Childhood constipation treatment, long-term prognosis and quality of life
Bongers, M.E.J.
Chapter 8

Course of life in young adults with a history of childhood constipation

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Submitted
ABSTRACT

Background & Aims
In a substantial subgroup of children, functional constipation is a chronic disorder which may influence children’s psychosocial development. This study aimed to evaluate autonomy, psycho-sexual and social development and socio-demographic outcomes in young adults with a history of childhood constipation with or without fecal incontinence.

Methods
At a Dutch tertiary centre, a cross-sectional study was performed in a long-term follow-up cohort of children with functional constipation. A total of 181 patients from this cohort, aged between 18 and 30 years, and 361 young adults from the general Dutch population filled out the Course of Life questionnaire.

Results
Compared to controls, course of life was delayed in adults with a history of childhood constipation. They achieved fewer milestones with respect to autonomy and social development. Delayed course of life was especially found in a subgroup of these adults who experienced fecal incontinence up to a maximum of 18 years, but not in adults who never experienced fecal incontinence or not after the age of 12. Educational level was lower among adults with a history of childhood constipation than among controls, and unemployment rate was higher.

Conclusions
Autonomy and social development of young adults grown up with functional constipation was delayed, especially in those with long duration of constipation-associated fecal incontinence up to adolescent age. Clinicians should encourage parents in stimulating their child in these areas. The impact of lower socioeconomic status in adults with a history of childhood constipation on course of life needs to be further evaluated.
INTRODUCTION

Functional constipation in children is a common disease with a worldwide prevalence of 8.9% (range 0.7-29.6%) \(^1\). Main symptoms in children with constipation are a low defecation frequency, hard stools, painful defecation and frequent episodes of fecal incontinence. Other frequently accompanying symptoms of childhood constipation are abdominal pain, poor appetite and urinary incontinence \(^2\), \(^3\). The underlying pathophysiology is still not fully understood. Treatment of childhood constipation is therefore mainly symptomatic consisting of education, behavioral advices such as toilet training and laxatives \(^4\), \(^5\). Despite intensive treatment and follow-up, 25-30% of children with constipation experience persistence of symptoms into adulthood \(^6\), \(^7\).

Growing up with a chronic disease or with chronic constipation may influence the child’s psychosocial development, such contacts and interaction with peers or becoming independent. Fulfillment of age-specific developmental tasks and achievement of developmental milestones during childhood and adolescence, referred to as ‘course of life’, are of great importance to the adjustment to later adult life \(^8\), \(^9\). A hampered course of life was found in young adults with chronic diseases during childhood, like cancer, end stage renal disease, and organic causes of chronic constipation and fecal incontinence (i.e. Hirschsprung’s disease and anorectal malformations) \(^10\). In those adults growing up with Hirschsprung’s disease or anorectal malformations, psychosexual development was found to be impaired, while patients who grew up with anorectal malformations also reported less favorable social development and less achievement of autonomy milestones.

To date, no knowledge exists on the achievement of developmental milestones of young adults grown up with functional constipation. Suffering from constipation and fecal incontinence may lead to decreased participation in both school-based and after school activities, e.g. participating in (school) sports, playing with friends. Distress of experiencing fecal incontinence during adolescence may negatively affect peer interaction and sexual development. Long-term symptoms and treatment of children with constipation can increase parental concerns and involvement, possible limiting the child’s acquisition of independence. Therefore, the aim of this study was to compare the autonomy, psycho-sexual and social development and socio-demographic outcomes in young adults with childhood constipation to a reference group of young adults from the Dutch population. Furthermore, the relationship between these developmental outcomes on the one hand and experiencing fecal incontinence during specific age periods (childhood and/or adolescence) on the other hand was evaluated.
METHODS

Procedure
A cross-sectional study was performed at the Department of Pediatric Gastroenterology and Nutrition of the Emma Children’s Hospital/Academic Medical Centre in Amsterdam. Patients were selected from an existing follow-up cohort of children with functional constipation formed between 1991-1999. Children were included in this follow-up cohort after participation in one of the research protocols on childhood constipation. Diagnosis of functional constipation was based on presence of at least two of the following criteria: 1) defecation frequency less than three per week; 2) two or more episodes of fecal incontinence per week; 3) passage of very large amounts of stool once every 7 – 30 days; 4) a palpable abdominal or rectal mass on physical examination. Patients under 5 years of age and/or patients with laxative treatment shorter than 2 months prior to inclusion in one of the research protocols were excluded, as those with organic causes of constipation. After ending the 6-8 weeks treatment protocols, follow-up was conducted 6 months and annually thereafter during a visit to the outpatient clinic or by phone using a standardized questionnaire.

