

ORIGINAL REPORT

## INACTIVE LIFESTYLE IN ADULTS WITH BILATERAL SPASTIC CEREBRAL PALSY

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**Objective:** To quantify the level of everyday physical activity in adults with bilateral spastic cerebral palsy, and to study associations with personal and cerebral palsy-related characteristics.

**Participants and methods:** Fifty-six adults with bilateral spastic cerebral palsy (mean age 36.4 (standard deviation (SD) 5.8) years, 62% male) participated in the study. Approximately 75% had high gross motor functioning. Level of everyday physical activity was measured with an accelerometer-based Activity Monitor and was characterized by: (i) duration of dynamic activities (composite measure, percentage of 24 h); (ii) intensity of activity (motility, in gravitational acceleration (g)); and (iii) number of periods of continuous dynamic activity. Outcomes in adults with cerebral palsy were compared with those for able-bodied age-mates.

**Results:** Duration of dynamic activities was 8.1 (SD 3.7) % (116 min per day), and intensity of activity was 0.020 (SD 0.007) g; both outcomes were significantly lower compared with able-bodied age-mates. Of adults with cerebral palsy, 39% had at least one period of continuous dynamic activities lasting longer than 10 min per day. Gross motor functioning was significantly associated with level of everyday physical activity (Rs -0.34 to -0.48;  $p \leq 0.01$ ).

**Conclusion:** Adults with bilateral spastic cerebral palsy, especially those with low-level gross motor functioning, are at risk for an inactive lifestyle.

**Key words:** cerebral palsy, motor activity, ambulatory monitoring.

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### INTRODUCTION

Cerebral palsy (CP) is one of the most frequently occurring conditions in childhood (1). Recently, a new definition has been developed in which CP is defined as “a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant

brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems” (2). Prevalence ranges from 1.39 to 2.80 per 1000 live births in Europe (1). The prevalence in the Netherlands is 1.51 per 1000 persons, but appears to be increasing over time (3). Life expectancy for persons with CP has increased over the past few decades and is close to that of the unaffected population for well-functioning adults with CP (4). The most frequently occurring type of CP, the spastic form, is characterized by velocity-dependent resistance to passive movement (5).

Children with CP tend to receive much physical rehabilitation at a young age, but this attention decreases significantly with advancing age. Several studies report decreased contact with the healthcare system following completion of formal education, and care is often disrupted when disabled persons enter adulthood (6, 7). However, many persons with CP return to rehabilitation care as adults for treatment of worsening symptoms such as contractures, pain and fatigue (8, 9).

This deterioration over time may lead to difficulties in performing daily activities (10) and, consequently, to an inactive lifestyle, with possible detrimental effects on physical fitness and symptoms (11). A negative cycle may develop: inactivity leads to lower physical fitness and worsening of symptoms, which in turn lead to further inactivity. Also, comparable to persons with other disabilities, inactivity may negatively influence health-related quality of life (12) and may increase the risk of cardiovascular disease, diabetes and cancer (13).

Despite the expectation that persons with disabilities are at a high risk for an inactive lifestyle (14), only limited information is available regarding the level of everyday physical activity (PA) of adults with CP. Some evidence exists that diplegic children (15) and adolescents with certain forms of CP (16) are less physically active than able-bodied age-mates. Maher and colleagues (16) also report a strong association between level of everyday PA and gross motor functioning, with lower gross motor functioning associated with a lower level of everyday PA. These findings have been corroborated by studies of PA level in adolescents with Gross Motor Functioning Classification System (GMFCS) level III vs those with GMFCS level I or II (17) and for non-ambulatory vs ambulatory adolescents

(18). In adults, van der Slot et al. (19) reported no differences in level of everyday PA between persons with unilateral spastic CP and able-bodied age-matched controls.

To our knowledge, no objective data are available regarding level of everyday PA for adults with bilateral spastic CP. The aims of this study were, therefore: (i) to quantify the level of everyday PA for adults aged 25–45 years with bilateral spastic CP, and compare them with the levels of able-bodied age-mates; and (ii) to determine whether personal and CP-related factors are associated with level of everyday PA, in order to identify subgroups at increased risk for inactivity.

## METHODS

### Study sample

We recruited eligible participants from 10 rehabilitation centres throughout the western and central regions of the Netherlands and via the Association of Physically Disabled Persons and Their Parents (BOSK). Inclusion criteria were a diagnosis of bilateral spastic CP (diplegia or quadriplegia) and age between 25 and 45 years. Exclusion criteria were full dependence on electric wheelchair propulsion, comorbidities impacting on PA, contraindications to progressive maximal ergometer testing (this study also evaluated maximal exercise tests for other purposes), legal inability, inadequate comprehension of the Dutch language, and cognitive impairment preventing understanding of the study protocol. An informational letter and invitation to participate was sent to eligible participants; a second letter was sent 4 weeks later to non-responders. All participants gave their written informed consent for participation. The study was approved by the medical ethics committee of the Erasmus Medical Centre and all the participating rehabilitation centres.

