

ORIGINAL REPORT

HEALTH ISSUES IN YOUNG ADULTS WITH CEREBRAL PALSY: TOWARDS A LIFE-SPAN PERSPECTIVE

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**Objective:** To obtain better insight into the health issues of young adults with cerebral palsy.

**Design:** Cross-sectional.

**Subjects:** Two data sources were used: 54 adults with cerebral palsy (age range 25–36 years) and 48 physicians (members of the Netherlands Society of Physical and Rehabilitation Medicine).

**Methods:** Adults with cerebral palsy participated in a physical examination and a semi-structured interview assessing several health issues and utilization of healthcare. Rehabilitation physicians completed a questionnaire on impairments they recognized as being related to cerebral palsy.

**Results:** In the patient sample, pain (59%) and joint deformities (19–57%) were observed most frequently. Evidence of a decrease in the utilization of healthcare services at adult age emerged. Lower gross motor function and cognitive level appeared to be determinants of motor and speech impairments and of the utilization of 3 allied healthcare services. Rehabilitation physicians reported pain (88%), joint deformities (86%) and fatigue (76%) as being cerebral palsy-related health problems in adults.

**Conclusion:** Based on the high prevalence of pain and joint deformities and the decrease in the utilization of healthcare services, systematic follow-up in adults with cerebral palsy seems warranted. Cerebral palsy needs to be considered as a life-long condition, requiring a life-span perspective in order to better organize optimal care.

**Key words:** cerebral palsy, adulthood, secondary impairments, rehabilitation care.

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INTRODUCTION

Cerebral palsy (CP) is a term used to describe a group of disorders of movement and posture, caused by non-progressive brain lesions. A recently proposed definition of CP refers to the "...non-progressive disturbances that occurred in the developing fetal or infant brain" (1). Such definitions emphasize the aetiology of the condition (e.g. brain damage), but do

not indicate the clinical manifestations and consequences for the patients. Others report that "the motor impairment and functional consequences of cerebral palsy may change or even worsen over time" (2), but how this change typically develops is not fully understood. As a result, adolescents and young adults with CP have a need for more information about CP and its long-term consequences (3, 4). More knowledge about the consequences of CP at adult age would improve rehabilitation programmes for the different age groups.

CP is still largely perceived as a "childhood disease"; in paediatric rehabilitation CP is the most frequently seen condition (5–7). However, because of the improved survival of individuals with CP (8), one might say that CP as a condition has survived paediatric rehabilitation. Nowadays CP forms one of the largest diagnostic groups in adolescents with a physical impairment (9).

*Physical complaints*

In late adolescence and adulthood, the above-mentioned change in impairments and consequences of CP (2) may become manifest in so-called secondary and associated conditions (10), which are directly or indirectly related to CP. These conditions may lead to further functional loss and may hamper an independent adult life. Pain is a major issue in adults with CP. An American study found that 84% of women with CP suffer from pain (11), with most pain being localized in the lower back, hips and legs (12). Bottos et al. (13) reported prevalences of hip complaints and scoliosis (> 30°) in adults with CP of 28% and 19%, respectively; they also found arthrosis in these adults, with increasing prevalence in older adults. A Norwegian study showed that CP adults, compared with the general population, report more complaints of chronic pain (28% vs 15%), fatigue (30% vs 22%) and suffer from a loss or deterioration of walking ability (44%) (14–16). Decreased walking ability has also been reported in other studies (13, 17–19). In addition to walking, other areas of functioning might be affected by ageing: over a 5-year period adults with a congenital disability were confronted with increasing dependence in several functional domains (20).

Apart from these musculoskeletal impairments, other conditions may also be present in adults with CP. Besides epilepsy (11, 14), cerebral damage can also cause auditory and visual disorders (13, 14, 21), disorders of the entire digestive system can arise (swallowing, gastric acid, bladder and bowel prob-

lems) (11, 13, 18, 21), and respiratory problems can occur (13, 14, 21).

#### Utilization of healthcare

Whereas most children with CP are attended to by paediatric rehabilitation care, their transition to adult care appears to be difficult, implying that the follow-up of young adults with CP is not optimal (3, 4, 22, 23). Hence, departments of adult rehabilitation have limited experience in treating adults with CP.

Some studies have suggested that the utilization of healthcare declines as adolescents with CP reach adulthood (22, 24–27). A Dutch study demonstrated that in a sample of young adults with CP of normal intelligence only 38% had consulted their rehabilitation physician in the past year (3). This decline concerns the utilization of allied healthcare as well as medical specialist care, reflecting a discontinuation in monitoring of and intervening in the functional and health status of these persons.