Between 2004 and 2007, patients aged between 18 and 30 years in this cohort were asked during standard follow-up to participate in this study by filling out the Course of Life questionnaire. After completion at home, the questionnaire could be returned in a stamped addressed envelope provided. In case of no response, the patient was reminded by phone with a maximum of two follow-up calls. Inclusion criteria for participation in the study were: 1) age 18-30 years before 1 January 2007; 2) the ability to read and understand the Dutch language of the questionnaire. Patients who did not want to participate were asked to give their reason for declining study participation by phone. All patients declining to fill in the Course of Life questionnaire did however answer questions regarding their defecation pattern. Therefore medical follow-up was conducted in all contacted patients. All participants signed an informed consent form. The study protocol was approved by the medical ethical committee of the Academic Medical Centre of Amsterdam.

Measures
Course of life
The Course of life questionnaire, a Dutch questionnaire developed by the Psychosocial department of the Emma children’s hospital/Academic Medical Centre, was used to retrospectively assess achievement of developmental
milestones in children. This instrument was developed to assess the course of life of young adults, aged between 18 and 30 years, who grew up with a chronic or life-threatening disease, in comparison with the course of life of peers without a history of disease. Most questions retrospectively ask whether the respondent has achieved factual developmental milestones (yes, no), or at which age (category) the respondent achieved the milestones. Questions do not go further back in time than primary school. Answers are dichotomized, where necessary, before being added to the scale-score. For this study, three scales of the Course of life questionnaire were used: (1) development of autonomy (6 items about autonomy at home and outside home; (2) psycho-sexual development (4 items about love and sexual relations); (3) social development (12 items about social contacts with peers, at school and in leisure time). A higher score on the scales indicates the accomplishment of more developmental milestones and therefore a more favorable course of life. Apart from these scales, the questionnaire measures social-demographic outcomes in young adulthood, such as living situation, education, and employment.

A normative population for the Course of life questionnaire was formed previously, including a sample of 508 young adults from the general Dutch population. As our study population was younger than this normative population, we selected adults in the comparable age range. Thus we included only those adults who were between 18 and 27 years of age as reference group for this study (n=361).

Validity, test-retest reliability and internal consistency of the Course of life scales are good, except for moderate internal consistency of the autonomy scale. Items in this scale concern diverging aspects of autonomy. The Cronbach’s alphas in the population under study were low to good: (1) development of autonomy: study population 0.39, reference 0.50; (2) psycho-sexual development: study population 0.77, reference 0.70; (3) social development: study population 0.78, reference 0.71. The use of scales with low to moderate internal consistency is acceptable for group comparisons because internal consistency is an indication of random error and has nothing to do with systematic error (bias).

Medical data
The following medical data were obtained from the follow-up database at the Department of Pediatric Gastroenterology & Nutrition: intake characteristics: age of onset, age, defecation frequency, fecal incontinence frequency, passage of large stools, presence of abdominal and/or rectal mass, duration of symptoms before intake; follow-up characteristics: duration of follow-up, age at last follow-up, presence of fecal incontinence at each follow-up moment.
Patients were categorized in subgroups based on the age at which they experienced fecal incontinence during childhood: 1) < age 6 years or never; 2) up to a maximum of 12 years; 3) up to a maximum of 18 years.

