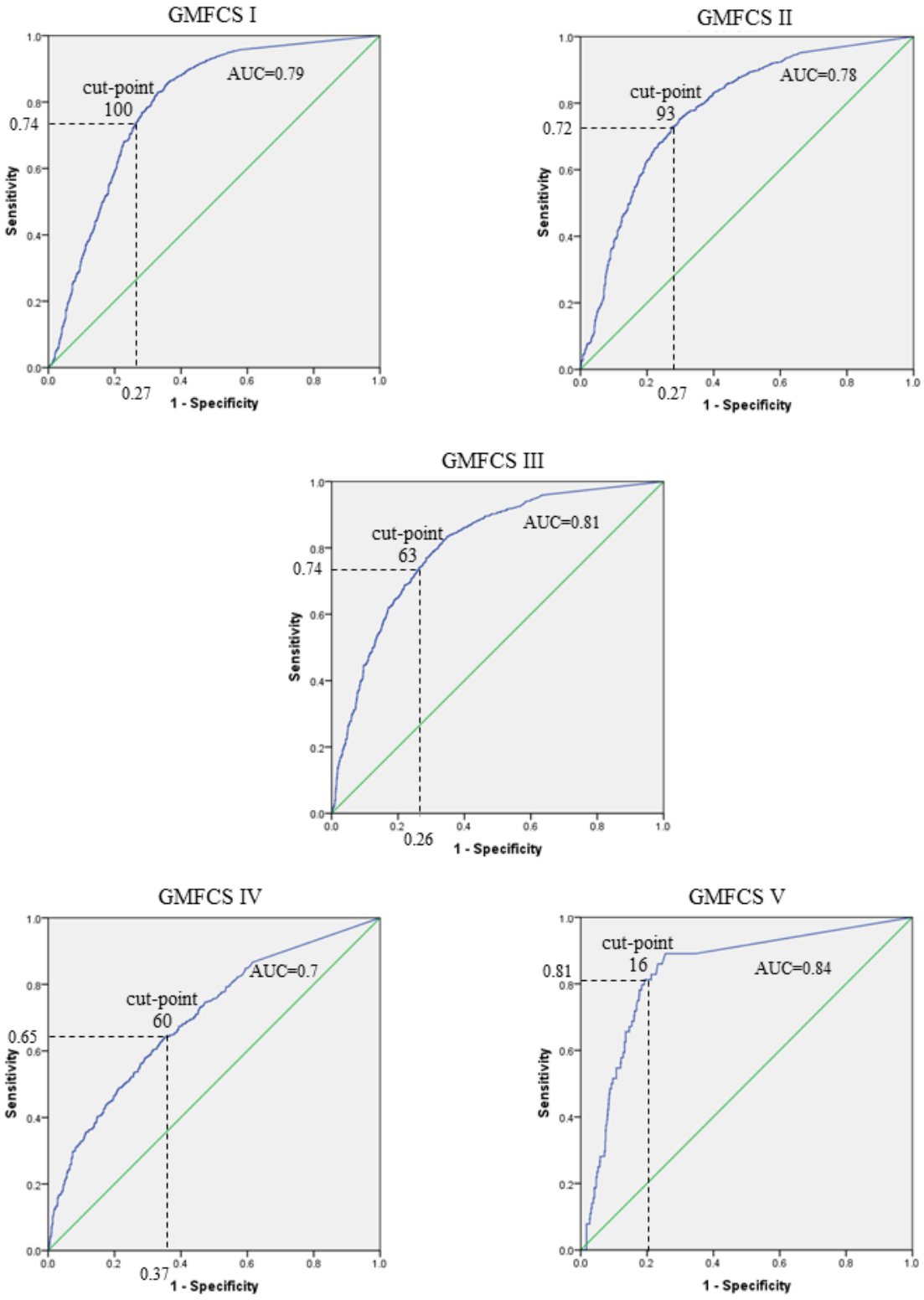

Figure 1 Receiver operating characteristic (ROC) curves in the calibration phase to determine classification accuracy and cut-points for sedentary time with maximum sensitivity and specificity in children with cerebral palsy GMFCS I (n=17), GMFCS II (n=13), GMFCS III (n=10), GMFCS IV (n=8), GMFCS V (n=7); AUC, Area under the ROC curve.

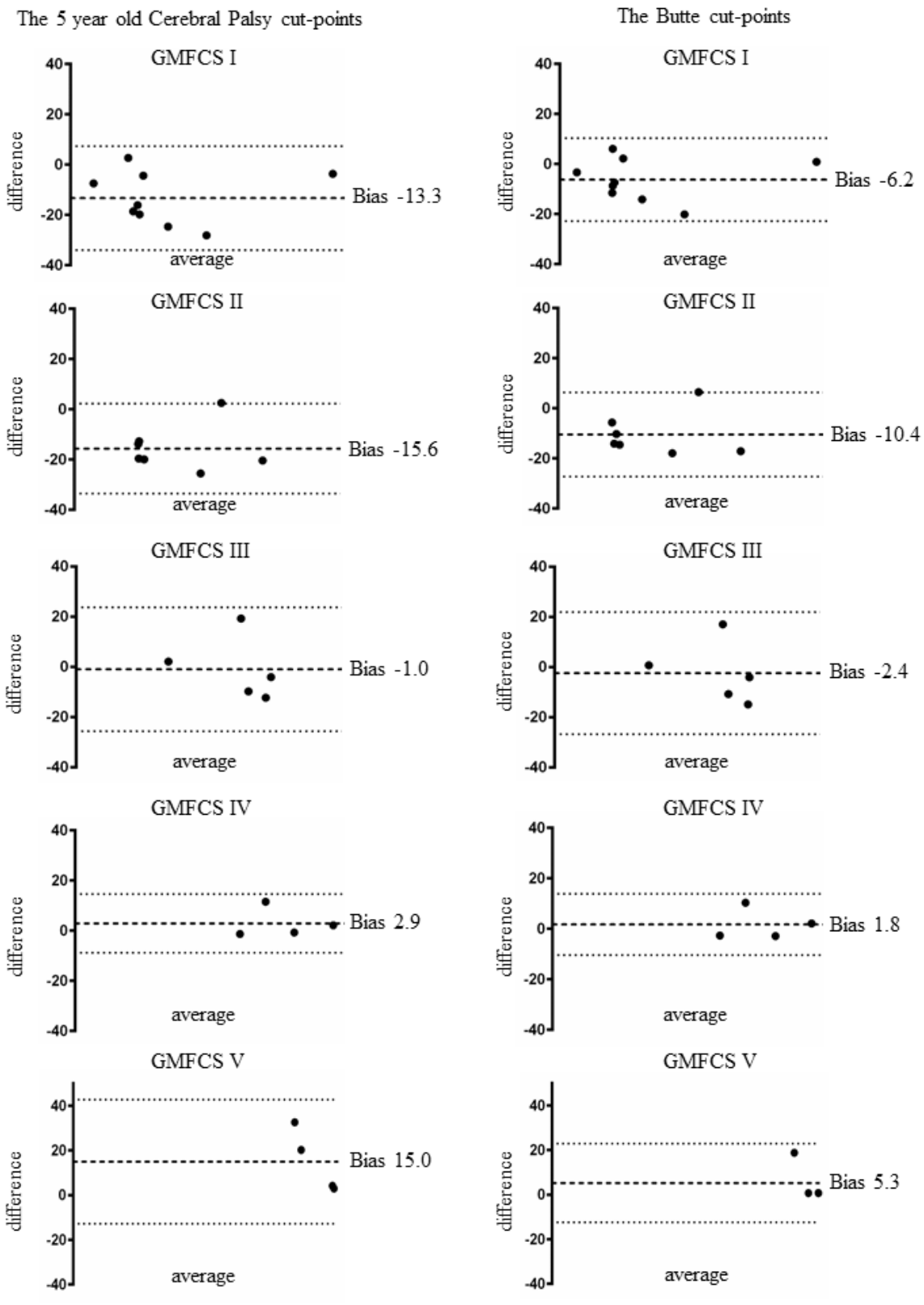

Figure 2 Bland-Altman graphs of percentage of time spent sedentary between direct observation and cut-points from children with CP (this study) and children with typical development (the Buttte NF. et al., 2014) in the validation sample

Dot lines (……) refer to 95% limits of agreement; GMFCS I (n=9), GMFCS II (n=7), GMFCS III (n=5), GMFCS IV (n=4), GMFCS V (n=4).

Supplementary Table 1 Bland-Altman analysis of percentages of time spent sedentary between direct observation and cut-points from children with CP (this study) and children with typical development (Butte NF. et al., 2014) in the validation sample.

GMFCS	n	Method	Sensitivity (%)	Specificity (%)	Sedentary time (mean (range); min)	Bland-Altman analysis		Paired t-test *p*-value
						Bias*	95% limits of agreement	
I	9	Observation	-	-	3.6 (0.4 – 8.0)	-	-	-
		CP cut-point (100 counts/5s)	78.6	84.0	6.0 (1.1 – 15.9)	-13.3%	-34.0% to 7.4%	0.037*
		TD cut-point (68 counts/5s)	84.1	79.6	4.8 (0.8 – 12.2)	-6.2%	-22.8% to 10.4%	0.091
II	7	Observation	-	-	6.6 (0.9 – 19.6)	-	-	-
		CP cut-point (93 counts/5s)	78.2	86.7	9.8 (1.7 – 21.7)	-15.6%	-33.5% to 2.3%	0.062
		TD cut-point (68 counts/5s)	81.7	83.2	8.6 (1.3 – 19.6)	-10.4%	-27.2 to 6.4%	0.125
III	5	Observation	-	-	13.2 (3.8 – 24.3)	-	-	-
		CP cut-point (63 counts/5s)	72.5	76.2	12.6 (3.6 – 20.6)	-1.0%	-25.6% to 23.7%	0.770
		TD cut-point (68 counts/5s)	71.8	77.0	12.9 (3.8 – 20.6)	-2.4%	-26.8% to 21.9%	0.890
IV	4	Observation	-	-	9.3 (7.1 – 11.0)	-	-	-
		CP cut-point (60 counts/5s)	79.7	87.6	8.9 (6.9 – 11.3)	2.9%	-8.8% to 14.6%	0.460
		TD cut-point (68 counts/5s)	79.0	88.7	9.1 (6.9 – 11.5)	1.8%	-10.4% to 13.9%	0.695
V	4	Observation	-	-	10.0 (8.4 – 11.2)	-	-	-
		CP cut-point (16 counts/5s)	50.0	86.7	8.6 (5.7 – 10.8)	15.0%	-12.7% to 42.8%	0.104
		TD cut-point (68 counts/5s)	50.0	94.7	9.6 (6.8 – 11.1)	5.3%	-12.4% to 23.0%	0.309

Key: CP, Cerebral Palsy; GMFCS, Gross Motor Function Classification System; min, minutes (1 minute = 12 epochs); TD, typical development

*Bias = difference of percentage of time spent sedentary of total valid time between direct observation and accelerometer cut-points.

4.3 Summary and conclusion

This study supports the use of the previously established cut-point for sedentary time (Butte et al., 2014[65]) of 820 counts per minute in children with CP aged 4-5 years across all functional abilities. A potential limitation of this study is the small number of participants (n=7-17 for calibration phase, and n=4-9 for validation phase), which might impact the classification accuracy estimate of the cut-points. Specific findings are as follows:

i) There was a small bias but wide 95% limit of agreement. This suggests that the cut-point is applicable on a group basis and not for individual children, as observed and predicted time spent sedentary for an individual child may be significantly different.

ii) The cut-point for sedentary time which was validated in children with CP allows measurement of active and sedentary time in children with CP aged 4-5 years, using the ActiGraph® triaxial accelerometer.

Chapter 5: Habitual physical activity in children with cerebral palsy aged 4-5 years across all functional abilities

5.1 Introduction to Chapter 5

This study was designed as a cross-sectional study to examine HPA and TSS in children with CP using the ActiGraph® triaxial accelerometer to monitor all waking activities for three days, two of which were weekdays and one was a weekend day. Sedentary time was determined using the validated cut-points from sub-study 2 (Chapter 4). Participants were grouped according to ambulatory status into three groups: independently-ambulant (GMFCS I-II), marginally-ambulant (GMFCS III) and non-ambulant (GMFCS IV-V). The results were compared between groups and compared with the Australian Physical Activity Guidelines.

5.2 Paper 3: Habitual physical activity in children with cerebral palsy aged 4 to 5 years across all functional abilities

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Title: Habitual physical activity in children with cerebral palsy aged 4 to 5 years across all functional abilities

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5.2.1. Abstract

Purpose: Habitual physical activity (HPA) and time spent sedentary (TSS) were compared between ambulatory status in children with cerebral palsy (CP) aged 4-5 years, and to compare their activity with physical activity guidelines.

Methods: Sixty-seven participants, independently-ambulant (GMFCSI-II, n=46), marginally-ambulant (GMFCSIII, n=7) and non-ambulant (GMFCSIV-V, n=14) wore accelerometers for three days. Time spent sedentary as a percentage of wear time

(%TSS) and activity counts (counts/minute) were compared between groups using regression analyses.

Results: There were significant differences in %TSS and activity counts between groups (mean difference; 95% confidence interval compared to GMFCSI-II; %TSS: GMFCSIII=16; 9,23 and GMFCSIV-V=35; 30,40; activity counts: GMFCSIII=-510; -790,-230 and GMFCSIV-V=-1107; -1317,-896) Independently-ambulant children were more likely to meet physical activity guidelines.

Conclusion: Children with CP spent more than half of their waking hours in sedentary time. Interventions to reduce sedentary behavior and increase HPA are needed in children with CP at age 4-5 years.

Key words: habitual physical activity, sedentary behaviour, children, cerebral palsy, gross motor function

5.2.2. Introduction

Physical activity has many potential health benefits in children including improvement of cardiorespiratory, cardiovascular, muscular fitness, bone health and mental health.[1, 2] Physical activity is defined as “any bodily movement produced by skeletal muscles which results in energy expenditure”. Physical activity in daily life refers to habitual physical activity (HPA).[3] Sedentary behavior has been defined as “any waking behavior characterized by energy expenditure ≤ 1.5 metabolic equivalents (METs) while in a sitting or reclining position”.[4] As physical activity is an important factor for ongoing health, the World Health Organization (WHO) has developed global recommendations on physical activity for health from 5 years old and throughout the life span.[1] Furthermore, many countries have developed physical activity guidelines.[2, 5, 6] The Australian Physical Activity Guidelines for children aged 0-5 years recommend that children should be physically active for at least three hours a day, which are similar to the Canadian Physical Activity Guidelines.[5, 6] In addition, children in this age group should not be sedentary for more than one hour at a time (except when sleeping).[5]

Children with cerebral palsy (CP) have limited motor capacity due to abnormal muscle tone and posture caused by a brain lesion in early life.[7] Children with CP can be classified into five levels of gross motor ability according to the gross motor function classification system (GMFCS). Categories range from I, independent ambulation without restriction, to V, limited voluntary control, dependent for transfers and mobility. Functional limitation of children with CP can impact on their HPA level. Ambulatory children and youth with CP spend less time in moderate to vigorous physical activity

and more time in sedentary behavior than their peers.[8, 9] Gross motor function (walking, running and jumping) is a potential predictor of physical activity in adolescents and young adults with CP.[10] A previous systematic review has reported that young people with CP (aged 5-18 years) across all functional classifications performed 13% to 50% less HPA than their peers.[11] Recently, a study found that sedentary behavior in independently ambulant toddlers with CP aged 18-36 months (GMFCS I-II) was not significantly different from toddlers with typical development while marginally-ambulant and non-ambulant toddlers (GMFCS III-V) had significantly higher sedentary time than those with typical development.[12]

Only 25% of children and adolescents with CP with GMFCS I-II (age 8 to 17 years) were found to have performed 60 minutes of moderate to vigorous physical activity (the recommendation of their age band) on at least one day of monitoring using the triaxial ActiGraph® accelerometer.[13] Recently evidence suggests that to improve HPA in children with CP requires not only increasing moderate to vigorous physical activity but also reducing sedentary behavior, as the effect of sedentary behavior is distinctly different from a lack of moderate to vigorous physical activity.[14] Additionally, the capacity for increasing moderate to vigorous physical activity in children with CP is limited so increasing light physical activity is more achievable. Limitations of moderate to vigorous physical activity in children with CP is due to not only their biomechanical constraints but also their fitness levels. Previous studies reported that children with CP have lower fitness levels including aerobic, anaerobic capacity, and muscle strength compared to their typically developing peers.[15-21]

Existing studies that investigated HPA in children with CP using objective measures are limited in ambulatory children with CP (GMFCS I-III) aged 2-13 years. Only one previous study has used accelerometers for measuring HPA across all functional abilities (GMFCS I-V) in toddlers with CP aged 1.5-3 years.[12] There are no studies that have specifically examined HPA in pre-school children with CP aged 4-5 years across all functional abilities (GMFCS I-V). The aim of this study was to objectively investigate HPA and sedentary behavior in children with CP age 4-5 years across all functional abilities and compare them to the Australian Physical Activity Guidelines.[5]

5.2.3. Methods

This cross-sectional study of 4-5 year old children with CP was conducted in Brisbane, Australia between October, 2010 and December, 2014. Data is derived from

two population-based cohort studies, the CP Child Study of Motor Function and Brain Development[22] and the CP Child Study of Growth, Nutrition and Physical Activity.[23] The inclusion criteria for these studies were birth between 2006 and 2009 with a diagnosis of CP in Queensland, Australia. Children diagnosed with a progressive brain disorder were excluded. In the CP Child Study of Motor Function and Brain Development, participants were assessed every 6 months from 18-36 months then at 48 and 60 months corrected age. The CP Child Study of Growth, Nutrition and Physical Activity assessed participants at three time points, 17-25 (depending on study entry), 36 and 60 months corrected age. Some participants who entered the study after age 25 months were assessed at age 48 months. All participants assessed at 48 or 60 months were included in this study. The study assessments were conducted at several hospitals and during home visits. Ethics approval was obtained from all sites where assessments were conducted. Informed consent was obtained by parents or legal guardians of participants.

Participants

One hundred and fifty-eight children which were representative sample of the Australian CP register were assessed.[24] Characteristics of the participants are reported in Table 1. Sixty-seven participants (42%) completed 3 days of activity monitoring. Ninety-one participants were excluded from analysis due to incomplete data (13 children reported 2 days of monitoring; 3 children reported 1 day and 75 children did not report any days). Reasons for not wearing the monitor included refusal to wear it and other difficulties in which parents were unable to complete the activity diary and attach the monitor to their child. There were no differences in characteristics of participants who were included and excluded from the study (Table 1). This implies that our sample for this study was a representative sample of the population. Participants with complete data (n=67) were grouped according to ambulatory status into three groups, independently-ambulant (GMFCS I-II, n=46), marginally-ambulant (GMFCS III, n=7) and non-ambulant (GMFCS IV-V, n=14) groups.

Outcome measures and procedures

Height and weight of all participants were measured to calculate body mass index (BMI). All participants were assessed motor type, distribution, classification and function by a research physiotherapist. The Gross Motor Function Classification System (GMFCS) was used to classify gross motor function and the Gross Motor Function Measure 66 items (GMFM-66) was used to assess motor function.

The ActiGraph® triaxial accelerometer (GT3X and GT3X+) was used to measure HPA. It was set to collect data at 5-second epochs to detect short bursts of activity. The monitors were worn at participants' lower back (L2) close to the center of gravity using a neoprene belt in order not to limit movement and accurately measure asymmetrical gait patterns.[25, 26] Placement of the ActiGraph® at lower back was validated in children with CP aged 1.5-5 years across all functional abilities.[27, 28] All waking activities except water-based activities were recorded by the monitor, which is not water resistant, for 3 days (2 weekdays and 1 weekend day), a minimum requirement to determine physical activity.[29] A three-day activity diary was completed by parents of participants. It included the time the child woke up, when the monitor was put on and taken off, when the child was being carried or pushed in stroller, and sleep times. Activity data were exported form the accelerometer via ActiLife® software. The data from three planes of movement (vertical, X; antero-posterior, Y and medio-lateral, Z) were combined into a vector magnitude ($VM=\sqrt{(X^2+Y^2+Z^2)}$; counts per 5-seconds). They were checked against the activity diaries and non-wear time was deleted from analyses. The "non-wear time" was the period that the ActiGraph® was removed from a child for sleeping, bathing, swimming, or other water-based activities. The period that a child was carried or transported in car was not deleted but were recorded as sedentary time. Any ambiguous data were clarified with the parents. Each day was manually filtered for non-wear time. The data were calculated using MATLAB (The MathWorks Inc., version R2012b) as wear time period (hours), time spent sedentary (TSS) and activity counts (counts per minute). Participants who had wear time period less than six hours per day were deleted from the analysis. As wear time varied, TSS was calculated into percentage of total wear time (%TSS). Number of participants who met the recommendations of TSS less than one hour at a time and active time more than three hours a day were calculated.

Time spent sedentary was determined by the cut-point of 68 counts per 5-second from children with typical development[30] which was validated in preschool children with CP in our previous study.[28] The ActiGraph® cut-points for sedentary time in children with CP aged 4-5 years were validated across all GMFCS levels (level I n=26, II n=20, III n=15, IV n=12, V n=11) against direct observation, a criterion measure. The cut-points with maximum sensitivity and specificity were derived using receiver operating characteristic curves for each GMFCS level. Cross-validation

analysis found that the cut-point of 68 counts per 5-second can be used to determine TSS across all GMFCS levels.

Statistical analysis

Characteristics of participants were compared using a linear regression for continuous variables and logistic regression for categorical variables. The activity data between weekdays and weekend days was compared using a paired t-test. Activity data between boys and girls were compared using linear regression. Differences in activity data between three ambulatory groups were compared by a linear regression. Physical activity patterns throughout a day were plotted by mean activity counts (counts per 5-second) in each hour against time from 7 am to 7 pm. The number of participants who met the Australian Physical Activity Guidelines for sedentary and active time on at least one day of activity monitoring were compared between three ambulatory groups using logistic regression. Relationships between %TSS, activity counts and GMFM-66 were analyzed using linear regression. All statistical analyses were performed using Stata statistical software v13.1 (StataCorp, College Station, TX, USA). Statistical significance was set at p=0.05.

5.2.4. Results

Sixty-seven participants with complete 3 days of activity monitoring were included. The motor type and distribution of included participants were unilateral spasticity=30 (45%), bilateral spasticity=30 (45%), dystonia=5 (8%), ataxia=1 (1%) and hypotonia=1 (1%); GMFCS I=37 (55%), GMFCS II=9 (13%), GMFCS III=7 (10%), GMFCS IV=3 (5%), GMFCS V=11 (16%). For participants who had two data sets, at 48 month and 60 months, the data at 60 months were used for this study. The BMI between the three groups were not significantly different. There were more boys than girls in all groups and no differences in proportion of sexes between GMFCS categories.

The analysis of different day types and sexes

Five participants wore the monitor only on weekdays. Differences between weekdays and weekend days were analyzed in 62 participants (Table 2). Wear time on weekdays was significantly longer than weekend days (Table 2). Participants had significantly higher %TSS on weekdays than weekend days. Activity counts on weekdays were significantly lower than weekend days (Table 2). Girls tended to have higher %TSS and lower activity counts than boys, but the results showed no significant differences between sexes (Table 2).

The analysis of different ambulatory status

There were no significant differences in mean wear time between ambulatory status groups. Time spent sedentary as percentage of wear time and activity counts were significantly different between the independently-ambulant group and the other two groups (GMFCS III-V) and also between the marginally-ambulant group and non-ambulant group (Table 1). The average daily physical activity patterns according to day by group, day type and gender are reported in Figure 1.

