



Original Research

Assessing Participation in Adolescents With Cerebral Palsy: Comparison of Life-Habits and USER-Participation



Gerjanne J. van Alphen, MD, MSc ^a,
Marjolijn Ketelaar, PhD ^{b,c},
Jeanine M. Voorman, MD, PhD ^d,
Eline W.M. Scholten, PhD ^{b,c}, Marcel W.M. Post, PhD ^{b,c,e}

^a Utrecht University, University Medical Centre Utrecht, Utrecht, The Netherlands

^b UMC Utrecht Brain Centre, University Medical Centre Utrecht, Utrecht, The Netherlands

^c De Hoogstraat Rehabilitation, Utrecht, The Netherlands

^d Wilhelmina Children's Hospital Utrecht, University Medical Centre Utrecht, Utrecht, The Netherlands

^e University of Groningen, University Medical Centre Groningen, Department of Rehabilitation Medicine, Groningen, The Netherlands

KEYWORDS

Accomplishment;
Adolescents;
Assessment;
Cerebral palsy;
Participation;
Rehabilitation;
Restrictions;
Satisfaction

Abstract Objective: To explore and compare the contents and scores of the Assessment of Life Habits (Life-H) with the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) in adolescents with cerebral palsy.

Design: Youth versions of both instruments were used for (1) content comparison and (2) analyses of relations between both instruments, based on cross-sectional data.

Setting: Clinic.

Participants: Participants were adolescents with cerebral palsy, aged 12-18 years; Gross Motor Function Classification System I-V; N=45.

Interventions: Not applicable.

Main outcome measures: Assessment of Life Habits (Life-H) with USER-Participation.

Results: Both instruments measure independence in participation, called accomplishment (Life-H) and restrictions (USER-Participation), and satisfaction with participation. Life-H provides a profile of 6 domain scores and the USER-Participation a total score per dimension. Compared with the USER-Participation, the Life-H contains more specific items, more items not-applicable to many participants and more ceiling effects. Total scores on the accomplishment/restrictions

List of abbreviations: CP, cerebral palsy; USER-Participation, The Utrecht Scale for Evaluation of Rehabilitation-Participation; Life-H, The Assessment of Life Habits; GMFCS, Gross Motor Function Classification System; ICF-CY, The International Classification of Functioning, Disability, and Health—Child and Youth version; PiP, Participation in Perspective project
PERRIN-PiP was supported by FNO (project no. 100-038), Amsterdam, The Netherlands.

Disclosures: None.

Cite this article as: Arch Rehabil Res Clin Transl. 2022;4:100240

<https://doi.org/10.1016/j.arrct.2022.100240>

2590-1095/© 2022 The Authors. Published by Elsevier Inc. on behalf of American Congress of Rehabilitation Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

and satisfaction scales between both instruments showed strong correlation coefficients (0.87 and 0.67, respectively). Correlations between domain scores were stronger within the accomplishment/restrictions scales (range 0.37-0.88) compared with the satisfaction scales (range 0.22-0.68).

Conclusions: Compared with the USER-Participation, the Life-H takes more effort to complete but provides a more comprehensive assessment of participation. Participation accomplishment/restrictions scores were more similar between the instruments compared with satisfaction scores. Researchers and clinicians should carefully compare participation instruments in selecting one that matches their purpose.

© 2022 The Authors. Published by Elsevier Inc. on behalf of American Congress of Rehabilitation Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Cerebral palsy (CP) is one of the most common childhood-onset conditions in pediatric rehabilitation with a rate of about 2-3.5 per 1000 livebirths.¹ CP is an umbrella term for a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive lesions in the fetal or infant brain.² These motor impairments are often accompanied by disturbances of perception, cognition, sensation, communication, and behavior, as well as by secondary musculoskeletal problems and epilepsy.² This broad range of symptoms may lead to many challenges in functioning that are dynamically changing throughout different stages of life.³⁻⁷

Adolescence is a crucial transition period in which change and adjustment may be more difficult for adolescents with impairments.^{4,6,8} Several studies have demonstrated the experience of participation restrictions in daily life activities and social participation in adolescents and adults with CP.^{4,7,9-12} Enabling participation, therefore, is one of the main goals of pediatric rehabilitation. The International Classification of Functioning, Disability, and Health—Child and Youth version (ICF-CY) defined participation as “involvement in a life situation”.¹³ Despite the wide acceptance of this definition, the conceptualization and measurement of participation remains challenging. One of the issues in this discussion focuses on the importance of the subjective experience of participation as an aspect of participation, including satisfaction with participation.^{14,15} There is no straightforward relation between participation accomplishment and satisfaction⁹ and appropriate instruments including both accomplishment of and satisfaction with participation for adolescents with CP are sparse.^{6,16-18}

The Assessment of Life Habits (Life-H) and the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) are participation instruments developed to assess both accomplishment of, and satisfaction with participation. Both instruments have been developed for use in adult populations and were later adapted for use in adolescent populations.