Statistical Analysis
Descriptive analysis was performed to assess the characteristics of the sample. To detect a priori differences between adults with childhood constipation and the reference group, demographic characteristics were compared using Student’s t-test and Chi-square-test. Univariate analyses of variance (ANOVA) were conducted to test group differences on the three Course of life scales, controlled for age at study and gender. Effect sizes (d) on the course of life scales were calculated by dividing the differences in mean score between adults with childhood constipation (total study population and subgroups categorized by age of experiencing fecal incontinence) and reference group by the standard deviation of the scores in the reference group. Effect sizes of 0.2, 0.5 and 0.8 were considered small, moderate and large, respectively. In order to gain detailed insight into the course of life of the participants, logistic regression with correction for age at study and gender was conducted to determine the main effect of group (total study population versus the reference group) on items of the scales on which significant differences between groups were found. In addition, logistic regression was conducted to determine differences between groups (total study population versus the reference group) in living situation, marital status, educational level (dichotomized: low versus middle/high) and occupational status, taking gender and age at study into account. Item frequencies and percentages are reported in a descriptive way. Due to the explorative nature of this study, priority was given to find phenomena that exist (avoiding type II errors) rather than correcting for multiple testing (avoiding type I errors). Therefore, a significant level of 0.05 was used for all analyses.

RESULTS
Population
From the existing follow-up cohort of 416 children with constipation, 299 patients reached the age of 18 years before January 2007. Of these adults, 68 patients (22.7%) dropped out from the follow-up cohort before 2004 for several
reasons: wrongly included in previous research protocols: n=9, protocol violation: n=2, lost to follow-up: n= 56 and diseased: n=1. No significant differences were found in gender, age of onset, age, defecation and fecal incontinence frequency at first visit to the outpatient clinic between drop-outs of the follow-up cohort compared to those available for follow up.

For this study, 231 young adults of the follow-up cohort were eligible. A total of 181 patients (58.0% males, mean (±SD) duration of follow-up 12.2 (±1.8) years) returned the questionnaire (response 78.3%). Clinical characteristics at first visit to the outpatient clinic of these young adults are shown in table 1. During childhood, fecal incontinence was never experienced or no longer present from the age of 6 years in 12% of patients, while 41% of patients

| Table 1. Demographic and clinical characteristics of the study population and reference |
|-----------------------------------------------|------------------|------------------|
| Study Population (n= 181) | Reference (n= 361) |
| **Demographic characteristics** | **Study Population** | **Reference** |
| Age at study (years)* | Mean | SD | Range | Mean | SD | Range |
| % | N | % | N |
| Gender** | 58.0 | 105 | 47.1 | 170 |
| Male | 42.0 | 76 |
| Female | 98.9 | 179 | 97.2 | 351 |
| Native Country | 1.1 | 2 | 2.8 | 10 |
| The Netherlands | Low | 35.8 | 59 | 36.8 | 125 |
| Other | Middle | 38.8 | 64 | 27.4 | 93 |
| Educational level parents** | High | 25.5 | 42 | 35.9 | 122 |
| Low | Middle | 2.9 | 3.2 | 0.0-16.0 | 0.0-16.0 |
| Defecation frequency / week | 13.1 | 11.2 | 0.0-56.0 | 0.0-56.0 |
| Fecal incontinence frequency / week | % | N | 5.1-17.1 |
| Passage of large stools | 64.6 | 117 |
| Abdominal scybalus | 21.5 | 39 |
| Rectal scybalus | 28.7 | 52 |
| Age of experiencing fecal incontinence# | % | N |
| < age 6 years or never | 11.6 | 21 |
| up to a maximum of 12 years | 40.9 | 74 |
| up to a maximum of 18 years | 47.5 | 86 |

*p= 0.001, Student’s T-test; **p= 0.02, Chi-square test. # during childhood
experienced fecal incontinence up to a maximum age of 12 compared to 48% with fecal incontinence up to a maximum age of 18 (table 1). Of the 50 adults with childhood constipation who did not complete the questionnaires (non-responders), 19 (38.0%) did not have enough time or did not feel like participating in the study and 31 (62.0%) agreed to fill out the questionnaires, but failed to return them. There was a higher percentage of women among the respondents compared to the non-responders (42.0% versus 22.0%, p=0.01).

