Romantic Relationships and Sexual Experiences of Adolescents and Young Adults with Cerebral Palsy

Diana Wiegerink

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This research has been performed as part of the PERRIN (Pediatric Rehabilitation Research in the Netherlands) research program.

With financial support from the Children's Fund Adriaanstichting (KFA grant number 01.08.06), the Netherlands Organisation for Health Research and Development and the National Rehabilitation Fund (ZonMw/NRF grant number 1435.0024), Johanna Children's Fund, Children's Fund Adriaanstichting, (JKF Number 07.02.28-2007/0042) and from the Fund for Scientific Research on Sexuality.

De omslag van dit proefschrift lijkt op een cover uit de Bouquet reeks. Die romantische verhalen hebben atltijd een 'happy end'. Dat wens ik ook alle jongeren met CP toe die aan dit onderzoek hebben deelgenomen.

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ISBN: 978-90-8559-129-0
Layout and printing: Optima grafische Communicatie, Rotterdam, The Netherlands

Romantic Relationships and Sexual Experiences of Adolescents and Young Adults with Cerebral Palsy

Verkering en seksuele ervaringen van jongeren en jongvolwassenen met cerebrale parese

Proefschrift

ter verkrijging van de graad van doctor aan de
Erasmus Universiteit Rotterdam
Op gezag van de rector magnificus

Prof.dr. H.G. Schmidt

en volgens besluit van het College van Promoties.

De openbare verdediging zal plaatsvinden op
woensdag 17 november 2010 om 11.30 uur

door

Dirkje Johanna Hendrika Gerco Wiegerink
geboren te Hengelo (O)

PROMOTIECOMMISSIE

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CONTENTS

CHAPTER 1

General introduction

CEREBRAL PALSY

Cerebral palsy (CP) encompasses a group of chronic disorders characterized by disturbances in posture and movement causing limitations in activities. Its etiology is attributed to non-progressive disturbances that occur in the developing brain of the foetus or infant. Posture and movement disorders in CP are often accompanied by disturbances in perception, cognition, communication and behaviour, as well as epilepsy.[1] CP is the most common cause of physical disability in childhood with a prevalence of 1.5-2.5 cases per 1,000 live births[2-5] and is one of the most frequently occurring medical conditions in childhood.[6, 7] Epidemiologic data suggest that the prevalence of CP in the Netherlands has not decreased over time.[8] Through improved medical care, many young people with a congenital disability now reach adulthood. If appropriate health care is available, affected children without significant co-morbidities have actuarial survival rates approaching that of the general population.[4, 9]

TRANSITION

The transition from childhood to adulthood is a critical period for reaching autonomous participation in adult life.[10] The transition from adolescence to adulthood is a normal developmental phase in which young people become independent in many areas of life. Key areas of change are the transition from school to work, dependent to independent living, development of personal financial responsibility, the formation of intimate relationships and sexuality, and the organization of independent transportation.[11] During transition, the focus of young people shifts away from family-centred activities toward an increase in attention and interest in their circle of friends. For young people with physical disabilities or chronic illness, the transition phase can be particularly difficult. Similar to others of their age, as people with disabilities grow into adulthood they have many new skills to learn. In addition to the usual new skills mentioned above, they need to learn how to cope with limitations in new social roles, at work and intimate relationships.[12] Most prior research and interventions have focused on healthcare issues or organization to care for young adults with physical disabilities.[13-17] However, young adults with CP also experience unmet needs regarding participation in society such as mobility, employment and social activities.[18, 19] Besides specific needs during the transition period, there is a global challenge to incorporate a lifespan perspective into the paediatric, transition phase, and adult health care services for persons with a childhood-onset disability.[10]

SEXUALITY

Sexual development is a multidimensional process, intimately linked to the basic human needs of being liked and accepted, displaying and receiving affection, feeling valued and attractive, and sharing thoughts and feelings. It not only involves anatomic and physiologic functioning, but it also relates to sexual knowledge, beliefs, attitudes, and values. Sexuality should be considered in a context that extends beyond genital sex to include gender-role socialization, physical maturation, body image, social relationships, and future social aspirations.[20]

Adolescence is a period of dynamic transition from childhood to adulthood marked by interrelated changes in the body, the mind, and social relationships. Functioning and behaviour become more complex. The body develops in size, reproductive capacity, and becomes more sexually defined. [21] Love, romance, and courtship are rites of passage for young people in Western society.[22]

The development of sexuality is also important for adolescents with chronic conditions or physical disabilities. [20 23] In his literature review of young people with physical disabilities, Lock [24] noted three developmental stages of adolescence; each of these phases can bring about specific problems for adolescents with physical disabilities related to relationships and sexuality. In the early phase (11-13 years), adolescents are concerned with physical (pubescent) development, such as secondary sex characteristics and changes in outward appearance, also related to the visibility of their disability. In the middle stage (14-16 years), contact with peers becomes central. Among peer groups, there is a lot to learn and share when it comes to dating and sexual experiences. For adolescents, however, social participation with peers can be difficult. In the final stage of adolescent development (17-19 years), building long-term intimate relationships becomes central and with that, questions about fertility and genetics, related to their physical disability, become prominent. Dependence on parents can make it difficult for some young people to develop adult roles that are important for building a relationship necessary for experiencing intimacy.

Prior studies have given insight into the sexual experience of young people with physical disabilities [25, 26], described specific aspects of secondary sexual characteristics in children with CP[27] and described the psychosexual functioning of adults with CP.[28] However, less is known about the romantic relationships, sexual development and experienced limitations of adolescents and young adults with CP.

INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH

The World Health Organization's International Classification of Functioning, Disability and Health (ICF)[29] is a useful tool in describing an individual's functioning in a unified language and in a structured framework. According to the ICF model, level of functioning is determined by body functions and structures, activities, and

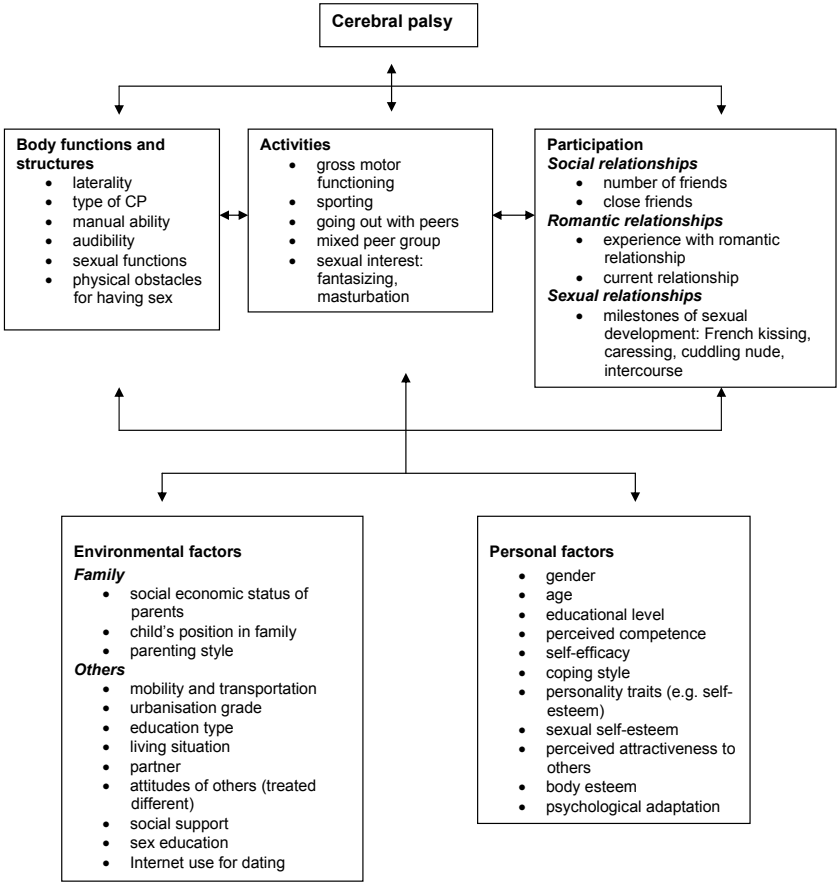

Figure 1. The ICF scheme including the parameters assessed in this thesis.

participation in interaction. These factors are placed within contextual variables such as environment and personal and psychological factors. Participation refers to the person-in-society and includes romantic relationships and sexual relationships. In line with the ICF model, factors of all domains can interact with each other and determine the outcome of romantic and sexual relationships. An overview of the ICF model including the parameters measured in the current study is presented in figure 1.

AIM OF THE PRESENT STUDY

The work presented in this thesis was carried out as part of the CP Transition Study of the Southwest Netherlands (http://www.erasmusmc.nl/revalidatie/research/transition/), which follows adolescents with CP as they transition into adulthood. At the start (T1) of the study, the participants were between 16 to 20 years old, and follow-up measurements were made after two (T2) and four years (T3). The CP Transition Study is part of the Paediatric Rehabilitation Research in the Netherlands (PERRIN) program (http://www.perrin.nl), within a Dutch research program in the field of paediatric rehabilitation. The purpose of PERRIN is to improve rehabilitation care for children, adolescents and young adults with CP.

The following research questions are addressed:

1. What is the participation level of adolescents and young adults with CP in the areas of social, romantic and sexual relationships?
2. What successes, concerns and problems do adolescents and young adults with CP experience regarding their social, romantic and sexual relationships and how do they cope?
3. How do adolescents and young adults with CP successfully develop from social relationships to dating, romantic and sexual relationships?
4. What is the development over time of social, romantic and sexual relationships of adolescents and young adults with CP?
5. What are psychological and environmental determinants of social, romantic and sexual relationships of adolescents and young adults with CP?
    a. What is the level of self-efficacy and sexual self-esteem of adolescents and young adults with CP and how do these factors contribute to forming romantic and sexual relationships?
    b. How do attitudes of parents and peers and other environmental factors, for instance the Internet, contribute to establishing romantic and sexual relationships of adolescents and young adults with CP?

OUTLINE OF THIS THESIS

In Chapter 2, we investigate the validity of the Rotterdam Transition Profile (RTP) in describing the transition process from childhood to adulthood in young adults with CP. Three developmental transition phases are distinguished. First the adolescent is dependent on adults; usually parents and teachers (phase 1). Next, the young adult orientates towards a more independent way of life (phase 2), and finally becomes (more-or-less) independent, managing his or her life autonomously (phase 3).

Chapter 3 reviews the literature focusing on one or more transition outcome parameters: i.e. social, romantic and sexual relationships or associated factors. We investigate possible barriers to successful social and sexual relationships in adolescents and young adults of normal intelligence with CP.

Chapter 4 focuses on the social, romantic and sexual relationship experiences of Dutch adolescents with CP compared with same aged, able-bodied peers. We describe perceived problems and experienced competency of adolescents with CP regarding the mentioned relationships.

In Chapter 5, we follow the development over time of romantic relationships and sexual activity of young adults with CP over a four year period with three biannual assessments. We investigate the possible link between the development over time of romantic relationships or sexual activity and demographic and physical characteristics. In addition, we compare the sexual activity of this group with a Dutch reference population of the same age.

Chapter 6 describes the beginning of romantic relationships and sexual activity from a broad perspective, addressing peer group activities, dating experience, experience with romantic relationships and sexual development. Participation in romantic relationships and sexual activities is generally preceded by developmental stages in which young people become engaged in peer group activities and dating. We investigate whether these preceding activities are associated with the development of romantic and sexual relationships among young adults with CP.

In Chapter 7, we investigate determinants of romantic relationships and sexual activity of young adults with CP, addressing psychological and environmental factors in addition to demographic and physical character-

istics. Psychological factors included self-efficacy, coping style, personality traits and sexual self-esteem. A broad range of environmental factors are described, including family factors, social support, type of education and physical environment.

In Chapter 8, we describe sexual experience and physical sexual functioning (sexual response cycle) physical and emotional problems regarding sexuality, and information needs of young adults with CP. By enhancing our understanding of the physical and emotional problems that may influence the formation of intimate and sexual relationships in young adults with CP we hope to contribute to improved multidisciplinary care for this group.

In Chapter 9, all findings are summarized and discussed along with the strengths and limitations of the study. Finally, we present clinical implications of our work and recommendations for future research.

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Developmental Medicine & Child Neurology 2008, 51:53-62

CHAPTER 2

Transition to adulthood: Validation of the Rotterdam Transition Profile for young adults with cerebral palsy and normal intelligence

ABSTRACT

Aim

The aim of this study was to investigate the validity of the Rotterdam Transition Profile (RTP) to describe the transition process from childhood to adulthood in young adults with cerebral palsy (CP).

Participants

Participants were recruited from rehabilitation centres and hospital departments of rehabilitation. In total, 81 young adults with CP (47 males, 34 females) and normal intelligence participated (mean age 20y5mo [SD1y-4mo] range age 18-22 years; 58% male, 95% spastic CP, 48% hemiplegia, 738% diplegia, 14% quadriplegia; 8% GMFCS level I, 83% MACS level I).

Measurements

The Rotterdam Transition Profile and the Assessment of LIFE-H questionnaire are used to measure transition and functioning in daily activities and participation.

Results

Almost all subjects were in the transition process or reached an independent adult lifestyle (ranging from 60-100%, housing 42%). Compared with able-bodied peers, young adults with CP lagged behind in their development in housing (25% versus 36%; $p<0.05$), employment (33% versus 49%; $p<0.05$) and intimate relationships (37% versus 76%; $p<0.01$). Associations were found between the phase of transition and age, parents' level of education, gross motor functioning, manual ability, level of education, and level of functioning in daily activities and participation.

Conclusion

The Rotterdam Transition Profile is a valid tool to gain more insight into the transition process, at the individual as well as at group level.

INTRODUCTION

Adolescence is a period of biological, social and emotional changes. In this period adolescents consolidate their identity, achieve independence from parents, establish adult relationships outside the family, and find a vocation.[1-6] For young people with disabilities the transition period is one of particular difficulty as they may be disadvantaged by their impairments, the extra health maintenance skills they need to acquire, lack of experience in activities and participation, social isolation or by other environmental, family and personal factors.[3; 6-12] Failure to make a successful transition to adulthood may result in unnecessary lifelong dependency, unemployment, less of achievement and poor quality of life.[4; 7; 10]

Transition to adulthood is a complex process which is extended over several years.[3] The process encompasses different developmental stages. At first the adolescent is dependent on adults, usually parents and teachers. Later, the young adult orientates towards a more independent way of life and finally becomes an independent autonomous adult who manages his or her own life. The transition process involves different domains of participation, e.g. employment, housing, leisure activities, financial situation, interpersonal relations and sexuality. The transition does not necessarily follow the same pace in each domain of participation. For example, young adults can be financially independent but still live with their parents. In the literature, information is lacking on which aspects of participation and in which phases of transition young persons with cerebral palsy (CP) are successful or may encounter difficulties.

During childhood, children with CP receive intensive and structured rehabilitation treatment and psychosocial support. However, after discharge from paediatric rehabilitation or leaving secondary school, the continuity of care is often disturbed. In general, during the transition process there is no structured rehabilitation treatment whereas, particularly during that period, major changes take place that may (temporarily) disrupt normal life and need both personal and environmental adjustments.

In the current paper we will describe the transition process in more detail by means of the Rotterdam Transition Profile (RTP), classifying a person's developmental stage for various domains of participation and health care. This study aimed to investigate the construct validity of the Rotterdam Transition Profile by comparing the transition of adolescents and young people with CP with able-bodied peers, assessing associations

of transition with participant characteristics and functioning in activities and participation and studying the transition over time.

METHOD

Development of the Rotterdam Transition Profile

We developed the Rotterdam Transition Profile as a tool to summarize the transition process of adolescents and young adults with CP. The profile may be used in research as well as in clinical practice to monitor adolescents and young adults during their transition to adulthood. According to theories of developmental psychology [13-15] and knowledge on transition to adulthood three developmental phases in transition are distinguished. First the adolescent is dependent on adults, usually parents and teachers (phase 1). Later, the young adult orientates towards a more independent way of life (phase 2) and finally becomes (more-or-less) independent, managing his or her life autonomously (phase 3).

Several major life events take place during the process of transition[4-6; 11; 16](i.e finishing school and starting a job, leaving home and living on your own). These events refer to domains of participation that are distinguished in the International Classification of Functioning, Disability and Health (ICF)[17] and in measuring instruments on participation and autonomy such as the Life Habits questionnaire (LIFE-H)[18]and the Impact on Participation and Autonomy questionnaire (IPA)[19]. The Rotterdam Transition Profile addresses six domains of participation, i.e. Finances, Education and employment, Housing, Intimate relationships, Transportation and Leisure activities and three healthcare domains: Rehabilitation services, Services & aids, Care demands (see Appendix 1). These domains were chosen following discussions with rehabilitation professionals in the Transition Research Group South West Netherlands.

Study design

This study is part of the Transition Research Group South West Netherlands study, a study into the course and determinants of functioning of adolescents and young adults with CP and normal intelligence.[20] Every two years, participants are invited for extensive assessments, including a functional evaluation and a semi-structured interview on activities, participation and transition issues. The results presented in this paper are mainly based on the 2-year follow-up assessments (T2).

Participants

Participants were recruited from eight participating rehabilitation centres and rehabilitation departments in the South West Netherlands. The inclusion criteria were: (1) diagnosis of CP and (2) born in the years 1982-1986 and (3) normal intelligence (roughly corresponding with an IQ above 70, excluding subjects who attended schools for those with learning disabilities). Cerebral palsy 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 fetal or infant brain.[21] Exclusion criteria were: (1) additional diagnosis with lasting effects on motor functioning, and (2) insufficient knowledge of the Dutch language.

Of a population of 437 adolescents and young adults with CP, 35% was excluded because of learning disabilities and 18% was lost due to incorrect addresses. An information letter about the study was send to 184 potential participants.

At baseline (T1) 103 adolescents and young adults participated, a response rate of 56%. No significant difference was found between responders and non-responders with respect to gender, age, type of CP, and CP limb distribution.[20] At 2-year follow-up (T2) participants were between 18 and 22 years old. There was a drop-out of 16% due to loss of interest (n=9), too busy (n=5) and moved to another country (n=2). The current paper presents results of all participants for whom data on transition are available at 2-year follow-up and at baseline (n=81). Compared with baseline characteristics of the study population, drop out was not selective regarding age, gender, gross motor function, limb distribution and educational level.

Participants gave verbal and written consent to participate. The Medical Ethics Committee of Erasmus MC University Medical Center Rotterdam approved the study.

Measurements

Demographic and clinical characteristics

The following characteristics were recorded: gender, age, type of CP, limb distribution of CP, gross motor functioning, manual ability, level of education and parents' level of education.

Gross motor functioning was classified with the Gross Motor Functioning Classification System (GMFCS).[22] The GMFCS is a 5-level classification system addressing severity of gross motor limitations.[22 ; 23] Manual ability was classified with the Manual Ability Classification System (MACS) a system to classify how children with CP use their hands when handling objects in daily activities, and is also valid in young adults with CP.[24; 25]

Three levels of education were distinguished; (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.

Participation and transition

Functioning in daily activities and participation was measured with the Life Habits questionnaire- shortened version (LIFE-H 3.0) addressing social participation of people with disabilities.[18] The LIFE-H was included in a large semi-structured interview. The short version, the LIFE-H 3.0 is composed of 69 life habits divided into 12 categories. These categories (number of items) are: nutrition (3), fitness (3), personal care (7), communication (7), housing (8), mobility (5), responsibilities (6), interpersonal relationships (7), community life (7), education (3), employment (7) and recreation (6). The first six categories refer to daily activities while the other six are associated with social roles.

The LIFE-H performance score is based on the level of difficulty and assistance required to carry out the activities or roles. The performance score ranges from 'not accomplished' (0) to 'accomplished without difficulty' (9). Mean scores were calculated for all categories, two subdomains and the LIFE-H total score. Mean scores below 8 indicate difficulty in performance. Good reliability was found for different groups of adult patients .[26; 27]

Transition to adulthood was scored using the Rotterdam Transition Profile which was filled out by the researcher in the last part of the interview. The participation domains "transportation" and "leisure activities" and the healthcare domains "services & aids" and "care demands" were assessed only at follow-up since at baseline these domains were not yet included in the transition profile.

Statistical analysis

Descriptive statistics were used to present subject characteristics of the study population, their level of functioning and the distribution on the Rotterdam Transition Profile. Because many participants did not need special health care services or special aids (n=34) this domain was excluded from further analyses.

In the absence of a criterion standard or other instruments to assess transition to adulthood, the construct validity of the Rotterdam Transition Profile was investigated. We focused on three aspects: comparison with able-bodied people of the same age, associations with subject characteristics and functioning in activities and participation, and change over time. We tested the expectations that: a) Young adults with CP will attain independence later in life than able-bodied people of the same age; b) the phase of transition is associated with age, and -to some extent- to gross motor functioning, manual ability, level of education and difficulties encountered in activities and participation and; c) in a period of two years young adults with CP will become more independent in the domains of the Transition Profile.
We compared participation of young adults with CP with age appropriate reference values of the Dutch population on work and education, housing (Statistics Netherlands) [28], and intimate relationships (Dutch expert centre on sexuality, Rutgers Nisso Group/SOAids)[29] by means of binomial tests.

The correlation between age and phase of transition was assessed with a Spearman's correlation coefficient. For other characteristics partial rank correlations were used correcting for age, since the developmental phases of the transition profile are partly age related. The bootstrap method is used to study the significance of the partial rank correlations.

To assess change over time at group level and individual level we compared results on the transition profile at follow-up (age 18-22 years) with baseline (age 16-20 years). At group level the increase or decrease of the percentage of persons in a specific phase and domain of transition was assessed by means of a marginal homogeneity test, which is an extension of the McNemar test. Regarding change in individual persons, the term "deterioration" indicates that at 2-year follow-up a person is in a lower phase of transition compared with baseline. We used the term deterioration because, in general, a typical development would follow the phases from 1 to 3.

Analyses were carried out using SPSS 12.0 for Windows and R 2.5.0.

RESULTS

Characteristics and functioning of the study population

Table I presents characteristics of the 81 participants. There were more male than female participants in the study, and there were relatively few persons in the youngest age group. The majority of the participants' parents had a medium or high level of education. More than 75% was classified at GMFCS level I and MACS level I. As a result of the inclusion criteria, none of the participants has a learning disability; 74% of them followed secondary general, upper vocational or higher education.

About 20% of the participants had difficulty in performance of daily activities and social participation (LIFE-H mean score <8). Most difficulties were encountered in mobility (31%), personal care (21%) and employment (28%).

Transition to adulthood

Table II presents the distributions on the transition profile at the age of 18-22 years (T2). Almost all the participants were in the transition process or had reached the independent adult phase on the participation domains, except for housing.

About 25% of the participants lived on their own, which is significantly less than Dutch able-bodied people of the same age (36%; $p<0.05$; reference age 18-22[28]). With respect to intimate relationships we see a comparable pattern. Less than 40% had an intimate relationship with intercourse (phase 3), a low percentage compared to Dutch able-bodied peers (76%; $p<0.01$; reference age 18-21[29]). Furthermore, the results show that 90% of the participants organised transportation independently (i.e. driving a car, calling a cab or using public transportation) and 80% went out in the evening to a party, a concert or the cinema. Regarding employment many participants were in transition, orientating on a job (58%) and 33% finished their training. In fact, 23% of the young adults with CP had a job, a low percentage compared with Dutch able-bodied peers (49%; $p<0.05$; reference age 18-24[28]). About 50% was independent regarding finances (i.e. disability benefits or paid job), the others were partially dependent on their parents.

Regarding transition in healthcare we found that about half of the total group did not visit a rehabilitation physician in the previous year and one third visited a rehabilitation physician in adult care. A comparable pattern

Table I: Characteristics of the study population at 2-year follow-up (n=81)

	n	%		n	%
Gender			**Type of CP**		
Male	47	58%	Spastic	77	95%
Female	34	42%	Ataxic	1	1%
			Dyskinetic	1	1%
Age (years)			Mixed	2	3%
18	5	6%			
19	22	27%	**CP limb distribution**		
20	12	15%	Hemiplegia	39	48%
21	23	28%	Diplegia	31	38%
22	19	24%	Quadriplegia	11	14%
mean (SD)	20.4	(1.3)			
Level of education			**Parents' level of education**[1]		
Low	21	26%	Low	10	12%
Medium	32	39%	Medium	36	44%
High	28	35%	High	29	36%
GMFCS			**MACS**[1]		
Level I	63	78%	Level I	65	83%
Level II	7	9%	Level II	7	9%
Level III	5	6%	Level III	4	5%
Level IV	5	6%	Level IV	1	1%
Level V	1	1%	Level V	1	1%
LIFE-H Daily activities		**Difficulty in performance**[2]	**LIFE-H Social Roles**		**Difficulty in performance**[2]
Communication	8	10%	Relationships[3]	7	9%
Mobility	25	31%	Education[3]	6	11%
Personal care	17	21%	Employment[3]	13	28%
Fitness[3]	7	11%	Responsibility	10	12%
Housing[3]	7	9%	Community	14	17%
Nutrition[3]	12	19%	Leisure[3]	14	18%
Daily activities	17	21%	**Social roles**	16	20%

[1] Missing data on parents' level of education (n=6) and MACS (n=3).

[2] Percentage of participants with difficulty in performance; LIFE-H mean score < 8.

[3] These domains (or more than 50% of the items within these domains) were not applicable for all participants, in these cases domain scores could not be calculated. Fitness (n=19), Housing (n=2), Nutrition (n=16), Relationships (n=4), Education (n=27), Employment (n=35), Leisure (n=4)

Table II: Distribution on the Transition Profile at 2-year follow-up

		2-year follow-up (age 18-22 years)		
Transition	N	Phase 1	Phase 2	Phase 3
Participation				
Finances	77	0%	52%	48%
Employment	81	9%	58%	33%
Housing	81	58%	17%	25%
Intimate relationship	81	40%	24%	37%
Transportation	81	6%	4%	90%
Leisure	78	9%	7%	80%
Healthcare				
Rehabilitation	81	14%	54%	32%
Services & aids	34	18%	50%	32%
Care demands	81	4%	32%	64%

was found for applying for services & aids, which was applicable for only 34 participants. The majority of the participants were able to formulate their care demands themselves (64%) or together with their parents (32%).

Associations

Association between transition and particiapnt characteristics

Except for gender, subject characteristics were related to the transition profile at the age of 18 to 22 years (T2), see Table III. All associations were corrected for age. The association between age and transition was expected from the developmental aspect of the transition profile. At baseline this association was even more obvious (r_s between 0.33 and 0.68).

Participants whose parents have a higher level of education were financially more dependent on their parents. A high level of motor functioning was related to financial dependence and to independence in transportation. In addition, participants with a high level of motor functioning were more often independent with respect to leisure activities (e.g. going out in the evenings to a party, concert or the cinema). A high level of manual ability was related to financial dependence and following general education (as opposed to having a job or following job education). It was also related to a more adult phase of intimate relationships and independence

Table III: Associations between subject characteristics and transition phases of the Rotterdam Transition Profile (n=81)

				Correlations corrected for age[2]			
Transition	**Age[1]**	**Gender**	**Parents' Education**	**GMFCS[3]**	**MACS[3]**	**Education**	**LIFE-H**
Participation							
Finances	0.05	0.05	-0.26*	-0.32**	-0.43**	-0.46**	-0.56**
Employment	0.34**	0.07	-0.18	0.01	-0.20*	-0.44**	-0.22
Housing	0.08	0.09	0.13	0.00	-0.09	0.07	0.01
Intimate relationship	0.37**	0.03	0.08	0.16	0.35**	0.05	0.27*
Transportation	0.35**	0.02	0.11	0.30*	0.39**	0.21	0.40**
Leisure	0.13	0.09	0.02	0.33**	0.40**	0.13	0.40**
Health care							
Rehabilitation	0.15	0.03	-0.05	0.03	-0.07	-0.21	-0.13
Care demands	0.05	0.06	0.17	0.24*	0.23*	0.25*	0.44**

* $p \leq 0.05$; ** $p \leq 0.01$

[1] Spearman correlations; [2] Partial rank correlations, correction for age; [3] GMFCS and MACS are recoded (higher score, better ability).

in transportation and leisure activities. Participants with a higher educational level were more dependent with respect to finances and a large part was still following education.

Regarding healthcare, participants with a higher level of motor functioning (gross motor and manual) and higher level of education were more likely to formulate their care demands independently. Whether participants consulted a paediatric or adult rehabilitation physician did not correlate to participant characteristics.

Association between transition and level of functioning in activities and participation

The last column of Table III presents data on the associations between transition and level of functioning in activities and participation (total LIFE-H score). Young adults who did not yet reach phase 3 in transportation, leisure activities and intimate relationships (n=13, n=8 and n=53, respectively), experienced more difficulties in activities and participation compared with young adults in phase 3. Also in the specific LIFE-H domains of transportation and leisure they encountered more difficulties (partial correlation between 0.28; $p<0.05$ and 0.40; $p< 0.01$; data not shown).

For transition in finances and housing participants who reached phase 3 experienced more difficulties in functioning, also in the specific LIFE-H domain of using money and managing their finances (partial correlation -0.37; p<0.01).

With respect to transition in healthcare participants with a higher level of functioning in activities and participation were more likely to formulate their care demands independently. For visiting a paediatric or adult rehabilitation department no association was found.

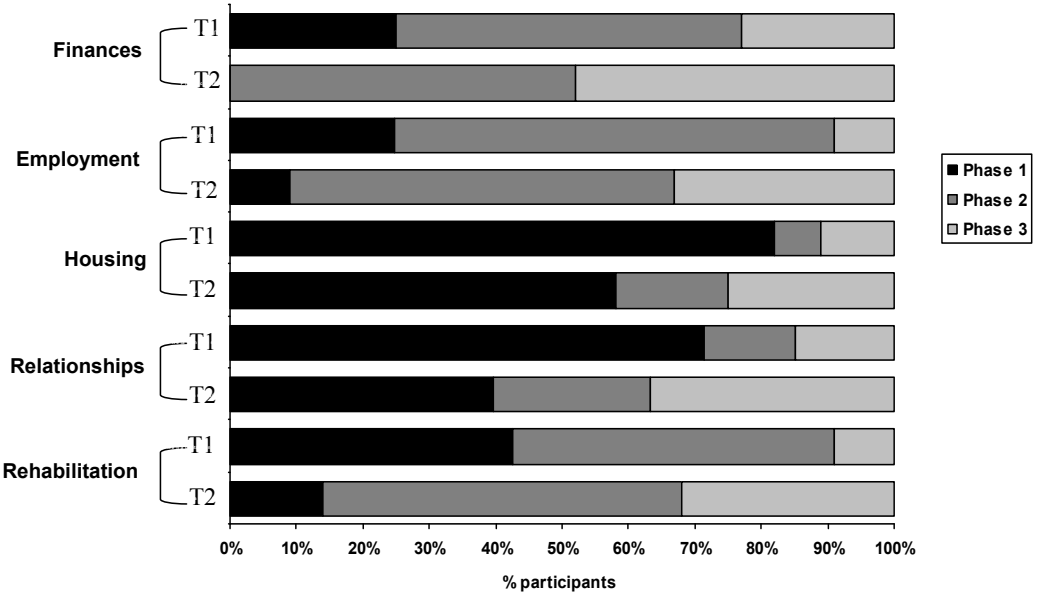

Figure I. Change on the transition profile over a 2-year period, for a cohort of young adults with CP and normal intelligence

Course of transition over time

During a period of two years participants became more independent on all domains of transition (marginal homogeneity test; p<0.01). Figure I presents the percentage of participants in each phase of transition at

baseline (T1) and at 2 years follow-up (T2). Over this period the percentage of participants in phase 1 diminished and in phase 3 increased substantially.