The Life-H has frequently been used in individuals with various health conditions including adolescents with CP,^{4,6,7,9,12} but has some challenges in its length and complex structure.¹⁹ For the purpose of the present study, the Life-H has been slightly adjusted in order to make the instrument appropriate from the age of 12. The USER-Participation is an instrument developed to measure frequency, restrictions, and satisfaction with participation in adults with various health conditions.¹⁴ It was designed as an

instrument that would be easier to administer than available other instruments, without sacrificing the complete evaluation of the multidimensional character of participation. It has been evaluated by patients as “easy to complete” and “relevant”.^{14,19} A slightly adapted version for use in adolescents has been developed previously.²⁰ At first sight, the Life-H and the USER-Participation seem to be substantively comparable participation instruments because both focus on accomplishment or restrictions of, and satisfaction with participation. A detailed comparison between the 2 will contribute to the awareness on the selection and operationalization of participation instruments and the ability to make well-advised choices between the available options. Therefore, the goal of this study was to explore and compare the contents and scores of the Life-H with the USER-Participation in adolescents with CP.

Methods

Instruments were compared on content (see Analysis) and based on data collected in the Participation in Perspective project (PERRIN-PiP).^{9,10}

Participants

Adolescents with CP previously engaged in PERRIN age cohorts 0-5 and 5-9 were eligible for inclusion in the PERRIN-PiP project (n=198). In this follow-up study, the focus was on participation in adolescents aged 12-18 years. For inclusion in the PERRIN cohorts, children had to be clinically diagnosed with CP. They were excluded if they had also been diagnosed with another motor functioning affecting condition or if their caregiver did not fully understand the Dutch language. Participants in the PERRIN-PiP project also had to be able to understand the informed consent themselves and needed to have the cognitive capacity to understand the questions with no or little help, which was decided in advance in consultation with the parents.

Procedure

Between January 2016 and October 2017, potential participants were invited by mail and contacted by phone or e-mail to determine whether they were interested in participating in this study.

In total, 50 adolescents and their parents gave their written informed consent for participation in the PERRIN-PIP project, and they were sent the Life-H and USER-Participation questionnaires, online or on paper, depending on their preference. The Medical Ethics Committee of the UMC Utrecht judged that this 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 local institutional review board of De Hoogstraat Rehabilitation.

Instruments

Life-H

The Life-H is a self-report instrument to evaluate social participation in adults with physical disabilities, irrespective of the diagnosis.²¹ It is based on the disability creation process model, in which participation is operationalized in terms of life habits, defined as “*daily activities and social roles that ensure the survival and development of a person in society*”.²¹ The short version of the Life-H contains 69 items in 6 domains on daily activities and 6 domains on social roles. The instrument evaluates each activity or role in 2 scales: accomplishment and satisfaction. For the accomplishment scale (ie, how a person experiences his or her level of participation accomplishment), the respondent records 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) are combined into 1 score ranging from 0 to 9 (appendix 1).

For the purpose of the present study, we focused on participation and thus only the 6 domains addressing social roles were considered, namely, Responsibilities, Interpersonal Relationships, Community Life, Education, Employment, and Recreation. Details on the contents of the Life-H are provided in the results section. The Life-H showed good discriminant and convergent validity and reliability in adults.^{22,23} The short version 3.0 can be used from the age of 14 and has been translated into Dutch in 2002 using a forward-backward procedure.²² With the help of a panel of experts by experience (12 adolescents with CP partnering in all stages of the PERRIN-PIP project),^{9,10} the Dutch short version 3.0 was piloted with a few adjustments in instructions and layout to make it more appropriate for adolescents from the age of 12 years, without changing the contents of the instrument.

For each domain, a domain score was calculated as the mean of the scores on all applicable items in that domain. To facilitate comparison with the USER-Participation, we calculated additional total scale scores for accomplishment and satisfaction as the mean of all domain scores in each scale. Life-H item, domain, and scale scores range from 0 to 9 (accomplishment) and 1 to 5 (satisfaction). Higher scores indicate better participation (higher levels of accomplishment and satisfaction).

USER-Participation

The USER-Participation is a self-report instrument for adults on participation in productive, leisure, and social activities and relationships. It consists of 3 scales: Frequency, Restrictions, and Satisfaction.¹⁴ Of the 3 scales, only the Restrictions and

Satisfaction scales can be compared with the Life-H and were included in the current study. The USER-Participation Restrictions scale consists of 11 items concerning difficulties experienced with vocational, leisure, and social activities. For each item, 4 response categories are available: “not possible”, “with assistance”, “with difficulty”, and “without difficulty”. The Satisfaction scale consists of 10 items, with score categories “very dissatisfied”, “dissatisfied”, “neutral”, “satisfied”, and “very satisfied”. Details on the contents of the USER-Participation are also provided in the results section. The USER-Participation has shown moderate to good reproducibility and good validity and responsiveness in various settings in adults.^{14,19,24,25} In the current study, the slightly adapted version for adolescents was used.²⁰ In this version, items on partner and family relationships were changed into parental and sibling relationships, respectively. Further, some examples were changed into examples more appropriate for adolescents, such as playing computer games. This version was piloted and discussed with the panel of experts by experience checking on clarity and missing items or examples. It was decided this version could be used in the PERRIN-PIP project without any adaptations. Total scores are calculated for each scale as the mean of the scores on all applicable items, converted into a 0-100 scale in which higher scores represent better levels of participation (less experienced restrictions and higher satisfaction). To enable comparison with the domain scores of the Life-H, items of the USER-Participation were sorted into 3 domains: Productivity, Leisure, and Social within each scale, as described in a recent publication.²⁶