### Measurement instruments

*Personal and CP-related characteristics.* We assessed several personal and CP-related characteristics: age, gender, educational level, student/employment status, housing status, limb distribution (diplegia or quadriplegia), gross motor functioning, and spasticity.

We subdivided educational level into: (i) low, including prevocational practical education or less; (ii) medium, including prevocational theoretical education and upper secondary vocational education; and (iii) high, including secondary non-vocational education, higher education and university.

We classified gross motor functioning according to the GMFCS, which is based on spontaneous movements related to sitting and walking (20). The GMFCS identifies 5 levels ranging from “walks without restrictions” (level I) to “self-mobility is severely limited even with use of assistive technology” (level V). The GMFCS was originally developed and validated for children (20), but also has demonstrated reliability and validity for describing gross motor function in adults with CP (21, 22).

We assessed spasticity in 4 lower extremity muscle groups (hip adductors, hamstrings, rectus femoris and gastrocnemius) using the Tardieu Scale for clinical assessment of passive joint range of motion (ROM) (23). The ROM for 2 different velocities was recorded, then the difference in joint angle between these 2 measurements was calculated. The intensity of muscle reaction to stretch was scored on a scale ranging from “no resistance in whole ROM” (0) to “presence of greater than 5 cycles of clonus” (5). In a recent review, Scholtes et al. (24) concluded that the Tardieu Scale is suitable for measuring spasticity in children with CP, although it is time-consuming and lacks the standardization of muscle stretch velocity evaluation. We defined muscle spasticity as a muscle reaction intensity score of 2, 3, 4 or 5; a difference in joint angle of greater than or equal to 15°, or both. We measured spasticity bilaterally, and when differences were found, values of the most affected limb were used. The numbers of

spastic muscle groups in the lower extremities on one side of the body are reported.

*Level of everyday physical activity.* To measure the level of everyday PA, we used an Activity Monitor (AM) (Temec Instruments BV, Kerkrade, The Netherlands). The AM is based on long-term ambulatory monitoring of signals from body-fixed accelerometers. The device consists of 4–6 accelerometers, a portable data recorder (15 × 9 × 4.5 cm; weight 700 g) and a computer with analysis software (25). The accelerometer signals allow calculation of movement duration, and rate and timing of activities associated with mobility (1 sec resolution). Stationary activities, such as lying, sitting and standing, can be distinguished from dynamic activities, such as walking, stair climbing, running, cycling, wheelchair propulsion (including hand-biking) and general non-cyclical movement. Furthermore, the variability of the acceleration signal (motility) can be measured as an indicator of body-segment movement intensity in which body motility addresses mean motility over a 24-h period (representing duration and intensity of everyday activity) and motility during walking and wheelchair propulsion (representing walking speed and wheelchair propulsion speed, respectively) ((25), unpublished data first author). The AM has been validated to quantify mobility-associated activities and to detect inter-group differences in levels of everyday PA (25, 26).

Participants wore the AM for 48 continuous hours on randomly selected weekdays. Participants were instructed to perform their ordinary activities except they were not permitted to swim or bathe. To avoid measurement bias, we fitted AM instruments in participants' homes and explained the principles of the AM to the participants after the measurement.

For ambulatory participants, we used 4 uniaxial piezo-resistive accelerometers (Analog Devices, Breda, The Netherlands, adapted by Temec Instruments, Kerkrade, The Netherlands; size: 1.5 × 1.5 × 1 cm). We attached one accelerometer to the skin of each thigh to detect anterior-posterior direction while standing, and two accelerometers to the skin of the sternum: one to detect anterior-posterior direction, and one to detect longitudinal direction. For participants using wheelchairs, additionally to the 4 sensors that were described above, we attached one accelerometer to each wrist to detect longitudinal direction while seated with the forearm horizontal in the mid-pronation/supination position.

Accelerometers were connected to the AM and worn in padded bags around the waist. Accelerometer signals were stored digitally on a PCMCIA flash card with a 32-Hz sampling frequency. Measurements were downloaded onto a computer for kinematic analysis using Vitagraph Software. A detailed description of the activity detection procedure has been described elsewhere (25).

We measured the following data per 24-h period: (i) duration of dynamic activities as a percentage of a 24-h period (composite measure of separately detected activities of walking, wheelchair propulsion, running, cycling, and general movement); (ii) number of transitions (includes all transitions except lying transitions between prone and supine positions); (iii) intensity of activities: (iiia) mean motility (in gravitational acceleration (g)), which reflected both duration and intensity of activity; (iiib) motility during walking; (iiic) motility during wheelchair propulsion; and (iv) distribution of continuous dynamic activity periods (5–10 sec; 10–30 sec; 30–60 sec; 1–2 min; 2–5 min; 5–10 min; or greater than 10 min). We also computed aggregated periods of 1–5 min and greater than 5 min of continuous dynamic activities. In addition to AM measurement, we assessed participants' satisfaction with level of everyday PA using a visual analogue scale (VAS), which has demonstrated reliability and validity (27). We asked participants to mark a 10-cm line according to their level of satisfaction with their current level of everyday PA (0 denotes “extremely dissatisfied” and 10 denotes “extremely satisfied”).

