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Original Research

Participation in Social Roles of Adolescents With Cerebral Palsy: Exploring Accomplishment and Satisfaction

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KEYWORDS
Adolescent;
Cerebral palsy;
Personal satisfaction;
Rehabilitation;
Social participation

Abstract *Objective:* To explore participation in social roles of adolescents (aged 12-18y) with cerebral palsy (CP), in terms of satisfaction compared with accomplishment.
Design: Cohort study as part of a prospective longitudinal research program.
Setting: Clinic.
Participants: Participants were adolescents (N=45; 58% male, mean age 15y 6mo) with CP at levels I-II (88%) and III-IV-V (12%) of the Gross Motor Function Classification System.
Interventions: Not applicable.

List of abbreviations: CP, cerebral palsy; GMFCS, Gross Motor Function Classification System; GMFM, Gross Motor Function Measure; ICF, International Classification of Functioning, Disability, and Health; Life-H, Life Habits questionnaire; MACS, Manual Ability Classification System; PEDI, Pediatric Evaluation of Disability Inventory; PERRIN, Pediatric Rehabilitation Research in the Netherlands; PiP, Participation in Perspective; UCL, Utrecht Coping List.

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Main Outcome Measures: Accomplishment (0-9 scale; with score <8 "having difficulties") and satisfaction (1-5 scale; with score 3 "neutral") were assessed using the Life-Habits questionnaire, on 6 domains (Responsibilities, Interpersonal relationships, Community life, Education, Employment, Recreation). Per domain, we analyzed scatterplots of accomplishment vs satisfaction. Additionally, we compared determinant-models (including factors of CP, activity, person, and environment) using regression analysis.
Results: For accomplishment, mean scores were <8.00 except for Interpersonal relationships. For satisfaction, mean scores varied between 3.85 and 4.34. Overall, individuals with similar levels of accomplishment showed large ranges in their levels of satisfaction, which was expressed by low explained variances, especially on Education (6%). Furthermore, different sets of determinants were found for accomplishment (predominantly CP factors) compared with satisfaction (predominantly environment factors).
Conclusions: This study revealed a dissociation between participation accomplishment and satisfaction with participation among adolescents with CP. For practice and research, we recommend not only to focus on accomplishment but also, if not mainly, on satisfaction.

More and more treatment and research in childhood disability is aimed for optimizing participation in society. So far, studies have mainly focused on one specific aspect of participation, namely the level of accomplishment. Studies seem to be less aware of other aspects of participation and have scarcely paid attention to comparing different aspects. With present explorative study, we compared participation accomplishment with participation satisfaction in a group of adolescents with cerebral palsy (CP).

First, this article adds to the conceptualization of participation. We provided evidence that there is an important discrepancy between accomplishment and satisfaction. Second, our article adds to practical insights regarding participation. The evidence that we have provided can be used for differentiated decisions within participation-focused interventions or treatments. Third, the article adds to promoting involvement of youth with disabilities in research that concerns them. We asked them about their experiences, ideas, and wishes not only in relation to the topic of the study ("participation in social roles") but also in relation to the execution of the study.

Children with CP grow up with permanent movement and posture disorders limiting their daily functioning.[1] Consequently, as they grow older toward adulthood, participating in society is often difficult for adolescents with CP.[2-7] Participation, particularly in social roles, is considered the ultimate outcome for patients in rehabilitation.[8,9]

The International Classification of Functioning, Disability, and Health (ICF) Child and Youth version describes participation as "involvement in a life situation," representing the social perspective of functioning.[10(p9),11] The ICF Child and Youth version focuses on the accomplishment of participation, that is, the degree of difficulty, restrictions, and dependence. However, more and more is recognized that it is important to distinguish accomplishment of participation from the more subjective feeling of how satisfied a person is with participation.[12-15] So far, in disability research in general as well as for CP, attention has been paid mainly to the accomplishment of participation rather than to the aspect of satisfaction.[16]

From the perspective of adolescents with CP, we can assume that the satisfaction aspect is very important in their everyday life. Paying attention to satisfaction with participation may help in prioritizing personal goals, staying motivated, and gaining self-confidence.[17,18] This may eventually also promote accomplishments in social role participation. Just as in adolescents without CP, these assumptions about satisfaction might depend on specific domains, for example, relationships, education, and recreation. To support these assumptions, we first need to gain more knowledge about satisfaction with participation in adolescents with CP and how it relates to accomplishment of participation.

Therefore, the aim of the present study was to explore participation in social roles of adolescents (aged 12-18y) with CP in terms of both accomplishment and satisfaction. We examined (1) the level of social role accomplishment, (2) the level of satisfaction with social roles, and (3) the relationship between accomplishment and satisfaction.

