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Research Paper

Gait and participation outcomes in adults with cerebral palsy: A series of case studies using mixed methods

Mary E. Gannotti, Ph.D., P.T.^{a,b,*}, George E. Gorton, III, B.S.^c,
Maureen T. Nahorniak, P.T., M.B.A., P.P.I., D.P.T.^b, and Peter D. Masso, M.D.^b

^aDepartment of Rehabilitation Sciences, University of Hartford, 200 Bloomfield Avenue, West Hartford, CT 06117, USA

^bShriners Hospital for Children, Springfield, MA, USA

^cClinical Outcomes Assessment Laboratory, Shriners Hospital for Children, Springfield, MA, USA

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Abstract

Background: There is a paucity of information on long-term outcomes of adults with cerebral palsy (CP) who received orthopedic interventions in childhood. Clinical effectiveness research requires assessment of outcomes that account for personal and environmental factors that may mediate the effects of treatment, in addition to body structures & function, activity, and participation.

Objective/hypothesis: The purpose of this study is to provide a descriptive analysis of characteristics associated with gait and participation outcomes in a series of case studies of adults with CP.

Methods: Participants had follow up gait analysis and clinical evaluation in adulthood and assessment of outcomes with the FIM[®] instrument, the SF-36[®] Health survey, the Canadian Occupational Performance Measure, and semi-structured questions.

Results: Twenty-two out of 26 participants (mean age = 25 years; GMFCS level I ($n = 9$); II ($n = 3$); III ($n = 11$); IV ($n = 3$)) maintained or improved childhood gait abilities, with levels of participation in society similar to age matched peers. Higher level of severity and personal choices impacted gait abilities in the four who declined. Majority of participants lost range of motion in hip flexion and knee extension, had pain, reported a fitness program, and increased in weight status. Personal factors and environmental factors played a role in both gait and participation outcomes.

Conclusion: Promotion of fitness activities and social advocacy are warranted for adults with CP. Clinical effectiveness research of long-term impact of orthopedic interventions should account for treatment effects on body structures & function, activity, participation, and modifying effects of personal, and environmental factors. © 2013 Elsevier Inc. All rights reserved.

Keywords: Cerebral palsy; Long-term outcomes; Gait; Participation; Personal values

Clinical effectiveness research is concerned with the question “what works best, for whom, and when?” Effectiveness research is concerned with the clinical effects of treatment (i.e., improved ROM, gait abilities, participation, quality of life, self perception) and with identifying

characteristics that predict which intervention would be most successful in an individual patient.¹ For rehabilitation professionals who work with ambulatory children with cerebral palsy (CP), important questions that have yet to be answered are 1) what are the clinical and patient relevant

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This abstract reports on 33 participants, 26 participated in gait analysis and interviews, and 7 who participated in interviews only.

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This article reports on a subset of 11 participants who had multi-level surgery, pre-operative, 1 year post-operative, and greater than 5 year follow up evaluations and a subset of 12 participants who had motion analysis evaluations in adolescence and then in young adulthood with no surgery in between. The initial evaluations reported in the enclosed article are different beginning points than those reported in the article mentioned above. Additionally, the article mentioned above does not contain the information on participation and activity outcomes.

* Corresponding author. Tel.: +1 860 768 5373; fax +1 860 768 4558. E-mail address: gannotti@hartford.edu (M.E. Gannotti).

long-term outcomes that may be associated with orthopedic management in childhood? and 2) what are some of the characteristics of patients that may be associated with positive long-term outcomes?

Unraveling the question of whether or not orthopedic interventions will make a difference in the long-term is a complex multifactorial problem. The complexity in addressing this problem involves many factors including the heterogeneous presentation of CP,² varying levels of severity,³ variation in approach to addressing gait pathology,² lack of systematic documentation of the natural history of gait in CP,^{4,5} and a limited understanding of the inter-relationships among gait kinematics, gait speed, growth, and levels of activity and participation.^{6–8} Finally, there is limited information on personal factors—values and life choices, and environmental factors—supports and barriers, associated with long-term outcomes of gait abilities.^{9,10}