Analysis

A qualitative comparison of the structure and contents of both instruments was made at scale, domain, and item level. The ICF-CY was used as conceptual framework to organize the contents of the instruments and illustrate the range of items covered within each domain. All items of the 2 instruments were linked to the most appropriate ICF-CY chapters.¹³

Statistical analyses were performed using IBM SPSS version 25.0. Descriptive statistics were computed to describe sample characteristics and scores on both instruments. Floor and ceiling effects were considered present if more than 15% of the participants scored the worst or the best score possible on a scale or domain. The relations between similar scales and domains of both instruments were assessed by observation of scatterplots and by calculating nonparametric Spearman's correlation coefficients. Spearman's correlation coefficients were regarded as strong if ≥ 0.50 .²⁷

Results

Participants

A total of 50 adolescents participated in PERRIN-PIP of whom 45 were included for the current analyses. Data from 5 participants were excluded because incomplete data on the Life-H (4 participants) or on both instruments (1 participant). Of the 45 study participants (aged 12-18 years), 26 (57.8%) were men and their mean age at the time of the study was 15.7 (SD 1.5)

years. Twenty-five (55.6%) adolescents were classified at Gross Motor Function Classification System (GMFCS) level I and 14 (31.1%) were classified at GMFCS level II. Six (13.3%) participants were classified at GMFCS levels III-V (n=2 for each level).

Qualitative comparison

The instruments showed several similarities at scale level (table 1). Both instruments evaluate the accomplishment of participation in terms of difficulty and need for assistance, as well as the satisfaction with participation. Their structure, however, differs. In the Life-H, each item is rated for difficulty and assistance, combining these into an accomplishment-score and each item is rated for satisfaction, whereas the USER-Participation contains separate, although largely similar series of items, for restrictions and for satisfaction. The USER-Participation includes assistance (in terms of a person providing assistance) as 1 of the response categories in the Restrictions scale, with assistance leading to a lower score. The Life-H accomplishment scale includes both assistance from a person as well as the use of assistive devices. In the Life-H, the 2 accomplishment scores (ie, difficulty and assistance) are combined into 1 score, where human assistance leads to lower scores compared with the use of assistive devices (appendix 1). Further, the Life-H contains

more items with more specificity. Overall, the Life-H is a longer questionnaire because it contains 3 questions for each item (difficulty, assistance, and satisfaction), and because it contains more (specific) items, and therefore provides more detail, but also takes more time to administer.

A detailed overview of all domains per instrument is presented in table 2. Three of the Life-H domains show similarities with the USER-Participation domains, that is the Life-H Interpersonal relationships domain with the USER-Participation Social domain and the Life-H Community life and Recreation that both cover similar items as the USER-Participation Leisure domain. The Life-H Community life domain assesses societal activities in 8 items, such as transportation and spiritual and religious activities. The USER-Participation Leisure domain covers these topics in items on outdoor mobility and religious activities.

Most differences can be found in the other domains of the instruments. For example, the Life-H Responsibilities domain covers a number of items on responsibility and respect, whereas these topics are not covered in the USER-Participation, except for household tasks. The assessment of education and employment also differs largely between both instruments. The Life-H includes separate Education (6 items) and Employment (1 item) domains, whereas in the USER-Participation school and work are evaluated together in 1 item as part of the Productivity domain. Both instruments cover a broad range of ICF-CY chapters, of

Table 1 Comparison of the structure of the Life-H and USER-Participation*

	Life-H Accomplishment	Life-H Satisfaction	USER-Participation Restrictions	USER-Participation Satisfaction
Number of items	36 (with 2 questions per item)	36	11	10
Structure	Each item is rated for accomplishment (A: level of accomplishment and B: type of assistance required) and satisfaction		Separate scales for restrictions and satisfaction, most items concern similar activities	
Response options	A: No difficulty With difficulty Accomplished by a proxy Not accomplished Not applicable B: No assistance Assistive device Adaptation Human assistance	Very dissatisfied Dissatisfied More or less satisfied Satisfied Very satisfied	Not possible With assistance With difficulty Without difficulty Not applicable	Very dissatisfied Dissatisfied Neutral Satisfied Very satisfied Not applicable
Item score	A + B: combined into 1 item score ranging from 0 to 9 [†]	1-5	0-3	0-4
Domain score	Mean score of all applicable items (range 0-9)	Mean score of all applicable items (range 1-5)	Mean score of applicable items within each domain converted to a score ranging from 0 to 100	
Total scale score	Mean score of all domain scores (range 0-9)	Mean score of all domain scores (range 1-5)	Mean score of applicable items on each scale converted to a score ranging from 0 to 100	

* The comparison has been made between components of both instruments: the social role domains of the Life-H Accomplishment and Satisfaction scales and the Restrictions and Satisfaction scales of the USER-Participation.

[†] Detailed information on the Life-H item scoring system is given in Appendix 1.