On an individual level about 32 to 40% of the participants improved over time on the domains of the transition profile, whereas about 56 to 64% did not. Seven participants deteriorated on one or two transition domains. Main reasons were changing from a vocational education to general education and moving back to the parental home.

DISCUSSION

The results of this study provided support for the construct validity of the Rotterdam Transition Profile to classify transition in young adults with CP, on both individual and group level. We compared transition of youth with CP to Dutch able-bodied people of the same age, related transition to participant characteristics and social participation (LIFE-H) and assessed change in transition over time. For these three aspects results were in accordance with the expectations tested.

First, the participants in this study were 18 to 22 years of age, and almost all were in the process of transition or had reached an independent adult lifestyle in several domains of participation. As expected, compared to Dutch able-bodied peers they lagged behind in their transition to adulthood. It should be noted that the Transition Profile is based on the Dutch situation and might be influenced, for example, by Dutch values on independent living, legislation regarding benefits and education or environmental factors such as good public transportation.

Secondly, the current study showed that the transition profile - addressing a developmental process - was correlated to age. In addition, the transition profile was correlated to motor functioning (GMFCS, MACS), level of education, and level of functioning in activities and participation. It should be noticed that the strength of these associations was only moderately or poor, which might be explained by the assumed influence of other factors on the transition process.

The negative associations found between level of education and the transition in finances and employment may be explained from the fact that a higher level of education takes additional years. Thus, people following higher education can be expected to reach independence in employment at a higher age and they might be financially dependent on their parents for a longer period. Besides the participant's level of education, transition in finances was also negatively related to the parents' level of education, motor functioning, and functioning in activities and participation. These results might be influenced by the Dutch system of additional benefits for (young) people with disabilities which makes them financially independent at the age of 18 years. Furthermore, participants who were functioning more independently (phase 3) with respect to leisure activities and transportation had a higher level of motor functioning and encountered less difficulties in activities and participation compared to persons in phase 1 or 2.

With respect to the transition in healthcare the majority of the participants formulated their care demands themselves and this was related to a high level of functioning. Half of the young adults with CP did not visit a rehabilitation physician in the previous year. Remarkably, the use of paediatric or adult rehabilitation services was not related to subject characteristics or difficulty in activities and participation.

Thirdly, addressing change over time, the results showed different mechanisms at work during the transition process. Regarding the process of ageing, as can be expected, a higher age coincided with a higher transition phase. Second, a low level of functioning was related to a slower transition or might lead to an unsuccessful transition. Evidence for the second mechanism were our finding that young adults with CP lagged behind their able-bodied peers, and that a high level of functioning was related to a more independent adult lifestyle in leisure activities and transportation. On the other hand, in a higher transition phase the expectations from the environment are also higher and therefore we assumed that young adults will encounter more difficulties in transition phase 3. This mechanism can be indicated as 'growing into a deficit'. An example of this third mechanism is that participants living on their own encountered more difficulties in housing activities. These results might imply that the Rotterdam Transition Profile can be used to formulate adequate treatment goals and to improve treatment of young adults with CP.

It should be emphasized that this study focused on young adults with CP without learning disabilities since we expect them to be capable of living an independent adult life. Therefore, the results of this study may only be generalized to the population of young adults with CP of normal intelligence. We performed some

additional checks whether the present cohort is truly representative for this group. First, in the Netherlands it is standard clinical practice to refer all children diagnosed with CP to paediatric rehabilitation care. Since we recruited subjects by means of the patients record systems of both paediatric and adult departments of rehabilitation centers and hospitals in the region, we had access to young adults with cerebral palsy who are still using health care as well as those who only visited the rehabilitation center or hospital in their childhood. Second, the distribution of GMFCS levels in our cohort was rather comparable to the normal intelligent subgroup of two Dutch population-based studies among young adults with CP[30] and school-aged children.[31] Respectively 86% and 73% of these study populations were classified in GMFCS level I and II [30,31]. On the other hand, it should be noted that the parents of the participants in this study were relatively highly educated compared to parents of children with CP in the European Study of Participation of Children with Cerebral Palsy Living in Europe (SPARCLE).[32] This might either be related to the exclusion of youth of subnormal intelligence or might reflect the possible mechanism that higher educated parents encouraged their child more strongly to participate in our study. Either way, in a previous publication we showed that the parents' level of education was not related to functioning in activities and participation of youth with CP.[20] These checks supported the generalizability of the results to the population of young adults with CP without learning disabilities.

CONCLUSION

The Rotterdam Transition Profile seems a valid tool to gain insight into the transition process, on both individual and group level. We found that young adults with CP of normal intelligence showed a delayed development in independent housing, intimate relationships and employment. The results indicated both facilitating and limiting factors at work to reach independent life. Overall, over a period of two years young adults with CP became more independent in all domains of participation.

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APPENDIX I:

Box I: Descriptions of the phases and domains of the Rotterdam Transition Profile

	Phase 1 (childhood)	**Phase 2** (transition)	**Phase 3** (adulthood)
PARTICIPATION			
Finances	Pocket money Clothing allowance	Job on the side Student grants	Benefits Job income
Education and Employment	General education	Vocational training	Paid job
Housing	Living with parents	Seeking housing Domestic training	Living independent
Intimate Relationships	No boy/girl friend No sexual activity	Dating, beginning of sexual activity	Sexual relationship with intercourse
Transportation	Parents or caretakers transport	Parents or caretakers arrange transportation	Young adult arranges transportation
Leisure (social activities)	Leisure activities at home	Leisure activities outside the home	Going out in the evening
HEALTH CARE			
Rehabilitation Services	Child rehabilitation	No rehab visits	Rehabilitation,
Services & Aids	Parents apply for services & aids	Young adult learns the procedures	Young adult applies for services & aids
Care demands	Parents formulate care demands	Parents & young adult formulate care demands together	Young adult formulates care demands

Box II:

Case Daniel

Daniel is a 21-year-old hemiplegic young adult, functioning on GMFCS level II and is ADL independent. He has a disability pension and is financially independent. He follows a job training, lives with his parents and is responsible for some housekeeping chores. Daniel has a girlfriend for several years and they have an adult intimate relationship with intercourse. With his girlfriend (and friends) he goes out during daytime as well as in the evenings. Two years ago, when he was 19 years old, he was not yet doing anything in the household and he was not yet going out in the evenings. Daniel did not visit a rehabilitation physician

Participation	**Transition phases**		
Domains	***Phase 1***	***Phase 2***	***Phase3***
Finances			**X**
Employment		**X**	
Housing	**T1** → **T2**		
Intimate relationships			**X**
Leisure activities		**T1** →	**T2**
Rehabilitation		**X**	

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Clinical Rehabilitation
2006;20:1023-1031

CHAPTER 3

Social and sexual relationships of adolescents and young adults with cerebral palsy: a review

ABSTRACT

Objective

To investigate possible barriers to successful social and sexual relation-ships in adolescents and young adults of normal intelligence with cerebral palsy (CP).

Design

A literature review based on a PubMed and PsycINFO search for the period 1990-2003. Included were studies focusing on one or more of the outcome parameters: i.e. social, intimate and sexual relationships or on associated factors, which described relationships with the outcome parameters.

Results

Fourteen papers were selected. Two studies investigated exclusively persons with CP whereas 12 concerned persons with a congenital disability and/or physical disabilities, including persons with CP. All studies addressed adolescents or adults of normal intelligence.

Social and sexual relationships. In social relationships adolescents and young adults with CP were less active compared with their age mates, and dating was often delayed and less frequent. Adolescents with congenital disabilities indicated that sexuality is an important aspect of their lives, but they experienced difficulties developing a sexual relationship.

Associated factors. Psychological maladjustment, insufficient self-efficacy, and low sexual self-esteem may impair the development of social and sexual relationships. Furthermore, an overprotective way of raising children with CP and the negative attitudes of other persons may have a negative influence on the self-efficacy of persons with CP.

Conclusion

The reviewed studies suggest many factors that may influence the development of social and sexual relationships in adolescents and young adults with CP. However, evidence was found only for the personal factors self-efficacy and sexual self-esteem and their interrelationships with the parents' way of raising their children and successful experiences in social situations.

INTRODUCTION

In adolescence, contacts with peers, social activities and developing intimate and sexual relationships are important aspects of the daily life and normal development of youngsters. Experiences with peers and dating enable adolescents to develop interaction skills and discover their wishes and desires regarding fulfilling relationships in the future.[1]
Cerebral palsy (CP) is defined as a persistent disorder of posture or movement, caused by a non-progressive pathological disorder of the developing brain, before the first birthday.[2]
Persons with CP may be hindered in the development of social, intimate and sexual relationships by several factors.[1, 3, 4] Although persons with CP may struggle with social and sexual barriers that are associated with having a physical impairment, the factors associated with developing and establishing social and sexual relationships have not been investigated extensively.

An important goal of rehabilitation for persons with CP is to improve their participation in society, in which social and sexual relationships play an important role. Insight into the factors associated with such relationships may enable more appropriate interventions at the right moment for these adolescents and young adults.

We reviewed the literature to explore possible factors for successful social and sexual relationships in adolescents and young adults of normal intelligence with CP.
The aim of this study was to provide a comprehensive review of the different aspects of social and sexual relationships, as described in the literature.

METHOD

We conducted a search in PubMed and PsycINFO for the period 1990 - 2003. Keywords were "adolescents with CP" and "young adults with CP". These two terms were combined with "social relations", "intimate relations" and "sexual relations" and with "personality", "self-concept", "self-esteem", "body image", "quality of life", "social life", "socialisation", "leisure activities", "dating", "peers", "family" and "parents". Because few papers were available on dating, intimate relations and sexual relations, an additional search was made using the terms "congenital disabilities" and "physical disabilities". Relevant references found in the papers were also included. A total of 76

papers were identified of which 43 contained general information not suitable for the subject of this review or describe measurements of one of our keywords. The remaining 33 papers were then judged on the following inclusion criteria: 1) the paper focused on a) one or more of the outcome parameters: i.e. social, intimate and sexual relationships, or b) associated factors, and also described relationships with the performance parameters; 2) the study population concerned either a) exclusively persons with CP, or b) persons with a congenital disease (including persons with CP), or c) persons with physical disabilities, including a described percentage of persons with CP; 3) the study population was of normal intelligence and thus able to participate independently in social, intimate and sexual relationships; 4) the study population concerned adolescents or adults; 5) the paper was an original report of a study and not a literature review. All criteria were applied independently by two authors (DJHG W, M D). In case of disagreement, consensus was reached by discussing the judgments with a third author (ME R). Subsequently, for each paper we noted the research method (quantitative or qualitative) and statistical analysis (descriptive statistics, assessing univariate or multivariate relationships) used and whether a comparison group was included.

RESULTS

Fourteen papers were considered suitable for the present review, including only two papers that exclusively addressed persons with CP. Table 1 presents an overview of the reviewed papers and the main characteristics of each study population; the papers are grouped according to the diagnosis (CP, congenital disabilities, physical disabilities including CP) and research method used (quantitative, qualitative), and then in alphabetical order of the first author's name.

For a comprehensive description of outcome and associated factors the International Classification of Functioning, Disability and Health (ICF) was used as a framework.[5] Outcome related to the participation dimension addressed three items: social relationships, intimate relationships and sexuality. We distinguished four groups of associated factors: personal factors, functional limitations, environmental factors and performing in social activities.

Table 1. The 14 papers included in this review.

Author	Country	Study population				Study design	
		Diagnosis	*Age (years)*	*IQ indication*	*N*	*Method (statistics)*	*Comparison group*
Stevenson et al.[7] 1997	UK	CP*	15-18 and 20-22	Normal	74	Quantitative descriptive	Healthy
Shuttleworth[13] 2000	USA	CP	18-51	Living independently	14 men and 17 relevant others	Qualitative	Healthy
Blum et al.[9] 1991	USA	CD*	12-22	Able to answer generic written questionnaire	162 (60 CP)	Quantitative descriptive	No
King et al.[17] 1993	Canada	CD	14-18	Normal	53 (27 CP)	Quantitative multivariate relationships	Norm values
Kokkonen et al.[10] 1991	Finland	CD	19-26	Below average and higher	52 (48 CP)	Quantitative descriptive	Healthy
McCabe et al.[12] 2000	Australia	CD	M=28,6 years	Normal	60	Quantitative, univariate relationships	Norm values
Specht et al.[21] 2002	Canada	CD	30-50	Normal	9 (5 CP)	Qualitative	No
Berman et al.[11] 1999	Canada	PD*	12-22	Normal	29 (12 CP)	Quantitative descriptive	No
Nosek et al.[15]** 2003	USA	PD	18-65	Normal	475	Quantitative multivariate relationships	Healthy
Nosek et al.[14]** 2001	USA	PD	18-65	Normal	504 women (10% CP)	Quantitative descriptive	Healthy
Nosek et al.[20]** 1996	USA	PD	18-65	Normal	475 women (11% CP)	Quantitative multivariate relationships	Healthy
Powers et al.[18] 1995	USA	PD	12-19	Normal	5 (4 CP) with treatment	Quantitative, multivariate relationships	5 (2 CP) without treatment
Rintala et al.[8]** 1997	USA	PD	18 +	Normal	250 women (12% CP)	Quantitative multivariate relationships	Healthy
Stevens et al.[6] 1996	Canada	PD	11-16	Able to answer generic written questionnaire	101 (48% CP)	Quantitative descriptive	Healthy

* CP = cerebral palsy CD = congenital disabilities PD = physical disabilities

**These 4 papers of Nosek et al. and Rintala et al. are based on the same study population

The results are divided into two sections. Section A addresses the outcome concerning social and sexual relationships and section B describes the associated factors. Each subsection concludes with a brief summary of the results found in the reviewed studies.

A. Social and sexual relationships

Social relationships

Although spontaneous social activity (such as visiting friends) is a central activity of able-bodied children and adolescents, adolescents with CP were less exposed to their peers' culture. Outside the school setting, adolescents with physical disabilities, including CP, less frequently than their age mates spent time with their friends both after school and in the evenings.[6] After leaving school young persons with CP tended to become less socially active and more isolated, whereas able-bodied young people became socially more active. Stevenson *et al*.[7] found a significant difference in the participation in social /leisure activities between adolescents with CP (15-22 years) and matched controls; also the older age group (20-22 years) was less socially active than the younger group (15-18 years).

Adolescents and young adults with CP were less active, especially in spontaneous social activity and leisure activities and spent less time with their friends. [6, 7]

Intimate relationships

Rintala *et al*.[8] studied 430 single women with physical disabilities and reported that the average age on the first date for women with physical disabilities (17.5 years) was approximately 15 months older than for women without disabilities. Only 29% of adolescents with physical disabilities had experience with dating.[6] In a study on adolescents with CP or spina bifida (SB) Blum *et al*.[9] found the same for the youth with CP, while they reported that 54% of their friends dated. Only 7% of the youth with CP had a steady boyfriend or girlfriend; of those who reported dating, the majority indicated that they had done so once a month or less. Kokkonen *et al*.[10] also reported that the social and sexual progress of their study group with CP was significantly delayed compared with age mates; dating started much later, about 50% had never dated, and 54% did not have any sexual experience (versus 11% and 15%, respectively, of the healthy subjects).

For adolescents with CP, dating is often delayed and the dating frequency is lower. [6, 8-10]

Sexuality

Persons with congenital physical disabilities have lower levels of sexual knowledge (43% accuracy on a questionnaire) and experience than their able-bodied age mates. The lowest scores were consistently seen in the participants with CP. Of the persons aged 16-18 years with physical disabilities in the study of Berman *et al.*[11], none had ever had a sexual relationship. In the study of McCabe *et al*.[12] although there were some negative feelings about sexuality, the young adults with physical disabilities indicated that sexuality was an important aspect of their lives and that they wanted to know more about sexuality. On the other hand, Shuttleworth[13] investigating 14 men with CP, showed that it was hard to develop a (romantic /sexual) relationship; and the same was reported for women with physical disabilities.[14] However, McCabe *et al*.[12] found that sexuality was hardly related to quality of life for people with congenital disabilities. On this topic, more specific information on adolescents and young adults with CP was lacking.

Although people with congenital disabilities showed lower levels of sexual knowledge they consider sexuality to be an important aspect of their lives. However, they experienced difficulties in developing a sexual relationship.[11-14]

B. Factors related to developing social and sexual relationships

Personal factors

General psychological characteristics

Women with physical disabilities perceived more personal barriers to dating and more constraints on attracting dating partners.[8] Detrimental self-cognitions led to lower intimate relationships for women with physical disabilities.[15]

Self-efficacy

Self-efficacy is the belief in one's capabilities to organize and execute the courses of action required to manage prospective situations.[16] Self-efficacy is thought to be an important component of social competence. Successful experiences in social situations, social modelling and persuasive forms of social influences are some of the factors developing one's sense of self-efficacy.[16, 17 18] Powers *et al*.[18] found that youth with physical disabilities showed significantly higher disability-related self-efficacy on community independence after mentoring them by comparable models.

In a study on 53 adolescents with different types of physical disabilities King *et al*.[17] demonstrated that self-efficacy was the only significant predictor of independence in interpersonal style; adolescents with CP had a less independent personal style, were less persistent and experienced lower self-efficacy compared to persons with other disabilities and compared to age mates.

Sexual self-esteem

A positive (sexual) self-esteem (feelings of self-acceptance and worthiness), was found to be an important determinant for dating. Nosek *et al*.[14] showed that women with disabilities who had a more positive sexual self-image and who perceived themselves to be approachable by potential romantic partners had higher levels of sexual activity. Disabled men with CP felt the dilemma of masculine ideals in relationships with those to whom they were sexually attracted; for these men the social comparison with able-bodied people hampered dating behaviour.[13] It is not known whether the same applies to adolescents and young adults with CP.
For persons with CP general psychological characteristics, low self-efficacy, and negative sexual self-esteem may impair an active, self-confident lifestyle and the development of social and sexual relationships. [13, 18, 19]

Functional limitations

Physical functioning

For persons with physical limitations, possibilities for ambulating were closely associated with accessibility of social activities.[8] Disabled persons (especially those with CP) perceived mobility and speech problems as personal barriers to dating. Shuttleworth[13] found that 5 of the 14 men with CP experienced bodily responses (e.g. the exacerbation of spasticity or dysarthric speech) to the gaze of the non-disabled other when negotiating sexual intimacy. In a national study (USA) Nosek *et al.*[14] found that women with physical disabilities reported problems with sexuality related to muscle weakness, vaginal dryness, lack of balance, hip or knee pain and spasticity of the legs. On the other hand, in women with physical disabilities no relation was present between the disability itself and the women's self-esteem, nor between the severity of disability and the level of sexual activity.[20] Also Kokkonen *et al.*[10] found that poor social progress was unrelated to severity of disability for youth with congenital disabilities.

Communication problems

For men with CP with speech impairments, the body was an important instrument to communicate non-verbally (eyes, feet). Participating in social activities, placing relationship advertisements in newspapers or on the Internet, flirting and humour were practical strategies which they employed to attain interpersonal contacts.[13] For persons with CP, functional limitations, bodily responses and speech impairments were perceived barriers to dating, but the severity of the disability appeared to be unrelated to social and sexual activity.[8, 13, 14, 20]

Environmental factors

Family

Of 60 interviewed adolescents with CP, 25% perceived their parents as overprotective and 33% of the respondents with CP said their parents infantilized them. [9] Compared to women without disabilities, women with physical disabilities experienced more overprotection during childhood.[15] Parents recommended to avoid activities and were inclined to give them less responsibility. This may have a negative effect on their self-esteem and social skills leading to a home-based lifestyle.[9, 10, 14, 15] Dependency on parents for personal care is another obstacle for women with physical disabilities to develop independent social lives.[14] According to Blum *et al*.[9] many adolescents with CP had a very close relationship with their parents; this made it difficult to make the natural shift away from parent-centred to peer-centred relationships. Moreover, only 50% of the parents in the study of Blum *et al*.[9] discussed pubertal maturation, sexuality and their possibility of a sexual life and marriage as adults with their child. Shuttleworth[13] found that parents almost uniformly sent negative messages to disabled children and adolescents with CP about their possibility of a sexual life and marriage as adults. In general, the denial of the expression of the sexuality of disabled adolescents was enhanced by parental doubts about sexual and reproductive capacities. Sexuality was therefore not integrated in their lives in a natural way.[9, 13]

Peers

Blum *et al*.[9] found that adolescents with CP considered friends to be very important; 82% of youth with CP had a best friend and of these best friends 36% was non-disabled.

Adolescents with CP had minimal opportunity to observe the social skills of their non-disabled peers, reducing their opportunity for modelling. In his study of 14 men with CP and 17 relevant others Shuttleworth[13] found that their ability to negotiate sexual intimacy as young adults was negatively affected if they were isolated from the peer culture where the learning of flirting etiquette takes place.

Attitudes of others and social support

The concern about being physically and sexually unattractive to others appeared to be influenced by negative feedback from the environment. Attitudes of society were one of the barriers in the limited opportunities for women with physical disabilities to establish romantic relationships.[14]

Accessibility and transportation

For older adolescents with CP Stevenson et al. found that accessibility to social leisure activities was a problem.[7] In the study of Specht *et al*.[21] persons with congenital disabilities experienced transportation problems as a barrier to leisure activities. Nosek *et al.*[14] found that for women with physical disabilities lack of transportation was an obstacle to social and recreational activities.

Parents of CP adolescents seem to be overprotective and are less inclined to discuss sexual matters than parents of non-disabled children. Adolescents with CP may experience accessibility and transportation obstacles to leisure activities. Poor peer contact might restrict the possibilities to develop sexual negotiation models. Negative attitudes of other people negatively affected the sexual self-esteem of persons with physical disabilities.[9, 13, 14]

Performing social activities

Socialisation occurs in the context of taking part in activities.

From the life stories of 9 people with CP or SB, Specht *et al*. [21] concluded that leisure activities were important for mental and physical health, enjoyment, self-esteem, friendship building and belonging; barriers to engage in leisure activities included transport problems and lack of support of significant others. Stevens[6] reported that adolescents with physical disabilities less frequently spent time with their friends after school and in the evenings outside the school setting. It is not known how adolescents and young adults with CP spend their time outside the school setting.

Young persons with CP and other physical disabilities were less socially active compared to non-disabled young persons.[6, 14, 21]

DISCUSSION

Limitations of the study

We limited our literature search to the period after 1990 because, over time, lifestyles have changed considerably and the earlier literature might be obsolete. Sexual attitudes have changed, computers and Internet have given new opportunities for social contacts, and styles of upbringing are probably different from 20 years ago. Another limitation of our review is that the results may not be applicable to other societies/cultures because the literature originated mainly from Canada, USA, Western Europe and Australia.

Only two of the 14 reviewed papers addressed social and sexual relationships in individuals with CP; in the remainder CP is one of the various diagnoses included in the studies.

Finally, for some of the factors associated with social and sexual relationships and for some relationships between the associated factors, the quality of the available studies was poor. Only descriptive statistics or qualitative methods were used, or the number of participants was small; this particularly applied to studies adressing environmental factors and performance in social activities. As a consequence, the evidence for these associated factors is inconclusive.

Overview of relationships

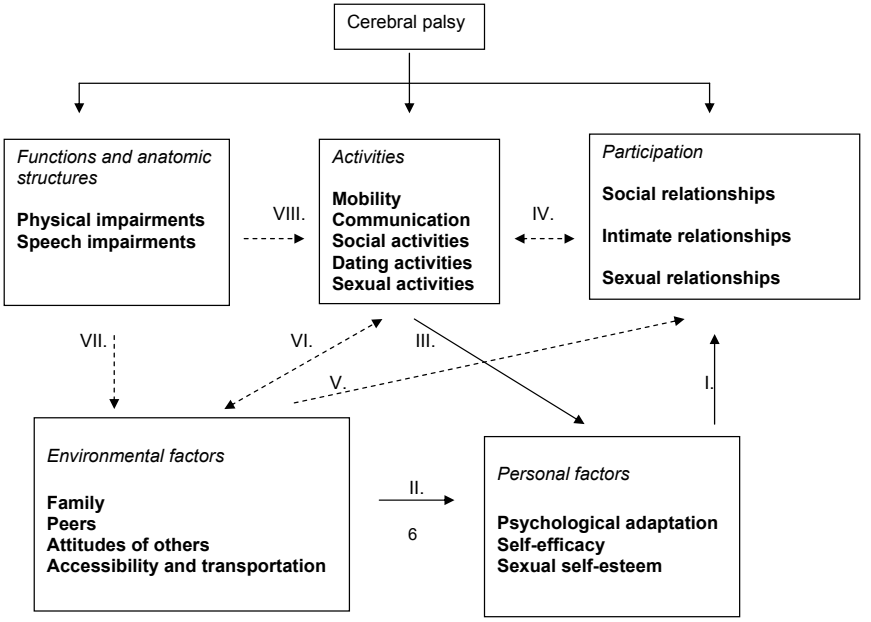
From the few available studies it emerges that in social relationships, adolescents and young adults with CP do not develop as well as their healthy peers. They are less active compared with their age mates, and dating is often delayed and less frequent. Although these adolescents show lower levels of sexual knowledge, they indicate that sexuality is an important aspect of their lives. In the literature many associated factors are mentioned which may influence the development of social and sexual relationships in adolescents and young adults with CP. These influences may work either directly or indirectly. Relationships may exist between outcome and associated factors, but also between the factors. The relations indicated between social, intimate and sexual relationships and these associated factors are presented in Figure 1 according to the ICF [5] and are summarized below.

Relationships between the associated factors and outcome

(the Roman numerals correspond with those in Figure 1):

I. An unfavourable psychological adjustment, self-efficacy and sexual self-esteem might impair the development of social and sexual relationships for people with CP.

Figure 1. The ICF scheme for potential associated factors and outcome on social, intimate and sexual relationships in adolescents and young adults with CP as found in literature.



The arrows with the dashed lines indicate suggested relationships that are suggested but lack evidence in the reviewed studies.

Interrelationships between associated factors:

II. Attitudes of parents (overprotecting or encouraging) may affect a sense of responsibility (negatively or positively).

III. Successful experiences in social situations and successful role models have a positive influence on one's sense of self-efficacy. On the other hand dating is important for maintaining positive (sexual) self-esteem.

Furthermore, the following relationships were indicated in the literature, but lack evidence; these suggested relationships are indicated with dashed arrows in Figure1.

Suggested relationships between associated factors and outcome:

IV. For adolescents with CP isolation from their peer culture will negatively affect their ability to learn flirting etiquette.
V. As a result of parental influence, youth with CP will have less contact with their peer culture and may not have integrated sexuality in their lives.

Suggested interrelationships between associated factors:

VI. Parents will recommend youth with CP to avoid activities. Because transport is a barrier to engage in leisure activities, adolescents with CP will be less exposed to their peer culture.
VII. Some adolescents with CP will perceive their parents to be overprotecting, because of their impairments.
VIII. Physical impairments, bodily responses and speech impairment will be perceived to have a negative influence on dating activities of young people with physical disabilities.

CONCLUSION

For relationships with others there is some evidence that the personal factors such as psychological adaptation, self-efficacy and sexual self-esteem are important for developing social and sexual relationships. But environmental factors such as family, peers, attitudes of others and transportation and social and dating activities influence the personal factors and in this way have an indirect influence on social and sexual relationships. More insight is needed into how these factors may affect interrelationships between various factors and their combined effect on the social and sexual relationships of adolescents and young adults with CP.

Clinical messages

- In social, intimate and sexual relationships young adults with CP develop at a slower pace than their healthy peers
- Self-efficacy and sexual self-esteem are important for successful dating activities and for developing social and sexual relationships

- Parents with an encouraging rather than an overprotective attitude may stimulate self-efficacy of adolescents with CP.

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Journal of Rehabilitation Medicine
2008;40:112-118

CHAPTER 4

Social, intimate and sexual relationships of adolescents and young adults with cerebral palsy compared with able-bodied age-mates

ABSTRACT

Objective
To describe the social, intimate and sexual relationships of Dutch adolescents with cerebral palsy (CP), compared with their able-bodied age--matched peers.

Design
Cross-sectional

Subjects
103 adolescents with CP 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 CP, 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 healthy 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 of healthy (Dutch) youth.

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

Conclusion
Although youth with CP 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.

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 youth with CP living into adulthood, problems associated with transition into adulthood are now more prominent.[2,3] For young people 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 in adolescence, only few studies have explored the social, intimate and sexual relationships of adolescents with CP. [4] The literature is fragmented and none of these studies cover the complete range of social and sexual topics. Addressing *social relationships*, Stevenson et al.[5] found that young persons with CP tended to become less socially active and more isolated after leaving school, whereas able-bodied young people became socially more 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 and feelings of belonging, making it more difficult to discover the flirting etiquette which is important when developing intimate and sexual relationships.[6,7]

Addressing *intimate and sexual relationships*, Shuttleworth[8] - investigating 14 men with CP - reported that it was difficult for them to develop an intimate romantic relationship. In a study on adolescents with CP or spina bifida Blum et al.[9] found the same for youth with CP; only 7% had a steady boyfriend or girlfriend, whereas 54% of their healthy friends dated. Kokkonen et al.[10] 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% did not have any sexual experience (versus 11% and 15%, respectively, of the healthy subjects). The delayed social sexual development seems contrary to the development of secondary sexual characteristics; Worley et al.[11] 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 for psychosexual dysfunction (e.g. lower sex-drive, higher level of psychological distress, more negative affect).[12]

To enhance our understanding of the needs of youth with CP we need a more comprehensive picture of the various aspects of their social and sexual functioning, with the aim to improve multidisciplinary care for this group. The first aim of the present study is 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 youth with CP in these domains with healthy Dutch age mates.

MATERIAL AND METHODS

Participants

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

Participants were recruited from eight rehabilitation centres and rehabilitation departments in the region. Inclusion criteria were: diagnosis of cerebral palsy (CP) and aged 16 to 20 years (years of birth 1982-1986). 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 who 103 participated (response rate 56%). At follow-up there was a drop-out of 16%, thus 87 participants of 18 to 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 healthy (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 Functioning Classification System (GMFCS) (13) which is a 5-level classification system by age-related severity of gross motor limitations.[13, 14] Level of education was used as an indicator of cognitive functioning.[15] We used three 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.[16] 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. Intra- and interrater reliability of the category Recreation was moderate and for Interpersonal Relationships it has not been described.[17-19]

The Vineland Adaptive Behaviour Scales-Survey Form (VABS) assesses adaptive behaviour in children aged 0 to 18 years.[20, 21] 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,

Table I. Characteristics of the study population (n=103)

		n	(%)
Gender			
	Male	62	(60%)
	Female	41	(40%)
Age, mean (SD) in years		17.9	(1.4)
GMFCS			
	I	78	(76%)
	II	7	(7%)
	III, IV,V (non-walkers)	18	(18%)
Type of CP[1]			
	Spastic	89	(86%)
CP limb distribution[1]			
	Hemiplegia	50	(49%)
	Diplegia	26	(25%)
	Quadriplegia	26	(25%)
Level of education[1]			
	Low	40	(39%)
	Medium	35	(34%)
	High	26	(25%)

[1] Missing data on: type of CP (n=2); CP limb distribution (n=1); level of education (n=2);

and moderate interrater reliability on the social domain.[20, 22] For comparison with our study group we used the norm values of the healthy American age group, because Dutch norm values are not available.