Studies about the gait abilities of adults with CP are primarily limited to survey research^{9,10}; and results indicate that with increased age, pain and fatigue contribute to a decline in gait. Level of severity, presence of seizures, complex medical co-morbidities, and intellectual function have been found to be associated with poor gait outcomes in children.¹¹ Similarly, both Bell et al⁴ and Johnson et al⁵ report a decline in popliteal angle in children who have a decline in gait in adolescence. It is likely that these factors are also associated with decline in gait in adults with CP.¹⁰

Priorities for independence in mobility, keeping up with peers, and assuming adult roles,¹² may supersede priorities for maintaining gait as the primary means of locomotion. Rehabilitation professionals who work with ambulatory children with CP should focus on the following unanswered questions: 1) What are the clinical and patient relevant long-term outcomes that may be associated with orthopedic management in childhood, and 2) What are some of the characteristics of patients that may be associated with positive long-term outcomes? The question of whether or not orthopedic interventions will make a difference in the long-term is complex multifactorial. The complexity in addressing this question involves many factors.^{9,10,13} Finally, there is a paucity of evidence about gait abilities of adults with CP; and what exists does not describe personal factors—values and life choices, and environmental factors—supports and barriers, which may modify clinical and patient relevant outcomes.^{14–16}

The purpose of this case series was to evaluate changes in gait abilities from initial evaluation during childhood to follow up during adulthood of ambulatory people with CP, to provide a descriptive analysis of characteristics

associated with gait and participation outcomes, and to highlight characteristics that should be considered in long-term outcome assessment of pediatric rehabilitation interventions aimed at improving gait. The results of this study may provide useful information for developing care plans and designing larger comparative studies about the effectiveness of orthopedic interventions on long-term outcomes in ambulatory adults with CP.

Methods

The study design was a series of case studies using a mixed methodology of clinical evaluation, motion analysis, standardized measures of health, and semi-structured interviews. Ethical approval was obtained by the Institutional Review Board of the participating institution, and a waiver was obtained to comply with Health Information Portability and Accountability Act.

Participants were recruited from a cohort of people with a diagnosis of spastic cerebral palsy who: 1) were over the age of 20 years who had received care at the Shriners Hospital for Children, Springfield; 2) had undergone a three dimensional gait analysis (3DGA) as part of their care at least 4 years earlier; and 3) would complete a series of patient reported outcome questionnaires and a follow up 3DGA evaluation.

Data collection tools were selected to sample the domains of the ICF. Table 1 maps the patient questionnaires, motion analysis, and clinical evaluation measures across the domains of the ICF. Patient questionnaires used included the: the FIM[®] instrument^d, the SF-36[®], and the COPM. The SF-36[®] has been used with adults with CP,¹⁰ and demonstrates excellent reliability ($\alpha = 0.93$).¹⁷ Domains assessed by the SF-36[®] include: physical functioning, role functioning, bodily pain, general health, vitality, social function, and mental health. The SF-36[®] has been used to measure pain in adults with CP.¹⁸ The validity and reliability of the COPM is well established¹⁹ and others have used it to measure the perceived barriers to participation of children with CP.²⁰ The FIM[®] instrument measures functional abilities in the area of self-care, sphincter control, transfers, locomotion, communication, and social cognition.²¹ The FIM[®] instrument has been used to document the function of young people and adults with cerebral palsy.^{22,23}

A semi-structured questionnaire was created to provide additional information about personal and environmental factors and participation. Questions included in the structured questionnaire were as follows: 1) What education or specialized training have you had since graduating from

^d The FIM[®] data set, measurement scale and impairment codes referenced herein are the property of Uniform Data System for Medical Rehabilitation, a division of UB Foundation Activities, Inc. The service marks and trademarks associated with the FIM[®] instrument are all owned by Uniform Data System for Medical Rehabilitation, a division of UB Foundation Activities, Inc. The use of the FIM[®] instrument to collect data for this research study was authorized and conducted in accordance with the

terms of a special purpose license granted to Licensee by Uniform Data System for Medical Rehabilitation a division of UB Foundation Activities, Inc. (“UDSMR”). The patient data collected during the course of this research study has not been processed by UDSMR. No implication is intended that such data has been or will be subjected to UDSMR’s standard data processing procedures or that it is otherwise comparable to data processed by UDSMR.