Methods

Study design

The present study, Participation in Perspective (PiP), was performed as part of Pediatric Rehabilitation Research in the Netherlands (PERRIN). PERRIN is a prospective longitudinal research program studying activities and participation of individuals with CP. PERRIN-PiP is a 10-year follow-up of 2 PERRIN age cohorts, namely PERRIN 0-5 (entry at $1^1/_2$ or $2^1/_2$ y)[19] and PERRIN 5-9 (entry at 5 or 7 y).[20] In this follow-up, data were collected with a focus on describing participation in social roles by adolescents (12-18y) with CP. In addition, these data from adolescence were linked to existing data from childhood, enabling exploration of early

determinants in relation to different participation outcomes.

Study respondents

Adolescents with CP who previously participated in the cohorts PERRIN 0-5 and PERRIN 5-9 were eligible for the PERRIN-PiP study. Candidates were sent information letters between January 2016 and October 2017. Respondents had to be able to understand the informed consent themselves and had to be able to answer questionnaires with no or little help, which was decided in advance in consultation with the parents.[7] Respondents were excluded from analyses if they had incomplete data on social roles (ie, ≥2 domain scores missing on the Life-Habits questionnaire [Life-H]).

In this exploratory study, we aimed at a sample of approximately 50 responding adolescents,[21] with various levels of functional ability according to 3 classifications[22] filled out by their parents: Gross Motor Function Classification System (GMFCS),[23] Manual Ability Classification System (MACS),[24] and Communication Function Classification System.[25] The basic characteristics of the participating adolescents are given in table 1.

Panel of ambassadors

In conducting the PERRIN-PiP study, participants were not only involved as respondents.

A panel of ambassadors (ie,12 adolescents with CP) was actively involved in various stages of the project,[7,26] including preparation of the information letter, piloting of questionnaires, and co-interpretation of the findings. The BOSK (Dutch association of persons with a physical disability) took care of coaching the ambassadors and coordinated their input.

Table 1 Basic characteristics of included adolescents with CP (N=45)

Characteristic	Subgroup	Mean ± SD or n (%)
Age		15 y 6 mo±1 y 7 mo
Sex	Boys	26 (58)
	Girls	19 (42)
GMFCS	Level I	25 (56)
	Level II	14 (32)
	Level III	2 (4)
	Level IV	2 (4)
	Level V	2 (4)
MACS	Level I	20 (45)
	Level II	15 (33)
	Level III	10 (22)
	Level IV	0
	Level V	0
CFCS	Level I	34 (75)
	Level II	7 (16)
	Level III	3 (7)
	Level IV	1 (2)
	Level V	0

Abbreviation: CFCS, Communication Function Classification System.

Ethical considerations

The adolescents and their parents gave their written informed consent for participation in the PERRIN-PiP study. The medical ethics committee of the UMC Utrecht judged that this follow-up study (protocol no. 15-669/C) did not fall under the scope of the Dutch Medical Research Involving Human Subjects Act. The study was also approved by the internal scientific committee of De Hoogstraat Rehabilitation.

Measures

Adolescent participation in social roles

Participation in social roles was measured using the Dutch version of the Life-H.[27] The Life-H is a self-report questionnaire that has good reliability and validity.[28,29] For the purpose of present study, both the accomplishment scale and the satisfaction scale were used, each including the same 6 domains for social roles: Responsibilities, Interpersonal relationships, Community life, Education, Employment, and Recreation. All domains consist of 6-8 items except for Employment, which had only 1 item in this study.

For the accomplishment scale (ie, how a person experiences his or her level of participation accomplishment), the respondent recorded the difficulty experienced ("no difficulty," "some difficulty," "accomplished by a proxy," or "not accomplished") as well as the assistance needed ("no assistance," "use of assistive device," "adaptation," and/or "with human assistance"). Per item, the 2 accomplishment scores (ie, difficulty and assistance) were combined into 1 score ranging from 0-9 (appendix 1). Per domain, a mean score of all applicable items could then be calculated as an interval scale, with a score of 9.00 indicating optimal accomplishment.[30] Domain scores ≥ 8.00 reflect independent functioning without difficulties, scores between 5.00 and 8.00 indicate independent functioning with difficulties, and scores≤5.00 indicate dependent functioning or not able to accomplish.[2,30]

For the satisfaction scale (ie, how satisfied a person is with his or her participation), the respondent recorded the level of satisfaction with participation in certain social roles. Satisfaction was filled out for the same items as on the accomplishment scale by selecting 1 of 5 options: "with this activity I am 'very dissatisfied' (score 1), 'dissatisfied' (2), 'more or less satisfied' (3), 'satisfied' (4), or 'very satisfied' (5)." Per domain, a mean score of all applicable items could be calculated as an interval scale, with a score of 5.00 indicating highest satisfaction.[31]