Table 2 Comparison of instruments at domain level

Life-H	Responsibilities	Interpersonal Relationships	Community Life	Recreation	Education	Employment
Number of items	7	6	8	8	6	1
Item topics	Financial responsibility Showing respect Taking responsibility Lend a hand at home	Relationship parents Relationship family Sexual awareness Friendships Social contact with adults	Getting to, entering, and using public buildings, commercial establishments, and neighborhood businesses Charity work Religious practices	Sports and games Arts and culture Tourist activities Getting to, entering, moving around, and using neighborhood recreational services	Going to and getting around in school Participating at school Using school facilities Doing homework Participating in extracurricular activities	Paid employment Unpaid employment
ICF-CY coverage	Chapter D2, D6, D7, D8	Chapter D7	Chapter D4, D8, D9	Chapter D4, D9	Chapter D4, D8	Chapter D8
USER-Participation	-	Social	Leisure		Productivity	
Number of items	-	4*, 3 [†]	5*, 5 [†]		2*, 2 [†]	
Item topics	-	Relationships with and contact with parents, siblings, and other friends and relatives	Transportation Physical exercise Outdoor and indoor leisure activities		Education/work Household tasks	
ICF-CY coverage	-	Chapter D7	Chapter D4, D9		Chapter D6, D8	

NOTE. ICF-CY Chapter D2—General tasks and demands; ICF-CY Chapter D4—Mobility; ICF-CY Chapter D6—Domestic life; ICF-CY Chapter D7—Interpersonal interactions and relationships; ICF-CY Chapter D8—Major life areas; ICF-CY Chapter D9—Community, social, and civic life.

* Restrictions scale USER-Participation.

† Satisfaction scale USER-Participation.

which most items concern chapters D6-9 and D4 for mobility items. Chapter D2 is only covered in the Life-H Responsibilities domain.

Comparison based on data

In [table 3](#), descriptive statistics on the scales and domains of the instruments are given. The scatterplots of similar scale and domain scores of both instruments were observed but no extreme values were found. The Life-H Accomplishment scale had a median score of 8.2 (IQR 6.1-8.9) and showed a ceiling effect. Domain scores also showed strong ceiling effects, as for 3 scales the median score equaled the maximum score. Forty-four out of 45 participants scored at least 1 item on the Accomplishment scale as “not applicable”. Most participants with “not applicable” items were found on the Community life domain, mainly on the items “religious practices” (n=34) and “participating in charity or community work” (n=29). The Life-H Satisfaction scale had a median score of 4.1 (IQR 3.9-4.8) with less “not applicable” items per domain compared with the Accomplishment scale (n=17; 38%). The scale did not show a floor or ceiling effect, but all domains within the scale did show ceiling effects. Most items with “not applicable” were found on the Community life domain, of which 11 cases on “participating in charity or community work”.

The USER-Participation Restrictions scale had a median score of 90.9 (IQR 75.6-99.2). All median domain scores were higher than 83.3. The total Restrictions scale score and included domains all showed ceiling effects. Most items with “not applicable” were found on the Leisure domain, mostly on “going out” (n=8). The USER-Participation Satisfaction scale had a median score of 75.0 (IQR 65.0-84.7). This total scale score showed no floor or ceiling effects and had low proportions of items with “not applicable” in 1 of the domains (n=12; 27%). Most of the items with “not applicable” were on the Satisfaction Leisure domain, on the item “going out” (n=4). Details on “not applicable” items per domain are given in [appendix 2](#).

[Table 4](#) shows Spearman’s correlation coefficients. At the scale level, the Life-H Accomplishment scale showed a strong correlation with the USER-Participation Restrictions scale (0.87). Both Satisfaction total scale scores also showed strong correlations (0.67). Regarding the domains, almost all domain scores within the Life-H Accomplishment and the USER-Participation Restrictions scales showed strong correlations except for Life-H Interpersonal Relationships and all 3 USER-Participation domains. Concerning the domains within the Satisfaction scales, correlations were weaker than on the Accomplishment and Restrictions scales. Moreover, the correlation between the Life-H Education domain and the USER-Participation Productivity domain is not even statistically significant.

Table 3 Distribution of scale and domain scores of the Life-H and the USER-Participation

Scales (Bold) With Domains	Median (IQR)	% Minimum Score	% Maximum Score	Number of Participants With Items NA, n (%)
Life-H Accomplishment	8.2 (6.1-8.9)	0.0	20.0	44 (98)
Responsibilities	8.3 (6.7-9.0)	0.0	40.0	19 (42)
Interpersonal relationships	9.0 (8.2-9.0)	0.0	57.8	15 (33)
Community life	9.0 (5.8-9.0)	0.0	53.3	39 (87)
Education	8.0 (5.8-9.0)	0.0	33.3	10 (22)
Employment*	9.0 (5.5-9.0)	8.0	56.0	20 (44)
Recreation	8.3 (5.2-9.0)	0.0	35.6	11 (24)
Life-H Satisfaction	4.1 (3.9-4.8)	0.0	4.4	17 (38)
Responsibilities	4.3 (3.9-4.9)	0.0	22.2	8 (18)
Interpersonal relationships	4.3 (4.0-5.0)	0.0	28.9	7 (16)
Community life	4.3 (4.0-4.9)	0.0	24.4	13 (29)
Education	4.2 (3.7-5.0)	4.4	28.9	4 (9)
Employment†	4.0 (3.0-5.0)	2.6	38.5	6 (13)
Recreation	4.3 (3.8-5.0)	0.0	31.1	11 (24)
USER-Participation Restrictions‡	90.9 (75.6-99.2)	0.0	25.0	15 (33)
Productivity	83.3 (54.2-100.0)	0.0	43.2	6 (13)
Leisure	85.0 (66.7-100.0)	0.0	27.3	12 (27)
Social	100.0 (85.4-100.0)	0.0	72.7	1 (2)
USER-Participation Satisfaction	75.0 (65.0-84.7)	0.0	2.0	12 (27)
Productivity	75.0 (62.5-87.5)	0.0	6.7	4 (9)
Leisure	75.0 (60.0-83.1)	0.0	6.7	8 (18)
Social	83.3 (75.0-100.0)	0.0	31.1	4 (9)

