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ORIGINAL RESEARCH

Cross-Sectional Study of Bowel Symptoms in Adults With Cerebral Palsy: Prevalence and Impact on Quality of Life

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Abstract

Objectives: To determine the prevalence and type of bowel symptoms, and their impact on health-related quality of life (HRQOL) in adults with cerebral palsy (CP).

Design: Prospective cross-sectional study.

Setting: Urban, outpatient rehabilitation facility.

Participants: Adults with CP (N=91; 46 men, 45 women; mean age, 36y; age range, 18–79y).

Intervention: Not applicable.

Main Outcome Measures: Participants were interviewed using standardized instruments to assess the frequency and types of bowel dysfunction. The International Consultation of Incontinence Questionnaire–Bowel was used to assess bowel incontinence and impact on quality of life, and constipation presence was determined using the Rome III criteria for constipation. Constipation symptoms were rated by the Patient Assessment of Constipation–Symptom Scale. Participants' mobility status was classified using the Gross Motor Function Classification System (GMFCS). Interactions between mobility measures, anthropometric measures, and bowel symptoms were assessed.

Results: Of the 91 participants enrolled, 62.6% were GMFCS IV or V. Twenty-eight participants (30.8%) reported severe difficulty with control of liquid stool (rating never or rarely); these participants were more likely to have a greater GMFCS level ($P=.0004$). Twenty-six participants (28.6%) reported that bowel function caused embarrassment some/most/all of the time. Fifty-nine participants (64.8%) met criteria for chronic constipation, which did not differ by GMFCS levels. Overall, 57.1% of participants reported that bowel symptoms interfered with life; 40.7% reported moderate to severe interference.

Conclusions: Bowel symptoms were frequent, a source of embarrassment, and impacted HRQOL in these adults with CP. Addressing bowel-related symptoms has the potential to improve HRQOL in these adults.

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Both worldwide and in the United States, cerebral palsy (CP) is a leading cause of childhood physical disability.[1] As more children with severe disability are surviving to adulthood, CP is also found with greater prevalence within the adult U.S. population.[2] CP is considered a nonprogressive motor disorder; however, it is increasingly recognized that a number of health problems progress as adults with CP age.[3-5] Comprehensive, quantitative assessments of the health of adults with CP are limited. To understand the potential factors that may impact the health status and quality of life of these adults, further studies are needed.[6]

Lower gastrointestinal (GI) tract problems are common in children with CP.[7,8] Both constipation and bowel control have been identified as problematic issues in this population.[9-13] Constipation rates reported in children with CP vary greatly, ranging from 26% to 74%; the frequency of such problems increases with worsening

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mobility impairment.[9-11] A study[12] of nonambulatory children with CP (Gross Motor Function Classification System [GMFCS] IV and V) reported that 57% were constipated, with fluid and fiber intake below recommended ranges. In addition to constipation, achievement of bowel control is delayed in children with CP.[13]

Although these issues of bowel control, incontinence, and constipation have been documented within the pediatric population, there has been very limited study of how lower GI abnormalities may present, progress, or impact adults with CP. Among the general adult population, bowel issues, specifically constipation, tend to increase with age. A multinational survey[14] of more than 13,000 adults found constipation symptoms present in 12.3%; increased odds of constipation were present for women and the elderly. It is likely then that constipation may be even more problematic in adults as compared with children with CP. In a cross-sectional survey study of adult women with CP, Turk et al[15] found that 56% of women reported "bowel problems"; however, that study did not detail the specific bowel issues identified by their group of women. We were unable to identify any further studies describing rates and types of constipation or bowel symptoms in adults with CP.

In population-based studies of adults,[16,17] lower GI tract dysfunction has been found to be associated with reduced health-related quality of life (HRQOL). Similar effects on HRQOL have been noted for persons with disabilities.[18,19] Thus, in addition to the associated medical morbidity, lower GI tract disorders have the potential to significantly impact the HRQOL of individuals with CP.