The Dutch version[23] of the Harter's Self Perception Profile of Adolescents[24], called Competentie Beleving Schaal voor Adolescenten (CBSA), has been developed for adolescents aged 12 to 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 two 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 scores are calculated for the domains. Higher scores correspond to a more positive perception of a competence. In-

ternal consistency of the subscales is acceptable to good with α between .66 (Scholastic Competence) and .88 (Athletic Competence).Test-retest reliability and validity seems to be good.[23] We used the Dutch norm values to compare with the youth with CP of 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 "[25] This study was performed in 2005 among Dutch youth aged 12 to 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".[26] Of the 2005 study a reference sample of healthy Dutch youth was available, consisting of 2002 persons aged 16 to 20 years.

From the interview of the Dutch ASPINE study (Adolescents with SPina bifida In the Netherlands) among Dutch adolescents with spina bifida[27] 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 disability28 This scale covers three dimensions, addressing attractiveness to others (three items), sexual esteem (three items) and body esteem (four 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 five-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 .74 - .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.[28]

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 below the standardized American age equivalent mean score[20]). 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 youth with CP with Dutch persons (CBSA) or adults with various physical disabilities in Western society (PDBSE).[23, 28] 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".[25] 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 sport matches was relatively low (48%). All participants had various social relationships, with parents, family, friends and acquaintances.[3]

Of the youth with CP 90% had three or more friends and 67% had three 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 to 28% was 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

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 & leisure time	37 (3.0)	20
Coping	34 (2.7)	28

or controlling anger. Level of education of youth 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 to 30% reported difficulties in the performance of such activities, e.g. in sporting (30%), creative activities (29%) and visiting sport matches (23%).

Youth with CP perceived themselves less competent in athletic competences and girls with CP perceived less social acceptance compared to 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 (see 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 (see 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 to 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 to 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.

Youth with CP used various dating skills in trying to get into contact with someone they like. About 76% tried to impress the other or used a friend to make contact, 63% just get 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. Notable, boys and girls with CP evaluated their physical appearance comparable to Dutch reference values (see Table III).

Table III. Perceived competence in social activities: Youth with CP compared to Dutch reference group

CBSA	Boys			Girls		
Domain	M_{CP}	M_{ref}	p	M_{CP}	M_{ref}	p
Scholastic competence	13.7	14.5	.04*	14.3	13.1	.01*
Social acceptance	14.8	15.3	.14	14.3	15.4	<.05*
Athletic competence	11.6	14.8	<.001*	9.7	12.4	<.001*
Physical appearance	14.4	14.7	.44	13.3	12.7	.33
Behavioural conduct	15.6	13.8	<.001*	16.7	14.8	<.001*
Close friendships	16.7	16.6	.74	17.6	17.7	.71
Global self-worth	16.0	16.0	.94	15.2	14.9	.58

* significant difference between youth with CP and Dutch reference group

Sexual development and relationships

Participation. At the age of 16 to 20 years, youth with CP were less focused on sexuality and had significantly less sexual experience compared with their age mates (see Table IV). Significantly less youth with CP had sexual fantasies and only half of them had experience with masturbation. A sexual carrier typically develops from (French) kissing and caressing under clothes to intercourse. About 55% (boys) to 66% (girls) of the adolescents with CP had experience with French kissing whereas only 20% (boys) to 24% (girls) had experience with intercourse. Youth with CP reported slightly less explicit heterosexual preference compared to age-mates (90% versus 97% in age mates) or did not know their sexual preference yet (4% versus 1% in age mates). Participation in intimate and sexual relationships of youth with CP was not related to background characteristics such as gross motor functioning (GMFCS), age, or level of education.

Perceived problems and experienced competence. About 47% of the youth with CP reported that it is more difficult to find a sexual partner due to their disability (but 29% disagree). About 25% of the youth with CP had experience with a sexual relation 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 of 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, youth with CP judged their sex education as sufficient.

Table IV. Participation in intimate and sexual relationships: Boys and girls with CP versus able-bodied Dutch age mates (Ref.)

	Boys (%)			Girls (%)		
	CP	Ref.	p- value	CP	Ref.	p-value
Falling in love and courtship						
Being in love once or more	92	95	.2	90	97	.02*
Experience with courtship	75	84	.09	71	85	.01*
Going steady at this moment	11	54	<.001*	32	38	.39
Sexual experience						
Masturbation	60	89	<.001	43	62	.014
French kissing	55	87	<.001	66	90	<.001
Feeling & Caressing	40	81	<.001	61	84	<.001
Making love nude	28	66	<.001	44	72	<.001
Intercourse	20	62	<.001	24	69	<.001

* *significant difference*

Youth 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 youth 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 (see Table V).

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).

Physical Disabilities Body and Sexual Esteem (PDBSE)	Boys				Girls				Comparison of boys and girls with CP
	CP		Ref[a] N=356		CP		Ref[a] N=375		
	N	Mean (SD)	Mean (SD)	p-value	N	Mean (SD)	Mean (SD)	p-value	p-value
Attractiveness to others	49	9.88 (2.67)	6.22 (3.09)	<.001[b]	30	11.17 (2.71)	7.23 (3.24)	<.001[b]	.09[c]
Sexual esteem	50	16.10 (3.34)	10.36 (4.49)	<.001[b]	30	16.60 (3.33)	11.72 (4.76)	<.001[b]	.07[c]
Body esteem	51	11.02 (2.27)	8.02 (3.46)	<.001[b]	32	11.09 (2.79)	8.20 (3.61)	<.001[b]	.06[c]

[a] References refer to people with various physical disabilities in Western society

[b] Significant differences between CP group and reference group

[c] No significant differences between males and females with CP

DISCUSSION

The present study provided a comprehensively 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 youth with CP in this respect with able-bodied age-mates. The availability of reference data on sexual development and experience of Dutch youth from large-scale national studies might be considered as one of the strong features of the present study, since this allowed us to make direct comparisons of Dutch youth with CP with their able-bodied age-mates.[25]

Some limitations of the study should be mentioned. First, it should be kept in mind that this study focused on youth with CP without severe cognitive disabilities who had the capacity to become independent participants of society. This criterion resulted in a relatively well-functioning cohort of youth with CP, in which about 75% functions on GMFCS level I. Secondly, although the Southwest part of the Netherlands is an urbanized multi-cultural society most of the participants were white adolescents. Even though we expected to find more names of non-Dutch origin in the archives of the rehabilitation centres we did not find them. So we cannot generalize the results to other cultural groups. Furthermore, in this study we used various instruments to assess participation and perceived competence of youth with CP in social, intimate and sexual relationships, and also 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 youth with CP had friends and participated in various social activities, one third socially functioned below their age level. They did not develop age adequate activities with peers such as going out with friends in the evenings. Possible explanations might be that youth 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.[29] Also 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 boy- or girlfriend) rather than with one other person.

Contrary to what we expected, we found that youth with CP judged their physical appearance comparable to youth 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.[30] 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. Possibly, psychological defensive mechanisms play a role in youth with CP in overestimating their physical appearance.

Although youth 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 youth with CP. Our results confirmed the perceived obstacles as described in a qualitative study of Shuttleworth.[8] 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 youth with CP had received sex education. This is a positive result in the Netherlands compared to sex education for people with physical disabilities in other Western countries.[4] It is remarkable that youth with CP had less sexual experience (individual and with partner) compared to their age mates. As sexual fantasies and masturbation are independent of sexual relationships, it may be that youth 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, youth with CP indicated physical disabilities, wheelchair-dependency and dependence on the help of others as obstacles. Of the 25% of youth with CP that had experience with a sexual relation 24% had perceived problems. More insight is needed whether CP specific factors such as aggravation of spasticity hampers sexuality.

Concerning psychological factors it is encouraging that for youth 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 youth with CP did not function adequately for their age on coping. Many adolescents with CP used active dating skills, but 41% of the youth with CP indicated lack of self-confidence for dating activities. Murray et al.[31] found that in romantic relationships healthy 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 for youth 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 suggest that attitudes of society might have a negative influence on the development of intimate and sexual relationships of youth with CP, but also 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.

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APPENDIX 1.

Instruments used and sources of reference data

Instruments	Reference data	
	Age	Group
Baseline (age 16-20 years)		
Life Habits (18)		n.a. [a]
Vineland Adaptive Behaviour Scale (VABS) (20)	16-19 years	Standard scores of healthy American age group[b]
Self Perception profile of Adolescents (Dutch version: CBSA) (23)	12-18 years	Dutch norm values
Questionnaire 'Sex under the age of 25' (25)	16-20 years	Healthy Dutch youth (N=2002; 1010 boys, 992 girls)
Questions of 'Youth and sex 95' (26)		n.a.
Questions of ASPINE study (27)		n.a.
2-year follow-up (age 18-22 years)		
Physical Disability Sexual and Body Esteem Scale (PDBSE) (28)	18-69 years	Physically disabled persons in Western Societies (N=748: 367 males, 381 females)

[a] n.a.= not applied

[b] Persons with CP aged 19 and 20 years were compared with standard scores of the maximum age (18 years and 11 months).

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Archives of Physical Medicine and Rehabilitation 2010;91(9):1423-1428

CHAPTER 5

Development of romantic relationships and sexual activity in young adults with cerebral palsy: a longitudinal study.

ABSTRACT

Objectives

To describe the development of romantic relationships and sexual activity of young adults with cerebral palsy (CP), to investigate whether this development is associated with demographic and physical characteristics, and to compare the sexual activity of this group with an age-appropriate Dutch reference population.

Design

Prospective longitudinal study with three biannual assessments.

Setting

Eight rehabilitation centers and departments in the southwestern regions of the Netherlands.

Participants

Young adults (N=103, 61 men, 42 women) with CP without cognitive disabilities, ranging from 16 to 20 years old at the first assessment, 82% Gross Motor Function Classification System level I-II.

Results

We observed a significant increase in dating in young adults with CP over the four-year period; however, the experience in romantic relationships did not largely increase over this period. Young adults with a lower education level began dating later then those with higher levels. Significantly more women were in current romantic relationships than men. During the four years, the sexual experience of the participants increased significantly for all the sexual milestones evaluated. The level of gross motor function was significantly associated with intercourse experience. Compared with an age-appropriate Dutch reference population, young adults with CP participated at a lower level in romantic relationships and sexual activities, but had an equal sexual interest at the final assessment.

Conclusions

Young ambulatory adults with CP had comparable sexual interests and they had increasing experiences with romantic relationships and sexual activities during the transition from late adolescence to young adulthood. However, the percentage of young adults with CP in current romantic relationship was low, especially for men.

INTRODUCTION

Cerebral palsy (CP) is the most common cause of physical disability in childhood with a prevalence of 1.5-2.5 per 1,000 live births.[1,2,3] If appropriate health care is available, affected children without significant co-morbidities have actuarial survival rates approaching that of the general population.[4,5] As increasing numbers of young people with CP are now living into adulthood, problems associated with the transition from childhood to adulthood are growing more prominent.[6,7]

Adolescence is a period of biological, social and emotional changes. One of the developmental stages during this period is establishing romantic relationships and develop sexual activities. From baseline measurements of our study of Dutch adolescents with CP (16 to 20 years), adolescents with CP reported less experience with romantic relationships (73%) than the reference population.[8] Additionally, fewer adolescents with CP reached sexual milestones (French kissing 59%, intercourse 22%) than the age-matched reference population.[8] These findings are in accordance with the literature on the social and sexual relationships of adolescents with CP in western countries.[9]

Previous studies have not examined the sexual development of young adults with CP throughout the transition to adulthood. Therefore, our first aim is to describe the development of sexual interest, romantic relationships and sexual activities in young adults with CP over a period of four years. Our second aim is to investigate whether the development of young adults with CP over this four-year period is associated with demographic and physical characteristics. Lastly, we compare the level of romantic and sexual functioning in young adults with CP between the ages of 20-24 years with an age-appropriate Dutch reference population.

METHODS

Participants

This prospective longitudinal study is part of the CP Transition Study of the Southwest Netherlands (http://www.erasmusmc.nl/revalidatie/research/transition/), which follows adolescents with CP as they transition to adulthood. At the start (T1) of the study, the participants were aged 16 to 20 years old, and follow-up measurements were made after two (T2) and four years (T3). The CP Transition Study is part of the Pediatric Rehabilita-

tion Research in the Netherlands (PERRIN) program (http://www.perrin.nl). The Medical Ethics Committee of Erasmus MC Rotterdam approved this study. All participants provided verbal and written informed consent to participate.

Participants were recruited from eight rehabilitation centers and departments in the Southwestern regions of the Netherlands. The inclusion criteria were a diagnosis of cerebral palsy (CP) and an age of 16 to 20 years at inclusion (birth year 1982-1986). The exclusion criteria were the existence of cognitive disabilities (IQ below 70), co-morbidity with persistent effect on motor functioning, and inadequate proficiency of the Dutch language. Of the 437 patients with CP who were initially recruited, 35% were ineligible because of cognitive disabilities (based on their medical charts), and 18% were ineligible due to incorrect addresses. An informational letter about the study was sent to 184 patients, and 103 chose to participate (response rate 56%). At T2, 16% of the 103 participants dropped out leaving 87 participants. At T3, 26% of the 103 initial T1 participants dropped out leaving 76 participants. The dropout at t3 occurred due to loss of interest (n = 13), competing time demands (n = 5), incorrect addresses (n = 5), reason unknown (n = 3) or relocation to another country (n = 1). No significant non-response or lost-to-follow-up biases were observed in terms of age, gender, gross motor functioning, and limb distribution of paresis. Compared to the T1 (39%) group, there were fewer participants with a low education level at T2 (33%, *P*=.03) and t3 (30%, *P*=.02).[10]

Measurements

Demographic data for gender, age and education level were collected (Table I).[6] We distinguished between two levels of education: 1) (low) pre-vocational, practical education or lower, and 2) (medium and high) ranging from pre-vocational theoretical education to post-secondary college and/or university. To assess the severity of gross motor limitations, trained physiotherapists used the Gross Motor Function Classification System (GMFCS), [11, 12] which has been validated for young adults with CP.[13, 14] Due to the small subgroups, the results of the GMFCS were dichotomized as levels I –II (walking without an aid) versus levels III-V (mobility with aid).

During each assessment, trained researchers administered a semi-structured face-to-face interview and self-report instruments. The questionnaire was a paper version of the Questionnaire of the Dutch National Study on Sexuality "Sex under the age of 25."[15] The questions we adopted addressed the following themes: sexual interest (sexual fantasy about boys and about girls asked to both sexes, and masturbating), experience with romantic relationships (a steady relationship based on emotional and physical attractiveness), current romantic

relationship, sexual activity and experience with forced sex. Sexual activity was examined in terms of four sexual milestones: French kissing, feeling and caressing under the clothes, cuddling nude (without intercourse),

Table 1: Demographic and physical characteristics at T1 (N=103)

Age Group (years)	N *(%)*	*Gender*	N *(%)*	*Educational level*	N *(%)*	*GMFCS**	N *(%)*
16	20 *(20)*	Men	61 *(59)*	Low	40 *(39)*	I-II	85 *(82)*
17	22 *(21)*	Women	42 *(41)*	Medium and High	63 *(61)*	III-V	18 *(18)*
18	23 (*22)*						
19	22 *(21)*						
20	16 *(16)*						

*GMFCS, Gross Motor Function Classification System

and intercourse (vaginal penetration). We added an additional question on dating (an amorous appointment) from the Vineland Adaptive Behavior Scales-Survey Form (VABS).[16, 17] The VABS assesses age-appropriate adaptive behavior in juveniles and is scored according to three multiple-choice responses: usually, sometimes or never.[17, 18] We verified that the participants could easily understand the questionnaires. The same interview and questionnaire was used for the baseline and follow-up measurements. The reliability of the follow-up answers was very high, and only one subject gave inconsistent answers.

We evaluated how sexual interest, romantic relationships and sexual activity developed over time. Three specific indicators, i.e. dating experience, current romantic relationship, and intercourse experience, were selected to investigate the associated factors in more detail. Dating experience can be a preceding stage in the development of a romantic relationship and/or sexual activity. A current romantic relationship represents the present situation, and intercourse is the last sexual milestone.

Statistical analysis

Descriptive statistics were performed using SPSS 16.0 for Windows, and longitudinal analyses were performed using SAS 9.1.3 (SAS Institute Inc., Cary, NC, USA). We performed repeated measures analyses using the PROC GENMOD procedure for generalized estimated equations (GEE), which considers the dependency of repeated measures within an individual. The working correlation is unstructured. Separate analyses were performed for dating experience, current romantic relationship, and intercourse experience, which served as the dependent variables. For each variable, several models were tested, which treated time as an independent factor along

with one additional factor (gender, educational level or GMFCS level at T1). First, we evaluated each factor's interaction effect with time. If no interaction effect was observed, the main effects of the factor and time were estimated. The level of significance for all analyses was .05.

To optimally use all of the available information from the three measurement times, we imputed missing values at T2 and T3, only if we had this information in a previous measurement. The number of imputed missing values varied from seven cases with experience with cuddling nude at T2 to 21 cases with experience French kissing at t3. For example if a participant has had a history of intercourse at T1 and this information was missing for T2 or T3, we imputed the score as 'yes.' On the other hand, if we only knew that a participant had experience with intercourse at t3, this item is unknown at T1 and T2 (missing values).

The outcomes at t3 were compared with those of an age-appropriate reference population of young people, who were surveyed in the Dutch National Study on Sexuality, which included 912 males and 901 females, aged 20 to 24 years in 2005.[15] Pearson's Chi-square tests (two-sided) were performed.

RESULTS

Development over time

The development of sexual interest, romantic relationships and sexual activity in young adults with CP over the four-year period is shown in Table 2. Sexual fantasizing was consistent over time, but masturbating significantly increased. More men than women had experience with sexual fantasizing and masturbating, but their development over time showed the same pattern. (see Table 2) The largest increase in dating activity was between T1 (52%) and T2 (74%), after which dating experience leveled off. Between T1 and T3, the experience with romantic relationships (73%, 79%, and 79%) and the percentage of young adults currently in a romantic relationship (19%, 23%, and 28%) did not significantly increase. For all other sexual milestones, the young adults with CP showed significant increases in sexual experience over the four-year period (Table 2).

Associations of demographic and physical characteristics

We found an interaction effect between education level and time (P=.02) in terms of dating experience. Young adults with lower education levels began dating later than those with higher education; however, from T2 on-

wards, there were no significant differences in dating experience between the two groups (Figure 1 and Table 3). No other significant interaction effects with time were identified (Table 3).

Table 2: Development over time of sexual interest, romantic relationships and sexual activity of young adults with CP, as compared to a Dutch reference group

	Frequencies			Sign differences		T3 compared to Dutch references	
	T1	T2	T3	ΔT3-T1	ΔT3-T2		
	N *(%)*	N *(%)*	N *(%)*	*P* IZI*	*P* IZI	N (%)	*P value*
Sexual interest							
Fantasizing about girls	48 *(48)*	52 *(57)*	53 *(66)*	.07	.57	981 *(54)*	.06
Fantasizing about boys	24 *(24)*	25 *(29)*	25 *(33)*	.46	.92	748 *(41)*	.1
Masturbating	52 *(53)*	62 *(70)*	68 *(80)*	**<.001**	**.04**	1476 *(85)*	.19
Romantic relationships							
Dating	53 *(52)*	70 *(74)*	73 *(76)*	**<.001**	.56	ND	ND
Experience with romantic relationships	74 *(73)*	77 *(79)*	77 *(79)*	.2	.98	1644 *(91)*	**<.001**
Current romantic relationship	20 *(19)*	20 *(23)*	21 *(28)*	.08	.16	1134 *(63)*	**<.001**
Sexual activity							
French kissing	60 *(59)*	71 *(74)*	77 *(83)*	**<.001**	**.009**	1657 *(91)*	**<.001**
Caressing	47 *(47)*	60 *(66)*	66 *(76)*	**<.001**	**.002**	1627 *(90)*	**<.001**
Cuddling nude	32 *(32)*	48 *(54)*	57 *(70)*	**<.001**	**<.001**	1503 *(83)*	**<.001**
Intercourse	20 *(20)*	36 *(40)*	47 *(60)*	**<.001**	**<.001**	1499 *(83)*	**<.001**

**P* IZI, *P* value of the absolute value of the Z-score

Significant differences in bold (*P*<.05)

For experience with romantic relationships, we did not observe an interaction effect with time or a main effect. None of the demographic or physical characteristics examined were associated with this aspect of development.

In terms of current romantic relationships, we observed a main effect of gender (*P*<.001). There were significantly more women in current relationships than men. After T2, the number of women in current relationships remained stable, but the number of men in current relationships increased (Figure 2 and Table 3). In spite of this increase, the difference between men and women remained significant at t3 (*P*=.04). We observed no associations between educational level or GMFCS level and current relationship status.

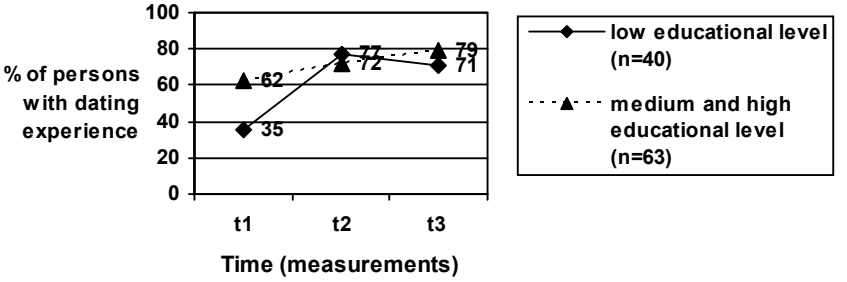

Figure 1: Interaction effect of educational level and time on experience with dating

The repeated measures models affirmed that experience with dating and intercourse increased over time. In addition, the level of gross motor functioning (GMFCSI-II versus III-V) was significantly associated with intercourse experience, but not with dating. Both GMFCS subgroups had increased intercourse experience over time, but ambulatory young adults (GMFCS I-II) had more experience at the baseline (T1) and showed a greater increase in intercourse experience over time than those who walked with limitations or used a wheelchair

Table 3: Associated factors for development over time for dating, current relationship and intercourse

	Dating		Current relationship		Intercourse	
Interaction effects	Chi square (df*)	*P value*	Chi square (df*)	*P value*	Chi square (df*)	*P value*
Gender * time	5.72 (2)	.06	1.56 (2)	.46	2.06 (2)	.36
Educational level * time	8.03 (2)	**.02**	2.17 (2)	.34	1.14 (2)	.56
GMFCS† * time	3.20 (2)	.20	2.17 (2)	.34	0.50 (2)	.78
Main effects						
Gender	.50 (1)	.48	12.89 (1)	**<.001**	0.59 (1)	.44
Time	16.37 (2)	**<.001**	3.31 (2)	.19	32.67 (2)	**<.001**
Educational level	NA	NA	1.80 (1)	.18	3.25 (1)	.07
Time	NA	NA	3.51 (2)	.17	20.15 (2)	**<.001**
GMFCS	2.35 (1)	.13	0.02 (1)	.90	5.16 (1)	**.02**
Time	16.03 (2)	**<.001**	3.15 (2)	.21	31.83 (2)	**<.001**

*df degrees of freedom, †GMFCS Gross Motor Function Classification System

Significant differences in bold ($P<.05$)

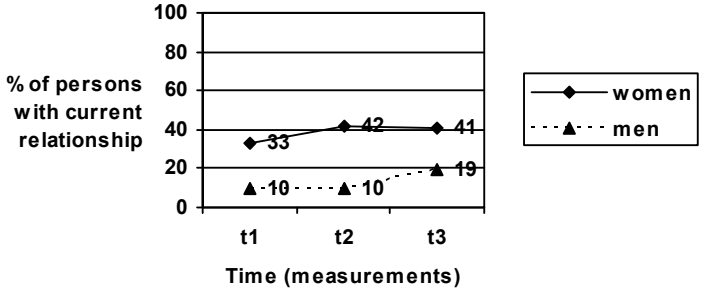

Figure 2: Main effect of gender on having a current romantic relationship

(Figure 3 and Table 3). We observed no associations of gender with dating and intercourse, and there were no associations between the level of education and intercourse experience.

Comparison with an age-appropriate Dutch reference population

In comparison to the references, the young adults with CP displayed a significantly delayed development for all relational aspects (Table 2). Many young people with CP reached sexual milestones significantly later than the Dutch reference group (Table 4). There were fewer men and fewer women with CP in current relationships

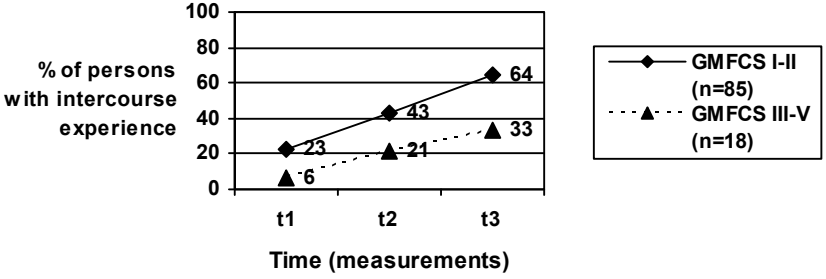

Figure 3: Main effects of level of gross motor functioning and time on experience with intercourse

in comparison to the gender-specific reference groups (56% and 69%, respectively, *P*<.001). Young adults with CP displayed similar levels of sexual activities without a partner (fantasizing and masturbation) at T3 when compared to the reference population.

DISCUSSION

This is the first study describing the development of sexual interest, romantic relationships and sexual activity in young adults with CP over time. Our results demonstrate that young adults with CP who had a lower educational level began dating later than those with higher educational levels. Significantly more women than men with CP were involved in steady romantic relationships. Additionally, non-ambulatory young adults had less experience with intercourse than ambulatory young adults did. Despite their increasing experience over the four-year period studied, young adults with CP participated at a lower level in terms of their romantic relationships and sexual activities when compared with an age-appropriate Dutch reference population.

Table 4: Age at first time of experience with sexual milestones

	CP year, month (SD*)	Dutch References year, month	Significant differences *P* value
French kissing	16.3 (2.4)	14.0	**<.001**
Caressing	16.5 (2.2)	15.4	**.001**
Cuddling nude	17.5 (2.2)	16.3	**.001**
Intercourse	18.4 (2.3)	16.7	**<.001**

*SD standard deviation

Significant differences in bold ($P<.05$)

Development over time

The present study showed an increase over time in the dating and sexual experience of young adults with CP. Our results are not surprising because these changes are expected between the ages of 16 to 24.

The number of individuals in current romantic relationships did not largely increase over time. The majority of the young adults with CP, especially men, had difficulties becoming involved in steady romantic relationships. These difficulties were not related to educational level or physical characteristics, so other factors, such as psychological (e.g. feelings of inferiority) or environmental factors (e.g. upbringing, attitudes of others, opportunity or living circumstances), may hinder the establishment of long-lasting relationships. This is an important topic for future research.

Associated factors

The Dutch study "Sex under the age of 25," demonstrated that young people with pre-vocational, practical education begin with sexual activities (including intercourse) earlier than their more highly educated age-mates.[15] These results were in contrast with the results of our study in which we observed no difference in intercourse experience between the two subgroups divided by education level. We observed that young people with a lower educational level began dating later than more highly educated young adults did. This difference might have been due to the inclusion of participants with IQs of 70-85 in this study, since this subgroup did not participate in the Dutch study because they did not attend regular schools. Post-hoc analysis confirmed that the subgroup of young people with an educational level roughly corresponding to an IQ of 70-85 had less dating experience. We speculate that these young adults are less enterprising regarding dating behavior or that overprotective parents may play a role in the limited dating activities of young adults with low educational levels.

Physical disabilities were associated with intercourse, but not with dating and romantic relationships. This is in agreement with the results of our cross-sectional study where we observed no associations between dating, overall sexual activities and the GMFCS level.[16] It is likely that physical restrictions hamper earlier sexual milestones to a lesser extent and may have a more prominent role in lowering intercourse activities. Although young adults with CP who had more physical restrictions (GMFCS III-V) showed increased intercourse experience from T1 to T3, they had less experience than ambulatory young adults with CP. These results agree with those of a previous study by Cho[19] At present, it is not clear in how physical restrictions hamper these individuals from experiencing sexual activities.

Comparison with reference population

By the age of 20 to 24, the sexual interest of young people with CP was comparable to that of the reference population. It is important for parents and professionals to recognize this normal psychosexual development. Despite their normal interest, young people with CP had fewer sexual experiences than the reference population. The delayed intercourse experience observed in this study differs from the results of a study by Cheng and Udry[20] of approximately 18,000 adolescents in U.S. schools from 1994-1995. They concluded that students with disabilities were as sexually experienced (coital sex) as their non-disabled counterparts.[20] Dutch young adults with CP reported less intercourse experience than the disabled American youth, but the intercourse experience of the American and Dutch reference populations were comparable. In contrast with our study, the

American report evaluated students with different disabilities in a regular education setting. Therefore, these differences may be due to differences in educational level, the types of disabilities evaluated, or other factors. Thus, it is important to study psychological and environmental determinants of sexual activity in young adults with CP in the Netherlands.

We cannot conclude that our results indicate that young adults with CP are 'slow starters,' because their delayed development did not catch up during the four-year period evaluated. A longer follow-up period will be necessarily to see whether their sexual experiences eventually become comparable to the Dutch reference population.

Limitations of the study

Most of the participants in this study were white, although the recruitment area is an urbanized multicultural area. Young adults with CP of non-Dutch origin were underrepresented in the rehabilitation centers. Therefore, these results cannot be generalized to groups of young adults with CP who are of non-Dutch origin.

At first measurement 3% (men) to 5% (women) of the participants was explicit homosexual.[8] This percentage is too small to analyze homosexuality as a separate subgroup.

Most of the sexual experiences reported were consensual; however, 6% of the participants had experienced forced sex. We did not include a differentiation for forced sex, although this type of sexual experience is not an aspect of normal sexual development and is an undesirable experience.

For our analyses, we considered intercourse as the final milestone of a sexual course. However, a recent Dutch study about sexual trajectories[21] showed that approximately one quarter of the participants followed a trajectory of having more sexually intimate behavior before their less sexually intimate experiences. This means that intercourse is not always the last milestone. We do not have this type of insight for the sexual trajectories of young adults with CP.

Implications

Compared to the reference group, young adults with CP of 20 to 24 years had a similar sexual interest, but had less experience establishing romantic relationships and with sexual activities. Therefore, health care profes-

sionals must include discussions of sexuality with young adults with CP, as for any other adolescent/young adult. To talk about these developmental aspects with young adults, the Rotterdam Transition Profile can be used,[7] and the easily remembered abbreviation HEADSS can be used to ask a sequence of questions about home, education, activities, drugs, sex, and suicide.[22-24] Professionals can also discuss the challenges of romantic relationships and sexual activity in young adults with CP. In non-ambulatory young adults with CP, physical restrictions can hamper their intercourse experiences. These specific problems require specialist treatment and an individual approach.

It is notable that only a few young adults were in steady romantic relationships, although most young adults at this age have the desire and the ability to be emotionally and sexually intimate. Previous research indicated that restricted participation in peer group activities and dating might be a barrier for young adults with CP.[16] However, it is unknown whether additional factors may impede the development of romantic relationships and sexual activity. Lock[25] postulated that incompletely resolved issues from earlier phases of sexual development may be present during later phases, including emotional and physical dependence on parents, anxiety about sexual abilities or body image or continued social withdrawal. Identifying the conditions necessary to develop romantic relationships should be a central point for further research by professionals in pediatric rehabilitation care.

CONCLUSIONS

Most young adults with CP had increasing experiences with romantic relationships and sexual activities during the transition to adulthood. However, compared to the reference population, young adults with CP participated at a lower level for all relational aspects. It appeared difficult for young adults with CP to establish steady relationships, even if they have had prior romantic relationships.

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accepted for publication in Sexuality and Disability, 2011

CHAPTER 6

Sexuality of young adults with cerebral palsy: experienced limitations and needs

ABSTRACT

Objective

To describe the problems young adults with Cerebral Palsy (CP) experience in the various stages of the sexual response cycle, and the physical and emotional obstacles they experience with sexuality.

