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# **RESEARCH PAPER**

# Relationship between quality of life and functional status of young adults and adults with cerebral palsy

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#### Abstract

*Purpose.* The aim of this study was investigate the relation between health related quality of life (HRQoL) and functional status in young adult or adult cerebral palsied individuals.

*Methods.* The study included 45 cerebral palsied subjects who were divided into two groups as young adults (n = 21, group 1) and adults (n = 24, group 2), over the age 15 years. Gross Motor Function Classification System (GMFCS), Functional Independence Measurement (FIM), Physical Mobility Scale (PMS), Nottingham Health Profile (NHP), Visual Analogue Scale (VAS) were used as outcome measures.

*Results.* In group 1, GMFCS and PMS scores were significantly correlated with total the total score of FIM (p < 0.05). Although total FIM, PMS, LS and GMFCS scores were not correlated with the total NHP score (p > 0.05), pain subscale of NHP was significantly correlated with self care and mobility subscales of FIM (p < 0.05). Also, self care, mobility, locomotion subscales and total score of FIM were highly correlated with the physical activity subscale of NHP (p < 0.05). In group 2, our findings were also similar to those of young adults when the relations between total NHP score and total FIM, PMS, LS and GMFCS were investigated (p > 0.05) and also some subscales of FIM and NHP presented high correlations in between. In addition, there were significant differences between the groups in GMFCS, LS and locomotion and self care subscales of FIM (p < 0.05).

*Conclusion.* Although HRQoL in young cerebral palsied individuals seems to be more effected by parameters related to physical condition, in cerebral palsied adults psychological and emotional aspects may be more important indicators related to HRQoL. For that reasons, more population specific measures have to be developed for in-depth analysis of these factors.

Keywords: Cerebral palsy, quality of life, mobility, ageing

#### Introduction

Cerebral palsy (CP) is one of the most prevalent impairments in children [1–4]. Parallel to the growing excellence in prenatal/perinatal care, survival rate of low-birth weight infants increase; which, in turn, creates an increment in the number of cerebral palsied children reaching adulthood [5]. One of the most striking data related to this issue was reported in 1989 by Hagberg et al., stating that, there had been a gradual increase in the prevalence of CP from 1960s to 1980s, though in a recent work by Krageloh–Mann overall rate was reported to be 2–3 per 1000 live-births [5–7].

Most developed countries manage properly with CP during childhood. However, because most

emphasis is on the pediatric aspects of CP, little is known about the quality of life of a cerebral palsied individual after school-age [1,3]. Although CP is medically accepted as non-progressive, the consequences of such a multi-faceted disorder may have a great impact on a cerebral palsied individual's overall quality of life [8]. Especially, CP is often accompanied by premature senility and other complications, which make patient's life hard and decrease their quality of life [9]. As a result in many social environments, these patients have difficulty getting a job and to going out [9,10]. The typical problems associated with CP such as physical and visual impairments, epilepsy, speech pathologies and mental retardation may result a faster decline of quality of life than normal individuals combined with normal

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ageing process [11]. In addition, adults with CP are more susceptible to degenerative diseases such as osteo-arthritis which alone may hamper all mobility related activities of daily living (ADL) and cause a reduction in life satisfaction (LS) [12,13]. As a result, adults with CP and those who deliver services to this population have both expressed some concern that individuals with CP experience negative effects of the ageing process earlier than non-disabled individuals [3,4,9]. For instance, in Andersson and Mattsson's [14] survey of 221 respondents with CP (ages 20-58 years), 27% had never walked, 64% could walk with or without walking aids, 35% reported decreased walking ability, and 9% had stopped walking. Interestingly, participants who had lost their walking ability reported that this occurred between the ages of 14-34. These participants reported that the loss was due to increased spasticity, balance problems and deterioration of condition and muscle strength [14]. Ando and Ueda investigated functional deterioration in 686 adults (ages 16-61 vears) with CP. Thirty-five per cent (n = 215)reported deterioration in daily activities. Furthermore, 39% of adults younger than 25 years reported deterioration and being completely dependent for ADL [15]. Thus, Strauss et al. [16] reported that the maintenance and promotion of mobility whenever possible is the first consideration for the welfare of adults with CP, similar to children.

With ageing future plans and life expectations of cerebral palsied children undergo changes similar to healthy individuals and the terms, quality of life, wellness and LS begin to mean somehow different than before. Factors like severity of the disability, functional status and health status seriously affect the social life and ADL of a cerebral palsied individual [17–21]. Studies conducted to investigate the relation between physical and/or functional limitations and health related quality of life (HRQOL) showed that level of motor function may be an indicator of the physical aspect of HRQOL, though they are controversial in defining its association with psychological aspects [22,23]. Thus, present study aims to determine the relationship between functional status and self assessed quality of life in order to identify basic problems encountered by young adult and adult cerebral palsied individuals in relation with the concept of quality of life.

#### Methods and materials

The study included 55 young adult and adult cerebral palsied individuals over the age of 15. Subjects were recruited from individuals who were referred to Hacettepe University Faculty of Health Sciences Department of Physical Therapy and

Rehabilitation. Of the 55 subject, 10 refused to participate in the study as they were not willing to participate in a face-to-face interview in a clinical setting. Subjects were interviewed by a physical therapist in Hacettepe University Faculty of Health Sciences, Department of Physical Therapy and Rehabilitation. All the questionnaires were completed during a single session face-to-face interview. Demographical data including age, height, weight, marital status, occupational status and physiotherapy reveived were provided by the subjects during interview. Gross Motor Function Classification System (GMFCS), Functional Independence Measurement (FIM), Physical Mobility Scale (PMS) were completed by a senior physiotherapist and Life Satisfaction (VAS) and Nottingham Health Profile (NHP) were self-completed by the subjects. The necessary help for the subjects with upper extremity disabilities preventing them to mark the questionnaires were provided by the same physiotherapist. Inclusion criteria were determined as being diagnosed as CP without any other neurological condition and no intellectual impairment.

Forty-five subjects were divided into two groups according to their ages. Group I consisted of subjects between the ages of 15 and 18 years (n = 21) and subjects over 18 years old (min-max; 19–43 years) formed group II (n = 24). Accordingly, subjects between the ages of 15 and 18 years were considered as young adults and subjects over 18 were considered as adults. The study was approved in 2006 by the Research Ethics Committee of the Faculty of Medicine, Hacettepe University (registration number LUT 06/18).

# Data collection

The standard data collection form for the study included:

- Level of motor function (GMFCS) [24]
- LS (Visual Analogue Scale-VAS) [25]
- Quality of life (NHP Turkish version) [26]
- Functional status (FIM) [27]
- Mobility level (PMS) [28]

#### Gross Motor Function Classification System

The GMFCS was used for classification of functional levels. The GMFCS was developed for use in children with CP between the ages of 18 months and 12 years. The focus is on self-initiated movements, with particular emphasis on functions of sitting and walking. The classification consists of five levels: children in level I have the most independent motor function and children in level V have the least. Studies in the recent years reported that GMFCS may also be used for cerebral palsied adults [24,29].

#### Life satisfaction

Life satisfaction of the individuals were evaluated using a VAS [25]. A line anchored at one end as '0' and at the other end as '10' was administrated to the subjects and they were asked to mark the number resembling their LS indicating that '0' is the worst possible point.

#### Nottingham Health profile

In order to collect information about HRQOL, the Turkish version of a generic instrument, NHP was used [26]. NHP consists of six domains with a total of 38 items (physical mobility (eight items), pain (eight items), sleep (five items), emotional reactions (nine items), social isolation (five items) and energy level (three items)). All items have a yes/no answer format. Scores for each section can range from 0 (indicating the best possible score) to 100 (the worst possible score).

### Functional Independence Measure

To provide a picture of basic personal ADL in terms of dependency or need for assistance, the Turkish translation [30] of the FIM [27] was used. It is divided into two domains with 13 physical (personal care, sphincter management, transfer, locomotion), five social and cognitive (communication and social cognition) items. It consists of a 7-level ordinal scale based on how much help the subject requires when performing a given activity, with ratings from total dependence (1), to complete independence (7). The range of the summarised score is between 18 (indicating maximum dependency) and 126 (indicating maximum independency).

#### Physical Mobility Scale

Physical Mobility Scale was used to evaluate mobility [28]. PMS is a respectively new measure that was designed by physiotherapists working in residential aged care in Western Australia. It was designed to allow the development of a resident's care plan using functional assessment that reflected both independent abilities and where and what type of assistance in care a resident requires. There are eight items included in the PMS, each describing specific mobility activities required for achieving an independent function. These are the mobility activities that a resident might require assistance from a caregiver or a piece of equipment to perform safely. In the PMS, the levels of ability are scored from 0, indicating the most dependent level, to 5, indicating independence in the selected activity. Thus, the higher the overall score on the PMS, the more independent the resident would be in ADL.

# Results

The distribution of levels obtained in GMFCS and also some basic demographics related to age, height, weight, gender, marital status, extremity involvement, occupational status, physioteharpy received and GMFCS levels are provided in Table I.

# Group 1 (young adult)

FIM vs. PMS, GMFCS, Life Satisfaction and NHP. The scores obtained for the subscales of self care, sphincter control, mobility and locomotion of FIM

Table I. Basic demographics and GMFCS level of the subject.

	Group I $(n=21)$	Group II $(n=24)$
	$(X \pm SD)$	$(X \pm SD)$
Age (year)	$16.14 \pm 1.01$	$28.17 \pm 6.98$
Height (cm)	$158.2\pm8.01$	$165.7\pm8.81$
Weight (kg)	$52.5 \pm 12.7$	$62.8 \pm 11.6$
	n	n
Gender		
Female	13	12
Male	8	12
Marital status		
Married	1	2
Single	20	22
Extremity involvement		
Hemiparesis	4	12
Diparesis	13	7
Quadriparesis	4	5
Occupational status		
Employee	-	9
Non-employee	6	10
Student	15	5
Physiotherapy received		
Yes	18	5
No	3	19
Level of GMFCS		
Level I	7	18
Level II	8	1
Level III	4	4
Level IV	2	1

were strongly correlated with PMS (respectively r = 0.785, p < 0.01; r = 0.833, p < 0.01; r =0.664, p < 0.05; r = 0.635, p < 0.05) and the level obtained in GMFCS (respectively; r = -0.719, p < 0.01; r = -0.664, p < 0.05; r = -0.670,p < 0.05; r = -0.732, p < 0.01). However, no subscale of FIM except 'social' was correlated with overall LS (p > 0.05). Self care, mobility and locomotion subscales of FIM were also correlated physical activity subscale of NHP (respectively; r = (0.656, p < 0.05; r = -0.819, p < 0.01;r = -0.762, p < 0.01). Self care and mobility subscales were also correlated with the pain subscale of NHP (respectively; r = -0.434, p = 0.05; r = -0.511, p < 0.05). Total FIM score was highly correlated with PMS, GMFCS and physical activity subscale of NHP (r = 0.774, p < 0.01; r = -0.738, p < 0.01; r = -0.722, p < 0.01). All correlations for group 1 are shown in Table II.

*NHP vs. PMS*, *GMFCS and LS*. Pain and physical activity subscales of NHP were correlated with the level obtained in GMFCS (respectively; r = 0.490, p < 0.05; r = 0.661, p < 0.05). Physical activity subscale of NHP was also in correlation with the score obtained in PMS (r = -0.631, p < 0.05). Correlations related to NHP for group 1 are provided in Table III.

# Group 2 (adult)

FIM vs. PMS, GMFCS, Life Satisfaction and NHP. Locomotion subscale of FIM was strongly correlated with PMS and GMFCS level (respectively; r = 0.696, p < 0.01, r = -0.783, p < 0.01) (Table IV). Also, the score obtained in communication subscale was correlated with pain, emotional reactions and total score of NHP (respectively; r = -0.485, p < 0.05, r = -0.468, p < 0.05, r = -0.447, p < 0.05). Also, social subscale was found to be related with sleep subscale of NHP (r = -0.477, p < 0.05). All correlations are shown in Table IV.

*NHP vs. PMI, GMFCS and LS.* No correlations were found between NHP and PMS, GMFCS level or LS except the correlation between physical activity subscale of NHP and the score obtained from PMS (p < 0.05) (Table V).

Group 1 vs. Group 2. In between analysis of the groups indicated difference in the aspects of LS, GMFCS level and the scores obtained in self care and locomotion subscales (FIM) (p < 0.05) (Table VI). The LS scores of the individuals in group 1 were higher than group 2.

level.

\*Correlation is significant at the 0.05

n = 21							NHP subscales				
FIM subscale		PMS	GMFCS	ΓS	Energy level	Pain	Emotional reactions	Social isolation	Sleep	Physical activity	Total-NHP
Self care	r	0.785	-0.719	0.425	0.058	-0.434	0.034	-0.014	-0.113	-0.656	-0.086
	þ	*000.0	*000.0	0.055	0.804	0.049 *	0.883	0.952	0.625	0.001*	0.710
Sphincter control	r	0.833	-0.664	0.230	0.177	-0.141	0.182	0.216	-0.001	-0.467	0.192
	đ	*000.0	0.001 *	0.317	0.441	0.543	0.429	0.347	0.996	0.033	0.403
Mobility	r	0.664	-0.670	0.315	-0.064	-0.511	-0.022	-0.054	-0.244	-0.819	-0.257
	đ	0.001*	0.001 *	0.164	0.782	0.018*	0.926	0.816	0.286	•000*	0.261
Locomotion	r	0.635	-0.732	0.332	0.058	-0.398	0.030	0.122	-0.088	-0.762	-0.121
	đ	0.002*	*000.0	0.141	0.803	0.074	0.896	0.599	0.706	•000*	0.600
Communication	r	0.051	0.011	0.159	0.254	0.166	0.137	0.149	0.032	0.061	0.162
	đ	0.828	0.962	0.491	0.267	0.472	0.554	0.518	0.889	0.793	0.483
Social	r	-0.202	0.247	0.552	0.254	0.166	0.112	-0.241	0.181	0.222	0.145
	þ	0.379	0.281	0.010*	0.267	0.472	0.628	0.292	0.431	0.332	0.532
Total FIM	r	0.774	-0.738	0.390	0.054	-0.427	0.041	0.028	-0.134	-0.722	-0.101
	þ	<b>*000</b> *0	+000.0	0.080	0.817	0.054	0.860	0.906	0.563	•000*	0.664
PMS, Physical Mobi	ility Sca	le; FIM, Func	ctional Indeper	ndence Mea	sure; GMFCS, Gr	oss Motor Fur	action Classification Syste	m; NHP, Nottinghai	m Health Prof	file; LS, life satisfactic	'n.
,	•		•				•				

and NHP

vs. PMS, GMFCS, life satisfaction

Table II. Correlations for group 1: FIM

Table III. Correlations for group 1: NHP vs. PMS, GMFCS and LS.

NHP Subscale		PMS	GMFCS	LS
Energy level	r	-0.007	0.032	0.145
	Þ	0.976	0.891	0.531
Pain	r	-0.370	0.490	-0.191
	Þ	0.098	0.024*	0.408
Emotional reactions	r	0.005	0.018	0.229
	Þ	0.984	0.938	0.318
Social isolation	r	-0.010	0.035	-0.268
	Þ	0.964	0.881	0.240
Sleep	r	-0.165	0.035	0.240
	Þ	0.475	0.881	0.295
Physical activity	r	-0.631	0.661	-0.265
	Þ	0.002*	0.001*	0.245
Total-NHP	r	-0.108	0.188	-0.008
	Þ	0.642	0.414	0.971

PMS, Physical Mobility Scale; GMFCS, Gross Motor Function Classification System; NHP, Nottingham Health Profile; LS, Life satisfaction.

\*Correlation is significant at the 0.05 level.

#### Discussion

This study analyses relation between functional status and self reported HRQoL and overall LS in young adults and adults with CP. In this study it is shown that there is no relation between functional status and HRQOL and between motor function and HRQOL in young adult and adult cerebral palsied individuals. However, young adult and adult cerebral palsied individuals seem to differ in terms of LS.

Severity of disability is considered as one of the main factors affecting functional status and thus independence in CP [9,31]. Lepage et al. [32] found that limitations in ADL are increased progressively with impairment type and severity level. On the contrary, Van Eck et al. [33] reported that functional status in their study was not correlated with the level obtained in GMFCS; though, they also emphasised that this result may be due to the number of subjects in GMFCS level I being higher in their study population. In the present study, we showed a clear correlation between overall level of independence indicated by the results of FIM and the level of GMFCS and PMS for young adults. However, this relation did not hold true for the subjects older. For the adult cerebral palsied subjects in this study, the only correlation observed was between GMFCS and the level of independence in the activities related to locomotion (FIM). One possible explanation could be that young adults are susceptible to more help especially from their parents/family/caregivers and depend more on them in the aspects of self care and mobility while the older cerebral palsied individuals tend to live on with the least possible help, doing much of the work themselves. This opinion may

Total-NHI -0.447 **0.029\*** -0.356 0.088 -0.1740.417  $\begin{array}{c} 0.639 \\ -0.206 \\ 0.334 \\ 0.130 \\ 0.544 \end{array}$ 0.779 0.101 0.061 PMS, Physical Mobility Scale; FIM, Functional Independence Measure; GMFCS, Gross Motor Function Classification System; NHP, Nottingham Health Profile; LS, life satisfaction. Physical activity 0.007 0.973 -0.0430.842-0.3130.136 -0.1400.513-0.095 $0.658 \\ -0.107 \\ 0.620$ 0.0400.8550.078 -0.477 **0.018\*** -0.144 0.502 0.316-0.0990.647-0.2430.2540.2520.2350.2140.367 Sleep Social isolation -0.8480.066 0.758 -0.1590.458-0.0320.884-0.0650.7640.0390.8580.4590.041 Emotional reactions NHP subscales 0.021\* -0.2260.2870.2700.202-0.4680.306 0.146 -0.184 0.389 0.561 -0.056 0.795 0.016\* -0.1480.4900.0390.855-0.2190.3050.1830.3930.485-0.1910.372-0.2130.317Pain Energy level 0.119 -0.048 0.824 0.139 0.305 -0.002 0.992 -0.089 0.679 -0.120 0.577 0.147 0.3270.311 0.250 0.262 0.583 **0.004\*** 0.265 0.3430.118 0.192 0.3920.066 0.771 0.300 0.175 LS -0.783 **0.000\*** GMFCS  $0.873 \\ -0.291 \\ 0.167$ -0.2270.2860.1650.441-0.1980.3540.1400.514-0.034\*000.0 0.096 0.657 0.6960.1050.020 0.926 0.206 0.334 0.336 0.625 0.550 0.205 PMS Ø Sphincter control Communication FIM subscale Locomotion Total FIM Mobility Self care n = 24Social

\*Correlation is significant at the 0.05 level

Table IV. Correlations for group 2: FIM vs. PMS, GMFCS, life satisfaction and NHP

Table V. Correlations for group 2: NHP vs. PMS, GMFCS and LS.

NHP subscale		PMS	GMFCS	LS
Energy level	r	0.172	-0.186	0.100
	Þ	0.421	0.385	0.659
Pain	r	0.111	-0.247	0.030
	Þ	0.605	0.244	0.893
Emotional reactions	r	0.360	-0.400	0.174
	Þ	0.084	0.053	0.438
Social isolation	r	-0.041	0.039	0.140
	Þ	0.850	0.857	0.535
Sleep	r	0.152	-0.055	-0.104
	р	0.479	0.800	0.645
Physical activity	r	-0.418	0.373	-0.157
	p	0.042*	0.073	0.485
Total-NHP	r	0.094	-0.125	0.025
	р	0.661	0.560	0.910

PMS, Physical Mobility Scale; GMFCS, Gross Motor Function Classification System; NHP, Nottingham Health Profile; LS, life satisfaction.

\*Correlation is significant at the 0.05 level.

Table VI. Overall difference between groups.

	2	Þ
LS	-2.005	0.045*
GMFCS	-2.268	0.023*
Self Care (FIM)	-2.300	0.021*
Locomotion (FIM)	-2.442	0.015*

\*Correlation is significant at the 0.05 level, Mann–Whitney U-test

further be advocated with the results of another study conducted by O'Grady et al. [34] on 71 cerebral palsied individuals between the ages of 13-36 years. In this study, participants' initial assessments were compared to their present self-reported functional abilities and subjects were found to be more functional than the description in their childhood records, which may indicate that there are other factors related to functional outcomes. Although our results are similar to this mentioned study, it should be noted that adult and young adult groups in our study are in fact different from each other in the aspects of severity CP and the amount of rehabilitation received as this study was conducted (younger individuals receiving more rehabilitation compared to older adults). Thus it would be unwise to reach absolute assumptions on how the mechanism of this difference between the two groups works, meaning is it the age or the severity?

Interestingly neither overall functional independence (FIM) nor health related quality of life (NHP) was found to be related with life satisfaction (VAS), except, in younger adults social independence seems to be related with overall satisfaction in life. This result may be due to a young adult's social role in school which is an important and probably the most frequent encounter between the subject and the environment. However, we think that this result should not be generalised as satisfaction in life may thematically be linked to meeting personal goals, feeling fulfilled and enjoying occupational roles as indicated by King et al. [35] who states that these parameters are more psychological aspects of quality of life that are unfortunately out of the interest of the traditional current health care system.

Another important issue was pain and its relation to functional status and HRQoL, as, chronic pain is a frequent complaint among adults with CP [14,36,37]. As reported by Schwartz et al. [38] individuals who experience chronic pain are often forced to change their life style which in turn, may be considered as a defeat and can cause psychological distress. We showed that the pain subscale of NHP was well correlated with self care and mobility subscales of FIM for young adults. This relation was also true with the severity of the impairment as indicated by GMFCS. However, surprisingly, we found that only independence in communication skills were related to pain in adults. This is harder to explain but a possible answer is that the pain subscale of NHP is formed of statements referring to a more normal daily life which necessitates casual interaction which may be hampered by chronic pain. However, this association between independence in communication and pain still may be a coincidence, because one may assume that if there is chronic pain affecting casual communication skills thoroughly, it may also lower the satisfaction in life, but we did not find any correlation between pain subscale of NHP and self rated overall LS.

As reported by Bax et al. [39] communication was a major problem for 60% of the adults with CP. Also in our study, independence in communication skills was strongly associated with emotional status and overall HRQoL in adult cerebral palsied individuals; however, it did not seem to be associated any aspect of HRQoL in younger cerebral palsied individuals. In other words it may be said that parallel to the increase in age, limitation in communication skills become a more important parameter related to emotional status. Factors such as the necessity to play more important social roles than young adults, obligation to interact in heterogeneous groups of able-bodied man compared to more isolated school environment of younger cerebral palsied adults and even more importantly getting a proper and a meaningful job may all be directly associated with the difference between young adult and adult cerebral palsied individuals in terms of the consequences of the rate of independence in communication skills.

In a study by Stevenson et al. [40] it is stated that adolescents and young adults with CP decline in their level of social activities and contact with friends. Similarly, Balandin and Morgan [4] indicated that respondents (ages 30-74 years) in their study noted that depression and anxiety are resulted in reduced social contact and therefore had an impact on independence and social interaction. Interestingly, despite these facts social independence was found to be more related with satisfaction in life in younger adults compared to adult cerebral palsied individuals for whom we could not show any association between. This result may be explained in a couple of ways. First, social independence may be the ultimate goal of a younger individual in life compared to an older adult who probably have achieved a satisfactory position in community before the younger one. In other words our result may indicate a normal consequence of a period of frustration of a young adult to succeed in life which may have nothing to do with CP. Secondly, our outcome measurement tools might not properly reflect and investigate the association of social independence and its interaction among with other parameters in older adults with CP. Further research should be conducted to probe the association between social independence and relevant issues.

Our study was designed to present data on some aspects of HRQoL and functional independence, and meanwhile to determine differences between young adult and adult cerebral palsied individuals in those aspects. However, it should be noted that one of the main outcome measurement tools used in this study (NHP) is a generic HRQoL tool not intended to be specifically used on cerebral palsied individuals. Thus, it may be considered as an insensitive tool to detect specific concerns of a cerebral palsied individual. For that reason we advocate that further research to develop target specific outcome tools has to be conducted if clear cut statements are to be introduced to the area of quality of life in CP.

Another limitation of our study was that, the sample of convenience selected for the study was among individuals followed with the diagnosis of CP by the same institution for years. Thus, a study population selection bias may be considered. Also the relatively small number of participants included in the study may be another factor affecting the interpretation of the results. Still, more work is needed to clarify the current needs of young adult or adult cerebral palsied individuals who have different priorities and necessities than pediatric cerebral palsied individuals in terms of HRQOL and functional independence.

## Conclusion

This study indicated that while physical aspects like the level of motor function and pain are more related to HRQOL for younger adults with CP, psychological and emotional aspects like communication skills, level of social interaction and the level of success in fulfilling the daily social roles seem to be more important for the cerebral palsied adults. Properly designed, target specific and self-reported instruments should be developed to achieve a greater understanding of the associations between HRQOL, LS and functional status of the young adult and adult cerebral palsied individuals.

**Declaration of interest:** The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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