The purpose of this study was to quantify the type and frequency of bowel dysfunction and incontinence experienced by adults with CP. In addition, we assessed risk factors for any GI-related symptoms and the effects of these symptoms on HRQOL. We hypothesized that both bowel-related incontinence and constipation would be seen with an increased frequency in adults with CP, and that these changes would negatively affect HRQOL and participation.

Methods

Study design and participants

This was a cross-sectional convenience sample survey study of adults with CP, aged ≥18 years, who presented to the outpatient clinics (eg, adult physiatry, orthopedics, transitional, therapy) at our urban academic rehabilitation center and who were able to provide consent for study participation, as determined by their treating physician Nonverbal participants were included and interviewed using their communication devices as required. Participants were recruited from July 2009 through January 2011. The diagnosis of CP was clinical and confirmed through the chart and the patient's clinician. This study population has been previously described.[20]

List of abbreviations:

BMI	**body mass index**
CP	**cerebral palsy**
GI	**gastrointestinal**
GMFCS	**Gross Motor Function Classification System**
HRQOL	**health-related quality of life**
ICIQ-B	**International Consultation of Incontinence Questionnaire−Bowel**
NHANES	**National Health and Nutrition Examination Survey**
PAC-SYM	**Patient Assessment of Constipation−Symptom Scale**

Our local institutional review board approved the study, and all participants provided informed consent before study procedures.

Participants were interviewed by research assistants using the questionnaires described below to assess for bowel incontinence, constipation symptoms, and the impact of symptoms on HRQOL. Research assistants were unaware of symptoms that participants reported to their health care professionals. The electronic medical records were reviewed for medications and medical information including height, weight, and comorbid diagnoses. Information on employment, education level, and place of residence was also obtained from the participants.

Gastrointestinal assessments

The following assessments were used to measure GI function:

- *International Consultation of Incontinence Questionnaire−Bowel (ICIQ-B):* The ICIQ-B is a validated scale that rates bowel symptoms, including incontinence, over the preceding 3 months. The scale is divided into 3 domains: bowel pattern (score range, 1−21), bowel control (score range, 1−28), and bowel symptom impact on HRQOL (score range, 0−26), with higher scores indicating greater impairment or symptoms. After each symptom rating, participants are asked to rate the degree to which each factor affected them (bothersome) from 0 to 10 (0, not at all; 10, a great deal). In addition, there are 4 items that do not form part of a score, but evaluate further bowel-related issues from the patient's perspective. These include a rating of the form of the patient's stool using the Bristol Stool Form Scale.[21] Stool form is scored into 1 of 7 types from hard to liquid, where type 1 is separate hard, lumpy stool and type 7 is watery stool with no solid pieces. The Bristol Stool Form Scale is a measure of gut transit time, and generally the midranges of the scale are considered optimal stool consistency. Reliability and validity of the ICIQ-B have been demonstrated.[22,23]
- *Rome III criteria for constipation:* The presence of constipation was determined using the Rome III criteria for constipation.[24] This consensus set of criteria is widely used in the GI literature. Participants must rate 2 or more of the following symptoms present over the last 3 months to be classified as having constipation: (1) straining during at least 25% of defecations; (2) lumpy or hard stools in at least 25% of defecations; (3) sensation of incomplete evacuation for at least 25% of defecations; (4) sensation of anorectal obstruction/blockage for at least 25% of defecations; (5) manual maneuvers to facilitate at least 25% of defecations (eg, digital evacuation, support of the pelvic floor); and (6) fewer than 3 defecations per week. Participants rate the percent of time each of the above symptoms is present (never, 25%, 50%, 75%, 100%).
- *Patient Assessment of Constipation−Symptom Scale (PAC-SYM):* Participants with constipation according to the ROME III criteria then rated their constipation symptoms using the PAC-SYM.[25] The PAC-SYM is a 12-item symptom scale with 3 domains: abdominal symptoms (4 items), rectal symptoms (3 items), and stool symptoms (5 items). Because the PAC-SYM is a symptom scale, higher numbers indicate more symptoms.

Medications

All medications taken by participants were recorded. Medications for lower GI symptoms were evaluated in detail. Participant ratings of effectiveness of the GI medications used for control of