ORIGINAL REPORT

SOCIAL, INTIMATE AND SEXUAL RELATIONSHIPS OF ADOLESCENTS WITH CEREBRAL PALSY COMPARED WITH ABLE-BODIED AGE-MATES

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Objective: To describe the social, intimate and sexual relationships of Dutch adolescents with cerebral palsy compared with their able-bodied age mates.

Design: Cross-sectional study.

Subjects: A total of 103 adolescents with cerebral palsy without severe learning problems aged 16–20 years.

Methods: We used a structured interview and questionnaires to assess subject characteristics such as age, type of cerebral palsy, gross motor function and level of education. Main outcome measures on social, intimate and sexual relationships are the Life-Habits questionnaire, the Vineland Adaptive Behaviour Scale, and a structured interview developed for Dutch studies in able-bodied persons and persons with spina bifida. Experienced competence was assessed with the Dutch version of the Self-Perception Profile of Adolescents and the Physical Disability Sexual and Body Esteem Scale. These data were compared with matching reference data, mainly from able-bodied (Dutch) adolescents.

Results: Approximately 30% of the subjects functioned socially below their age level. Adolescents with cerebral palsy find it difficult to develop intimate relationships and they have less sexual experience than their able-bodied age mates.

Conclusion: Although adolescents with cerebral palsy do have social relationships, it is difficult for them to develop intimate relationships. They perceive various barriers, but seem to have a positive self-perception.

Key words: cerebral palsy, adolescents, social relationships, sexual relationships.

J Rehabil Med 2008; 40: 112-118

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Submitted January 29, 2007; accepted September 3, 2007.

INTRODUCTION

Cerebral palsy (CP) is the most common cause of physical disability in childhood. CP is a persistent disorder of posture or

movement, caused by a non-progressive pathological disorder of the developing brain, arising before the first birthday (1). With the increasing numbers of adolescents with CP living into adulthood, problems associated with transition into adulthood are now more prominent (2). For adolescents with CP the transition into adulthood is one of particular difficulty because of their impairments. To participate independently in adult life adolescents have to find a vocation, achieve independence from their parents, and establish intimate and sexual relationships. The present study focuses on the latter aspect.

Contacts with peers, social activities, and developing intimate and sexual relationships are important aspects in the development of adolescents. Social experiences with peers and dating activities enable youngsters to develop interaction skills and discover their wishes and desires regarding a fulfilling relationship in the future. Although this is an important aspect of adolescence, few studies have explored the social, intimate and sexual relationships of adolescents with CP (3). The literature is fragmented and none of these studies cover the complete range of social and sexual topics. Regarding social relationships, Stevenson et al. (4) found that young persons with CP tended to become less socially active and more isolated after leaving school, whereas able-bodied adolescents became more socially active. This may imply that adolescents with CP had fewer social relationships than their peers. As a consequence fewer peer contacts might restrict their possibilities for modelling relationships and feelings of belonging, making it more difficult to learn the flirting etiquette, which is important when developing intimate and sexual relationships (5, 6).

Regarding *intimate and sexual relationships*, Shuttleworth (7), investigating 14 men with CP, reported that it was difficult for them to develop intimate romantic relationships. In a study on adolescents with CP or spina bifida Blum et al. (8) found the same for adolescents with CP; only 7% had a steady boyfriend or girlfriend, whereas 54% of their able-bodied friends dated. Kokkonen et al. (9) also reported that the social progress and the attainment of sexual milestones of their study group with CP was significantly delayed compared with age mates; dating started much later, about 50% had never dated, and 54% had no sexual experience (vs 11% and 15%, respectively, of

© 2007 Foundation of Rehabilitation Information. ISSN 1650-1977 doi: 10.2340/16501977-0137 the able-bodied subjects). The delayed social sexual development seems contrary to the development of secondary sexual characteristics; Worley et al. (10) concluded in their study that development of secondary sexual characteristics started earlier and ended later in white children with CP with moderate and severe motor impairments, compared with white children in the general population. In South Korea married people with CP were found to have a high level of psychological symptoms e.g. a negative body image or a high risk of psychosexual dysfunction (e.g. lower sex-drive, higher level of psychological distress, more negative affect) (11).