Potential determinants for participation (variables collected in childhood)

Variables collected in childhood (age≤7y) were organized in 4 components, based on the ICF framework. For *health condition*, prematurity was operationalized as pregnancy of <37 weeks (yes/no), and severity of CP was classified using the GMFCS and MACS (both dichotomized in level I-II vs

III-IV-V). For *activity*, children's motor capacity was measured using the Gross Motor Function Measure (GMFM-66),[32,33] and children's capabilities in self-care and social functioning were measured using the Functional Skills Scale of the Pediatric Evaluation of Disability Inventory (PEDI) (scaled scores).[34,35] For *personal factors*, children's internalizing behavior (eg, withdrawal) and externalizing behavior (eg, aggression) were assessed using the Child Behavior Checklist (dichotomized in deviant vs nondeviant).[36] For *environmental factors*, 3 parental factors were included: amount of assistance given in self-care and social functioning, using the Caregiver Assistance Scale of the PEDI[34,35]; maternal coping styles "active confronting" (ie, problem-focused) and "passive reactions" (ie, emotion-focused), assessed using the Utrecht Coping List[37]; and parental level of education, operationalized as lower (vocational education) or higher (higher education).

Procedures

All adolescents participating as respondents in the PERRIN-PiP study were sent the Life-H questionnaire, online or on paper, depending on their preference. With help of the project ambassadors, we piloted a few adjustments in instructions and display without changing the essence of this instrument. In present study, the Life-H could thus be applied appropriately as a self-report questionnaire for adolescents (12-18y) with CP, which was not available for this age group in the Netherlands before.

Regarding the early childhood variables, we had access to the PERRIN 0-5 and PERRIN 5-9 databases, including information at baseline, concerning CP-classifications, GMFM-66, and PEDI (administered by trained researchers) and concerning prematurity, Child Behavior Checklist, Utrecht Coping List, and parental education (parent report).

Data analyses

Analyses were performed using SPSS version 24.[a] Descriptive statistics (mean $\pm$ SD) were computed on all 6 domains of social roles on the Life-H, both for accomplishment and for satisfaction, for the total group and also by GMFCS level (I-II vs III-IV-V).

After describing social role participation by level of accomplishment and by level of satisfaction, we explored the relation between accomplishment and satisfaction by observation (scatter plots), by explained variances (R^2), and by statistical modeling (linear regression).

In the regression analyses, different Life-H domains were separately entered as dependent variables, both for accomplishment and for satisfaction. Early childhood variables (ie, factors of the health condition, activity, person, and environment) were entered as independent variables. Those independent variables with $P<.15$ in univariate analyses were candidates for multivariate analyses.[38] Multivariate models were formed using the backward procedure (with $P<.05$). The assumptions for regression analyses were met, including normal distribution of the residuals in the final models.

Results

A flowchart of the sample selection and recruitment process is shown in figure 1. A total of 50 adolescents participated, of whom 45 were included for analyses (see table 1). Compared with the included adolescents, the excluded adolescents had lower functional abilities according to the GMFCS.

Descriptive statistics on social role participation

In table 2, mean scores on the Life-H are given for accomplishment and satisfaction. For accomplishment, all mean scores were <8.00 (indicating presence of difficulties) except for the domain of Relationships (8.39). The lowest mean score for accomplishment was on the domain of Employment (6.84), which also had a high proportion "not applicable" (44%). See appendix 2 for details per domain.

For satisfaction, all mean scores were ≥ 3.00 (indicating relatively high level of satisfaction), with the domain of Responsibilities having the highest mean (4.34). The lowest mean score was, again, on the domain of Employment (3.85). See appendix 3 for details per domain.

Split into functional ability by dichotomized GMFCS, levels I-II showed higher scores than levels III-IV-V both on accomplishment and satisfaction. For accomplishment, these differences were significant ($P<.05$) except for the domain of Relationships. For satisfaction, these differences were significant ($P<.05$) except for Relationships and Education.

Because the domain of Employment consisted of only 1 item, and this item was quite often not applicable for the respondents in this study, further analyses were performed without this domain.

Relation between accomplishment and satisfaction

Figure 2 presents the scatterplots of accomplishment vs satisfaction in different domains. From these scatterplots and table 2, large variation in scores was observed, particularly in the domains of Recreation (for accomplishment) and Education (for satisfaction). Least variation was observed in the domains of Responsibilities and Relationships, both for accomplishment, showing high scores and a ceiling effect, and for satisfaction.