Table 1
Assessment of domains of the international classification of functioning, health, and disability

Domain	Construct	Outcome measure
Body structures and function	Changes in joint kinematics	Motion analysis; Gillette Gait Index
	Changes in range of motion	Clinical evaluation; range of motion
	Changes in weight status	Clinical evaluations; height and weight
	Pain	SF-36 health survey [®] , bodily pain domain
	Co-morbidities	Interview
	Mental health	SF-36 health survey [®] , mental health and vitality domains
Activity	Change in gait speed	Motion analysis
	Change in gross motor functional classification level	Clinical evaluation
	Activity of daily living abilities	The FIM [®] instrument
	Use of personal care attendant	Interview
	Ability to drive	Interview
Participation	Work outside the home	Interview
	Living arrangements	Interview
	Social role	SF-36 health survey [®] , social role domain
	Emotional role	SF-36 health survey [®] , emotional role domain
Personal characteristics	Level of education	Interview
	Significant other	Interview
	Satisfaction with care	Interview
	Perceived factors related to success	Interview
	Lifestyle habits related to fitness and physical health	Interview
	Importance of walking	Interview
	Self description	Interview
Environment	Perceived barriers to participation	Canadian occupational performance measure

high school? 2) What are your current living arrangements? 3) Do you need assistance for activity of daily living (e.g., for activities of daily living, transportation, assistance with managing health issues), and if so, who are the people that provide you with assistance? 4) Do you work outside the home, go to school, volunteer, or have paid employment? 5) Do you have a regular exercise routine? If so, what is it? 6) How satisfied are you with the care you received at the hospital? 7) What factors do you perceive as contributing to your success and happiness as an adult? 8) How important is it for you to maintain your walking abilities? 9) How would you describe yourself? 10) Do you have a significant other? 11) Do you drive, and if not, why?

Two interviewers were present for all interviews with participants. Interviewers were trained in administration of the structured questionnaires, and had experience and training in semi-structured interviews with families of children with CP and with persons with CP. One interviewer administered the survey questions to the participant, and the other observed. Both interviewers transcribed answers to these questions verbatim. Both interviewers reviewed the transcriptions for accuracy, and changes were made if needed. Answers were entered into a spreadsheet, and frequency analysis identified common responses.²⁴ Six of the participants, selected based on their: 1) willingness to review research findings, 2) diversity of experiences with orthopedic management and outcomes, and 3) differences

in lived experiences as adults with CP, acted as key informants and reviewed the themes extracted to confirm the trustworthiness of the findings after analysis.²⁴

Changes in gait abilities were measured by evaluating changes in Gross Motor Functional Classification System (GMFCS) Levels²⁵ and changes in spatio-temporal parameters of walking. Initial GMFCS Level was evaluated using review of archived videos and clinical notes. Consensus among the research team members was obtained before assigning GMFCS Level. The inter-rater reliability of the GMFCS has been documented at levels of 0.75 for children over age two.²⁶ Items from the Gross Motor Function Measure²⁷ (stair climbing ability) and clinical observation were used to classify current GMFCS Level for participants at follow up evaluation.

Weight status was categorized using Centers for Disease Control (CDC) recommended cut offs for body mass index (BMI) and age-adjusted BMI percentiles (BMI-a).^{28,29} Range of motion at the hip, knee, and ankle were recorded for each evaluation and compared over time. The inter-rater reliability of goniometric measurements at the knee for subjects with cerebral palsy have been reported to be less than 0.80, with a 15–20° change needed to truly document change.³⁰

Participants also underwent 3DGA, which was compared to previous evaluation(s). Joint kinematics was calculated using the conventional gait model as implemented in Plug in Gait (Vicon Workstation, Oxford,

England). Measurement error from variation in marker placement between evaluations was minimized by using two examiners trained according to the standardized protocol developed by Shriners Motion Analysis Laboratory Network (SMALnet).³¹

The Gillette Gait Index (GGI) was used as a measure of gait deviations.³² GGI is a numerical value calculated from 16 gait parameters and indexed to a normal population³³; closer to 0 indicates a more normal gait pattern. The normal population consisted of 25 participants, ages 12–18 years, selected from a pool of 50, aged 7–18 years. GGI values were calculated using three representative trials of the right leg (arbitrarily selected), or on the involved side for participants with hemiplegia. All participants were instructed to walk using customary devices. Comparisons with previous evaluations were done with matching conditions (e.g., follow up evaluation performed with braces and shoes compared with initial evaluation performed with braces and shoes).