Design

Prospective cohort study

Subjects

74 young adults (46 men; 28 women) with CP and normal intelligence, aged 20-24 years.

Results

20% of these young adults with CP experienced anorgasmia, 80% reported physical problems with sex related to CP and 45% emotional inhibition to initiate sexual contact. In 90% of the participants sexuality had not been discussed during the rehabilitation treatment.

Many adolescents reported wanting information about the impact of CP on sexuality and reproduction (35%), about interventions (26%), tools and medicines (16%) and about problems with their partner (14%).

Conclusion

Young adults with CP can experience various problems/challenges with sexuality. For preventing sexual difficulties and treating sexual problems, health care professionals need to proactively take the initiative to inform young people with CP about sexuality.

INTRODUCTION

Cerebral palsy (CP) is defined as a group of permanent disorders in the development of posture and movement which cause limitations in activities, and is attributed to non-progressive disturbances that occur in the developing brains of a fetus or baby.[1] Posture and movement disorders in CP are often accompanied by disturbances in perception, cognition, communication and behaviour, as well as by epilepsy.[1] Cerebral Palsy (CP) is the most common cause of physical disability in childhood with a prevalence of 1.5-2.5 per 1000 live births. [2, 3]

Through improved medical care, many young people with a congenital disability now reach adulthood. Even after the transition to adulthood this group still requires care. The importance of "life-span care" is receiving increasing attention. [4, 5]

The transition from adolescence to adulthood is a normal developmental phase in which young people become independent in many areas of life. Key areas are: the transition from school to work, independent living, development of personal financial responsibility, forming intimate relationships and developing sexual identity, and organizing independent transportation.[6] During this period, the focus of young people shifts away from family-centred activities giving more attention and interest to their circle of friends. For young people with physical disabilities or chronic illness, this phase can be extra difficult. Like others of their age, they have many new skills to learn. In addition they need to learn how to cope with their limitations in new social situations, such as at work and in intimate relationships.[7]

The period between 12 and 25 years of age is essential for human sexual development: physical changes, masturbation, dating, beginning intimate relationships and sexual experiences. This applies to people with and without physical disabilities or chronic illnesses.

Lock[8] in his literature review of young people with physical disabilities notes three developmental stages of adolescence; each of these phases can bring about specific problems related to relationships and sexuality. In the early phase (11-13 years), adolescents are concerned about physical (pubescent) development, such as secondary sex characteristics development and a different outward appearance In the middle stage (14-16 years), the contacts with peers become central. Especially in peer groups, there is a lot to learn and share when it comes to dating and sexual experiences. Research focusing on young adults with CP shows that a peer group

is conducive to going out together and engaging in dating activities.[9] In the final stage (17-19 years), developing long-term intimate relationships becomes central and with that, questions about fertility and genetics become more prominent. Dependence on parents can make it difficult for some young people to develop the adult roles that are important for building a relationship necessary for experiencing intimacy. Also, the undesirability that they will be dependent on a potential partner for their personal care worries young adults with physical disabilities. Investigations into the sexual experience of young people with physical limitations show very divergent results. Some American and Spanish studies[10-12] indicated that these young people had as much experience with sexual contact and sexual intercourse as their peers without disabilities. A recent Swedish study[13] indicated that young people with physical disabilities had, relatively speaking, much experience with intercourse. The young people in this study, however, were very diverse in the kinds of disabilities,. Dutch studies in adolescents and young adults with spina bifida[14] and CP[15] have shown a different picture: they have less experience with all the steps of sexual development when compared to age appropriate references. From a previous study we know that young adults with CP (18-22 years) were significantly less experienced with dating (77%) than their non-disabled peers (89%). At the time of this survey among young people with CP, only a few of them had a current romantic relationship (23% versus 61% of Dutch peers.[9]) Many young people with CP start later than other Dutch young people with their first kiss and sexual debut (intercourse): on average, 16.3 versus 14 years of age and 18.4 versus 16.7 years of age.[16, 17]

In their development of intimate relationships and sexuality young people with CP are confronted with physical limitations. Pubescent physical development in children with CP is known to start earlier and end later than children without CP.[18] Yet, little is known about the sexual functions and the physical problems these young adults can experience with sex.

The aim of the present study was to describe sexual experience and sexual response cycle functioning, physical and emotional problems regarding sexuality, and information needs of young adults with CP. By enhancing our understanding of the physical and emotional problems that may influence the formation of intimate and sexual relationships in young adults with CP we hope to contribute to improved multidisciplinary care for this group.

METHOD

Participants

In the CP Transition study, we followed 103 young people (62 men, 41 women) within the average range for intellectual functioning and aged 16-20 for four years, focusing on various aspects of social participation, including the development of intimate and sexual relationships.[6, 15, 19]The CP Transition Study is part of the Pediatric Rehabilitation Research in the Netherlands (PERRIN) program (http://www.perrin.nl). The Medical Ethics Committee of Erasmus MC Rotterdam approved this study. All participants provided verbal and written informed consent to participate. Participants were recruited from eight rehabilitation centers and departments in the Southwestern regions of the Netherlands. Inclusion criteria were a diagnosis of CP and an age between 16-20 years (birth year 1982-1986). Exclusion criteria were the existence of cognitive disabilities (IQ below 70), comorbidity with a persistent effect on motor functioning, and inadequate proficiency with the Dutch language. Of 437 potential subjects, 35% were excluded because of cognitive disabilities and 18% were lost due to incorrect addresses. An information letter about the study was sent to 184 patients, and 103 participated (response rate 56%). At four-year follow-up, 74 young adults (20-24 years) participated (see Table 1). The results of this latter measurement will be presented here.

Demographic data for gender, age and education level were collected (Table I). We distinguished three levels of education: 1) *low*: pre-vocational practical education or less (special education for IQ 70-85); 2) *medium*: pre-vocational theoretical education and upper secondary vocational education (vocational high school); and 3) *high:* secondary education, post-secondary college and/or university level education (preparatory high school and high school).

Gross motor functioning was classified with the Gross Motor Functioning Classification System (GMFCS) [20], a 5-level classification system for assessing severity of gross motor limitations.[20, 21] Manual ability was classified with the Manual Ability Classification System (MACS), a system designed to classify how children with CP use their hands when handling objects during daily activities, which is also valid for young adults with CP.[19, 22] Trained physiotherapists (AdG and EC) conducted the GMFCS and MACS assessments and examined paresis distribution (49% unilateral) and CP type (94% spastic).

Questionnaires

Using a self-developed written questionnaire, participants were extensively asked about sexual experiences such as masturbation and the sexual milestones French kissing, caressing under clothes, cuddling nude and intercourse. Based on the classification of aspects of the sexual response cycle by Masters and Johnson, and complemented by Kaplan[21] young adults with CP were asked how they functioned in terms of the following aspects: seeking sexual stimulation (seeking out erotic images, sexual fantasies), having sexual desires (do you ever think about what it is like having sex, how you would like to have sex), experiencing sexual arousal, and having an orgasm. For these topics we have used questions from the survey "Sex under the age of 25".[17] For CP-related experiences and problems with sex we used questions from the survey "Does rehabilitation also include sex?".[23]

Statistical analysis

The results for men and women are shown separately and were tested with a Pearson Chi-square test. Answers about the sexual response cycle were dichotomized as yes (very often, often, regularly, sometimes) and no (almost never, never). Responses to perceived problems were dichotomized as yes (a lot, quite a bit, not a little/ not a lot, little effect on sex) and no (no effect on sex). For the statistics, we made use of SPSS 16.0.

Not all the participants had experience with all the sexual issues discussed. This led to a variance in the number of participants per question.

RESULTS

Participants

The mean age of the participants was 22 years and 8 months. The total of the cohort can be characterised as mainly having a spastic parese, a relatively high level of gross motor functioning and manual ability, good audibility and normal cognitive functioning (see Table 1).

Sexual experiences

Seventy-six percent of the participants had experience with masturbation. Most young adults with CP had reached one or more sexual milestones;78% had experience with French kissing, 70% with caressing under

Table 1: Characteristics of the participants

Characteristics	N		N	%
Gender	74	Men	46	62
		Women	28	38
Age (years)	74	20	7	10
		21	17	23
		22	12	16
		23	21	28
		24	12	16
		25	5	7
Educational level	72	Low	14	20
		Middle	29	40
		High	29	40
Laterality	74	Uni	36	49
		Bi	38	51
GMFCS	74	I	56	76
		II	6	8
		III	4	5
		IV	7	10
		V	1	1
MACS	73	I	62	85
		II	8	11
		III	2	3
		IV	-	-
		V	1	1
Speech	74	Audible	67	91
		Audible, although disturbed	6	8
		Disturbed, not audible	1	1

clothing, 65% with cuddling nude and 54% with sexual intercourse. Twenty percent had no sexual experience with a partner.

Sexual functioning

Significantly more men (50%) than women (7%) sought out erotic pictures of the opposite sex or fantasized about them (respectively 86% and 56%). Many (78%) reported experiencing feelings of sexual arousal, and two-thirds of the group had experienced an orgasm. (see Table 2).

Table 2: Sexual functioning in young adults with CP

(N=68)	men %	women %	difference men-women (Chi²)	*p*
Seeking sexual stimuli:				
- looking for erotic pictures, photos, stories, movies	50	7	19.99	**.001**
- sexual fantasies about men	9	56	28.03	**<.001**
- sexual fantasies about women	86	16	34.89	**<.001**
Sexual desire:				
- do you ever think about what it's like to have sex?	94	69	13.52	**.01**
- how would you like to have sex with someone (on a scale from 1-10: ≥ 7) *	58	40	14.60	.10
Arousal experienced during sexual intercourse or masturbation	74	84	9.98	.08
Orgasm during sexual intercourse or masturbation (regularly, often, always)	67	64	11.07	.09

* This question answered by only 24 people (19 men, 5 women)

Bold *p* values indicate significant differences

Problems with sex

Physical problems

There was a wide variation in the physical problems with sex experienced by young adults with CP, and in the frequency of the problems reported: from spasticity (41%) to urinary incontinence, paralysis or numbness (5%) (see Table 3). These problems may limit young adults in terms of positions and postures during sexual activities: "It's all less flexible." In addition, they had less persistence, it took them more time than their partner or they became tired too soon. Also, restricted manual ability was mentioned by the participants as an obstacle. Young adults were not always able to specify concretely how they experienced an obstacle; "It's just more difficult" is how it was put. The problems experienced did not always lead to obstacles in having sex; 20% indicated they experienced no obstacles due to physical limitations.

Some young adults (6%) indicated that they depended on the assistance of others in preparing for sex (such as being put on a bed). It seemed that some had not found a solution for this, as was apparent from answers such as "I don't do it" or "no experience." Possibly no partner was available.

Table 3: Top 10 of the physical obstacles most cited by young adults with CP in having sex

	Bothered by:	*% of young adults experiencing problems*		
		Total group	*Men*	*Women*
		N=59	*N=38*	*N=21*
1.	Spasticity	41	34	52
2.	Difficulty spreading legs	31	31	33
3.	Difficulties with pelvic tilt	29	29	29
4.	Stiffness of joints and muscles	28	19	43
5.	Fatigue*	25	14	43
6.	Balance problems	22	11	38
7.	Impaired manual ability	20	17	25
8/9.	Lack of energy*	18	8	35
8/9.	Loss of strength	18	14	25
10.	Trembling	13	17	5

* women experience significantly more problems here than men, respectively p=0.02 (fatigue) and p=0.05 (lack of energy).

Emotional problems

More than half (55%) of young adults with CP reported no emotional limitations when it came to sexuality, while 19% said they lacked self-confidence. The term shame was also used; being ashamed of one's own body (15%) or of its limitations (11%) came up, while 9% experienced their scars as a hindrance.

With CP, the body has often been approached in a very functional way (by doctors, nurses, caregivers, physiotherapists, etc). One consequence of this is that 20% experienced their body differently from people without disabilities. Remarks made in this vein were: "I keep people at a distance," "Because I need help from caregivers, I cannot have sex in an uninhibited way," "I am almost always aware of the limitations I have" and "I have to concentrate on actions other people never have to think about."

Positive effects from sexuality on physical complaints

Having sex (not specified in greater detail) could also have beneficial effects on spasticity or stiffness; relaxation was an especially positive effect (12%).

Information needs

From the first measurement[15] we know that 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.

Although many young people (59%) at the time of the trial had no contact with a rehabilitation specialist, most had had some in the past (6). When asked whether the subject of sexuality had come up in rehabilitation, 90% said that it had not. Yet there are many issues regarding sexuality that young adults with CP would like information about: 35% about the impact of CP on sexuality and fertility, 26% about treatment options, 16% (medical) devices and medicines, and 14% would like to discuss sexual problems they had with a partner.

DISCUSSION

We found differences between men and women with CP in seeking sexually stimulating pictures and desire for sex, which are consistent with differences between men and women without physical disabilities known from the literature: men have more sexual fantasies and think more about sex, whereas women are sensitive to a broader range of sexual stimuli.[24] The differences in fantasizing about sexual partners were as expected; most women fantasize about men and most men fantasize about women.

A fairly large portion (one fifth) of the participants did not have orgasms. This appears to be more prevalent in young adult men with CP than in Dutch men (5% of Dutch men have regular or frequent problems with orgasm). In women with CP, however, orgasm problems appear to be less common than in Dutch women (27% of Dutch women have regular or frequent problems with orgasm). Maybe the context of reference for women with CP differs from that of the Dutch age mates: quantifications as 'sometimes' or 'regularly' may have a different meaning related to the frequency of experience. If women with CP were less frequently experienced with orgasm compared to Dutch age mates, their context of terms as 'sometimes' or 'regularly' may be different. What is 'regularly' for women with CP may be 'sometimes' for the Dutch references. Anorgasmia does not necessarily indicate a dysfunction; therefore the difficulties had to be experienced as a problem.

Although three quarter of the group was functioning on the highest level of the GMFCS, many participants reported physical obstacles in having sex. This implies that they, notwithstanding few restrictions in gross motor functioning, still experience physical limitations with sex. The reported physical problems were diverse. It is notable that women significantly more than men reported to experience problems with energy and fatigue. However, in the study by Jahnsen no difference was found for fatigue between men and women with CP [25]. Patterns of response to sexual desire and sexual arousal differ between men and women; men easier permit sexual arousal and experience positive emotions.[24] This can implicate that for men the drive of having sex is more important than their lack of energy. Otherwise women react more cautious. In that case lack of energy and fatigue are more prominent experienced as limitations for having sex.

Lack of confidence and uncertainty often play a role in the first sexual experiences for many young people without physical disabilities[26], but young adults with CP have extra hurdles to overcome: developing a positive relationship with their bodies, learning to deal with their own physical limitations, possibilities and needs regarding sex, and being able and daring to discuss all this with a partner . This calls for a challenging need of skills and confidence on their part, especially considering that they are at the beginning of their sexual career.

Also notable is the reported shame about their bodies and the psychological barrier that scars can represent. This can mean that, as a result, young adults with CP had a positive image of their appearance (with clothes), but they can have a negative body image (the naked body).

It is clear that many young adults with CP need support with their problems with sex. This involves help with physical aspects such as spasticity and restricted manual ability, on the one hand. On the other hand, it also involves psychological support for acceptance of their physical and sexual self-image, as well as learning to discuss limitations and opportunities with a partner. In addition, information on aspects of reproduction and genetics is needed.

Despite the perceived problems and the need for information, it is striking that sexuality rarely comes up as a topic of discussion in the rehabilitation of young adults. In pediatric rehabilitation, sexuality is not a subject that is discussed with parents by health care professionals. The physical constraints are paramount, followed by behavioral and learning issues. This is partly due to parents' unawareness that their disabled child is also a

sexual being. They often do not realize that developing a positive body image is important, or that they should provide space for the sexual feelings of their child.

Because many young people with relatively mild disabilities leave pediatric rehabilitation at an early age, sexuality has commonly not been a topic of discussion for professionals, parents and youngsters. During the transition phase, young people have to learn to understand their bodies, their illness and limitations, and they also need to learn to request help. In addition, in this phase it becomes increasingly important for the young person to be able to speak without his parents about sexuality. Sexuality is a subject that many young people do not easily talk about in the presence of their parents, especially if parents also do not feel comfortable discussing the topic.

As so many people find it difficult to discuss sexuality, it is the responsibility of the professional to raise this issue. Our research clearly shows that a significant number of young adults with CP experience problems with sexuality, and that they need help and diagnosis-specific information. In adult rehabilitation, professionals usually are faced with the consequences of the recent onset of disease. In contrast, CP is a congenital disability. Problems with sex should thus be seen more from a developmental perspective. Developing intimate relationships and exploring sexuality are central, instead of changes in sexuality. Because people with CP are developing sexually at an older age[16], they are confronted with sexual problems later.

CONCLUSION

A significant number of young adults with CP experiences both physical and emotional problems with sex. They need diagnosis-specific information and may need assistance discussing sexual issues with their partner. Rehabilitation professionals need to take the initiative during their regular contact to discuss potential problems with sex that young adults with CP might encounter.

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Developmental Medicine & Child Neurology 2010;52:576-582

CHAPTER 7

Importance of peers and dating in development of romantic relationships and sexual activity of young adults with cerebral palsy

ABSTRACT

Aims

To describe peer group activities, romantic relationships and sexual activity of young adults with cerebral palsy (CP) and interrelations.

Methods

A cross-sectional study was performed with 87 participants (51 males) aged 18-22 years, mean age 20 y 4 mos. (SD: 1 y 3 mos.) without cognitive disabilities; 94% spastic CP, 49% unilateral CP, 78% GMFCS level I, 84% MACS level I. Peer group activities, dating, romantic relationships and sexual activity were assessed with an interview and questionnaire. Associations were analyzed using logistic regression analyses.

Results

The study cohort reported having friends and participating in activities with peers; 71% had experience with dating, 23% had a current romantic relationship, and 38% had experience with intercourse. Young adults with CP had less experience in romantic and sexual relationships than an age-appropriate Dutch reference population. Peer group activities and dating favored development of romantic relationships and a sexual activity. Older age was associated with greater sexual experience. Motor functioning, education level and gender did not correlate with romantic relationships or sexual activity.

Interpretation

Being involved in peer group activities and creating a context to arrange dates seems relevant for young adults with CP to develop romantic relationships and sexual career.

INTRODUCTION

Cerebral palsy (CP) is the most prevalent cause of physical disability in children.[1] The consequences of CP are diverse, with the severity of effects on ambulation, hand function, speech and cognition varying greatly. CP-related impairments can make the transition to adulthood particularly difficult. Problems associated with this transition are becoming more prominent as the population of young adults with CP increases.[2] To participate independently in adult life, they must find employment, achieve independence, and ideally establish romantic and sexual relationships. The present study focuses on the latter aspect.

Prior work suggests that, relative to an age-appropriate reference population, persons with CP have less experience with dating and romantic relationships and are less likely to reach sexual milestones as adolescents.[3 - 5] Typically developing young people also engaged in a broader range of social activities, which may precede romantic relationships, than young people with CP. [6, 7]

A framework to study the development of intimate relationships can be derived from the literature on able-bodied adolescents. In typically developing young people, there is a shift away from family-centered activities toward peer-centered activities during adolescence. Within the context of peer relationships, contacts with opposite-sex peers, social activities with age mates, and romantic and sexual relationships develop.[8 -11] This development is accompanied by a progression from romantic activities within a mixed peer group to dating activities as a couple.[12, 13] Sexual interest and masturbation are aspects of sexual development that precede sexual activities with a partner.[14, 15]

Little is known regarding the development of romantic relationships of persons with CP. The first aim of this study was to describe this development from a broad perspective, addressing *peer group activities, dating experience, experience with romantic relationships* and *sexual development*. Participation in romantic relationships and sexual activities can be influenced by several factors, including demographic factors and physical functioning, and is generally preceded by developmental stages in which young people become engaged in peer group activities and dating. The second aim of this study was to investigate whether these preceding activities are associated with the development of romantic relationships and a sexual career among young adults with CP.

METHODS

Participants

This study is part of the CP Transition study of Southwest Netherlands [part of the PERRIN (Pediatric Rehabilitation Research in the Netherlands) research program], a prospective longitudinal study of adolescents with CP aged 16-24 years, focusing on their transition to adulthood. The Medical Ethics Committee of Erasmus MC Rotterdam approved the study. All participants gave verbal and written consent to participate. The results presented here are based on 2-year follow-up measurements.

Participants were recruited from eight rehabilitation centers and departments in the Southwestern regions of the Netherlands. Inclusion criteria were a diagnosis of CP and an age in the range of 16-20 years (birth year 1982-1986). Exclusion criteria were the existence of cognitive disabilities (IQ below 70), co-morbidity with a persistent effect on motor functioning, and inadequate proficiency with the Dutch language. Of 437 potential subjects, 35% were excluded because of cognitive disabilities and 18% were lost due to incorrect addresses. An information letter about the study was sent to 184 patients, and 103 participated (response rate 56%). At the 2-year follow-up appointment, the participants were between 18 and 22 years old; at this time 16% were lost to follow-up (n = 87). No significant non-response bias or lost-to-follow-up bias was observed with respect to age, gender, gross motor functioning level, limb distribution of paresis, or educational level.

Demographic and physical characteristics

Demographic data for gender, age and education level were collected (Table I). We distinguished among three levels of education: 1) *low*: pre-vocational practical education or less (special education for IQ between 70-85); 2) *medium*: pre-vocational theoretical education and upper secondary vocational education (vocational high school); and 3) *high:* secondary education, post-secondary college and/or university level education (preparatory high school and high school).

Gross motor functioning was classified with the Gross Motor Functioning Classification System (GMFCS)[16], a 5-level classification system for assessing severity of gross motor limitations.[16, 17] Manual ability was classified with the Manual Ability Classification System (MACS), a system designed to classify how children with CP use their hands when handling objects during daily activities, which is also valid for young adults with CP.[2, 18]

Table 1: Demographic and CP-related characteristics of study cohort of 87 young adults with CP.

	N	(%)
Age		
18	5	6
19	22	25
20	13	15
21	27	31
22	20	23
Gender		
Men	51	59
Women	36	41
*Level of education**		
Low	23	27
Medium	35	41
High	28	32
CP distribution		
Unilateral	43	49
Bilateral	44	51
GMFCS		
I	68	78
II	8	9
III	5	6
IV	5	6
V	1	1
*MACS***		
I	65	84
II	7	9
III	4	5
IV	1	1
V	1	1

* N = 86

** N = 78

Trained physiotherapists (AdG and EC) conducted the GMFCS and MACS assessments and examined paresis distribution (49% unilateral) and CP type (94% spastic).

Peer group activities

As part of the assessment, trained researchers (MD, CN and DW) administered a written questionnaire and a semi-structured verbal interview. The interview included questions on social activities that were adopted from the Vineland Adaptive Behaviour Scales-Survey Form (VABS), addressing participation in sports, youth clubs, and activities outside school with friends. The VABS assesses age-appropriate adaptive behavior in juveniles[19, 20] and is scored according to the multiple-choice responses of usually, sometimes or never.[19] Questions on number of friends, contact with boys and or girls, and going out activities (nightlife, dancing, going to bars and cafés, attending (birthday) parties) were derived from the Dutch "Youth and Sex" study that addressed young people's opinions on sexuality and sexual behavior. [21]

Romantic relationships and sexual activity

We used a paper version of the questionnaire of the Dutch study on Sexuality "Sex under the age of 25", the successor of the "Young people and Sex" instrument.[4] The Dutch study on sexuality provided an age-appropriate reference population of young people. The questions adopted for this study addressed the following topics: falling in love, experience with romantic relationships, current romantic relationship, sexual fantasy about boys/girls, masturbation, number of sexual partners, and *sexual activity.* The topic of sexual activity was examined in terms of four sexual milestones: French kissing, feeling and caressing under the clothes, cuddling nude, and intercourse.[14, 15] We confirmed that the questionnaire sheets were easy for the participants to pick up.

To use all information and to reduce the number of variables, scales for 'going out' and 'sexual activity' were constructed with sum scores ranging from 0 to 4. Factor analyses (maximum likelihood, oblique rotation) confirmed one-dimensional scales for 'going out' (Cronbach's alpha = 0.73) and sexual experience, referring to four milestones (Cronbach's alpha = 0.87), see Appendix 1.

Statistical analysis

Romantic and sexual relationship data were examined separately for each gender subgroup[4]. Pearson's Chi-square tests (two-sided) were applied to reveal differences between the CP study group and the age-appropriate Dutch reference population (988 males and 974 females, aged 18-22 years).[4]

Using univariate and multivariate regression analyses, we explored factors affecting four dependent variables: 'going out', 'dating experience', 'romantic relationship experience' and 'sexual activity'. We selected 'going out'

as an indicator of peer group activities since it refers to *performance* of social activities *per se,* in contrast to relational variables. Dependent variables were dichotomized as yes/no for participating in at least three peer group activities (going out), any experience with dating/romantic relationship, and experience with at least two sexual milestones. Demographic and physical characteristics and peer group activities were studied as independent variables.

To accommodate the small sample size, we performed multivariate analyses in several steps. First, a basic model encompassing associated demographic and physical characteristics was developed for each dependent variable. Additional independent variables for peer group activities were added to these basic models, one at a time. For the latter models, experience with preceding developmental activities (dating, romantic relationship) was also included, adding one factor at a time. We checked for interaction effects of independent variables with basic characteristics and, if present, performed further analyses for subgroups. Odds ratios (ORs), with 95% confidence intervals (95% CI), *p* values and explained variances (Nagelkerke R^2) of the multivariate models are reported. Analyses were carried out using SPSS 16.0 for Windows.

RESULTS

Performance of peer group activities, dating, romantic relationships and sexual activity

Peer group activities

Friendships.

Most (74%) young adults with CP had five or more friends and two-thirds (67%) had three or more close friends. Number of friends and number of close friends were strongly correlated (r_s = 0. 63). The number of close friends was comparable to the Dutch reference population (64%, p = 0.31).

Peer contacts.

Among young adults with CP, 47% had social contacts with both men and women, while only 16% had contacts limited mainly to same-sex peers. Regarding social activities, 73% of the respondents indicated that they participate in sports; 52% played sports 1- 4 hours a week (compared to 42% of a Dutch reference population),

and 20% played sports 5 hours or more a week (vs. 29% of the reference population).[22] Only 28% were members of a youth club.

Going out.

Most (84%) young adults with CP reported participating in activities outside school. About half went out once a week or more for activities such as dancing or going to bars or cafés at least once a month, and about half went to (birthday) parties monthly. According to the 'going out' scale addressing these activities (see Appendix 1), 10% of the persons with CP did not participate in any of these peer group activities, 37% participated in one or two, and 53% performed three or four.

Dating

Dating skills.

Many participants had relatively active dating skills, including initiating contact (54%), or being contacted (43%). These skills did not differ between males and females. Active and passive dating practices correlated (r_s = 0.43).

Dating experience.

In our study group, 71% had experience with a date, defined as an amorous appointment with one person. The mean age for the first date was 16 years; 18% of the participants were younger than 15 years and 11% were older than 18 years on their first date. There was no difference between men and women in this respect.

Romantic relationships

Falling in love and romantic relationships.

The vast majority (94%) of the young adults with CP had fallen in love at least once and 77% had experience with a romantic relationship; these rates were similar in males and females. At the time of the interview, 23% of the participants had a current romantic relationship, including 37% of females and 14% of males (females vs. males, p = 0.01). Significantly fewer young people with CP had a current romantic relationship than the age-appropriate Dutch reference population (61%) (see Table 2).

Table 2: Romantic and sexual relationship experience of young adults with CP compared to age appropriate Dutch references.

Experience in % *(N)*	Total			Men			Women		
	CP	Dutch references	*p*	CP	Dutch references	*p*	CP	Dutch references	*p*
Romantic relationship									
Has fallen in love	94 *(81)*	98 *(1895)*	0.04	96 *(49)*	97 *(948)*	0.63	91 *(32)*	98 *(947)*	0.007
Experience with romantic relationship	77 *(67)*	89 *(1728)*	<0.001	75 *(39)*	88 *(860)*	0.004	80 *(28)*	90 *(868)*	0.05
Currently engaged in courtship	23 *(20)*	61 *(1049)*	<0.001	14 *(7)*	54 *(464)*	<0.001	37 *(13)*	67 *(585)*	<0.001
Sexual milestones									
French kissing	73 *(61)*	94 *(1759)*	<0.001	67 *(35)*	92 *(869)*	<0.001	74 *(26)*	95 *(890)*	<0.001
Feeling and caressing	65 *(54)*	91 *(1707)*	<0.001	60 *(31)*	89 *(839)*	<0.001	66 *(23)*	92 *(868)*	<0.001
Cuddling nude	53 *(44)*	81 *(1525)*	<0.001	46 *(24)*	78 *(735)*	<0.001	57 *(20)*	84 *(790)*	<0.001
Intercourse	38 *(32)*	80 *(1501)*	<0.001	37 *(19)*	77 *(722)*	<0.001	37 *(13)*	82 *(779)*	<0.001
Sexual career (scale score): experience with 2, 3 or 4 milestones	65			63			68		

Sexual development and experience

Sexual interest.

Most young adults with CP were interested in sex; 87% (both men and women) reported having fantasized about lovemaking. More men than women reporting fantasizing about the other sex (79% versus 51%). These percentages were lower than in the Dutch reference population (89% and 78%, respectively) (*p*'s < 0.001).

Males with CP were more likely to have masturbated (75%) than females (53%). Nevertheless, the masturbation rate for men with CP was significantly less than that among males in the Dutch reference population (93%), while the rate for women with CP did not differ significantly from females in the reference population (70%, p = 0.35).

Sexual activity.

About a third, 35%, of the study cohort had achieved none or only one of the milestones, while 28% had achieved two or three of them. Thirty-seven percent had experience with all four milestones. Young people with CP had significant less experience with the various milestones than the Dutch reference population (Table 2).

In our study group,70% of those who had experience with intercourse were between 16 and 19 years of age when they had their first intercourse experience, 15% were younger than 16, and 15% was older than 19.