Overall, in adolescents with similar levels of accomplishment, large ranges at the level of satisfaction were visible (and vice versa). For example, among adolescents with an accomplishment score of about 7.00 in the domain of Education, satisfaction scores varied over the whole range between 1.00 and 5.00.

Explained variances (R^2) range between 6% (Education) and 44% (Responsibilities, confirming the findings from the scatterplots: accomplishment explains only a small proportion of satisfaction).

Determinant models for accomplishment and satisfaction

Using the ICF framework, the childhood variables that are potential determinants for adolescent participation in social roles are described in table 3.

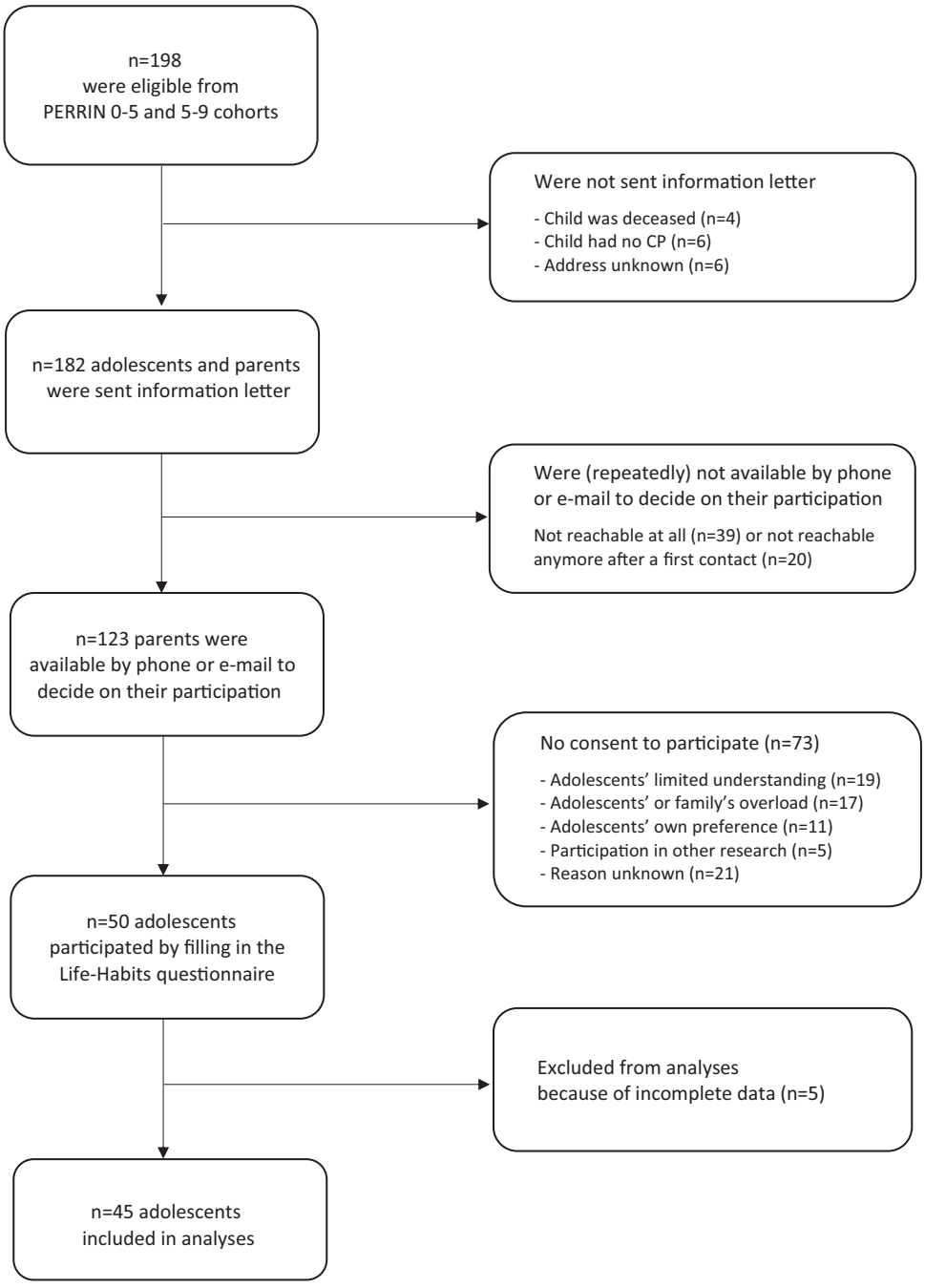

Fig 1 Sample selection and recruitment in the PERRIN-PiP study (10-year follow-up of PERRIN 0-5 and PERRIN 5-9 cohorts).