A descriptive analysis of participant characteristics associated with positive gait outcomes and with positive participation outcomes allowed for the comparison of the shared characteristics across outcomes. Additionally, descriptive analysis allowed for the identification of possible indirect and direct relationships between gait and participation outcomes and identification of personal and environmental characteristics that may modify outcomes. Descriptive analysis included: frequency counts, means, standard deviations, and ranges. Paired sample *t*-tests evaluated changes from initial to follow up evaluation on clinical and motion analysis evaluations, and correlation analysis evaluated association of scores on the SF-36[®] with changes in gait parameters. SPSS version 18.0 (Chicago, IL) was used for all data analysis.

Results

Characteristics of the sample

Fifty-nine people were located from medical records review, 9 were excluded after further review of medical record, 9 refused due to lack of time or interest, 8 canceled, 7 completed interviews, and 26 completed interviews and 3DGA (11 males; mean age 25 years [range 20–36]; mean time between evaluations 13.6 [range 5–16 years], diplegia = 19, quadriplegia = 6, hemiplegia = 1). GMFCS level at follow up evaluation was: I (*n* = 9); II (*n* = 3); III (*n* = 11); IV (*n* = 3).

Two participants had dorsal rhizotomies prior to initial evaluation. Between initial evaluation and follow up evaluations, 17 out of the 26 had orthopedic surgery or botulinum toxin injections, physical therapy, and bracing after their initial evaluation as children, and the remaining 9 received physical therapy and bracing only.

At follow up, 2 had seizure disorders; other medical issues included gastro-intestinal reflux/issues (*n* = 1), visual problems (*n* = 2), and metabolic issues (*n* = 1). Five

participants had depression/anxiety, which was managed with medication. Mean scores on the sub-domains of the FIM[®] instrument were 0–3 points from ceiling scores (see Table 2).

Gait outcomes and selected sample characteristics

Changes in gait deviations as measured by the GGI indicated 22/26 participants maintained (*n* = 12) or improved (*n* = 10) their gait abilities at follow up (see Table 2). Of those who improved, all had received orthopedic surgery in the interim between baseline and follow up evaluation. Details of the four participants who had decline in gait abilities are as follows: 1) change to use of powered mobility at age 18 years, current age 36 years; 2) an increase in lumbar lordosis following rhizotomy; 3) pregnancy at age 29 years, current age 33 years; and 4) limited ambulation abilities initially (initial GGI = 740; final GGI = 880; GMFCS level IV). Pooled values of joint kinematics at the hip, knee, and ankle demonstrate no significant changes from initial evaluation to follow up evaluation, except for a small increase in maximum dorsiflexion in stance (*p* < 0.002, see Table 2). Similarly, there was no significant change in gait velocity from initial evaluation to follow up evaluation.

Based on clinical examination, hip flexion ROM decreased in 9/26 (Paired *t*-test = 4.3; *p* < 0.001; 95% CI = 6–16); knee extension ROM decreased in 11/26 (Paired *t*-test = 3; *p* < 0.009, 95% CI = 1–7); popliteal angle decreased in 5/26; dorsiflexion with knee extension decreased in 3/26; and hip extension decreased in 1/26 (see Table 2). ROM of hip flexion and popliteal angle declined in all four of the participants who experienced a decline in gait abilities.

Weight status increased in 13/26, from underweight or normal weight to overweight or obese. For those who declined in gait abilities, 2/4 had an increase in weight status. Pain was reported by 20/26 of participants (lower extremity *n* = 15, low back *n* = 15, upper extremity *n* = 2). More than half (*n* = 15) were below the mean normative value on the Bodily Pain domain of the SF-36[®], indicating more severe and limiting pain than aged matched peers. The four with decrease in gait abilities as measured by the GGI reported pain in their low back, lower extremities, and/or arms and were all below the mean on the Bodily Pain domain of the SF-36[®]. Eighteen out of 26 participants scored lower than the mean normative value on Vitality domain of the SF-36[®]; all participants who declined in gait abilities had Vitality scores below the mean, indicating they felt more tired and had less energy than age matched peers.