Table 3: Results of univariate logistic regression analyses

	Going out				Dating			
	OR	**95% CI**	**p**	**R^2**	**OR**	**95% CI**	**p**	**R^2**
GMFCS	**0.23**	**0.09 - 0.58**	**0.002**	**0.21**	0.69	0.37 – 1.30	0.25	0.02
Uni/bilateral	0.37	0.16-0.88	0.03	0.08	0.59	0.23 – 1.50	0.27	0.02
MACS	0.26	0.08 - 0.80	0.02	0.13	0.51	0.23 – 1.12	0.09	0.05
Gender	0.68	0.29 –1.60	0.38	0.01	0.86	0.34 – 2.20	0.75	0.002
Age	1.47	1.03 – 2.09	0.03	0.07	1.62	1.10 – 2.41	0.02	0.01
Education	**2.18**	**1.20 – 3.94**	**0.01**	**0.11**	1.04	0.57 – 1.91	0.89	<0.001
Sporting	0.35	0.13 – 0.95	0.04	0.07	0.37	0.13 – 1.03	0.06	0.06
Club	0.74	0.29 – 1.91	0.53	0.01	2.29	0.84 – 6.20	0.10	0.04
Number of friends	**3.83**	**2.07 – 7.11**	**<0.001**	**0.37**	**1.82**	**1.18 – 2.80**	**0.01**	**0.12**
Mixed peers	0.98	0.41 – 2.36	0.97	-	2.45	0.95 – 6.36	0.07	0.06
Going out					**1.85**	**1.28 – 2.68**	**0.001**	**0.19**
Dating								

	Romantic relationship				Sexual activity			
	OR	**95% CI**	**p**	**R^2**	**OR**	**95% CI**	**p**	**R^2**
GMFCS	0.77	0.39 – 1.51	0.44	0.01	0.62	0.33 – 1.19	0.15	0.03
Uni/bilateral	0.35	0.12 - 1.01	0.05	0.07	0.47	0.19 -1.19	0.11	0.04
MACS	0.61	0.27 – 1.38	0.24	0.03	**0.31**	**0.12 - 0.78**	**0.01**	**0.13**
Gender	1.42	0.50 – 4.00	0.51	0.01	1.27	0.51 – 3.18	0.61	.004
Age	1.46	0.97 – 2.21	0.07	0.06	**2.05**	**1.35 – 3.12**	**0.001**	**0.20**
Education	0.09	0.46 – 1.76	0.76	0.002	1.70	0.92 – 3.14	0.09	0.05
Sporting	**0.25**	**0.08 – 0.71**	**0.01**	**0.11**	0.39	0.14 – 1.06	0.06	0.06
Club	1.17	0.39 – 3.50	0.78	0.001	1.45	0.53 – 3.97	0.47	0.01
Number of friends	1.46	0.95 – 2.26	0.09	0.05	1.53	1.01 – 2.32	0.04	0.07
Mixed peers	2.05	0.74 – 5.64	0.17	0.03	1.45	0.57 – 3.67	0.43	0.01
Going out	**1.67**	**1.14 – 2.44**	**0.01**	**0.13**	**2.09**	**1.42 – 3.06**	**<0.001**	**0.25**
Dating	**17.10**	**5.07 – 57.63**	**<0.001**	**0.38**	**58.89**	**11.70 – 296.44**	**<0.001**	**0.56**
Rom. relationship					**76.50**	**9.26 – 631.98**	**<0.001**	**0.50**

Significant values in **bold** ($p \leq 0.01$)

About a quarter of the study cohort, (26%) had no sexual experience with a partner. Males and females did not differ in terms of their sexual experience.

Sexual partners.

Of the 32 persons who had experience with intercourse, 54% of the women and 26% of the men had experience with only one partner. Similar portions of the men (84%) and women (85%) had experience with 1-3 partners. Half of the people met their most recent sexual partner during unorganized activities such as going out, through friends, or via the Internet, the other half at organized activities such as a club meeting, holiday camp, school or work.

Factors associated with the development of romantic relationships and sexual career

Univariate analyses are presented in Table 3, whereas the results of the multivariate analyses are given in Table 4.

Peer group activities.

Multivariate logistic regression analyses showed that persons with better gross motor functioning and a medium or high level of education participated in more going out activities. Corrected for demographic and physical characteristics, young adults with more than 5 friends or those who participated in sports participated in more going out activities.

Dating.

Being some years older was associated with dating experience. Corrected for age, young people with more friends had four times more experience with dating than those with few friends. Greater participation in going out activities was associated with dating for men, but not women (Table 4); this association was also present for young adults with a medium education level (OR = 8.83, $p = 0.03$, $R^2 = 0.37$).

Romantic relationships.

More persons with unilateral CP had experience with a romantic relationship than those with bilateral CP. Both contacts with mixed gender peers and participating in sports were associated with experience with a romantic relationship (Table 4).

Table 4: Multivariate models for dating, romantic relationship and sexual career.

	Dating (N = 62)				Romantic relationship (N = 67)				Sexual activity: 2, 3 or 4 steps (N = 55)			
	N (%)	OR (95% CI)	*p*	R^2	N (%)	OR (95% CI)	*p*	R^2	N (%)	OR (95% CI)	p	R^2
Step 1: Demographic and CP-related characteristics				0.10				0.09				0.21
GMFCS		-				-				-		
Uni-bilateral												
Uni		-			37 (55)	0.29 (0.09-0.90)	.03			-		
Bi					30 (45)							
Age												
18	2 (3)								- (0)			
19	14 (23)	1.61 (1.09-2.39)	.02			-			11 (20)	2.12 (1.38-3.24)	.001	
20	7 (11)								7 (13)			
21	22 (36)								19 (34)			
22	17 (27)								18 (33)			
Education level		-				-				-		
*Step 2: Peer group activities**												
Number of friends												
≤ 5	11 (18)	4.05 (1.40-11.66)	.01	0.20		-			9 (16)	1.68 (1.06-2.67)	.03	0.28
≥ 6	51 (82)								46 (84)			
Mixed peers												
Same gender		-			22 (33)	3.17 (1.02-9.79)	.05	0.16		-		
Mixed gender					45 (67)							
Sporting												
Yes		-			53 (80)	0.22 (0.07-0.68)	.01	0.21		-		
No					13 (20)							
Going out												
≤ 2 activities	10 (27)	73.64* (3.16-1714.61)	.01	0.25	27 (40)	4.15 (1.34-12.87)	.01	0.12	18 (33)	4.56 (1.57-13.24)	.01	0.33
3 or 4 activities	27 (73)				40 (60)				37 (67)			
	14 (56)	-										
	11 (44)											
*Preceding stages**												
Dating												
No				0.10	10 (15)	22.76 (5.85-88.49)	<.001	0.47	2 (4)	107.79 (14.74-788.47)	<.001	0.68
Yes					57 (85)				53 (96)			
Romantic relationship												
No		-							1 (2)	118.18 (11.16-1251.86)	<.001	0.61
Yes									54 (98)			

* Independent variables entered one at a time, corrected for significant demographic and CP-related characteristics.

Sexual activity.
The older persons had more sexual experience. In addition, having more friends was associated with having more sexual experience (Table 4).

Preceding developmental stages.
Going out with friends and dating can precede developing a romantic relationship and sexual activities. Corrected for demographic and physical characteristics, those who went out regularly with friends were four times more likely to have romantic relationships and sexual experience. Those with dating experience were much more likely to have experience with a romantic relationship and with sexual activities (Table 4).

DISCUSSION

The present results confirmed that young adults with CP had significantly less experience in romantic and sexual relationships than typically developing Dutch peers. This distinction emerged despite the fact that this study specifically assessed people without cognitive disabilities who have the capacity to become independent participants in society. Hence the data describe relatively high motor functioning youth with CP, with 78% functioning on GMFCS level I.

Peer group activities

More young adults with CP participated in sports than the Dutch reference population, although at a lesser frequency. [22] A similar difference was found in an Australian study.[23] In the Netherlands, sport facilities for youth are organized outside of school. This differs from the situation in the USA, hampering further comparison.

The observation that young adults with CP formed friendships at a rate similar to that of typically developing young people suggests that they have the support of friends, and can use their advice and encouragement when starting a romantic or sexual relationship. Gender-mixed peer contacts are considered to be an important precondition for the development of romantic and sexual relationships in adolescents.[9] In our study group, we found a positive association of mixed peer contact with romantic relationships, but not with dating or sexual career. We expect that the influence of a gender-mixed peer group may be less important in young

adulthood than in early adolescence. Indeed, adults are likely to have regular contacts with people of both sexes in a variety of workplace and leisure situations.

Dating

Our findings that dating was an important activity for the development of romantic relationships and for advancement of a sexual activity are not surprising. The finding that dating can be facilitated by having more friends or going out indicates that, similar to the situation with typically developing people, networks create a context in which romantic relationships can develop for young people with CP.[10]

Romantic relationships and sexual activity

This study contributes to the evidence indicating that the influences of social and dating activities on developing romantic relationships and sexual activity that are acting in the general population are also applicable for youth with CP.[5] In addition, different factors were associated with romantic relationships (CP distribution, mixed peers and playing sports) than with sexual career (age, number of friends). Hence, it appears that distinct processes and personal and environmental factors may influence the two outcomes.

Remarkably, CP-related characteristics were not strongly associated with the development of romantic relationships and sexual activity. Thus, the differences between these young people with CP who are of normal intelligence and the Dutch reference population cannot be explained by our study participants' physical disabilities. It should be noted that the majority of the participants in this study had a high level of gross motor functioning. If those individuals with more limited motor functioning did go out with peers, their chances of dating tended to increase. Hence, Cho et al.'s finding that non-ambulatory persons with CP had significantly less sexual experience than their ambulatory counterparts could potentially be explained by their lesser experience with going out and dating.[24]

Limitations

Although the recruitment area of our study (southwest Netherlands) was an urbanized multi-cultural area, most of the participants were white. Indeed young adults with CP of non-Dutch origin were underrepresented in the rehabilitation centers. Furthermore, the age of the participants in this study was restricted to a range of 18- 22 years. Hence, we cannot generalize our results to older people with CP and their development over

time. We tested a large number of associations on a relatively small sample size. The results indicated a considerable uncertainty in the estimated ORs, and should be interpreted with some caution.

CONCLUSION

Young adults with CP have less experience with romantic relationships and sexual activities than their typically developing young people of similar age. These outcomes were strongly associated with participation in peer group activities and dating, but only weakly with CP related characteristics or gender. Thus being involved in peer group activities and creating a context or opportunity to arrange dates seems relevant for young adults with CP to develop romantic relationships and a sexual career.

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Appendix

A. "Going out" scale

	Factor loading
Activities outside school	0.55
Nightlife	0.68
Dancing, going to bar or cafés	0.91
(Birthday) parties	0.45

Cronbach's alpha = 0.73

B. "sexual activity" scale

	Factor loading
French kissing	0.74
Feeling and caressing	0.91
Cuddling nude	0.86
Intercourse	0.67

Cronbach's alpha = 0.8

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CHAPTER 8

Psychological and environmental factors contributing to participation in romantic relationships and sexual activity of young adults with cerebral palsy

ABSTRACT

Aim

To study determinants of romantic relationships and sexual activity of young adults with cerebral palsy (CP), focusing on psychological and environmental factors.

Methods

A prospective cohort study was performed with 74 young adults (46 men; 28 women) aged 20-24 years with CP (49% unilateral CP, 76% GMFCS level I, 85% MACS level I). All participants were within the average range of intellectual functioning. Romantic relationships, sexual activity, psychological and environmental factors were assessed. Associations were analyzed using logistic regression analyses.

Results

More females than males were in a current *romantic relationship*. Self-efficacy, self-esteem, sexual esteem and attractiveness contributed positively to having current romantic relationships. A negative parenting style contributed negatively to having romantic relationships. Age and gross motor functioning explained 20% of the variance in *experience with intercourse*. In addition, self-efficacy, self-esteem, sexual esteem and attractiveness contributed significantly to intercourse experience. Having a (sexual) partner with physical limitations contributed negatively to experience with intercourse.

Interpretation

For young adults with CP psychological factors contributed more than environmental factors to current romantic relationships and sexual experiences. Parents and professionals need to focus on self-efficacy, self-esteem, sexual self-esteem and perceived attractiveness to others in young adults with CP.

INTRODUCTION

As increasing numbers of young people with cerebral palsy (CP) are now living into adulthood, problems associated with the transition from childhood to adulthood[1, 2] are growing more prominent and life-span care is receiving increasing attention.[3, 4]

The period between 12 and 25 years of age is essential for human sexual development for people with and without physical disabilities. However, previous studies [5, 6]found that adolescents and young adults with CP have less experience with all sexual milestones compared to their peers. A previous study on adolescents with CP[7] has shown the importance of social and dating activities with peers for the successful progression from social relationships to intimate relationships. However, other domains of the International Classification of Functioning, Disability and health (ICF)[8] may influence these intimate relationships. A better understanding of relevant environmental and personal factors is needed to provide adequate counselling to adolescents and young adults with CP regarding the delay in romantic relationships and sexual milestones.

Self-efficacy and level of social participation are positively correlated in young adults with physical disabilities.[9, 10] In addition, a supportive environment (family coping, strong support network) and individual adaptability (motivation, perseverance) are key determinants of quality of life, with disability characteristics being less important.[11] While prior studies have focused on psychological and environmental determinants of social participation, predictors of participation in romantic and sexual relationships have not been well studied.

The aim of the present study was to investigate determinants of romantic relationships and sexual activity of young adults with CP, addressing psychological and environmental factors in addition to demographic and physical characteristics.

METHODS

Participants

The current study was conducted as part of the CP Transition Study of the Southwest Netherlands (http://www.erasmusmc.nl/revalidatie/research/transition/), which describes the course and determinants of func-

tioning of adolescents with CP as they transition into adulthood.[12] At the start (T1) of the study, participants were aged 16 to 20 years. Follow-up measurements were made after two (T2) and four years (T3). Data described in the current study were collected at T3 (participants aged 20 to 24 years). The CP Transition Study is part of the Pediatric Rehabilitation Research in the Netherlands (PERRIN) program (http://www.perrin.nl). The study was approved by the Medical Ethics Committee of Erasmus MC. All participants provided verbal and written informed consent.

Participants were recruited from eight rehabilitation centres and departments in the south western regions of the Netherlands. Inclusion criteria were a diagnosis of CP and an age of 16 to 20 years at inclusion (birth year 1982-1986). The exclusion criteria were the existence of cognitive disabilities (IQ below 70), co-morbidity with a persistent effect on motor functioning, and inadequate proficiency of the Dutch language.

At T3, 28% of the 103 initial participants dropped out due to loss of interest (n = 13), competing time demands (n = 5), incorrect addresses (n = 5), reason unknown (n = 3) or relocation to another country (n = 1) leaving 74 participants. No significant non-response or lost-to-follow-up biases were observed in terms of age, gender, gross motor functioning, and limb distribution of paresis. Compared to the starting group, there were fewer participants with a low education level at T3 (39% versus 30%, $P = 0.02$).[2]

Measurements

Demographic and physical characteristics

Demographic data for gender, age and education level were collected. We distinguished three levels of education: 1) *low*: pre-vocational practical education or less (special education for IQ 70 to 85); 2) medium: pre-vocational theoretical education and upper secondary vocational education (vocational high school); and 3) *high:* secondary education, post-secondary college and/or university level education (preparatory high school and high school).

Gross motor functioning was classified with the *Gross Motor Functioning Classification System (GMFCS)*, a 5-level classification system for assessing severity of gross motor limitations.[13, 14] Manual ability was classified with the *Manual Ability Classification System (MACS)*, a system designed to classify how children with CP use their hands when handling objects during daily activities, (also valid for young adults with CP).[15, 16] Due to small subgroups,

the results of the GMFCS and the MACS were divided into three categories, namely level I, II and III-V. Trained physiotherapists conducted the GMFCS and MACS assessments and examined paresis distribution, CP type and audibility.

Romantic relationships and sexual activities

Trained researchers administered a semi-structured face-to-face interview and self-report instruments. A paper-and-pencil version of the *Questionnaire of the Dutch National Study on Sexuality "Sex under the age of 25"* was administered.[17] The questions addressed the following themes: experience with romantic relationships (a steady relationship based on emotional and physical attractiveness), current romantic relationship, sexual activity, the use of the Internet for dating and sex, and (sexual) partner characteristics. The answers to the question on using the Internet for dating and sex ('Have you ever made a date with someone you met via the Internet?') were dichotomized as no (never) or yes (sometimes, regularly). Sexual activity was examined in terms of four sexual milestones: (no/yes experience with) French kissing, feeling and caressing under the clothes, cuddling nude (without intercourse), and intercourse (vaginal penetration). We focused on 'having a current romantic relationship' as an outcome parameter for romantic relationships, and 'experience with cuddling nude' and 'experience with intercourse' as outcome parameters for sexual activity.

Psychological factors

We assessed self-efficacy with the Dutch language version of the *General Self-Efficacy Scale-12 (GSES-12)*.[18, 19] Items are scored on a 5-point Likert scale. The scale is divided into three subscales: (1 - Initiative) willingness to initiate behaviour; (2 - Effort) willingness to expend effort in completing behaviour; and (3 - Persistence) persistence when facing adversity. The total scale and subscales showed satisfactory levels of internal consistence and test-retest reliability.[18, 20] We compared the results with a reference sample of Dutch students (N = 196, 79% women, mean age 20.5 years).

Coping was measured with the *Coping Inventory for Stressful Situations- short form (CISS-21)* [21, 22] The CISS-21 assesses three coping strategies, scored on a 5-point Likert-type scale; task-oriented coping (solve the problem), emotional coping (become upset, blame oneself) and avoidant coping (going out, visit a friend). Good internal consistency has been shown. [23]

The *Dutch Personality Questionnaire (NPV)* is derived from the California Psychological Inventory,[24, 25] consisting of 133 items divided over 7 scales: neuroticism (21 items), social adequacy (15 items), rigidity (25 items), hostility (19 items), egoism (16 items), dominance (17 items) and self-esteem (19 items). Every item is a statement (e.g. "I trust people only when I know them well") scored as applicable or not, or do not know. Psychometric properties were found to be good. [24] We used Dutch normative values for individuals of 15 years and older. The NPV was administered at T2.

We used the *Physical Disability Sexual and Body Esteem Scale (PDSBES)* to assess capacity to feel positive about sexuality and body-image while living with a physical disability.[26] This scale covers three dimensions, scored on a five-point Likert scale: 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". The PDSBES showed good psychometric properties.[26]

Environmental factors

Socio-economic status (SES) of parents, position in family (eldest child, middle, youngest or only child), living situation (with parents or independent (alone, with partner, with others), urbanization grade (number of addresses per km^2; (low) < 1500 and (high) ≥ 1500), mobility, type of primary and secondary education (special or mainstream education) and parenting style were measured as environmental factors.

Parental highest degree of education was used as an indicator of the *SES*. Two levels were distinguished; (low) pre-vocational practical education or less, pre-vocational theoretical education, secondary education and vocational education; and (high) higher education, degree and university.

Mobility was measured by the *Impact on Participation and Autonomy (IPA)*.[27] The IPA measures the impact of a chronic condition on participation and autonomy. The answer to the question 'Can you go where and when you want?' was dichotomised as moderate or poor versus good.

Parenting style was assessed using the *short form of the EMBU* (Egna Minnen av Barndoms Uppfostran-My memories of upbringing). [28, 29] The s-EMBU measures perceived parental rearing behaviour and consists of three scales, Rejection (7 items), Emotional Warmth (6 items), and (Over) Protection (9 items), plus 1 un-scaled

item. The 23 items are statements (e.g. "My parents tried to encourage me to become the best") scored on a 4-point scale. The s-EMBU was found to be reliable and valid.[28, 30]

Social support was assessed with the *Social Support List 12 - Interaction (SSL-12)*.[31] The SSL-12 consists of three subscales: Daily Support (4 items), Support Problems (4 items), Appreciation (4 items). We added an additional subscale Negative Interactions (7 items). The items are (e.g. "sometimes someone gives you advice?') scored on a 4-point scale. The test-retest reliability varies from 0.56 (negative interactions) to 0.71 (daily support).[31]

Statistical analyses

We used descriptive statistics to describe demographic and physical characteristics, psychological factors, environmental factors, and participation in romantic relationships and sexual activities. Because clinically relevant cut-off scores were not available for all questionnaires we dichotomized the results of the subscales and the total scores of all questionnaires based on the median of the study sample, identifying relatively low (0) scores and high (including the median) scores (1), whereby the low scores had a relatively negative significance. To interpret the results of the logistic analyses in a uniform manner, we recoded the following subscales in a uniform direction: s-EMBU (rejection) and NPV (neuroticism, social inadequacy, rigidity, hostility, egoism),

One-sample t-tests were performed with available normative values of the GSES-12 and the NPV. Chi-square tests (two-sided) were applied for comparison of romantic relationships and sexual activity of the study population with reference values of Dutch age mates , using the data of the study "Sex under the age of 25".[17]

We analysed factors affecting the dependent variables 'a current romantic relationship', 'experience with cuddling nude' and 'experience with intercourse' with univariate and multivariate logistic regression analyses. To accommodate the small sample size, we performed multivariate analyses in several steps. First, a basic model including associated demographic and physical characteristics was developed for the dependent variables. We assessed the associations of gender, age, educational level, laterality of CP and GMFCS univariate with the dependent variables. Manual ability (MACS) and audibility were unevenly distributed. We therefore choose the GMFCS as an indicator of motor functioning. Significant ($p < 0.05$) independent variables (gender, age and GMFCS) for one or more of the outcome variables were added to the basic model. Next, significant ($p < 0.10$) additional independent variables based on the results of univariate logistic regression analyses for psychological factors and for environmental factors were added to these basic models, one at a time. Odds ratios (ORs),

with 95% confidence intervals (95% CI), p values and explained variances (Nagelkerke R^2) of the multivariate models are reported. Analyses were carried out using SPSS 16.0 for Windows.

RESULTS

Description of the participants

Demographic and physical characteristics

The majority of participants had a spastic paresis (94%), a relatively high level of gross motor functioning and manual ability, good audibility, and normal cognitive functioning (see Table 1).

Participation in romantic relationships and sexual activities

While 73% of the young adults with CP had experience with a romantic relationship, only 26% had a current relationship. Most participants (78%) had experience with French kissing and 54% had experience with intercourse. These percentages are significantly lower than a peer reference group (91%, 63%, 91% and 83% respectively).[17]

Psychological factors

Self-efficacy did not differ between young adults with CP and a Dutch reference group (see Table 2). Participants scored significantly higher on persistence than the reference group. Willingness to initiate behaviour and effort to complete behaviours were comparable with the Dutch references.

Compared with normative values of Dutch references on the different domains of the NPV, the participants of the present study scored higher on rigidity; young adults with CP were less flexible in searching for alternative solution strategies and strongly preferred a systematic approach. Females with CP scored higher on dominance, had a more active attitude within groups and desired more leadership compared to a peer reference group. No reference values were available for the CISS-21.

Environmental factors

Most participants (40%) were the eldest child. Social economic status of parents was evenly distributed. About half of the participants (47%) were living independently and two thirds lived in less urban areas (see Table 3).

Table 1: Demographic and physical characteristics of participants and categories used for the analyses

Characteristics	N*		n	%
Gender	74	Men	46	62
		Women	28	38
Age (years)	74	20	7	10
		21	17	23
		22	12	16
		23	21	28
		24	12	16
		25	5	7
Educational level	72	Low	14	20
		Middle	29	40
		High	29	40
Laterality	74	Uni	36	49
		Bi	38	51
GMFCS	74	I	56	76
		II	6	8
		III (n=4), IV (n=7) and V (n=1)	12	16
MACS	73	I	62	85
		II	8	11
		III (n=2), IV (n=0) and V (n=1)	3	4
Speech	74	Audible	67	91
		Audible, although disturbed	6	8
		Disturbed, not audible	1	1

* If N<74 there are missing values

Most participants (88%) reported that they could go wherever and whenever they wanted. The majority of the participants had followed regular education; 59% at elementary school and 75% at secondary school. A small group (21%) used the Internet for dating. Thirteen percent had a (sexual) partner with physical disabilities.

No reference data were available for s-EMBU and SSL-12.

Table 2: Psychological characteristics of the participants

	$Median_{CP}$	$Min\text{-}max_{CP}$	M_{CP}	SD	M_{ref}	T-test *p* value
GSES (N*=73)						
Total	46	32-56	45.4	5.7	45.3	0.84
Effort	15	5-20	15.0	3.6	15.4	0.38
Persistence	21	14-25	20.9	2.9	18.3	**<0.01**
Initiative	11	5-15	11.2	2.8	11.6	0.20
Coping (CISS 21) (N*=72)						
Emotion oriented	19	9-31	19.0	5.8	n.a.	
Task oriented	27	12-34	26.4	4.6	n.a.	
Avoidance	23	9-35	22.3	5.8	n.a.	
Dutch personality Questionnaire (NPV) (N*=71)						
$Neuroticism_{men}$	11**	0-31	12.1	8.1	9.7	0.06
$Neuroticism_{women}$			11.9	5.9	13.1	0.29
Social adequacy	8	0-28	9.5	7.1	10.4	0.29
$Rigidity_{low\ educational\ level}$	28**	9-41	26.5	7.3	21.7	**<0.01**
$Rigidity_{middle\ and\ high\ educational\ level}$			30.1	5.7	25.4	**0.01**
$Hostility_{low\ educational\ level}$	16**	1-32	14.7	6.4	16.1	0.12
$Hostility_{middle\ and\ high\ educational\ level}$			16.4	6.9	19.0	0.17
$Egoism_{low\ educational\ level}$	10**	1-23	10.1	4.2	10.7	0.26
$Egoism_{middle\ and\ high\ educational\ level}$			14.1	3.6	13.9	0.86
$Dominance_{men}$	16**	3-31	16.4	5.8	15.8	0.47
$Dominance_{women}$			14.9	4.7	12.5	**0.01**
Self-esteem	28**	9-38	27.9	5.9	27.9	0.97
PDSBES (N*=69)						
Sexual esteem	16	5-20	16.1	4.0	11.1	**<0.01**
Attractiveness to others	11	3-15	10.9	3.3	6.7	**<0.01**
Body esteem	12	5-15	11.6	2.7	8.1	**<0.01**
Total	39	5-50	38.2	9.4	25.9	**<0.01**
Total men	40	14-50	39.3	9.0	24.6	**<0.01**
Total women	37	5-50	36.8	9.8	27.1	**<0.01**

***** If N<74 there are missing values

** Median scores were calculated for the total group

Table 3: Environmental characteristics of the participants and the (dichotomized) categories used in the analyses

	N*				n	%
SES	70	Low			35	50
		High			35	50
Child's position in family	73	Eldest child			29	40
		Middle child			14	19
		Youngest child			21	29
		Only child			9	12
Living situation	68	With parents			36	53
		Independent: alone (n=14), with partner (6), with others (12)			32	47
Urbanisation grade	74	Low			49	66
		High			25	34
Can go where and when he wants	74	Poor, moderate			9	12
(mobility)		Good			65	88
Primary education	69	Special school			28	41
		Regular school			41	59
Secondary education	69	Special school			17	25
		Regular school			52	75
Dating with someone you know via the Internet	72	Never			57	79
		Sometimes/very often			15	21
(sex) Partner	55	With physical restrictions			7	13
		Without physical restrictions			48	87
			$Median_{CP}$	**$Min\text{-}max_{CP}$**	**M_{CP}**	**SD**
s-EMBU	69	Rejection	8	6-16	8.3	1.9
		Emotional warmth	19	12-24	19.9	2.7
		(over) Protection	20	12-30	20.5	4.0
SSL-12	70	Daily support	12	7-16	11.8	1.9
		Support problems	11.5	6-16	11.4	2.2
		Appreciation	11.5	8-16	11.5	1.9
		Negative interactions	11	7-21	11.1	2.9

* if N < 74 there are missing values

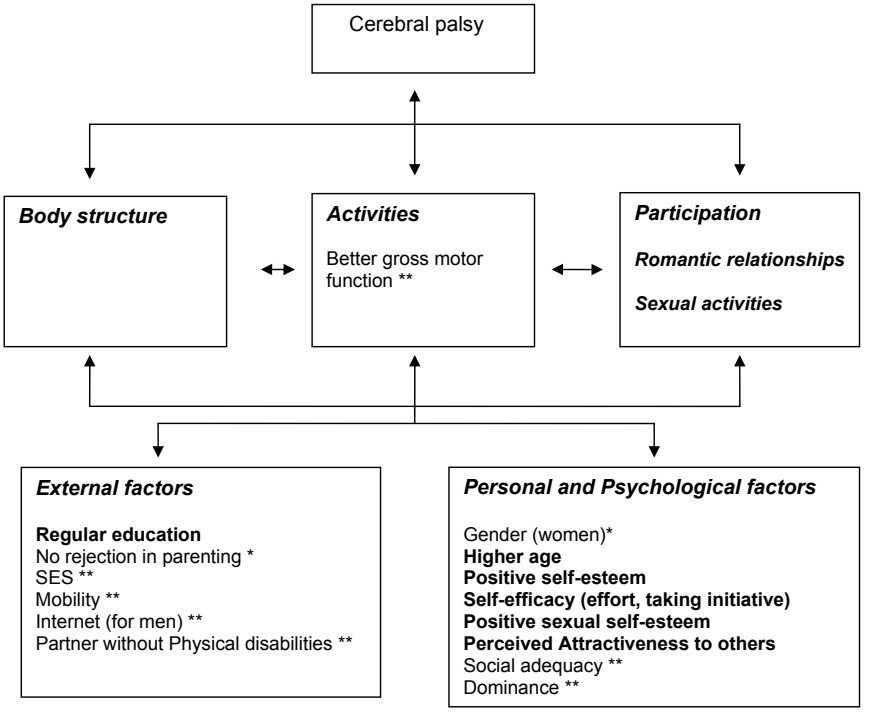

Figure 1: Factors positively associated with romantic and sexual relationships of young adults with cerebral palsy based on the framework of the ICF

Factors in bold are associated with both romantic and sexual relationships

* Only associated with romantic relationships

** Only associated with sexual relationships (cuddling nude, intercourse)

Factors associated with participation in romantic relationships and sexual activities (see Figure 1)

Demographic and physical characteristics

A limited number of participants with MACS levels II-V or with disturbed speech had a current romantic relationship (n = 0 and n = 1, respectively), experience with cuddling nude (n = 2 and n = 2, respectively) or intercourse experience (n = 2 and n = 2, respectively).

Univariate logistic regression analyses showed that more females than males had a current romantic relationship, that more participants at an older age (between 20 to 24 years) had experience with intercourse and more participants with better gross motor functioning had experience with cuddling nude and intercourse (see Table 4). The multivariate basic models for these outcome parameters explained 8% (romantic relationship), 19% (cuddling nude) and 20% (intercourse) of the variance. (Table 5).