In table 4, the 7 childhood variables that showed significant contributions in multivariate regression models are indicated as determinants for certain participation domains. The sets of identified determinants for accomplishment and satisfaction appeared to be quite different. For accomplishment, the various domains showed to be determined predominantly by factors of CP (severity) and activity (motor capacity) and less by factors of environment. For satisfaction, it showed to be reversed: predominantly environmental factors (maternal passive coping and parental education) and to a lesser extent factors of CP and activity. Personal factors (behavior) were quite evenly present as determinants when comparing the accomplishment and satisfaction models. In addition, table 4 shows that the determinant models for accomplishment had much higher explained variances (R^2 between 51% and 86%) than the determinant models for satisfaction (R^2 between 13% and 40%).

Discussion

The aim of this study was to explore participation in social roles of adolescents with CP in terms of both

Table 2 Scores for participation in social roles in terms of accomplishment and satisfaction, by GMFCS level (dichotomized)

Construct	Measure	Mean Scores ± SD			
		Total Group (N=45)	GMFCS		
			Level I-II (n=39)	Level III-V (n=6)	*P* Value
Accomplishment	Life-H: accomplishment, 0-9 scale				
	Responsibilities	7.66±1.68	7.98±1.42	5.58±1.87	<.05
	Interpersonal relationships	8.39±1.22	8.57±0.85	7.23±2.41	.23
	Community life	7.41±2.31	7.90±1.97	4.24±1.85	<.05
	Education	7.34±1.88	7.75±1.59	4.73±1.51	<.05
	Employment*	6.84±3.09	7.12±2.80	-	-
	Recreation	7.05±2.39	7.67±1.87	3.06±1.29	<.05
Satisfaction	Life-H: satisfaction, 1-5 scale				
	Responsibilities	4.34±0.57	4.42±0.55	3.87±0.48	<.05
	Interpersonal relationships	4.32±0.61	4.38±0.59	3.95±0.66	.11
	Community life	4.27±0.67	4.39±0.59	3.52±0.69	<.05
	Education	4.12±0.94	4.14±1.01	4.03±0.13	.53
	Employment†	3.85±1.14	4.06±1.04	2.40±0.55	<.05
	Recreation	4.30±0.64	4.38±0.63	3.78±0.44	<.05

* n=25, with GMFCS I-II n=24 and GMFCS III-V n=1.
† n=39, with GMFCS I-II n=34 and GMFCS III-V n=5.

accomplishment and satisfaction. Our results showed that, at average, the level of participation accomplishment in adolescents with CP was quite low, whereas their level of satisfaction with participation was quite high. For both aspects, large variations in scores were noticed. Subsequently, lower scores for accomplishment did not automatically imply lower scores for satisfaction (and vice versa). Thus, we found a discrepancy between accomplishment and satisfaction.

This main finding was then deepened by describing and comparing models of determinants for both aspects of participation. We noted different sets of early childhood determinants. Participation accomplishment appeared to be determined predominantly by factors of the motor disorder (CP). Participation satisfaction, on the other hand, showed to be determined mainly by factors of the social environment.

The observation that adolescents with CP experience difficulties in accomplishment of participation in social roles concurs with several recent studies.[2-7] The major novelty of our study concerns uncovering the satisfaction aspect of participation and exploring its discrepancy with accomplishment. Adolescents with CP appeared satisfied rather than dissatisfied with their social role participation, showing a different pattern of domain scores, when compared with their accomplishment. So far, very few studies have paid attention to this satisfaction aspect in adolescents with CP. However, some have been touching this topic using other related concepts, such as "quality of life" and "enjoyment."[39,40] Our study provides some first insights in early childhood determinants for adolescent participation. For participation accomplishment, our findings fit with 3 previous studies showing important child and family determinants.[41-43] For participation satisfaction, however, the role of the social environment is quite novel, with some indications of a role of maternal coping. This specific observation advocates paying attention to the parenting style in relation to later life participation in society.[44-47]

Study limitations

Some methodological considerations should be discussed before interpretation and implication of our results. The present study had a sample of adolescents with CP that was relatively small (N=45), with a selection excluding adolescents with low intellectual abilities (post hoc analyses revealed that 60% functioned age appropriately on the Vineland Socialization Scale). Nevertheless, the study was the first of its kind and therefore explorative. The sample was also a realistic consequence of performing self-reports in youth with CP.

Additional methodological considerations relate to the instrument to measure participation. Using the Life-H in adolescents with CP matched our aim but was also challenging. At the time of our study, the Life-H was not available yet as a self-report for our entire age group. This entailed, especially for the youngest adolescents, that we had to make a few adjustments in instructions (age-appropriate wording) and display (more straightforward layout). Still, with the help of the adolescents themselves, we were able to first pilot the adjustments, and we could assure ourselves of reliability and validity in the study.