GMFCS level was maintained (*n* = 16) or improved (*n* = 8) in 24/26 participants (see Table 2). Of those who improved, all 8 had orthopedic surgery in the interim. Of those who declined, one decided to use powered mobility (and also experienced a decline in GGI) and the other chose to use an assistive device to improve independent mobility, resulting in changes in GMFCS levels.

Table 2

Impairment and activity outcomes

<i>N</i> = 26	Initial evaluation <i>Mean (SD, range)</i>	Follow up <i>Mean (SD, range)</i>
<i>Body structures and function</i>		
Gillette Gait Index		
Improved, <i>N</i> = 10*	436 (152, 229–674)	233 (150, 63–441)
Maintained, <i>N</i> = 12	290 (222, 76–767)	293 (215, 50–715)
Declined, <i>N</i> = 4	388 (247, 170–741)	762 (182, 513–913)
Kinematics		
Hip flexion range	43 (22, 13–136)	40 (9, 22–59)
Knee flexion at initial contact	30 (16, 0–73)	28 (14, 8–59)
Knee flexion maximum as % swing	0.80 (0.07, 0.67–0.96)	0.78 (0.07, 0.64–0.93)
Knee flexion range in swing	22 (12, 0.3–42)	26 (12, 5–51)
Maximum dorsiflexion in stance*	13 (8, –8 to 27)	20 (9, 4–42)
Range of motion		
Hip extension range of motion	–7 (7, –20 to 0)	–4 (6, –20 to 0)
Hip flexion range of motion [†]	111 (10, 90–130)	101 (15, 50–125)
Knee extension range of motion [‡]	–2 (7, –30 to 5)	–6 (9, –25 to 10)
Popliteal angle range of motion	54 (16, 25–90)	48 (14, 30–90)
Weight status		
Underweight	3	3
Healthy weight	19	6
Overweight	4	11
Obese	0	6
SF-36 health survey [®] , bodily pain domain		77 (22, 22–100) [81] [#]
SF-36 health survey [®] , mental health domain		76, 21, 16–96 [75] [#]
SF-36 health survey [®] , vitality domain		56, 10, 30–70 [64] [#]
<i>Activity</i>		
Gait velocity (cm/s)	79 (33, 28–143)	83 (37, 13–142)
Gross motor functional classification levels		
	I <i>n</i> = 1	I <i>n</i> = 9
	II <i>n</i> = 12	II <i>n</i> = 3
	III <i>n</i> = 11	III <i>n</i> = 11
	IV <i>n</i> = 2	IV <i>n</i> = 3
The FIM [®] instrument [max score]		
Self care [42]		38 (7, 17–42)
Sphincter control [14]		14 (1, 10–14)
Transfers [21]		18 (4, 4–21)
Locomotion [14]		12 (2, 7–14)
Social cognition [21]		20 (3, 8–21)
Communication [14]		14 (1, 6–14)
Ability to drive		4
Need for personal care attendant		13

**p* = 0.000; [†]*p* < 0.001; [‡]*p* < 0.009; [#]Normative mean value for males and females ages 25–34 years (Ware JE, Kosiski M, Gandek B. SF-36[®] Health Survey: Manual and Interpretation Guide. Lincoln, RI: Quality Metric Incorporated; 2002).

All but one participant who had surgery (16/17) perceived improved gait or sitting abilities as a result. All participants were satisfied with the care that they received at the hospital and felt it made a difference in their current gait abilities. Twenty-four out of 26 reported having a regular fitness program consisting of aerobic and anaerobic exercise at least three times a week or a physical therapy program. Two had no formal exercise interventions. For all, maintaining walking/standing abilities was very important. All those who declined in walking abilities reported having some type of formal exercise routine.

Participation outcomes and sample characteristics

Participation outcomes are detailed in Table 3. Twenty-one out of 26 “worked” outside the home, as a student,

volunteer, part time, or full time, in a variety of settings. Only one participant worked full time as a professional; this participant had the greatest decline in gait abilities and needed assistance for personal care. Details of the five participants who did not work outside the home are as follows: 1 had uncontrolled seizures, 1 lacked reliable personal care assistance, and 3 valued safe and non-stressful activities as more important than work. Nineteen out of 26 had education or specialized training beyond high school.