* Life-H Accomplishment Employment domain: n=25. Because this domain only contains 1 item and “not applicable” cases are regarded as missing, the number of applicable cases on this domain is 25.

† Life-H Satisfaction Employment domain: n=39.

‡ USER-Participation Restrictions scale: n=44. One respondent answered all items on this scale with “not applicable” and no total score could be calculated.

Table 4 Spearman's correlation coefficients between domains within matching scales of the Life-H and the USER-Participation

Measure	USER-Participation Restrictions Scale*				Life-H Satisfaction	USER-Participation Satisfaction Scale			
	Productivity	Leisure	Social	Total scale		Productivity	Leisure	Social	Total scale
Life-H Accomplishment									
Responsibilities	0.67 [†]	0.75 [†]	0.64 [†]	0.76 [†]	Responsibilities	0.44 [†]	0.64 [†]	0.61 [†]	0.69 [†]
Interpersonal relationships	0.37 [†]	0.46 [†]	0.40 [†]	0.46 [†]	Interpersonal relationships	0.48 [†]	0.39 [†]	0.68 [†]	0.60 [†]
Community life	0.53 [†]	0.75 [†]	0.68 [†]	0.70 [†]	Community life	0.41 [†]	0.53 [†]	0.51 [†]	0.56 [†]
Education	0.64 [†] (I)	0.76 [†]	0.63 [†]	0.78 [†]	Education	0.22 (III)	0.37 [†]	0.26	0.40 [†]
Employment [§]	0.60 [†] (II)	0.68 [†]	0.59 [†]	0.67 [†]	Employment [§]	0.59 [†] (IV)	0.66 [†]	0.35 [†]	0.65 [†]
Recreation	0.69 [†]	0.88 [†]	0.70 [†]	0.86 [†]	Recreation	0.37 [†]	0.55 [†]	0.47 [†]	0.58 [†]
Total scale	0.71 [†]	0.86 [†]	0.70 [†]	0.87 [†]	Total scale	0.46 [†]	0.60 [†]	0.57 [†]	0.67 [†]

* USER-Participation Restrictions scale: n=44.

[†] Denotes statistically significant correlation; $P < .01$.

[‡] Denotes statistically significant correlation; $P < .05$.

[§] Life-H Employment domain: Accomplishment scale n=25; Satisfaction scale n=39. I Correlation coefficient for USER-Participation item Education: $r_s = 0.57$ [†]. II Correlation coefficient for USER-Participation item Work: $r_s = 0.37$. III Correlation coefficient for USER-Participation item Education: $r_s = 0.25$. IV Correlation coefficient for USER-Participation item Work: $r_s = 0.45$.

Discussion

In exploring and comparing content of Life-H and USER-Participation, both instruments showed many similarities at scale level, as evidenced by comparable scale components (accomplishment/restrictions and satisfaction). However, when zooming in more differences were found, as the Life-H and USER-Participation vary substantively in a number of items, item contexts and content, and in the amount of detail. Exploration and comparison of the scales and domain-scores of both instruments showed strong correlations between similar scales. The correlation between the Accomplishment (Life-H) and Restrictions (USER-Participation) scale scores was sufficiently strong as to suggest that 1 might consider the scales interchangeable. It is however important to keep in mind that scales can still be conceptually quite different when they are correlated. Therefore, the comparison of content is imperative too when selecting an instrument. Moreover, in general, satisfaction domains showed weaker correlations between the instruments than the accomplishment/restrictions domains.

The complexity of the participation construct and the inconsistent operationalization of it impedes comparison and efficient use of participation instruments.^{15,28-30} In the present study, we have chosen to use the ICF-CY framework to structure the comparison of the Life-H and the USER-P, including the ICF-CY definition of participation as "involvement in a life situation". The chapters of the ICF-CY are helpful in comparing the content of the domains of the instruments (table 2). Both instruments cover several ICF-CY chapters, including chapters D6-9 (D6 Domestic Life; D7 Interpersonal Interactions and Relationships; D8 Major Life Areas, and D9 Community, Social, and Civic Life) and chapter D4 for mobility items. The lack of distinction between the activity and participation in or between the chapters in the ICF is often criticized. In general, the authors agree chapters D6-9 can be seen as the most characteristic of participation as they are related to the performance of social roles, often described as crucial for the concept of participation.^{31,32} Both the Life-H and the USER-Participation include some items in other chapters, that is, Mobility (D4) and