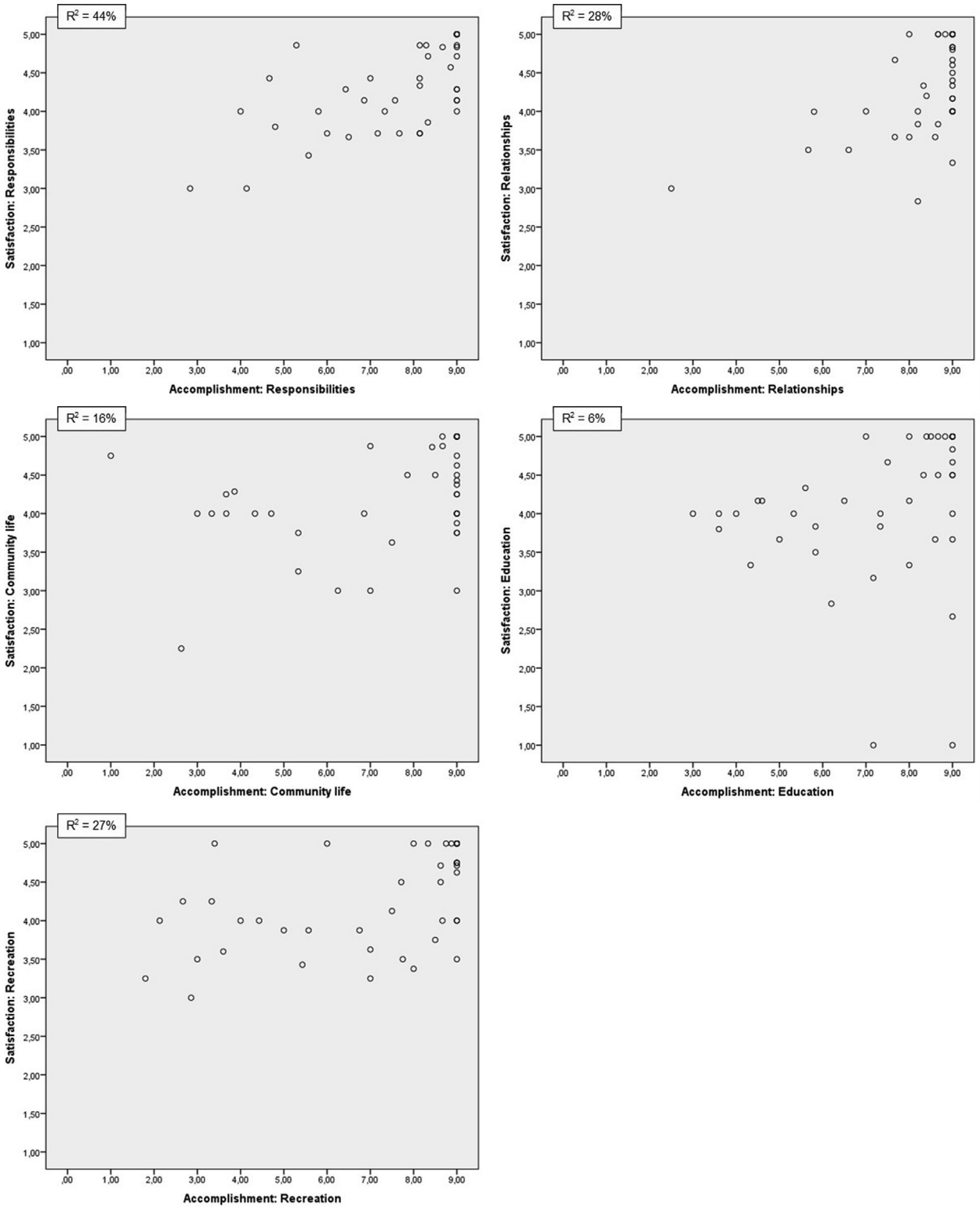

Fig 2 Scatterplots and percentage explained variances (R^2) of accomplishment vs satisfaction in 5 Life-H domains: Responsibilities, Relationships, Community life, Education, and Recreation. * In this analysis, the domain of Employment has been omitted due to limited data.