The majority of the participants were above mean normative values on the Social Functioning (*n* = 21), Mental Health (*n* = 16) and Role-Emotional (*n* = 21) domains of the SF-36[®] (see Table 3). No relationship existed between changes in GGI and scores on the SF-36[®] Mental Health, Social Functioning, or Role-Emotional

Table 3

Participation outcomes, personal and environmental characteristics	
<i>Participation</i>	<i>N</i> = 26
Work activities	
Working outside home in some capacity	21
Not working outside the home	5
SF-36 health survey [®] , social functioning (mean, SD, range)	86, 27, 12–100 [85] ^a
SF-36 health survey [®] , role-emotional (mean, SD, range)	84, 36, 0–100 [82] ^a
Living arrangements	
With parents	11
Independently	13
Long-term care facility	2
<i>Personal characteristics</i>	
Level of education	
High school	7
Associates degree/post-secondary training	9
Bachelor's degree	6
Master's degree	4
Has a significant other	11
<i>Environment</i>	
Experiences barriers to participation	20

^a Normative mean value for males and females ages 25–34 years (Ware JE, Kosiski M, Gandek B. SF-36[®] Health Survey: Manual and Interpretation Guide. Lincoln, RI: Quality Metric Incorporated; 2002).

domains. Only one of the ten participants who scored below the normative value on the SF-36[®] Mental Health domain had a decline in gait abilities.

The majority of the participants lived independently of their parents, did not have a significant other, and did not drive. Of the thirteen who needed help with self care activities, 3 had personal care attendants, 2 lived in long-term care facilities, and 8 relied on family for care. Two of the four participants who had a decline in gait abilities required a personal care attendant, and three of the ten who had Mental Health scores on the SF-36[®] below the norm required personal care attendants.

Six of the participants identified no barriers to participation as measured by the COPM. The remaining 20 listed the following: lack of transportation ($n = 8$); employment opportunities ($n = 9$); and socialization ($n = 3$). All participants with Mental Health scores on the SF-36[®] below the norm identified barriers to participation.

Twenty-four out of 26 participants used the following phrases to describe themselves- “do all that can to be independent”; “try to ignore CP”; “demand people accept them as they are”; and “self advocate”. Two described themselves as “slightly depressed” or “with very limited social activities”. All 26 reported strong family support in the form of assistance with living, socialization, and/or activities of daily living. All 26 attributed their success in life to combination of both “family support” and “personality”. All 26 reported the orthopedic care they received at the hospital played an important role in optimizing their abilities as a child and currently, and contributed to their current level of success.

Discussion

The majority of participants in this study maintained their gait abilities from initial evaluation as children to follow up as young adults, and had levels of participation in society similar to age matched peers without CP (lived independently of parents, worked outside the home, education beyond high school). Participants reported highly valuing their gait abilities, engaging in regular fitness activities, and choosing to use gait as primary form of locomotion in one or more environments. Participants also reported they perceived their strong personality—self acceptance and desire to best that they could be, social support, and excellent orthopedic care contributed to their success.

The majority of participants lost ROM in hip flexion and knee extension, had pain, and increased in weight status. Life factors, such as choosing alternative modes of mobility (power chair, use of an assistive device) or choosing to become pregnant, along with level of severity appeared to play a role in decline of gait abilities in this sample. In this sample, a decline in gait abilities did not appear to be associated with social functioning, employment, independent living, or mental health. Personal factors—such as values, and environmental factors—such as lack of transportation or employment opportunities, appeared to play a role in participation.

Nonetheless, for the participants in this sample, maintaining gait abilities was very important and should be assessed in long-term outcome studies of gait abilities. The personal value for maintaining gait abilities is an individual characteristic should be assessed in long-term outcome studies of gait abilities. Participants, for the most part, reported performing an exercise program aimed at maintaining their gait abilities, and made efforts to maximize gait with braces and assistive devices as needed. All participants reported orthopedic care as a positive factor for success, and for the most part were satisfied with care. All participants reported strong family support, and most described self as “independent”. Perceived positive support from rehabilitation services and family may have indirectly promoted self-efficacy or self-concept in participants. However, self-efficacy and self-concept were not measured in this study, but may also indirectly influence outcomes for gait and participation.