Table 4: Univariate logistic regression analyses

Univariate		***Current romantic relationship***				***Cuddling nude***				***Intercourse***			
Characteristics		OR	95% CI	p	R^2	OR	95% CI	p	R^2	OR	95% CI	p	R^2
Gender	0=men 1=women	3.07	1.05-9.01	**0.04**	0.08	1.62	0.56-4.69	0.37	0.02	2.43	0.87-6.74	**0.09**	0.08
Age	0=20 years 1=21 years 2=22 years 3=23 years 4=24 years 5=24 years	1.42	0.96-2.11	**0.08**	0.06	1.42	0.97-2.07	**0.07**	0.07	1.50	1.04-2.16	**0.03**	0.09
Educational level	0=low 1=middle 2=high	0.78	0.39-1.57	0.48	0.01	0.79	0.39-1.60	0.52	0.01	0.82	0.43-1.57	0.56	0.01
Laterality (uni/bi)	0= unilateral 1=bilateral	0.81	0.28-2.29	0.69	<0.01	0.68	0.25-1.86	0.46	0.01	0.70	0.27-1.80	0.46	0.01
GMFCS	0= level I 1=level II 3=level III,IV,V	0.58	0.28-1.22	0.15	0.06	0.45	0.23-0.88	**0.02**	0.11	0.45	0.22-0.92	**0.03**	0.10
Psychological factors													
Self-efficacy (GSES)													
total	0=low 1=high	1.28	0.44-3.67	0.65	< 0.01	2.65	0.95-7.39	**0.06**	0.07	2.37	0.90-6.27	**0.08**	0.06
Effort	0=low 1=high	3.75	1.10-12.77	0.03	0.10	1.11	0.41-3.03	0.83	0.001	0.89	0.34-2.33	0.81	<0.01
Persistence	0=low 1=high	1.73	0.57-5.24	0.33	0.02	1.88	0.69-5.14	0.22	0.03	1.83	0.70-4.80	0.22	0.03
Initiative	0=low 1=high	1.61	0.53-4.87	0.40	0.02	3.00	1.07-8.40	**0.04**	0.09	3.88	1.41-10.70	**<0.01**	0.13

Univariate		*Current romantic relationship*				*Cuddling nude*				*Intercourse*			
Coping (CISS)													
Avoidance	0=less 1=more	1.07	0.38-3.06	0.90	0.00	2.00	0.72-5.53	0.18	0.04	2.18	0.83-5.73	0.12	0.05
Emotional	0=less 1=more	0.56	0.19-1.61	0.28	0.02	0.50	0.18-1.38	0.18	0.04	0.59	0.22-1.52	0.27	0.02
Task-oriented	0=less 1=more	3.14	0.99-9.95	**0.05**	0.08	1.88	0.69-5.14	0.22	0.03	2.08	0.79-5.47	0.14	0.04
Personality (NPV)													
Neuroticism	0= more neurotic 1=less neurotic	2.34	0.77-7.10	0.13	0.05	2.29	0.81-6.52	0.12	0.05	1.89	0.71-5.02	0.20	0.03
Social adequacy	0=less adequate 1=more adequate	1.18	0.41-3.41	0.76	<0.01	7.29	2.24-23.75	**<0.01**	0.24	2.81	1.03-7.61	**0.04**	0.08
Rigidity	0=less rigid 1=more rigid	0.77	0.27-2.21	0.63	<0.01	1.58	0.56-4.42	0.39	0.02	1.47	0.56-3.90	0.44	0.01
Hostility	0=more hostile 1=less hostile	0.61	0.21-1.76	0.36	0.02	1.91	0.68-5.37	0.22	0.03	1.28	0.49-3.39	0.62	0.01
Egoism	0=more egoistic 1=less egoistic	2.73	0.90-8.30	0.08	0.07	1.58	0.56-4.42	0.39	0.02	1.04	0.39-2.73	0.94	<0.01
Dominance	0=less dominant 1=more dominant	1.49	0.51-4.29	0.47	0.01	4.24	1.39-12.95	**0.01**	0.14	1.75	0.66-4.65	0.26	0.03
Self-esteem	0=less self-esteem 1=more self-esteem	4.73	1.38-16.2	**0.01**	0.14	3.75	1.26-11.12	**0.02**	0.12	3.65	1.32-10.11	**0.01**	0.13
PDSBES total	0=less 1=more	4.26	1.23-14.73	**0.02**	0.12	6.15	1.96-19.28	**<0.01**	0.21	3.87	1.38-10.83	**0.01**	0.14

Univariate		*Current romantic relationship*				*Cuddling nude*				*Intercourse*			
Sexual esteem	0=less 1=more	4.26	1.10-16.57	**0.04**	0.11	10.94	3.23-37.02	**<0.01**	0.33	5.71	1.88-17.38	**<0.01**	0.20
Attractiveness	0=less 1=more	11.05	2.29-53.29	**<0.01**	0.26	5.77	1.83-18.20	**<0.01**	0.20	4.86	1.68-14.03	**<0.01**	0.18
Body esteem	0=less 1=more	1.03	0.35-3.03	0.96	<0.01	1.84	0.65-5.18	0.25	0.03	1.76	0.66-4.72	0.26	0.03
Environment													
SES	0=low 1=high	1.83	0.61-5.47	0.28	0.03	3.05	1.04-8.96	**0.04**	0.09	2.16	0.80-5.82	0.13	0.05
Child's position in family	0=eldest 1=middle 2=youngest 3=only	0.97	0.59-1.59	0.91	<0.01	1.09	0.68-1.75	0.73	<0.01	1.12	0.75-1.87	0.46	0.01
Living with(out) parents	0=with 1=without	0.87	0.29-2.56	0.80	<0.01	0.83	0.29-2.32	0.72	<0.01	0.66	0.25-1.77	0.41	0.01
Urbanisation grade	0=low 1=high	0.28	0.07-1.08	**0.07**	0.08	0.61	0.21-1.75	0.35	0.02	0.78	0.28-2.14	0.63	0.01
Mobility	0=poor, fair 1=good	3.06	0.36-26.27	0.31	0.03	7.17	1.32-38.93	**0.02**	0.12	4.15	0.78-22.41	0.10	0.06
Primary (special) school	0=special 1=regular	1.90	0.59-6.18	0.28	0.03	0.91	0.32-2.58	**0.86**	<0.01	1.15	0.43-3.09	0.79	0.02
Secondary (special) school	0=special 1=regular	7.11	0.87-58.33	**0.07**	0.11	3.75	1.1-12.51	**0.03**	0.10	3.47	1.04-11.57	**0.04**	0.09
Dating via Internet	0=never 1= yes	0.39	0.08-1.95	0.25	0.03	4.13	0.84-20.28	**0.08**	0.08	8.13	1.67-39.55	**<0.01**	0.17
Partner with(out) Phys. disabilities	0=with 1=without	n.a.				7.24	1.32-36.63	**0.02**	0.15	19.09	2.07-176.26	**0.01**	0.24
Parenting (s-EMBU)													
Rejection	0=more rejection 1=less rejection	5.48	1.14-26.34	0.03	0.12	3.40	1.14-10.15	0.03	0.10	2.20	0.77-6.30	0.14	0.04

Univariate		*Current romantic relationship*				*Cuddling nude*				*Intercourse*			
Emotional warmth	0=less warmth 1=more warmth	3.03	0.95-9.70	0.06	0.08	2.21	0.78-6.29	0.14	0.05	1.31	0.49-3.52	0.59	0.01
Overprotection2	0=less protection 1=more protection	0.91	0.32-2.62	0.87	<0.01	1.32	0.47-3.67	0.60	0.01	1.23	0.46-3.25	0.68	0.01
Social support (SSL-12)													
Social support daily problems	0=less support 1=more support	2.57	0.74-8.87	0.14	0.05	2.82	0.98-8.10	0.05	0.08	1.81	0.66-4.96	0.25	0.03
Support problems	0=less support 1=more support	1.83	0.61-5.47	0.28	0.03	0.73	0.26-2.00	0.54	0.01	0.85	0.32-2.23	0.74	<0.01
Appreciation	0= less appreciation 1=more appreciation	0.93	0.32-2.71	0.89	<0.01	1.04	0.38-2.87	0.94	0.00	0.95	0.36-2.48	0.91	<0.01
Negative interaction	0= more negative interactions 1= fewer negative interactions	1.06	0.34-3.29	0.92	<0.01	1.99	0.69-5.74	0.20	0.03	1.37	0.49-3.81	0.55	0.01

Significant p values for univariate analyses (p<0.10) in bold

Current romantic relationships

Psychological factors

Univariate logistic regression analyses showed that a current romantic relationship was positively associated with more effort (feelings of competence), a task-oriented coping style, a higher self-esteem, egoism, positive

Table 5: Multivariate logistic analyses

Multivariate basic models	***Current romantic relationship***				***Cuddling nude***				***Intercourse***			
Characteristics	OR	95% CI	p	R^2	OR	95% CI	p	R^2	OR	95% CI	p	R^2
Gender	3.07	1.05-9.01	**0.04**	0.08	ns			0.19	ns			0.20
Age	ns				1.50	1.00-2.25	**0.05**		1.57	1.07-2.31	**0.02**	
GMFCS	ns				0.45	0.23-0.88	**0.02**		0.45	0.22-0.92	**0.03**	
Multivariate models corrected for gender, age, GMFCS												
Psychological factors	***Current romantic relationship***				***Cuddling nude***				***Intercourse***			
Self-efficacy (GSES) total					ns				ns			
Effort	5.35	1.45-19.74	**0.01**	0.20								
Initiative	ns				ns				5.66	1.79-17.90	**<0.01**	0.25
CISS Task-oriented	ns											
Personality (NPV)												
Social adequacy					9.72	2.55-37.08	**<0.01**	0.35	ns			
Egoism	ns											
Dominance					4.24	1.39-12.95	**0.01**	0.14				
Self-esteem	5.20	1.45-18.64	**0.01**	0.21	3.81	1.23-11.86	**0.02**	0.21	3.76	1.30-10.88	**0.02**	0.21
PDSBES total	5.67	1.49-21.59	**0.01**	0.22	8.84	2.42-32.27	**<0.01**	0.31	5.28	1.68-16.61	**<0.01**	0.32
Sexual esteem	6.22	1.42-27.15	**0.02**	0.22	15.28	3.81-61.28	**<0.01**	0.40	10.54	2.67-41.56	**<0.01**	0.35
Attractiveness	14.37	2.71-76.19	**<0.01**	0.35	5.77	1.83-18.20	**<0.01**	0.20	5.60	1.72-18.24	**<0.01**	0.32
Environmental factors												
SES2					3.05	1.04-8.96	**0.04**	0.09				
Urbanisation	ns											
Mobility2					7.17	1.32-38.93	**0.02**	0.12	ns			
Secondary (special) school	7.11	0.87-58.33	0.07	0.11	3.75	1.12-12.51	**0.03**	0.10	3.47	1.04-11.57	**0.04**	0.09
Internet dating					ns							
Internet dating men									11.00	2.03-59.75	**<0.01**	0.27
Internet dating women									ns			
(sex) Partner	n.a.				7.24	1.32-39.63	**0.02**	0.15	37.69	2.85-498.54	**<0.01**	0.43
Parenting: Rejection	5.48	1.14-26.34	**0.03**	0.12								
Emotional warmth	ns											
Social support (daily problems)	ns											

Significant p values ($p<0.05$) in bold, ns: not significant in multivariate analysis, n.a.: not applicable

sexual esteem and feelings of attractiveness (see Table 4). The extended multivariate models showed that effort, self-esteem, and sexual esteem explained approximately 20% of the variance. Feelings of attractiveness explained 35% of the variance in romantic relationships (see Table 5).

Environmental factors

The univariate analyses showed positive associations with romantic relationships for regular secondary education and living in a less urban environment. A rejecting parenting style was negatively associated with a current romantic relationship, while an emotional warm style was positively related (see Table 4). Multivariate analyses showed that only type of education and a rejecting parenting style remained associated with a current romantic relationship (see Table 5).

Cuddling nude

Psychological factors

Univariate analyses revealed that experience with cuddling nude was positively associated with self-efficacy, taking initiative, social adequacy, dominant behaviour, self-esteem, sexual esteem, and feelings of attractiveness (see Table 4). The multivariate analyses showed that social adequacy, dominance, higher self-esteem, higher sexual esteem, and feelings of attractiveness were related to cuddling nude and raised the explained variance to 35%, 21%, 40% and 20% respectively. The total score of the PBSBES (sexual self-esteem, attractiveness and body-esteem) raised the explained variance to 32% (see Table 5).

Environmental factors

Using univariate analyses, we found positive associations for cuddling nude with regular secondary education, a socio-economic status of parents, mobility, dating via the Internet, having a sexual partner without physical disabilities and daily social support. A rejecting parenting style was negatively associated with cuddling nude experience (see Table 4). The multivariate model showed that higher socio-economic status, more mobility, regular secondary education and having a sexual partner without physical disabilities were related to experience with cuddling nude, but none of these factors raised the total explained variance (see Table 5).

Intercourse

Psychological factors

Univariate analyses showed that intercourse was positively associated with self-efficacy, taking initiative, social adequacy, self-esteem, sexual esteem and feelings of attractiveness (see Table 4). Multivariate analyses showed that intercourse was positively related to taking initiative, self-esteem, sexual esteem and attractiveness. The explained variance increased to 21% (self-esteem) and 35% (sexual self-esteem) (see Table 5).

Environmental factors

Univariate analyses showed positive associations for intercourse with regular secondary education, mobility and having a partner without physical disabilities. For dating via the Internet we found an interaction effect with gender; the probability of experience with intercourse increased for men who used the Internet for dating (see Table 4). Multivariate analyses showed that Internet dating for men and having a partner without physical disabilities increased the explained variance to 27% and 43%, respectively. Only 7 participants had a sexual partner with physical disabilities and therefore these results must be interpreted with caution (see Table 5).

DISCUSSION

Physical disabilities in sexual activities

We expected that physical disabilities would interfere more with intercourse than with cuddling. However, we found that severity of gross motor functioning was related to cuddling nude. *Post hoc* analyses showed that unlike earlier measurements (T1 and T2), severity of gross motor functioning negatively affected earlier sexual milestones such as kissing and caressing.

Psychological determinants

Psychological factors seem to contribute more to romantic and sexual relationships than environmental factors. In agreement with prior studies,[32, 33] self-esteem of young adults with CP was comparable to Dutch references. Perceived attractiveness to others was also an important factor related to romantic and sexual relationships. Both perceived attractiveness to others and a high sexual self-esteem are aspects of self-consciousness

which can facilitate flirting and dating, making involvement in romantic relationships and /or sexual activities more likely.[7] In turn, intimate relationships may amplify perceived attractiveness and sexual self-esteem.

Different factors affect romantic relationships and sexual activities

We found different associated factors for current relationships (gender, parenting style) and sexual activities (social adequacy, mobility). Development of romantic relationships or sexual activities can be different processes. Manning.[34] found that 60% of sexually active American teenagers have had sex in both romantic and non-romantic contexts. Within a romantic context, intimacy and understanding of a partner's motivation and behaviour are important; while for sexual activities without romance, the desire to establish a sexual identity, hormones, and sexual experimentation may initiate behaviour, making psychological and environmental factors (such as mobility) crucial.

The severity of gross motor functioning contributed to sexual activities, but not to having a current romantic relationship. For sexual activities young adults with CP may be hindered by their physical limitations. In a romantic relationship emotional involvement and intimacy are more important.[35]

Participants who had experienced rejection from their parents were less likely to have a current romantic relationship. Auslander et al.[36] found that positive qualities of parent–child relationships (e.g. acceptance and involvement) are linked to positive qualities in later adult romantic relationships.

Different aspects of self-efficacy contributed to developing romantic relationships (effort) and sexual activity (taking initiative). Moore[37] found that young adults with low social self-efficacy have difficulties not just in romantic relationships, but in making friends, joining in conversations and taking initiative.

Special education

Special secondary education hindered the development of romantic and sexual relationships. However, *Post hoc* analyses found no differences between regular education and special education in level of gross motor functioning or social adequacy. Therefore, school environment appears to contribute to the exploration of sexual activities. The environment of a regular school (size, location) may offer more opportunities for sexual exploration (less supervision) or less dependency on transportation creates more possibilities for contact with peers after school.

Limitations of the study

A large proportion of our study population had only slight limitations in gross motor functioning. Therefore this study gives limited understanding of the consequences of severe limitations in gross motor functioning for sexual activities. Although the recruitment area of our study (southwest Netherlands) was an urbanized multi-cultural area, most of the participants were white. Young adults with CP of non-Dutch origin were underrepresented in rehabilitation centres. Furthermore, the age of the participants in this study was restricted to 20 to 25 years. Hence, we cannot generalize our results to older people with CP. Finally, we tested a large number of associations on a relatively small sample size. The results indicated a considerable uncertainty in the estimated ORs, and should be interpreted with caution.

CONCLUSIONS

Psychological factors contribute more than environmental factors to current romantic relationships and sexual experiences for young adults with CP. Parents and professionals should focus on self-efficacy, self-esteem, sexual self-esteem and perceived attractiveness to others during development and counselling. Special secondary schools seem to restrict the development of romantic relationships and sexual experiences.

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CHAPTER 9

General Discussion

Here we summarize the main findings and discuss the strengths and limitations of our study. In addition, we present the clinical implications of our findings and recommendations for future research.

Participation in intimate relationships is an important element in the transition from adolescence into adulthood. As a part of the CP Transition study we explored the development of romantic relationships and sexuality in adolescents and young adults with CP.

The aim of this thesis was two-fold. First, we were interested in gaining insight into the romantic relationships and sexuality of adolescents and young adults with CP in comparison to an age-matched Dutch reference group, to follow the development of these factors over four years and to describe the experienced limitations and needs in romantic relationships and sexuality. The second aim was to determine associated activities and physical, psychological and environmental factors related to romantic relationships and sexual activity using the framework of the International Classification of Functioning, Disability and Health (ICF)[1].

PARTICIPATION IN SOCIAL AND ROMANTIC RELATIONSHIPS AND SEXUAL ACTIVITIES.

Social Participation

We systematically reviewed the literature on the subject of potential barriers to successful social and sexual relationships in adolescents and young adults with CP (Chapter 3). After reviewing fourteen papers we concluded that adolescents with CP seem to have less exposure to the culture experienced by their peers. They were less active compared to able-bodied age mates, especially in spontaneous social activities and leisure activities and spent less time with friends.[2, 3] Our results however, indicate that nearly all CP participants (98%) participated in one or more recreational activities and all had a variety of social relationships. The number of close friends (three or more for 67% of the adolescents) was comparable to an age- appropriate Dutch reference sample. Although our findings seem to indicate a more positive outlook than that found in previous literature, the number of activities and friends are not the only factors that define the quality of social functioning. We also found that 20% of the CP population functioned below an age-appropriate level in play and leisure time and 28% had low coping skills.

Donkervoort et al.[4] found restrictions for young people affected with CP in other aspects of social participation such as taking responsibility, community living and employment. These findings were especially robust for the younger participants (within the range of 16-20 years). Voorman et al.[5] studied the course of social participation in children (9-16 years old) with CP over a three year period and found that 45% of participants had restrictions in social participation (for instance interactions with others, play, sensitivity to others) at baseline. In addition, over a three year period there was a general decrease in social functioning. These results confirm the delays in social functioning of adolescents with CP. The delays appear during childhood and increase during adolescence.[6, 7]

In addition to social functioning, prior research has found that the frequency of social participation of children with disabilities is lower compared to age mates (Law et al.[7]).
The above results may indicate that children with disabilities have fewer opportunities to develop social skills. We found (Chapter 4) that girls with CP perceived less social acceptance compared to their peers without disabilities. Various studies have shown that children with CP have significantly more behavioural problems compared to children without disabilities [5, 8], which may be related to problems in social functioning.

Difficulties with social participation are not unique to adolescents and young adults with CP; the same has been shown with adolescents and young adults with spina bifida (SB). [9-12] It is possible that the brain damage associated with the disruption of motor functioning in SB and CP is related to brain areas associated with social relationships.[13]

The observed delay in the development of social functioning compared to age-matched peers coincides with the transition from primary to secondary education. During this period typically developing youth make a shift away from family-centred activities and towards peer-centred activities. Romantic and sexual relationships develop within the context of peer relationships, including contact with opposite-sex peers and social activities with same-age mates. The delay in social development of adolescents with CP may hinder the growth of intimate relationships in adolescence and young adulthood. The present study adds to the evidence that the opportunity for social activities with peers is an important component in the development of intimate relationships and sexual activities.

Sexual development

Although adolescents and young adults with CP are sexually active, on average their first kiss and sexual debut occur two years later than their non-disabled Dutch peers. Level of gross motor functioning explains 10% of the variance and after correction for GMFCS, gender, age, the psychological factors self-esteem, sexual self-esteem and perceived attractiveness explain about 21%-35% of the variance. These results indicate that there are a variety of factors contributing to the delay in sexual development and that some factors are yet to be discovered.

Physical factors

Perhaps skeletal age is related to sexual development. Bone age is a better indicator for adolescent growth spurt and pubertal development than height in healthy adolescents with short stature.[14] However, a longitudinal study by Van Eck et al.[15] showed that the bone age of girls with CP is advanced compared to chronological age. For boys, however, this was not true. These results may indicate that puberty in girls with CP begins earlier than in the general population.

In another study[16] it was found that puberty begins earlier and ends later in white children with CP compared to the general white population. In our study we found a difference (but smaller) in first menarche of females; 12 years and 9 months (mean) for girls with CP compared to 13 years and 2 months for the general population.[17] There are several indications, therefore, that puberty starts earlier in children with CP compared to the general population. Therefore the timing of puberty cannot explain the delay in sexual development of adolescents and young adults with CP.

Previous research has shown that epilepsy can impact sexual functioning, including problems with libido, arousal and orgasm.[18] In the present study, 12 % of the participants at T3 had experienced an epileptic episode once or more. Problems in sexual functioning may affect sexual development in that a decrease in excitement or sexual satisfaction, may decrease the sex drive and therefore, less sexual activities will be undertaken.[17] This can be a possible explanation for the delay in sexual development for this small subgroup with epileptic episodes, but not for the study population as a whole.

Cerebral palsy is defined as a group of permanent disorders in the development of posture and movement which cause limitations in activities and is attributed to non-progressive disturbances that occur in the devel-

oping brains of a foetus or baby.[19] The brain plays an important role in sexuality. Different areas of the brain are involved in the various stages of the sexual response cycle.[20] It is possible that disturbances in the developing brains of adolescents with CP not only affect motor functioning and behaviour[5], but also the control of sexual functioning. We did not find literature related to CP. Adolescence is a period of great change and growth in the brain[21], it may be possible, therefore, that the brain of adolescents with CP develops at a slower pace, whereby sexual functioning starts later and consequently sexual development as well.

Personal and psychological factors

The delay in social functioning likely influences the development of romantic and sexual relationships. First flirting and dating experiences take place within peer groups. As adolescents with CP function at a lower age level, it may be difficult to understand unwritten social codes and non verbal flirting etiquette[22, 23], therefore making the process difficult. Alternatively, it may be that adolescents with CP are not ready or not yet interested in sexuality, flirting or dating.

Environmental factors

One consequence of functioning at a lower age level may be that adolescents with CP choose peers at more or less the same developmental level. This may mean that sexuality, flirting and dating are not topics of interest in their peer group.

As it takes two to tango, understanding choice of potential partner of an adolescent or young adult with CP may be helpful. In a study on attractiveness and sexual behaviour among Australian heterosexual young adults, Rhodes et al.[24] found that males with masculine bodies had more short-term sex partners while females with more feminine faces had more long-term sex partners compared to their peers. In addition, women with symmetric faces became sexually active at an earlier age than their peers. People with CP often have a non-symmetric appearance, which can make them less attractive as a potential mate for a short-term or long-term relationship. The gait, speech and hand movements of people with CP contribute to an unhealthy appearance leading to the perception that they would be less attractive as a mate. If adolescents with CP perceived themselves as healthy, they might feel themselves more attractive and their appearance might appeal more attractiveness.[25] However, a study by Van der Slot et al.[26] showed that adults with bilateral CP perceived a low health-related quality of life (compared to Dutch references).

Parents can also influence the sexual development of their child with CP. In our study (Chapter 3) we found that nearly all participants had some form of sex education with 63% of the participants mentioning parents as an important source of information. These results indicate that one third of the participants did not speak with their parents about sexuality. Antle et al.[27] found that while parents of disabled adolescents have concerns that their child will encounter difficulties in relationships and sexuality, they may be afraid to talk to them about sex. It is difficult for children and adolescents to express their sexual feelings if they have not had the opportunity to discuss this topic. Parents may miss the chance to guide their adolescent with a disability regarding the development of intimate relationships and sexual expression.

Transition and sexual development

Clinical settings, such as hospitals and rehabilitation centres and the literature [28-32] have shown an increasing interest in the transition of adolescents with chronic disabilities into adulthood. Besides the transition from paediatric care to adult care and aspects of self-management[30, 33] changes in various life domains need attention.[34]

At the two year assessment (T2), using the Rotterdam Transition Profile, we found that young adults with CP had reached less autonomy in the participation domains of 'housing' and 'intimate relationships' compared to age-matched references.[34] After a four year period (T3), young adults with CP (20-24 years) had reached more autonomy in all domains.[35] However, it is remarkable that 42% of participants were still in phase one (childhood, dependency on parents) in the domain of 'intimate relationships'. These results suggest that they had no experience with dating or courtship. For other participation domains the percentage of participants in phase one varied from 1% (finances) to 20% (housing). Therefore, the delay in development of intimate relationships is a significant problem compared to the development of autonomy in other domains of participation.

While interventions have been developed for all participation domains[36], our results emphasize the importance of specific interventions regarding intimate relationships of young adults with CP. The effectiveness of the recently developed module 'Friends, courtship and sex' [37] has to be tested, but if it turns out to be effective, young adults with CP and other physical disabilities will have more tools for arranging a date or for experimenting with sexual activities.

DETERMINANTS OF PARTICIPATION IN SOCIAL AND ROMANTIC RELATIONSHIPS AND SEXUAL ACTIVITIES.

ICF

We used the ICF framework[1] to explore factors associated with romantic and sexual relationships of young adults with CP (Chapters 7 and 8). We found that all domains of the ICF contributed to romantic and sexual relationship status (see Figure 1). The most important factors related to romantic relationships and sexual activity are activities with peers and dating and psychological factors.

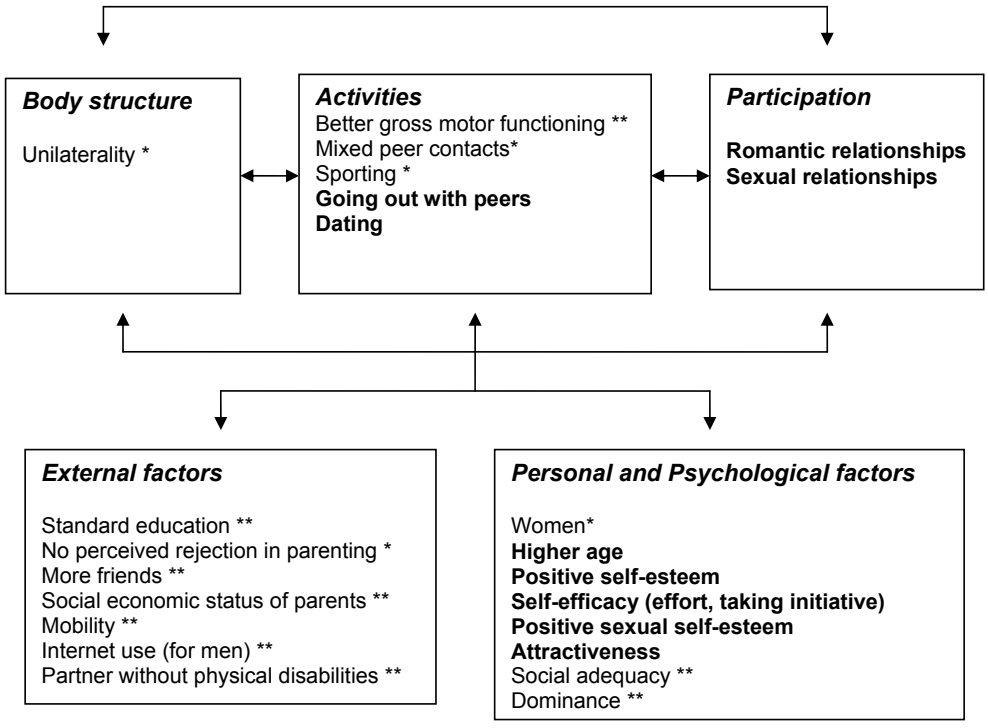
However, the domains varied in the degree of impact and in addition, there were differences between factors associated with romantic and with sexual relationships. These results are not surprising, in that different processes underlie romantic relationships and sexual activities. An American study found that many adolescents have sex with partners outside the dating context or outside romantic relationships.[38] Consequently, we have split the domain 'intimate relationships' into 'Intimate relationships' and 'sexuality' within the Rotterdam Transition Profile (www.erasmusmc.nl/Reva/Research/transition/RTPv1.0).

Psychological determinants

Aspects of a positive self image as self-efficacy, self-esteem, sexual self-esteem and perceived attractiveness to others are all psychological factors that were positively associated with both romantic and sexual relationships. In a study on career counselling[39] clients with a more positive view of both their own and their counsellor's in-session behaviours expected and experienced more positive and autonomous behaviours.

It is possible that this positive and autonomous behaviour also affects behaviour regarding intimate relationships. Bandura[40] postulated that effective self-management of sexual situations requires social and self-regulated skills and a sense of personal efficacy. It is imperative to exercise influence over one's self as well as others when managing sexuality.[40] Moreover, a good sense of self-efficacy strengthens positive experiences and expectations in interactions with others, including sexual and intimate relationships. Effective self-management can be taught through modelling and role-playing, whereby adolescents learn to communicate effectively about sexual matters.[40] The relationship of psychological factors to romantic relationships and sexual activity is important for the development of new interventions that may help adolescents and young adults in their development of romantic relationships and sexual activities.

Figure 1: Factors positively associated with romantic and sexual relationships of young adults with cerebral palsy based on our study



Factors in bold are associated with both romantic and sexual relationships

* Only associated with romantic relationships

** Only associated with sexual relationships (cuddling nude, intercourse)

Appearance

The present study found that adolescents and young adults with CP had a perceived physical appearance comparable to age-matched references (Chapter 4). Dutch adolescents with CP had a significantly higher sexual self-esteem and body-esteem, and felt significantly more attractive, than those with physical disabilities in other Western societies (Chapter 4). We did not find differences between males and females regarding these factors.

People without physical disabilities often have opinions about people with physical disabilities which are not held by the physically disabled group. Den Brok-Rouwendal coined this phenomenon cultural validism.[41] Validism means discrimination based on physical, mental or psychic conditions. Cultural validism is the judgements made by a society on a group of people with disabilities. In Western societies physical appearance is important. Therefore, people with an atypical appearance are often considered pitiful or inferior.[41] This can obviously have a negative influence for adolescents and young adults with CP on dating opportunities and romantic and sexual relationships.

It is important for professionals treating adolescents with CP to realise that their opinion of the patient is not necessarily in accordance with the opinion of the adolescent himself. This difference in viewpoint was found in a study by Pangalila et al. (personal communication) on the quality of life of young men with Duchenne muscular dystrophy. A lower general quality of life was expected for this population, however, this was not realised. Professionals, therefore, should be aware of the influence of cultural validism on their way of thinking and acting.

On the other hand, it is often difficult for adolescents in general to hold a realistic view of many aspects of life, especially regarding such sensitive topics as appearance or sexuality. As a defence mechanism they may be more positive or exaggerate their opinion. In addition, self-reflection is difficult in this stage of life. Therefore it is possible that adolescents with CP have an opinion of their appearance that is not consistent with the general opinion.

Gross Motor Functioning

The contribution of gross motor function to social participation, romantic relationships and sexual activity differed. We also found that the contribution of the GMFCS on sexual activity increased over time. The following may help us understand these findings.

Social participation

Social relationships are an important aspect of social participation. Various studies have shown that children and youth with severely impaired walking ability have a lower level of participation in most domains than those without or with less impaired walking.[42-44] Adolescents with CP, compared to children with CP, participated in more activities with friends and outside the house. Moreover, adolescents with fewer restrictions in

walking participated in more activities outside the house and with friends than those with more restrictions.[43] We found that GMFCS level was related to activities that require leaving the house, such as activities outside school, nightlife activities and going to bars or (birthday) parties. Our study adds to the evidence that children, adolescents and young adults with CP with more severe gross motor impairments have more restrictions in social participation.

Romantic relationships

It is remarkable that, compared to the restrictions in social participation, level of gross motor functioning was not associated with dating, experience with courtship or having a current romantic relationship. We only found that young adults with unilateral CP compared to bilateral CP are somewhat more likely to have experiences with romantic relationships. Laterality explains 9% of the variance. For adolescents the concept of romantic relationships develops over time from affection to intimacy.[45] Spending time together or holding hands can also be expressions of affection, especially for younger adolescents. In these cases of affection, physical disabilities do not necessarily hinder relationships. Besides gross motor function, we found that some other factors are related to romantic relationships while others are related to sexual activities. Participation in romantic relationships can be a different process than participation in sexual activities, although there can also be some overlap. Manning et al. found that the majority of sexually active teens have had some sexual experience outside of a romantic relationship.[46] This mean that this appeals to different features, skills and environment for romantic relationships and sexual activity.

