Development of Romantic Relationships and Sexual Activity in Young Adults With Cerebral Palsy: A Longitudinal Study

Diana J. Wiergerink, MSc, Henk J. Stam, MD, PhD, FRCP, Jan Willem Gorter, MD, PhD, FRCP(C), Peggy T. Cohen-Kettenis, PhD, Marij E. Roebroeck, PhD, Transition Research Group Southwest Netherlands


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 3 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 (age range at first assessment, 16–20y; 82% Gross Motor Function Classification System level I or II).

Interventions: Not applicable.

Main Outcome Measures: Sexual interest, romantic relationships, and sexual activity.

Results: We observed a significant increase in dating in young adults with CP during the 4-year period; however, the experience in romantic relationships did not increase largely during this period. Young adults with a lower education level began dating later than those with higher levels. Significantly more women were in current romantic relationships than men. During the 4 years, participants’ sexual experience increased significantly for all sexual milestones evaluated. Level of gross motor function was associated significantly 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 equal sexual interest at the final assessment.

Conclusions: Young ambulatory adults with CP had similar sexual interests and 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 relationships was low, especially for men.

Key Words: Cerebral palsy; Longitudinal studies; Rehabilitation; Sexuality; Young adult.

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CEREBRAL PALSY IS THE most common cause of physical disability in childhood, with a prevalence of 1.5 to 2.5 per 1000 live births.1-3 If appropriate health care is available, affected children without significant comorbid conditions have actuarial survival rates approaching those of the general population.4,5 Because increasing numbers of young people with CP are now living into adulthood, problems associated with the transition from childhood to adulthood are becoming 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 developing sexual activities. From baseline measurements of our study of Dutch adolescents with CP (aged 16–20y), adolescents with CP reported less experience with romantic relationships (73%) than the reference population.8 In addition, 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 was to describe the development of sexual interest, romantic relationships, and sexual activities in young adults with CP during a period of 4 years. Our second aim was to investigate whether the development of young adults with CP during this 4-year period was associated with demographic and physical characteristics. Last, we compared the level of romantic and sexual functioning in young adults with CP aged 20 to 24 years with an age-appropriate Dutch reference population.

List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>CP</td>
<td>Cerebral palsy</td>
</tr>
<tr>
<td>GMFCS</td>
<td>Gross Motor Function Classification System</td>
</tr>
<tr>
<td>IQ</td>
<td>Intelligence quotient</td>
</tr>
<tr>
<td>t1</td>
<td>Start of the study</td>
</tr>
<tr>
<td>t2</td>
<td>2 years after the start of the study</td>
</tr>
<tr>
<td>t3</td>
<td>4 years after the start of the study</td>
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</table>

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From the Department of Rehabilitation Medicine and Physiotherapy, Erasmus MC, University Medical Center, Rotterdam, The Netherlands (Wiergerink, Stam, Roebroeck); Rijndam Rehabilitation Center, Rotterdam, The Netherlands (Wiergerink); Rehabilitation Center De Hoogstraat, Utrecht, The Netherlands (Gorter); CanChild Centre for Childhood Disability Research, McMaster University, Hamilton, ON, Canada (Gorter); and the Department of Medical Psychology, VU University Medical Center, Amsterdam, The Netherlands (Cohen-Kettenis).

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Reprint requests to Marij E. Roebroeck, PhD, Erasmus MC, Dept of Rehabilitation Medicine, PO Box 2040, 3000 CA Rotterdam, The Netherlands, e-mail: m.roebroeck@erasmusmc.nl.0003-9993/10/0910-0034$36.00/0 doi:10.1016/j.apmr.2010.06.011

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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 up adolescents with CP as they transition to adulthood. At t1, participants were aged 16 to 20 years at inclusion (birth years, 1982–1986). Exclusion criteria were the existence of cognitive disabilities (IQ<70), comorbid conditions with a 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 because of incorrect addresses. An informational letter about the study was sent to 184 patients, and 103 chose to participate (response rate, 56%). At t2, a total of 16% of the 103 participants dropped out, leaving 87 participants. At t3, a total of 26% of the 103 initial t1 participants dropped out, leaving 76 participants. The dropout at t3 occurred because of 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 nonresponse or lost-to-follow-up biases were observed in terms of age, gender, gross motor functioning, and limb distribution of paresis. Compared with 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 1).6 We distinguished between 2 levels of education: (1) low (prevocational practical education or lower), and (2) medium and high (ranging from prevocational theoretical education to postsecondary college and/or university). To assess the severity of gross motor limitations, trained physiotherapists used the GMFCS,11,12 which has been validated for young adults with CP.13,14 Because of the small subgroups, results of the GMFCS were dichotomized as levels I to II (walking without an aid) versus levels III to V (mobility with aid).

During each assessment, trained researchers administered a semistructured 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 4 sexual milestones: French kissing, feeling and caressing under the clothes, cuddling nude (without intercourse), and intercourse (vaginal penetration). We added an additional question about dating (an amorous appointment) from the Vineland Adaptive Behavior Scales-Survey Form.16,17 The Vineland Adaptive Behavior Scales-Survey Form assesses age-appropriate adaptive behavior in juveniles and is scored according to 3 multiple-choice responses: usually, sometimes, or never.17,18 We verified that participants could easily understand the questionnaires. The same interview and questionnaire was used for baseline and follow-up measurements. The reliability of follow-up answers was very high, and only 1 subject gave inconsistent answers.