General Tasks and Demands (D2), which might be disputed as being part of assessment of participation. When looking at these items, we feel these might be regarded as prerequisites for participation, such as transportation and handling responsibilities. One might argue if instruments aiming to assess participation should include items focusing on prerequisites. Moreover, both the Life-H and the USER-Participation also incorporate assistance into their scoring. In the USER-P, performing an activity "with assistance from another person" is scored as less restricted compared with "not possible", but as more restricted compared with performance "with difficulty" or "without difficulty". The Life-H considers both assistance from a person as well as the use of assistive devices. Human assistance leads to lower scores compared with use of assistive devices, and use of assistive devices leads to lower scores compared with performance without such devices (appendix 1). Thus, both Life-H and USER-Participation include assistance in their scoring, but in a different way. Again, one might argue if it makes sense to reflect the use of assistance or assistive devices in the scoring, while someone might participate very well, *because* of this help or the use of assistive devices.

These issues, related to the assessment of participation, including the domains, incorporation of prerequisites for participation, and use of assistance, come back to a more conceptual ongoing discussion on the definition of participation and how to measure participation. Some of the thought-provoking discussions on the definition of participation focus on the definition used in the ICF. For example, the group of Imms et al¹⁵ presented the Family of Participation-Related Constructs framework, distinguishing attendance ("being there") and involvement ("the experience" of participation when attending) as 2 essential components of participation. Other concepts such as Activity Competence and Self-regulation are described as concepts related to participation, that influence participation and are influenced by past and present participation.^{15,30} When using this framework, one could conclude the Life-H and USER-Participation focus on the "broad" framework of participation, including participation-related constructs. Future conceptual discussions certainly will follow, leading to less ambiguity in language and terminology around participation.

For the purpose of the present paper, we aimed to explore and compare 2 instruments developed and used in research and clinical practice to assess participation in adolescents with CP. One important aspect, also emphasized by adolescents with CP themselves,⁹ is related to the appraisal of it, focusing on satisfaction with their own participation. After all rehabilitation is aimed at coping with individual daily limitations and obstacles and not at achieving the maximum score on accomplishment. This distinction between accomplishment and satisfaction is also relevant because low correlations were found between these 2 components.⁹ Both the Life-H and the USER-Participation include a scale on satisfaction. Interestingly, we found relatively low correlations between the Life-H satisfaction scores and the USER-Participation satisfaction scores. This might be explained by the difference in level of detail, with the Life-H including more items with more detail, and the USER-Participation including more broad items with examples.

Finally, besides the contents of the instruments and the type of information that can be extracted from the results, the feasibility of administration (eg, number of items, completion time, and difficulty level) is also important to keep in mind when selecting an appropriate instrument. As mentioned earlier, 5 eligible participants were excluded because completion of (1 of them) instruments was too difficult. Four participants reported this difficulty for the Life-H and 1 participant for both instruments. Also, the Life-H has been evaluated in other studies as difficult to complete because of its long and complex structure.^{19,22} The number of “not applicable” items per domain or scale can also be an indication of feasibility. The Life-H showed more “not applicable” items than the USER-Participation. Dang et al also found many “not applicable” cases on the Life-H in adolescents with CP, with most of these items in the Accomplishment Community life domain.¹² This is in line with our findings. Other studies using the Life-H in adolescents with CP provided little details on the non-applicable items, therefore no further comparison can be done.

Strengths and limitations

This study is 1 of the few comparative studies between (participation) instruments and is helpful in gaining insight into the characteristics of the instruments. Also it gives insight to which extent the scores on both instruments can be compared. The contents of the instruments were strictly analyzed and the data-based analyses were additive in order to explore the scale and domain scores in adolescents with CP. Our focus on adolescents is valuable, because it is crucial to distinguish them from children and adults. One of the limitations of this study is the relatively small study sample ($n=45$), which could be due to the strictly defined inclusion criteria or because of the extensive questionnaires adolescents had to fill in. Further the data appear largely to reflect the experiences of ambulatory adolescents with CP, which might explain the ceiling effects found in the data. Especially because both instruments contain some items related to mobility and because in both instruments assistance leads to lower scores.

Implications for clinical practice and future research

The findings of the present study underline the importance of critical comparison of available instruments and careful selection of which instrument to use when. It is essential to assess whether the instrument fits the intended purpose: brief or comprehensive assessment, aimed for screening or to collect more in-depth information. The USER-Participation can be helpful for screening because it provides an overall image of participation, including satisfaction. The Life-H provides more detailed information and can for example be useful to get insight in specific daily restrictions or elements one is dissatisfied with. For future research, this first exploration can be widened by comparing these instruments with other available participation instruments that can be used in adolescents, such as the Children’s Assessment of Participation and Enjoyment (optionally extended by the Preferences for Activities of Children questionnaire) or the Lifestyle Assessment questionnaire for CP or the Participation and Environment Measure for Children and Youth.³³⁻³⁵ Further research should include more respondents with various diagnoses, including those with more severe participation restrictions to gain more insight in the characteristics, properties, and usefulness of participation instruments in adolescents with disabilities.

Conclusions

The Life-H and USER-Participation show many similarities at scale level in scale components, but differ at domain level in terms of item content and context and the level of detail. Compared with the USER-Participation, the Life-H might be more difficult to complete but provides a more comprehensive evaluation of participation. Data analyses showed strong correlations between similar scales and between Accomplishment (Life-H) and Restrictions (USER-Participation) domains. Weaker correlations were found between satisfaction domains. Further research on (comparing) participation instruments is recommended, as well as careful selection of participation instruments for research and clinical practice.