Sexual activities

At T3, we found an association of gross motor functioning with cuddling nude and with intercourse (Chapter 8). The longitudinal analyses showed a main effect of gross motor functioning on intercourse experience (Chapter 5). The differences between young adults with walking abilities (GMFCS I-II) and young adults with walking aids (GMFCS III, IV, V) became larger over time in the domain of sexual activities, where gross motor impairments restricted the latter group to a greater extent. Additional analyses showed no significant associations between the GMFCS and sexual activities such as French kissing, caressing under clothes, cuddling nude and intercourse at T1 or T2. However, at T3 the associations between GMFCS with all the above mentioned activities were significant. It may be that the first signs of decreased functional ability are emerging at T3 as has been found among adults with CP in other studies.[47-49]

In general, adolescents exaggerate their experiences and abilities. Moreover, regarding sexuality, many people – not only adolescents – exaggerate their sexual experiences. It can therefore be difficult for adolescents to be honest about their sexual experiences. At the final measurement (T3) of the current study the participants were 4 years older than at the start of the study and were possibly more honest about their experiences. This possibly explains that at this time point we found that the relationship between sexual experiences and physical restrictions became more prominent. However, the answers to the questions about sexual experience were consistent over time. It is possible that a ´yes´ at T3 is more reliable than a ´yes´ at T1.

At T3 78% (French kissing) to 54% (intercourse) of the young adults had some experience with sexual activity. Many participants experienced physical obstacles during sexual activity such as spasticity (41%) and trembling (13%). Some physical obstacles were strongly (spreading legs, pelvic tilt) or moderately (spasticity, pain) correlated with level of the GMFCS, but other problems such as fatigue and loss of strength were not.

High level of gross motor functioning

The severity of motor impairments partly explained participation in social (10% going out) and sexual (10% intercourse and 20% sexual career) activities. However, this study showed that young adults with less walking restrictions had less experience with sexual activities compared to a Dutch reference sample.[50] In total, these results promote the importance for professionals to focus on adolescents and young adults with a high level of gross motor functioning.

Gender differences

The current study found no differences between males and females in dating activities, experience with romantic relationships or sexual relationships. However, there was a difference between genders in current romantic relationships with significantly more females having a current relationship compared to males (Chapter 4, 5, 8). The same difference between males and females was also found in the Dutch study 'Sex under the age of 25' [50] and in young people of Anglo-Australian, Chinese, and Southern European background.[51] In the latter study, Moore found that women had more romantic attitudes, were less fearful of closeness and were more interested in relationships while men were only interested in romantic relationships that were virtually problem-free. The difference we found in young adults with CP therefore appears to be typical between men and women in the general population.

As with the prior Dutch study[50], we found that more boys than girls had experience with masturbation.

Parenting style

Parenting style significantly contributes to a child's behaviour and may also be related to a child's participation in society. In the current study we found that young adults who perceived rejection from their parents (for example 'My parents treated me as the 'scapegoat' of the family') are less likely to have a current romantic relationship. In another study on the same young adults Donkervoort et al.[4] found a relationship between perceived rejection and aspects of social participation. Other studies have found a link between parental rejection and child anxiety and hostility.[52, 53] While a prior study among able-bodied young people found an association between an emotionally warm parenting style and increased sexual behaviour[50], we did not find this association in our study with young adults with CP.[50]

It is remarkable that an overprotective style of rearing was not associated with romantic or sexual relationships. Previous studies have shown that people with CP or other physical disabilities perceive their parents as overprotective: parents advised their child, for instance, to avoid certain social activities.[54, 55] Overprotective parenting could lead to less opportunities for romantic or sexual activities. However, other studies found that overprotective upbringing was not an important factor in determining a child's behaviour in general.[52, 53] In general, an overprotective parenting style is often considered an impediment to the exploratory needs of children. Our results suggest that negative effects of an overprotective parenting style may be overestimated.

STRENGTHS AND LIMITATIONS

Strengths

Study population

We selected participants aged 16 to 20 years without severe learning disabilities (IQ > 70). The purpose of the present research was to study social participation and the transition to an independent adult life. Young adults with severe learning disabilities need counselling based on their cognitive impairments, and therefore, their lives as adults differ from those of people without severe learning disabilities. Our selection criteria made it possible to gain insight into the consequences of motor impairments independently from cognitive impairments.

We performed some additional checks on whether the present cohort is truly representative for this group. First, in the Netherlands it is standard clinical practice to refer all children diagnosed with CP to paediatric rehabilitation care. Since we recruited participants by means of the patients' record systems of both paediatric and adult departments of rehabilitation centres and hospitals in the region, we had access to young adults with CP who were still using health care as well as those who only visited the rehabilitation centre or hospital in their childhood.
Second, the distribution of GMFCS levels in our cohort was rather comparable to the normal intelligent subgroup of two Dutch population-based studies among young adults with CP[47] and school-aged children[56] Respectively, 86 and 73% of these study populations were
classified in GMFCS Levels I and II.

The present study used a multi-centre approach in which participants were recruited from rehabilitation centres and departments of rehabilitation in the south-western part of the Netherlands and Utrecht. Our participant were from an urbanized multi-cultural part of the country, including the big cities of Rotterdam, The Hague and Utrecht and also small towns, rural villages and the countryside, making our results representative of all the Netherlands.

Study design

The major strength of this study is the longitudinal design. We followed the participants at three time points during a four year period through their transition into adulthood. The advantage of a longitudinal design is that it provides information about characteristics of transition over time. Our design enabled us to measure the development of dating, romantic relationships and sexual activity over time (Chapter 5).

Comparison with Dutch reference sample.

In addition to the longitudinal design, an important strength of the current study is the comparison of our sample to results of the recently conducted Dutch study about sexual behaviour in healthy children and adolescents 'Sex under the age of 25'.[50] The Rutgers Nisso Group (RNG) allowed us to use their questionnaire, which enabled us to ask the same questions for comparison and allowed the use of their data in our analyses. These factors made the comparison with this age matched Dutch reference sample more reliable.

Outcome measures

In addition to the use of the ICF[29] framework, we started our investigation with a review of previous literature to establish all possible determinants for social, intimate and sexual relationships (Chapter 3). The ICF provides a framework for recording and organizing information about health and health-related status in a standardized, common language that facilitates communication between various disciplines and scientific fields.[57, 58] It is a strength of this study that we focused on all aspects of the ICF and factors found through our literature review: body function, activities, participation, environmental factors, personal and psychological factors.

Limitations

Study population.

A consequence of limiting our population to participants with an IQ above 70 may be that most participants in our study had a relatively high level of gross motor functioning. Prior studies have shown evidence for a correlation between level of gross motor functioning and cognition, however this is not always the case.[59, 60] It is conceivable that people with CP who have more severe motor impairments, may have greater issues. In any case, our results are not generalizable to all people with CP.

Although this was a multi-centre study in a multi-cultural part of the country, most of the participants were white adolescents; we found fewer than expected participants of non-Dutch origin. Thus we cannot generalize our results to other cultural groups. Due to the small number of homosexual participants, it was also not possible to analyse the results for this subgroup separately. We expect that both adolescents and young adults with CP from non-Dutch origins as well as homosexual participants encounter unique issues in the development of intimate and sexual relationships. To gain more knowledge about these issues, future studies should include a larger number of participants in these subgroups.

At the start of the study 103 adolescents with CP chose to participate (a response rate of 56%). At T2, 16% of the 103 participants dropped out leaving 87 participants. At T3, 26% of the 103 initial T1 participants dropped out leaving 76 participants. Reasons for dropout at T3 were loss of interest (n = 13), competing time demands (n = 5), incorrect addresses (n = 5), reason unknown (n = 3) or relocation to another country (n = 1). No significant non-response or lost-to-follow-up biases were observed in terms of age, gender, gross motor functioning, or limb distribution of paresis. The loss of interest at T3 may indicate a psychological difference between participants and dropouts. The participants that continued throughout the study may have a more responsible

and positive attitude. This factor may affect the results of the study, especially the impact of psychological determinants on participation. Conversely, drop outs may have fuller and richer lives that make participation in the study difficult to complete.

Study design

We found that the sexual development of young adults with CP was delayed. The four year period of the study was too short to cover the entire developmental time span. We therefore cannot draw any conclusions about how these young adults will develop in romantic and sexual relationships over a longer period of time.

We used logistic regression analyses to determine relationships between variables. Due to the relatively small sample size, we were restricted in the number of variables for the multivariate models. To accommodate the large number of determinants, the multivariate analyses were carried out in several steps. After studying a basic model with personal and physical determinants, other determinants (activities, psychological and environmental factors) were added stepwise one by one to the basic model. The extended model was therefore restricted to the basic model plus one other determinant. It was not possible to create a total extended model for the outcome variables, whereby the relative importance of all other variables could not be determined.

Socially desirable answers

Sexuality is a very personal topic, making it difficult to honestly answer questions. Participants may also want to answer in a socially desirable way. Although we used a written questionnaire, young adults may feel uncomfortable about the questions. Only 43% of participants answered the final question, 'Did you find it difficult to answers the questions about sex?' Of those that answered, 39% found it difficult. Of all participants (N = 73) 70% reported that they answered the questions 'as well as possible'. These results suggest that about one third of participants may have given socially desirable answers, which may have increased positive responses about self-image, perceived attractiveness and sexual experience. If this is the case, then the results presented here give an overly optimistic picture, indicating that the problem is actually larger than described.

Cultural differences

We found differences in sexual experience between American adolescents with physical disabilities and the Dutch young adults with CP in the present study, while the experience of American and Dutch able-bodied adolescents was similar.[61] These results imply that there are cultural differences between the American and

Dutch situation for adolescents with physical disabilities. We also found differences between our results and those from Spanish and Swedish studies.[62, 63] Social participation has also been shown to vary substantially between regions within Europe.[42] Sexual development may be influenced by differences in living situation (home or institute), mobility, attitudes regarding sexuality of adolescents with physical disabilities, or availability of contraceptives.

CLINICAL IMPLICATIONS

The present thesis showed the importance of social participation for the development of romantic relationships and sexual activity among adolescents with CP. Although most participants were involved in various social activities, a percentage of the adolescents behaved at a lower age level and the girls, particularly perceived less social acceptance. Consequently, clinical intervention should be centred on increasing social skills as a condition for adequate participation in social activities. While social development has traditionally been a focus of paediatric rehabilitation care, our results suggest that this area is also of great importance during the transition into adulthood as a delay in social functioning may hinder social participation.

Furthermore, the sexual development of young adults with CP continues after transition into adulthood signifying that professionals in adult rehabilitation care must also be aware of the possible problems these young adults with CP can encounter regarding development of romantic relationships and sexuality.

According to the ICF romantic and sexual relationships are aspects of interpersonal interactions. Therefore these topics should be included in rehabilitation care. However, the present study provided evidence that sexuality is not often a topic of discussion in rehabilitation care. Many young adults with CP have an unmet need for diagnosis-specific information about physical and emotional problems associated with sex. Knowledge about sexuality and development of intimate relationships should be disseminated among rehabilitation professionals caring for CP patients both in paediatric as well as adult care settings. This issue should be integrated into rehabilitation physician training (the course on CP).
Furthermore, it is well known that many professionals find it difficult to talk about sex. To date, information on patient sexuality is only available in training programs for professionals caring for adults,[64, 65] However, our

study suggests that dissemination of this information is also necessary for professionals in paediatric care training programs.

The development of a website and an information leaflet specifically geared toward information needs of adolescents and young adults would be helpful along with the use of the board game 'SeCZ-TaLK' (http://www.opeigenbenen.nu/nl/projecten/secz-talk/meer-info/).

Sexual development starts at a young age. The Dutch framework 'Sexuality education' provides lessons for children starting at four years old (www.seksuelevorming.nl) from the perspective of sexual health regarding physical and emotional sexual development, reproduction, resilience, relationships, sexuality and safe sex. All these aspects of sexuality are also important to those with physical disabilities and should be integrated and implemented into existing guidelines for CP questionnaires and team communication tools such as the Children's Rehabilitation Activity Profile (kinder RAP) and the ICF-CY.

RECOMMENDATIONS FOR FUTURE RESEARCH

We followed young adults with CP until the ages of 20 to 24 years. However, the sexual development of this group is not yet completed. Our results do not indicate whether these young adults are delayed in sexual development and romantic relationships or whether a percentage of the young adults with CP continue to experience less sexual activity. Longitudinal studies on development of sexuality in young people with CP should have follow-up measurements for a longer period of time.

Our study does not provide insight into suitable coaching methods, available tools or even which adolescents and young adults need treatment or assistance
Based on the results of this study restrictions in gross motor impairment are not the leading problems for initiating sexual activity among adolescents with CP. Psychological factors such as self-esteem, self-efficacy and sexual self-esteem are better indicators for success or problems in romantic relationships and sexual activities than physical barriers. Even for young people without physical disabilities, sexuality is a process of experimentation and trial-and-error and most will eventually succeed. This is also true for young people with CP making it important to follow the sexual development and to discuss sexual issues with these adolescents and young

adults as an ongoing process to get insight into their questions and unsolved problems. Possibly the evaluation of the previously mentioned coaching program, 'Friends, courtship and sex' [37] can give insight in this process and problems to improve coaching in regular contacts.

At the moment that young people with CP have sexual experience, they may face physical obstacles to sex as we inventoried in this study. For an appropriate medical treatment or counselling first these physical obstacles have to be investigated.

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Summary

This thesis describes social and romantic relationships and sexual activity of adolescents and young adults with cerebral palsy (CP) with normal intelligence. With a growing interest in participation of adults with a congenital disability, knowledge about functioning, limitations and needs of these young adults in the area of intimate relationships is scarce.

CP is defined as a group of permanent disorders in the development of posture and movement which cause limitations in activities and is attributed to non-progressive disturbances that occur in the developing brains of a foetus or baby. Posture and movement disorders in CP are often accompanied by disturbances in perception, cognition, communication and behaviour, as well as by epilepsy. CP is the most common cause of physical disability in childhood with a prevalence of 1.5-2.5 per 1000 live births. CP is the most common diagnosis in the paediatric rehabilitation care setting. As increasing numbers of young people with CP are now living into adulthood, problems associated with the transition from childhood to adulthood are growing more prominent and the life-span care is receiving increasing attention.

The International Classification of Functioning, Disability and Health (ICF) published in 2001 by the World Health Organization (WHO) considers one domain of participation to be interpersonal relationships with a sub domain of intimate relationships. This sub domain is dived into romantic, spousal and sexual relationships. The current thesis describes functioning of adolescents and young adults with a focus on romantic relationships and sexual activity. At this age spousal relationships are rare and because sexual experiences also can happen outside the context of a relationship we chose the term sexual activities. Romantic relationships, dating and sex develop in a social context and therefore we describe social relationships as a preceding stage to intimate relationships.

The current thesis is part of the Rotterdam CP Transition study where we followed 103 adolescents with CP as they transitioned into adulthood. Participants were from eight rehabilitation centres and departments in the south western regions of the Netherlands. Determinants of functioning and outcome during a 4 year period were described. At the start (T1) of the study, the participants were aged 16 to 20 years old, and follow-up measurements were made after two (T2) and four years (T3).

In **Chapter 2**, the Rotterdam Transition Profile is described and validated. This profile was developed for the CP transition study to describe the transition process from childhood to adulthood in young adults with CP

(see Appendix). Transition is the change from one phase of life to another and is accompanied by changes in environment and demands for new skills. For adolescents this means a move towards independence in work, housing, developing intimate relationships and financing. During this transition stage, young adults must take control of their lives by making their own choices. Transition is a developmental process in which three phases can be distinguished: dependency on parents, experimenting and orientating with the future, and finally, independent living.

By T2 (18 to 22 years) most participants were in the transition process or had already reached an independent adult lifestyle. Compared with able-bodied peers, young adults with CP lagged behind in their development in housing, employment and intimate relationships. We found that older adolescents were more likely to be at the transition phase level. A high level of motor functioning was related to financial dependence and to independence in transportation. In addition, participants with a high level of motor functioning were more often independent with respect to leisure activities (e.g. evening outing to a party, concert or the movies). A high level of manual ability was related to a more adult phase of intimate relationships and independence in transportation and leisure activities.

The Rotterdam Transition Profile is a valid tool to gain insight into the transition process, at the individual as well as at the group level.

In **Chapter 3**, previous literature is reviewed, focusing on possible barriers to successful social, romantic and sexual relationships in adolescents and young adults of normal intelligence with CP. Fourteen papers were selected. Two studies exclusively investigated people with CP whereas 12 papers included people with a congenital disability and/or physical disabilities of which some had CP. All studies addressed adolescents or adults of normal intelligence.

The literature review indicated that adolescents and young adults with CP were less active compared with their age mates, and dating was often delayed and less frequent. While adolescents with congenital disabilities indicated that sexuality is an important aspect of their lives, they experience difficulties developing sexual relationships. Our literature review revealed that poor psychological adaptability, insufficient self-efficacy, and low sexual self-esteem may impair the development of social and sexual relationships in adolescents with disabilities. In addition, overprotective parenting and negative attitudes of society may have a negative influ-

ence on the self-efficacy of people with CP. While the reviewed studies suggest many influencing factors in the development of social and sexual relationships among adolescents and young adults with CP, evidence was found for self-efficacy and sexual self-esteem and their interrelationships with parenting. We focused on these factors as the starting point for the research in the current study.

Chapter 4 describes the social, romantic and sexual relationships of Dutch adolescents with CP at the age of 16 to 20 years (T1). We assessed perceived competences and experienced problems regarding these relationships. In addition, experiences regarding social, romantic and sexual relationships were compared with able-bodied age-mates. Data for the able-bodied adolescents regarding romantic and sexual relationships, were obtained from a recent study (2005) by the Rutgers Nisso Group (RNG) on sexuality in Dutch young people, 'Sex under the age of 25'.
The results showed that although almost all adolescents with CP had friends and participated in various social activities, 33% functioned below age level in the *social domain*. In addition, age appropriate activities such as going out with friends in the evenings were hardly practiced by adolescents with CP. Judgement of physical appearance was not significantly different between adolescents with CP and their age mates. Girls with CP perceived less social acceptance compared to their age mates while the experienced competence in close friendships and global self-worth of both boys and girls with CP was comparable with that of their able-bodied age mates.

Although youth with CP did not experience problems in maintaining close friendships, maintaining *romantic relationships* was a problem. The number of participants with a steady boyfriend/girlfriend was rather small in spite of experience with courtship. Participants reported a perceived lack of self-confidence (41%) and perceived different treatment (23%) as obstacles, in starting a relationship.

At 16 to 20 years of age, youth with CP were less focused on *sexuality* and had significantly less sexual experience compared with their age mates respectively in masturbation (53% vs. 75%), French kissing (59% vs. 88%), and intercourse (20% vs. 66%). About 47% of the youth with CP reported that it is more difficult to find a sexual partner due to their disability (29% disagree). Encouraging findings were that youth with CP were positive about their sexual esteem and that almost all youth with CP had received sex education, a finding quite different from that on sex education for the physically disabled in other Western countries.

Chapter 5 describes the development of romantic relationships and sexual activity of young adults with CP over a four-year period, and investigates whether this development is associated with demographic and physical characteristics. In addition, sexual activity of this group is compared with the able-bodied age mates of the RNG study.

We observed a significant increase in dating in young adults with CP during the transition from late adolescence to young adulthood. The maintenance of steady romantic relationships, however, did not significantly increase over this period. A small minority of the young adults with CP, especially women, were involved in steady romantic relationships. Young adults with a lower education level began dating later then those with higher levels. However, involvement in romantic relationships was not related to educational level or physical characteristics.

During the four years of investigation, the sexual experience of the participants increased significantly for all the sexual milestones evaluated. Physical disabilities were associated with intercourse, but not with dating or romantic relationships. Although young adults with CP with more severe physical restrictions (GMFCS III-V) showed increased intercourse experiences from T1 to T3, they had less experience than ambulatory young adults with CP. At the final assessment (T3), young adults with CP participated at a lower level in romantic relationships and sexual activities, but had an equal sexual interest compared with the Dutch reference population (RNG).

Chapter 6 describes the problems that young adults with CP experience in the various stages of the sexual response cycle, and the physical and emotional obstacles they experience with sexuality at T3 (age 20 to 25 years). Furthermore, needs pertaining to sexuality were discussed.

Young adults with CP can experience various problems and challenges with sexuality. The sexual response cycle consists of various phases including seeking sexual stimulation, having sexual desires, experiencing sexual arousal, and having an orgasm. Of the participants with CP 20% experienced anorgasmia. Physical problems with sex related to CP were reported by 80% of the participants. There was a wide variation in the physical problems experienced and in the frequency of the problems reported. Spasticity (41%), difficulty in spreading legs (31%), difficulty in pelvic tilt (29%),stiffness of joints and muscles (28%), fatigue (25%) and urinary incontinence, paralysis or numbness (5%) were among the problems reported. These problems limit

young adults in terms of positions and postures during sexual activities. Having sex (not specified in greater detail) could also have beneficial effects on spasticity or stiffness; relaxation was an especially positive effect. Besides physical problems, 45% of the young adults reported emotional problems regarding inhibition to initiate sexual contact.

While many participants (59%) were not in contact with a rehabilitation specialist at the time of the study, most had had some contact in the past. When asked whether the subject of sexuality had come up in rehabilitation, 90% reported that it had not. However, young adults with CP reported the need for more information on many issues regarding sexuality such as the impact of CP on sexuality and fertility (35%), treatment options (26%), (medical) devices and medicines (16%), and 14% reported a desire to discuss with their partner sexual problems they were experiencing. Rehabilitation professionals should initiate discussion, during their regular contact, about potential problems related to sexual activity that young adults with CP may encounter.

Chapter 7 focused on the development of *peer group activities to dating experience, experience with romantic relationships* and *sexual development* from a broad perspective. Participation in romantic relationships and sexual activities can be influenced by several factors, including demographic factors and physical functioning, and is generally preceded by developmental stages in which young people become engaged in peer group activities and dating. We investigated whether these preceding activities are associated with the development of romantic relationships and sexual activity among young adults with CP at T2 (age 18 to 22 years).

Young adults with CP formed friendships at a rate similar to that of typically developing young people which suggests that they have the support of friends, and can use their advice and encouragement when starting a romantic or sexual relationship.
Our finding that dating is an important activity for the development of romantic relationships and for advancement of sexual activities is not surprising. In turn, dating can be facilitated by having more friends or going out, indicating that, similar to typically developing youth, networks create a context in which romantic relationships can develop for young people with CP. These data contribute to evidence indicating that the influences of social activities and dating on developing romantic relationships are applicable for young people with CP as they are for the general population. Remarkably, CP- related characteristics were not strongly associated with the development of romantic relationships and sexual activity. Thus, the differences between young people with CP who are of normal intelligence and the Dutch reference population (RNG) cannot be

explained by the physical disabilities of the study participants. Involvement in peer group activities and the opportunity to arrange dates appear to be important factors in the development of romantic relationships and sexual activities for young people with CP.

Chapter 8 presents psychological and environmental factors related to romantic relationships and sexual activity.
About half of the participants (47%) were living independently from parents. The majority of the participants were enrolled in regular education; 59% at primary school and 75% at secondary school. General self-efficacy and self-esteem of young adults with CP at T3 (age 20 to 25 years) were comparable to Dutch references.
Different processes take place between developing romantic relationships and sexual activities.

Romantic relationships.
More self-efficacy, higher self-esteem and positive sexual esteem and self perceived attractiveness increase the chance of romantic relationships for young adults with CP. Participants who followed special secondary education or perceived a rejecting parenting style were less likely to have a current romantic relationship.

Sexual activities.
Psychological factors as taking initiative, social adequacy, higher self-esteem, higher sexual esteem and feelings of attractiveness positively contributed to having sexual experiences such as cuddling nude or intercourse.

Psychological factors appear to contribute more than environmental factors to both romantic relationships and experience with sexual activities. The environment of a special secondary school may restrict the development of romantic relationships and sexual experiences, whereas the living situation (with or without parents) had no effect.

Chapter 9 discusses the main findings of the study, and relates them to earlier reports. Several strengths and limitations of our studies are also addressed. Possible directions for future research are discussed. Finally, the clinical implications of our findings are presented concerning:
- the need, in the paediatric rehabilitation care setting, for a structured focus on social skills as a condition for adequate participation in social activities.

- the need for training programs for professionals in paediatric care to learn how to talk about sex with adolescents with CP.
- the need for awareness in the adult rehabilitation care setting about the development of romantic relationships and sexuality and the possible problems young adults with CP may encounter.

Samenvatting

Dit proefschrift beschrijft de sociale contacten, verkering en seksuele ervaringen van jongeren en jongvolwassenen met cerebrale parese (CP) met normale intelligentie. Er is een groeiende belangstelling voor de maatschappelijke participatie van volwassenen met een aangeboren lichamelijke beperking. In dit opzicht is er echter weinig bekend over het functioneren, de beperkingen en behoeftes van deze groep jongvolwassenen als het om intieme relaties gaat.

CP is een verzamelnaam voor een groep van aandoeningen gekenmerkt door blijvende houdings- of bewegingsstoornis die voortkomen uit een niet-progressieve beschadiging van de hersenen van een foetus of baby. Dit gaat vaak gepaard met verstoringen in waarneming, cognitie, communicatie en gedrag. Ook epilepsie kan hierbij voorkomen. Op volwassen leeftijd kunnen klachten als pijn, vermoeidheid of vergroeiing ontstaan. Per jaar worden in Nederland ongeveer 200.000 kinderen geboren, van wie er 400 tot 500 kinderen de diagnose CP blijken te hebben. In de kinderrevalidatie is CP de meest voorkomende diagnose. Een toenemend aantal jongeren met CP wordt volwassen, waardoor problemen gerelateerd aan de transitie van kind naar volwassene meer naar voren komen en ook de levenslange zorg (life-span care) voor deze groep steeds meer aandacht krijgt.

Volgens de Internationale Classificatie van het menselijk Functioneren (ICF), die in 2001 door de Wereld Gezondheidsorganisatie (WHO) is gepubliceerd, zijn 'interpersoonlijke relaties' een domein van het gebied participatie en 'intieme relaties' zijn daarvan een subdomein. Dit subdomein in onderverdeeld in romantische, echtelijke en seksuele relaties. Omdat in dit proefschrift het functioneren van jongeren en jongvolwassenen wordt beschreven, richten we ons op romantische relaties (verkering) en seksuele ervaringen. Op deze leeftijd zijn echtelijke relaties nog uitzonderlijk en omdat seksuele ervaringen ook kunnen plaatsvinden buiten een relationele context hebben we gekozen voor de termen seksuele ervaringen of seksuele activiteiten.
Verkering, dating en seks ontwikkelen in een sociale context. Daarom beschrijven we sociale relaties als een fase die vooraf gaat aan intieme relaties.

In de Rotterdamse CP-Transitie studie hebben we 103 jongeren met CP gevolgd tijdens hun transitie naar volwassenheid. Hun functioneren en factoren die hiermee samenhangen zijn beschreven en hun maatschappelijke participatie na 4 jaar. Acht revalidatiecentra en revalidatieafdelingen van ziekenhuizen in Zuidwest Nederland en Utrecht hebben hier aan meegewerkt. Bij de start van dit onderzoek (T1) waren de deelnemers

tussen 16 en 20 jaar en na twee en vier jaar hebben er vervolg metingen plaats gevonden. Dit proefschrift is een onderdeel van deze studie.

In **hoofdstuk 2** wordt het Rotterdams Transitieprofiel beschreven en gevalideerd (=meet het wat we verwachten dat het meet). Dit profiel is ontwikkeld voor de CP transitie studie om het transitieproces kan kind naar volwassenheid te beschrijven (zie de Appendix). Transitie is de overgang van de ene levensfase naar een volgende. Dit gaat vergezeld van veranderingen in de leefwijze en omgeving van mensen en daar zijn nieuwe vaardigheden voor nodig. Voor jongeren betekent dit de stap naar zelfstandigheid in werk, op zichzelf gaan wonen,financiële onafhankelijkheid en het ontwikkelen van intieme relaties. Ze bepalen hun eigen leven en maken hun eigen keuzes. Transitie is een ontwikkelingsproces, waarin drie fases zijn te onderscheiden: afhankelijkheid van ouders, experimenteren en oriënteren op de toekomst, zelfstandig leven.

Bijna alle deelnemers waren bij de tweede meting (18 tot 22 jaar) in dit transitieproces of hadden een zelfstandig leven als volwassene bereikt. Vergeleken met leeftijdgenoten waren jongeren met CP achter in hun ontwikkeling met betrekking tot huishouden en wonen, werk en intieme relaties. De onderzoeksresultaten lieten zien dat jongeren die wat ouder waren (binnen deze leeftijdsgroep) meer kans hadden om in een hogere transitiefase te zijn. Jongeren die een hoger niveau van motorisch functioneren hadden, hadden meer kans op financiële afhankelijkheid en op zelfstandigheid qua vervoer. Tevens was deze groep vaker onafhankelijk in hun vrijetijdsbesteding (bv. 's avonds uitgaan). Jongeren met een betere handfunctie hadden vaker een volledige seksuele relatie en waren vaker onafhankelijk in vervoer en vrijetijdsbesteding.

Het Rotterdams Transitieprofiel is een valide instrument om meer inzicht te krijgen in het transitieproces, zowel bij individuele jongeren als op groepsniveau.

In **hoofdstuk 3** is de bestaande literatuur onderzocht, gericht op mogelijke belemmeringen voor succesvolle sociale, romantische en seksuele relaties bij jongeren en jongvolwassenen met CP met normale intelligentie. We hebben veertien artikelen geselecteerd. Twee daarvan richtten zich uitsluitend op mensen met CP, terwijl de in de overige 12 artikelen mensen met een aangeboren lichamelijke beperking of mensen met lichamelijke beperkingen zijn onderzocht. Een deel van deze mensen had CP. Bij alle studies betrof het jongeren of volwassenen met normale intelligentie.

Uit dit literatuuronderzoek kwam naar voren dat jongeren en jongvolwassenen met CP minder actief waren dan leeftijdgenoten en dat zij minder vaak en op latere leeftijd ervaring hebben met dating. Jongeren met aangeboren lichamelijke beperkingen gaven aan dat seksualiteit een belangrijk aspect in hun leven is, hoewel zij problemen hebben in het aangaan van seksuele relaties. Ons literatuuronderzoek liet zien dat de ontwikkeling van sociale en seksuele relaties bij jongeren met lichamelijke beperkingen bemoeilijkt kan worden door beperkt psychologisch aanpassingsvermogen, onvoldoende eigen regie (zelfbepaling) en een laag seksueel zelfbeeld. Daarbij kunnen overbeschermende ouders en een negatieve houding van de samenleving een negatieve invloed hebben op de zelfbepaling van mensen met CP. Hoewel veel onderzochte studies suggereerden dat er verschillende factoren van invloed kunnen zijn op de ontwikkeling van sociale en seksuele relaties van jongeren en jongvolwassenen met CP, hebben we alleen bewijs gevonden voor de invloed van zelfbepaling en seksueel zelfbeeld in relatie tot opvoedingsstijl. Deze factoren zijn het uitgangspunt geweest voor de huidige studie.

Hoofdstuk 4 beschrijft de sociale, romantische en seksuele relaties van Nederlandse jongeren met CP op de leeftijd van 16 tot 20 jaar (T1). We onderzochten ervaren competenties en ondervonden problemen van deze jongeren met betrekking tot deze relaties. Tevens zijn de ervaringen met betrekking tot sociale, romantische en seksuele relaties vergeleken met Nederlandse leeftijdgenoten. De gegevens over Nederlandse leeftijdgenoten zijn afkomstig uit de recente studie (2005) van de Rutgers Nisso Groep (RNG) 'Seks onder je 25e', over seksualiteit bij Nederlandse jongeren.