To enhance our understanding of the needs of adolescents with CP we need to develop a more comprehensive picture of the various aspects of their social and sexual functioning, with the aim of improving multidisciplinary care for this group. The first aim of the present study was therefore to describe the social, intimate and sexual relationships of adolescents and young adults with CP. We address actual participation, perceived problems and experienced competence in these domains. Secondly, we compare the functioning of adolescents with CP in these domains with able-bodied Dutch age mates.

MATERIAL AND METHODS

Participants

This study is part of the CP Transition study South West Netherlands, a prospective cohort study focusing on the transition into adulthood of adolescents with CP aged 16–24 years. The study is part of the PERRIN research program (Pediatric Rehabilitation Research in the Netherlands). The results presented in this paper are based mainly on the baseline measurements.

Participants were recruited from 8 rehabilitation centres and rehabilitation departments in the region. Inclusion criteria were: diagnosis of CP and aged 16–20 years (years of birth 1982–86). Exclusion criteria were: severe learning disabilities (IQ below 70), co-morbidity with lasting effect on motor functioning, and insufficient knowledge of the Dutch language. Of a total of 437 patients with CP, 35% were ineligible because of severe learning disabilities (based on medical charts) and 18% due to an outdated address. An information letter about the study was sent to 184 patients, of whom 103 participated (response rate 56%). At follow-up there was a drop-out of 16%, thus 87 participants of 18–22 years remained. No significant non-response bias or lost-to-follow-up bias was observed regarding age, gender, gross motor functioning, limb distribution and educational level. The Medical Ethics Committee of Erasmus MC Rotterdam approved the study. Participants gave verbal and written consent to participate.

Procedures

As part of the assessment, written questionnaires and a semi-structured interview were administered by two psychologists (MD and DW), addressing characteristics of the participants, their participation in social, intimate and sexual relationships, and perceived problems and experienced competence in this respect. Appendix 1 shows the measurement instruments we used at baseline, and available reference data of able-bodied (Dutch) age mates or persons with other physical disabilities. For the Physical Disability Sexual and Body Esteem Scale we used data of the 2-year follow-up measurement.

Measures

Characteristics of the participants. We recorded gender, age, type of cerebral palsy, limb distribution of cerebral palsy, and level of education. Gross motor functioning was classified with the Gross Motor Function-

ing Classification System (GMFCS) (12), which is a 5-level classification system by age-related severity of gross motor limitations (12, 13). Level of education was used as an indicator of cognitive functioning (14). We used 3 levels of education; (low) pre-vocational practical education or lower; (medium) pre-vocational theoretical education and upper secondary vocational education; and (high) secondary non-vocational education, higher education and university (see Table I).

Social relationships. The Life Habits questionnaire (LIFE-H) measures the social participation of people with disabilities (15). The short version (the LIFE-H 3.0) comprises 69 life habits covering 12 categories, of which we used Recreation and Interpersonal Relationships in this study. The Life-H score ranges from "not accomplished" (0) to "accomplished without difficulty" (9). Mean scores were calculated for the categories; scores below 8 indicated difficulty in performance. Intraand inter-rater reliability of the category Recreation was moderate and for Interpersonal Relationships it has not been described (16–18).

The Vineland Adaptive Behaviour Scales-Survey Form (VABS) assesses adaptive behaviour in children aged 0–18 years (19, 20). The VABS comprises 4 domains, of which we used the domain Socialization including sub-domains Interpersonal Relationships, Play and Leisure, and Coping Skills. Items are listed in developmental order and associated age, based on the standardization data. In this study we used a starting point of age 8 years. Items are scored 2) usually, 1) sometimes or 0) never performed. The VABS has high internal consistency and moderate inter-rater reliability on the social domain (19, 21). For comparison with our study group we used the norm values of the able-bodied American age group, because Dutch norm values are not available.