The relationship to the physical activity guidelines

Ninety-one percent and 86% of children in the independently and marginally-ambulant group met the Australian Physical Activity Guideline[5] for sedentary time (TSS ≤ 60 minutes at a time) for all three days of monitoring, respectively while almost all children in the non-ambulant groups had TSS over 60 minutes at a time. The proportion of participants who met the recommendations for sedentary time on at least one day was significantly higher in the independently-ambulant group than in the non-ambulant group (Table 1). Sixty-seven percent and 43% of children in the independently and marginally-ambulant groups met the guidelines of active time more than three hours per day for all three days of monitoring, respectively while almost all children in the non-ambulant group did not met this guidelines. Children who met the guidelines for active time on at least one day in the independently-ambulant group were significantly higher than the non-ambulant group (Table 1).

The relationships between physical activity and motor capacity

The %TSS was significantly associated with GMFM-66 (β=-0.61, 95%CI= -0.69 to -0.53, R^2=0.74, p<0.001) and activity counts were significantly associated with GMFM-66 (β=20, 95%CI=17.1 to 23.0, R^2=0.69, p<0.001, regression analyses). Motor capacity was directly associated with sedentary behavior and physical activity levels.

5.2.5. Discussion

Children with CP aged 4-5 years performed more physical activity on weekend days than weekdays, however wear time on weekend days and weekdays were significantly different. The time spent sedentary as a percentage of wear time, was normalized by wear time in each participant, was higher on weekdays than weekend days. The average physical activity pattern by day type (Figure 1) also showed that physical activity on weekend days in the afternoon was higher than on weekdays due to sport or family active leisure activities. It is reasonable to assume that children with CP aged 4-5 years spent more sedentary time on weekdays than weekend days. A

large study of Australian preschool children with typical development aged 3-5 years also found that children were more physically active on weekend days than weekdays.[31] In younger children with CP, a previous study in toddlers with CP (1.5-3 years, n=58) reported no significant difference of %TSS between weekdays and weekend days.[12] The differences of HPA and %TSS between weekdays and weekend days may be influenced by school program. Further studies in school age children with CP may be of interest. Regarding sex, our results found that girls tend to have higher %TSS and lower HPA than boys but there were no significant differences between sexes. A previous study in children with typical development aged 3-5 years, boys had total physical activity higher than girls but no significant difference between sexes in screen-based behaviors.[32] As sedentary behavior is influenced by many factors, any intervention to reduce sedentary behavior should be applied during weekdays, weekend days and both sexes.

Comparison of %TSS and HPA between children with CP according to ambulatory status found that the independently-ambulant group had the lowest %TSS and the highest HPA. Physical activity patterns by ambulatory groups (Figure 1) demonstrated that all three groups had similar patterns throughout a day while the non-ambulant group had minimal HPA. The previous study in toddlers with CP aged 1.5-3 years reported that %TSS were 52% in GMFCS I-II, 62% in GMFCS III and 74% in GMFCS IV-V.[12] When compared to this study, preschool children with CP had higher %TSS than those toddlers in all groups. Non-ambulant children with CP age 4-5 years had a larger %TSS (93%) when compared to those aged 1.5-3 years (74%). This evidence suggests that interventions to reduce sedentary behavior in children with CP are needed in younger aged children with CP especially for those who are unable to walk. In addition, motor capacity, measured by GMFM-66, was associated with time spent sedentary and activity counts. These data confirm that functional abilities impact on sedentary behavior and physical activity in children with CP.[33]

Our results showed that the independently-ambulant children with CP (GMFCS I-II) aged 4-5 years spent an average of 42% (range 27-56%) of wear time being physically active. A total of 67% of independent-ambulant group met the Australian Physical Activity recommendation of three hours active time per day. This is in contrast to a previous large study in Australian preschool children with typical development aged 3-5 years by Hinkley et al. (n=1004) which found that children with typical development spent only 16% of their time being active and 5% of their participants met

the recommendation.[32] Although active time in independently-ambulant children with CP appears to be higher than in children with typical development, different activity monitors and cut-points were used. The Hinkley study measured HPA using uniaxial ActiGraph® (GT1M) and the cut-points are higher than our study.[32] Also the epoch for data collection in the Hinkley study was 15-second which might not small enough to capture active and sedentary time in young children.[32] It is possible that procedures to detect non-wear time might explain some of the differences. The Hinkley[32] study defined non-wear time as consecutive zero counts for 10 minutes or more which may underestimate HPA. Our study used the activity diaries as recorded by the family to filter for non-wear time. Regarding the activity counts (counts per minute), variability in activity counts of the independently-ambulant children with CP (mean=1324.3, SD=365.2, range=620-2383) were higher than the Hinkley study (mean=708, SD=182, range=318-1470).[32] In addition, all of children with typical development in the Hinkley study attended preschools or childcare centers which might have prolonged sitting due to academic activity while some of our participants did not attend preschool.[32] In contrast, another study in Australian preschool children with typical development aged 3-5 years used a parent-reported physical activity and exercise questionnaire, finding that 56% and 79% of their participants met the active recommendation on weekdays and weekend days.[34] Furthermore, previous large studies in Canadian preschool children with typical development aged 3-4 years using uniaxial accelerometers reported that 73-84% of their participants met active time of three hours a day.[35, 36] Regarding sedentary time, a previous review study reported that preschool children with typical development had sedentary time that ranged from 34% to 94% of their day.[37] Our results found that independently-ambulant children with CP (GMFCS I-II) spent an average of 58% (range 44-74%) of total wear time in sedentary, which is within in the range reported for children with typical development. The differences of measurements and cut-points of all studies may influence the results; however, HPA and TSS had high variability even in children with typical development. Considering these findings, it may be assumed that HPA and TSS in independently-ambulant children with CP were not different from children with typical development. Although more than half of the independently-ambulant children with CP met the guidelines, most of them had high TSS. Our study suggests that independently-ambulant children with CP should be encouraged to be physically active to maintain high levels of HPA throughout their life span.

The ActiGraph® accelerometer has been widely used in children with typical development and can be used in free living conditions.[26] Use of multiple accelerometer placements, for example placement at wrist, ankle, and trunk, might improve accuracy to measure physical activity in non-ambulatory activities but this has not been investigated in children.[26] The use of multiple monitors may provide small improvements in accuracy when compared to a single monitor[26], but it might interrupt movement and daily living activity in children with CP and reduce participant adherence to the study protocol. A previous study in adults with CP using hip- and wrist-worn accelerometers reported that data from wrist-worn accelerometers were complicated and failed to achieve normality.[38] Furthermore, placement of an accelerometer at lower back was validated in young children with CP across all GMFCS levels[27, 28] so this placement was chosen in the present study. A recent study of the ActiGraph® cut-points in ambulatory youths with CP (mean aged 12.5 years) identified new models for determining activity intensity, decision trees.[39] The study found that cut-points for moderate to vigorous physical activity were specific for each GMFCS level; however cut-points for sedentary time were not different between GMFCS level I-III.[39] A previous validation study in preschool children with CP aged 4-5 years derived specific cut-points for sedentary time in each GMFCS level but cross-validation analyses supported the use of the same cut-point in all GMFCS levels.[28] In toddlers with CP, cut-points for sedentary time were different between GMFCS level I-III and GMFCS level IV-V.[27] These evidence suggest that cut-points in children with CP are specific for activity intensities and age ranges. Future studies should identify the appropriate cut-points according to age and functional capacity (GMFCS level).

This study has some potential limitations in that it did not have a group of children with typical development to compare with children with CP. Although the overall sample size was 67, the study was sufficiently powered to allow us to detect clinically significant between-GMFCS category differences of 150 counts per minute or greater. The ActiGraph® activity monitor also has limitations which cannot detect water-based activity and some light activity may be detected as sedentary activity due to stability of the trunk during standing and bike riding and as a results of positioning devices in non-ambulant children with CP. Although the ActiGraph® has been validated in non-ambulatory children with CP, it was created for and has been validated for ambulatory wearers.[26] Placement of the monitor was based on the best placement for ambulatory participants.[26] Thus, it is possible that this outcome measure may not

have captured the optimal information for assessing physical activity levels in the non-ambulatory participants.

5.2.6. Conclusion

Children with CP aged 4-5 year old spent more than half of their waking hours in sedentary time (58% for GMFCS I-II, 74% for GMFCS III, and 93% for GMFCS IV-V). Time spent sedentary were significantly greater in marginally-ambulant and non-ambulant children with CP than independently-ambulant children with CP. Non-ambulant children with CP spent almost all of their day in sedentary time. Furthermore, independently-ambulant children with CP were more likely to meet the Australian Physical Activity Guidelines than other ambulatory status. Interventions to reduce sedentary behavior and increase physical activity are needed in children with CP age 4-5 years especially for marginally-ambulant and non-ambulant groups of both gender.

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Table 1 Characteristics of participants, mean (SD), and comparison of activity data between three ambulatory groups of children with cerebral palsy.

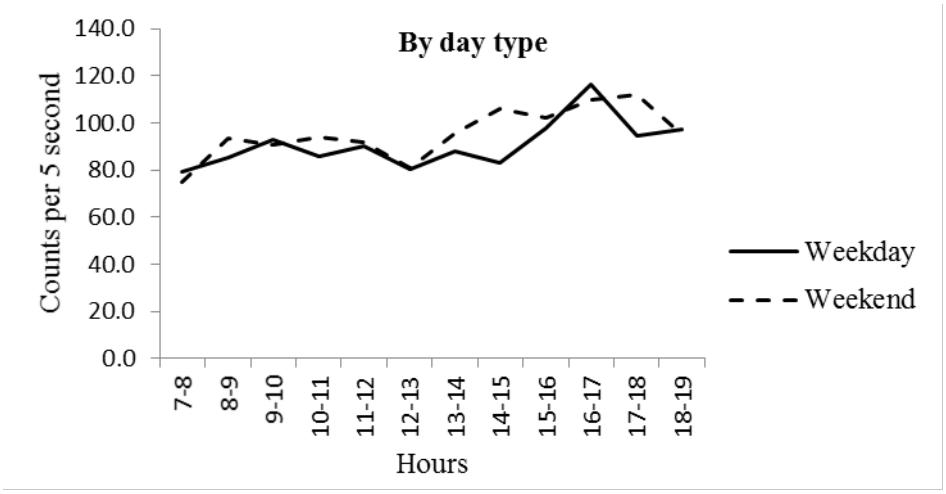
	Group	Excluded participants	Included participants	Independently-ambulant (GMFCS I-II)	Marginally-ambulant (GMFCS III)	Non-ambulant (GMFCS IV-V)
Characteristics	Boys (n)	52	43	31	4	8
	Girls (n)	39	24	15	3	6
	Age	4 y 10 m (4 m)	4 y 11 m (3 m)	4 y 11 m (3 m)	4 y 10 m (5 m)	4 y 10 m (4 m)
	BMI	15.7 (1.8)	15.6 (1.9)	15.2 (2.9)	16.0 (1.3)	15.7 (2.7)
	GMFM-66 (score)	60.4 (20.4)	77.7 (117.5)	77.6 (9.7)	52.7 (3.3)[a]	24.3 (9.6)[a, b]
Activity data	Wear time (hours)			10.7 (1.4)	11.1 (1.3)	10.2 (2.2)
	%TSS			57.6 (8.5)	73.6 (12.7)[a]	92.7 (6.4)[a, b]
	Activity count (counts per min)			1324.3 (365.2)	814.5 (445.4)[a]	217.7 (184.1)[a, b]
Number of participants met sedentary recommendation (TSS ≤ one hour at a time)						
	0 day (n, %)			0	0	7 (50.0)
	1 day (n, %)			0	1 (14.3)	3 (21.4)
	2 days (n, %)			4 (8.7)	0	3 (21.4)
	3 days (n, %)			42 (91.3)	6 (85.7)	1 (7.1)[a]
Number of participants met active recommendation (active time ≥ three hours per day)						
	0 day (n, %)			0	3 (42.9)	12 (85.7)
	1 day (n, %)			4 (8.7)	1 (14.3)	1 (7.1)
	2 days (n, %)			11 (23.9)	0	1 (7.1)
	3 days (n, %)			31 (67.4)	3 (42.9)	0[a]

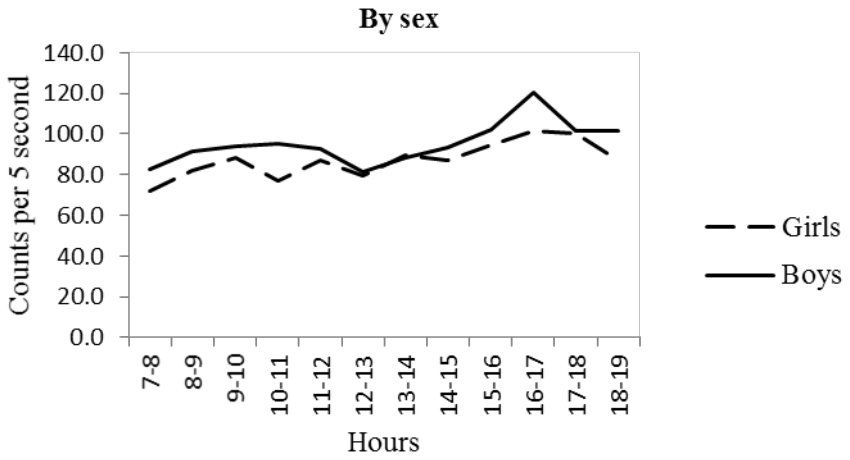
BMI, body mass index; GMFCS, Gross Motor Function Classification System; GMFM-66, 66-item Gross Motor Function Measure; %TSS; time spent sedentary as a percentage of total wear time; linear regression for continuous variables; logistic regression for categorical variables; [a], significant differences compared to independently-ambulatory group $p<0.001$; [b], significant differences compared to marginally-ambulant group, $p< 0.001$.

Table 2 Comparison of accelerometer wear time (hour), time spent sedentary as a percentage of wear time (%TSS) and activity count (counts per minute) between weekdays/weekend days and sexes.

Type	Wear time (hr)				%TSS			Activity counts (counts per minute)		
	n	Mean (SD)	MD (95% CI)	*p*-value	Mean (SD)	MD (95% CI)	*p*-value	Mean (SD)	MD (95% CI)	*p*-value
Weekdays	62	10.9 (1.6)	0.8	0.003*	66.9 (17.0)	2.0	0.041*	1013.3 (566.6)	-113.8	0.001*
Weekend days	62	10.1 (2.3)	(0.3 to 1.4)		64.9 (16.4)	(0.1 to 3.9)		1127.1 (593.1)	(-181.7 to -45.8)	
Boys	43	10.7 (1.5)	0.2	0.709	65.5 (16.1)	-3.0	0.478	1082.8 (556.2)	119.9	0.410
Girls	24	10.5 (1.8)	(-0.7 to 1.0)		68.5 (17.9)	(-11.6 to 5.5)		962.8 (588.2)	(-169.0 to 408.8)	

MD, mean difference; SD, standard deviation; *, significant differences between weekdays and weekend days, Paired t-test (n=62, 5 participants wore the ActiGraph® only on weekday); linear regression for differences between boys and girls.





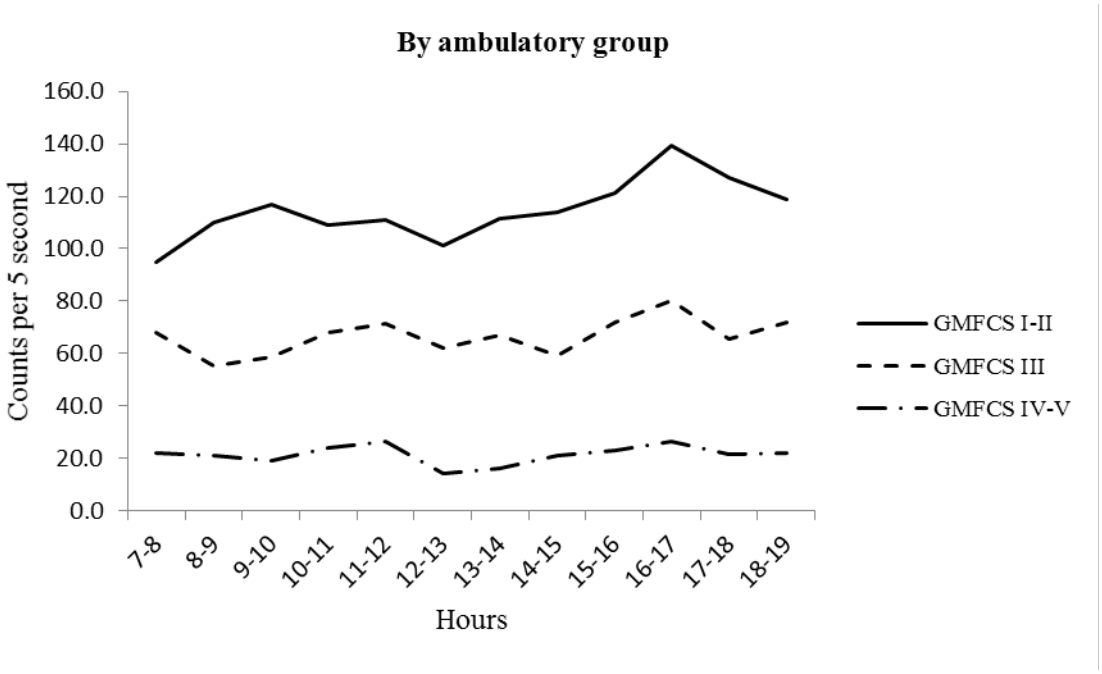


Figure 1 Average daily physical activity (counts per 5-second) patterns throughout a day (7am-7pm) by day type, sex and ambulatory group.

5.3 Summary and conclusion

This study found that children with CP aged 4-5 years were in sedentary time for more than half of their waking hours. The independently-ambulant children with CP were more likely to meet the Australian Physical Activity Guidelines compared to marginally and non-ambulant children with CP. Strategies to increase HPA and reduce sedentary time are needed in young children with CP aged 4-5 years especially for those who are marginally-ambulant and non-ambulant. A potential limitation of this study is the limited number of participants in GMFCS level III-V (n=7-14). Specific findings are as follows:

i) Independently-ambulant participants spent 57% of their day in sedentary time.

ii) Marginally-ambulant participants spent 73% of their day in sedentary time.

iii) Non-ambulant participants spent almost all their day in sedentary time, 93% of their waking period.

iv) The marginally-ambulant and non-ambulant groups had significantly lower HPA and higher TSS compared to independently-ambulant group ($p<0.001$).

v) In relation to the Australian Physical Activity Guidelines, 91% of participants in the independent-ambulant group met the guidelines for sedentary time (TSS ≤ one hour at a time) compared to 56% of the marginally-ambulant group.

vi) The physical activity guidelines of active time for more than three hours a day were met by 67% of participants in the independent-ambulant group compared to 43% of participants in the marginally-ambulant group.

vii) In the non-ambulant group, there was only one participant (7%) who met the guidelines for sedentary time and no participants met the guidelines for active time for 3 days of HPA monitoring.

Chapter 6: Evaluation of relationship between habitual physical activity, motor capacity and capability in children with cerebral palsy aged 4-5 years across all functional abilities

6.1 Introduction to Chapter 6

This study examined the relationships between HPA, TSS, motor capacity and capability in children with CP aged 4-5 years. Physical activity was measured by the ActiGraph® accerelometer. The GMFM-66 was used to assess motor capacity in a structured environment, and the PEDI functional skills of the mobility domain was used to assess motor capability in the natural environment. The hypothesis was that motor capacity and capability were associated with HPA and TSS.

6.2 Paper 4: Relationship between habitual physical activity, motor capacity and capability in children with cerebral palsy aged 4-5 years

This paper was submitted to Disability and Rehabilitation on 25 July 2016, and is currently under review.

> Keawutan P, Bell KL, Oftedal S, Davies PS, Ware RS, Boyd RN. (2016). Relationship between habitual physical activity, motor capacity and capability in children with cerebral palsy aged 4-5 years.

This paper was presented as a scientific poster at the 7th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine, March 2014, Hunter Valley, NSW, Australia.

> Keawutan P, Bell K, Davies PS, Boyd RN. (2014). How mobile for school are they? Relationship between habitual physical activity, motor capacity, and performance for children with cerebral palsy. *Developmental Medicine and Child Neurology.* 56(S2): 69.

This paper was also presented as a free paper presentation at the 8th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine, April 2016, Adelaide, SA, Australia, and as a scientific poster at the 5th International Conference on Cerebral Palsy and other Childhood-onset Disabilities, June 2016, Stockholm, Sweden.

Title: Relationship between habitual physical activity, motor capacity and capability in children with cerebral palsy aged 4-5 years

Authors: Piyapa Keawutan, Kristie L Bell, Stina Oftedal, Peter SW Davies, Robert S. Ware, Roslyn N Boyd

6.2.1. Abstract

Purpose To investigate the relationship between habitual physical activity (HPA), sedentary time, motor capacity and capability in children with cerebral palsy (CP) aged 4-5 years.

Method Sixty-seven children with CP aged 4-5 years were classified using Gross Motor Function Classification System (GMFCS), assessed for motor capacity (66-item gross motor function measure; GMFM-66) and wore accelerometers for three days. Parents completed the Pediatric Evaluation of Disability Inventory (PEDI) functional skills of the mobility domain for motor capability and activity diary. Mixed-effects regression models were used for analyses using GMFCS level I as a reference group.

Results As GMFCS level increased, HPA significantly decreased and sedentary time significantly increased. The GMFM-66 was positively associated with HPA (mean difference (MD)=19.6 counts/min; 95%CI=16.6, 22.7) and negatively associated with sedentary time (MD=-0.6%; 95%CI=-0.7, -0.5). The PEDI was also associated with HPA (MD=16.0 counts/min; 95%CI=13.1, 18.8) and sedentary time (MD=-0.5%; 95%CI=-0.6, -0.4). After stratification for ambulatory status GMFM-66 and PEDI were associated with HPA and sedentary time in ambulatory participants but not in non-ambulatory participants.

Conclusions Gross motor capacity and motor capability are related to HPA and sedentary time in ambulatory children with CP. Measuring GMFM-66 or PEDI functional skills of mobility domain does not give any more information than GMFCS level.

Key words: habitual physical activity, sedentary behaviour, motor capacity, capability, children, cerebral palsy

6.2.2. Introduction

According to the International Classification of Functioning, Disability and Health: Children and Youth version (ICF-CY), the activity and participation domains contain two constructs which are capacity and performance.[1] Capacity is defined as what a person can do in a standardized, controlled environment.[2] Performance refers to what a person actually does do in his/her environment.[2] As environmental factors are one of contextual factors that impact on activity and participation [1], capability could be another structure that can impact on a person's ability. Capability is defined as what a person can do in his/her environment.[2]

Habitual physical activity (HPA) is one of the performance that has many potential health benefits such as improved bone health, cardiorespiratory and muscular fitness.[3, 4] Habitual physical activity refers to any bodily movement in daily life which results in energy expenditure.[5] Another performance that should be concerned is sedentary behaviour. Sedentary behaviour is a major global health problem associated with a number of conditions including cardiovascular disease and diabetes.[4] Sedentary behaviour is defined as any activity using energy expenditure ≤ 1.5 metabolic equivalents such as lying, sitting and reclining.[6]

Previous studies of tracking physical activity and sedentary behaviour in the general population reported that the behaviour in childhood and adolescence can remain stable until adulthood.[7, 8] A systematic review suggested that early childhood (0-6 years) is a critical period for carry-over of an active or sedentary lifestyle.[9] Consequently, it is important to understand physical activity in young children, including children with disabilities, for adjusting behaviour at an early age in order to prevent detrimental outcomes including cardiovascular and metabolic diseases in adulthood.