Table 3 Description of early childhood variables (potential determinants for participation)*

Characteristic	Subgroup		Mean ± SD or n (%)
Age at baseline			5 y 2 mo±2 y 1 mo
Starting age	Age $1^1/_2$ y		6 (13)
	Age $2^1/_2$ y		6 (13)
	Age 5 y		15 (34)
	Age 7 y		18 (40)
Health condition (CP)			
Prematurity	No		23 (51)
	Yes		22 (49)
GMFCS†	Level I-II		36 (80)
	Level III-IV-V		9 (20)
MACS†	Level I-II		39 (87)
	Level III-IV-V		6 (13)
Activity (motor, self-care, social)			
GMFM-66	Scaled score (0-100)		66.22 (17.55)
PEDI-FSS	Self-care, Scaled score (0-100)		66.45 (15.64)
	Social, Scaled score (0-100)		70.27 (14.15)
Personal factors (behavior)			
CBCL	Internalizing problems		8 (20)
	No internalizing problems		32 (80)
			Missing: 5
	Externalizing problems		9 (22)
	No externalizing problems		31 (78)
			Missing: 5
Environmental factors (parents)			
PEDI-CAS	Self-care, scaled score (0-100)		60.48 (17.65)
	Social, scaled score (0-100)		66.05 (20.67)
UCL	Active coping (mother)	Below	4 (10)
		Average	23 (55)
		Above	15 (35)
			Missing: 2
	Passive coping (mother)	Below	12 (29)
		Average	18 (42)
		Above	12 (29)
			Missing: 2
Education	Lower (vocational education)		19 (42)
	Higher (higher education)		26 (58)

Abbreviations: CBCL, Child Behavior Checklist; PEDI-CAS, Pediatric Evaluation of Disability Inventory-Caregiver Assistance Scale; PEDI-FSS, Pediatric Evaluation of Disability Inventory-Functional Skills Scale; UCL, Utrecht Coping List.

* Variables at baseline measurements of the PERRIN 0-5 and PERRIN 5-9 age cohort studies

† GMFCS and MACS levels from early childhood were dichotomized, and that in a few cases these early classifications were a bit different from those in adolescence (see table 1).

Finally, regarding the childhood determinants in our regression analyses, this concerned variables available from prior projects (PERRIN 0-5 and PERRIN 5-9). To gain more insight in the role of personal and environmental factors further research is needed. In our determinant models, the long-term relationships should be considered as trends that need further examination in future research. Besides, it should be taken into account that especially for the accomplishment aspect, a longitudinal association with early childhood determinants is considered logical. The satisfaction aspect, however, might rather be determined by more instantaneous conditions, such as mental state, which are still underexposed in the pediatric rehabilitation. In that regard, our results demonstrated that early determinants for satisfaction were quite difficult to grasp quantitatively (see lower explained variances in table 4). This pleads for qualitative deepening if we really want to know more about participation.[7]

Overall, our message is that within the concept of participation, different aspects should be distinguished for practice and research involving individuals with a disability, such as CP. This message fits well in current discourses about participation.[48-51]

Table 4 Determinant models (multivariate) for accomplishment and for satisfaction in 5 Life-H domains*

Outcome Variable	Determinants†							Percentage-Explained Variance, %
	CP	Activity		Personal Factors (Behavior)	Environmental Factors (Parents)			
	Severity (GMFCS)	Motor Capacity (GMFM)	Self-care Capability (PEDI-FSS)	Internalizing Problems (CBCL)	Assistance in Self-care (PEDI-CAS)	Passive Coping Mother (UCL)	Educational Level Parents	
Life-H: Accomplishment								
Responsibility	X (−)	X (+)		X (−)				51
Relationships		X (+)				X (−)		51
Community	X (−)		X (+)					66
Education	X (−)	X (+)				X (−)		64
Recreation	X (−)	X (+)	X (+)	X (−)	X (+)			86
Life-H: Satisfaction								
Responsibility		X (+)				X (−)	X (−)	40
Relationships						X (−)		19
Community	X (−)					X (−)		32
Education						X (−)	X (−)	23
Recreation				X (−)				13

NOTE. X's indicate those variables that significantly contributed to the determinant model of a certain Life-H domain. (+) indicates a positive association and (−) indicates a negative association.
Abbreviations: CBCL, Child Behavior Checklist; PEDI-CAS, Pediatric Evaluation of Disability Inventory-Caregiver Assistance Scale; PEDI-FSS, Pediatric Evaluation of Disability Inventory-Functional Skills Scale; UCL, Utrecht Coping List.
* In this analysis, the domain of Employment has been omitted because of limited data.
† Six variables were not associated, either in univariate analyses (ie, prematurity, child's capability in social functioning, and parents' assistance in social functioning) or in multivariate analyses (ie, child's manual ability, child's external behavior, and maternal active coping).