The Dutch version (22) of the Harter's Self Perception Profile of Adolescents (23), called Competentie Beleving Schaal voor Adolescenten (CBSA), has been developed for adolescents aged 12–18 years. This scale measures Global Self-worth (e.g. "satisfied with being who you are") and perceived competence on the domains Scholastic Competence, Social Acceptance ("by peers"), Athletic Competence, Physical Appearance ("satisfied with own looks"), Behavioural Conduct ("behave according to the rules") and Close Friendship ("ability to establish close friendship"). Each item consists of 2 opposing statements, for example "Some adolescents have many friends but other adolescents don't have many friends". Respondents choose the description they think fits those best, and indicate whether this is somewhat or very true. Item scores range from 1 to 4, and sum

Table I. Characteristics of the 103 adolescents with cerebral palsy (CP)

62 (60)
62 (60)
62 (60)
02 (00)
41 (40)
17.9 (1.4)
78 (76)
7 (7)
18 (18)
89 (86)
50 (49)
26 (25)
26 (25)
40 (39)
35 (34)
26 (25)

*Missing data on: type of CP (n = 2); CP limb distribution (n = 1); level of education (n = 2).GMFCS: Gross Motor Functioning Classification System; SD: standard deviation.

scores are calculated for the domains. Higher scores correspond to a more positive perception of a competence. Internal consistency of the subscales is acceptable to good with α between 0.66 (Scholastic Competence) and 0.88 (Athletic Competence). Test-retest reliability and validity seems to be good (22). We used the Dutch norm values to compare with the adolescents with CP in our study.

Intimate and sexual relationships. We used a paper version of the Questionnaire of the Dutch National Study on Sexuality "Sex under the age of 25" (24). This study was performed in 2005 among Dutch adolescents aged 12–25 years, addressing opinions about sexuality and sexual experience and behaviour. We added some questions on having close friends and going out with friends, which we selected from the preceding study "Youth and Sex 95" (25). Of the 2005 study, a reference sample of able-bodied Dutch adolescents was available, consisting of 2002 persons aged 16–20 years.

From the interview of the *Dutch ASPINE study (Adolescents with spina bifida In the Netherlands)* (26) we selected some questions on courtship, experienced limitations for a relationship and sex education.

We used the Physical Disability Sexual and Body Esteem Scale (PDSBE scale) to assess respondents' capacity to feel positive about their sexuality and their body while living with a physical disability (27). This scale covers 3 dimensions: addressing attractiveness to others (3 items), sexual esteem (3 items) and body esteem (4 items). Examples of items of these subscales are "I feel that people are not sexually interested in me because of my disability", "I feel that my disability interferes with my sexual enjoyment", and "I would like to hide my disability as much as possible". Items are scored on a 5-point Likert scale ranging from 1) strongly agree to 5) strongly disagree, and sum scores are calculated for the subscales. The PDSBE scales showed good test-retest reliability and validity (28). Internal consistency of the subscales was good (α 0.74–0.81), although the distribution of men on the Attractiveness to Others and Sexual Esteem subscales was skewed towards low scores. Reference values are available of 748 persons with physical disabilities (27).

Statistical analysis

Descriptive statistics were used to describe social, intimate and sexual relationships of the study population. Because of expected differences between boys and girls concerning sexuality issues, results of intimate and sexual relationships were examined separately for both gender groups. Correlations with other background characteristics of the participants, such as gross motor functioning (GMFCS), level of education and age were assessed using Spearman correlation coefficient (Rs). For the domains of the LIFE-H, group percentages on persons with difficulties are presented. Regarding socialization on the VABS, we presented percentages of participants performing below their adequate age level, (1 standard deviation (SD) below the standardized American age equivalent mean score (19)). On the VABS, participants aged 19 and 20 years were compared with the standard scores of the maximum age (18 years and 11 months).

We used one-sample *t*-tests to compare the present results of adolescents with CP with Dutch persons (CBSA) or adults with various physical disabilities in Western society (PDBSE) (22, 27). Chi-square tests (two-sided) were applied for comparison of the CP study group with reference values of Dutch age mates, using data from the Dutch study "Sex under the age of 25" (24). Analyses were carried out using SPSS 12.0 for Windows.

RESULTS

Social activities and relationships

Participation. Most of the adolescents with CP in our study (98%) participated in one or more recreational activities, including sporting, going to the film, holidays and visiting a library. Participation in creative activities and visiting

Table II. Participation in social activities. Functioning below age level

Vineland Adaptive Behaviour Socialization subscales	Raw scores Mean (SD)	% below age level
Inter-relationships	51 (3.1)	13
Play and leisure time	37 (3.0)	20
Coping	34 (2.7)	28

SD: standard deviation.

sport matches was relatively low (48%). All participants had various social relationships, with parents, family, friends and acquaintances (2).