Cerebral palsy (CP) is a group of disorders of movement and posture causing activity limitations.[10] Functional ability of children with CP can be classified by Gross Motor Function Classification System (GMFCS) into five levels from level I; walking without restriction, to level V; dependent ambulation.[11] Activity limitations and participation restrictions in children with CP can impact on their HPA.[12-16] A systematic review reported that children with CP aged 5-18 years had 13-53% less HPA than their peers and twice the maximum recommended sedentary time.[13] Recent studies found that ambulatory children with CP (GMFCS I-III) aged 6-10 years had less HPA and more sedentary time than children with typical development.[14, 15]

In addition, ambulatory youth with CP aged 8-17 years have been reported to spend more time sedentary than their peers.[16] Reduced levels of HPA and increased sedentary time were associated with elevated blood pressure in children with CP aged 6-17 years [17] and increased risk of developing cardiometabolic disease in adults with CP aged 18-62 years.[18] Almost all previous studies that measure HPA were conducted in school aged ambulatory children and adolescents (6-18 years) with CP (GMFCS I-III). Only one study has been conducted in toddlers with CP age 1.5-3 years; it reported that HPA and sedentary time in toddlers with CP classified as GMFCS I-II were not different from toddlers with typical development.[19] Active and sedentary time was found to differ between toddlers without CP and toddlers with CP classified as GMFCS III-V.[19] There is a gap between age 4 and 5 years in evidence of HPA in children with CP.

Regarding the relationship between HPA (performance) and motor capacity, previous studies in ambulatory children with CP found that the Gross Motor Function Measure (GMFM) correlated with HPA [20] and the GMFM dimension E (walking, running and jumping) were important predictors of HPA in adolescents and young adults with CP.[21] A systematic review confirmed that motor capacity was directly related with HPA in children with CP but there are limited studies using objective measures of HPA in non-ambulatory children with CP at age less than 5 years.[22]

Previous studies examined the relationship between motor capacity, capability and performance in children with CP aged 2.5 years.[2] The study reported that although there were high correlations between motor capacity, capability and performance, motor performance are only partly reflected by motor capacity and motor capability.[2] Motor performance was measured using the Pediatric Evaluation of Disability Inventory (PEDI) functional skills of caregiver assistance which is a questionnaire.[2] It would be of interest to measure motor performance using objective measure of HPA and sedentary behaviour. The aim of this study was to investigate the relationship between HPA, sedentary time, motor capacity and capability in children with CP aged 4-5 years across all functional abilities.

6.2.3. Methods

This study was conducted in Queensland, Australia between October, 2010 and December, 2014. Data were derived from two population-based cohort studies, the Queensland CP Child Study of Motor Function and Brain Development (n=227) [23] and the Queensland CP Child Study of Growth, Nutrition and Physical Activity

(n=175).[24] Queensland children who were born in 2006-2009 and have a diagnosis of CP were eligible for the studies. Children with progressive neurological disorders were excluded.

The CP Child Study of Motor Function and Brain Development assessed children every 6 months from 18 to 36 months corrected age, and then at 48 and 60 months corrected age. The Queensland CP Child Study of Growth, Nutrition and Physical Activity assessed children at 3 time points depending on study entry, which were 17 to 25 months, 36 months and 60 months corrected age with additional assessment at 48 months for those who entered to the study after 25 months corrected age. This present study included participants from those two cohort studies who were assessed at 48 and 60 months of age. Ethics were approved by the University of Queensland Medical Research Ethics Committee (2008002260) and regional hospitals across Queensland, Australia. Informed consent was signed by all parents or legal guardians of participants.

Outcome measures and procedures

Participants were classified using the GMFCS and assessed for motor capacity (in a structured environment) using the GMFM-66 by a research physiotherapist. The GMFM-66 is a standardized criterion-referenced measure which assesses motor capacity in children with CP over 5 dimensions (A: lying/rolling, B: sitting, C: crawling/kneeling, D: standing and E: walking/running/jumping). It contains 66 items; each item is scored in 4-point ordinal scales from 0 (does not initiate) to 3 (completed activity).[25] Parents of participants completed the 59-item Pediatric Evaluation of Disability Inventory (PEDI) functional skills of the mobility domain to determine motor capability (activities the child can do in a natural environment). The PEDI was scored either capable to do (1) or unable to do (0) for each item. The raw score was converted to scaled score from 0-100.[26]

Participants wore the ActiGraph® accelerometer centered at their lower back (L2) for all waking activities except water-based activities for at least three days (two weekdays and one weekend).[27] Reasons for wearing the monitor at the lower back were to avoid limitation of participants' movement and to minimise the influence of asymmetrical gait movement in some participants.[28, 29] Wearing an accelerometer at lower back and hip are not significantly different for detecting activity counts.[29] Corresponding activity diaries which were completed by parents of participants contained the time when the child woke up, when the monitor was put on/taken off,

reasons for taking off the monitor, when the child was being carried or pushed in pram, and sleep time. This study used the ActiGraph® triaxial accelerometer (GT3X and GT3X+) which detected acceleration of the body in three planes, vertical (X), antero-posterior (Y) and mediolateral (Z). Habitual physical activity was indicated by activity counts (count per epoch of time) which were calculated from vector magnitude ($VM=\sqrt{X^2+Y^2+Z^2}$). The monitor was set at 5 second-epochs to detect short bursts of physical activity in children with CP. Activity data were downloaded via ActiLife software® (Actigraph, FL, USA). Wear time periods were checked with activity diaries and non-wear time periods were deleted from analyses. The “non-wear time” was the period that the ActiGraph® was removed from a child for sleeping, bathing, swimming, or other water-based activities. The period that a child was carried or transported in car were not deleted but were recorded as sedentary time.” Any ambiguous data were clarified with the parents. Each day was manually filtered for non-wear time. Wear time period (hours), activity counts (counts per minute) and sedentary time as a percentage of wear time of each participant were calculated using MATLAB (The MathWorks Inc., version R2012b). Time spent sedentary was determined using the cut-point for sedentary time of 820 counts per minute [30] which was validated in children with CP aged 4-5 years in a previous study.[31] Accelerometer cut-points for sedentary time in children with CP aged 4-5 years across all functional abilities have been validated against direct observation, a criterion measure.[31] The cut-points for each GMFCS level were derived using Receiver Operating Characteristic (ROC) curves. The cut-points that derived from each GMFCS level and the previously established cut-point from children with typical development [30] were applied in an independent sample of children with CP for cross-validation. Bland-Altman agreement statistics were calculated to compare predictive validity. Results support the use of the previously established cut-point for sedentary time of 820 counts per minute [30] in a group basis for all GMFCS levels.[31]

Statistical analysis

Based on prior knowledge we expected our sample size of 67 individuals to complete approximately 80 assessments. We calculated we would be able to detect a difference of 150 counts per minute or greater between GMFCS levels with 80% power and alpha=0.05 (G*Power Version 3.1.9.2).

Characteristics of participants who were included and excluded from this study were compared by independent t-test (continuous variables) and Fisher’s exact test

(categorical variables). Mixed-effects regression models, with child included as a random effect were used to investigate differences of physical activity data between GMFCS levels (GMFCS level I as a reference group) and relationships between HPA, sedentary time, motor capacity and capability. The GMFCS level, GMFM-66 and PEDI score were independent variables while activity counts and sedentary time were dependent variables. All statistical analyses were performed using Stata® v13.0 (StataCorp, College Station, TX, USA). Statistical significance was set at alpha=0.05.

6.2.4. Results

Two hundred and ten assessments were conducted in 158 children with CP aged 4-5 years across Queensland, Australia. Ninety-one children were excluded because of incomplete activity data (2-day monitoring in 13 children, 1-day monitoring in 3 children and 0-day monitoring in 75 children). Reasons for not wearing the activity monitor were rejection from participants and inability of parents to attach the monitor to their child. Total participants with sufficient data were 67 children with 84 assessments, mean age 4.9 years. Characteristics of included and excluded participants were not significantly different in age, sex and GMFM-66 score. Characteristics of included participants were 43 (64%) boys; unilateral spasticity, n=30 (45%); bilateral spasticity, n=30 (45%); dystonia, n=5 (7%); ataxia, n=1 (1%); and hypotonia, n=1 (1%).

Physical activity data in each GMFCS level are shown in Table 1. Wear time of the activity monitor were not significantly different between GMFCS levels. Activity counts in children with CP classified as GMFCS II-V were significantly lower than GMFCS I. Sedentary time as a percentage of wear time in children with CP classified as GMFCS I and II were not significantly different while children with CP classified as GMFCS III-V had significantly higher sedentary time than GMFCS I.

Separate regression analyses in all participants showed that both the GMFM-66 and PEDI functional skills of the mobility domain were associated with activity counts and sedentary time (Table 2). Regression analyses according to ambulatory status found that the relationships in children with GMFCS I-III were the same as in all participants. In children with GMFCS IV-V, neither the GMFM-66 nor the PEDI were associated with the physical activity data (Table 2).

6.2.5. Discussion

Activity counts significantly decreased and sedentary time significantly increased when GMFCS levels increased, except for sedentary time between GMFCS

level I and II. High motor capacity (GMFM-66) and capability (PEDI functional skills of the mobility domain) were associated with high HPA levels and low sedentary time in children with CP aged 4-5 years. Both motor capacity and motor capability contributed to HPA and sedentary behaviour in ambulatory children with CP (GMFCS I-III). Although motor capacity and capability are associated with activity performance, a previous longitudinal study suggested that “change in motor capacity does not automatically translate to change in motor capability and change in motor capability does not automatically translate to change in motor performance”.[32] In addition, there are many factors to consider including access to physical activity opportunities, environmental barriers and child and family motivation to engage in physical activity. In non-ambulatory children with CP (GMFCS IV-V), motor capacity and capability do not contribute to HPA and sedentary time. Different ActiGraph® placement would be possible to measure HPA and TSS in non-ambulatory children with CP. Wrist worn monitors might be able to capture physical activity in non-ambulatory children with CP but in a different paradigm. Emphasis of our studies was on changes in centre of mass then we chose to attach the Actigraph® close to the centre of mass of the body.

Facilitators and barriers for participating in physical activity for children and adolescent with CP have been identified. Various personal and environmental factors impact their ability to participate in physical activity such as experiences enjoyment, parental awareness of benefits of physical activity, pain, fatigue, lack of opportunities for sport and physical activity.[33] A previous study in preschool children with typical development found that parental participation in physical activity is a mediator of their children’s physical activity participation.[34] An active family of children with CP may promote their children to be active as well. Fatigue has been identified as a personal barrier to participate in physical activity.[33] A previous study reported that fatigue was associated with physical inactivity and increasing physical activity may help reduce fatigue.[35]

Physical activity data are rarely available for children with CP classified as GMFCS IV-V. A strength of the current study is that it has provided HPA and sedentary time in non-ambulatory children with CP using an objective measure. It is a challenge to attach an activity monitor to young children with CP. A potential limitation of this study was a small number of participants in the non-ambulatory group. Also, there was a large amount of missing data which suggest that accelerometry may not be feasible to use in a clinical setting in young children with CP. The ActiGraph® also has some

limitations in that it cannot measure water-based activities and some light activities may be detected as sedentary activities where the trunk is not moving for example bike riding and standing. The placement of the monitor (at center of lower back of participant) may lead to a higher level of non-compliance rate for accelerometer data in non-ambulatory children with CP. Further studies may use other placements for example wrist worn monitor which might be more suitable for non-ambulatory children with CP. However, new cut-points for other ActiGraph® placements would have to be validated.

6.2.6. Conclusion

Gross motor capacity and motor capability were associated with HPA and sedentary behaviour in ambulatory children with CP (GMFCS I-III) aged 4-5 years but not in non-ambulatory children (GMFCS IV-V). Measuring GMFM-66 or PEDI functional skills of mobility domain does not give any more information than GMFCS level.

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Table 1 Physical activity data in children with CP according to Gross Motor Function Classification System (GMFCS) level

GMFCS	N (%)	Wear time (hour)			Activity counts (counts/min)			Sedentary time (% of wear time)		
		Mean (SD)	MD (95%CI)	*p*-value	Mean (SD)	MD (95%CI)	*p*-value	Mean (SD)	MD (95%CI)	*p*-value
I	48 (57)	10.6 (1.4)	Reference group		1388 (367)	Reference group		56.1 (8.7)	Reference group	
II	9 (11)	10.9 (1.3)	0.2 (-0.8, 1.3)	0.69	1017 (186)	-274 (-488, -59)	0.012	64.3 (6.6)	4.9 (-0.5, 10.2)	0.08
III	9 (11)	10.9 (1.4)	0.3 (-0.9, 1.5)	0.61	838 (422)	-573 (-819, -327)	<0.001	72.9 (11.9)	17.2 (11.0, 23.5)	<0.001
IV	4 (5)	10.1 (0.9)	-0.7 (-2.4, 1.0)	0.41	469 (172)	-933 (-1290, -576)	<0.001	85.4 (5.2)	29.5 (20.4, 38.6)	<0.001
V	14 (17)	10.4 (2.3)	-0.3 (-1.3, 0.7)	0.52	154 (144)	-1216 (-1421, -1011)	<0.001	94.5 (5.4)	37.6 (32.4, 42.8)	<0.001

Key: GMFCS, Gross Motor Function Classification System; MD, mean difference; SD, standard deviation; Mixed-effects regression models

Table 2 Mixed-effects regression models of 66-item gross motor function (GMFM-66) and motor capability (PEDI) on activity counts and sedentary time as a percentage of wear time

	Independent variables	**Activity counts (counts/minute)**		**Sedentary time (% of wear time)**	
		MD (95% CI)	*p*-value	MD (95% CI)	*p*-value
All participants (n=84)	GMFM-66	19.6 (16.6, 22.7)	<0.001*	-0.6 (-0.7, -0.5)	<0.001*
	PEDI	16.0 (13.1, 18.8)	<0.001*	-0.5 (-0.6, -0.4)	<0.001*
GMFCS I-III (n=66)	GMFM-66	17.4 (10.4, 24.4)	<0.001*	-0.4 (-0.6, -0.2)	<0.001*
	PEDI	11.8 (6.1, 17.6)	<0.001*	-0.3 (-0.5, -0.2)	<0.001*
GMFCS IV-V (n=18)	GMFM-66	8.4 (-1.1, 17.9)	0.083	-0.2 (-0.6, 0.1)	0.199
	PEDI	2.7 (-3.5, 8.9)	0.391	-0.02 (-0.2, 0.2)	0.836

Key: GMFCS, Gross Motor Function Classification System; GMFM-66, 66-item Gross Motor Function Measure; MD, mean difference; PEDI, Pediatric Evaluation of Disability Inventory

6.3 Summary and conclusion

This study has confirmed the result of sub-study 1 (Chapter 2: “Systematic review of the relationship between HPA and motor capacity in children with CP”[67]) that motor capacity was associated with HPA. Higher motor capacity was associated with higher HPA and lower TSS. After controlling for ambulatory status, the association was found in ambulant children with CP but not in non-ambulant children with CP. Measuring GMFM-66 or PEDI functional skills of mobility domain does not give any more information than GMFCS level. Smaller number of participants in GMFCS levels II-V (n=4-14) is a potential limitation of this study. Specific findings are as follows:

i) Both motor capacity defined by the GMFM-66, and motor capability defined by the PEDI functional skills of the mobility domain, were positively associated with HPA and negatively associated with TSS.

ii) Separate regression analyse according to ambulatory status showed that neither the GMFM-66 nor the PEDI functional skills of the mobility domain were associated with HPA and TSS in non-ambulant children with CP (GMFCS IV-V).

Chapter 7: Quality of life and habitual physical activity in children with cerebral palsy aged 5 years: a cross-sectional study

7.1 Introduction to Chapter 7

This study investigated QOL in children with CP aged 5 years using the Cerebral Palsy Quality of Life questionnaire for Children (CP QOL-Child) parent-proxy version. The CP QOL-Child measures well-being specifically in children with CP across seven domains: social well-being and acceptance, feelings about functioning, participation and physical health, emotional well-being and self-esteem, access to services, pain and impact of disability, and family health. The CP QOL-Child scores were compared between ambulant (GMFCS I-III) and non-ambulant (GMFCS IV-V) children with CP. Linear regression models were used to examine the relationship between QOL and HPA controlling for motor function (GMFM-66).

7.2 Paper 5: Quality of life and habitual physical activity in children with cerebral palsy aged 5 years: a cross-sectional study

This paper was submitted to Clinical Rehabilitation on 22th September 2016, and is currently under review.

> Keawutan P, Bell KL, Oftedal S, Davies PS, Ware RS, Boyd RN. (2016). Quality of life and habitual physical activity in children with cerebral palsy aged 5 years: a cross-sectional study.

This paper was presented as a free paper presentation at the 69th Annual Meeting of the American Academy of Cerebral Palsy and Developmental Medicine Conference, October 2015, Austin, USA.

> Keawutan P, Bell K, Stevenson R, Davies P, Boyd R. (2015). Relationship between habitual physical activity and quality of life in children with cerebral palsy aged 5 years. Developmental Medicine and Child Neurology, 57(S5): 64.

This paper was also presented as a free paper presentation at the 8th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine, April 2016, Adelaide, SA, Australia, and at the 5th International Conference on Cerebral Palsy and other Childhood-onset Disabilities, June 2016, Stockholm, Sweden.

Title: Quality of life and habitual physical activity in children with cerebral palsy aged 5 years: a cross-sectional study

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7.2.1. Abstract

Purpose: To compare parent-reported quality of life (QOL) according to ambulatory status and investigate the association with habitual physical activity (HPA) in children with cerebral palsy (CP) aged 5 years.

Methods: Fifty-eight participants were classified using the Gross Motor Function Classification System (GMFCS) as level I=33, II=8, III=6, IV=3 and V=8 and assessed motor function using the 66-item Gross Motor Function Measure (GMFM-66). Participants wore the ActiGraph® triaxial accelerometer for 3 days to measure HPA. Parents completed the parent proxy Cerebral Palsy Quality of Life questionnaire for Children (CP QOL-Child). Linear regression analyses were performed.

Results: Ambulant children with CP (GMFCS I-III) had better parent-reported QOL than non-ambulant children (GMFCS IV-V) in all domains except social well-being and acceptance, and access to services. HPA was weakly associated with QOL domains of feelings about functioning, participation and physical health, and emotional well-being and self-esteem but was not significant when controlling for motor function. The GMFM-66 accounted for 39% of variation for feelings about functioning domain (mean difference (MD)=0.4; 95% confidence interval (CI)=0.2,0.6; *p*=0.001), 27% for emotional well-being and self-esteem domain (MD=0.3; 95%CI=0.1,0.5; *p*=0.01), and 18% for access to services domain (MD=0.4; 95%CI=0.1,0.7; *p*=0.008).

Conclusions: In children with CP aged 5 years, HPA was not associated with parent-reported QOL. Gross motor function contributed to QOL domains of feelings about functioning, emotional well-being and self-esteem, and access to services.

Key words: quality of life, habitual physical activity, motor function, children, cerebral palsy.

7.2.2. Introduction

Cerebral palsy (CP) is one of the most common physical disabilities in children with a prevalence of CP of 2 per 1000 live births [1]. It is defined as a group of disorders of movement and posture caused by a lesion in the developing brain [2]. The World Health Organization (WHO) defined QOL as “an individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” [3]. Quality of life (QOL) is multidimensional and can be assessed using either generic or condition-specific measures [4]. Generic QOL questionnaires can be used in broad populations and allow comparison with a variety of patient populations, including the KIDSCREEN [5], the Child Health Questionnaire (CHQ) [6] and the Pediatric Quality of Life Inventory (PedsQL 4.0) [7]. Generic questionnaires may not cover all domains related to children with CP. The Cerebral Palsy Quality of Life questionnaire for children (CP QOL-Child) is a condition-specific measure developed to assess well-being for children with CP aged 4-12 years [8]. It has demonstrated the strongest psychometric properties among condition-specific QOL measures for children with CP [9].

Determinants of QOL in children with CP have been investigated in many studies [10-15]. Functional ability, as classified by the Gross Motor Function Classification System (GMFCS), is one of the determinants associated with various QOL measures in physical, but not psychological, domains [10-15]. The Study of Participation of Children with Cerebral Palsy Living in Europe (SPARCLE), a large population-based study of 818 children from seven European countries, reported that the GMFCS was significantly associated with both self-reported and parent-reported KIDSCREEN for domains of physical well-being and autonomy [10, 11]. In addition, the GMFCS was significantly associated with physical domains of the CHQ and the PedsQL4.0 [12-14]. The GMFCS has been shown to be significantly associated with all domains of the parent proxy CP QOL-Child except access to services [15]. The Gross Motor Function Measure (GMFM), a criterion-referenced motor function measure, had the strongest association with the CHQ and PedsQL4.0 [13].

Habitual physical activity (HPA) has been defined as “any bodily movement produced by skeletal muscles which results energy expenditure in daily life” [16]. Our previous study found that marginally-ambulant (GMFCS III) and non-ambulant (GMFCS IV-V) children with CP aged 4-5 years had significantly lower HPA and were less likely to meet the Australian Physical Activity Guidelines compared to

independently-ambulant children with CP (GMFCS I-II) [17]. In the past decade, interventions for children with CP have shifted from a focus on improved developmental motor skills to include improved HPA [18-20]. Recently, physical activity guidelines for people with CP were launched to promote healthy lifestyle and prevent risk of cardiovascular and metabolic diseases [21]. Studies in children with typical development indicated that HPA in early childhood were sustained levels until young adulthood [22, 23]. In children with typical development, there is strong evidence that HPA can improve physical health, including improving cardiorespiratory, cardiovascular, muscular fitness and bone health [24]. In addition, moderate evidence has shown that HPA can improve mental health including improved self-esteem, and reducing depression and anxiety [24, 25]. Regarding children with neurodevelopmental disabilities, a previous systematic review reported that active physical leisure activities (for example bicycling, playing sports, doing water sports, horse riding, and joining organized activities) was positively associated with better QOL[26]. Exercise training can improve health-related quality of life in children with CP aged 7-18 years [20]. Higher levels of HPA in children with CP may improve their QOL. To date there have been no studies examining the relationship between QOL specifically in young children with CP and levels of HPA. The aim of this study was to use a condition-specific QOL measure for children with CP and objective physical activity measures to (i) compare parent-reported QOL between functional abilities, and (ii) examine relationships between HPA and parent-reported QOL in children with CP aged 5 years.

7.2.3. Methods

This cross-sectional study is a sub-study of two larger population-based cohort studies, the Queensland CP Child Study of Motor Function and Brain Development [27] and the Queensland CP Child Study of Growth, Nutrition and Physical Activity [28]. Queensland children with CP born in 2007-2009 were eligible for inclusion. Children with progressive disorders were excluded. Participants were selected for this sub-study if data on the CP QOL-Child and HPA were available at 60±1 months corrected age. Ethics were approved by the University of Queensland Medical Research Ethics Committee (2008002260) and regional hospitals across Queensland, Australia. Informed consent was obtained by all parents or legal guardians of participants.

Outcome measures and procedures

Participants were classified for motor type and distribution according to the Surveillance of Cerebral Palsy in Europe (SCPE) definitions [29]. Gross motor function was classified using the Gross Motor Function Classification System (GMFCS) into five levels: level I, independent walking without restriction; level II, independent walking with limited on uneven surface; level III, walking with an assistive device; level IV, limited self-mobility; level V, severely limited self-mobility [30]. The Gross Motor Function Measure (GMFM) 66 items was used to assess motor function by a research physiotherapist. The GMFM is a criterion-referenced measure of motor function in children with CP. It is scored in 4-point ordinal scales; 0=does not initiate, 1=initiates <10% of activity, 2=partially completes 10% to <100% of activity, 3=completes activity, and the scores are converted to 0-100 scores using the Gross Motor Ability Estimator (GMAE) software (CanChild, ON, Canada) [31]. Although the GMFCS and the GMFM are closely correlated, using the GMFM, which is a continuous variable, as a controlling factor in regression models would present more details than using the GMFCS.