Corresponding author

M. Ketelaar, PhD, University Medical Center Utrecht, Brain Center, Department of Rehabilitation Medicine, Physical Therapy Science and Sports, Huispostnummer W01.121, PO Box 85500, 3508 GA Utrecht, The Netherlands. *E-mail address:* m.ketelaar-2@umcutrecht.nl.

Acknowledgments

We would like to thank the panel of experts by experience, 12 adolescents with CP who were actively involved in all stages of the PIP-project.

Appendix 1. Scoring System Life-H Accomplishment Scale: A Combination Score of Difficulty Level and Assistance Type

Item score (0-9)	Difficulty Level	Assistance Type
>0	Not accomplished	-
1	Accomplished by a proxy	-
2	With difficulty	Assistive device (or adaptation) and human assistance
3	With difficulty	Human assistance
4	No difficulty	Assistive device (or adaptation) and human assistance
5	No difficulty	Human assistance
6	With difficulty	Assistive device (or adaptation)
7	With difficulty	No assistance
8	No difficulty	Assistive device (or adaptation)
9	No difficulty	No assistance

Appendix 2. Cases With “Not Applicable” on the Life-H and USER-Participation

Measure	Number of cases, n (%)	Most frequent items, n
Life-H Accomplishment scale		
Responsibilities	19 (42)	Using bank cards and ATMs (15)
Interpersonal relationships	15 (33)	Being involved or participating in sexual awareness (12)
Community life	39 (87)	Participating in religious or spiritual activities (34) and Participating in charity or community work (29)
Education	10 (22)	Doing homework (6)
Employment	20 (44)	Performing small paid or unpaid jobs (all cases)
Recreation	25 (56)	Taking part in artistic, cultural, or craft activities (15)
Life-H Satisfaction scale		
Responsibilities	8 (18)	Using bank cards or ATMs (7)
Interpersonal relationships	7 (16)	Being involved or participating in sexual awareness (all cases)
Community life	13 (29)	Participating in charity or community work (11)
Education	4 (9)	Doing homework (3)
Employment	6 (13)	Performing small paid or unpaid jobs (all cases)
Recreation	11 (24)	Attending sporting events (7)
USER-Participation Restrictions scale		
Productivity	6 (13)	Household tasks (6)
Leisure	12 (27)	Going out (8)
Social	1 (2)	All items (1)
USER-Participation Satisfaction scale		
Productivity	4 (9)	Household tasks (4)
Leisure	8 (18)	Going out (4)
Social	4 (9)	Sibling relationship (4)