Of the adolescents with CP, 90% had 3 or more friends and 67% had 3 or more close friends, which was comparable with Dutch age mates. Sixty-six percent went out with friends in the evenings. With regard to socialization, Table II shows that 13–28% were not functioning adequately for their age, e.g. 62% did not belong to a youth club and 48% did not go out on single dates. In addition, 21% did not go to evening events with friends and 25% did not participate in non-school sports. Regarding coping, some participants did not function adequately on aspects that are considered adequate for younger children, e.g. repaying borrowed money or controlling anger. Level of education of adolescents with CP was related to their level of socialization according to the VABS (Rs = 0.42).

Perceived problems and experienced competence. Although most of the participants undertook recreational activities, 10–30% reported difficulties in the performance of such activities, e.g. in sporting (30%), creative activities (29%) and visiting sport matches (23%).

Adolescents with CP perceived themselves less competent in athletic competences and girls with CP perceived less social acceptance compared with their age mates. The experienced competence in close friendships and global self-worth of both boys and girls with CP was comparable to their age mates (Table III).

Dating and intimate relationships

Participation. Most of the adolescents with CP (91%) had been in love and most (73%) had some experience with courtship

Table III. Perceived competence in social activities. Adolescents with cerebral palsy (CP) compared with Dutch reference group (Ref)

	Boys	(mean)	Girls (mean)			
CBSA	CP	Ref	p	CP	Ref	p	
Domain							
Scholastic competence	13.7	14.5	0.04*	14.3	13.1	0.01*	
Social acceptance	14.8	15.3	0.14	14.3	15.4	< 0.05*	
Athletic competence	11.6	14.8	< 0.001*	9.7	12.4	< 0.001*	
Physical appearance	14.4	14.7	0.44	13.3	12.7	0.33	
Behavioural conduct	15.6	13.8	< 0.001*	16.7	14.8	< 0.001*	
Close friendships	16.7	16.6	0.74	17.6	17.7	0.71	
Global self-worth	16.0	16.0	0.94	15.2	14.9	0.58	

^{*}Significant difference between adolescents with CP and Dutch reference group.

CBSA: Competentie Beleving Schaal Voor Adolescenten.

Table IV. Participation in intimate and sexual relationships: boys and girls with cerebral palsy (CP) vs able-bodied Dutch age mates (Ref)

	Boy	Boys (%)			ls (%)	
	CP	Ref.	p	CP	Ref.	p
Falling in love and courtship						
Being in love once or more	92	95	0.2	90	97	0.02*
Experience with courtship	75	84	0.09	71	85	0.01*
Going steady at this moment	11	54	< 0.001*	32	38	0.39
Sexual experience						
Masturbation	60	89	< 0.001	43	62	0.014
French kissing	55	87	< 0.001	66	90	< 0.001
Feeling and caressing	40	81	< 0.001	61	84	< 0.001
Making love nude	28	66	< 0.001	44	72	< 0.001
Intercourse	20	62	< 0.001	24	69	< 0.001

^{*}Significant difference between adolescents with CP and Dutch reference group.

(Table IV). Although 44% usually had a date, only 19% of the adolescents (11% of the boys and 32% of the girls) with CP had a steady girlfriend or boyfriend at the moment of the interview, compared with 46% of their Dutch age mates. Adolescents with CP had significantly less experience in dating and intimate relationships than their age mates. For girls and boys with CP this lack of experience concerned different stages of pair bonding; girls with CP had relatively less experience with falling in love and courtship than girls without CP, whereas relatively few boys with CP had a steady girlfriend.

Perceived problems and experienced competence. In starting a relationship many participants (41%) perceived a lack of self-confidence as an obstacle, or experienced that they were treated differently (23%). Other perceived problems were physical disabilities (21%) or wheelchair-dependency for non-ambulators (11%). Boys and girls did not differ regarding the obstacles they perceived in intimate relationships. Of all participants, 1–3% encountered other obstacles, such as dependence on the help of others, no private transportation, appearance, attitudes of others and difficulty with body contact, or not wanting a relationship yet.