Physical activity was assessed using the ActiGraph® triaxial accelerometer (GT3X and GT3X+) over a period of three days. The ActiGraph® detects acceleration ranging in magnitude form 0.5 to 2.0 g and digitized by 12 bit analog to digital converter at rate of 30 Hz. Acceleration of bodily movement is detected in three directions, vertical (X), antero-posterior (Y) and mediolateral (Z) which is combined into vector magnitude ($VM=\sqrt{X^2+Y^2+Z^2}$). Vector magnitude is calculated per epoch of time called activity counts (counts per epoch of time). The monitor was set for recording at 5-second epoch to detect short bursts of activity in children with CP. Reliability and validity of the ActiGraph® in 5- year-old children with CP have not been investigated; however, a previous study reported excellent inter-instrument reliability (ICC=0.98) and concurrent validity of the ActiGraph® against indirect calorimeter (rho=0.83) in youth with CP aged 6-20 years classified as GMFCS I-III [32]. Participants wore the monitor on center of their lower back (L2) for three days as a minimum requirement [33] except when sleeping and during water-based activities. Wearing the monitor at lower back was used to prevent limitations of participants' movement and minimising influence of asymmetrical gait movement in some participants [34]. Placement of the monitor at lower back was used to validate cut-points for active and sedentary time [34, 35] and measure HPA in young children with CP aged 1.5-5 years across all GMFCS levels [17, 36]. Use of multiple placements may provide more accurate

physical activity for non-ambulant participants but this has not yet been examined [37]. In addition, multiple monitors may disturb daily living activity in young children with CP. Activity diaries were completed by parents of participants. It recorded the time when the monitor was put on, taken off, reasons for taking off, when the child was pushed in pram and/or being carried. Wear time was checked against the activity diary and non-wear time was removed from the analysis. The “non-wear time” was the period that the ActiGraph® was removed from a child for sleeping, bathing, swimming, or other water-based activities. The period that a child was carried or transported in car were not deleted but were recorded as sedentary time. Any ambiguous data were clarified with the parents. Each day was manually filtered for non-wear time. Activity data from the ActiGraph® were downloaded via ActiLife software (Actigraph, FL, USA). Total wear time and activity counts (counts per minute) were calculated by MATLAB® v.R2012b (The MathWorks Inc., Natick, MA, USA.).

Quality of life was measured using the CP QOL-Child parent proxy version, which has good psychometric properties, internal consistency ranged from 0.74 to 0.92, and test-retest reliability ranged from 0.76 to 0.89 (intraclass correlation coefficient) [9, 38, 39]. Parent-reported QOL is appropriate for 5-year-old children with CP as clinical care is provided to a family unit. The questionnaire contains 65 items in 7 domains: feelings about social well-being and acceptance, feelings about functioning, participation and physical health, emotional well-being and self-esteem, access to services, pain and impact of disability, and family health where the questions begin with “How do you think your child feels about…” [8]. The questions in pain and impact of disability domain are ‘yes/no’ questions and ‘how’ questions such as “Is your child bothered by hospital visits?” and “How much pain does your child have?” The family health domain starts a question with “How do you feel about…”. The questionnaire is scored on nine-point scales from 1=very unhappy to 9=very happy except for one item in the pain and impact of disability domain. This item is “Does your child worry about who will take care of them in the future?” and it is scored on a five-point scales from 1=never to 5=always. Raw scores were recoded into a range of 0-100 scores, higher scores indicating better QOL except in pain and impact of disability domain, lower scores indicating better QOL [8].

Statistical analysis

Summary statistics are presented as mean (standard deviation) for continuous variables and as frequency (percentage) for categorical variables. Characteristics of

children with CP who were included and excluded from this study were compared using Fisher's exact test for categorical variables and independent t-test for continuous variables. Participants were grouped according to ambulatory status into two groups: ambulant (GMFCS I-III) and non-ambulant (GMFCS IV-V) and were compared according to wear-time, activity counts, the GMFM and the CP QOL-Child score using linear regression models. Multiple linear regression analyses were performed to investigate relationships of activity counts on each domain of the CP QOL-Child controlling for gross motor function. All statistical analyses were performed using Stata statistical software v13.1 (StataCorp, College Station, TX, USA). Statistical significance was set at p=0.05.

7.2.4. Results

One hundred and thirty-two children with CP whose parents completed the parent-reported CP QOL-Child were eligible for inclusion in this study. Seventy-four children with CP were excluded from analysis due to incomplete 3-day physical activity monitoring (2-day monitoring in 11 children, 1-day monitoring in 3 children, and 0-day monitoring in 60 children). Incomplete 3-day activity monitoring was due to children refusing to wear the monitor and parental difficulty attaching the monitor to their child and completing activity diaries. Sex, motor type and distribution, and GMFCS levels were not significantly different between participants who were included and excluded (Table 1). The CP QOL-Child score in all domains according to GMFCS levels were not significantly different between children who were included and excluded. Fifty-eight participants completed all outcome measures and were categorized as either ambulant (GMFCS I-III; n=47) or non-ambulant (GMFCS IV-V; n=11). ActiGraph® wear time periods were not significantly different between the two groups (Table 2). The ambulant group had higher activity counts than the non-ambulant group (mean difference=1006 counts per minute; 95%CI, 745-1267; p<0.001; Table 2). The GMFM score of the ambulant group was higher than the non-ambulant group (Table 2). When considering the parent-reported CP QOL-Child, the ambulant group had significantly better QOL compared to the non-ambulant group in all domains except social well-being and acceptance, and access to services (Table 2). For example, for the domain of feelings about functioning, the ambulant group had higher CP QOL-Child scale score than non-ambulant group (mean difference=20 scores; 95%CI, 12-28; p<0.001; Table 2).

Univariate regression analyses between activity counts and the CP QOL-Child domains found that activity counts were significantly associated with domains of feelings about functioning (mean difference (MD)=13.4 1,000 counts per minute; 95% confidence interval (CI)=7.4, 19.5), participation and physical health (MD=12.5 1,000 counts per minute; 95% CI=5.7, 19.3), and emotional and self-esteem (MD=9.6 1,000 counts per minute; 95% CI=4.3, 15.0). Multiple linear regression models of activity counts on the CP QOL-Child domains adjusted for the GMFM showed that activity counts were not significantly associated with any domains of the CP QOL-Child (Table 3). The GMFM was significantly associated with the domains of feelings about functioning, emotional well-being and self-esteem, and access to services (Table 3). The GMFM explained 39% of the variance in feelings about functioning, 27% of the variance in emotional well-being and self-esteem, and 18% of the variance in access to services (Table 3). The domains of social well-being and acceptance, participation and physical health, pain and impact of disability, and family health were not significantly associated with activity counts and the GMFM (Table 3).

7.2.5. Discussion

Parent-reported QOL in ambulant children with CP was significantly better compared to non-ambulant children in all domains except social well-being and acceptance, and access to services which were equivalent. This data could be interpreted that ambulatory status may impact parent-reported QOL of children with CP across broad domains at early age. The results from the present study are similar to previous studies [15, 40]. A previous study in Victorian children with CP aged 4-12 years (mean aged 8.3 years) reported that the GMFCS level was significantly associated with the parent proxy CP QOL-Child in all domains except access to services [15]. Another study in Finnish children with CP age 4-12 years (mean aged 8 years) found that the GMFCS level was significantly associated with the parent-reported CP QOL-Child domains of feelings about functioning, participation and physical health [40]. As QOL is a multidimensional concept, functional ability is one of the factors that impacts on QOL. Environmental factors have also been reported to influence QOL of children with CP [41, 42]. Environmental barriers such as lack of assistive devices, financial support, and physical/emotional support from other people were associated with low QOL [41].

There was no relationships between HPA and domains of QOL on the CP QOL-Child after controlling for motor function. Motor function defined by the GMFM was

significantly associated with the domains of feelings about functioning, emotional well-being and self-esteem, and access to services. The relationships between HPA and QOL may depend on age and severity of children with CP, and sensitivity and specificity of measurement tools. A previous study by Bjornson et al. in ambulant youth with CP (GMFCS I-III; age range 10-13 years) found similar results to the present study in that HPA was not associated with self-reported QOL [14]. Conversely, a study by Maher et al. in children and adolescent with CP (GMFCS I-V; age range 11-17 years) reported significant associations between HPA and QOL in physical and social domains [43]. The developmental differences between adolescents and 5-year-old children would impact on their QOL not only their performance but also contextual factors. Regarding HPA measurements, the Bjornson study [14] used both objective and subjective measures (the StepWatch™ and Activity Scale for Kids) while the Maher et al. [43] study used a subjective measure (the Physical Activity Questionnaire for adolescents). Our study used the ActiGraph® accelerometer which is an objective measure. Objective HPA measurements may be more accurate compare to subjective measurements as subjective measurements may present recall bias. Both previous studies [14, 43] used generic QOL questionnaires (the Youth Quality of Life Instrument-Research Version (YQOL-R) [14] and the PedsQL4.0 generic core scales [43]) whereas our study used a condition-specific QOL questionnaire (the CP QOL-Child). Generic QOL measure may not cover all domains relevant to children with CP.

Furthermore, there are various factors that influence QOL. A previous study examined factors related to psychosocial QOL using the parent-reported CP QOL-Child domains of social well-being and acceptance, and emotional well-being and self-esteem [44]. They found that comorbidities, including impairment in hearing, sight, epilepsy, and language or developmental delay are strongly associated with psychosocial QOL while age, sex, race, and severity of children are not associated [44]. In addition, well-being is controlled by positive cognitive biases of self-esteem, control, and optimism [45]. As the definition QOL depends on individual's perception and expectation [3], wide-ranging factors including both personal and environmental factors may impact on QOL.

To our knowledge, this is the first study that examines the relationship between physical activity and QOL in young children with CP aged 5 years across all GMFCS levels. Strengths of this study include using condition-specific QOL questionnaire and objective physical activity measure. The ActiGraph® also has some limitations which

cannot detect water-based activities and some activities where the trunk is kept relatively still, for example bike riding. Another potential limitation for this study was the small sample size of non-ambulant children with CP. Further studies should recruit a higher number of non-ambulant children with CP.

7.2.6. Conclusion

Parent-reported QOL for ambulant children with CP aged 5 years was significantly better than that of non-ambulant children with CP in the domains of feelings about functioning, participation and physical health, emotional well-being and self-esteem, pain and impact of disability, and family health. Gross motor function contributed to parent-reported QOL domains of feelings about functioning, emotional well-being and self-esteem, and access to services. Habitual physical activity was not associated with parent-reported QOL of children with CP at age 5 years.

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Table 1 Characteristics of children with cerebral palsy (CP) from the Queensland CP Child Study who were eligible for this study

Characteristics	**Included (n=58)**	**Excluded (n=74)**	***p*-value**
Sex	N (%)	N (%)	0.37
Boys	39 (67.2)	44 (59.5)	
Girls	19 (32.8)	30 (40.5)	
Type of CP			0.28
Unilateral spasticity	26 (44.8)	20 (27.0)	
Bilateral spasticity	26 (44.8)	40 (54.1)	
Dystonia	4 (6.9)	4 (5.4)	
Ataxia	1 (1.7)	6 (8.1)	
Hypotonia	1 (1.7)	4 (5.4)	
GMFCS level			0.15
I	33 (56.9)	28 (37.8)	
II	8 (13.8)	16 (21.6)	
III	6 (10.3)	13 (17.6)	
IV	3 (5.2)	9 (12.2)	
V	8 (13.8)	8 (10.8)	

Key: CP, Cerebral Palsy; GMFCS, Gross Motor Function Classification System; Fisher's exact test for categorical variables and independent t-test for continuous variables; 74 children were excluded from the study due to incomplete activity monitoring; *$p<0.05$.

Table 2 Comparison of physical activity, motor function and the Cerebral Palsy Quality of Life questionnaire for Children (CP QOL-Child) scaled score (mean ± SD) in children with cerebral palsy aged 5 years according to ambulatory status

Variables	Ambulant (GMFCS I-III; n=47)	Non-ambulant (GMFCS IV-V; n=11)	Mean difference	95%CI	*p*-value
Total Wear time (hour)	10.8 ± 1.4	10.5 ± 2.4	0.3	-0.8, 1.3	0.64
Physical activity counts (counts/min)	1256.0 ± 419.6	250.2 ± 193.6	1005.8	744.8, 1266.8	<0.001*
GMFM-66 score	74.2 ± 12.6	25.2 ± 10.7	49.0	40.7, 57.2	<0.001*
CP QOL-Child					
Social well-being and acceptance	86.7 ± 11.5	81.5 ± 10.6	5.3	-2.4, 12.9	0.17
Feelings about functioning	80.9 ± 12.1	61.0 ± 13.3	20.0	11.7, 28.2	<0.001*
Participation and physical health	78.9 ± 14.7	64.3 ± 14.6	14.5	4.7, 24.4	0.005*
Emotional well-being and self-esteem	89.4 ± 11.1	76.9 ± 12.3	12.5	4.8, 20.1	0.002*
Access to services	72.2 ± 17.0	61.6 ± 15.1	10.7	-0.5, 21.9	0.06
Pain and impact of disability	19.2 ± 15.2	31.0 ± 15.1	-11.7	-21.9, -1.5	0.03*
Family health	71.5 ± 17.5	59.7 ± 12.6	18.9	0.7, 23.1	0.04*

Key: CP QOL-Child, Cerebral Palsy Quality of Life questionnaire for Children; GMFCS, Gross Motor Function Classification System; GMFM-66, 66-item Gross Motor Function Measure; linear regression; *p<0.05.

Table 3 Regression analyses of physical activity counts on the Cerebral Palsy Quality of Life questionnaire for Children (CP QOL-Child) domains controlling for motor capacity (n=58)

Parameter	Mean difference	95% CI	*p*-value	R^2
Social well-being and acceptance				
Activity counts	-2.4	-11.7, 6.9	0.61	5%
GMFM-66	0.2	-0.1, 0.4	0.16	
Feelings about functioning				
Activity counts	-0.8	-10.2, 8.6	0.86	39%
GMFM-66	0.4	0.2, 0.6	0.001*	
Participation and physical health				
Activity counts	3.1	-8.3, 14.5	0.59	23%
GMFM-66	0.3	-0.01, 0.5	0.06	
Emotional well-being and self-esteem				
Activity counts	0.01	-8.7, 8.8	0.99	27%
GMFM-66	0.3	0.1, 0.5	0.01*	
Access to services				
Activity counts	-6.6	-19.7, 6.4	0.32	18%
GMFM-66	0.4	0.1, 0.7	0.008*	
Pain and impact of disability				
Activity counts	0.1	-12.8, 12.9	0.99	6%
GMFM-66	0.2	-0.5, 0.1	0.26	
Family health				
Activity counts	3.7	-10.3, 17.8	0.60	4%
GMFM-66	0.1	-0.3, 0.4	0.67	

Key: Activity counts, 1000 counts per minute; GMFM-66, 66-item Gross Motor Function Measure; multiple linear regression; *p<0.05.

7.3 Summary and conclusion

This study showed that ambulant children with CP had better QOL compared to non-ambulant children with CP across broad domains at age 5 years. Gross motor function had a strong association with parent-reported QOL while HPA had only a weak association. Habitual physical activity has many potential health benefits in children however it may not impact on QOL in children with CP aged 5 years. A potential limitation of this study was a small sample size of non-ambulant children with CP (n=11). Further studies should recruit a higher number of non-ambulant children with CP. Specific findings are as follows:

i) Ambulant children with CP had significantly better QOL than non-ambulant children with CP in the domains of feelings about functioning (p<0.001), participation and physical health (p=0.005), emotional well-being and self-esteem (p=0.002), pain and impact of disability (p=0.03), and family health (p=0.04).

ii) The QOL domains of social well-being and acceptance, access to services were not significantly different between ambulant and non-ambulant children with CP.

iii) Habitual physical activity was weakly associated with the parent-reported CP QOL-Child domains of feelings about functioning, participation and physical health, and emotional well-being and self-esteem but was not significant when controlling for motor function.

iv) Gross motor function was significantly associated with the parent-reported CP QOL-Child domains of feelings about functioning (p=0.001), emotional well-being and self-esteem (p=0.01), and access to services (p=0.008).

v) The GMFM-66 explained 39% of the variance in feelings about functioning, 27% of the variance in emotional well-being and self-esteem, and 18% of the variance in access to services.

Chapter 8: Longitudinal physical activity and sedentary behaviour in preschool aged children with cerebral palsy across all functional levels

8.1 Introduction to Chapter 8

This study investigated changes in HPA and TSS of children with CP from the age of 18 months to 5 years across all functional abilities. Assessments were made 4 time points; 18-24, 30-36, 48 and 60 months corrected age. A total of 159 assessments completed three-day activity monitoring using the ActiGraph® accelerometer in 95 participants. Fifteen participants were assessed at three time points, 34 participants were assessed at two time points and 46 participants were assessed at one time points. The hypothesis was that HPA levels and TSS were stable over time. In addition, activity data of children with typical development from previous studies were compared with children with CP classified as GMFCS I-II.

8.2 Paper 6: Longitudinal physical activity and sedentary behaviour in preschool aged children with cerebral palsy across all functional levels.

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Title: Longitudinal physical activity and sedentary behaviour in preschool aged children with cerebral palsy across all functional levels

Short title: Longitudinal physical activity and sedentary behaviour in cerebral palsy

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8.2.1. Abstract

Aim: To investigate longitudinal changes of habitual physical activity (HPA) and sedentary time in children with cerebral palsy (CP) aged 18 to 60 months across all functional abilities.

Methods: At study entry 95 children (62 male) were classified using the Gross Motor Function Classification System as GMFCS I=50, II=9, III=16, IV=6 and V=14. Physical activity was recorded on a total of 159 occasions at four possible time points: 18-24, 30-36, 48 and 60 months using ActiGraph® for three days. Mixed effects-regression models were used for analyses.

Results: Participants classified as GMFCS I-II had stable HPA as they aged. HPA significantly decreased at 60 months in children classified as GMFCS III-V. Sedentary time significantly increased at 48 and 60 months in all participants. Annual HPA significantly reduced in children classified as GMFCS III-V (-123 counts/minute, 95%CI=-206, -40) while annual sedentary time significantly increased in all participants (GMFCS I-II: 2.4%, 95%CI=0.7, 4.1 and GMFCS III-V: 6.9%, 95%CI=4.6, 9.2).

Interpretation: Children with CP at all GMFCS levels should be encouraged to be physically active from early childhood as HPA levels start to decline from 48 months. Breaks in sedentary time are required for all children with CP from the age of 3 years.

Key words: habitual physical activity, sedentary behaviour, gross motor function, preschool aged children, cerebral palsy.

8.2.2. Introduction

Cerebral palsy (CP) is a group of disorders caused by brain lesions that leads to activity limitations.[1] Children and youth with CP had lower habitual physical activity (HPA) levels than children with typical development.[2-4] There is limited data on levels of HPA in a representative population of preschool aged children with CP and no longitudinal data.[5] Evidence in the general population suggests that low physical activity levels can increase the risk of cardiovascular and metabolic disease.[6, 7] A large population-based sample in the USA (n=1015) reported that adults with CP had significantly higher prevalence of chronic diseases including heart conditions, hypertension, stroke and diabetes than adults without CP.[8] Reduced physical activity and increased sedentary behaviour have been associated with elevated blood pressure in children with CP (6-17 years)[9] and increasing risk of developing cardiometabolic diseases in young adults with CP (18-62 years).[10] The adverse effects

of limited moderate to vigorous physical activity and high sedentary behaviour are independent and have a different mechanism.[11] People who have short periods of moderate to vigorous physical activity, for their age, who are sedentary for most the day are still at high risk of cardiovascular disease and diabetes.[12] It is important that not only to increase moderate to vigorous physical activity but also to reduce sedentary time in order to enhance health benefits for children with CP.[11]

Recently, international recommendations of physical activity for people with CP were published.[13] People with CP should have moderate to vigorous physical activity for 60 minutes, 5 days a week or higher and sedentary time less than 2 hours a day or should break up sitting for 2 minutes every 30 to 60 minutes.[13] The physical activity guidelines for young children with typical development age at birth to five years[14-16] are different from the recommendations for older children and adults with CP.[13] The guidelines for children age at birth to five years recommend that children should be physically active every day for at least three hours and should not be sedentary, restrained, or kept inactive for more than one hour at a time, with the exception of sleeping.[14-16] It is recommended that young children with CP (birth to five years) should adhere to the same physical activity guidelines as children with typical development[14-16] however there are no longitudinal data in preschool aged children with CP on which to base these recommendations.

Previous studies tracking physical activity in children with typical development reported that physical activity levels at age 3 and 6 years significantly predicted physical activity into youth and young adulthood.[17] In addition, early childhood (birth to 6 years) is a critical period to promote active lifestyles.[18] In children with physical disabilities, interventions which aim to improve physical activity levels also recommend that physical activity should commence in early childhood and continue throughout adolescence and adulthood.[19] To date studies of HPA have been targeted in school-aged children and adolescents with CP.[2-5] Few studies have investigated HPA in young children with CP aged less than 5 years.[5, 20] Interventions for young children with CP have focused on improvement of developmental motor abilities as children with CP will reach the highest motor capacity at approximately 5 years.[21] Although motor capacity is directly associated with HPA[5], there are many other factors associated with HPA including both personal and environmental factors.[19] In addition, most studies only examined HPA in ambulant children with CP (GMFCS I-III). Objective physical activity data are rarely available in non-ambulant children with CP[22,

[23] and there are no longitudinal studies of HPA in young children with CP. The aims of this study were to: 1) describe HPA and sedentary behaviour in young children with CP from 18 to 60 months of age, 2) compare HPA and sedentary behaviour between time points, and 3) examine rate of change in HPA and sedentary behaviour across all gross motor functional abilities.

8.2.3. Methods

This prospective population-based longitudinal study was conducted in Queensland, Australia between 2007 and 2014. Participants were drawn from two population-based cohort studies, the Queensland CP Child Study of Motor Function and Brain Development[24] and the Queensland CP Child Study of Growth, Nutrition and Physical Activity.[25] Queensland children who were born in 2006-2009 and diagnosed with CP by a medical physician were eligible. Children with progressive disorders were excluded. Assessments of physical activity were scheduled at up to four time points (18-24, 30-36, 48 and 60 months of age). This study includes data from all participants who completed three-day physical activity monitoring at any of the time points. Ethics were approved by the University of Queensland Medical Research Ethics Committee (2008002260) and regional hospitals across Queensland, Australia. Informed consent was obtained by all parents or legal guardians of participants.

Outcome measures and procedures

At each assessment, participants were classified for gross motor function by a research physiotherapist using the Gross Motor Function Classification System (GMFCS) which contains five levels; level I, independent walking without restriction; level II, independent walking with limited on uneven surface; level III, walking with mobility device; level IV, self-mobility with limitation; and level V, who require full assistance.[26]

Habitual physical activity was measured using the ActiGraph® (GT3X and GT3X+) triaxial accelerometer. The ActiGraph® is an objective physical activity measure which records acceleration of bodily movement ranging in magnitude 0.5-2.0 g. The three planes of movement detected by the monitor, vertical (X), antero-posterior (Y), and mediolateral (Z), are combined into vector magnitude ($VM=\sqrt{X^2+Y^2+X^2}$). Output of the ActiGraph® is vector magnitude per epoch of time called activity counts (counts per epoch of time) which were used to define HPA in this study. Activity counts have been reported excellent inter-instrument reliability in ambulant youth with CP (ICC=0.981).[27] Physical activity in children is an intermittent burst and varying interval

with the median duration of 6 seconds for low and moderate intensity activities.[28, 29] Epochs were set at 5-seconds in order to detect short bursts of activity in children with CP. Participants wore the ActiGraph® for three days, two weekdays and one weekend day, as a minimum requirement[30] except for water-based activities and sleep time. Excellent reliability (ICC=0.84) has been reported for measuring sedentary time in preschool aged children with CP.[31] The monitor was placed at participants' lower back to avoid any movement limitations and minimize the influence of asymmetrical gait.[32, 33] Posterior placement on the lower back was found to be acceptable and valid[31, 34] in preschool aged children of all GMFCS levels from 18 to 60 months of age. Parents completed a corresponding activity diary which recorded time of wake/sleep, wear/non-wear of the monitor, reasons for non-wear, pushed in a stroller and/or carrying. Any ambiguous data were checked with parents until clarification. Activity data were downloaded via ActiLife software (ActiGraph, FL. USA.). Non-wear times were checked against activity diary and deleted from the analysis. The "non-wear time" was the period that the ActiGraph® was removed from a child for sleeping, bathing, swimming, or other water-based activities. The period that a child was carried or transported in car were not deleted but were recorded as sedentary time. Total wear time, activity counts (HPA; counts per minute) and sedentary time were calculated using MATLAB® (The Math Works Inc., version R2012b). Time spent sedentary was determined by cut-points for sedentary time in children with CP aged 18-60 months across all GMFCS levels which were validated in our previous studies.[31, 34] The cut-points of 40 counts per 5-second for participants aged 18-36 months classified as GMFCS I-III; 10 counts per 5-second for participants aged 18-36 months classified as GMFCS IV-V; and 68 counts per 5-second for participants aged 48-60 months across all GMFCS levels were used. Sedentary time as a percentage of wear time was calculated to normalize wear time.