References

- Colver A, Fairhurst C, Pharoah POD. Cerebral palsy. *Lancet* 2014;383:1240-9.
- Rosenbaum P, Paneth N, Leviton A, et al. A report: the definition and classification of cerebral palsy. *Dev Med Child Neurol Suppl* 2006;109(suppl 109):8-14.
- Schmidt AK, van Gorp M, van Wely L, et al. Autonomy in participation in cerebral palsy from childhood to adulthood. *Dev Med Child Neurol* 2020;62:363-71.
- van Gorp M, Van Wely L, Dallmeijer AJ, de Groot V, Ketelaar M, Roebroek ME. Long-term course of difficulty in participation of individuals with cerebral palsy aged 16 to 34 years: a prospective cohort study. *Dev Med Child Neurol* 2019;61:194-203.
- Livingston MH, Stewart D, Rosenbaum PL, Russell DJ. Exploring issues of participation among adolescents with cerebral palsy: what's important to them? *Phys Occup Ther Pediatr* 2011;31:275-87.
- Michelsen SI, Flachs EM, Damsgaard MT, et al. European study of frequency of participation of adolescents with and without cerebral palsy. *Eur J Paediatr Neurol* 2014;18:282-94.
- Donkervoort M, Roebroek M, Wiegerink D, Van der Heijden-Maessen H, Stam H. Transition Research Group South West Netherlands. Determinants of functioning adolescents and young adults with cerebral palsy. *Disabil Rehabil* 2007;29:453-63.
- Donkervoort M, Wiegerink DJHG, Van Meeteren J, Stam HJ, Roebroek ME. Transition to adulthood: validation of the Rotterdam Transition Profile for young adults with cerebral palsy and normal intelligence. *Dev Med Child Neurol* 2009;51:53-62.
- Smits DW, van Gorp M, van Wely L, et al. Participation in social roles of adolescents with cerebral palsy: exploring accomplishment and satisfaction. *Arch Rehabil Res Clin Transl* 2019;1:100021.
- Wintels SC, Smits DW, van Wesel F, Verheijden J, Ketelaar M, PiP Study Group PERRIN, et al. How do adolescents with cerebral palsy participate? Learning from their personal experiences. *Heal Expect* 2018;21:1024-34.
- Tan SS, Wiegerink DJHG, Vos RC, et al. Developmental trajectories of social participation in individuals with cerebral palsy: a multicentre longitudinal study. *Dev Med Child Neurol* 2014;56:370-7.
- Dang VM, Colver A, Dickinson HO, et al. Predictors of participation of adolescents with cerebral palsy: a European multi-centre longitudinal study. *Res Dev Disabil* 2015;36:551-64.
- WHO. International Classification of Functioning, Disability and Health: Children and Youth version: ICF-CY. Geneva: World Health Organization; 2007.
- Post MW, van der Zee CH, Hennink J, Schafrat CG, Visser-Meily JM, van Berlekom SB. Validity of the Utrecht Scale for Evaluation of Rehabilitation-Participation. *Disabil Rehabil* 2012;34:478-85.
- Imms C, Granlund M, Wilson PH, Steenbergen B, Rosenbaum PL, Gordon AM. Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability. *Dev Med Child Neurol* 2017;59:16-25.
- Resch C, Van Kruijsbergen M, Ketelaar M, et al. Assessing participation of children with acquired brain injury and cerebral palsy: a systematic review of measurement properties. *Dev Med Child Neurol* 2020;62:434-44.
- Chien CW, Rodger S, Copley J, Skorka K. Comparative content review of children's participation measures using the international classification of functioning, disability and health-children and youth. *Arch Phys Med Rehabil* 2014;95:141-52.
- Adair B, Ullenhag A, Rosenbaum P, Granlund M, Keen D, Imms C. Measures used to quantify participation in childhood disability and their alignment with the family of participation-related constructs: a systematic review. *Dev Med Child Neurol* 2018;60:1101-16.
- van der Zee CH, Priesterbach AR, van der Dussen L, et al. Reproducibility of three self-report participation measures: the ICF Measure of Participation and Activities Screener, the Participation Scale, and the Utrecht Scale for Evaluation of Rehabilitation-Participation. *J Rehabil Med* 2010;42:752-7.
- The Utrecht Scale for Evaluation of Rehabilitation-Participation—Youth version [Internet]. Available at: <https://www.kccru-trecht.nl/producten/user-p/>. Accessed August 15, 2020.
- Fougeyrollas P, Noreau L, Bergeron H, Cloutier R, Dion SA, St-Michel G. Social consequences of long term impairments and disabilities: conceptual approach and assessment of handicap. *Int J Rehabil Res* 1998;21:127-41.
- Lemmens J, van Engelen EISM, Post MWM, Beurskens AJHM, Wolters PMJC, de Witte LP. Reproducibility and validity of the Dutch life habits questionnaire (LIFE-H 3.0) in older adults. *Clin Rehabil* 2007;21:853-62.
- Noreau L, Desrosiers J, Robichaud L, Fougeyrollas P, Rochette A, Viscogliosi C. Measuring social participation: reliability of the LIFE-H in older adults with disabilities. *Disabil Rehabil* 2004;26:346-52.
- Van Der Zee CH, Post MW, Brinkhof MW, Wagenaar RC. Comparison of the Utrecht scale for evaluation of rehabilitation-participation with the ICF measure of participation and activities screener and the WHO disability assessment schedule ii in persons with spinal cord injury. *Arch Phys Med Rehabil* 2014;95:87-93.
- van der Zee CH, Kap A, Mishre RR, Schouten EJ, Post MWM. Responsiveness of four participation measures to changes during and after outpatient rehabilitation. *J Rehabil Med* 2011;43:1003-9.
- Mol TI, van Bennekom CAM, Schepers VPM, et al. Differences in societal participation across diagnostic groups: secondary analyses of eight studies using the Utrecht Scale for Evaluation of Rehabilitation-Participation. *Arch Phys Med Rehabil* 2021;102:1735-45.
- Cohen J. *Statistical power analysis for the behavioural sciences*. 2nd ed. New York: Academic Press; 1988.
- Magasi S, Post MW. A comparative review of contemporary participation measures' psychometric properties and content coverage. *Arch Phys Med Rehabil* [Internet] 2010;91(9 Suppl):S17-28. <https://doi.org/10.1016/j.apmr.2010.07.011>. Available at.
- Whiteneck G, Dijkers MP. Difficult to measure constructs: conceptual and methodological issues concerning participation and environmental factors. *Arch Phys Med Rehabil* 2009;90(11 Suppl):S22-35.
- Imms C, Adair B, Keen D, Ullenhag A, Rosenbaum P, Granlund M. "Participation": a systematic review of language, definitions, and constructs used in intervention research with children with disabilities. *Dev Med Child Neurol* 2016;58:29-38.
- Piškur B, Daniëls R, Jongmans MJ, et al. Participation and social participation: are they distinct concepts? *Clin Rehabil* 2014;28:211-20.
- Hammel S, Magasi A, Heinemann G, Whiteneck J, Bogner E, Rodriguez. What does participation mean? An insider perspective from people with disabilities. *Disabil Rehabil* 2008;30:1445-60.
- Coster W, Bedell G, Law M, et al. Psychometric evaluation of the participation and environment measure for children and youth. *Dev Med Child Neurol* 2011;53:1030-7.
- Coster W, Law M, Bedell G, Khetani M, Cousins M, Teplicky R. Development of the participation and environment measure for children and youth: conceptual basis. *Disabil Rehabil* 2012;34:238-46.
- King G, Law M, King S, et al. *Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC)*. San Antonio, TX, USA: Harcourt Assessment, Inc; 2004.