Adolescents with CP used various dating skills in trying to make contact with someone they liked. About 76% tried to impress the other or used a friend to make contact, 63% just got on with it, and 59% (66% boys and 49% girls) trusted their physical appearance or let the other person initiate the contact. There was no significant difference between boys and girls in contact strategies, except for the passive style, which girls used significantly more. Notably, boys and girls with CP evaluated their physical appearance compared with Dutch reference values (Table III).

Sexual development and relationships

Participation. At the age of 16–20 years, adolescents with CP were less focused on sexuality and had significantly less sexual experience compared with their age mates (Table IV). Significantly less adolescents with CP had sexual fantasies and only half of them had experience with masturbation. A sexual career typically develops from (French) kissing and caressing under clothes to intercourse. About 55% (boys) to 66% (girls)

of the adolescents with CP had experience of French kissing whereas only 20% (boys) to 24% (girls) had experience of intercourse. Adolescents with CP reported slightly less explicit heterosexual preference compared with age-mates (90% vs 97% in age mates) or did not yet know their sexual preference (4% vs 1% in age mates). Participation in intimate and sexual relationships of adolescents with CP was not related to background characteristics such as gross motor functioning (GMFCS), age, or level of education.

Perceived problems and experienced competence. Approximately 47% of the adolescents with CP reported that it is more difficult to find a sexual partner due to their disability (but 29% disagreed). Approximately 25% of the adolescents with CP had experience with a sexual relationship, of whom 24% reported problems in the performance of sexual activities. Additionally, 22 participants (26%) indicated they were not able to act sexually as they would like because of their physical limitations. Three persons in this group needed assistance in preparing for sex.

Nearly all respondents had received sex education about reproduction, birth control and sexual transmitted diseases. School (99%) and parents (63%) appeared to be important sources of information, whereas literature (42%), radio/television (40%) and peers (37%) also contributed to their knowledge. Sixty percent of the boys and 88% of the girls had received information about sexual harassment, but only 14% had received specific information on disability and sexuality. Overall, adolescents with CP judged their sex education as sufficient.

Adolescents with CP were positive about their sexual esteem; 82% of the participants reported that they did not feel sexually frustrated because of their physical disabilities, and only 7% reported that their sexual enjoyment was influenced by their physical disabilities. Dutch adolescents with CP had a significantly higher sexual self-esteem, body esteem and felt more attractive to others compared with persons with physical disabilities in Western societies (Table V).

DISCUSSION

The present study provided a comprehensive description of social, intimate and sexual relationships of adolescents and young adults with CP, addressing both actual participation and perceived problems and experienced competence in these domains. We compared the functioning of Dutch adolescents with CP in this respect with able-bodied age mates. The availability of reference data on sexual development and experience of Dutch adolescents from large-scale national studies might be considered one of the strong features of the present study, since this allowed us to make direct comparisons of Dutch adolescents with CP with their able-bodied age mates (24).

Some limitations of the study should be mentioned. First, it should be kept in mind that this study focused on adolescents with CP without severe cognitive disabilities who had the capacity to become independent participants in society. This criterion resulted in a relatively well-functioning cohort of

Table V. Experienced sexual competence: sexual and body esteem in boys and girls with cerebral palsy (CP) and people with various physical disabilities in Western society (Ref).

Dhysical Dischility	Boy	Boys				S	Comparison of hour		
Physical Disability Sexual and Body Esteem	CP		Ref $n = 356$		CP		Ref $n = 375$		Comparison of boys and girls with CP
(PDSBE)	n	Mean (SD)	Mean (SD)	<i>p</i> -value	n	Mean (SD)	Mean (SD)	<i>p</i> -value	<i>p</i> -value
Attractiveness to others	49	9.88 (2.67)	6.22 (3.09)	< 0.001†	30	11.17 (2.71)	7.23 (3.24)	< 0.001†	0.09‡
Sexual esteem	50	16.10 (3.34)	10.36 (4.49)	< 0.001†	30	16.60 (3.33)	11.72 (4.76)	< 0.001†	0.07‡
Body esteem	51	11.02 (2.27)	8.02 (3.46)	< 0.001†	32	11.09 (2.79)	8.20 (3.61)	< 0.001†	0.06‡

[†]Significant differences between CP group and reference group.

adolescents with CP, in which about 75% function on GM-FCS level I. Secondly, although the south-west part of the Netherlands is an urbanized multi-cultural society most of the participants were white adolescents. We found fewer than expected names of non-Dutch origin in the archives of the rehabilitation centres. Thus we cannot generalize the results to other cultural groups. Furthermore, in this study we used various instruments to assess participation and perceived competence of adolescents with CP in social, intimate and sexual relationships, and applied various sources of reference data. Therefore, a comparison between subnormal performances on various aspects should be interpreted with caution.