Statistical analysis

We calculated that, with 95 participants assessed an average of 1.5 times each, we would have at least 80% power to detect a difference in effect size across time within GMFCS categories (I-II and III-V) of 0.5 or greater, assuming alpha=0.05 and correlation between repeated measures on the same participant=0.5). Summary statistics are presented as frequency (percentage) for categorical variables. The association between the binary variable GMFCS category (I-II/III-V) and physical activity was investigated using linear mixed effects models in order to account for the

possible non-independence of repeated observations from the same child.[35, 36] GMFCS category and time point (18-24/30-36/48/60 months) were entered as fixed effects. To investigate the change in motor ability over time a GMFCS-by-time interaction effect was entered into models. Child was included as a random intercept. Models used the Gaussian family, identity link and independent covariance matrix for the random effects. Effect estimates are presented as mean difference with 95% confidence intervals. Statistical significance was set at alpha=0.05 (two-tailed). All statistical analyses were performed using Stata v13.0 (StataCorp, College Station, TX, USA).

8.2.4. Results

Ninety-five participants completed three days of activity monitoring on a total of 159 occasions. At study entry the 95 children with CP were classified as GMFCS I=50; II=9, III=16, IV=6 and V=14 and 65.3% (n=62) were male. Fifteen participants were assessed at three time points, 34 at two time points, and 46 at one time point. Number of participants at study entry are shown in Table 1. Wear time periods were not significantly different between GMFCS levels with mean of around 10 hours a day. Figure 1 shows average HPA and sedentary time between two GMFCS groups. In addition, average HPA and sedentary time in 111 children with typical development aged 3-5 years from a previous study conducted in the USA (Butte et al., 2016)[37] are shown in Figure 1. Children classified as GMFCS I-II had significant higher HPA and lower sedentary time than children classified as GMFCS III-V at all time points (Figure 1 and Supplementary Table 1).

Activity counts in children classified as GMFCS I-II who walk independently remained stable as they aged. In marginal and non-ambulant children classified as GMFCS III-V, activity counts significantly decreased at 60 months of age (Figure 1A and Table 2). Regarding sedentary time, both GMFCS groups (GMFCS I-II and III-V) had significant higher sedentary time at 48 and 60 months compared with 18-24 months (Figure 1B and Table 2).

Linear regression models including age as a continuous main effect found that at mean age of all participants (46 months) with each increase of 1 year, the average HPA dropped by 15 counts per minute for GMFCS I-II and significantly decreased by 123 counts per minute for GMFCS III-V. With each increase of 1 year, sedentary time significantly increased by 2.4% for GMFCS I-II and 6.9% for GMFCS III-V (Table 3).

8.2.5. Discussion

This prospective longitudinal study investigated changes in HPA and sedentary time in preschool aged children with CP from the age of 18 to 60 months across all levels of gross motor function. This study used activity counts (vector magnitude) to report HPA with respect to translating activity counts to changes in actual HPA. Independently ambulant children with CP (GMFCS I-II) had stable HPA over the period and gradually increased sedentary time over the period. As functional severity increased, children with CP had declining HPA from aged 48 months and sedentary time gradually increased from the age of 30-36 months. In children classified as GMFCS III-V, HPA significantly decreased at the age of 60 months. It should be noted that sedentary time significantly increased at the age of 48 and 60 months compared to 18-24 months in all GMFCS groups. These data suggest that children with CP should be encouraged to be physically active from the age of 48 months especially for children with CP classified as GMFCS III-V. More importantly, breaks in sedentary time should be introduced in all children with CP from the age of 36 months. Changing position to standing can be used for sedentary breaks in all GMFCS levels as standing with support in children with GMFCS V is still found to be light activity.[38] The present study did not include effect of gender on HPA as our previous studies found that gender does not impact on HPA in preschool aged children with CP.[22, 23]

Regression analyses investigating the rate of change found that in the average HPA significantly decreased every year for children with CP classified as GMFCS III-V and sedentary time significantly increased every year for all GMFCS levels. These data suggest that children with CP classified as GMFCS III-V are needed to encourage to be physically active. Sedentary breaks are urgently required for children with CP at all levels of functional ability from early childhood. In addition, breaks in sedentary behaviour by introducing light activity in children with CP are more achievable than increased moderate to vigorous physical activity.

Children with CP classified as GMFCS level III-V had significant lower HPA and higher sedentary time compared to children with CP classified as GMFCS level I-II at all time points. These data can be interpreted that HPA and sedentary time are strongly related to gross motor capacity from an early age. Although functional ability can impact on HPA and sedentary time in children with CP, many factors need to be considered to improve and maintain an active lifestyle including self-motivation, family-motivation, awareness of benefits of physical activity, and access to sport or active

leisure facilities in the home, community and preschool environment.[19, 39, 40] Previous studies suggest that to achieve and maintain functional capability in children with chronic health conditions, a sustained physically active lifestyle is crucial.[41] Our data suggest that encouragement to be physically active with less sedentary time in children with CP should be commenced from early childhood (aged 3 years) and continued throughout their life span.

Our previous study in children with typical development aged 18-36 months (mean=26.5, SD=6 months) found that mean activity counts were 1416 (SD=283) counts per minute; sedentary time were mean 49 (SD=5) percentage of wear time which were not significantly different compared to independently ambulant children with CP (GMFCS I-II).[22] A previous study from Butte et al., 2016 reported that activity counts in children with typical development aged 36 months were mean 821 (SD=150); aged 48 months were mean 853 (SD=179); aged 60 months were mean 859 (SD=157) counts per minute (calculated from counts per day).[37] Although children with CP classified as GMFCS level I-II in our study had higher activity counts than children with typical development from the Butte study (Figure 1A), activity counts in children with CP were more variable (SD ranged from 259 to 379 counts per minute). Periods of monitoring however between our study and the Butte study were different. The Butte study monitored physical activity 24 hours a day for 7 days, except during swimming or bathing while our study monitored only waking hours for 3 days. Measurement of physical activity in preschool aged children with typical development for 3 days was reported to have acceptable reliability (ICC=0.7).[42] In preschool aged children with CP, 3-day activity monitoring was found to have excellent reliability (ICC=0.84) for measuring sedentary time.[31] The definition of non-wear time were also different. The Butte study defined non-wear time as consecutive zero counts for 20 minutes or more and record from activity diary (sleep or removal of the monitor). Non-wear time of our study was only when the monitor was removed according to the activity diary. Furthermore, children with CP classified as GMFCS I-II have lower motor control than children with typical development which may lead to high accelerations due to poor co-ordination. These may account for the high variability of activity counts between children with and without CP.

According to sedentary time, the Butte study and our study used the same cut-points for sedentary time in participants aged 48 and 60 months which were 820 counts per minute.[34, 43] The Butte study normalized sedentary time as a percentage of

awake time and our study also normalized sedentary time as a percentage of wear time. The Butte study reported that sedentary time of children with typical development aged 48 months were 44%; aged 60 months were 46% while sedentary time of children with CP in the present study ranged from 56% to 58% (Figure 1B). Children with CP classified as GMFCS I-II seem to have higher sedentary time than children with typical development; however, sedentary time in preschool children with typical development (2-5 years) has been reported across a wide range from 34% to 94%.[44] These may assume that HPA and sedentary time in children with CP classified as GMFCS I-II aged 18-60 months were not different from children with typical development. Greater differences of HPA and sedentary time between ambulant children with CP and children with typical development could be found after the age of 5 years.[2-4] Many factors can impact on HPA and sedentary time in school aged children with CP both personal and environmental factors for example developed secondary impairments or attending school.

This study provides longitudinal data of objective physical activity in young children with CP across all gross motor functional abilities. Strengths of this study included changes of HPA and sedentary time in children with CP from the aged of 18 to 60 months across all GMFCS levels including objective physical activity data in non-ambulant children with CP. Knowledge of HPA and sedentary time across all GMFCS levels at different ages may enhance strategies to maintain or improve an active lifestyle in children with CP. Our findings suggest that patterns of HPA and sedentary behaviour may be evident from 3 years of age, with lifetime impacts on active lifestyles and health outcomes. Greater emphasis needs to be placed on monitoring HPA in addition to motor capacity in preschool aged children with CP and more importantly the impact of sedentary behaviour on health outcomes.

A potential limitation was that there have been no reliability studies done for the cut-points for sedentary time in terms of minimally detectable differences in longitudinal data. The differences in sedentary time found in this study may be due to using different cut-points but not actual changes. These findings suggest that activity counts (HPA) would be a more reliable measure for longitudinal studies. Another potential limitation of this study was the smaller number of participants in GMFCS level III-V as attachment of activity monitors in young children with CP was a challenge. Also there are some limitations of the ActiGraph® itself which cannot be used for

water-based activities and some light activities may be detected as sedentary due to stationary trunk during standing with or without support and bike riding.

8.2.6. Conclusion

This longitudinal study of HPA and sedentary time in children with CP from the age of 18 to 60 months found that children with CP classified as GMFCS level I-II had stable HPA. Children with CP classified as GMFCS level III-V significantly declined their HPA at the age 60 months and every year they increased with age. Sedentary time significantly increased at age 48 and 60 months in children with CP at all functional abilities. In addition, sedentary time significantly increased with increasing age in young children with CP across all functional abilities. Our findings suggest that breaks in sedentary time and promotion of active lifestyles should be encouraged from the age of 36 months in children with CP.

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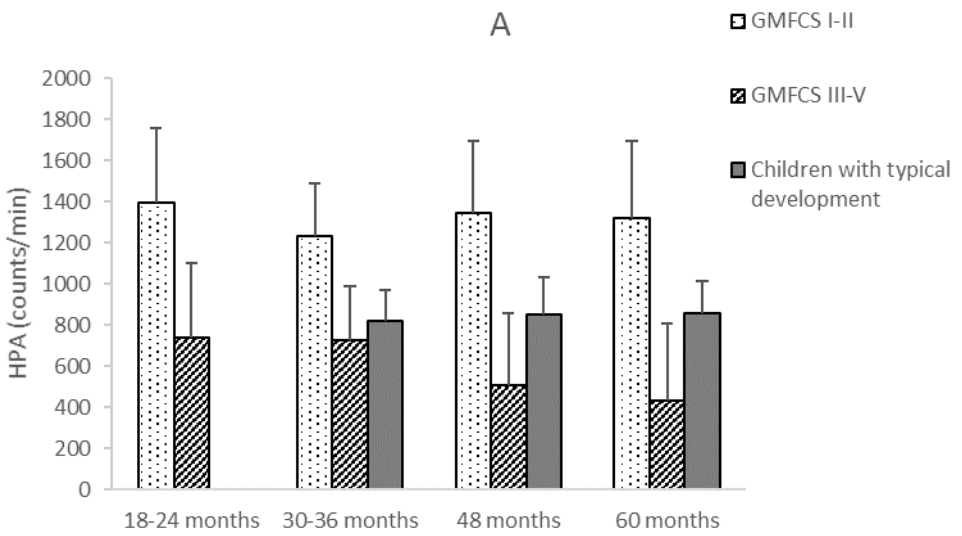
Table 1 Number of participants at study entry according to gross motor function classification system (GMFCS), n (%).

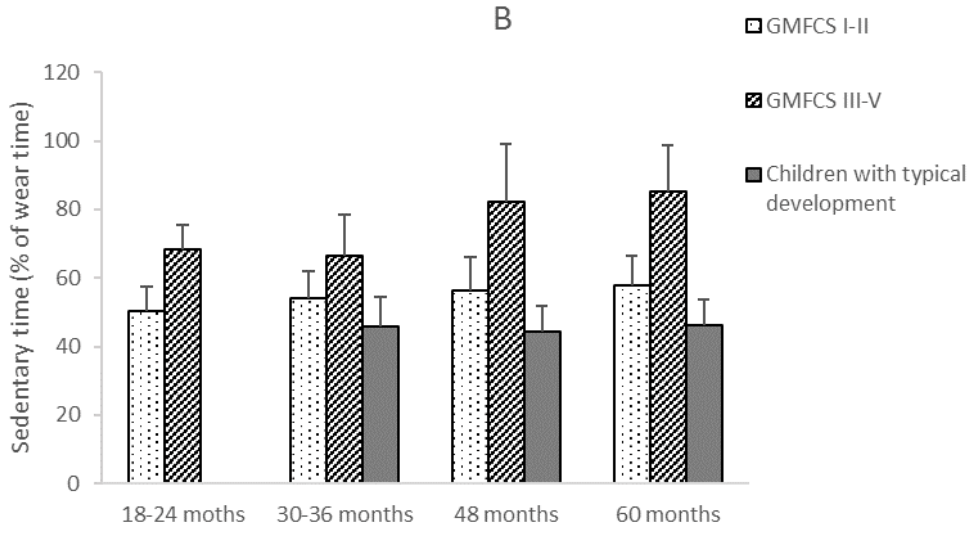
GMFCS level	18-24 months	30-36 months	48 months	60 months	Total
GMFCS I	14 (56)	12 (39)	12 (60)	12 (63)	50
GMFCS II	3 (12)	1 (3)	2 (10)	3 (16)	9
GMFCS III	6 (24)	8 (26)	1 (5)	1 (5)	16
GMFCS IV	1 (4)	4 (13)	1 (5)	0 (0)	6
GMFCS V	1 (4)	6 (19)	4 (20)	3 (16)	14
Total	25 (100)	31 (100)	20 (100)	19 (100)	95

Key: GMFCS; Gross Motor Function Classification System

Figure 1 Habitual physical activity (A) and sedentary time (B) in children with cerebral palsy aged 18 to 60 months and children with typical development (data from the Butte et al., 2016).



GMFCS I-II	n=17	n=25	n=16	n=42
GMFCS III-V	n=8	n=23	n=10	n=18
Children with typical development	N/A	n=36	n=37	n=38



GMFCS I-II	n=17	n=25	n=16	n=42
GMFCS III-V	n=8	n=23	n=10	n=18
Children with typical development	N/A	n=36	n=37	n=38

Table 2 Comparison of habitual physical activity (HPA) and sedentary time between time points.

	HPA (counts/minute)				Sedentary time (percentage of wear time)			
Time point	**GMFCS I-II**		**GMFCS III-V**		**GMFCS I-II**		**GMFCS III-V**	
	Mean (SD)	mean difference (95% confidence interval)	Mean (SD)	mean difference (95% confidence interval)	Mean (SD)	mean difference (95% confidence interval)	Mean (SD)	mean difference (95% confidence interval)
18-24 months	1397 (362)	Reference	783 (343)	Reference	50.3 (7.2)	Reference	68.4 (7.0)	Reference
30-36 months	1231 (259)	-115 (-268, 39)	727 (404)	-42 (-261, 176)	54.0 (8.0)	2.7 (-1.1, 6.4)	66.3 (12.2)	-0.56 (-5.9, 4.8)
48 months	1345 (351)	-35 (-232, 161)	510 (494)	-209 (-479, 61)	56.2 (9.8)	6.5 (1.6, 11.3)	82.4 (16.6)	12.6 (5.9, 19.3)
60 months	1319 (379)	-49 (-198, 100)	431 (431)	-236 (-462, -9)	57.7 (8.8)	7.6 (3.9, 11.2)	85.2 (13.4)	13.5 (7.9, 19.0)

Table 3 Rate of change in habitual physical activity (HPA) and sedentary time at mean age of all participants (46 months).

HPA (counts/minute)		Sedentary time (percentage of wear time)	
GMFCS I-II mean difference (95% confidence interval)	**GMFCS III-V** mean difference (95% confidence interval)	**GMFCS I-II** mean difference (95% confidence interval)	**GMFCS III-V** mean difference (95% confidence interval)
-15 (-75, 44)	-123 (-206, -40)	2.4 (0.7, 4.1)	6.9 (4.6, 9.2)

Key: mixed-effects linear regression models including age as a main effect.

Supplementary Table 1 Average wear time, habitual physical activity (HPA) and sedentary time at each time point and comparison between gross motor function classification system (GMFCS) groups at each time point.

	Wear time (minutes)			**HPA (counts/minute)**			**Sedentary time (percentage of wear time)**		
Time point	**GMFCS I-II** mean (SD)	**GMFCS III-V** mean (SD)	Mean difference (95% Cl)	**GMFCS I-II** mean (SD)	**GMFCS III-V** mean (SD)	Mean difference (95% CI)	**GMFCS I-II** mean (SD)	**GMFCS III-V** mean (SD)	Mean difference (95% CIl)
18-24 months	585 (83)	587 (115)	-7 (-81, 67)	1397 (362)	738 (343)	-632 (-890, -374)	50.3 (7.2)	68.4 (7.0)	18.2 (11.6, 24.8)
30-36 months	578 (88)	595 (95)	14 (-36, 64)	1231 (259)	727 (404)	-560 (-747, -373)	54.0 (8.0)	66.3 (12.2)	15.0 (10.1, 19.9)
48 months	632 (82)	594 (87)	-57 (-126, 13)	1345 (351)	510 (494)	-806 (-1054, -558)	56.2 (9.8)	82.4 (16.6)	24.4 (18.0, 30.8)
60 months	641 (83)	445 (122)	7 (-42, 56)	1319 (379)	431 (431)	-819 (-1001, -637)	57.7 (8.8)	85.2 (13.4)	24.1 (19.3, 28.9)

Key: CI, Confidence interval

8.3 Summary and conclusion

This study found that HPA in children with CP classified as GMFCS I-II were stable from 18 to 60 months. Habitual physical activity significantly decreased in children with CP classified as GMFCS III-V at 60 months and every year they increased with age. Children with CP at all functional levels had a significant increase in TSS at age 48 and 60 months and every year they increased with age. Children with CP classified as GMFCS III-V should be encouraged to be physically active to improve HPA level from early childhood. Breaks in sedentary time are required in children with CP at all functional levels from the age of 36 months. A potential limitation was the small number of participants in GMFCS III-V (n= 8-23). Specific findings are as follows:

i) Independently-ambulant children with CP classified as GMFCS I-II had stable HPA levels and a significant increase in TSS at 48 (p=0.009) and 60 months (p<0.001) compared to 18-24 months.

ii) Habitual physical activity in children with CP classified as GMFCS III-V significantly increased at 60 months (p=0.041). Sedentary time significantly increased at 48 (p<0.001) and 60 months (p<0.001) compared to 18-24 months.

iii) For each successive year of age, HPA decreased by 15 counts per minute for GMFCS I-II, and significantly decreased by 123 counts per minute (p=0.004) for GMFCS III-V.

iv) Sedentary time significantly increased every year by 2.4% for GMFCS I-II (p=0.005), and 6.9% for GMFCS II-V (p<0.001).

v) Motor capacity is directly related to HPA and TSS from early childhood as children with CP classified as GMFCS III-V had significantly lower HPA and higher TSS than GMFCS I-II (p<0.001) at all time points.

Chapter 9: Grand Discussion

To our knowledge, this program of research is the first comprehensive study describing HPA in children with CP aged 4-5 years across all functional abilities using an objective measure of physical activity. The ActiGraph® triaxial accelerometer is an objective physical activity monitor which provides robust data on activity intensity, duration and frequency. Previous studies mainly focused on HPA in ambulant school-aged children and adolescents with CP (GMFCS I-III). The systematic review study (Chapter 2) showed that HPA was directly related to motor capacity; however, no previous study specifically examined HPA using objective measurement in children with CP under 5 years of age across all functional abilities. This limitation may be due to the limited validation of activity intensity cut-points in this age group. In addition, cut-points of the ActiGraph® had not been validated in specific age ranges and conditions. This research program validated the ActiGraph® cut-point for sedentary time in children with CP aged 4-5 years, thereby allowing further examination of sedentary and active time in this group of children (Chapter 4). The cross-sectional studies also undertaken (Chapter 5-7) describe HPA and TSS and their relation to motor capacity, motor capability and parent-reported QOL in children with CP under 5 years of age. The longitudinal study (Chapter 8) examined changes in physical activity levels over time from aged 18 months to 5 years.

9.1 Overview

Details for each sub-study are discussed according to each hypothesis for this doctoral thesis.

Sub-study 1: Systematic review of the relationship between HPA and motor capacity in children with CP

Hypothesis 1: Habitual physical activity will be directly related with motor capacity in children with CP.

Gross motor functional limitations are the major reason for low physical activity in children with CP. The results of this systematic review confirmed that HPA was directly associated with motor capacity in children with CP aged 2-17 years. A meta-analysis could not be performed in this study because the HPA measurements across studies included both subjective[15, 68-70] and objective measures.[14, 30-34] The objective HPA measurements were the StepWatch®[14, 30-33] and the ActiGraph®.[34] The

StepWatch® measures physical activity as step counts, and is therefore not appropriate for non-ambulant children. There were three studies that included non-ambulant children with CP and all of these studies used subjective HPA measurements.[15, 69, 70] Additionally, three studies recruited children with CP from 2 years of age, but only ambulant children (GMFCS I-III) were observed.[32, 33, 68] No study investigated HPA using objective measurements in all functional abilities of children with CP. In addition, data on HPA in non-ambulant children with CP is not available. This systematic review identified specific areas in the literature that require further investigation, and provided the basis for this research program.

Sub-study 2: Validation of accelerometer cut-points in children with CP aged 4-5 years

Hypothesis 2: Both the developed and the previously established cut-points for sedentary time will be valid for measuring sedentary time in children with CP aged 4-5 years across the spectrum of gross motor ability.

This study derived the ActiGraph® cut-points for sedentary time in each GMFCS level against direct observation using ROC curves.[71] The results found that children with CP classified as GMFCS III and V had good classification accuracy; GMFCS I and II had adequate classification accuracy, while GMFCS IV had fair classification accuracy. The developed and the previously established cut-points[65] were applied in an independent sample of children with CP for cross-validation analyses. The results support the use of the previously established cut-point from children with typical development for sedentary time of 820 counts per minute,[65] which demonstrated smaller bias and narrower 95% limits of agreement compared with the cut-points from children with CP. It is important to note that the cut-points should be used on a group level and not for individuals. Using the cut-points in an individual child may result in significant differences between observed and predicted time spent sedentary. A previous study derived cut-points for sedentary time in toddlers with and without CP aged 1.5-3 years which were 480 counts per minute for ambulant toddlers with and without CP, and 120 counts per minute from non-ambulant toddlers with CP.[72] The present study demonstrated that validated cut-points for sedentary time in children with CP aged 4-5 years are higher than the cut-points in toddlers with CP aged 1.5-3 years. In addition, children with CP aged 4-5 years at all functional abilities can use the same cut-points for sedentary time as children with typical development.

Our present study provides the validated cut-points for sedentary time in children with CP aged 4-5 years across all functional abilities. This will allow further studies for investigating sedentary and active time in young children with CP. Time spent sedentary and active could be the outcome measures for the examination of interventions in children with CP and also when comparing HPA levels to the physical activity guidelines.[16]

Sub-study 3: Habitual physical activity in children with CP aged 4-5 years across all functional abilities

Hypothesis 3a: Children with CP with higher functional capacity (GMFCS I-II) will have higher physical activity and lower time spent sedentary (TSS) than children with lower functional capacity (GMFCS III-V)

This cross-sectional study investigated HPA and TSS in children with CP using the cut-point for sedentary time in the validation study (sub-study 2). Independently-ambulant children with CP had significantly higher HPA and lower TSS than marginal- and non-ambulant children with CP. Comparison of TSS between preschool children with CP and toddlers with CP aged 18-36 months showed that preschool children had a higher percentage of TSS compared to toddlers.[35] Differences in the percentage of TSS between preschool children and toddlers with CP were 6% in independently-ambulant, 12% in marginal-ambulant and 19% in non-ambulant groups. These findings suggest that increased HPA and decreased TSS are needed in young children with CP aged 4-5 years especially in the marginal- and non-ambulant groups.