We evaluated how sexual interest, romantic relationships, and sexual activity developed over time. The 3 specific indicators, 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 by using SPSS 16.0 for Windows,9 and longitudinal analyses were performed by using SAS 9.1.3.3 We performed repeated-measures analyses by using the PROC GENMOD procedure for generalized estimated equations, 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 that treated time as an independent factor along with 1 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, then the main effects of the factor and time were estimated. The level of significance for all analyses was .05.

To optimally use all available information from the 3 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 7 participants with experience with cuddling nude at t2 to 21 participants 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.” However,
if we knew only that a participant had experience with intercourse at t3, this item is unknown at t1 and t2 (missing values).

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 men and 901 women aged 20 to 24 years in 2005. Pearson chi-square tests (2 sided) were performed.

**RESULTS**

**Development Over Time**

The development of sexual interest, romantic relationships, and sexual activity in young adults with CP during the 4-year period is listed 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, 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, young adults with CP showed significant increases in sexual experience during the 4-year period (see 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 onward, there were no significant differences in dating experience between the 2 groups (fig 1; table 3). No other significant interaction effects with time were identified (see table 3).

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 (fig 2; table 3). Despite 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.

Repeated-measures models affirmed that experience with dating and intercourse increased over time. In addition, gross motor functioning level (GMFCS levels I–II vs III–V) was associated significantly with intercourse experience but not with dating. Both GMFCS subgroups had increased intercourse experience over time, but ambulatory young adults (GMFCS levels I–II) had more experience at baseline (t1) and showed a greater increase in intercourse experience over time than those who walked with limitations or used a wheelchair (fig 3; table 3). We observed no associations of gender with dating and intercourse, and there were no associations between education level and intercourse experience.

**Comparison With an Age-Appropriate Dutch Reference Population**

In comparison with the reference population, young adults with CP showed significantly delayed development for all relational aspects (see 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 in comparison with the gender-specific reference groups (56% and 69%, respectively; P<.001). Young adults with CP showed similar levels of

**Table 2: Development Over Time of Sexual Interest, Romantic Relationships, and Sexual Activity of Young Adults With CP Compared With a Dutch Reference Group**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequencies</th>
<th>Sign Differences</th>
<th>t3 Compared With Dutch References</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Δt3–t1</td>
<td>Δt3–t2</td>
</tr>
<tr>
<td>Sexual interest</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fantasizing about girls</td>
<td>48 (48)</td>
<td>52 (57)</td>
<td>53 (66)</td>
</tr>
<tr>
<td>Fantasizing about boys</td>
<td>24 (24)</td>
<td>25 (29)</td>
<td>25 (33)</td>
</tr>
<tr>
<td>Masturbating</td>
<td>52 (53)</td>
<td>62 (70)</td>
<td>68 (80)</td>
</tr>
<tr>
<td>Romantic relationships</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dating</td>
<td>53 (52)</td>
<td>70 (74)</td>
<td>73 (76)</td>
</tr>
<tr>
<td>Experience with romantic relationships</td>
<td>74 (73)</td>
<td>77 (79)</td>
<td>77 (79)</td>
</tr>
<tr>
<td>Current romantic relationship</td>
<td>20 (19)</td>
<td>20 (23)</td>
<td>21 (28)</td>
</tr>
<tr>
<td>Sexual activity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>French kissing</td>
<td>60 (59)</td>
<td>71 (74)</td>
<td>77 (83)</td>
</tr>
<tr>
<td>Caressing</td>
<td>47 (47)</td>
<td>60 (66)</td>
<td>66 (76)</td>
</tr>
<tr>
<td>Cuddling nude</td>
<td>32 (32)</td>
<td>48 (54)</td>
<td>57 (70)</td>
</tr>
<tr>
<td>Intercourse</td>
<td>20 (20)</td>
<td>36 (40)</td>
<td>47 (60)</td>
</tr>
</tbody>
</table>

NOTE: *Significant differences (P<.05).
Abbreviations: ND, no data; P|zI, P for the absolute value of the z score; Δt3–t1, the difference between t3 and t1.
sexual activities without a partner (fantasizing and masturbation) at t3 compared with the reference population.

**DISCUSSION**

This is the first study, to our knowledge, describing the development of sexual interest, romantic relationships, and sexual activity in young adults with CP over time. Our results show 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. In addition, nonambulatory young adults had less experience with intercourse than ambulatory young adults. Despite their increasing experience during the 4-year period studied, young adults with CP participated at a lower level in terms of romantic relationships and sexual activities compared with an age-appropriate Dutch reference population.