Regarding social relationships, this study showed that, although almost all adolescents with CP had friends and participated in various social activities, one-third functioned below their age level socially. They did not develop ageadequate activities with peers, such as going out with friends in the evening. Possible explanations might be that adolescents with CP were perhaps younger in emotional functioning and did not feel the need for these activities, or activities with friends did not take place after school time as found in the study of Stevens (28). In addition, external factors, such as overprotective parents, travel distance to friends, or problems in accessibility, might be possible barriers. On the other hand, we might have underestimated age-adequate functioning using the VABS, since some questions may not be applicable to the Dutch situation; e.g. there are only a few youth clubs in the Netherlands, and most adolescents often go out with a group of friends (including their boyfriend or girlfriend) rather than with one other person.

Contrary to what we expected, we found that adolescents with CP judged their physical appearance comparably to adolescents without CP. This was in agreement with a Dutch study on children with CP aged 9–13 years, reporting no difference in judgement of physical appearance between children with CP and their age mates (29). Although the majority of the participants walked without assistance (GMFCS level I), some did have a deviant walking pattern or other visible differences, which can have a negative influence on their physical appearance. It is possible that psychological defensive mechanisms play a role in adolescents with CP, leading to them overestimating their physical appearance.

Although adolescents with CP did not have problems in maintaining close friendships, maintaining courtship seems to

be a problem. It is likely that this early phase of pair bonding is the most problematic for adolescents with CP. Our results confirmed the perceived obstacles, as described in a qualitative study of Shuttleworth (7). The significant difference between boys and girls in having a steady girlfriend/boyfriend might be the result of a gender difference in defining courtship, implying that girls probably more often define an intimate relationship as courtship than boys.

Almost all adolescents with CP had received sex education. This is a positive result in the Netherlands compared with sex education for people with physical disabilities in other Western countries (3). It is noteworthy that adolescents with CP had less sexual experience (individual and with partner) compared with their age mates. As sexual fantasies and masturbation are independent of sexual relationships, it may be that adolescents with CP reach their psychosexual milestones later than their able-bodied age mates. This is in line with the assumption that they might be younger in emotional functioning.

Physical limitations were not mentioned as an obstacle in social relationships. For dating, however, adolescents with CP indicated physical disabilities, wheelchair-dependency and dependence on the help of others as obstacles. Of the 25% of adolescents with CP that had experience with a sexual relationship 24% had perceived problems. More insight is needed whether CP-specific factors, such as aggravation of spasticity, hamper sexuality.

Concerning psychological factors, it is encouraging that, for adolescents with CP, maintaining close friendship and appreciating their own physical appearance was comparable to Dutch age mates. This also applied to their global self-worth. It is noteworthy that some adolescents with CP did not function adequately for their age in coping. Many adolescents with CP used active dating skills, but 41% of the adolescents with CP indicated lack of self-confidence in dating activities. Murray et al. (30) found that in romantic relationships ablebodied people with low self-esteem reacted to self-doubt with heightened doubt about their partners' regard. So it seems that lack of self-confidence in developing intimate relationships is not specific to adolescents with CP. Girls with CP experienced less social acceptance from peers. In dating activities, 23% of the adolescents with CP experienced that they were treated differently and about half of them found it difficult to find a sexual partner. The above results suggest that attitudes of society might have a negative influence on the development of

[‡]No significant differences between boys and girls with CP.

SD: standard deviation.

intimate and sexual relationships of adolescents with CP, but also that personality aspects can be important. Future studies should focus on the associations of these factors with social, intimate and sexual relationships of young adults with CP.