De resultaten laten zien dat bijna alle jongeren met CP vrienden hebben en participeerden in verschillende sociale activiteiten, maar dat 33% beneden leeftijdsniveau functioneerden op *sociaal gebied*. Ook leeftijdsadequate activiteiten, zoals 's avonds uitgaan met vrienden, werden nauwelijks ondernomen door jongeren met CP. In de beoordeling van hun uiterlijk vonden we geen verschillen tussen jongeren met CP en hun leeftijdgenoten. Meisjes met CP ervaarden minder sociale acceptatie vergeleken met Nederlandse meisjes van dezelfde leeftijd. Daarentegen was de ervaren competentie in hechte vriendschappen en hun gevoel voor zelfwaardering zowel voor jongens als meisjes met CP vergelijkbaar met Nederlandse leeftijdgenoten zonder lichamelijke beperkingen.

Hoewel jongeren met CP geen problemen ondervonden in het onderhouden van hechte vriendschappen, was het onderhouden van *romantische relaties* moeilijker. Het aantal deelnemers met vaste verkering was

betrekkelijk klein, terwijl zij wel ervaring met frekeirng hadden. De deelnemers noemden een gebrek aan zelfvertrouwen (41%) en ondervonden dat ze anders behandeld werden bij het aan (willen) gaan van een relatie.

Op de leeftijd van 16 tot 20 jaar waren jongeren met CP minder gefocust op seksualiteit en hadden minder seksuele ervaring dan Nederlandse leeftijdgenoten, zoals met masturberen (53% versus 75%), tongzoenen (59% versus 88%) en met geslachtsgemeenschap (20% versus 66%). Bijna de helft (47%) van de jongeren met CP vindt dat, als gevolg van hun lichamelijke beperkingen, het moeilijker is om een seksuele partner te vinden, maar 29% is het daar niet mee eens. Het is bemoedigend dat jongeren met CP positief zijn over hun seksueel zelfbeeld en dat bijna al deze jongeren algemene seksuele voorlichting hebben gehad. Dit laatste is anders in andere Westerse landen.

Hoofdstuk 5 beschrijft de ontwikkeling van romantische relaties en seksuele ervaringen van jongvolwassenen met CP over een periode van vier jaar en onderzoekt of er relaties zijn tussen deze ontwikkeling en persoonlijke en lichamelijke kenmerken van de deelnemers. Tevens is de seksuele ervaring van deze groep vergeleken met de Nederlandse leeftijdgenoten van de RNG studie.

We vonden een duidelijke toename in dating bij jongvolwassenen met P gedurende de transitie van late adolescentie naar jongvolwassenheid. Het hebben van verkering was echter niet duidelijk toegenomen in deze periode. Een kleine minderheid van de jongvolwassenen met CP, vooral vrouwen, had verkering. Jongvolwassenen met een lager opleidingsniveau begonnen later met daten dan degenen met hogere opleidingsniveaus. Het hebben van verkering was echter niet gerelateerd aan opleidingsniveau of lichamelijke kenmerken.

Gedurende de vier jaar van dit onderzoek is de seksuele ervaring van de deelnemers, van alle onderzochte mijlpalen, duidelijk toegenomen. Er was een relatie tussen lichamelijke beperkingen en geslachtsgemeenschap, maar niet met dating en verkering. Hoewel seksuele ervaring van jongvolwassenen met CP met meer ernstige lichamelijke beperkingen (GMFCS III-V) toeneemt tussen T1 en T3, hebben zij minder ervaring dan jongeren met CP met minder beperkingen in het lopen. Bij de laatste meting (T3) komt naar voren dat minder jongeren met CP verkering hebben en seksueel actief zijn, maar hun seksuele belangstelling is vergelijkbaar met de Nederlandse jongeren uit de RNG studie.

Hoofdstuk 6 beschrijft de problemen die jongeren met CP ervaren in de verschillende stadia van de seksuele respons cyclus en de ondervonden lichamelijke en emotionele beperkingen met seksualiteit op T3 (leeftijd 20 tot 25 jaar). Ook worden de wensen en behoeftes van jongeren met CP op het gebied van intieme relaties en seksualiteit besproken.

Jongvolwassenen met CP kunnen verschillende problemen en uitdagingen ervaren met seks. De seksuele responscyclus bestaat uit verschillende fases inclusief het zoeken van seksuele stimulatie, seksuele verlangens, seksuele opwinding en orgasme. Van de deelnemers met CP ervaart 20% geen orgasme en 80% van de deelnemers rapporteert lichamelijke problemen met seks. Er was een grote variatie in de ervaren lichamelijke problemen evenals in de frequentie dat deze problemen werden genoemd, zoals spasticiteit (41%), moeite met beenspreiding (31%), moeite met bekken kantelen (29%), stijfheid in gewrichten of spieren (28%), vermoeidheid (25%) en urineverlies, verlammingen of gevoelloosheid (5%). Deze problemen beperken de jongvolwassenen in mogelijke posities en houdingen tijdens seksuele activiteiten. Seks kan ook positieve effecten hebben op spasticiteit of stijfheid, vooral ontspanning wordt als positief effect genoemd. Naast lichamelijke problemen ervaart 45% van de jongvolwassenen met CP emotionele problemen bij het aangaan van seksuele contacten.

Ten tijde van het onderzoek hadden veel deelnemers (59%) geen contact met een revalidatie specialist, maar de meesten hebben dit wel gehad in het verleden. Op de vraag of seksualiteit ter sprake is geweest tijdens de revalidatie behandeling, antwoordde 90% dat dit niet het geval was. Toch hadden veel jongvolwassenen met CP behoefte aan meer informatie over seksualiteit, zoals de invloed van CP op de vruchtbaarheid (35%), behandelingsmogelijkheden (26%), medicatie en hulpmiddelen (16%). Daarnaast heeft 14% behoefte aan hulp om (problemen met) seksualiteit met hun partner bespreekbaar te maken. Professionals in de revalidatie zouden het initiatief moeten nemen om deze onderwerpen te bespreken met de jongvolwassenen met CP tijdens de reguliere contacten.

Hoofdstuk 7 richt zich op de ontwikkeling van *sociale contacten binnen vriendengroepen naar dating, verkering en seksuele ervaringen* vanuit een breed perspectief. Verkering krijgen en seksuele activiteiten ontplooien kunnen worden beïnvloed door verschillende factoren, inclusief persoonlijke factoren en lichamelijk functioneren, en worden in het algemeen vooraf gegaan door ontwikkelingsfases waarin jongeren meer betrokken raken bij vriendengroepen en dating activiteiten. Wij hebben onderzocht of deze eerdere ontwikkelingsfases

en activiteiten gerelateerd zijn aan de ontwikkeling van verkering en seksuele ervaringen bij jongeren met CP op T2 (leeftijd van de jongeren is dan 18 tot 22 jaar).
Jongvolwassenen met CP ontwikkelen net zoveel vriendschappen als andere jongeren. Dit veronderstelt dat zij net zoveel steun van vrienden hebben en hun aanmoediging en adviezen kunnen gebruiken bij het ontwikkelen van verkering of seksuele activiteiten.
Onze bevinding dat dating een belangrijke activiteit is voor de ontwikkeling van verkering en bevorderlijk is om seksuele ervaring op te doen is niet verrassend. Een grotere vriendenkring of uitgaan vergemakkelijken dating activiteiten. Dus net als bij jongeren zonder CP creëert hun netwerk een context waarin intieme relaties zich kunnen ontwikkelen voor jongeren met CP. De onderzoeksresultaten laten zien dat het gegeven dat sociale activiteiten en dating van invloed zijn op het ontwikkelen van intieme relaties ook van toepassing is op jongeren met CP, net als bij gewone jongeren. Opvallend is dat CP gerelateerde kenmerken geen sterke relatie hadden met de ontwikkeling van romantische relaties en seksuele activiteiten. Dus de verschillen tussen jongeren met CP met normale intelligentie en de Nederlandse jongeren uit het RNG onderzoek kunnen niet worden verklaard door de lichamelijke beperkingen van de deelnemers. Belangrijke factoren om romantische relaties te ontwikkelen en seksuele ervaring op te doen voor jongeren met CP zijn deelname aan activiteiten met vrienden en de kans hebben om te daten.

Hoofdstuk 8 presenteert psychologische en omgevingsfactoren die gerelateerd zijn aan romantische relaties en seksuele ervaringen.

Bijna de helft van de deelnemers (47%) woont onafhankelijk van hun ouders. De meeste deelnemers volgden regulier onderwijs: 59% op de basisschool en 75% in het voortgezet onderwijs. Het algemene gevoel van zelfbepaling (eigen regie) en de zelfwaardering van jongvolwassenen met CP op T3 (leeftijd 20-25 jaar) was vergelijkbaar met Nederlandse leeftijdgenoten.
Bij de ontwikkeling van verkering en het ontplooien van seksuele activiteiten spelen verschillende processen een rol.

Romantische relaties.
Meer zelfbepaling, hogere zelfwaardering, positief seksueel zelfbeeld en zichzelf aantrekkelijk voelen vergroten de kans op verkering voor jongeren met CP. Jongeren die speciaal onderwijs hebben gevolgd of die afwijzing in de opvoeding door hun ouders hebben ervaren, hebben minder kans om nu verkering te hebben.

Seksuele ervaring.
psychologische factoren als initiatief nemen, sociaal adequaat functioneren, hogere zelfwaardering, positiever seksueel zelfbeeld en zichzelf aantrekkelijk voelen dragen positief bij aan de kans op seksuele ervaringen als naakt vrijen en geslachtgemeenschap.

Psychologische factoren blijken meer dan omgevingsfactoren bij te dragen aan de kans op zowel romantische relaties als ervaring met seksuele activiteiten. De omgeving van het speciaal voortgezet onderwijs kan beperkend zijn voor relatievorming en seksuele ervaring bij jongeren met CP. De woonsituatie van de jongere met CP (met of zonder ouders) had geen invloed relatievorming en seksualiteit.

Hoofdstuk 9 bediscussieert de belangrijkste bevindingen van dit onderzoek en legt verbanden met eerdere studies. Verschillende sterke kanten en beperkingen van de huidige studies worden benoemd. Mogelijke richtingen voor verder onderzoek worden aangegeven.

Ten slotte worden er adviezen voor de praktijk geformuleerd met betrekking tot:
- het belang om structureel aandacht te besteden in de kinderrevalidatie aan sociale vaardigheden als een voorwaarde voor adequate deelname aan sociale activiteiten
- de noodzaak voor trainingsprogramma's voor professionals in de kinderrevalidatie om seksualiteit met jongeren met CP bespreekbaar te maken.
- het belang van bewustzijn in de volwassenenrevalidatie dat relatievorming en seksualiteit bij jongeren met CP nog volop in ontwikkeling is en zij daarbij problemen kunnen ervaren.

Dankwoord

BEDANKT VOOR ALLE STEUN EN

Ben Drentje

Sander Hilberink

Jan Willem Gorter

Henk Stam

Mireille Donkervoort

Alle 103 deelnemers aan het onderzoek

Contactpersonen van de deelnemende centra: dhr. Bergen, dhr. Buijs (Rijndam revalidatiecentrum), dhr. Nieuwstraten, dhr. Terburg (Sophia Revalidatie), mw. Van der Heijden-Maessen (Rijnlands revalidatie centrum), dhr. Arendzen, mw. Van Wijlen-Empel (LUMC), mw. Voogt (Revant), dhr. Gorter (revalidatiecentrum De Hoogstraat).

Marij Roebroeck

Channah Nieuwenhuijsen

Peggy Cohen-Kettenis

Arthur de Grund

Emmy Celen

Sarah Bon

Michael Bergen

MEDEWERKING!

Sten Willemsen

Rita van de Berg-Emons

Jim Bender

Wilma van der Slot

Marco van den Heuvel

Mieke Verbaarschot

Jeannet Verkleij

Marjolijn Ketelaar

De 16e: Agnes, Janneke, Mark, Bart, Berbke, Bianca, Laurien, Fabiënne, Wim, Robert, Karin, Marian, Jorrit, Carla, Nienke, Jan-Wiebe, Javad, Monique, Wilma

Ans Steenbrink

PERRIN onderzoekers

Laraine Visser

Pa en Ma

Theo !!

Betty Koehorst

Jetty van Meeteren

CURRICULUM VITAE

Diana Wiegerink was born in Hengelo (O) on 18th of November 1958. She finished her athenaeum at 'Bataafse' Kamp in Hengelo in 1977. Next she obtained her degree as a teacher at the 'Rijks Pedagogische Academie Twente' in 1980. Besides her work as a teacher in secondary education, an later in a paediatric psychiatric institution and secondary special education, she started studying Developmental and Clinical Psychology at the University of Utrecht in 1984 and finished the Master of Science education in 1989.
After this she started to work as a psychologist in the paediatric department of Rijndam rehabilitation centre and Mytylschool (special education) in Rotterdam in 1991.
In 2000 Diana became involved as a consultant in the research project ´CP Transition Study South West Netherlands´ of the Department of Rehabilitation Medicine and Physiotherapy of Erasmus MC. From 2002 she started with her PhD thesis on social, romantic and sexual relationships of adolescents and young adults with cerebral palsy at the same department besides her work as a clinical psychologist at Rijndam rehabilitation centre or rehabilitation centre De Hoogstraat in Utrecht (in 2005-2009).
In addition, she taught at the gz- psychology course in Nijmegen from 2001 to 2004.
From 1994 to 2003 Diana has been a member of the board of the section Rehabilitation of the NIP (Nederlands Instituut voor Psychologen). Since 2005 she is the representative of the NIP in LINK (Landelijk Innovatieprogramma Kinderrevalidatie) since 2010 called LOOK (Landelijke Overleg Onderwijs en Kinderrevalidatie).
Diana lives together with Theo Rem, who has two children Erwin (1969) and Minouche (1973).

Diana Wiegerink is geboren in Hengelo (O) op 18 november 1958. In 1977 behaalde zij haar VWO-diploma aan het 'Bataafse Kamp' in Hengelo. Daarna ging zij naar de 'Rijks Pedagogische Academie Twente' waar zij in 1980 haar bevoegdheid haalde. Naast haar werk in het voortgezet onderwijs, en later in de kinder- en jeugdpsychiatrie en speciaal voortgezet onderwijs, begon ze in 1984 met de studie klinische en ontwikkelingspsychologie aan de universiteit van Utrecht, die ze in 1989 afrondde.
In 1991 begon ze haar werk als psycholoog bij de kinderafdeling van Rijndam revalidatiecentrum en de Mytylschool in Rotterdam.
In 2000 raakte Diana betrokken als adviseur bij het onderzoeksproject 'CP Transitiestudie Zuidwest Nederland' van de afdeling Revalidatiegeneeskunde en Fysiotherapie van het Erasmus MC. In 2002 startte ze met haar promotieonderzoek 'Sociale, romantische en seksuele relaties van jongeren met CP' op dezelfde afdeling naast haar werk als psycholoog op Rijndam revalidatiecentrum en later bij revalidatiecentrum De Hoogstraat (in 2005 t/m 2009).
Daarnaast gaf ze les aan de opleiding voor gz-psychologen aan de universiteit in Nijmegen van 2001 tot 2004. Van 1994 tot 2003 was Diana lid van het bestuur van de sectie Revalidatie van het NIP (Nederlands Instituut voor Psychologen). Sinds 2005 is zij de vertegenwoordiger van het NIP in LINK (Landelijk Innovatieprogramma Kinderrevalidatie) dat in 2010 LOOK (Landelijke Overleg Onderwijs en Kinderrevalidatie) is geworden.
Diana woont samen met Theo Rem, die twee kinderen heeft Erwin (1969) en Minouche (1973).

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- 3.3 Cerebrale parese
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  S. van der Doef, MJ Meihuizen-de Regt en **DJHG Wiegerink**
- 2.2 De psychoseksuele ontwikkeling en beleving verstoordMJ Meihuizen-de Regt, **DJHG Wiegerink** en S. van der Doef
- 6.1 Omgaan met kinderen en jongeren
  MJ Meihuizen-de Regt, **DJHG Wiegerink** en S. van der Doef

APPENDIX

Rotterdam Transition Profile (English version)

Rotterdams Transitie Profiel (Nederlandse versie)

Rotterdam Transition Profile

Version 1.0 March 2010

What is Transition?

Transition is the change from one phase of life to another and is accompanied by changes in a person's environment or demands for new skills. For adolescents this means a move towards independence in work, housing, developing intimate relationships and financing. They take control over their life, for instance by making their own choices.
Transition into adulthood is not the same for each adolescent. Changes in domains do not have to occur at the same age or simultaneously. These changes are not necessarily problematic.

Transition profile

For transition into adulthood the following aspects are important:

a. Transition takes place in different domains of participation. Research shows that transition does not occur in all domains at the same time. Transitions will also take place for healthcare related domains.
b. Transition is a developmental process in which three phases can be distinguished:
    1. Dependent on parents
    2. Experimenting and orientating with the future
    3. Independent life

In phase 2 adolescents experiment with increasing independency. Therefore, they have to develop new skills and possibly experience problems. In this period parents become aware of the fact that their child has to learn to make choices independently to take control over their life. Filling in the Transition Profile for a young adult gives insight into the transition phase for each domain.

The Rotterdam Transition Profile is an outline of the transition phases in domains of participation. The development of the Rotterdam Transition Profile is an ongoing

process, which will be evaluated regularly based on research and clinical practice.

We look forward to your experiences and suggestions for improvement.

www.erasmusmc.nl/revalidatie/research

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Translaters: the authors and Frederike van Markus-Doornbosch

Rotterdam Transition Profile

Version 1.0 March 2010

Participation	0	1	2	3
Education and employment **0**. No education following, no job **1**. General education **2**. Vocational training, work placement **3**. Paid job, volunteer work				
Finance **0.** No pocket money **1**. Pocket money, clothing allowance **2**. Job on the side, student grant **3**. Economically independent: job income, benefits				
Housing **1.** Living with parents, not responsible for household activities **2.** Domestic training or partly responsible for household activities **2.** Seeking housing **3**. Living independently				
Leisure (social activities) **1**. Young adult arranges leisure activities with peers at home **2**. Young adult arranges leisure activities with peers outside the home, during daytime hours **3**. Young adult goes out in the evening with peers				
Intimate Relationships **0**. Young adult has no experience with dating **1**. Young adult has experience with dating, but not yet with courtship **2**. Young adult has experience with courtship **3**. Young adult has a current romantic relationship / a partner				
Sexuality **0.** Young adult has no experience with French kissing **1.** Young adult has experience with French kissing **2.** Young adult has experience with caressing under clothes, cuddling nude **3.** Young adult has experience with sexual intercourse				
Transportation **1**. Parents or caregivers transport the adolescent / young adult **2**. Parents or caregivers arrange transportation, but they do not go with him **3**. Young adult arranges transportation him/herself				

Rotterdam Transition Profile

Version 1.0 March 2010

Health care	*1*	*2*	*3*
Care demands **1**. Parents formulate care demands **2**. Parents and young adults formulate demands together **3**. Young adult formulate care demands him/herself			
Services and aids **1**. Parents apply for services and aids **2**. Young adult learns the procedures to apply for services & aids **3**. Young adult applies for services and aids him/herself			
Rehabilitation services **1**. Young adult consulted paediatric rehabilitation care in the past year **2**. No consultation of paediatric rehabilitation care in the past year **3**. Young adult consulted adult rehabilitation services			

Rotterdams Transitieprofiel

Versie 1.0 Maart 2010

Wat is transitie

Transitie is de overgang van de ene levensfase naar de volgende en gaat gepaard met veranderingen in omgeving of doet een beroep op nieuwe vaardigheden.
Bij jongeren gaat het om de stap naar een zelfstandig leven. Zoals werken, wonen relatievorming en financiën. Ze nemen zelf de regie over hun eigen leven in handen, onder andere door het zelfstandig maken van keuzes.
Niet bij elke jongere zal transitie voor alle domeinen plaats vinden op dezelfde leeftijd of hetzelfde moment. Ook hoeven er niet op alle gebieden problemen te ontstaan.

Transitieprofiel

Bij transitie zijn de volgende aspecten van belang:

a. transitie vindt plaats op verschillende domeinen van participatie. Onderzoek laat zien dat transitie niet op alle domeinen tegelijkertijd plaatsvindt. Ook voor zorg gerelateerde domeinen vinden transities plaats.
b. transitie is een ontwikkelingsproces waarin 3 fases zijn te onderscheiden:
    1. afhankelijkheid van ouders
    2. experimenteren en oriënteren op de toekomst
    3. zelfstandig leven

Voor sommige domeinen kan er ook sprake zijn van fase nul als de jongere geen ervaring heeft op dat gebied of als de fases 1 t/m 3 niet van toepassing zijn. In fase twee gaan jongeren experimenteren met meer zelfstandigheid en onafhankelijkheid. Ze moeten daarvoor nieuwe vaardigheden ontwikkelen en daarbij kunnen zij mogelijk problemen ervaren. In deze fase worden ouders zich bewust van het gegeven dat hun kind moet leren zelfstandig keuzes te maken om de regie van zijn leven in eigen hand te kunnen nemen. Door het transitieprofiel in te vullen wordt voor elk domein inzichtelijk in welke transitiefase een jongere zit.

Het Rotterdams Transitieprofiel is een schema waarin per domein de transitiefases worden benoemd. In gesprek met de jongere vult de professional samen het profiel in.

Tevens is een jongerenversie toegevoegd, die door de jongere zelf kan worden ingevuld en m.b.v. de aparte scoreversie door de professional omgezet kan worden in het profiel.

De ontwikkeling van het transitieprofiel is een doorgaand proces. Het schema zal dan ook regelmatig worden geëvalueerd en worden aangevuld aan de hand van praktijkervaringen en op basis van onderzoeksgegevens.
Wij zien uw ervaringen en suggesties voor verbetering graag tegemoet.

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Rotterdams Transitieprofiel

Versie 1.0 Maart 2010

Participatiedomeinen	0	1	2	3
Onderwijs en werk **0.** geen onderwijs en geen baan **1.** Algemeen vormend onderwijs **2.** Beroepsopleiding, stage (MLK, MBO, HBO, universiteit) **3.** betaalde baan of (onbetaald) vrijwilligerswerk				
Financiën **0.** Geen zakgeld **1.** Zakgeld, kleedgeld **2.** Bijbaantje, studiefinanciering **3.** Economisch zelfstandig: salaris of (aanvullende) uitkering				
Huishouden en wonen **1.** Thuiswonend, niet verantwoordelijk voor huishoudelijke taken **2.** Woontraining of thuis deels verantwoordelijk voor huishoudelijke taken **2.** Woningzoekend **3.** Zelfstandig, zelfverantwoordelijk wonen				
Vrije tijd (Sociale aspect) **1.** Jongere maakt afspraken met leeftijdsgenoten bij elkaar thuis **2.** Jongere maakt met leeftijdgenoten afspraken buitenshuis, overdag **3.** Jongere gaat met leeftijdsgenoten 's avonds uit				
Intieme relaties **0.** Jongere heeft geen ervaring met daten **1.** Jongere heeft wel ervaring met daten, nog geen verkering gehad **2.** Jongere heeft weleens verkering gehad **3.** Jongere heeft nu verkering/een partner				
Seksualiteit **0**. Jongere heeft geen ervaring met (tong-)zoenen **1**. Jongere heeft ervaring met (tong-)zoenen **2**. Jongere heeft ervaring met strelen onder de kleren en/of naakt vrijen **3.** Jongere heeft ervaring met geslachtsgemeenschap				
Vervoer voor vrije tijd **1.** Ouders halen en brengen de jongere **2.** Ouders regelen het vervoer (openbaar, aangepast), maar gaan niet mee met jongere **3.** Jongere regelt zelf zijn eigen vervoer				

Erasmus MC
Universitair Medisch Centrum Rotterdam

transitienet

Rotterdams Transitieprofiel

Versie 1.0 Maart 2010

Zorgdomeinen	***1***	***2***	***3***
Hulpvraag **1.** Hulpvraag wordt geformuleerd door ouders **2.** Hulpvraag wordt geformuleerd door jongere met ouders of hulpverlener / therapeut **3.** Hulpvraag wordt geformuleerd door jongere			
Voorzieningen **1.** Ouders vragen voorzieningen aan **2.** Jongere leert waar hij op moet letten bij aanvragen voorzieningen **3.** Jongere vraagt zelf voorziening aan of weet waar hij hiervoor terecht kan			
Revalidatiebehandeling **1.** Jongere is laatste jaar voor controle of behandeling in de kinderrevalidatie geweest **2.** Jongere is het laatste jaar niet voor controle bij de kinderrevalidatie-arts **3.** Jongere is voor controle of behandeling in de volwassenenrevalidatie geweest			

PHD PORTFOLIO SUMMARY

Erasmus MC
Universitair Medisch Centrum Rotterdam

Summary of PhD training and teaching activities

Name PhD student: Diana Wiegerink	PhD period: 1 august 2002- 15 august 2010
Erasmus MC Department: Rehabilitation	Promotor(s): prof Henk Stam
Research School: none	prof Peggy Cohen-Kettenis (VUmc)
	Supervisor: dr. Marij Roebroeck

1. PhD training

	Year	Workload
Research skills		
Principes van epidemiologische data-analyse Postinitieel Masteronderwijs Epedimiologie, VU Medisch Centrum, Amsterdam	2007	40 hours
Atlas –TI, Kwalitative analyses, HRO, Rotterdam	2004	8 hours
Logistische regressie en analyse van overlevingsduren Postinitieel Masteronderwijs Epedimiologie, VU Medisch Centrum, Amsterdam	2004	48 hours
Presentations		
Patiënteninstroom in CP Transitieonderzoek ZWN. Regionale refereeravond Den Haag	2002	20 hours
Maatschappelijke participatie van jongeren met cerebrale parese: transitie van kind naar volwassene in de kinderrevalidatie. PERRIN symposium Utrecht	2002	20 hours
Transition into adulthood: profile to study adolescents and young adults with cerebral palsy. Presentatie Congres European Academy of Childhood Disability (EACD). Oslo, Noorwegen	2003	20 hours
Onderzoek naar relatievorming en seksualiteit bij jongeren en jong volwassenen met cerebrale parese. Regionale refereeravond Rotterdam	2003	8 hours
Kinderen met cerebrale parese; transitie naar volwassenheid. Utrecht: Refereeravond RC De Hoogstraat, 26 januari 2004.	2004	8 hours
Onderzoek naar relatievorming en seksualiteit bij jongeren en jong volwassenen met cerebrale parese Tafel presentatie. Symposium "Kennis delen', BOSK/PERRIN Utrecht	2004	8 hours
Sociale en seksuele relaties bij jongeren met CP. Presentatie Tweede PERRIN-symposium: CP: Hoe leef je ermee? Van baby tot volwassene. Utrecht	2004	16 hours
*Social and sexual relationships of adolescents and young adults with cerebral palsy in the Netherlands***.** Postergalerij Transitieonderzoek ZWN VRA Najaarssymposium Kinderrevalidatie, een volwassen vak, Arnhem	2005	8 hours
Opvoeden tot zelfstandigheid. Presentatie Amy Schenk Symposium, Transitie bij jongeren met Cerebrale Parese.Utrecht	2005	12 hours
Het Transitieprofiel. Presentatie regionale refereeravond revalidatieartsen regio Utrecht, Utrecht,	2005	8 hours

Social and sexual relationships of adolescents and young adults with cerebral palsy in the Netherlands. Presentatie European Academy of Childhood Disability (EACD), Monaco	2005	16 hours
Social and sexual relationships of adolescents and young adults with cerebral palsy in the Netherlands. Poster International Academy of Sex Research (IASR) 32nd annual meeting, Amsterdam, The Netherlands	2006	24 hours
Social and sexual relationships of youth with CP in the Netherlands. Poster. PERRIN symposium Kinderen en jongvolwassenen met CP: hun ontwikkeling, onze zorg. Utrecht	2006	8 hours
Seksuele vorming bij kinderen met lichamelijke beperkingen. Presentatie ouderavond Mytylschool De Brug Rotterdam	2007	20 hours
Rotterdams Transitieprofiel. Presentatie t.b.v. Knowledgebrokers project. Utrecht	2008	6 hours
Social, intimate and sexual relationships of adolescents and young adults with cerebral palsy in the Netherlands. Presentation American Academy Of Cerebral palsy and Childhood Disabilities (AACPDM). Atlanta	2008	12 hours
Relatievorming en Seksualiteite bij jongeren met CP. Presentatie voor landelijke expertmeeting van TransitieNet .Utrecht	2009	12 hours
Importance of peers and dating in development of romantic and sexual relationships among young adults with CP. (AACPDM) Arizona	2009	16 hours
Rotterdams Transitieprofiel. Presentatie t.b.v. Knowledgebrokers project. Utrecht maart 2010	2010	3 hours
Importance of peers and dating in development of romantic and sexual relationships among young adults with CP. EACD 2010 Brussel	2010	6 hours
Sexuality of young adults with cerebral palsy: experienced limitations and needs. (AACPDM) Washington september 2010	2010	16 hours
International conferences		
The 15th annual Congres of the European Academy of Childhood Disability (EACD). Oslo, Noorwegen	2003	24 hours
The 17th annual Congres of the European Academy of Childhood Disability (EACD). Monaco	2005	24 hours
The 32nd annual meeting of the International Academy of Sex Research (IASR), Amsterdam	2006	16 hours
The 19th annual Congres of the European Academy of Childhood Disability (EACD). Groningen.	2007	24 hours
The 62nd Congres of the American Academy Of Cerebral palsy and Childhood Disabilities (AACPDM). Atlanta, Georgia	2008	40 hours
The 63rd Congres of the American Academy Of Cerebral palsy and Childhood Disabilities (AACPDM) Scottsdale, Arizona	2009	30 hours
The 22nd annual Congres of the European Academy of Childhood Disability (EACD), Brussel	2010	20 hours
The 64th Congres of the American Academy Of Cerebral palsy and Childhood Disabilities (AACPDM), Washington	2010	24 hours
Seminars and workshops		
Zelfbeeld en sociale relaties bij jongvolwassenen met CP. Workshop. Utrecht: BOSK Landelijke informatie-en ontmoetingsdag Cerebrale Parese, april 2005.	2005	16 hours
Let's talk about sex. Instructional course European Academy of Childhood Disability (EACD). Groningen: 14-16 Juni 2007. *Congresboek* 2007: 68.	2007	24 hours
Transitie en seksualiteit bij jongeren met lichamelijke beperkinge. Workshop. Congres "Seksualiteit bij ziekte en lichamelijke beperking: revalidatie, begeleiding en zorg", n.a.v. het uitkomen van het gelijknamige boek.	2008	20 hours

Other		
Research meetings, department of Rehabilitation Medicine and Physical Therapy	2002-2010	150 hours
2. Teaching activities		
	Year	**Workload**
Lecturing		
Lecture at the VRA-PAOG course for rehabilitation physicians Relatievorming en seksualiteit: een lasting issue bij transitie van kind naar volwassene, Nijmegen	2010	20 hours
Other		
Deelname aan Expertmeeting Aspecten van seksualiteit bij kinderen en jongeren met een lichamelijke beperking/ chronische ziekte. Rutgers Nisso Groep en revalidatiecentrum De Hoogstraat, Utrecht	2006	4 hours
Adviseur bij het ontwikkelen van module "Vriendschap, Verkering en Vrijen"	2008	4 hours
Projectadviseur voor het project "SECZ!, Seksualiteit & jongeren met Chronische Ziekten" , ontwikkelen van het spel SeCZ-TaLK	2009	40 hours
Bijdrage aan de DVD over CP (onderwerp seksuele ontwikkeling) van de BOSK	2009	8 hours
Lid van Congrescommissie congres Transitie en Seks (Me, My body and You 03-02-2011) bij jongeren met lichamelijke beperkingen of chronische aandoeningen.	2009-2010	10 hours
Deelname aan Expertmeeting 'Seksuele gezondheid en mensen met een beperking / (chronische ziekte'. Ministerie van VWS	2010	8 hours