Age of onset and age, defecation and fecal incontinence frequency at first visit to the outpatient clinic were not significantly different between responders and non-responders, as well as follow-up duration and age at last follow-up (data not shown).

The reference group appeared to be different from the study population with respect to age, gender and educational level of their parents (table 1).

Course of life scales: autonomy, psycho-sexual and social development

**Total study population versus the reference group**

Adults grown up with childhood constipation had significantly lower scale scores on autonomy development (F(1,529)=9.9, p=0.002) and social development (F(1,489)=5.5, p=0.02), than the reference group (table 2). The

<table>
<thead>
<tr>
<th>Study Population</th>
<th>Reference</th>
<th>Effect size (d)1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age experiencing fecal incontinence</td>
<td>Total</td>
<td>Total</td>
</tr>
<tr>
<td>&lt;6 y or Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autonomy development</td>
<td>n= 21</td>
<td>n= 69</td>
</tr>
<tr>
<td>Mean</td>
<td>9.10</td>
<td>8.93</td>
</tr>
<tr>
<td>SD</td>
<td>1.51</td>
<td>1.51</td>
</tr>
<tr>
<td>Psycho-sexual development</td>
<td>n= 21</td>
<td>n= 70</td>
</tr>
<tr>
<td>Mean</td>
<td>7.38</td>
<td>7.19</td>
</tr>
<tr>
<td>SD</td>
<td>1.02</td>
<td>1.22</td>
</tr>
<tr>
<td>Social development</td>
<td>n= 20</td>
<td>n= 63</td>
</tr>
<tr>
<td>Mean</td>
<td>21.65</td>
<td>20.62</td>
</tr>
<tr>
<td>SD</td>
<td>1.73</td>
<td>2.73</td>
</tr>
</tbody>
</table>

*p<0.05; **p<0.01; univariate ANOVA’s of Course of life scales by group, gender and age at study. 1 Effect sizes for comparison between total study population and reference.
differences between adults with a history of childhood constipation and the reference group were small: effect sizes (d) of 0.33 and 0.21 respectively. In addition, a main effect of age at study was found on social development (F(1,489)=4.1, p=0.04). Older participants (both in the study population and the reference group) had reached more social developmental milestones. No differences were found for psycho-sexual development.

Subgroups of study population versus the reference group
Significantly lower scores, with small effect sizes, on autonomy (F(1,439)=10.7, df=1, p=0.001, d= 0.42) and social development (F(1,406)=6.1, df=1, p=0.01, d= 0.32) were found among adults who experienced fecal incontinence up to a maximum of 18 years of age than among the reference group (table 2). Adults with no history of fecal incontinence or those who experienced fecal incontinence up to a maximum age of 12 years showed no difference in developmental achievements compared to the reference group.

Course of life on item level
Table 3 shows the individual milestones frequencies of the Course of life scales autonomy and social development for both the total study population and their healthy peers. With respect to autonomy development, a significant predictive effect of group was found on two items. A lower percentage of the study population than the reference group had a regular task in their family during secondary school (odds ratio=0.66, 95%CI (0.46-0.96), p=0.03). In addition, gender was a significant predictor of this item, with males reporting a regular task in their family during secondary school less often than females (odds ratio=0.64, 95%CI (0.45-0.91), p=0.01). The study population reported that they went less often on holiday without adults before the age of 17 years than the reference group (odds ratio=0.68, 95%CI (0.47-0.98, p=0.04). A younger age at intake was also predictive for a lower percentage of going on holiday without adults (odds ratio= 0.93, 95%CI (0.87-0.99), p=0.04).