ACNOWLEDGEMENTS

We thank all the participating young adults with CP. The following members of the Transition Research Group South West Netherlands contributed to this study: Department of Rehabilitation Medicine, Erasmus MC, University Medical Centre, Rotterdam, (J v Meteren MD PhD); Rijndam Rehabilitation Center, Rotterdam (MP Bergen MD PhD, D Spijkerman MD, E.Wijnmalen PT); Sophia Rehabilitation, The Hague (W Nieuwstraten MD)/ Delft (M Terburg MD, E Celen PT); Rijnlands Rehabilitation Center, Leiden (H vd Heijden-Maessen MD); Rehabilitation Center "de Waarden", Dordrecht (HJR Buijs MD); Foundation of Rehabilitation Medicine Zeeland, Goes (Th Voogt MSc); Department of Rehabilitation Medicine, Leiden University Medical Center (JH Arendzen MD PhD, MS van Wijlen-Hempel MD PhD). In addition the Rehabilitation Center De Hoogstraat, Utrecht (JW Gorter MD PhD) co-operated.

This research was performed as part of the PERRIN (Pediatric Rehabilitation Research in the Netherlands) research program. The authors thank the National Rehabilitation Fund (grant number 14350024), the Netherlands Organisation for Health Research and Development (grant number 1435.0011), and Children's Fund Adriaanstichting (KFA grant number 01.08.06) for their financial support.

REFERENCES

- Mutch L, Alberman E, Hagberg B, Kodama K, Perat MV. Cerebral palsy epidemiology: where are we now and where are we going? Dev Med Child Neurol 1992; 34: 547–551.
- Donkervoort M, Roebroeck M, Wiegerink D, Van der Heijden-Maessen H, Stam HJ. Determinants of functioning of adolescents and young adults with cerebral palsy. Disabil Rehabil 2007; 29: 453–463.
- Wiegerink DJHG, Roebroeck ME, Donkervoort M, Stam HJ, Cohen-Kettenis PT. Social and sexual relationships of adolescents and young adults with cerebral palsy: a review. Clin Rehabil 2006; 20: 1023–1031.
- Stevenson CJ, Pharoah PO, Stevenson R. Cerebral palsy the transition from youth to adulthood. Dev Med Child Neurol 1997; 39: 336–342.
- Wadsworth JS, Harper DC. The social needs of adolescents with cerebral palsy. Dev Med Child Neurol 1993; 35: 1019–1022.
- Neufeld J, Klingbeil F, Nelson Bryen D, Silverman B, Thomas A. Adolescent sexuality and disability. Phys Med Rehabil Clin N Am 2002; 13: 857–873.
- Shuttleworth RP. The search for sexual intimacy for men with cerebral palsy. Sex Disabil 2000; 18:263–282.
- Blum R, Resnick M, Nelson R, St Germaine A. Family and peer issues among adolescents with spina bifida and cerebral palsy. Pediatrics 1991; 88: 280–285.
- Kokkonen J, Saukkonen AL, Timonen E, Serlo W, Kinnunen P. Social outcome of handicapped children as adults. Dev Med Child Neurol 1991; 33: 1095–1100.
- Worley G, Houlihan CM, Herman-Giddens ME, O'Donnell ME, Conaway M, Stallings VA, et al. Secondary sexual characteristics in children with cerebral palsy and moderate to severe motor impairment: a cross-sectional survey. Pediatrics 2002; 110: 897–902.