We therefore designed 2 investigations to address the following questions. First, to assess which impairments and health problems were present in a sample of adults with CP (age range 25–36 years) and to explore which subgroups were at risk for these conditions. Secondly, to assess the utilization of healthcare by adults with CP at the end of paediatric rehabilitation care (18 years of age) and at young adult age (25–36 years of age) and to explore associated factors. Thirdly, to establish which conditions rehabilitation physicians in adult rehabilitation care recognize as CP-related.

## METHODS

### Subjects

**Adults with CP.** In a previous phase of this study young adults were identified according the following criteria: (i) a known diagnosis of CP; (ii) born between 1 January 1965 and 31 December 1974; and (iii) known to the rehabilitation centre in The Hague, a centre with a regional function, covering the city of The Hague and the surrounding area. Van der Dussen et al. (28) reported on the functional level of this cohort of 80 young adults with CP. The present study addresses the 5-year follow-up measurements that we performed on this cohort. At this time, patients were aged 25–36 years (Table I). For the follow-up measurements we invited the cohort of 80 persons, and an additional 8 patients of the same age who consulted the rehabilitation centre in the past years. Of these 88 adults, 54 (62%) agreed to participate in the follow-up measurements, addressing a physical examination and a semi-structured interview. Reasons for drop-out were: being unwilling to participate in this part of the study ( $n = 17$ ); not showing up at the examination appointment ( $n = 9$ ); unknown address ( $n = 6$ ); or reason unknown ( $n = 2$ ). Drop-out analysis showed that non-compliance was not associated with sex, age and limb distribution of the paresis. The Medical Ethics Committee of Reinier de Graaf Medical Centre, Delft, approved the study. Participants gave their informed consent.

**Rehabilitation physicians.** In spring 2005 all members of the Netherlands Society of Physical and Rehabilitation Medicine ( $n = 461$ ) received an invitation to complete a questionnaire. Rehabilitation physicians with less than one year experience in rehabilitation medicine were excluded from the sample. A total of 105 rehabilitation physicians (22.8%) returned the questionnaire; 2 of these were excluded due to lack of experience. The remaining 103 participants (67% females)

Table I. Characteristics of the adults with cerebral palsy (CP) ( $n = 54$ )

Variable	Adults with CP
<i>Demographics</i>	
Sex (%)	
Male	48
Female	52
Age in years (mean (SD))	30.0 (3.4)
Education (%)	
No education/school for severe learning disabilities	46
Junior general/vocational education	15
Secondary general/advanced vocational education	30
Higher education: institution / university	9
Employment (%)	
Paid job	28
Sheltered job	26
Volunteer job/school/housekeeping	15
Day-centre	31
Civil status (%)	
Living with parents	28
Special community	32
Single	22
Living together/married	18
Having children (%)	9
<i>CP characteristics</i>	
GMFCS (%)	
Level I	28
Level II	34
Level III	7
Level IV	24
Level V	7
Limb distribution of spastic paresis (%)	
Hemiplegia	37
Diplegia	22
Quadriplegia	41

GMFCS: Gross Motor Function Classification System; SD: Standard deviation.

had a mean of 9.3 years (standard deviation (SD) = 7.4, range = 1–32) of experience. All regions of the Netherlands, as well as most of the university medical centres, were represented in the sample. In total, 48 of the rehabilitation physicians (47%) had experience in treating adults with CP; they were currently treating a median of 10 adults (SD = 16.6), whereas 9 physicians (19%) had a patient population of at least 21 adults with CP (range 21–80). These 48 participants had 11.2 years of experience (SD = 6.6) compared with 7.6 years (SD = 7.8) in the physicians not treating adults with CP ( $t = 2.4$ ,  $df = 97$ ,  $p = 0.017$ ).