On three out of the 12 items of social development, group was a significant predictive factor for the difference between the study population and the reference group. During primary school, a lower percentage of the study population spent their playing time with friends compared to the reference group (odds ratio=0.38, 95%CI (0.23-0.63), p<0.001). Furthermore, a lower percentage of the study population than the reference group had been a member of a sports club for at least a year during secondary school (odds ratio=0.44, 95%CI (0.30-0.66), p<0.001). Being member of a sports club for at least a year was also lower in the study population for the period after
Table 3. Frequencies of the individual (dichotomized) items of two Course of life scales

<table>
<thead>
<tr>
<th>Study population</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
<td>N</td>
</tr>
</tbody>
</table>

### a) Autonomy development

- **Regular task in your family, primary school**
  - yes: 38.5% (69) vs 44.4% (160), no: 61.5% (110) vs 55.6% (200)
- **Paid jobs, primary school**
  - yes: 27.8% (50) vs 34.2% (123), no: 72.2% (130) vs 65.8% (237)
- **Regular task in your family, secondary school**
  - yes: 49.7% (89) vs 59.6% (214), no: 50.3% (90) vs 40.4% (145)
- **Paid jobs, secondary school**
  - at the age of 18 or younger: 86.0% (154) vs 87.5% (316), at the age of 19 or older/never: 14.0% (25) vs 12.5% (45)
- **For the first time being on holiday without adults**
  - at the age of 17 or younger: 46.1% (83) vs 54.3% (196), at the age of 18 or older/never: 53.9% (97) vs 45.7% (165)
- **Leaving your parents place**
  - not living with your parents: 37.0% (67) vs 51.8% (187), still living with your parents: 63.0% (114) vs 48.2% (174)

### b) Social development

- **At least one year of membership in a sports club, primary school**
  - yes: 81.8% (148) vs 86.4% (311), no: 18.2% (33) vs 13.6% (49)
- **Number of friends in first-third grade, primary school**
  - less than 4: 33.7% (60) vs 33.7% (121), 4 or more: 66.3% (118) vs 66.3% (238)
- **Number of friends in fourth-sixth grade, primary school**
  - less than 4: 32.8% (59) vs 28.3% (102), 4 or more: 67.2% (121) vs 71.7% (258)
- **Best friend, primary school**
  - yes: 71.8% (130) vs 74.0% (267), no: 28.2% (51) vs 26.0% (94)
- **Most of the time playing with ..., primary school**
  - friends: 79.2% (141) vs 90.1% (319), brothers and/or sisters, parents, on your own: 20.8% (37) vs 9.9% (35)
- **At least one year of membership in a sports club, secondary school**
  - yes: 59.8% (107) vs 75.3% (272), no: 40.2% (72) vs 24.7% (89)
- **Number of friends, secondary school**
  - less than 4: 29.1% (52) vs 26.7% (96), 4 or more: 70.9% (127) vs 73.3% (264)
- **Best friend, secondary school**
  - yes: 74.2% (132) vs 72.2% (260), no: 25.8% (46) vs 27.8% (100)
- **Belonging to a group of friends, secondary school**
  - yes: 81.5% (145) vs 82.1% (293), no: 18.5% (33) vs 17.9% (64)
- **Leisure time, mainly with ..., secondary school**
  - friends: 84.4% (146) vs 86.6% (311), brothers and/or sisters, parents, on your own: 15.6% (27) vs 13.4% (48)
  - going out to a bar or disco, secondary school
  - sometimes / often: 79.6% (144) vs 85.3% (308), never: 20.4% (37) vs 14.7% (53)
- **At least one year of membership in a sports club, after secondary school**
  - yes: 32.2% (56) vs 48.7% (171), no: 67.8% (118) vs 51.3% (180)

*p<0.05; **p<0.001: Significance for group according to logistic regression corrected for age at study and gender.
secondary school (odds ratio=0.48, 95%CI (0.33-0.71) p<0.001). Besides this predictive effect of group, gender was another significant predictor of this item, with males being more often member of a sport club after secondary school than females (odds ratio=1.53, 95%CI (1.07-2.18), p<0.02).