- Cho SR, Park ES, Park IP, Na CI. Characteristics of psychosexual functioning in adults with cerebral palsy. Clin Rehabil 2004; 18: 423–429.
- Palisano R, Rausenbaum 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.
- Wood E, Rausenbaum P. The gross motor function classification system for cerebral palsy: a study of reliability and stability over time. Dev Med Child Neurol 2000; 42: 292–296.
- 14. Vanstiphout CHG, Donkervoort M, Pangalila R, Roebroeck ME, Stam HJ. Cognitive functioning and social participation in adolescents and young adults with cerebral palsy without severe learning disabilities. Dev Med Child Neurol 2005; 47 Suppl 103: 59.
- Fougeyrollas P, Noreau L, St-Michel G, editors. Life Habits measure-shortened version (LIFE-H 3.0). Lac St-Charles, Quebec, Canada: CQCIDIH; 2001.
- Noreau L, Desrosiers J, Robichaud L, Fougeyrollas P, Rochette A, Viscogliosi C. Measuring social participation: reliability of the LIFE-H in older adults with disabilities. Disabil Rehabil 2004; 26: 346–352.
- 17. Fougeyrollas P, Noreau L, Bergeron H, Cloutier R, Dion SA, St-Micgel G. Social consequences of long term impairments and disabilities: conceptual approach and assessment of handicap. Int J Rehabil Res 1998; 21: 127–141.
- Desrosiers J, Noreau L, Robichaud L, Fougeyrollas P, Rochette A, Viscogliosi C. Validity of the Assessment of Life Habilts in older adults. J Rehabil Med 2004; 36: 177–182.
- Sparrow SS, Balla DA, Cicchetti DV, editors. The Vineland Adaptive Behavior Scales. Circle Pines, MN: American Guidance Service Inc.; 1984.
- Berckelaer-Onnes IA van, Buysse WH, Dijkxshoorn YM, Gooyen JBM, Ploeg DA van der, editors. Dutch Translation of the Vineland Adaptive Behavior Scales. Leiden: University Leiden; 1997.
- Cicchetti DV, Sparrow SS. Developing criteria for establishing interrater reliability of specific items. Application to assessment of adaptive behavior. Am J Mental Deficiency 1981; 86: 341–350.
- 22. Treffers Ph DA, Goedhart AW, Veerman JW, Bergh van den BRH, Ackaert L, L Rd, editors. Competentiebelevingsschaal voor adolescenten [Dutch edition of the Self-Perception Profile for Adolescents]. Lisse: Harcourt Assessment BV; 2002 (in Dutch).
- Harter S, editor. Manual for the self-perception profile for adolescents. Denver: University of Denver; 1988.
- 24. Graaf de H, Meijer S, Poelman J, Vanwesenbeeck I, editors. Seks onder je 25e. Seksuele gezondheid van jongeren in Nederland anno 2005 [Sex under the age of 25. Sexual health of youth in the Netherlands in 2005]. Delft: Eburon; 2005 (in Dutch).
- 25. Brugman E, Goedhart H, Vogels T, Zessen van G, editors. Jeugd en seks 95: Resultaten van het nationale scholierenonderzoek [Youth and sex 95: results of the national research about pupils]. Utrecht: SWP; 1995 (in Dutch).
- 26. Verhoef M, Barf HA, Vroege JA, Post MW, Van Asbeck FW, Gooskens RH, et al. Sex education, relationships, and sexuality in young adults with spina bifida. Arch Phys Med Rehabil 2005; 86: 979–987.
- Taleporos G, McCabe MP. Development and validation of the physical disability sexual and body esteem scale. Sex Disabil 2002; 20: 159–176.
- Stevens SE. Adolescents with physical disabilities: some psychosocial aspects of health. J Adolesc Health 1996; 19: 157–164.
- Schuengel C, Voorman J, Stolk J, Dalmeyer A, Vermeer A, Becher J. Self-worth, perceived competence, and behaviour problems in children with cerebral palsy. Disabil Rehabil 2006; 28: 1251–1258.
- Murray SL, Holmes JG, MacDonald G. Through the looking glass darkly? When self-doubts turn into relationship insecurities. J Pers Soc Psy 1998; 75: 1459–1480.

APPENDIX 1. Instruments used and sources of reference data

	Reference data			
Instruments	Age, years	Group		
Baseline (age 16–20 years)				
Life Habits (17)		n.a.		
Vineland Adaptive Behaviour Scale (VABS) (19)	16-19	Standard scores of able-bodied American age group*		
Self Perception profile of Adolescents (Dutch version: CBSA) (22)	12-18	Dutch norm values		
Questionnaire "Sex under the age of 25" (24)	16-20	Able-bodied Dutch adolescents ($n = 2002$; 1010 boys, 992 girls)		
Questions of "Youth and sex 95" (25)		n.a.		
Questions of ASPINE study (26)		n.a.		
2-year follow-up (age 18–22 years)				
Physical Disability Sexual and Body Esteem Scale (PDSBE) (27)	18–69	Physically disabled persons in Western Societies ($n = 748$: 367 males, 381 females)		

^{*}Persons with CP aged 19 and 20 years were compared with standard scores of the maximum age (18 years and 11 months).

n.a: not applied; CBSA: Competentie Beleving Schaal Voor Adolescenten; ASPINE: adolescents with spina bifida in the Netherlands.