Clinical implications

It is clear the concept of participation has different aspects that should be considered. We discussed the findings with the panel of the project ambassadors (ie, adolescents with CP themselves, in particular those mentioned in the acknowledgments). Most of them recognized from their personal experiences that participation accomplishment was indeed quite difficult and depended on the setting or domain. Further, they interpreted the high level of participation satisfaction as a very advantageous message, which should be addressed more often. However, they also emphatically emphasized the relativity of the high satisfaction. First of all, satisfaction is domain dependent, entailing a great variation among and within individuals. Someone can be quite satisfied with participation in relationships but not at all with participation at school. Second, despite the fairly high average scores, satisfaction with participation is not something that can be taken for granted, often requires special efforts, and is preceded by a whole process in which personal and environmental factors play an important role.[7] Third, the level of satisfaction seems to be high but is not extraordinarily high, and in most cases there is still a lot to be gained. Consequently, the ambassadors perceived the satisfaction aspect of participation as the most important outcome, more important than accomplishment. They noted that health care practitioners should address adolescents' satisfaction with participation more often and as a continuous recurring topic because it is important from a lifelong perspective. From this notion, they recommended to reconsider the idea about the direction of the relationship between concepts: we are often inclined to start with improving accomplishments with the implicit assumption that it will improve satisfaction. The adolescents themselves suggested to regard satisfaction from now on as the starting point for optimizing participation.

Conclusions

This present study provides evidence that, among adolescents (12-18y) with CP, there is a dissociation between their participation accomplishment and their satisfaction with participation. For practice and research, we recommend not only to focus on accomplishment, which seems to be the standard procedure but also, if not mainly, on satisfaction. The satisfaction aspect may well offer new starting points for treatments and interventions focused on optimizing participation.

Supplier

a. SPSS version 24; IBM.

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Appendix 1 Scoring on the Accomplishment Scale of the Life-H: A Combination of Difficulty Level and Assistance Type (Van Gorp et al, 2019[30])

Item Score (0-9)	Difficulty Level	Assistance Type	Level of Accomplishment Trichotomized
9	No difficulty	No assistance	Score ≥8 = no difficulty and independent Score between 5 and 8 = difficulty and independent Score ≤5 = dependent or unable
8	No difficulty	Assistive device (or adaptation)	
7	With difficulty	No assistance	
6	With difficulty	Assistive device (or adaptation)	
5	No difficulty	Human assistance	
4	No difficulty	Assistive device (or adaptation) and human assistance	
3	With difficulty	Human assistance	
2	With difficulty	Assistive device (or adaptation) and human assistance	
1	Accomplished by a proxy	-	
0	Not accomplished	-	

Appendix 2 Accomplishment of Social Roles: Levels of Scoring and Not Applicable Items per Life-H Domain, Among the Respondents (N=45)

	Level of Accomplishment, n (%)			Number of Cases With Items NA, n (%) *and Most Frequent Items NA*
	No Difficulty and Independent (mean score ≥8.00)	Difficulty and Independent (mean score 5.00-8.00)	Dependent or Unable (mean score ≤5.00)	
Responsibilities (7 items)	28 (62)	12 (27)	5 (11)	19 (42) *In most cases (n=15)* *"Using bank cards and ATMs"*
Personal relationships (6 items)	38 (85)	6 (13)	1 (2)	15 (33) *In most cases (n=12)* *"Being involved or participating in sexual awareness"*
Community life (8 items)	28 (62)	8 (18)	9 (20)	39 (87) *In most cases (n=34)* *"Participating in religious or spiritual activities" and (n=29)* *"Participating in charity or community work"*
Education (6 items)	25 (55)	12 (27)	8 (18)	10 (22) *In most cases (n=6)* *"Doing homework"*
Employment (1 item)	15 (60)	4 (16)	6 (24)	20 (44) *In all cases "Performing small paid or unpaid jobs"*
Recreation (8 items)	25 (55)	9 (20)	11 (24)	25 (56) *In most cases (n=15)* *"Taking part in artistic, cultural, or craft activities"*

Abbreviation: NA, not applicable.

Appendix 3 Satisfaction With Social Roles: Levels of Scoring and Missing Items per Life-H Domain, Among the Respondents (N=45)

	Level of Satisfaction, n (%)		Number of cases with missing items, n (%) *and most frequent missing items*
	Satisfied (mean score ≥3)	Dissatisfied (mean score <3)	
Responsibilities (7 items)	45 (100)	0	8 (18%) *In most cases (n=7) "Using bank cards and ATMs"*
Personal relationships (6 items)	44 (98)	1 (2)	7 (16%) *In all cases "Being involved or participating in sexual awareness"*
Community life (8 items)	44 (98)	1 (2)	13 (29%) *In most cases (n=11) "Participating in charity or community work"*
Education (6 items)	41 (91)	4 (8)	4 (9%) *In most cases (n=3) "Doing homework"*
Employment (1 item)	40 (89)	5 (11)	6 (13%) *In all cases "Performing small paid or unpaid jobs"*
Recreation (8 items)	45 (100)	0	11 (24%) *In most cases (n=7) "Attending sporting events"*

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