Hypothesis 3b: Children with CP with higher functional capacity (GMFCS I-II) will be more likely to meet the Australian Physical Activity Guidelines than children with lower functional capacity (GMFCS III-V).

Our findings suggest that independent-ambulant children with CP were more likely to meet the Australian Physical Activity Guidelines than marginal- and non-ambulant children with CP. When compared to the physical activity guidelines, it was clear that improved HPA and decreased TSS in marginal- and non-ambulant children with CP were needed at age 4-5 years.

Regarding previous studies in children with typical development, a large study by Hinkley et al[73] in Australian preschool children aged 3-5 years (n=703) reported that 5% of participants met the guidelines for active time of more than three hours per

day.[73] Previous studies in Canadian preschool children with typical development aged 3-4 years (n=89 and 459) found that 73-84% of participants had active time more than three hours per day.[74, 75] Our results showed that 67% of participants in independently-ambulant children with CP (GMFCS I-II) met the guidelines for active time. All studies used different HPA measurements and cut-points, which may account for these discrepancies. In addition, activity counts in independently-ambulant children with CP were more variability than those in children with typical development. These findings suggest that independently-ambulant children with CP did not have lower HPA levels than children with typical development; however, they should be encouraged to be physically active to maintain high levels of HPA throughout their life span.

Sub-study 4: Relationship between HPA, motor capacity and capability in children with CP aged 4-5 years across all functional abilities

Hypothesis 4: Motor capacity and capability will be associated with HPA and TSS in children with CP aged 4-5 years.

We investigated the associations between HPA, motor capacity (what the child can do in a structured environment) measured by the GMFM-66 and motor capability (what the child can do in a natural environment) measured by the PEDI functional skills of the mobility domain. Both the GMFM-66 and PEDI were associated with HPA and TSS in ambulant children with CP (GMFCS I-III). These findings supported the results in the systematic review (sub-study 1) that motor capacity was directly related to HPA. Both motor capacity and capability contribute to activity performance; however, motor capacity, capability and performance are separate measures.[38] Other factors such as the desire to be active, awareness of benefits of physical activity, family support, pain and opportunity for sport and physical activity can impact HPA and TSS.[39, 76, 77] In non-ambulant children with CP (GMFCS IV-V), both motor capacity and capability were not associated with HPA and TSS. These findings suggest that HPA and TSS may be used as clinical outcomes for interventions in ambulant children with CP aged 4-5 years, but not for non-ambulant children.

Sub-study 5: Quality of life and habitual physical activity in children with CP aged 5 years: a cross-sectional study

Hypothesis 5a: Parent-reported QOL between ambulant and non-ambulant children with CP will not be different in all domains.

Comparison of the parent-reported CP QOL-Child between ambulant and non-ambulant children with CP found that ambulant children with CP had significantly better QOL than non-ambulant children in the domains of feelings about functioning, participation and physical health, emotional well-being and self-esteem, pain and impact of disability, and family health. The domains of social well-being and acceptance, and access to services were not significantly different. These suggest that ambulatory status may have an impact on broad domains of QOL in young children with CP. The results are similar to previous studies that reported that the GMFCS are associated with broad domains of the CP QOL-Child.[78, 79] Quality of life is a multidimensional concept depending on the individual's perception. Although QOL is associated with motor function, it has been reported to be associated with environmental factors such as lack of support from others, financial support and assistive devices.[80, 81]

Our study did not support the disability paradox that children with severe disability report higher QOL.[46] A previous study found that non-ambulant children with CP reported better health status than ambulant children in the behaviour domain.[82] In addition, QOL between children with and without CP reported no significant differences.[83-85] CP QOL domains such as feelings about function, and participation and physical health had a lower score in children with CP compared to children with typical development.[83]

Hypothesis 5b: Habitual physical activity will be postitively associated with broad domains of parent-reported QOL in children with CP aged 5 years.

We investigated the relationships between HPA and domains of the parent-reported CP QOL-Child controlling for functional severity on the GMFM-66. The results showed that HPA was weakly associated with the CP QOL-Child domains of feelings about functioning, participation and physical health, and emotional well-being and self-esteem but was not significant when controlling for gross motor function. Gross motor function contributed to the domains of feelings about functioning, emotional well-being and self-esteem, and access to services. Although HPA has benefits for health outcomes, it may not impact on QOL in children with CP at age 5 years. Furthermore, the relationships between HPA and QOL may depend on sensitivity and specificity of measurements. A previous study reported that HPA measured by the Activity Scale for Kids (ASKp38) and the StepWatch® were not associated with the self-reported

Youth Quality of Life Instrument-Research Version (YQOL-R).[42] On the other hand, HPA measured by the self-reported Physical Activity Questionnaire for adolescents (PAQ-A) was associated with QOL measured by the Pediatric Quality of Life Inventory (PedsQL) 4.0 generic core scale.[43]

Sub-study 6: Longitudinal physical activity in preschool aged children with CP across all functional levels

Hypothesis 6: Habitual physical activity levels in children with CP will be stable from aged 18 months to 5 years.

We examined changes in HPA and sedentary time in children with CP from the age of 18 to 60 months. Physical activity was recorded at four time points; 18-24, 30-36, 48 and 60 months corrected age. Children with CP classified as GMFCS I-II had stable HPA and gradually increased sedentary time over the period while other GMFCS levels had declining HPA from aged 48 months and increasing sedentary time from the age of 30-36 months. HPA decreased and sedentary time significantly increased every year for all functional levels. Decreases in HPA were not significantly different, but increases in sedentary time were significantly different. These findings suggest that children with CP should be encouraged to be physically active from the age of 48 months. Breaks in sedentary time are urgently required for all children with CP from the age of 36 months. Sedentary breaks can be performed by shifting from lying/sitting to standing. A previous study reported that standing with support in children with CP classified as GMFCS V is classified as light activity.[86] It is important to note that reliability of the cut-points for sedentary time to detect minimal changes over time have not been established. The differences in sedentary time in this study may be due to the use of different cut-points, and are therefore not actual changes. The activity counts that represent HPA would be a more reliable measure.

A previous study using the same participants aged 18-36 months as this study reported that HPA and sedentary time in children with CP classified as GMFCS I-II were not significantly different compared to children with typical development.[35] A previous study by Butte et al., 2016[87] reported HPA in children with typical development aged 36, 48 and 60 months which were lower activity counts compared to children with CP classified as GMFCS I-II. However, activity counts in children with CP were more variable, and activity monitoring periods were different. Our study monitored waking hours for three days while the Butte study monitored 24 hours a day

for 7 days. Higher accelerations in children with CP may be due to poor co-ordination. For sedentary time, our study used the same cut-points for sedentary time in children aged 48-60 months as the Butte study. Children with CP classified as GMFCS I-II aged 48-60 months had higher sedentary time than children with typical development. Reported sedentary time in children with typical development aged 2-5 years ranges from 34% to 94% of their day.[88] Independently ambulant children with CP at preschool age may be assumed to have the same HPA and sedentary time as children with typical development with differences occurring in older children after the age of 5 years.[4, 28, 31]

This study addresses some of the unanswered questions of previous studies of HPA in children with CP. Longitudinal changes of HPA in young children with CP across all functional abilities could be used to enhance the efficiency of future research, maintain or promote active lifestyle, and increase awareness of HPA in children with CP.

9.2 Limitations

The following are potential limitations of this research program:

i. There were a small number of non-ambulant children with CP (GMFCS IV, n=3-12; GMFCS V, n=8-14) which could impact on the results of validation cut-points study and in the cross-sectional study. Records of physical activity in non-ambulant children with CP were a challenge as their parents were engaged in all of their daily living activity and unable to complete the activity diary. Although non-ambulant children with CP were a small number, their physical activity levels were consistent and had low variability. These findings suggest that these results are preliminary for the physical activity in non-ambulant children with CP. In addition, participant numbers in GMFCS II and III were limited in the validation cut-points study (GMFCS II, n=7-13; GMFCS III, n=5-10) and the cross-sectional study (GMFCS III n=7).
ii. Children with typical development were not included as a reference group. Although previous studies in children with typical development could be compared to this study, there were some limitations according to HPA measurements, period of monitoring and the cut-points for sedentary time.
iii. The ActiGraph® has some limitations in that it prohibits measurement of water-based activities. Also the ActiGraph® may have classified light activities such

as bike riding, standing with and without support as sedentary activity because the trunk is stable and there is no change in the centre of mass.

iv. Placement of the activity monitor on the child's back may have led to a low non-compliance rate with non-ambulant children with CP.

v. There have been no reliability studies performed for the cut-points for sedentary time in the longitudinal study as the cut-points are specific to different aged ranges. Differences in sedentary time at different age ranges may not be actual changes; however, the activity counts are reliable data.

9.3 Clinical implications

The following are potentially important clinical applications of this research program for management of young children with CP:

i. The ActiGraph® cut-points for sedentary time of 820 counts per minute can be used to determine sedentary and active time in children with CP aged 4-5 years.

ii. Interventions to increase HPA and reduce sedentary time are required in children with CP aged 4-5 years and should focus on marginally-ambulant and non-ambulant children with CP (GMFCS III-V).

iii. Gross motor capacity and capability are directly related to HPA and sedentary time in ambulant children with CP.

iv. Habitual physical activity and time spent sedentary may be useful and valid outcome measures for determining the effects of interventions in groups of ambulant children with CP, but not in non-ambulant children with CP.

v. Gross motor function is strongly associated with parent-reported QOL domains of feelings about functioning, emotional well-being and self-esteem, and access to services.

vi. Active lifestyle and breaks in sedentary time in children with CP should be encouraged from aged 36 months.

9.4 Research implication and future directions

The following are possible gaps in the literature highlighted by this research program that may be the focus of future research:

i. Measurement of physical activity on a group basis in preschool children with CP aged 4-5 years across all functional abilities, using the ActiGraph® cut-points for sedentary time.
ii. Consistent processing of raw data of the ActiGraph® (definition of wear time, non-wear time, cut-points for activity intensity, etc.) as per previous studies in order to be able to compare results.
iii. Validation of other ActiGraph® placements for non-ambulant children with CP to increase compliance rate.
iv. Activity performance defined by activity counts and time spent sedentary used as an outcome measure for research in ambulant children with CP.
v. Identification of effective interventions to increase physical activity levels and reduce sedentary time in preschool children with CP from the age of 3 years.
vi. Investigate interventions to increase HPA and reduce TSS in marginally-ambulant and non-ambulant children with CP.
vii. Longitudinal studies designed to investigate changes of HPA and sedentary time from preschool to school aged children with CP.
viii. Further knowledge of activity monitoring, HPA and sedentary behaviour in preschool aged children with CP.

9.5 Conclusion

This research program examined relationships between HPA, TSS, motor capacity, community mobility and quality of life in children with CP aged 4-5 years across the full spectrum of functional severity (GMFCS I-V). The ActiGraph® triaxial accelerometer cut-point for sedentary time of 820 counts per minute are appropriate for determining sedentary and active time in children with CP aged 4-5 years. Marginal and non-ambulant children with CP (GMFCS III-V) had significantly lower HPA and a higher proportion of TSS compared to independent-ambulant children with CP (GMFCS I-II). Independent-ambulant children with CP were more likely to meet the physical activity guidelines than marginal and non-ambulant children. Physical activity interventions should focus on both marginal and non-ambulant children with CP. Motor capacity and capability were associated with HPA and TSS in ambulant children with

CP, but not in non-ambulant children with CP. HPA and TSS measurements may be used as clinical outcomes in ambulant children with CP. Although HPA has many health benefits, it was weakly associated with parent-reported QOL of children with CP aged 5 years. Children with CP had decreased HPA and significantly increased sedentary time from the age of 36 months. Active lifestyle and breaks in sedentary time should be encouraged in children with CP from the age of 36 months.

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Chapter 11: Appendices

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Appendix 1. The University of Queensland ethics approval

THE UNIVERSITY OF QUEENSLAND

Institutional Human Research Ethics Approval

Project Title:	Queensland Cerebral Palsy Child - Growth, Nutrition And Physical Activity (GNPA) – 07/03/2014 - AMENDMENT
Chief Investigator:	Prof Peter S.W. Davies, Prof Roslyn Boyd, Dr Kristie Bell
Supervisor:	None
Co-Investigator(s):	Prof Richard Stevenson, Dr Sean Tweedy, Kelly Weir, Dr Stewart Trost, Dr Robert Ware, Christine Finn, Rachel Jordan, Stina Oftedal, Laura Pareezer, Dr Lynne McKinlay, Dr Kate Sinclair, Jacqueline Walker, Laura Pareeza, Katherine Benfer, Piyapa Keawuran, Camilla Davenport
School(s):	Children's Nutrition Research Centre, UQ
Approval Number:	2008002260
Granting Agency/Degree:	NHMRC
Duration:	31st December 2014

Comments/Conditions:

Note: if this approval is for amendments to an already approved protocol for which a UQ Clinical Trials Protection/Insurance Form was originally submitted, then the researchers must directly notify the UQ Insurance Office of any changes to that Form and Participant Information Sheets & Consent Forms as a result of the amendments, before action.

Name of responsible Committee:
Medical Research Ethics Committee
This project complies with the provisions contained in the *National Statement on Ethical Conduct in Human Research* and complies with the regulations governing experimentation on humans.

Name of Ethics Committee representative:
Professor Bill Vicenzino
Chairperson
Medical Research Ethics Committee

Signature _____ Date 12 MAR 2014

Appendix 2. The Children's Health Services District ethics committee approval

ROYAL CHILDREN'S HOSPITAL & HEALTH SERVICE DISTRICT
ETHICS COMMITTEE

Professor John Pearn (Chair) 3365 5323
Mrs Amanda Smith (Ethics Officer) 3636 9167

Queensland Government

Queensland **Health**

Level 3, RCH Foundation Building
Royal Children's Hospital
Herston QLD 4029 Australia
Telephone (07) 3636 9167
Facsimile (07) 3365 5455

3rd December 2008

Dr Kristie Bell
Dietician/Clinical Postdoctoral Research Fellow
Queensland Cerebral Palsy & Rehabilitation Centre
Royal Children's Hospital & Health Service District
Herston QLD 4029

Dear Dr Bell,

The Queensland Cerebral Palsy Child Study – Growth, Nutrition and Physical Acitivty.

Many thanks for your letter of the 17th November together with the application for Ethics approval for the above project.

This was tabled and reviewed at our meeting on the 1st December and the Committee are happy to give their approval for this work.

An ethics number will be sent to you as soon as possible.

Please do not hesitate to contact me should you have any queries.

With kindest regards,

Professor John Pearn
Chair
Royal Children's Hospital and Health Service District Ethics Committee

Cc: Ethics Committee files (Professor John Pearn)
Members of the Ethics Committee

J:\Ethics\Ethics\bell031208.doc

At a meeting of the Royal Children's Hospital and Health Service District Ethics Committee held on [1st December 2008], the Committee reviewed the above Protocol. It is advised that Royal Children's Hospital and Health Service District Ethics Committee have approved your request for ethical approval.

During the conduct of the study you are required to adhere to the following conditions:

The Royal Children's Hospital & Health Service District Ethics Committee complies with all National Health and Medical Research Council (NHMRC) series of guidelines in accordance with the *National Statement on Ethical Conduct in Human Research 2007,* the *Guidelines under Section 95 of the Privacy Act 1998* and the *Guidelines approved under Section 95A of the Privacy Act 1998.*

1. This letter gives Ethics approval for your project. Approval for research is a two-step process. The second step requires Institutional approval from the District Executive Committee of the Royal Children's Hospital and Health Service District who considers each application, after Ethics approval is given. **Research can not commence until this is obtained.**

2. We require an annual progress report (or sooner if the project is completed) concerning the study. This must include progress to date or outcome in the case of completed research. (In accordance with National Statement 5.5.3)

3. In accordance with the National Statement (3.3.12), before beginning the clinical phase of the research, researchers should register clinical trails in a publicly accessible domain.

4. If the project does not proceed, the Committee must be informed as soon as possible. (In accordance with National Statement 5.5.6)

5. The Committee must be informed of any potential or realised problem with bioethical implications, if such occurs during the conduct of the research project.

5. Any serious adverse event (SAE) that arises in the context of this research, or involving a researcher conducting this research, must be reported to the Ethics Committee within 72 hours and reported to the sponsor (if applicable) within the stipulated time frame.

   Serious Adverse Event Reports that are generated off-site during multi-centre trials are required to be submitted to the Chair of the RCH & HSD Ethics Committee on receipt by the researcher. A summary of the SAE reports is to accompany the submission. Information required includes; patient details (age & sex), adverse event, outcome and the likelihood of the event being related to the study drug/device/procedure.

   With respect to all SAEs, the researcher must provide his or her opinion as to whether the SAE is directly related to the research intervention.

   A copy of the SAE Summary must be provided. (This can be obtained from the Ethics Officer)

6. The Ethics Committee will conduct a randomly identified audit of a proportion of research projects approved by the Committee. That audit process will look at such issues as;
   a. Security of Documents
   b. Consent Form Register
   c. Serious Adverse Events Register
   d. Withdrawal of Participants – who and why
   e. The de-identification of data

7. We require researchers to give a declaration of intention to publish their findings in a refereed journal or similar peer-reviewed forum.

   Your work must be in accordance with the following:

   - National Statement on Ethical Conduct in Human Research: http://www.nhmrc.gov.au/publications/synopses/_files/e72.pdf
   - Queensland Health Management Research Policy: http://www.health.qld.gov.au/cpic/documents/ethics/research_policy.pdf
   - Joint NHMRC / AVCC Statement and Guidelines on Research Practice (1997): http://www.nhmrc.gov.au/funding/policy/researchprac.htm
   - Declaration of Helsinki: http://www.health.qld.gov.au/ethics/Documents/24938_policy.pdf
   - Guidelines under Section 95 of the Privacy Act1995 and Guidelines approved under Section 95A of the Privacy Act 1995. http://www.comlaw.gov.au/ComLaw/Legislation/ActCompilation1.nsf/0/B471AB909A18D172CA25725C0083858A/$file/Privacy1988_WD02HYP.pdf
   - Queensland Health Privacy Guidelines IS42 & IS42A: http://qheps.health.qld.gov.au/privacy/resources.htm

8. The Committee wishes you well with your research. Please contact our office if you require any assistance.

Appendix 3. The Cerebral Palsy League of Queensland ethics approval

Cerebral Palsy League

Cerebral Palsy League of Queensland
Head Office: 55 Oxlade Drive, New Farm Qld 4005
ABN 27 009 942 269

21 December 2010

Professor Peter Davies
c/o Dr Kristie Bell
Study Coordinator
Queensland Cerebral Palsy and Rehabilitation Research Centre,
School of Medicine, The University of Queensland
Royal Children's Hospital
Herston Road, HERSTON QLD 4006

Dear Peter,

Re: ***Extension to study CPLQ2009/2010-1029***
"Queensland Cerebral Palsy Child – Growth, Nutrition and Physical Activity"
Davies P et al.

I am pleased to advise you that your application for amendment to the above research protocol has been approved as follows:

1. ***Extension*** of the study clearance period to enable more time for recruitment

The committee discussed your request for an extension until December 2014, however as the CPL and QCPR are involved in recruitment only, the decision was made to ***approve an extension*** for further recruitment for a period of twelve months, i.e. from ***December 2010 to December 2011***.

2. ***Amendment*** of the study protocol to enable repeat mailouts through the CPL and QCPR

This item ***could not be processed*** at the 14 December meeting as no gatekeeper approvals were received with the request. A decision will be held over until gatekeeper letters/forms are received.

Please note that the CPL Ethics Committee is authorized to conduct random audits of research carried out at the CPL at any time. If any further changes or amendments are required, or if you have not completed your research by the expiry date, an amendment must be submitted for consideration of the committee. If a serious or unexpected adverse event occurs, please advise me immediately.

If you have any questions or further submissions regarding the above, please contact Dr Leanne Johnston, Principal Advisor - Research & Ethics on 0419 706 949 or ljohnston@cplqld.org.au.

The CPL wishes you well with your ongoing study.

Yours Sincerely,

Peter Mewett
General Manager, Services

55 Oxlade Drive
New Farm Qld 4005
PO Box 386
Fortitude Valley Qld 4006
T +61 7 3358 8011
F +61 7 3254 1291
exec@cplqld.org.au
cplqld.org.au

Appendix 4. Gold Coast Health Service District Human Research ethics committee approval

Kristie

Queensland Government

Queensland **Health**

Office of the Human Research Ethics Committee

23 November 2009

Enquiries to:
Phone: (07) 5519 7204
Fax: (07) 5518 8718
Our Ref: HREC/09/QGC/88
E-mail GCHResearch_GCHResearch @health.qld.gov.au

Professor Peter Davies
Children's Nutrition Research Centre
Discipline of Paediatrics and Child Health
Lvl 3 Foundation Building
Herston QLD 4029

Dear Professor Davies

HREC Reference number: HREC/09/QGC/88
Project title: Queensland Cerebral Palsy Child - Growth, Nutrition and Physical Activity
Protocol number:

Thank you for submitting the above project for ethical and scientific review. This project was first considered under the mutual acceptance of the review performed by the Royal Children's Hospital & Health Services District Ethics Committee which has been ratified by the Gold Coast Health Service District Human Research Ethics Committee (HREC). Approval was granted to this study on 23 November 2009.

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007)* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*. Attached is the HREC Composition with specialty and affiliation with the Hospital (Attachment I).

I am pleased to advise that the Human Research Ethics Committee has granted approval of this research project. The documents reviewed and approved include:

Document	*Version*	*Date*
Application		22 July 2009
Covering Letter		29 September 2009
Study Flyer		
Email from Dr Susan Moloney (Director of Paediatrics, GCH) Supporting the Project		21 July 2009
Ethical Approval Letter from the University of Queensland		17 December 2007
Royal Children's Hospital & Health Service District Ethics Committee Approval Letter		03 December 2008
Protocol		
Patient Information Sheet/Consent Form	2	01 June 2009
Patient Information Sheet/Consent Form	3	01 June 2009

Please note the following conditions of approval:

1. The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including:
    a. Unforeseen events that might affect continued ethical acceptability of the project. Serious Adverse Events must be notified to the Committee as soon as possible. In addition the Investigator must provide a summary of the adverse events, in the specified format, including a comment as to suspected causality and whether changes are required to the Patient Information and Consent Form. In the case of Serious Adverse Events occurring at the local site, a full report is required from the Principal Investigator, including duration of treatment and outcome of event.

2. Amendments to the research project which may affect the ongoing ethical acceptability of a project must be submitted to the HREC for review. Major amendments should be reflected in a revised online NEAF (accompanied by all relevant updated documentation and a cover letter from the principal investigator, providing a brief description of the changes, the rationale for the changes, and their implications for the ongoing conduct of the study). Hard copies of the revised NEAF, the cover letter and all relevant updated documents with tracked changes must also be submitted to the HREC coordinator as per standard HREC SOP. Further advice on submitting amendments is available from http://www.health.qld.gov.au/ohmr/html/regu/regu_home.asp

3. Amendments to the research project which only affect the ongoing site acceptability of the project are not required to be submitted to the HREC for review. These amendment requests should be submitted directly to the Research Governance Office/r (by-passing the HREC).

4. Proposed amendments to the research project which may affect both the ethical acceptability and site suitability of the project must be submitted firstly the the HREC for review and, once HREC approval has been granted, then submitted to the RGO.

5. Amendments which do not affect either the ethical acceptability or site acceptability of the project(e.g. typographical errors) should be submitted in hard copy to the HREC coordinator. These should include a cover letter from the principal investigator providing a brief description of the changes and the rationale for the changes, and accompanied by all relevant updated documents with tracked changes.

6. The HREC will be notified, giving reasons, if the project is discontinued at a site before the expected date of completion.