**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 and 24 years. The number of individuals in current romantic relationships did not increase largely over time. Most 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; therefore, other factors, such as psychologic (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” showed that young people with prevocational practical education begin with sexual activities (including intercourse) earlier than their more highly educated age-mates. These results were in contrast to results of our study, in which we observed no difference in intercourse experience between the 2 subgroups divided by education level. We observed that young people with a lower educational level began dating later than more highly educated young adults. This difference might have been caused by the inclusion of participants with IQs of 70 to 85 in this study because this subgroup did not participate in the Dutch study because of not attending regular schools. Post hoc analysis confirmed that the subgroup of young people with an educational level corresponding approximately to an IQ of 70 to 85 had less dating experience. We speculate that these young adults are less enterprising regarding dating behavior or that overprotective parents may have 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 agrees with results of our cross-sectional study, in which we observed no associations between dating, overall sexual activities, and GMFCS level. 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 levels 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

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**Table 3: Associated Factors for Development Over Time for Dating, Current Relationship, and Intercourse**

<table>
<thead>
<tr>
<th>Variables</th>
<th>Dating $\chi^2$/df</th>
<th>$P$</th>
<th>Current Relationship $\chi^2$/df</th>
<th>$P$</th>
<th>Intercourse $\chi^2$/df</th>
<th>$P$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interaction effects</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender × time</td>
<td>$\chi^2=5.72$</td>
<td>.60</td>
<td>$\chi^2=1.56$</td>
<td>.46</td>
<td>$\chi^2=2.06$</td>
<td>.36</td>
</tr>
<tr>
<td>Educational level × time</td>
<td>$\chi^2=8.03$</td>
<td>.020*</td>
<td>$\chi^2=2.17$</td>
<td>.34</td>
<td>$\chi^2=1.14$</td>
<td>.56</td>
</tr>
<tr>
<td>GMFCS × time</td>
<td>$\chi^2=3.20$</td>
<td>.200</td>
<td></td>
<td></td>
<td>$\chi^2=0.50$</td>
<td>.780</td>
</tr>
</tbody>
</table>

**Main effects**

- Gender: $\chi^2=5.50$, $P=.480$
- Time: $\chi^2=16.37$, $P<.001^*$
- Educational level: NA
- Time: NA
- GMFCS: $\chi^2=2.35$, $P=.130$
- Time: $\chi^2=18.03$, $P<.001^*$

NOTE: *Significant differences (P<.05).
Abbreviation: NA, not applicable.
observed in this study differs from results of a study by Cheng

the reference population. The delayed intercourse experience
young people with CP had fewer sexual experiences than
normal psychosexual development. Despite their normal inter-
sexual activities.

Comparison With the Reference Population

By the age of 20 to 24 years, the sexual interest of young
people with CP was similar to that of the reference population.
It is important for parents and professionals to recognize this
normal psychosexual development. Despite their normal inter-
interest, young people with CP had fewer sexual experiences than
the reference population. The delayed intercourse experience
observed in this study differs from results of a study by Cheng
and Udry20 of approximately 18,000 adolescents in U.S.
schools from 1994 to 1995. They concluded that students with
disabilities were as sexually experienced (coital sex) as their
nondisabled counterparts.20 Dutch young adults with CP re-
ported less intercourse experience than disabled American
youth, but the intercourse experience of the American and
Dutch reference populations was similar. In contrast to our
study, the American report evaluated students with different
disabilities in a regular education setting. Therefore, these
differences may be caused by differences in educational level,
types of disabilities evaluated, or other factors. Thus, it is
important to study psychologic and environmental determi-
nants of sexual activity in young adults with CP in the Neth-

We cannot conclude that our results indicate that young
adults with CP are “slow starters,” because their delayed de-
velopment did not catch up during the 4-year period evaluated.
A longer follow-up period will be necessary to see whether
their sexual experiences eventually become comparable with
the Dutch reference population.

Limitations of the Study

Most 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 partici-
pants were explicit homosexuals.5 This percentage is too small
to analyze homosexuality as a separate subgroup.

Most sexual experiences reported were consensual; how-
ever, 6% of 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 de-
velopment 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 trajectories31 showed that approximately one
quarter of 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 with the reference group, young adults with CP
aged 20 to 24 years had similar sexual interest but less expe-
rience establishing romantic relationships and with sexual ac-

tivities. Therefore, health care professionals must include dis-
cussions of sexuality with young adults with CP as for any
other adolescent/young adult. To talk about these developmen-
tal aspects with young adults, the Rotterdam Transition Profile
can be used,27 and the easily remembered abbreviation
HEADSs (home, education, activities, drugs, sex, and suicide)
can be used to ask a sequence of questions about home,
education, activities, drugs, sex, and suicide.22–24 Professionals
also can discuss the challenges of romantic relationships and
sexual activity in young adults with CP. In nonambulatory
young adults with CP, physical restrictions can hamper their
intercourse experiences. These specific problems require spe-
cialist 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 ability to be emotionally and sexually
intimate. Results of previous research indicated that restricted
participation in peer-group activities and dating might be a
barrier for young adults with CP15; however, it is unknown
whether additional factors may impede the development of
romantic relationships and sexual activity. Lock25 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 rela-
tionships 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 transi-
tion to adulthood. However, compared with the reference pop-
ulation, 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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