Socio-demographic outcomes
Socio-demographic outcomes of the total study population and the reference group are depicted in table 4. Still living with their parents was significantly associated with age at study and gender (odds ratio=0.74, 95%CI (0.29-0.63) and odds ratio=1.6, 95%CI (1.4-1.7) respectively; p<0.001), but not with group. For both young adults in the study population as those in the reference group, it was found that younger participants and males more frequently still lived at home with their parents. Similarly, the percentage of adults being single was predicted by age at study (odds ratio=1.56, 95%CI (1.40-1.73), p<0.001) and gender (odds ratio=0.46, 95%CI (0.29-0.74), p=0.002), showing that the percentage of singles was for higher younger participants and males. No association with group was found. The highest completed level of education was lower for the study population than the reference group (low educational level: 51.2% versus 29.2), with group being a significant predictor

Table 4. Percentage and differences between study population and reference group in socio-demographic outcomes

<table>
<thead>
<tr>
<th></th>
<th>Study population Total</th>
<th>Reference Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Living with their parents</td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>63.0</td>
<td>114</td>
</tr>
<tr>
<td>no</td>
<td>37.0</td>
<td>67</td>
</tr>
<tr>
<td>Marital status</td>
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<td></td>
</tr>
<tr>
<td>married / living together</td>
<td>16.4</td>
<td>29</td>
</tr>
<tr>
<td>Single</td>
<td>83.6</td>
<td>148</td>
</tr>
<tr>
<td>Educational level(^1)</td>
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<td></td>
</tr>
<tr>
<td>low</td>
<td>51.2(^*)</td>
<td>87</td>
</tr>
<tr>
<td>middle</td>
<td>45.3</td>
<td>77</td>
</tr>
<tr>
<td>high</td>
<td>3.5</td>
<td>6</td>
</tr>
<tr>
<td>Employment status(^2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>employed</td>
<td>77.8(^*)</td>
<td>70</td>
</tr>
<tr>
<td>not employed</td>
<td>22.2</td>
<td>20</td>
</tr>
</tbody>
</table>

\(^*\) p<0.001; Significance for group according to logistic regression corrected for age at study and gender. 1 Highest level completed: Low: primary education, technical and vocational education, lower and middle general secondary education Middle: Middle vocational education, higher general secondary education, pre-university education High: Higher vocational education, University 2 Students excluded
(odds ratio=0.44, 95%CI (0.30-0.64), p<0.001). In addition, males and older patients had increase odds to complete lower educational level (gender: odds ratio=0.62, 95%CI (0.43-0.91); age at study: odds ratio=1.12, 95%CI (1.02-1.20) respectively; p=0.01). Furthermore, the study population and reference group differed also with respect to unemployment status (22.2% versus 4.5%). Only group was found to be a predictive factor of unemployment (odds ratio=6.19, 95%CI (2.58-14.89), p=<0.001).

DISCUSSION

To our knowledge, this is the first study addressing the achievement of developmental milestones and the current socio-demographic outcome in a cohort of young adults grown up with functional childhood constipation. These adults reported a delayed course of life compared to that of the reference group, as they achieved fewer milestones on autonomy and social development than their peers. Furthermore, a delayed course of life was especially found in the subgroup of adults with fecal incontinence up to a maximum of 18 years of age, but not in adults who never experienced fecal incontinence or those without fecal incontinence after the age of 12. With regards to socio-demographic outcomes, our study population, showed lower educational level than the reference group, while unemployment rate was higher.

In line with our hypothesis a delayed course of life was found in adults who experienced constipation during childhood, especially during adolescence. A less favorable course on autonomy and social development could have great implications. It is well-known that achievement of developmental milestones in youth is of importance in the adjustment to adult life. In our study, children and adolescents grown up with constipation reported less playing with friends during primary school and less participation in sports during secondary school and thereafter, indicating limited participation in specific social activities with peers. Social withdrawal due to shame and fear of bullying by peers in relation to constipation and fecal incontinence could be one explanation. In one of our own studies on disease related quality of life, we found that 50% children with constipation reported shame about their fecal incontinence and 20% reported being bullied (submitted). In addition, parental concern about peer rejection of their child due to fecal incontinence while playing with friends, may also have led to less stimulation to participate in social activities. On the other hand, the ability to become a member of a sports club may be limited by financial means given the lower socioeconomic status of our patients’ cohort.
Supporting our findings, earlier observations reported that children with fecal incontinence show mainly internalizing behavioral problems such as social withdrawal and lower self-esteem\textsuperscript{16-18}. Indeed, it has been recognized that interaction with peers is of importance for the child’s development of self-competence and self-esteem through friendships and comparisons\textsuperscript{19, 20}. Furthermore, a previous study on quality of life in children and adolescents with organic causes of constipation and/or fecal incontinence, i.e. Hirschsprung’s disease and anorectal malformations, showed that children with high athletic competencies improved more in disease-specific functioning and self-esteem over time than their less athletic peers\textsuperscript{21}. This may very well be true for children with functional defecation problems. Therefore, we suggest that professional caretakers should specifically encourage participation in athletic activities in children and adolescents with constipation to promote bowel peristalsis and to encourage peer-activities.