### Measurements

**Adults with CP.** Two experienced physiotherapists performed a semi-structured interview and physical examination. If the adult was not capable of providing adequate answers because of intellectual disability, the interview was held with the adult and a proxy (26%). Socio-demographic data collected were sex, age, current employment status, living situation and having children. The level of gross motor functioning was classified according to the Gross Motor Function Classification System (GMFCS) (29, 30). Limb distribution of spastic paresis was subdivided as diplegia, hemiplegia and quadriplegia (28). Level of education was used as an indicator of cognitive functioning (30, 31); we distinguished 4 levels of education: (i) severe learning disabilities or no education; (ii) junior general or junior vocational education; (iii) secondary general or advanced vocational education; (iv) higher educational institutions or university (32). The interview addressed impairments of body functions, physical complaints and

self-assessed health experience. Presence of epilepsy, respiratory and gastrointestinal impairments were scored based on medication use (e.g. respiratory medication, anti-convulsants and antacids). Presence of pain and its localization was patient-assessed. Pain severity and impact of pain were assessed with 2 sections of the MPQ-DLV (33), the Dutch version of the McGill Pain Questionnaire (34). To indicate the impact of pain, the Quality of Life Index (QLI) was calculated (9 items, range 0–15, Cronbach's alpha = 0.73). Adults were asked to indicate the pain severity when they suffered pain the least, the most and currently on a visual analogue scale (VAS), with illustrations of a neutral and painful face at either end of a 100-mm long line (34, 35).

As part of the physical examination the physiotherapist assessed the presence of joint deformities at the spine and extremities according to predefined cut-off angles. **Cut-off angles for joint deformities at the leg** were set at 90° of hip flexion, -10° of knee extension and 0° of ankle dorsiflexion, and at the arm at 135° of shoulder anteflexion, -45° of elbow extension and neutral position of the wrist with extended fingers. These cut-off angles were based on clinical experience (WN, LJ). **For the spine the presence of kyphosis, scoliosis and lordosis** were assessed. For the most affected leg and the most affected arm, global indicators of joint deformities were determined (36) as a deficit in passive range of motion in at least one out of 3 joints of the extremity. Finally, some items related to the utilization of healthcare at the end of paediatric rehabilitation care (at 18 years of age; assessed retrospectively) and at adult age (assessed over the past year), addressing both allied healthcare and medical specialist care.

**Rehabilitation physicians.** The rehabilitation physicians received a postal questionnaire with 17 (partly closed) items. In addition to general characteristics of the physician and experience with treating patients with CP, the questionnaire inventoried which complaints in adult patients physicians recognized as CP-related according to their clinical experience. Physicians were asked to indicate these complaints on a list of predefined physical complaints (e.g. joint deformities, pain, epilepsy), with the following question: "Please indicate which of the following physical complaints you consider as being related to CP".

### Analyses

Descriptive statistics were applied to summarize the characteristics of patients and physicians and to show the frequencies of the various impairments and health issues. To compare the utilization of care in the past year with care at age 18 years, binominal non-parametric tests were applied. To explore determinants of specific impairments or utilization of healthcare, univariate logistic regression analyses (for impairments and utilization of healthcare) or linear regression analyses (for pain severity) were performed. The main characteristics of adults with CP (sex, age, level of education, Gross Motor Function Classification System (GMFCS) (dichotomized as levels I–II vs levels III–V) and limb distribution of spastic paresis) were entered as independent variables, one at a time. To indicate the proportion of explained variance in the logistic regression models, the Nagelkerke R-square was used. Associations with the utilization of healthcare were explored only when at least 15% of the adults made use of the specific services.

Impairments were allocated for 3 domains, by combining some categories of body functions from the International Classification of Functioning, Disability and Health (ICF) (37): (i) musculoskeletal impairments (joint deformities) and pain (maximal possible number is 6 impairments); (ii) sensory impairments (vision, auditory), speech and epilepsy (maximal number is 4 impairments); and (iii) digestive and urinary impairments (swallowing, gastrointestinal, bowel and bladder) and respiratory impairments (maximal number is 6 impairments). As a global indicator of impairments, the total number of impairments was calculated. Utilization of healthcare was grouped into 2 categories: (i) allied healthcare; and (ii) care provided by medical specialists.

## RESULTS

### Adults with CP

**Sample characteristics.** The patient sample comprised 26 males (48%) and 28 females (52%) with a mean age of 30.0 years (SD = 3.4) (Table I). Regarding motor function, 62% had GMFCS scores of I–II; hemiplegia and quadriplegia were fairly equally represented, while there were less adults with diplegia. Regarding cognitive functioning, 54% of the adults had no severe learning disabilities. About one-third of the adults with CP (31%) visited a day-centre, 24% found sheltered work and 26% had a regular paid job. A minority (18%) was living with a partner (either married or living together) and 9% had children.

**Impairments.** The most frequently mentioned condition was pain (59%) (Table II). Joint deformities were observed in 15–57% of the adults. Speech and swallowing impairments occurred in about 20% of the adults. Impairments of the visual system were indicated by 22% of the adults with CP, whereas auditory problems were rare (7%). Adults suffered from a mean of 3.2 (SD = 2.1) impairments. Although 94% usually felt healthy, about 25% indicated that their activities were limited by their health problems.