The four participants with a decline in gait abilities all had a decrease in popliteal angle. Changes in ROM, particularly an increase in popliteal angle, have been reported in children with CP who experience a decline in gait abilities.^{4,5} More interesting is the overall decrease noted in hip flexion ROM. Decreased hip flexion ROM may impact lumbar spine mechanics, and may contribute to increased risk for low back pain. Chronic low back, lower extremity, and upper extremity pain, along with fatigue, have been reported as primary reasons adults with CP lose gait abilities.^{9,10,34} Activity aimed at promoting

active range of motion of the hips and knees is indicated for adults with CP.³⁵

The level of chronic pain (54%) in this sample of participants is similar to findings in other studies.³⁶ Pain and the prevention of pain is an important issue to address in the care of adolescents and young adults with CP.¹⁰ Although the majority reported a fitness program, at follow up more than half were overweight or obese. Increased weight status coupled with decreased hip flexion and knee extension ROM can increase abnormal joint kinematics and kinetics during walking, and contribute to chronic pain. Weight gain has not been directly associated with decline in gait.^{16,37} However, after the second decade, risk for metabolic disease, chronic pain, and fatigue will have a cumulative effect on in gait abilities. Overall, vitality was below age-matched peers; and chronic pain and obesity may be contributing factors.^{38–40} Fatigue has been noted to be a health problem of adults with CP,³⁴ aerobic exercise is indicated for young adults with CP.^{35,41}

In this case series, the prevalence of depression treated with medication is similar to the overall US population (20%),⁴² and mental, social, and emotional functioning of the sample was similar to age-matched peers. Low levels of depression and average self-concept have been reported in a larger sample of adults with CP with varying physical, social, and economic characteristics.⁴³ All participants with mental health functioning below peers identified barriers to participation in society. Improving participation in society by addressing environmental barriers is an important area for intervention that may also improve mental health. Advocacy for reliable personal care attendants, accessible transportation, employment opportunities, and socialization is warranted to promote the participation and mental health of adults with CP. Surgical or robotic interventions may hold promise for improving self care for some⁴⁴ and may lead to increased participation. However, interventions aimed at reducing social barriers are also needed to improve participation. Changing public policy and systems for care are indicated.

In this sample, the participant with the highest level of participation (full time professional, living independently) had the greatest decline in gait abilities; and overall, there appeared to be no direct relationship between gait and participation outcomes. There are many reports of a lack of congruence among outcomes for body structures and function, activity, and participation.⁴⁵ Personal, social, and environmental characteristics can mediate impairments and facilitate participation.⁴⁶

The results of this study were limited by design, sample size methodology and are generalizable only to people with similar characteristics. This sample of convenience was biased because the majority of the sample highly valued their gait abilities, were satisfied with the hospital, and had an education past high school. This satisfaction may have contributed to the positive findings for gait and participation outcomes.

Although measures were taken to minimize error, a margin of error exists with 3DGA and clinical examination with multiple examiners over time.⁴⁷ The GGI is validated, but does not have optimal characteristics, and others have suggested the GDI as a more accurate measure of gait pattern.⁴⁸ Additionally, the use of BMI as a way to estimate adiposity in people with CP has its limitations,⁴⁹ and may underestimate adipose tissue.

The results are also limited by outcome measures employed in the study design. An alternative measure of participation for adults with CP includes the LIFE-Habits questionnaire.⁵⁰ Standardized psychological assessments of self-concept⁵¹ or personality traits⁵² were not administered. Personality traits were self reported using semi-structured interviews. A measure of personal values or “guiding principles of one’s life” has been developed,⁵³ although its usefulness in clinical outcome studies may be limited. Validation of a likert scale for measuring the importance of maintaining gait abilities and a checklist of reasons why gait is not used as a means of locomotion is warranted.

Conclusion

Evaluating the long-term effectiveness of orthopedic management of ambulatory children with CP is challenging due to multiple intervening factors. The findings of this study support the importance of personal and environmental characteristics on long-term outcomes. Studies should consider personal values for the importance of maintaining gait abilities, fitness routines, and environmental features that limit or support gait abilities in daily life. Large, multi-center studies, that have purposeful sampling of persons with CP, ranging in level of severity, functional abilities, geographic and socioeconomic status, and personal characteristics are required to model possible direct and indirect relationships among gait abilities, participation outcomes, interventions, personal and environmental characteristics. Clinicians should maintain preventative interventions through adolescence and young adulthood to promote fitness and social advocacy to promote health and participation.

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