The fact that especially young adults experiencing fecal incontinence, both as child and adolescent, reported delayed autonomy and social development, while this was not found for adults without a history of fecal incontinence or those without fecal incontinence after the age of 12 years, suggests that still experiencing fecal incontinence as adolescent has major impact. With respect to autonomy development, one could hypothesize that longstanding fecal incontinence unresponsive to medical or behavioral interventions results in frustration, anger and denial of the problems. Consequently, these adolescents are not able to take their own responsibility for their primary need to defecate. Furthermore, it is our daily clinical experience that parents often report to play an important role in reminding their child to regular toileting and to clean up their dirty underwear, even during adolescence. This could indicate that these parents pamper their children instead of stimulating them to acquire more independence. With regard to social development, adolescents in general are going through insecurities about their developing body. Feelings of shame or frustration caused by fecal incontinence could negatively influence self-esteem and social competence even more.

Surprisingly, however, psychosexual development was neither delayed in our total study population, nor in those young adults with ongoing fecal incontinence during adolescence. This is in contrast to findings in patients grown up with anorectal malformations and Hirschsprung’s disease\textsuperscript{10}. We speculate that this difference could at least partly be explained by the prevalence of other congenital malformations or a stoma in these patients with congenital bowel disease, which is not the case in children with functional constipation.

With regard to socio-demographic outcome, the percentage of low educational level was almost twice as high in adults grown up with functional constipation
than their peers, while unemployment was more than five times higher in this group of patients. Low educational level subsequently resulted in a higher unemployment rate: 27.8% compared to 6.3% in middle to high educated adults. Lower educational level found in parents of these young adults most likely correlates with lower educational level in their children. In fact, our study population showed an even lower level than their parents, who only differed in middle and high educational level with parents of the reference group. Conflicting data exist with respect to socioeconomic factors and its relation with functional constipation in children. In adults however, several studies have shown that the presence of constipation is related to both lower income and lower educational levels. Risk factors such as different lifestyle and dietary habits, or increase social stress might be responsible for the higher prevalence of functional gastrointestinal disorders among the disadvantaged classes. On the other hand, we do not know whether loss to follow up may have influenced our data. Possibly adults who no longer lived with their parents or who worked were not found or did not respond.

Some limitations of this study need to be addressed. Firstly, only a limited number of variables for correction could be taken into account. In our analyses, no correction was made for the difference in educational level between parents of the study population and those of the reference group. This may have resulted in an overestimation of the found differences in scale scores on autonomy and social development. In the reference population, less achievement of milestones correlated with lower parental educational level. As the percentage of parents with low educational level in our study population was similar to that of the reference group, overestimation is probably limited. Secondly, this study had mainly an explorative nature, as this is the first study addressing the relationship between the course of life and functional constipation in young adults. Therefore, no correction for multiple testing was done. Subsequently, phenomena’s may exist in our study population, but may not apply to other study populations. Lastly, the differences found in this study could be due to other medical factors than fecal incontinence, such as chronic pain, or be influenced by psychosocial factors, such as coping mechanisms, family functioning or interaction between children and parents. Future studies should further evaluate the protective and risk factors for a delayed course of life in children growing up with functional constipation in more detail.

In conclusion, clinicians treating children with chronic functional constipation should stimulate children in their social interaction with peers and encourage parents to stimulate their child’s independence, especially when fecal incontinence continues into adolescence. The impact of lower socioeconomic
Course of life in adults with childhood constipation

status in adults with a history of childhood constipation on course of life needs to be further evaluated.

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REFERENCES