7. The Principal Investigator will provide an annual report to the HREC and at completion of the study in the specified format.

8. The District administration and the Human Research Ethics Committee may inquire into the conduct of any research or purported research, whether approved or not and regardless of the source of funding, being conducted on hospital premises or claiming any association with the Hospital; or which the Committee has approved if conducted outside Gold Coast Health Service District.

HREC approval is valid for 12 months from the date of this letter.

Should you have any queries about the HREC's consideration of your project please contact Dr Brian Bell, Chair Gold Coast Health Service District HREC. The HREC terms of Reference, Standard Operating Procedures, membership and standard forms are available from http://www.health.qld.gov.au/ohmr/html/regu/regu_home.asp

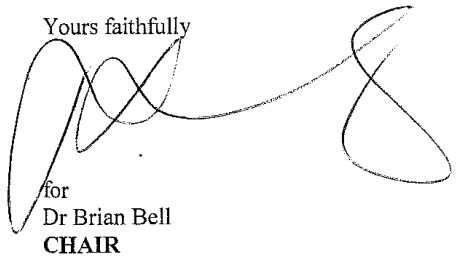
You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a site until separate authorisation from the District CEO or Delegate of that site has been obtained.

A copy of this approval must be submitted to the District Research Governance Officer/Delegated Personnel with a completed Site Specific Assessment (SSA) Form for authorisation from the CEO or Delegate to conduct this research at the Gold Coast Health Service District.

Once authorisation to conduct the research has been granted, please complete the Commencement Form (Attachment II) and return to the office of the Human Research Ethics Committee.

The HREC wishes you every success in your research.

Yours faithfully



for
Dr Brian Bell
CHAIR
HUMAN RESEARCH ETHICS COMMITTEE
GOLD COAST HEALTH SERVICE **DISTRICT**

cc. Dr. Sue Moloney, Director Paediatrics, Gold Coast Health Service District

Appendix 5. The Townsville Health Services District Human Research ethic committee approval

Queensland Government

Office of the Human Research Ethics Committee

Queensland **Health**

TOWNSVILLE HEALTH SERVICE DISTRICT

Enquires to: Tanya Cameron – Medical Administration
Telephone: 07 4796 1140
Facsimile: 07 4796 1051
Email: tanya_cameron@health.qld.gov.au
File Number: Ethics – Protocol_ 09/96
Our Reference: dbs/ethics/Protocol/2009/0996

12 October 2009

Professor Peter Davies
Children's Nutrition Research Centre
Discipline of Paediatrics and Child Health
Lvl 3 Foundation Building
Herston QLD 4029

Dear Professor Davies

HREC Reference number: **HREC/09/QTHS/96**
Project title: **Queensland Cerebral Palsy Child - Growth, Nutrition and Physical Activity**

Thank you for submitting the above research project to the Townsville Health Service District Human Research Ethics Committee for ethical and scientific review, which was received on 12 October 2009.

Your project has been assigned the Reference number: HREC/09/QTHS/96.
This number must be quoted in all correspondence to this HREC.

You may monitor the progress of your application to this HREC by logging in to your user account at www.ethicsform.org/au and clicking on the 'Manage/Lock HREC Form' link on the Forms page and clicking on the 'See the progress of your application' link located in the top left hand corner of the Manage HREC Application screen. For more information or assistance please visit the website's Help page

Detailed information about the Queensland Health process for submission and authorisation of research can be obtained from the Research Ethics and Governance Unit website:
http://www.health.qld.gov.au/ohmr/html/regu/regu_home.asp

Should you require any additional information, please contact the HREC Co-ordinator, Tanya Cameron on ☎ (07) 4796 1140.

Yours sincerely

Tanya Cameron
Co-ordinator
Human Research Ethics Committee

Appendix6. Rockhampton Health Services District Human Research ethics committee approval

District Research Governance

Queensland Government

Queensland **Health**

1 September 2011

Enquiries to: Mr Rod Boddice
Phone: 07 4920 5765
Fax: 07 4920 6335
Our Ref: SSA/10/QCQ/13
E-mail Rod_Boddice@health.qld.gov.au

Dr Kristie Bell
Clinical Specialist Dietitian
Queensland Paediatric Rehabilitation Service
Royal Children's Hospital
HERSTON QLD 4029

Dear Dr Bell

HREC reference number: **HREC/08/QRCH/112**
SSA reference number: **SSA/10/QCQ/13**
Project title: **The Queensland Cerebral Palsy Child Study – Growth, Nutrition & Physical Activity**

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to take place at the following site(s):

Rockhampton Hospital

The following conditions apply to this research proposal. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval.

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project are to be submitted to the HREC for review. A copy of the HREC approval/rejection letter must be submitted to the RGO;

2. Proposed amendments to the research protocol or conduct of the research which only affects the ongoing site acceptability of the project, are to be submitted to the research governance officer;

3. Proposed amendments to the research protocol or conduct of the research which may affect both the going ethical acceptability of the project and the site acceptability of the project are to be submitted firstly to the HREC for review and then to the research governance officer after a HREC decision is made.

Yours sincerely

Maree Geraghty
Chief Executive Officer
Central Queensland Health Service District

Appendix 7. The Mater Health Services District Human Research ethics committee approval.

Mater
Exceptional People. Exceptional Care.

- When you propose a change to an approved protocol, which you consider to be minor, you are required to submit a written request for approval to the Chairperson, through the Secretary. Such requests will be considered on a case by case basis and interim approval may be granted subject to ratification at the next meeting of the Committee.
- Where substantial changes to any approved protocol are proposed, you are required to submit a full, new proposal for consideration by the Human Research Ethics Committee.
- You are required to advise the Research Ethics Coordinator immediately of any complaints made, or expressions of concern raised, in relation to the study, or if any serious or unexpected adverse events occur.
- Under the *NHMRC National Statement on Ethical Conduct in Research Involving Humans*, research ethics committees are responsible for monitoring approved research to ensure continued compliance with ethical standards, and to determine the method of monitoring appropriate to each project. You are required to provide written reports on the progress of the approved project annually, the first report being due on **28th March 2012** and finally on completion of the project. *(The Progress Report is located at http://www.mater.org.au/Home/Research/Human-Research-Ethics-Committee.aspx or can be accessed through the Mater Intranet, Applications, Research Register then under the project name or alternately can be emailed to you).* Please inform the Committee of publications, presentations at Conferences, education and quality improvement outcomes from this study. The Committee may also choose to conduct an interim audit of your research.
- Please be aware that all study procedures including follow up of participants and data analysis should be completed within the approval time frame or an extension should be requested.

Please contact the Executive Director in the participating hospital/hospitals prior to commencing of the study. To access medical records, for the purpose of this study, please provide a copy of this approval letter to the Corporate Health Information Manager. I would also be grateful if you could confirm the date of commencement. (All correspondence should be directed to the Mater Research Ethics Coordinator.)

Yours sincerely

Dr Andrew Crowden
Chairperson
Mater Health Services Human Research Ethics Committee

Research Ethics Coordinator, Room 5453 Level 3 Queries Building, Ph: 07 3163 1585 Fax: 07 3163 1571 Email: research.ethics@mmri.mater.org.au
Mater Misericordiae Health Services Brisbane Limited
ACN 096 708 922
Raymond Terrace, South Brisbane
Queensland 4101 Australia
Phone +61 7 3163 8111
www.mater.org.au

Appendix 8. Parent/guardian information sheet and consent form of the Queensland CP Child Study of Motor Function and Brain Development

Queensland cerebral palsy & rehabilitation research

Queensland Government Queensland Health

Royal Children's Hospital and Health Services District
STANDARD PARENT/GUARDIAN INFORMATION STATEMENT AND CONSENT FORM

Project Number: HREC/07/QRCH/107 EHRC 25010E and HREC Ref *05077C and CPLQ – 2007/08 - 10010

Title of Project: "QldCPchild" – Queensland prospective cohort study of children with cerebral palsy

Investigators: A/Prof Roslyn Boyd, Dr Lynne McKinlay, Dr Kate Sinclair, Ms Megan Kentish, Mrs Meredith Wynter, Mr Michael Delacey, Ms Laura Pareezer, Ms Christine Finn, Ms Rachel Jordan.

Thank you for taking the time to read this Information Statement.
This information statement and consent is 5 pages long. Please make sure you have all the pages.
For people who speak languages other than English:
If you would also like information about the research and the Consent Form in your language, please ask the person explaining this project to you.

Your child is invited to participate in a Research Project that is explained below.
What is an Information Statement?
These pages contain information about a research project we are inviting your child to take part in. The purpose of this information is to explain to you clearly and openly all the steps and procedures of this project. The information is to help you to decide whether or not you would like your child to take part in the research. Please read this information carefully. You can ask us questions about anything in it. You may also wish to talk about the project with others eg friends or health care worker. Once you have understood what the project is about, if you would like your child to take part please sign the consent form at the end of this information statement. You will be given a copy of this information and consent form to keep.

What is the Research Project about?
This project is about the motor development, and muscle and bone development of children who have cerebral palsy. Cerebral palsy is a physical disability caused by early brain injury. It occurs in 1 in 500 children. Delayed motor development is a feature of cerebral palsy. The project will follow the development of 240 children who have cerebral palsy, and who were born in 2006, 2007 2008 and 2009. These children will attend a specialist "QldCPchild clinics" at the Royal Children's Hospital (RCH) in Brisbane or at one of the outreach clinics of the Queensland Paediatric Rehabilitation Service (QPRS) or the Queensland Cerebral Palsy Health Service (CP Health) six times between the age of 18 months and 5 years. (See later for details). Children will attend the usual clinics at RCH and these additional assessments will be organised to coincide with those regular appointments you may have to minimise any additional visits to the RCH.

At the specialist QldCPchild clinic we will get measures of your child's motor development, muscle and bone development (including hip development) and see if these are related to the child's brain structure at 24 months. Your child would attend this clinic at 18, 24, 30, 36, 48 and 60 months corrected age (6 visits and one potential additional visit for a brain MRI). Children who have delayed motor development which may be due to cerebral palsy are seen regularly by paediatricians and in several clinics at RCH, such as the Hip Surveillance Clinic, Neuromuscular Clinic, Neurology Clinic and/or the Orthopaedic clinics to review your child's medical status. These clinics and people get information about your child as part of the 'best practice' management of a child with delayed motor

development. The Specialist QldCPchild Clinic will use this information. As well, the specialist QldCPchild clinic will add the following information. These tests are performed as part of best clinical practice for surveillance of children with cerebral palsy.

Measure	Specialist "QldCPchild" clinic
1) Motor assessment and measures of range of motion by the Research Physiotherapist on 6 occasions over the entire study.	
2) Regular Hip X-ray (6- 12 monthly) will be requested by Dr Lynne McKinlay or Dr Kate Sinclair if this is not currently performed.	
3) A questionnaire of your child's participation and health related quality of life will be completed by the parent.	
4. A record of what treatments and interventions your child receives will be recorded.	

Each of the six visits will take no more than 1.5 to 2 hours. There may be on additional visit for an MRI Scan from 24 months only.

Who are the Researchers?

All of these researchers work at the **Royal Children's Hospital (RCH) Brisbane and/or the University of Queensland.**

- A/Prof Roslyn Boyd is a Physiotherapist. She will co ordinate the project and supervise the movement assessments and conduct of the project.
- Dr Lynne McKinlay is a Rehabilitation Specialist. She will discuss the clinical features of your child's delayed motor development and the diagnosis of cerebral palsy
- Dr Kate Sinclair is a neurologist. She will be involved in interepreting your infant's brain MRI scans and discussing the results with you.
- Ms Megan Kentish is a physiotherapist and Head of the Cerebral Palsy Health Service. She will co supervise the Physiotherapists performing the motor assessments.
- Mrs Meredith Wynter is a Senior Physiotherapist in the Queensland Cerebral Palsy Health Service. She will co supervise the Physiotherapists performing the motor assessments.
- Mr Michael Delacey is a researcher who runs the Queensland Cerebral Palsy Register.
- Ms Laura Pareezer is a research nurse within the Queensland Cerebral Palsy and Rehabilitation Research Centre. She will be helping collect data in the assessments and will coordinate appointments.
- Ms Christine Finn is a research physiotherapist within the Queensland Cerebral Palsy and Rehabilitation Research Centre. She will be involved in motor assessments and data collection.
- Ms Rachel Jordan is a research physiotherapist within the Queensland Cerebral Palsy and Rehabilitation Research Centre. She will be involved in motor assessments and data collection.

Why is my child being asked to be in this research project? Your child has delayed motor development that may be due to cerebral palsy.

What are my child's alternatives to participating in this project? There is no obligation to participate in this project. Should you choose not to participate in this project, your child will have all the usual access to treatment at the Royal Children's Hospital and District Health Service.

What does my child need to do to be in this research project?
Your child will be seen 6 times at 18, 24, 30, 36, 48 & 60 months of age. Each visit will take about two hours. The appointments will be planned to minimize any inconvenience to you and to coincide with any other appointment that you may have in the hospital.
At each visit the following things will happen:

1) The research physiotherapist will videotape your child's motor development and measure their functional abilities. She will also perform an assessment of your child's range or motion in their lower limbs, will ask you about the use of their hands for every day living tasks.
2) A medical professional will review your child's medical status and order a pelvic radiograph (6 –12 monthly as required).
3) You will be asked to complete 3 questionnaires on: your child's participation in everyday life (daily routines), your perception of their quality of life and of their communication skills.
4) The amount and type of therapy and treatments that your child receives will be recorded.

Information will be collected about your child's birth history from the hospital medical record and from any details that you yourself can provide. These clinic assessments will take approximately two hours at the hospital. During this time, videotape records of your child's motor development will be made, and you will have opportunity to discuss any concerns that you may have about your child's development. We will provide parking fees and assist with travel costs. The information gained from these assessments will be explained to you and put in a report and if you wish, any information collected can be sent to your child's treating doctor.

Magnetic Resonance Image Scan (MRI) of your child's brain
If your child has not had a brain Magnetic Resonance Imaging (MRI) Scan previously, it will be offered when your child is 24 months old. The scanner will take pictures of your child's brain using magnetic and radio waves. No X- rays are used. Your child will have an anaesthetic for the MRI scan as it is a very noisy and constrained environment that may be frightening, and the child also needs to be completely still for the test. MRI brain scans are routinely done at this age for infants who have a suspected brain injury to determine the nature of the brain injury. The risks associated with performing an anesthetic are the same as they are for any anaesthetic, there is no additional risk for it being performed in the MRI. The formal report of the scan will be given to you along with a time to discuss the results with a member of our research team. Although the MRI is offered and may provide helpful information, your child can participate in the study even if you choose not to have the MRI scan.

Is there likely to be a benefit to my child?
All results about your child's developmental progress will be reported back to you. You will have the opportunity to discuss your child's progress and any concerns with the research team You will have the opportunity to have an MRI of your child's brain. This may be helpful for providing advice about the cause of the cerebral palsy and any associated genetic implications (which are unusual).

Is there likely to be a benefit to other people in the future?
Most of the benefit will be to other children with cerebral palsy and their families in the future. If we find a relationship between motor development, brain structure on MRI and musculoskeletal development, we will be able to plan treatments at the appropriate time and learn about the specific needs and potential outcomes of children with cerebral palsy. This information may change the way we do things, benefiting future children with cerebral palsy and their families.

What are the possible risks and/or side-effects?
There are no known risks associated with Magnetic Resonance Imaging. MR imaging is done for clinical purposes for infants with brain injury. These scans are routinely performed under general anaesthesia for many children with cerebral palsy. You are under no obligation to consent to your child having a brain MRI scan.

What happens if something abnormal or unexpected is found in my child's MRI scan?
In this study, we will take a number of pictures of your child's brain, or will review pictures that have already been taken. After your child's scan, a specialist will examine these pictures. This will not be done on the day of the scan. With cerebral palsy there is a high chance of finding an abnormality on the brain scan. There is the possibility that the scan will show up something in your child's brain that we had not expected. If this happens, we will arrange for you to meet with a medical professional who can explain the findings to you. If any of the results of the scan are distressing for you, we will offer you counseling with specially trained staff.

What are the possible discomforts and/or inconveniences?
The MRI scanner is noisy so that protective earmuffs will be placed over your child's ears during the scan. The only inconvenience to you and your child is the time that the assessments will take, and the trips you will have to make to the hospital.
The MRI visit is an additional visit to the hospital. If you are travelling from outside Brisbane we will pay for the costs of travel and parking, both for the scan and the other visits.
What will be done to make sure the information is confidential?
All results of scans or assessments will be stored without your child's name on them. Data collection sheets recording the motor assessment scores will be stored in a secure filing cabinet and only the researchers will have access to this information. These data sheets will be kept for 25 years at the Royal Children's Hospital. If we give talks or write about the results of this project, we will not use any names.
Will I be informed of the results when the research project is finished?
You will receive a report about your child's progress after each visit. A 6 monthly newsletter will also be sent to you to keep you updated on the progress of the study. At the end of the study, all families will be sent a summary of the results. If at any time you would like more information about your child's results, an appointment will be organised with one of the research staff.
You can decide whether or not to give permission for your child to take part in this research project. You can decide whether or not you would like to withdraw your child at any time without explanation. Your decision whether or not for your child to participate will not prejudice your child's future relations with the Royal Children's Hospital and District Health Service. If you decide for your child to participate, you are free to withdraw your consent and discontinue participation at any time. The decision to withdraw from the study will not affect their routine medical treatment or their relationship with the people treating them. You may like to discuss your child's participation in this research project with your family and with your doctor. You can ask for further information before deciding to take part.
If you would like more information about the study or if you need to contact a study representative in an emergency, the person to contact is:
Name: A/Prof Roslyn Boyd, A/Professor Cerebral Palsy and Rehabilitation Research,
Contact telephone: (07) 3365 5315 **mobile:-** 0434 608 443

What are my child's rights as a participant?
1. I am informed that except where stated above, no information regarding my child's medical history will be released. This is subject to legal requirements.
2. I am informed that the results of any tests involving my child will not be published so as to reveal my child's identity. This is subject to legal requirements.
3. The detail of the procedure proposed has also been explained to me. This includes how long it will take, how often the procedure will be performed and whether any discomfort will result.
4. It has also been explained that my child's involvement in the research may not be of any benefit to him or her. I understand that the purpose of this research project is to improve the quality of medical care in the future.
5. I have been asked if I would like to have a family member or a friend with me while the project is explained to me.
6. I understand that this project follows the guidelines of the National Statement on Ethical Conduct in Research Involving Humans (1999).
7. I understand that this research project has been approved by the Royal Children's Hospital Ethics Committee on behalf of the Royal Children's Hospital and Health Services District, Brisbane.
8. I have received a copy of this document.

Contact:-
The Research Ethics Committee of the Royal Children's Hospital and Health Services District has approved this study. Should you wish to discuss the study with someone not directly involved, in particular in relation to matters concerning policies, information about the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, at any time, you may contact the Co-ordinator on the ethics committee, Royal Childrens Hospital and Health Services District, c/o Dept of Pediatrics and Child Health, Level 3, Foundation building, Herston. QLD. 4029.
Telephone (07) 3636 9167. If this phone is unattended, there is a 24 hour contact number.

This study (CPLQ – 2007/08 – 10010) has been approved by the Cerebral Palsy League of Queensland Ethics Committee. If needed verification can be obtained either by writing to the Cerebral Palsy League Ethics Committee c/o Cerebral Palsy League of Queensland, 55 Oxlade Drive, New Farm, Brisbane, 4005, PO Box 386, Fortitude Valley, QLD 4006, Tel: 07 3358 8056/ Mobile 041320 1054/ fax:- 07 325 31487? Email:- grose@cplqld.org.au;

Queensland
cerebral palsy & rehabilitation research

Queensland Government
Queensland Health

STANDARD INFORMED CONSENT FOR PARENT/GUARDIAN TO GIVE CONSENT FOR THEIR CHILD TO PARTICIPATE IN A RESEARCH PROJECT

Project Number

HREC/07/QRCH/107 EHRC 25010A and HREC Ref *05077C

Title of Project

"QldCPchild" – prospective cohort study of children with cerebral palsy

Investigator(s)

A/Prof Roslyn Boyd, Dr Lynne McKinlay, Dr Kate Sinclair, Ms Megan Kentish, Mrs Meredith Wynter, Mr Michael DeLacey, Ms Laura Pareezer, Ms Christine Finn, Ms Rachel Jordan.

I (Parent/Guardian name) _____

voluntarily consent for my child to take part in the above titled Research Project, explained to me by

Mr/Ms/Dr/Professor _____

Child's Name _____

Address

Contact Number/s _____

- I have received a Parent/Guardian Information Statement to keep and I believe I understand the purpose, extent and possible effects of my child's involvement
- I have been asked if I would like to have a family member or friend with me while the project was explained
- I have had an opportunity to ask questions and I am satisfied with the answers I have received
- I understand that the researcher has agreed not to reveal results of any information involving my child, subject to legal requirements
- If information about this project is published or presented in any public form, I understand that the researcher will not reveal my child's identity
- I understand that if I refuse to consent to my child's participation, or if I withdraw my child from the project at any time without explanation, this will not affect my child's access to the best available treatment options and care from the Royal Children's Hospital and Health Services District.
- I understand I will receive a copy of this consent form

I am happy for my infant to receive the Brain MRI scan under general anaesthesia at 24 months corrected age (circle) Yes/No

SIGNATURE _____ Date _____

I have explained the study to the parent/guardian who has signed above, and believe that they understand the purpose, extent and possible effects of their child's involvement in this study.

RESEARCHER'S SIGNATURE _____ Date _____

Note: All parties signing the Consent Form must date their own signature.

Appendix 9. Parent/guardian information sheet and consent form of the Queensland CP Child Study of Growth, Nutrition and Physical Activity

Queensland cerebral palsy & rehabilitation research centre

Queensland Government

The University Of Queensland AUSTRALIA

Children's Health Service District - Royal Children's Hospital
PARENT/GUARDIAN INFORMATION STATEMENT AND CONSENT FORM

Research Project Title: Queensland Cerebral Palsy Child Study: Nutrition, Growth and Physical Activity of Children

Researchers: Prof Peter Davies, Prof Roslyn Boyd, Dr Kristie Bell, Dr Sean Tweedy, Prof Richard Stevenson, Dr Stewart Trost, Dr Robert Ware, Ms Kelly Weir, Dr Lynne McKinlay, Dr Kate Sinclair, Christine Finn, Rachel Jordan, Jacqueline Walker, Katherine Benfer, Stina Oftedal, Laura Pareezer, Piyapa Keawutan and Camilla Davenport.

Thank you for taking the time to read this information Statement. This Information Statement and Consent Form is 6 pages long. Please make sure you read all pages.
For people who speak languages other English: If you would also like information about the research and a Consent Form in your language, please ask the person explaining this project to you.

You are invited to participate in the research project that is explained below.
What is an Information Statement?
These pages tell you about the research project. It explains to you all the steps and procedures of the project. The information is to help you decide whether or not you would like your child to take part in the research. Please read this Information Statement carefully. You are welcome to ask us questions about anything in it. You may wish to talk about the project with your family, friends or health care worker.

Participation in this research is entirely voluntary. If you don't want your child to take part, you don't have to. You can withdraw your child from the study at any time without explanation and there will be no penalty from any staff at the Royal Children's Hospital or the University of Queensland. Withdrawal will not affect your child's care in any way.

What is this research project about?
This project is about growth, nutrition, diet and physical activity of children who have cerebral palsy. Cerebral palsy is a physical disability caused by early brain injury. It occurs in 1 in 500 children. Children with cerebral palsy may be shorter and thinner than their typically developing peers. This project will look at how eating and drinking skills, dietary intake, and the amount of physical activity that children with cerebral palsy do effects the way they grow and develop, their quality of life, participation and the amount of health care used. You and your child have already consented to participate in the "**Queensland Cerebral Palsy Child study – A prospective study of brain structure and motor function**".