### Data analysis

Because there were no significant differences in the duration of dynamic activities between the first and second day of the measure-

ment (paired samples *t*-test,  $p=0.89$ ), results were averaged over the 2 measurement days. Descriptive statistics were used to summarize level of everyday PA and satisfaction with level of everyday PA for the total group and for subgroups. To determine potential deficits in level of everyday PA, participant data on dynamic activity duration and mean motility were compared with those of able-bodied age-mates (age  $\pm 5$  years) ( $n=45$ ) using independent-samples *t*-tests. These age-mates were part of a large reference sample of persons without known impairments who had previously been measured with the above described AM protocol.

We examined associations between 3 main aspects of the level of everyday PA (duration of dynamic activities, mean motility and aggregate number of periods of continuous dynamic activities (1–5 min, and greater than 5 min)) and personal and CP-related characteristics (age, gender, educational level, limb distribution, gross motor functioning, and spasticity), using Spearman's correlation coefficients (*R*s). When significant associations were found, we examined differences between subgroups using analysis of variance (ANOVA) with a Scheffe *post-hoc* test. Because there were few persons in GMFCS level IV and none in GMFCS level V, GMFCS levels III and IV were combined for the purpose of analysis. Statistical analyses were performed using SPSS for Windows version 12.0.1. A *p*-value of less than or equal to 0.05 was considered significant.

## RESULTS

### Personal and CP-related characteristics

Of 226 eligible participants, 56 participated in the final study (response rate 25%). Reasons for refusal to participate were lack of time, lack of interest in the study, and burden to the adult with CP or caregiver. There were no differences between participants and non-participants regarding gender or affected limb distribution. On average, participants were older than non-participants (mean difference 2.5 years; *t*-test,  $p \leq 0.01$ ).

The mean participant age was 36.4 (standard deviation (SD) 5.8) years; 62% were male. Affected limb was evenly distributed between quadriplegics and diplegics (Table I). Most participants (73%) had high gross motor functioning (GMFCS level I or II). Seven participants used wheelchairs; 3 GMFCS level IV participants used wheelchairs as their primary mode of ambulation, and 4 GMFCS level II participants used wheelchairs for long distances or participation in sports. All participants demonstrated spasticity in 2 or more muscle groups in one lower extremity. Nearly half of participants had a medium level of education and most were employed (70%). Sixty-four percent of participants lived alone, and 29% lived with a partner or others.

### Level of everyday physical activity

On average, participants had a mean dynamic activity duration of 8.1 (SD 3.7) %, which corresponds to 1 h and 56 min of dynamic activities per day (Table II). With regard to intensity of activities, we found a mean motility of 0.020 (SD 0.007) g. Motility during walking was 0.155 (SD 0.037) g, and motility during wheelchair propulsion was 0.034 (SD 0.011) g.

Table III shows the distribution of periods of continuous dynamic activities. Almost all participants had at least one period per day of continuous dynamic activities lasting 1–5 min. Periods of at least 5 min of continuous dynamic activity occurred

Table I. Personal and cerebral palsy-related characteristics

Characteristics	Participants ( $n=56$ )
Age, years, mean (standard deviation)	36.4 (5.8)
25–29 years, $n$ (%)	10 (18)
30–34 years, $n$ (%)	12 (21)
35–39 years, $n$ (%)	15 (27)
40–45 years, $n$ (%)	19 (34)
Gender, $n$ (%)	
Male	35 (62)
Female	21 (38)
Limb distribution, $n$ (%)	
Diplegia	30 (54)
Quadriplegia	26 (46)
GMFCS, $n$ (%)*	
Level I	13 (23)
Level II	28 (50)
Level III	11 (20)
Level IV	4 (7)
Level V	0 (0)
Spasticity in one lower extremity, $n$ (%)†	
2 muscle groups	5 (10)
3 muscle groups	19 (38)
4 muscle groups	26 (52)
Educational level, $n$ (%)	
Low	15 (27)
Medium	24 (43)
High	17 (30)
Student/employment, $n$ (%)	
Student	2 (4)
Remunerative employment	39 (70)
Receiving social benefits	15 (26)
Housing status, $n$ (%)	
Living with partner/others	16 (29)
Living alone	36 (64)
Living with parents	4 (7)

\*Wheelchair-users were distributed over GMFCS level II ( $n=4$ ) and GMFCS level IV ( $n=3$ ).

†Spasticity was not assessed in 6 participants ( $n=50$ ).

GMFCS: Gross Motor Functioning Classification System.

for 57% of participants (range 0–6), and 39% had at least one period per day lasting longer than 10 min (range 0–2).

The mean level of satisfaction with level of everyday PA measured 6.7 (SD 2.3) cm on a scale of 0–10 cm, or moderate satisfaction (Table II). Level of satisfaction was not related to the 3 main aspects of level of everyday PA (*R*s range –0.13 to 0.09).

### Comparison with able-bodied age-mates

In comparison with able-bodied age-mates, adults with CP had significantly shorter durations of dynamic activity (8.1% vs 10.9%, respectively;  $p \leq 0.01$ ), and significantly lower mean motility (0.020 g vs 0.027 g;  $p \leq 0.01$ ) (Fig. 1a and b). Women with CP had significantly shorter durations of dynamic activity compared with able-bodied women (8.4% vs 12.2%, respectively;  $p \leq 0.01$ ). For men, this difference was not statistically significant (7.8% vs 9.4%,  $p=0.11$ ). In both women and men, mean motility was lower compared with able-bodied age-mates (women: 0.021 g vs 0.028 g,  $p=0.03$ ; men: 0.019 g vs 0.027 g,  $p \leq 0.01$ ).

Table II. Level of everyday physical activity, by level of gross motor functioning. All values are presented as means (standard deviation)

	All (n=56)	Level of gross motor functioning		
		GMFCS I (n=13)	GMFCS II (n=28)	GMFCS III-IV (n=15)
Duration of static activity (% of 24 h)	91.9 (3.7)	89.7 (2.6) <sup>a</sup>	91.7 (3.7)	94.3 (3.1)
Lying	35.2 (5.9)	36.4 (3.5)	34.2 (4.9)	36.0 (8.8)
Standing	9.7 (5.3)	13.0 (4.8)	10.8 (4.0)	4.7 (4.5)
Sitting	47.1 (9.4)	40.3 (6.7)	46.7 (7.2)	53.6 (10.9)
Duration of dynamic activities (% of 24 h)	<b>8.1 (3.7)</b>	<b>10.3 (2.6)<sup>a</sup></b>	<b>8.3 (3.7)<sup>c</sup></b>	<b>5.7 (3.1)</b>
General movement	2.0 (1.5)	2.1 (1.4)	2.0 (1.2)	2.3 (2.0)
Walking	5.1 (3.1)	7.3 (1.9)	5.5 (2.9)	2.3 (2.1)
Wheelchair propulsion	0.2 (0.7)	0 (0)	0.2 (0.6)	0.4 (1.0)
Cycling	0.8 (1.0)	0.8 (0.7)	0.7 (1.0)	0.7 (1.2)
Running	0 (0.5)	0 (0.1)	0 (0)	0 (0)
Mean motility, g*	<b>0.020 (0.007)</b>	<b>0.024 (0.006)<sup>a</sup></b>	<b>0.020 (0.007)<sup>c</sup></b>	<b>0.015 (0.005)</b>
Motility during walking, g*	0.155 (0.037)	0.168 (0.030)	0.160 (0.035)	0.133 (0.042)
Motility during wheelchair propulsion, g*	0.034 (0.011)	–	0.037 (0.015)	0.032 (0.006)
Number of transitions	123 (45)	136 (35)	134 (38)	92 (53)
Periods of 1–5 min continuous dynamic activities	<b>16 (11)</b>	<b>21 (7)</b>	<b>17 (13)</b>	<b>12 (9)</b>
Periods of greater than 5 min continuous dynamic activities	<b>1 (1)</b>	<b>2 (2)<sup>b</sup></b>	<b>1 (2)</b>	<b>1 (1)</b>
VAS satisfaction with physical activity	6.7 (2.3)	6.9 (2.3)	6.8 (2.3)	6.5 (2.2)

\*Mean motility and motility during walking were assessed for ambulators only (n=49). Motility during wheelchair propulsion was assessed for those using a wheelchair during the measurement (n=7: 4 GMFCS level II participants and 3 GMFCS level III-IV participants). Motility is expressed in g (1g=9.81 m/s<sup>2</sup>).

<sup>a</sup>Significant difference between GMFCS level I and GMFCS level III-IV at p≤0.01.

<sup>b</sup>Significant difference between GMFCS level I and GMFCS level III-IV at p≤0.05.

<sup>c</sup>Tendency for difference between GMFCS level II and GMFCS level III-IV at p<0.10.

Transitions: all transitions between postures except between lying transitions. Associations with personal and CP-related characteristics were explored for bold variables.

GMFCS: Gross Motor Functioning Classification System; VAS: visual analogue scale.

### Factors associated with level of everyday physical activity

Gross motor functioning was the only factor significantly associated with the 3 main aspects of level of everyday PA (Table IV). ANOVA and *post-hoc* analyses revealed significant differences between GMFCS level I and GMFCS level III/IV participants in duration of dynamic activities (p≤0.01), mean motility (p≤0.01), and number of periods of continuous dynamic activities greater than 5 min (p≤0.05). The difference in number of 1–5 min periods of continuous dynamic activities was not significant (p=0.10) (Table II).

Although not statistically significant, duration of dynamic activities and mean motility were higher in GMFCS level II

Table III. Periods of continuous dynamic activities (5–10 sec; 10–30 sec; 30–60 sec; 1–2 min; 2–5 min; 5–10 min; and >10 min)

	Number of participants with at least one period of continuous dynamic activities per day		Number of periods	
	n	(%)	Mean (SD)	Range
5–10 sec	56	(100)	112 (43)	39–204
10–30 sec	56	(100)	128 (53)	35–279
30–60 sec	56	(100)	40 (30)	5–197
1–2 min	55	(98)	13 (9)	0–42
2–5 min	52	(93)	4 (4)	0–15
5–10 min	32	(57)	1 (1)	0–6
>10 min	22	(39)	0 (1)	0–2

SD: standard deviation.

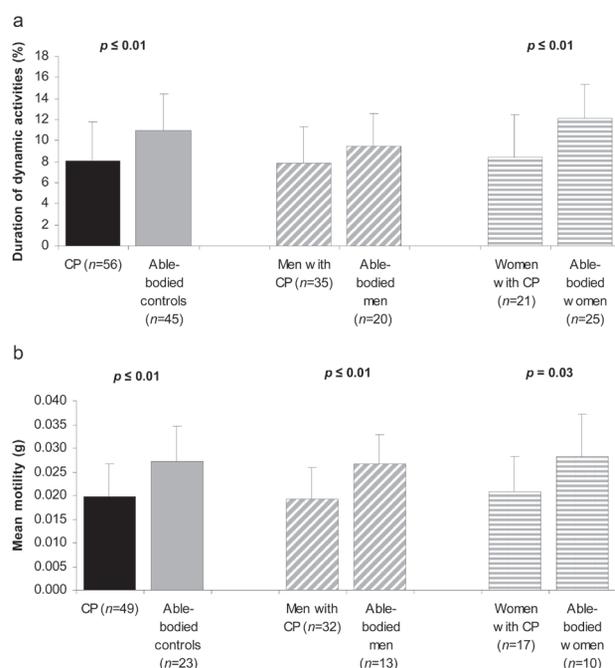


Fig. 1. (a) Duration of dynamic activities in adults with bilateral spastic cerebral palsy and able-bodied age-mates, as percentage of a 24-h period. (b) Intensity of activities (mean motility) in adults with bilateral spastic cerebral palsy and in able-bodied age-mates, expressed in gravitational acceleration (1g=9.81 m/s<sup>2</sup>).

Table IV. Spearman correlations (*R*s) between personal and cerebral palsy-related characteristics and level of everyday physical activity

	Duration of dynamic activities (% of 24 h)	Mean motility (g)	Periods of continuous dynamic activities of 1–5 min ( <i>n</i> )	Periods of continuous dynamic activities of > 5 min ( <i>n</i> )
Age	0.00	-0.11	-0.04	-0.08
Gender	0.04	0.09	0.06	-0.24
Level of education	-0.12	-0.09	-0.18	-0.08
Limb distribution	-0.24	-0.25	-0.11	0.02
GMFCS	-0.48*	-0.46*	-0.37*	-0.34*
Spasticity	0.01	0.09	0.08	0.15

\*Significant association at  $p \leq 0.01$ .

GMFCS: Gross Motor Functioning Classification System. A higher GMFCS level indicates a lower level of gross motor functioning.

compared with GMFCS level III/IV participants ( $p=0.06$  and  $p=0.09$ , respectively). The number of 1–5 min and greater than 5 min periods of continuous dynamic activities did not differ between GMFCS level II and GMFCS level III/IV participants ( $p=0.32$  and  $p=0.58$ ). In addition, differences between GMFCS level I and GMFCS II were not significant for the 3 main aspects of level of everyday PA.

## DISCUSSION

This is the first study objectively measuring level of everyday PA in adults with bilateral spastic CP. We have demonstrated that adults with bilateral spastic CP, and particularly those with low-level gross motor functioning, have inactive lifestyles when compared with able-bodied age-mates. Personal and CP-related characteristics other than gross motor functioning were not associated with level of everyday PA.

### *Level of everyday physical activity in adults with CP*

On average, participants were dynamically active for nearly 2 h per day (116 min), which is higher than levels reported in a study of adults aged 19–66 years, who were only active an average of 52 min per day (28). However, this latter study used self-report questionnaires, which may be susceptible to social desirability and recall bias (29) and which may not capture all activities of daily living that are challenging for disabled persons (30). A previous study using the same measurement procedures as the current study showed that ambulatory adults with unilateral spastic CP aged 25–35 years were dynamically active for 152 min per day, a finding that did not differ significantly from able-bodied age-mates (19). These results were predictable given that study participants had near-normal lower extremity muscle tone and therefore mobility-related activities were not likely to be limited (19).

In contrast to findings in adults with unilateral CP (19), adults with bilateral CP in our study were significantly less physically active than able-bodied age-mates (excluding differences in mean duration of dynamic activities for men with CP and able-bodied age-mates, which were not significant). The inactive lifestyle reported in this study is consistent with studies of diplegic children (15) and adolescents (16–18) in which different measurement procedures, including doubly-labelled water, step counts and questionnaires, demonstrated

lower levels of everyday PA in persons with CP compared with able-bodied age-mates.

In the present study, only 39% of participants had one or two periods of continuous dynamic activities for at least 10 min per day. Furthermore, only 57% had at least one period of continuous dynamic activity lasting 5–10 min each day. To maintain and promote health, able-bodied persons are recommended to engage in 30 min of moderate intensity PA each day, which can be divided into 10-min intervals (31). Most adults with CP in our study did not achieve this minimum recommended level. This failure to achieve PA goals has also been demonstrated in other studies of adults with CP (28), and other physically disabled persons (32). It is uncertain whether guidelines for the general population are appropriate for persons with disabilities such as CP (14). Also, the intensity of activities performed by study participants is unknown. We suspect that adults with CP experience greater physical strain compared with the general population for similar activities; however, it is unknown if this level of exertion meets the moderate intensity exercise goals. Further research concerning the level of physical strain during everyday PA is needed.

Low levels of everyday PA in adults with CP may be explained by higher energy requirements for daily activities due to reduced muscle mass or inefficient locomotion (30). Increased energy expenditure during everyday physical activities such as walking has been reported in children (33) and adults with CP (34). Published data also supports a relationship between level of everyday PA and energy expended during walking (35). Factors such as a lower physical fitness, fatigue, and pain may contribute to lower levels of everyday PA. Another reason for lower activity levels could be limited opportunities for activities such as sports participation. Several barriers exist for disabled persons, including transportation, access to equipment and facilities, and lack of awareness of facilities (36).

We found no association between mean duration of dynamic activities and satisfaction with level of everyday PA. This is in contrast with findings of van der Slot and colleagues (19), where adults with unilateral spastic CP with longer durations of dynamic activities were less satisfied with level of everyday PA. Adults with unilateral involvement may function at a higher level of everyday PA, and may therefore perform more physically demanding tasks or set higher personal goals (and have higher expectations) for functioning. The adults in our study

with bilateral involvement did not attain levels of dynamic activities as high as the participants of the aforementioned study and since they might not be capable of higher levels of PA they may be quite satisfied with their current level of everyday PA.

#### *Factors associated with level of everyday PA*

Only gross motor functioning was associated with level of everyday PA in the present study. Inactive lifestyles were mostly found in adults with low-level gross motor functioning (GMFCS level III–IV); this finding is consistent with previous studies in adolescents with CP (16–18). Evaluating our findings in the context of the published literature is difficult because other studies of adults with CP use different definitions and measurement methods (37, 38), or do not report GMFCS level (19, 28, 38). Previous studies provide contradictory data regarding level of everyday PA; some authors report no relationship (19, 38), whereas others report that lower levels of motor functioning are associated with less physical activity (28, 37).

In our study, level of everyday PA for persons with the high-level gross motor function (GMFCS level I; mean duration of dynamic activities 10.3%) was similar to that of able-bodied age-mates (10.9%). Similar results have been found in adolescents with CP (17) and, although not reported in their publication, in the study of van der Slot et al. (19) among adults with unilateral spastic CP. In the latter sample, ambulatory adults with GMFCS level I had a mean duration of dynamic activities of 11.1%, compared with 11.2% of able-bodied age-mates (personal communication).

We did not find associations between other personal and CP-related characteristics and level of everyday PA. The lack of a relationship with age and educational level is consistent with findings in adults with unilateral CP (19), but may also be explained by homogeneity of personal characteristics in the current study. Other studies in adolescents (16, 17, 36) and adults (19) did not report gender differences in level of everyday PA. To our knowledge, no information is available regarding the relationship between level of everyday PA and spasticity or affected limb distribution.

#### *Limitations of the study*

There are some noteworthy limitations of using the AM to measure level of everyday PA. First, we measured level of everyday PA over 2 days, but it has been suggested that at least 3–5 days of monitoring may be necessary to characterize habitual PA patterns (39). Secondly, we may have underestimated the level of everyday PA because subjects could not swim during measurements. In several studies, swimming is noted as a frequent PA of persons with CP (37, 38). The size and the wires of the AM may also have hampered some activities in daily life. We asked the participants whether they performed their regular activities during the measurement period and this was confirmed, so influence of the measurement equipment itself is considered to be little. Additionally, we focused on comparing level of everyday PA with that of able-bodied age-mates; because able-bodied age-mates also were not permitted

to swim and were also possibly hampered by the measurement equipment, these factors are believed not to have an effect on study results. Fourthly, we may have overestimated the level of everyday PA because of selection bias. Adults with CP who are interested in PA and fitness (and may therefore have had a higher level of everyday PA) may have been more likely to participate than those with less interest and physical activity.

#### *Implications for treatment*

Our study shows that adults with bilateral spastic CP have inactive lifestyles compared with able-bodied age-mates, and that they fail to achieve recommended activity levels. Because particularly adults with low-level gross motor functioning (GMFCS level III or IV) have a low level of everyday PA, interventions to increase the level of everyday PA should be targeted to this group. However, even participants with GMFCS levels I and II (who achieved mean duration of dynamic activities and mean motility levels comparable to able-bodied age-mates) did not achieve minimum exercise recommendations. Furthermore, we expect that disabled persons may experience increased physical complaints secondary to ageing and functional deterioration (14, 40), which may lead to reduced levels of everyday PA. We therefore believe that adults with a relatively high-level gross motor functioning would also benefit from lifestyles that are more active. Studies into the relationships between level of everyday PA, health-related fitness, and fatigue and pain symptoms may further elucidate the significance of physical activity to optimize health in adults with CP.

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#### REFERENCES

1. SCPE. Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. *Surveillance of Cerebral Palsy in Europe (SCPE)*. *Dev Med Child Neurol* 2000; 42: 816–824.
2. Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, et al. A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl* 2007; 109: 8–14.

3. Wichers MJ, van der Schouw YT, Moons KG, Stam HJ, van Nieuwenhuizen O. Prevalence of cerebral palsy in The Netherlands (1977–1988). *Eur J Epidemiol* 2001; 17: 527–532.
4. Strauss D, Shavelle R. Life expectancy of adults with cerebral palsy. *Dev Med Child Neurol* 1998; 40: 369–375.
5. Stempien LM, Gaebler-Spira D. Rehabilitation of children and adults with cerebral palsy. In: Braddom RL, editor. *Physical medicine and rehabilitation*. Indianapolis: WB Saunders; 1996, p. 1113–1132.
6. Bax MC, Smyth DP, Thomas AP. Health care of physically handicapped young adults. *Br Med J (Clin Res Ed)* 1988; 296: 1153–1155.
7. Ng SY, Dinesh SK, Tay SK, Lee EH. Decreased access to health care and social isolation among young adults with cerebral palsy after leaving school. *J Orthop Surg (Hong Kong)* 2003; 11: 80–89.
8. Andersson C, Mattsson E. Adults with cerebral palsy: a survey describing problems, needs, and resources, with special emphasis on locomotion. *Dev Med Child Neurol* 2001; 43: 76–82.
9. Turk MA, Geremski CA, Rosenbaum PF, Weber RJ. The health status of women with cerebral palsy. *Arch Phys Med Rehabil* 1997; 78: 10–17.
10. Jahnsen R, Villien L, Egeland T, Stanghelle JK, Holm I. Locomotion skills in adults with cerebral palsy. *Clin Rehabil* 2004; 18: 309–316.
11. van den Berg-Emons HJG, Bussmann JB, Meyerink HJ, Roebroek ME, Stam HJ. Body fat, fitness and level of everyday physical activity in adolescents and young adults with meningomyelocele. *J Rehabil Med* 2003; 35: 271–275.
12. Pate RR, Pratt M, Blair SN, Haskell WL, Macera CA, Bouchard C, et al. Physical activity and public health. A recommendation from the Centers for Disease Control and Prevention and the American College of Sports Medicine. *JAMA* 1995; 273: 402–407.
13. Crespo CJ. Exercise and the Prevention of Chronic Disabling Illness. In: Frontera WR, Dawson DM, Slovik DM, editors. *Exercise in rehabilitation medicine*. Champaign, IL: Human Kinetics; 1999, p. 151–172.
14. Rimmer JH. Exercise and physical activity in persons aging with a physical disability. *Phys Med Rehabil Clin N Am* 2005; 16: 41–56.
15. van den Berg-Emons HJ, Saris WH, de Barbanson DC, Westertep KR, Huson A, van Baak MA. Daily physical activity of schoolchildren with spastic diplegia and of healthy control subjects. *J Pediatr* 1995; 127: 578–584.
16. Maher CA, Williams MT, Olds T, Lane AE. Physical and sedentary activity in adolescents with cerebral palsy. *Dev Med Child Neurol* 2007; 49: 450–457.
17. Bjornson KF, Belza B, Kartin D, Logsdon R, McLaughlin JF. Ambulatory physical activity performance in youth with cerebral palsy and youth who are developing typically. *Phys Ther* 2007; 87: 248–257; discussion 257–260.
18. Bandini LG, Schoeller DA, Fukagawa NK, Wykes LJ, Dietz WH. Body composition and energy expenditure in adolescents with cerebral palsy or myelodysplasia. *Pediatr Res* 1991; 29: 70–77.
19. van der Slot WM, Roebroek ME, Landkroon AP, Terburg M, Berg-Emons RJ, Stam HJ. Everyday physical activity and community participation of adults with hemiplegic cerebral palsy. *Disabil Rehabil* 2007; 29: 179–189.
20. Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Dev Med Child Neurol* 1997; 39: 214–223.
21. Jahnsen R, Aamodt G, Rosenbaum P. Gross Motor Function Classification System used in adults with cerebral palsy: agreement of self-reported versus professional rating. *Dev Med Child Neurol* 2006; 48: 734–738.
22. Sandstrom K, Alinder J, Oberg B. Descriptions of functioning and health and relations to a gross motor classification in adults with cerebral palsy. *Disabil Rehabil* 2004; 26: 1023–1031.
23. Boyd RNHKG. Objective measurement of clinical findings in the use of botulinum toxin type A for the management of children with cerebral palsy. *Eur J Neurol* 1999; 6: S23–S35.
24. Scholtes VA, Becher JG, Beelen A, Lankhorst GJ. Clinical assessment of spasticity in children with cerebral palsy: a critical review of available instruments. *Dev Med Child Neurol* 2006; 48: 64–73.
25. Bussmann JB, Martens WL, Tulen JH, Schasfoort FC, van den Berg-Emons HJ, Stam HJ. Measuring daily behavior using ambulatory accelerometry: the Activity Monitor. *Behav Res Methods Instrum Comput* 2001; 33: 349–356.
26. Postma K, van den Berg-Emons HJ, Bussmann JB, Sluis TA, Bergen MP, Stam HJ. Validity of the detection of wheelchair propulsion as measured with an Activity Monitor in patients with spinal cord injury. *Spinal Cord* 2005; 43: 550–557.
27. Scott J, Huskisson EC. Vertical or horizontal visual analogue scales. *Ann Rheum Dis* 1979; 38: 560.
28. Gaskin CJ, Morris T. Physical activity, health-related quality of life, and psychosocial functioning of adults with cerebral palsy. *J Phys Act Health* 2008; 5: 146–157.
29. Sallis JF, Saelens BE. Assessment of physical activity by self-report: status, limitations, and future directions. *Res Q Exerc Sport* 2000; 71: S1–S14.
30. Heath GW, Fentem PH. Physical activity among persons with disabilities – a public health perspective. *Exerc Sport Sci Rev* 1997; 25: 195–234.
31. Haskell WL, Lee IM, Pate RR, Powell KE, Blair SN, Franklin BA, et al. Physical activity and public health: updated recommendation for adults from the American College of Sports Medicine and the American Heart Association. *Med Sci Sports Exerc* 2007; 39: 1423–1434.
32. Rimmer JH. Physical activity among adults with a disability – United States, 2005. *MMWR Morb Mortal Wkly Rep* 2007; 56: 1021–1024.
33. Waters RL, Mulroy S. The energy expenditure of normal and pathologic gait. *Gait Posture* 1999; 9: 207–231.
34. Johnson RK, Hildreth HG, Contompasis SH, Goran MI. Total energy expenditure in adults with cerebral palsy as assessed by doubly labeled water. *J Am Diet Assoc* 1997; 97: 966–970.
35. Maltais DB, Pierrynowski MR, Galea VA, Bar-Or O. Physical activity level is associated with the O<sub>2</sub> cost of walking in cerebral palsy. *Med Sci Sports Exerc* 2005; 37: 347–353.
36. Longmuir PE, Bar-Or O. Factors influencing the physical activity levels in youths with physical and sensory disabilities. *Adapted Physical Activity Quarterly* 2000; 17: 40–53.
37. Jahnsen R, Villien L, Aamodt G, Stanghelle J, Holm I. Physiotherapy and physical activity – experiences of adults with cerebral palsy, with implications for children. *Adv Physiother* 2003; 5: 21–32.
38. Heller T, Ying Gs GS, Rimmer JH, Marks BA. Determinants of exercise in adults with cerebral palsy. *Public Health Nurs* 2002; 19: 223–231.
39. Trost SG, Pate RR, Freedson PS, Sallis JF, Taylor WC. Using objective physical activity measures with youth: how many days of monitoring are needed? *Med Sci Sports Exerc* 2000; 32: 426–431.
40. Hilberink SR, Roebroek ME, Nieuwstraten W, Jalink L, Verheijden JM, Stam HJ. Health issues in young adults with cerebral palsy: towards a life-span perspective. *J Rehabil Med* 2007; 39: 605–611.