**Pain.** In the subgroup of 32 adults reporting pain (59%), pain was located mostly in the hip or leg (32%), back (28%) and neck, shoulder, arm region (25%). We assessed pain severity and the impact of pain on daily life. In adults with pain the mean VAS score was 7.0 (SD = 11.9) when the pain was least severe, 69.1 (SD = 29.1) when they suffered worst pain, and currently experienced pain scored 22.2 (SD = 22.0). Pain did not appear to affect

Table II. Health issues in adults with cerebral palsy (CP): prevalence of impairments and experienced health assessed in adults with CP (n = 54)

Impairments and experienced health (%)	Adults with CP
Joint deformities	
Kyphosis	22
Scoliosis	20
Lordosis	19
In most affected leg*	57
In most affected arm*	15
Pain	59
Medication for epilepsy	17
Vision	22
Auditory	7
Speech	20
Medication for respiratory problems	2
Swallowing	19
Medication for gastrointestinal problems	9
Bladder and bowel	
Bladder (incontinence)	9
Bowel (incontinence)	6
Regular defecation problems	15
Experienced health	
Usually feel healthy	94
Worry about health	33
Health problems limit activities	24

\*Joint deformity in at least one joint.

daily functioning in these adults, reflected by a median score of 1.8 (SD = 4.1) on the QLI of the MPQ-DLV.

**Utilization of healthcare.** A decline in the utilization of healthcare between 18 years and adulthood (25–36 years) appeared ( $p < 0.001$ ), showing a decrease in visits to all allied healthcare disciplines (Table III). Of the adults with CP, 32% visited their rehabilitation physician during the past year and 15% had seen a neurologist in this period. On average, adults with CP consulted a mean of 1.2 (SD = 1.2) services of the allied healthcare services in the past year and 1.1 (SD = 1.1) services of medical specialists.

Table III. Healthcare utilization at age 18 years and past year in percentages ( $n = 54$ )

Services/visits medical professional	At age 18 years	At adult age (25–36 years)†
Interventions aimed at mobility	82	63*
Physical therapy	80	57*
Hydrotherapy/swimming	39	28*
Horse riding	22	9*
Speech therapy	33	6*
Occupational therapy	32	15*
Dietician	n.a.	6
Welfare worker	9	4*‡
Pedagogue	2	n.a.
Rehabilitation physician	n.a.	32
Neurologist	n.a.	15
Urologist	n.a.	6
Orthopaedic	n.a.	4

n.a.: not assessed.

†At least one visit.

\* $p < 0.001$  (non-parametric binominal test, utilization of care at age 18 years as test proportion).

‡In this item, welfare worker/psychologist were taken together.

Table IV. Determinants of impairments in adults with cerebral palsy (CP) ( $n = 54$ )

Impairment and determinants	OR	95% CI	$p$	$R^2$
<b>Scoliosis</b>				
Cognitive impairment	4.8	1.1–20.9	0.039	0.14
GMFCS*	5.1	1.2–21.1	0.025	0.15
<b>Deformity in most affected leg</b>				
Cognitive impairment	3.4	1.1–10.8	0.036	0.11
GMFCS*	3.6	1.1–12.2	0.040	0.11
<b>Speech</b>				
Cognitive impairment	18.7	2.2–160.1	0.008	0.32
GMFCS*	29.1	3.3–254.0	0.002	0.42
<b>Limb distribution of spastic paresis</b>				
Diplegia	1.7	0.10–30.5	0.709	
Quadriplegia	13.2	1.5–116.7	0.021	
Hemiplegia	Ref			
<b>Swallowing</b>				
Cognitive impairment	6.4	1.2–33.5	0.029	0.17

Ref.: reference category; GMFCS: Gross Motor Function Classification System; 95% CI: 95% confidence interval; OR: Odds ratio.

\*Dichotomized: level I–II (0) vs III–IV–V (1).

**Determinants of impairments and healthcare utilization.** Exploratory analyses were performed to detect determinants of impairments and pain indices (Table IV). For 4 specific impairments some characteristics of CP appeared to be predictive. A higher GMFCS level (III–V) was related to a higher prevalence of scoliosis, joint deformities of the leg, and speech impairment. Adults with a low level of cognitive functioning had an increased risk of problems concerning joint deformity, speech and swallowing, while in persons with quadriplegia more speech impairments were present. No associations were found with the severity or impact of pain on daily functioning, nor with the experienced health.

Some determinants of the utilization of healthcare at age 18 years emerged (Table V). At this age, having a cognitive impairment, GMFCS level III–V and having quadriplegia were determinants of using several allied healthcare services. The GMFCS level appeared to be a strong predictor for speech therapy at this age: 49% of the variance can be explained by gross motor functioning. At adult age some weak associations were found. The GMFCS level and cognitive level explained 12–16% of the variance in utilization of mobility-related therapy and occupational therapy.

Associations between impairments and consulting a rehabilitation physician and a neurologist at adult age were explored. Adults with pain more frequently consulted their rehabilitation physician compared with adults without pain (Odds ratio (OR) = 4.9 (1.2–20.1),  $p = 0.026$ ,  $R^2 = 0.15$ ), while

Table V. Determinants of utilization of allied healthcare ( $n = 54$ )

Healthcare utilization and determinants	OR	95% CI	$p$	$R^2$
<b>At age 18 years</b>				
<b>Interventions aimed at mobility*</b>				
Cognitive impairment	10.8	1.3–92.7	0.030	0.21
<b>Occupational therapy</b>				
Cognitive impairment	11.0	2.6–46.2	0.001	0.31
GMFCS†	7.5	2.1–27.0	0.002	0.25
<b>Limb distribution of spastic paresis</b>				
Diplegia	0.36	0.04–3.7	0.393	0.24
Quadriplegia	4.8	1.2–19.1	0.026	
Hemiplegia	Ref			
<b>Speech therapy</b>				
Cognitive impairment	13.0	3.1–54.8	0.000	0.35
GMFCS†	25.0	5.5–114.1	0.000	0.49
<b>Limb distribution of spastic paresis</b>				
Diplegia	1.8	0.22–14.8	0.585	0.36
Quadriplegia	15.8	2.9–86.2	0.001	
Hemiplegia	Ref			
<b>At adult age</b>				
<b>Interventions aimed at mobility*</b>				
Cognitive impairment	4.3	1.3–14.5	0.019	0.14
GMFCS†	4.0	1.1–14.5	0.035	0.12
<b>Occupational therapy</b>				
GMFCS†	6.2	1.1–34.5	0.037	0.16

\*Includes physiotherapy, hydrotherapy and horse riding

Ref. = reference category

†Dichotomized: Level I–II (0) vs III–IV–V (1)

GMFCS: Gross Motor Function Classification System; OR: Odds ratio; CI: confidence interval

using medication for epilepsy was associated with consulting a neurologist in the past year (OR = 17.5 (3.0–101.8),  $p = 0.001$ ,  $R^2 = 0.32$ ). No other specific impairment was correlated with consulting these 2 medical specialists.

#### Rehabilitation physicians

*CP-related physical impairments.* Most rehabilitation physicians reported pain (88%), joint deformities (85%) and fatigue (75%) as CP-related impairments at adult age (Table VI). Epilepsy was mentioned by about 50% of the physicians, while approximately 30% recognized swallowing problems, impaired bladder and bowel function, and visual impairments as related to CP. Finally, 21% of the physicians reported that a functional deterioration in adults with CP was noticeable. Rehabilitation physicians who had more than 20 adults with CP in their patient population indicated more often that impairments were related to CP (Table VI).

### DISCUSSION

The present study explored several health issues in young adults with CP. Although the patient sample was limited in size, it was considered representative according to the check on completeness of the population performed by Van der Dussen et al. (28), and a non-selective drop-out for the 5-year follow-up measurements. The patient sample in the present study covered a broad range of types and severity of CP, and was not confined to patients who were currently under the control of a rehabilitation physician. Pain and joint deformities were found to be the most prevalent impairments in young adults with CP; data on fatigue were unfortunately not collected. Bottos et al. (13) found a comparable percentage of scoliosis (20.3%) in a sample of adults with CP (19–65 years). With respect to pain, a lower percentage of pain (59%) was found compared with other studies reporting prevalences of 82–84% (11, 14); however, the definitions of pain used were not uniform, which hampered an appropriate comparison. As indicated by Jahnsen et al. (14), the distinction between pain and chronic pain is

important, as the prevalence of chronic pain is reported to be only 28%. As indicated by the QLI-score in our group, pain had little effect on their daily functioning, which might be explained by the relatively young age of our sample or by the patients' acceptance that pain is part of their condition. This mildly experienced burden of pain might be a reason for overlooking it and thus leading to under-treatment of pain in adults with CP (12). It should be noted that we assessed the prevalence of impairments in a rather young sample of adults with CP (25–36 years). Thus, results cannot be generalized to adults over 36 years of age. Although Bottos et al. (13) did not find significant associations of impairments with age, from clinical experience we might expect that the prevalence of secondary conditions will increase at older age. Future studies in older adults with CP are needed in order to achieve insight into health conditions for a longer life-span.

Young adults with more severe consequences of CP regarding gross motor function and cognitive level had a higher prevalence of physical and speech impairments. The high OR we found for speech impairments indicate that, in adults with severe learning disabilities or who are dependent on assistive devices for their mobility, the prevalence of speech impairments is 19–29 times increased. Bottos et al. (13) also reported that speech impairment correlated with older age. Our results on joint deformities are in line with previous studies; Bottos et al. (13) found that adults with "more severe syndromes" (such as tetraplegia and dystonia) had an increased risk of scoliosis, and Majd et al. (38) reported that immobilization is considered an important determinant of scoliosis. Because scoliosis can continue to progress in adult age (39) maintaining attention for joint deformities (e.g. systematic follow-up) is important.

Our finding that the utilization of allied healthcare significantly decreased between the end of paediatric rehabilitation and adult care confirmed previous reports on a discontinuity of care (22, 24–27). Only one-third of the young adults with CP consulted a rehabilitation physician in the past year. In contrast to the end of paediatric rehabilitation, at adult age utilization of allied healthcare services seemed to correspond only weakly with CP-related factors, such as level of gross motor function and cognitive functioning. Thus, it might be questioned whether those in need of care actually receive it (40). In order to improve the continuation of care across the boundaries of paediatric rehabilitation, we need a shift in paradigm towards a life-span perspective and adequate follow-up of patients who are at risk of developing secondary conditions.

In the present study some methodological aspects need to be addressed when interpreting the results. Firstly, the impairments were self-reported (except the joint deformities, which were assessed by a physical examination), which might lead to some distortion. Secondly, some issues, such as fatigue and functional deterioration, were not assessed; however, the results of our survey among rehabilitation physicians and previous studies (14–17) indicate that these might be serious impairments in adults with CP. Thirdly, because the relatively small patient sample precluded multivariate

Table VI. Percentage of rehabilitation physicians that identify CP-related impairments ( $n = 48$ )

Impairments seen as being related to CP	Rehabilitation physicians (%)
Joint deformities	85
Pain	88
Fatigue	75
Epilepsy	46
Vision	27
Auditory	15
Respiratory*	19
Swallowing*	31
Gastrointestinal*	13
Bladder and bowel	29

\*Impairment significantly more frequently recognized as related to CP by physicians treating more than 20 adults with CP.

CP: cerebral palsy

analyses, the relative contribution of gross motor function and cognitive functioning to the prevalence of impairments and utilization of healthcare remains unclear. Therefore, the determinants found in this study should be interpreted with some caution.

Of the rehabilitation physicians, less than 50% reported having experience with the treatment of adults with CP; only 19% of physicians had more than 20 adults with CP currently under their care. Physicians treating a large number of adult patients with CP appear to be more sensitive to relate some impairments to CP. This suggests that the majority of rehabilitation physicians have limited knowledge about these adults and their needs. Consequently, educational programmes for rehabilitation physicians should include issues on the management of CP during adulthood. Rehabilitation physicians with experience in treating adults with CP are most frequently confronted with impairments such as pain, joint deformities and fatigue, while other impairments are seen less often. This suggests that these complaints form an important reason for adults to seek treatment again. Our finding that suffering from pain was a determinant for consulting a rehabilitation physician in the past year provides some support for this suggestion. It is important to stress that the rehabilitation physicians accumulate their knowledge based on a selective group of adults with CP, namely those who have a systematic follow-up by an adult rehabilitation physician and those who have experienced functional deterioration or decompensation.

To conclude, adults with CP reported a number of impairments, of which pain and joint deformities (but also vision, speech and swallowing problems) were frequently indicated. About half of the rehabilitation physicians had some experience with the treatment of adults with CP, but only a limited number had a substantial population of adults with CP under their care. Physicians consider fatigue, pain and joint deformities to be CP-related complaints in this group. A large decrease in the utilization of healthcare is observed after discharge from paediatric rehabilitation. Adopting a life-span perspective might contribute to realizing adequate follow-up for patients with CP in adult rehabilitation care.

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