The present information is related to a separate project where you are invited to contribute to a new project on growth, nutrition and physical activity. Children will attend specialist "QLDCPchild clinics" at the Royal Children's Hospital in Brisbane or at one of the outreach clinics of the Queensland Paediatric Rehabilitation Service (QPRS) or the Queensland Cerebral Palsy Health

Service (CP Health) three times between the age of 18 months and 5 years (see later for details). Children will attend the usual clinics at RCH and these assessments will be organised to coincide with appointments you may already have to minimise any additional visits to the RCH.

Who are the researchers?

- Professor Peter Davies is the Director of the Children's Nutrition Research Centre at the University of Queensland.
- Professor Roslyn Boyd is a Paediatric Physiotherapist and Scientific Director at the Queensland Cerebral Palsy and Rehabilitation Research Centre, University of Queensland and the Royal Children's Hospital (Brisbane).
- Dr Kristie Bell is a Paediatric Dietician at the Royal Children's Hospital and the University of Queensland. She will coordinate the project and supervise the assessments.
- Professor Richard Stevenson is a Paediatrician at the Kluge Children's Rehabilitation Centre in the United States of America.
- Dr Sean Tweedy is an Exercise Physiologist at the University of Queensland.
- Ms Kelly Weir is a speech pathologist at the University of Queensland and the Royal Children's Hospital, she will analyse the video of your child's eating.
- Dr Lynne McKinlay is a Rehabilitation Specialist and Director of the Department of Rehabilitation at the Royal Childrens Hospital. She will discuss the the diagnosis of cerebral palsy.
- Dr Kate Sinclair is a neurologist at the Royal Children's Hosptial. She will discuss the diagnosis of cerebral palsy.
- Associate Professor Stewart Trost from the Department of Nutrition and Exercise Science, Oregon State University, will provide advice regarding the collection of the physical activity data.
- Dr Robert Ware is a statistician with the University of Queensland.

Why is my child being asked to be in this research project?

We are asking your child to take part because he/she has delayed motor development that may be due to cerebral palsy and was born in Queensland in one of the following years: 2006, 2007, 2008 or 2009.

What are the alternatives to taking part in this project?

There is no obligation to participate in this project. Should you choose not to participate in this project, your child will have all the usual access to treatment at the Royal Children's Hospital and District Health Service.

What does my child need to do to be in this research project?

Your child will be seen 3 times at:

1. between 18 - 30 months,
2. between 36 - 42 months
3. 5 years of age.

Each visit will coincide with assessments for the QLD CP Child study and will take approximately 2 - 2.5 hours in total. You may be invited to have a follow-up mealtime video taken to evaluate the accuracy of the feeding assessment. This will be for 20-30 minutes and can be conducted at the hospital or at home.

At each of these visits the following assessments will be performed:-

1. Anthropometry

a. Growth:- We will measure your child's height or length and weight as well as their knee height, upper arm length, head circumference and upper arm circumference.

b. Skinfold Thickness:- The thickness of the skin will be measured at two sites: one on the back of the upper arm (tricep) and one under the shoulder blade (subscapular). This will provide information regarding your child's body fat stores.

2. Body Composition:- The following two methods will provide information regarding the amount of water in your child's body.

a. Bioelectrical impedance analysis:- This is a simple, painless and safe technique to measure body composition. The technique requires that your child lie quietly for a few minutes with surface electrodes taped lightly to their wrist and ankle. A very small electrical current passes through the body. This current is completely safe and so mild that it cannot be felt. The measurement only takes a few seconds during which your child will not be able to wear shoes, socks and metallic jewelry.

b. Heavy water:- This is a very simple technique that involves your child drinking a special type of water called deuterium that we then measure the concentration of in their urine. Deuterium is naturally occurring, non-toxic and non-radioactive and tastes exactly the same as tap water. It is totally harmless and has been used in worldwide studies from premature babies to pregnant women and the elderly. All you need do is collect a single urine sample prior to the dose and a second one 5 hours after. The urine samples will be collected from you by a certified courier at a time that is convenient to you.

3. Feeding Evaluation:- You will be asked to bring a small snack to the hospital for your child to consume during your visit. The type of snack will be discussed with you prior to the visit. Your child will be videotaped whilst eating this snack. The video will be reviewed by a speech pathologist to determine if your child has any difficulty with eating.

4. Feeding Questionnaire:- You will be asked to complete a questionnaire regarding your child's feeding ability and eating/drinking skills. This will be sent out to you prior to your appointment so that you can complete it at home and bring it in with you.

5. Physical Activity:- Following your appointment your child will be required to wear a small activity monitor called an Actigraph around their waist. Your child needs to wear the Actigraph every day for 3 days whilst they are awake. It can be taken off when your child goes to bed and put back on when they wake. It can also be taken off when your child bathes or goes swimming. You will be asked to record the time of day when the monitor is worn on a form provided.

6. Dietary Intake:- Following your appointment you will be required to record all food and drink consumed by your child over a 3 day period on a form provided. Detailed instructions regarding how to do this will be discussed with you and provided on a separate form.

You will be asked to consent for the following data collected in the Queensland Cerebral Palsy Child study (NHMRC458500) to be provided to the chief investigators of the present study. These measures include:-

1. Classification of motor type and distribution of cerebral palsy;
2. Participation: using the Paediatric Evaluation of Disability Inventory (PEDI);
3. Quality of Life: using the parent-report condition specific measure (CP-QOL- child);
4. Relationship between motor prognosis and resource use (cost and consequence analysis) using a questionnaire developed with our Health Economics investigator on NHMRC 468500.

How will this study benefit my child?

The study will provide you with information about your child's growth and dietary intake. You will have the opportunity to discuss your child's progress and any concerns with the research team. The final study results will be summarized and reported back to you at the conclusion of the study.

How will this study benefit other people in the future?
The results of this study will provide valuable information that will help us to identify why some children with cerebral palsy grow poorly and how poor growth, dietary intake and physical activity may impact on their quality of life, participation and the amount of health care used. It will also assist us to determine which children need help to improve their nutrition, growth and physical activity and at what age is the best time to do this. In addition, it will provide us with information about how well different methods can measure the body composition of children with cerebral palsy and allow us to make recommendations on their use for others working with children with cerebral palsy.

What are the risks for my child?
There are no additional risks for your child with these measurements over and above that experienced in every day life. All procedures are safe and will not discomfort your child in any way. All procedures are frequently used for clinical and research purposes.

What are the possible inconveniences?
The assessment appointments will be planned to minimize any inconvenience to you and to coincide with any other appointment that you may have at the hospital. The assessments will take about 2 to 2.5 hours in total and you will be required to come to the hospital on 3 occasions over a 3 year period. These visits coincide with visits for the QLD CP Child study. We will pay for the cost of parking your car at the hospital during these visits. In addition, once home you will be required to complete a 3 day food diary and your child will need to wear a physical activity monitor for 3 days.

What will be done to make sure the information is confidential?
Data from these assessments will be stored electronically without your child's name. A number will be used to identify them. This number will be linked to your child's name and the linking file will be kept confidential and only made available to the researchers. A separate database will contain your contact information and those results required for the generation of clinical reports. All databases will be password protected with limited access available to the researchers involved in the study.

Data collection sheets recording the assessments and the videotapes of the assessments will be stored in an individual file for your child in a secure, locked, fire proof filing cabinet. Only the researchers will have access to this information. These data sheets will be kept for 7 years at the Royal Children's Hospital. If we give talks or write about the results of this project, we will not use any names.

All names and identifying information will be removed from data prior to any analysis.

Will I be informed of the results when the research project is finished?
You will receive a written report about your child's progress after each visit. If at any time you would like more information about your child's results, an appointment may be organized with one of the researchers. A regular newsletter will also be sent to you about the progress of the study. At the end of the study all families will be sent a summary of the results. The newsletters and final summary will talk about the children as a group and your child will not be identified in person.

You can decide whether or not to give permission for your child to take part in this research project. You can decide whether or not you would like to withdraw your child at any time without explanation. Your decision whether or not for your child to participate will not

prejudice your child's future relations with the Royal Children's Hospital and District Health Service. If you decide for your child to participate, you are free to withdraw your consent and discontinue participation at any time. The decision to withdraw from the study will not affect their routine medical treatment or their relationship with the people treating them. You may like to discuss your child's participation in this research project with your family and with your doctor. You can ask for further information before deciding to take part.

If you would like more information about the study or if you need to contact a study representative in an emergency, the person to contact is:

Name: A/Prof Roslyn Boyd, A/Professor Cerebral Palsy and Rehabilitation Research,
Contact telephone: (07) 3365 5315 **mobile:-** 0434 608 443

Or
Name: Dr Kristie Bell, Clinical Postdoctoral Research Fellow
Contact telephone: (07) 3646 5537.

What are my child's rights as a participant?
I am informed that except where stated above, no information regarding my child's medical history will be released. This is subject to legal requirements. I am informed that the results of any tests involving my child will not be published so as to reveal my child's identity. This is subject to legal requirements. The detail of the procedure proposed has also been explained to me. This includes how long it will take, how often the procedure will be performed and whether any discomfort will result. It has also been explained that my child's involvement in the research may not be of any benefit to him or her. I understand that the purpose of this research project is to improve the quality of medical care in the future. I have been asked if I would like to have a family member or a friend with me while the project is explained to me. I understand that this project follows the guidelines of the National Statement on Ethical Conduct in Research Involving Humans (1999).I understand that this research project has been approved by the Royal Children's Hospital Ethics Committee on behalf of the Royal Children's Hospital and Health Services District, Brisbane. I have received a copy of this document.

Contact:-
The Research Ethics Committee of the Royal Children's Hospital and Health Services District has approved this study. Should you wish to discuss the study with someone not directly involved, in particular in relation to matters concerning policies, information about the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, at any time, you may contact the Co-ordinator on the ethics committee, Royal Childrens Hospital and Health Services District, c/o Dept of Pediatrics and Child Health, Level 3, Foundation building, Herston. QLD. 4029. This study adheres to the Guidelines of the ethical review process of The University of Queensland. Whilst you are free to discuss your participation in this study with project staff (contactable on 07 3636 5542), if you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Officer on 3365 3924.

This study has been approved by the Cerebral Palsy League of Queensland Ethics Committee (**CPLQ- 2009/10 – 1029**). If needed, verification can be obtained by writing or telephoning the Cerebral Palsy League Ethics Committee, c/-Cerebral Palsy League of Queensland, 55 Oxlade Drive, New Farm, Brisbane Qld 4005 or PO Box 386, Fortitude Valley QLD 4006 Tel: 07 33588101

Queensland cerebral palsy & rehabilitation research centre

Queensland Government

The University Of Queensland AUSTRALIA

STANDARD INFORMED CONSENT FOR PARENT/GUARDIAN TO GIVE CONSENT FOR THEIR CHILD TO PARTICIPATE IN A RESEARCH PROJECT

Project Number

EHRC No 2008002260

Title of Project

QLD CP Child study: Nutrition, Growth and Physical Activity

Investigator(s)

Prof Peter Davies, Prof Roslyn Boyd, Dr Kristie Bell, Dr Sean Tweedy, Prof Richard Stevenson, Dr Stewart Trost, Dr Robert Ware, Ms Kelly Weir, Dr Lynne McKinlay, Dr Kate Sinclair, Christine Finn, Rachel Jordan, Jacqueline Walker, Katherine Benfer, Stina Oftedal, Laura Pareezer, Piyapa Keawutan and Camilla Davenport.

I (Parent/Guardian name) _____

voluntarily consent for my child to take part in the above titled Research Project, explained to me by

Mr/Ms/Dr/Professor _____

Child's Name _____

Address _____

Contact Phone Numbers _____

- I have received a Parent/Guardian Information Statement to keep and I believe I understand the purpose, extent and possible effects of my child's involvement
- I have been asked if I would like to have a family member or friend with me while the project was explained
- I have had an opportunity to ask questions and I am satisfied with the answers I have received
- I understand that the researcher has agreed not to reveal results of any information involving my child, subject to legal requirements
- If information about this project is published or presented in any public form, I understand that the researcher will not reveal my child's identity
- I understand that if I refuse to consent to my child's participation, or if I withdraw my child from the project at any time without explanation, this will not affect my child's access to the best available treatment options and care from the Royal Children's Hospital and Health Services District.
- I understand I will receive a copy of this consent form

I give permission for the summary report of my child's progress from the study to be included in the hospital record (please tick): ❑ yes ❑ no

SIGNATURE _____ **Date** _____

I have explained the study to the parent/guardian who has signed above, and believe that they understand the purpose, extent and possible effects of their child's involvement in this study.

RESEARCHER'S SIGNATURE _____ **Date** _____

Note: All parties signing the Consent Form must date their own signature.

Appendix 10. Recruitment flyer

Queensland cerebral palsy & rehabilitation research centre

The University Of Queensland

Qld CPchild: Brain Function & Motor Development Study
The class of 2006-2009

Can you help us?
Researchers from the Queensland Cerebral Palsy & Rehabilitation Research Centre (at the Royal Children's Hospital) are looking for **all children** with **Cerebral Palsy born in Queensland** in the **birth years of 2006, 2007, 2008 and 2009.** Please note your child can enter the study at any age.

The study will measure your child's motor development, muscle and bone development and see if these are related to the nature of the brain injury they have sustained. Information from the study will help many children with Cerebral Palsy and their families in the future. The information will allow us to learn more about the specific needs and potential outcomes of children with Cerebral Palsy.

Benefits: Your child will receive regular, comprehensive surveillance. All information will be reported back to you after each visit and the results sent to your child's paediatrician and therapists to keep them informed of your child's progress. If you child has not had a brain MRI we would discuss with you howthis would be helpful.

The study involves 6 visits over 4 years to the Royal Children's Hospital or your regional hospital (whichever is more convenient). These visits will be performed when your child is 18, 24, 30 and 36 months of age, and then around their 4th and 5th birthdays. Each visit takes about 1.5 – 2 hours.

Qld CPchild: Growth, Nutrition & Physical Activity Study The class of 2006-2009

Another study is being conducted in conjunction with the Qld CP Child study, and researchers are looking for **all children** with **cerebral palsy born in Queensland** in the **birth years of 2006 - 2009.** Your child can enter the study at any time from 18 months to 5 years.

The study will measure your child's growth, nutrition, diet and physical activity and see if these relate to health outcomes, participation and health related quality of life.

Benefits: Your child will receive regular, comprehensive surveillance of their growth, nutrition and physical activity, with all information reported back to you and your therapists as mentioned above.

The study involves 3 visits over 4 years to the Royal Children's Hospital or your regional hospital. These visits will be performed when your child is 18-24 months, and then around their 3rd and 5th birthdays. These visits will coincide with assessments for the Qld CP Child study. Each visit takes about 2 – 2.5 hours in total.

If you would like to find out more about either study please contact either:

Rachel Jordan, Study Coordinator and Physiotherapist, (07) 3646 5541, Rachel_Jordan1@health.qld.gov.au

Dr Kristie Bell, Paediatric Dietitian & Growth, Nutrition & Physical Activity Study Coordinator, (07) 3636 5537, kristie_bell@health.qld.gov.au

Laura Pareezer, Clinical Nurse Consultant, Clinical Trials, (07) 3646 5061, laura_pareezer@health.qld.gov.au

A/Professor Roslyn Boyd, Scientific Director, QCPRRC, 0434608443, r.boyd@uq.edu.au

Queensland Cerebral Palsy & Rehabilitation Research Centre
Royal Children's Hospital
Herston Road, Herston QLD 4029 Australia
Telephone 07 3646 5542 • Facsimile 07 3646 5538
Email CP&Rehab_Research_Centre@health.qld.gov.au

Appendix 11. ActiGraph Validation Recording Form

ActiGraph file name:
Age group:

Checklist for ActiGraph Validation data collection

Before patient arrive:

1. Check you have
   - ❑ An external time piece (digital clock or watch that you can take to testing)
   - ❑ An Actigraph computer, a USB line, an Actigraph
   - ❑ A belt for attaching the Actigraph to patient's body
   - ❑ A camera (with a tape and a battery/power supply line) and a tripod
   - ❑ Data recording form
   - ❑ A paper written with assessment information (Patient's name, age, assessment date and location)

2. Initialize ActiGraph
   - ❑ Check computer clock is synchronized with external timepiece.
   - ❑ Plug in a ActiGraph
   - ❑Check Actigraph's battery
   - ❑ Initialize Actigraph and check setting:
     - ❑ Epoch is "1" sec
     - ❑ # of axis = "3"
     - ❑ Filter = normal
   - ❑ Actigraph starting date and time: start time of assessment
   - ❑ Patient's name (eg. SmithF090119)
   - ❑Check camera memory
   - ❑Check camera battery

When patient arrive and before testing:

- ☐ Check belt is fixed around patient's waist, with ActiGraph in the middle of back
- ☐ Cameraman film the paper which has assessment information on it
- ☐ Cameraman film the external time piece for 10 sec before assessment begins

When test nearly finished:

- ☐ Cameraman film the external time piece for 10 sec after test finish and then turn off the camera

After test:

- ☐ Download the data
- ☐ Check/recharge Actigraph's battery
- ☐ Document child name in J:\QCPRRC\Research\Research Projects-Current\Growth Nutrition & Activity in CP\Physical Activity\Actigraph Validation data.xls

ActiGraph file name:
Age group:

Data Recording Form

This form to be completed by camera person

Patient's name: _____ GMFCS level: _____
Date of birth: _____ Gender: _____

GMFM examiner: _____ Cameraman: _____
Date of assessment: _____ Location: _____

Actigraph number: _____
Actigraph Start time: _____

Video Start time: _____ End time: _____

Actigraph put on time: _____ take off time: _____

Actigraph data downloaded time: _____

Notes:

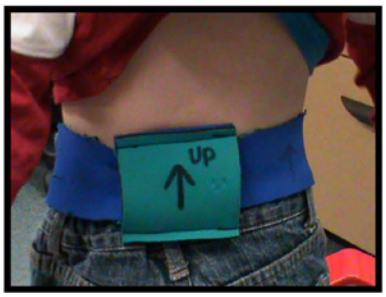
Appendix 12. 3-day physical activity diary

QLD CPChild: Growth, Nutrition and Physical Activity

3 Day Physical Activity Monitor Log

Thank-you for agreeing to help with our research!
This study aims to identify when your child is active and when they are inactive. To do this we are using an activity monitor together with a logbook of wear time. To help make sure our measures are as accurate as possible, please read the instructions below.

The Activity Monitor:



- **Placement**: The belt should be worn around the child's waist, with the monitor in the middle of the back (as shown), and the arrows pointing upwards. Remember the monitor is already on and recording and do not worry if it flashes.
- **How many days?**: Three days, comprising two week days and a weekend day; the same days that you complete the food and drink record for.
- **When to wear it**: The monitor should be worn as much as possible during waking hours. Take the monitor off only:
    - **When going to sleep**
    - **For water activities** such as bathing/showering or swimming.

The Logbook
The log book has two columns to be completed:

- On / Off time: Write in the times the monitor was put on and taken off, and indicate the reasons why (eg 6.30am Monitor on). Shade the times when your child was wearing the monitor. When they are not, leave unshaded and indicate why (i.e., sleeping or water activities).
- Carrying / pushing time: Mark any time your child was wearing the monitor but they were being moved by somebody or something , rather than moving by themselves., for example:
    1. Carrying (in backpack, in your arms or on your hip);
    2. Pushing (in pram or buggy)
    3. Swings
    4. Bike riding

Note that there is no need to indicate driving in a car.

- Sleep time: please record when your child was actually sleeping. For example, the monitor was taken off at 7.00pm but the child did not fall asleep until 8.00pm.

The next page shows an example log. The last section is free space where you can make any notes / comments you think may be relevant to the research team. If you have any queries during the time you are monitoring your child, feel free to contact either Camilla Davenport or Stina Oftedal.

Camilla Davenport
Ph: 36465540
e-mail: camilla.davenport@uq.edu.au

Stina Oftedal
Ph: 36465372
e-mail: s.oftedal@uq.edu.au

Once again, thank you very much for your help!

Name of Child:..... Date of Birth:	
Office Use Only	
Log checked with parent/ carer (name): ..... ❑ in person ❑ by phone ❑ NA	
RA signature:	RA name:
Date:	Study ID #:

Example Activity Log: This is an example log from a parent whose child received the activity monitor at an appointment on Tuesday 24th Feb and started recording on Wednesday 25th. The child slept until 6:00am, and the activity monitor was put on at 6:30am. At 9am they went to the park. This was a 15min walk and the child was pushed there in a stroller. They played at the park until 10, including 10min on a swing. They left at 10am and walked 15min to home again, had some morning tea and the child went down for a sleep at 10:45 (monitor off). He slept till 1pm (monitor on), had lunch and stayed at home till 3pm when they drove to the pool, swam for 30min from 3:15 to 3:45pm and then drove home again. He then kept the monitor on for the rest of the day, until he was put to bed at 6.45pm. The child was actually asleep by 7:15pm.

Day (circle) Mon Tue (Wed) Thu Fri Sat Sun Date: 25.2.09

Time	On / Off (why)	Lift / Carry / Push time	Time	On / Off (why)	Lift / Carry / Push time
Midnight to 1am	Off - sleep		12noon to 1pm		
1am to 2am			1pm to 2pm	1.00 Awake/Monitor on	
2am to 3am			2pm to 3pm		
3am to 4am			3pm to 4pm	3.15 Swim/Monitor off 3.45 Monitor on	
4am to 5am			4pm to 5pm		
5am to 6am			5pm to 6pm		
6am to 7am	6.00 Child awake 6.30 Monitor on		6pm to 7pm	6.45 Monitor off	
7am to 8am			7pm to 8pm	7.15 Child alseep	
8am to 9am			8pm to 9pm		
9am to 10am		15 min pram 10 min swings	9pm to 10pm		
10am to 11am	10.45 Sleep/Monitor off	15 min pram	10pm to 11pm		
11am to 12noon			11pm to Midnight		

ACTIVITY LOG

Day (circle) Mon Tue Wed Thu Fri Sat Sun **Date: _____**

Time	On / Off (why)	Lift / Carry / Push time	Time	On / Off (why)	Lift / Carry / Push time
Midnight to 1am			12noon to 1pm		
1am to 2am			1pm to 2pm		
2am to 3am			2pm to 3pm		
3am to 4am			3pm to 4pm		
4am to 5am			4pm to 5pm		
5am to 6am			5pm to 6pm		
6am to 7am			6pm to 7pm		
7am to 8am			7pm to 8pm		
8am to 9am			8pm to 9pm		
9am to 10am			9pm to 10pm		
10am to 11am			10pm to 11pm		
11am to 12noon			11pm to Midnight		

Notes / comments:

ACTIVITY LOG

Day (circle) Mon Tue Wed Thu Fri Sat Sun **Date: _____**

Time	On / Off (why)	Lift / Carry / Push time	Time	On / Off (why)	Lift / Carry / Push time
Midnight to 1am			12noon to 1pm		
1am to 2am			1pm to 2pm		
2am to 3am			2pm to 3pm		
3am to 4am			3pm to 4pm		
4am to 5am			4pm to 5pm		
5am to 6am			5pm to 6pm		
6am to 7am			6pm to 7pm		
7am to 8am			7pm to 8pm		
8am to 9am			8pm to 9pm		
9am to 10am			9pm to 10pm		
10am to 11am			10pm to 11pm		
11am to 12noon			11pm to Midnight		

Notes / comments:

ACTIVITY LOG

Day (circle) Mon Tue Wed Thu Fri Sat Sun **Date: _____**

Time	On / Off (why)	Lift / Carry / Push time	Time	On / Off (why)	Lift / Carry / Push time
Midnight to 1am			12noon to 1pm		
1am to 2am			1pm to 2pm		
2am to 3am			2pm to 3pm		
3am to 4am			3pm to 4pm		
4am to 5am			4pm to 5pm		
5am to 6am			5pm to 6pm		
6am to 7am			6pm to 7pm		
7am to 8am			7pm to 8pm		
8am to 9am			8pm to 9pm		
9am to 10am			9pm to 10pm		
10am to 11am			10pm to 11pm		
11am to 12 noon			11pm to Midnight		

Notes / comments: