

Readiness of independency in health care management for young adults with cerebral palsy

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Abstract. Transition from paediatric to adult health care services is a crucial process for young adults with long-term medical conditions and well organized and coordinated transition process has been strongly highlighted. The aims of this research were to assess the young adults with cerebral palsy overall readiness for adult life, the independency in health care management and independency impacting factors. Eighty young adults (age range 16–21 years) with CP and normal or slightly decreased mental function participated. There were done “face-to-face” structured interviews using the Rotterdam Transition Profile and the Transition Readiness Assessment Questionnaire also the characteristics of participants were obtained. It was revealed that young adults with cerebral palsy show low levels of participation in almost all domains of transition to adult life, the level of attendance of rehabilitation services is not sufficient, and the level of independency for young adults with CP in health care management is between phases of preparation and action. The most impacting factor for independency in health care management was found to be the cognitive status.

Key words: cerebral palsy, transition age, health care, young adult.

1 Introduction

It has been long thought that cerebral palsy (CP) is a medical condition more attributed to paediatric care, even though most persons with CP now survive to adulthood [1]. The prevalence of CP in Europe has been estimated 2 per 1000 live births [2]. Although the neurological injury causing CP is defined as non-progressive, the musculoskeletal, neurological and mental conditions worsen in the course of time [3–5]. Adults with CP face health problems such as decreased mobility and self-care [6], hypoactivity [7], chronic pain [3, 8], sarcopenia [9, 10], spasticity [11, 12], musculoskeletal deformities (e.g., articular contractures [12, 13], osteopenia [14], degenerative arthritis [14, 15], deformities of hips [16, 17], knees [16, 18], ankles [12, 19], feet [16, 17] and spine [20–22], epilepsy [3], genitourinary problems [16, 23] and depression and anxiety [24]. It has been proven that as the age for persons with CP progresses also the use of certain medication (respectively, analgesic, antispastic, and psychotropic drugs in ambulatory patients and psychotropic, antispastic, antiepileptic, and digestive drugs in non-ambulatory patients)

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increases [3]. However, the physical medicine and rehabilitation doctor follow-up, the use of orthoses, and receiving rehabilitation decreases with age [3]. Young adults with CP have reported having too few information about their medical condition [25] and that there is a lack of real life opportunities of becoming independent [26]. Unsuccessful transition to adult life may lead to unnecessary lifelong dependency, unemployment and low quality of life [27, 28]. The transition from paediatric to adult health care is crucial process for persons with CP [29–34] and specific therapeutic approach is essential [35–38]. The aims of this research were to assess young adults with CP overall readiness for transition to adult life, the readiness of independency in health care management and the factors having impact on readiness for independency in health care management.

2 Material and methods

2.1 Study design

The design of the study was a cross-sectional, non-experimental research.

2.2 Study sample

Participants were searched through the data basis of Children’s Clinical University Hospital and through open invitations in smaller rehabilitation centres. “Face-to-face” structured interviews using the assessment scales and questionnaires were done from October 2017 till June 2018. Permissions from Ethics Committee of Rīga Stradiņš University (August 2016) and from Children’s Clinical University Hospital (July 2016) were received. Before signing the consent form, potential participants and their parents read the explanation form of the research and received answers to any questions concerning the participation. For participants under the age of 18 the consent form was signed by the legal representative (all cases – one of the parents). The inclusion criteria were: young adults aged 16–21 years, diagnosed with cerebral palsy (G80-G83, International Statistical Classification of Diseases and Related Health Problems, 10th revision), with normal or slightly decreased cognitive status and able to understand the research procedure. Exclusion criteria were: not actually having cerebral palsy (having other cause of the paresis), severe overall physical and cognitive status (MMSE less than 24 points), not living in or coming from family (living in social institution), not living in Latvia, was not possible to gain contact information, not answering to phone call over three times, dead. Two hundred twenty – five potential participants were identified. Considering exclusion criteria and having the will to participate, a total of 80 persons participated.

2.3 Measures

For the characteristics of participants (age, gender, type of cerebral palsy, status of speech, vision, hearing, epilepsy, the need of assistant, place of living, level of income, parent status, number of siblings) we used a structured descriptive questionnaire. Type of cerebral palsy was detected through participants’ medical records. Sever problems with speech, vision and hearing were detected if others often cannot understand the person’s speech and/or the participant’s health status was not fully compensated with medical assistive devices (e.g. glasses, hearing aids). Having epilepsy was approved if the person was using anti-epileptic drugs prescribed by doctor. Level of average income to a household was defined as 1017.60eurper month (index of year 2016) [39]. “Brought up by both parents” was marked as “yes” even if one of the parents was a step-parent and as “no” if only one parent raised the participant.

2.3.1 Functional status

The gross motor function was assessed using Gross Motor Function Classification System (GMFCS) [40], which is a five-level classification system, where the fifth level (person is transported in a manual wheelchair) is the most severe and first level (person walks without limitations) is the least. The manual abilities were assessed using Manual Ability Classification System (MACS) [41], which also is a five-level classification system, where the fifth level (person does not handle objects and has severely limited ability to perform even simple actions) is the most severe and the first (person handles objects easily and successfully) – the least. The cognitive status was assessed with Mini-Mental State Examination (MMSE) [42], in which the maximum score of points is 30 and the less points a participant receives the more cognitive impairments he/she might have, whereas 24–30 points indicate none or some/uncertain cognitive deficit.

2.3.2 Transition process to adult life, the Rotterdam Transition Profile

The readiness for transition to adult life was assessed using the Rotterdam Transition Profile (RTP) [43]. It is a ten transitional domain assessment tool. First seven domains are applied to measure participation and the last three – health care. The assessment of each domain is ranged in three or four phases: phase 0 – the young adult has no experience in a particular field, phase 1 – the young adult is dependent on adults, phase 2 – the young adult is experimenting and orientating towards a more independent life, phase 3 – the young adult has achieved more-or-less independence and autonomy. The total score of RTP is 30 points – the more points a participant has received the more independent and autonomous he or she is.

2.3.3 Readiness of independency in health care management, the Transition Readiness Assessment Questionnaire

The readiness of independency in health care management was assessed using the Transition Readiness Assessment Questionnaire (TRAQ) [44]. The TRAQ consists of 20 questions evaluating: medication managing, appointment keeping, tracking health issues, talking with providers and managing daily activities. Each question is scored from 1–5 points, describing the independency level of health care task managing: 1 – *No, I do not know how* (primary idea), 2 – *No, but I want to learn* (intent), 3 – *No, but I am learning to do this* (preparation), 4 – *Yes, I have started doing this* (action), 5 – *Yes, I always do this when I need to* (maintenance). The total score of TRAQ is 100 points – the bigger score, the better health care management.

2.4 Statistical analysis

Statistical analysis was conducted using SPSS software (IBM SPSS Statistics, v. 23.0, Chicago, IL, USA). The sample was tested for the normality of distribution of the measurements of scales and age by the means of Shapiro-Wilk test. As the sample did not reveal normal distribution, quantitative data was in median (Me) with inter-quartile range (IQR) and non-parametric statistics were performed. Mann-Whitney U test for interval data comparison, Wilcoxon test for time course of interval data, Spearman rho for correlation of interval data, Pearson chi square or Fisher's exact test for categorical data. TRAQ data was divided by median of ≤ 3.00 points and ≥ 3.01 points to find the impact of factors: characteristics of participants, functional status, and the readiness for transition to adult

life. The correlation analysis was done with TRAQ groups to find the strongest association with the impacting factors. Correlation coefficient interpretation: up to $|\pm 0.19|$ very weak, $|\pm 0.20| - |\pm 0.39|$ weak, $|\pm 0.40| - |\pm 0.59|$ moderate, $|\pm 0.60| - |\pm 0.79|$ strong, $|\pm 0.80| - |\pm 0.999|$ very strong [45]. Adjusted residual was marked as significant with value more than $|\pm 1.96|$. Binary logistic regression analysis was done for separate impacting factor to find best (Wald criterion and percentage predicted probability) association with TRAQ data. Second time Binary logistic regression analysis was done for multivariate impacting factors to find most exact and strongest impacting factor. Criterion of choice was Wald, significance $p < 0.05$ and odds ratio. In all analyses $p < 0.05$ was significant. Graphs were done in SPSS software or MS office Excel (2010).

3 Results

3.1 Characteristics of the study sample

Table 1 presents the personal characteristics, type of cerebral palsy and the functional level of the 80 young adults aged 16 to 21 years with cerebral palsy who participated in the study. The median age was 18 (IQR 20-17) years and 41% percent were men. Thirty-four percent of the participants had quadriplegia, 74% had high level of gross motor function and 70% had high level of manual ability (GMFCS and MACS level I or II). Fifty percent of the participants had full or almost full score of the MMSE (29–30 points), indicating normal cognitive status and 16% had severe speech problems. The need of an assistant marked 52% of the participants. For 38% of the participants the place of living was town (other than capital city) and 61% had the income level below the average. Seventy-one percent of the participants were brought up by both parents and 66% had one sibling.

3.2 Transitional process to adult life

The outcomes of the RTP (see Fig. 1) show the general phases of the transition process of the participants.

3.3 Readiness of independency in health care management and the impacting factors

Table 2 demonstrates participants' median values of TRAQ, grouped in five health care management related themes.

The median value of the TRAQ score for women was 3.5 (IQR 4.4-3.0) and for men 3.3 (IQR 4.1-2.6). The median values in relation to participants' age, functional and cognitive level are demonstrated in Fig. 2.

To analyze the outcomes of the TRAQ and the outcome impacting factors the score was divided in two groups: ≤ 3.00 points, group I (the participant is rather in passive than in active phase of task managing) and ≥ 3.01 points, group II (the participant is rather in active than in passive phase of task managing). The statistical significance of the impacting factor on the participants' appearance in group I or group II was tested with Mann-Whitney U tests and for dichotomous parameters Pearson chi square tests. Person chi square was also done if the data was more demonstrative with this method (factors – Need of an assistant and Level of income) and if p -value was not significant, but in some categories adjusted residual was (factors- Level of income and Finance) (see Table 3).

Statistically significant were found to be the level of GMFCS, MACS, MMSE, whether the participant had or had not severe speech problems and the need of an assistant. When

Table 1. Characteristics of the study participants ($n = 80$).

Age in years, Me (IQR)	18 (20-17)		
Gender, n (%)			
Men	41 (51)		
Women	39 (49)		
Type of CP, n (%)	MMSE, n (%)		
Quadriplegia	27 (34)	30 points	17 (21)
Diplegia	24 (30)	29 points	23 (29)
Hemiplegia	16 (20)	28 points	8 (10)
Other	13 (16)	27 points and less	32 (40)
GMFCS, n (%)	MACS, n (%)		
Level I	35 (44)	Level I	23 (29)
Level II	24 (30)	Level II	33 (41)
Level III	13 (16)	Level III	16 (20)
Level IV	8 (10)	Level IV	8 (10)
Level V	0 (0)	Level V	0 (0)
Severe problems with speech, n (%)	no 67 (84) yes 13 (16)		
Severe problems with vision, n (%)	no 73 (91) yes 7 (9)		
Severe problems with hearing, n (%)	no 79 (99) yes 1 (1)		
Epilepsy, n (%)	no 72 (90) yes 8 (10)		
Need of an assistant, n (%)			
No	38 (48)		
Only for transportation	25 (31)		
All the time outside the home	17 (21)		
Place of living, n (%)			
Capital city	29 (36)		
Other town	30 (38)		
Rural area	21 (26)		
Level of income, n (%)			
Below average	49 (61)		
Average	18 (23)		
Above average	13 (16)		
Brought up by both parents, n (%)	no 23 (29) yes 57 (71)		
Number of siblings >1, n (%)	no 53 (66) yes 27 (34)		

Me: median, IQR: inter-quartile range.

CP: cerebral palsy, GMFCS: Gross Motor Function Classification System, MACS: Manual Ability Classification System, MMSE: Mini-Mental State Examination.

testing the impact of the scores of RTP on the participants' appearance in group I or group II, significant were found to be almost all the domains of RTP, except for Rehabilitation services. The correlation analysis was made to detect the most associated factors. For further binary logistic regression were chosen factors with $r_s > 0.39$ (see Table 4).

The impacting factors with the score of Wald >10.00 (MMSE 17.50, Transportation 15.92, Total score of RTP 14.13 and Leisure (social activities) 12.39) were analyzed in binary logistic regression model of equation (see Table 5).

The only impacting factor with $p < 0.01$ was the MMSE – level of participants' cognitive status (OR 2.27, 95% CI 1.36–3.79). Model correctly classified 85% of cases.

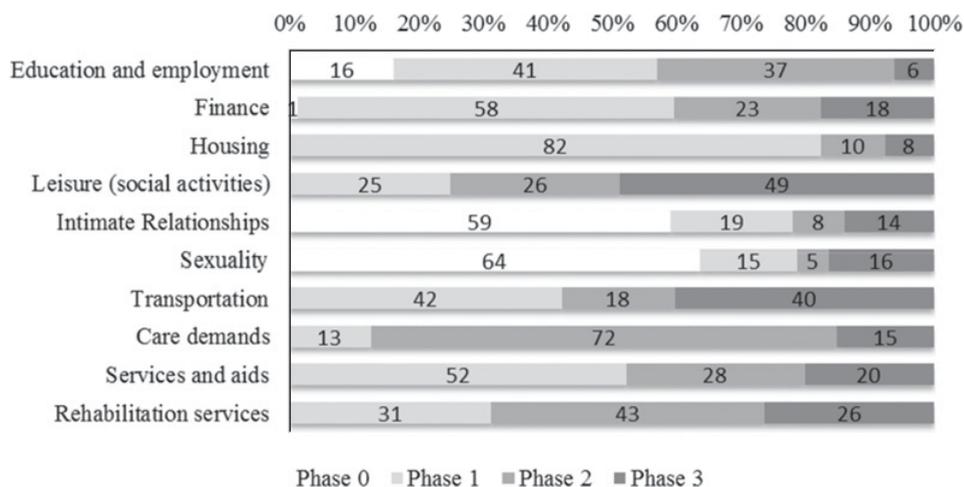


Figure 1. Percentage of participants in the transitional phases (the Rotterdam Transition Profile): 0 – no experience, 1 – dependent on parents, 2 – experimenting and orientating, 3 – independence and autonomy.

Table 2. Median values of TRAQ.

TRAQ themes	<18 y (IQR)	≥ 18 y (IQR)	All (IQR)	<i>p</i> -value*
Managing Medications	3.0 (3.8-2.0)	3.6 (4.8-2.8)	3.5 (4.3-2.5)	<0.01
Appointment Keeping	2.6 (3.0-2.0)	3.0 (4.0-2.4)	2.9 (3.9-2.2)	<0.05
Tracking Health Issues	3.0 (3.8-2.3)	3.3 (4.1-2.5)	3.3 (4.0-2.5)	0.23
Talking with Providers	4.5 (5.0-4.0)	5.0 (5.0-4.0)	5.0 (5.0-4.0)	0.25
Managing Daily Activities	4.7 (5.0-3.3)	4.7 (5.0-4.0)	4.7 (5.0-4.0)	0.63
TRAQ total	3.3 (3.6-2.8)	3.6 (4.4-3.0)	3.5 (4.2-2.9)	<0.05

*Median differences' significance associated with participants' age (minor vs. adult).

Y: years, IQR: interquartile range, TRAQ: Transition Readiness Assessment Questionnaire.

4 Discussion

This is the first study in Latvia that measures the readiness for transition to adult life and the impacting factors for independency in health care management for persons with CP.

We have demonstrated the levels of transitional phases according to the RTP for the young adults with CP at the process of becoming independent and autonomous. At the level of education and employment we found that almost one quarter of participants were not learning or having a job, and at the level of financial independency more than half were still dependent on parents/care takers. Less than one fifth of participants were orientating or already obtaining some independency in housing activities. Only half of the participants were able to spend time on leisure activities outside home having no restrictions on whether it is day time or late evening. More than half of the participants had completely none experience in intimate and sexual relationships. Also, more than half of the participants were fully or partially dependent on parents/care givers at the transportation domain. Seventy-two percent of participants claimed that they take part in decision-making about their health care management, but again – more than half of finding services and aids were done by parents/care givers. Even though persons with CP require throughout life health care, 43% had not received any rehabilitation

Table 3. Values of factors in comparison to TRAQ group I and group II.

Factors	<i>p</i> -value	Adj.res.	TRAQ	
			≤ 3.00	≥ 3.01
Gender		<1.96		
Age	0.44			
GMFCS, level 1–5 (IQR)	< 0.01		2(3-2)	1(2-1)
MACS, level 1–5 (IQR)	< 0.01	3 (3-2)	2(2-1)	
MMSE, points 30–24 (IQR)	< 0.01		26 (28-25)	29 (30-27)
Severe problems with speech, <i>n</i> (%)		> 1.96		
no			16(20)	51(64)
yes			8 (10)	5(6)
Severe problems with vision		<1.96		
Severe problems with hearing		<1.96		
Epilepsy		<1.96		
Need of an assistant, <i>n</i> (%)	< 0.01	> 1.96		
No			2(3)	36(45)
Only for transportation			16(20)	9 (11)
All the time outside the home			6(7) *	11(14) *
Place of living	0.88			
Level of income, <i>n</i> (%)	0.14	<1.96		
Below medium			17(21)*	32(40)*
Medium			6(8)*	12(15)*
Above medium			1(1)**	12(15)**
Brought up by both parents		<1.96		
Number of siblings		<1.96		
RTP, phases 0–3 (IQR)				
Education and employment	0.02		1 (2-0)	2 (2-1)
Finance, <i>n</i> (%)	0.13	> 1.96		
Phase 0			0 (0)*	1(1)*
Phase 1			17(21)*	30(38)*
Phase 2			6(8)*	12(15)*
Phase 3			1(1)	13(16)
Housing	0.01		***	1 (2-1)
Leisure (social activities)	< 0.01		2(2-1)	3(3-2)
Intimate Relationships	< 0.01		0 (0-0)	1 (2-0)
Sexuality	< 0.01		0 (0-0)	0 (2-0)
Transportation	< 0.01		1 (1-1)	3(3-1)
Care demands	< 0.01		2 (2-1)	2(2-2)
Services and aids	< 0.01		1 (1-1)	2(3-1)
Rehabilitation services	0.12			
Total score of RTP, points 6–30 (IQR)	< 0.01		11(14-9)	17(21-13)

*Adj. res. <1.96, ** adj.res. =1.9, ***constant when TRAQ ≤3.00.

Adj.res.: adjusted residual, IQR: interquartile range, RTP: Rotterdam Transition Profile, Phase 0 – no experience, Phase 1 – dependent on parents, Phase 2 – experimenting and orientating, Phase 3 – independence and autonomy (RTP).

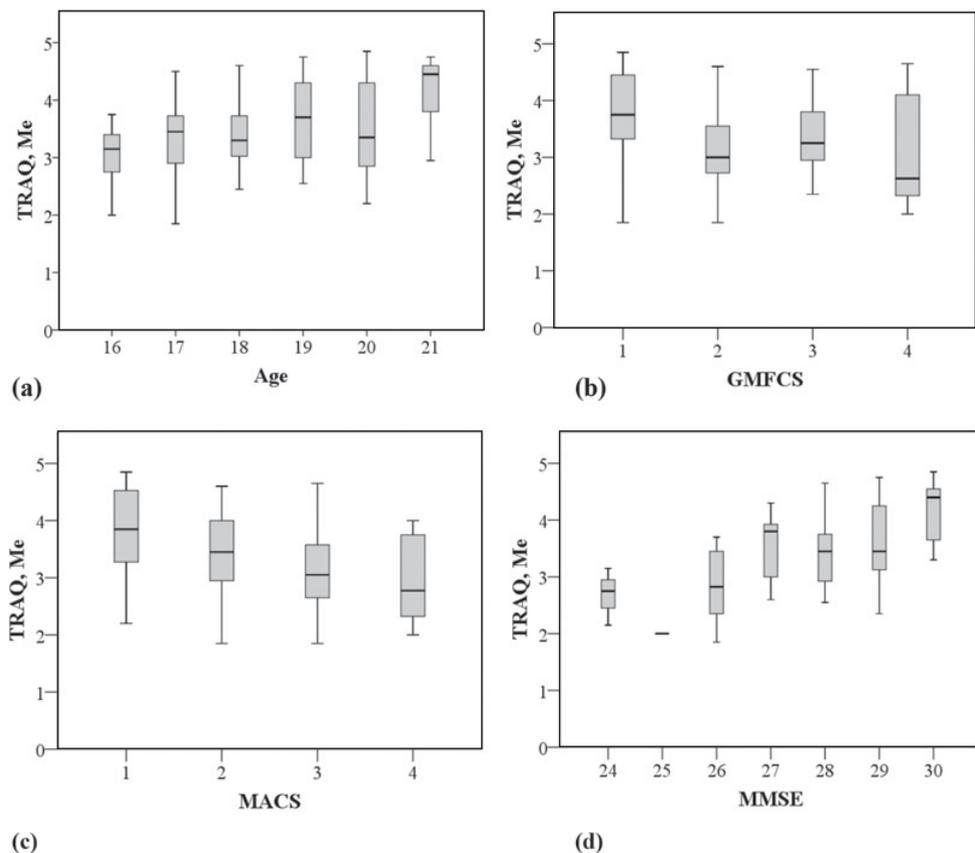


Figure 2. Median values of the Transition Readiness Assessment Questionnaire (TRAQ) total score impacted by: (a) age, (b) gross motor function (Gross Motor Function Classification System, GMFCS), (c) manual abilities (Manual Ability Classification System, MACS), and (d) cognitive status (Mini-Mental State Examination, MMSE).

services during the past year. These results are closely associated with findings in previous researches done in the Netherlands [6, 43].

In our research we analyzed the readiness of independency in health care management as the median scores of TRAQ. The lowest scores were found in thematic block “Appointment keeping” with median value 2.9 which indicates an inactive phase in making appointments, following-up on referral for test or check-ups, health change related call making to specialists etc. Thematic block “Talking with Providers” received the highest median score (Me 5.0). This was similarly seen also in the results of RTP – young adults with CP are being involved in discussions, but the real action is done by others (parents/care takers). It has been previously revealed that the assessment of health care management with generic and condition-specific measures can unfold targeted interventions and specific supports in achieving independence [46]. Our results for the total median value of TRAQ are found to be lower than those of previous research done in Latvia by L. Baranova and A. Vētra, 2016 [47] (Me 3.6 vs. 4.3, age 18–21 years). This could be explained by the fact that our research included only participants with CP and even those who had slightly decreased cognitive status. Research done by L. Baranova and A. Vētra included participants with functional limitations, not only with CP, although the cognitive status of participants was not described.

Table 4. Correlations and binary logistic regressions of the impacting factors.

	Spearman's rho	Wald	Predicted, %	OR (95% CI)
GMFCS	-0.41	9.98	73	0.43 (0.26–0.73)
MACS	-0.36			
MMSE	0.53	17.50	79	2.18 (1.51–3.13)
Severe problems with speech	-0.30			
Need of an assistant	-0.40	9.26	64	0.36 (0.19–0.70)
Education and employment	0.26			
Housing	0.30			
Leisure (social activities)	0.43	12.39	73	3.19 (1.67–6.09)
Intimate Relationships	0.36			
Sexuality	0.39			
Transportation	0.52	15.92	75	5.16 (2.31–11.56)
Care demands	0.34			
Services and aids	0.36			
Total score of RTP	0.53	14.13	76	1.43 (1.19–1.73)

$p < 0.05$.

OR: odds ratio, CI: confidence interval.

Table 5. Binary logistic regression equation* of the impacting factors.

	Wald	p -value	OR (95% CI)
MMSE	9.89	< 0.01	2.27 (1.36–3.79)
Leisure (social activities)	0.38	0.54	1.37 (0.51–3.67)
Transportation	0.68	0.41	1.65 (0.50–5.41)
Total score of RTP	3.46	0.06	1.37 (0.98–1.91)

*85.0 percentage correct.

In our study it was found that the highest scores of TRAQ median were associated with the increase of participants' age, gross motor function, manual abilities and cognitive status. A linear increase was detected in the association with manual abilities. Other factors demonstrated non-linear increase of the TRAQ median score. It might be induced that a person with lower gross motor function have relatively high independency in health care management, and a person at an older age might not be as independent as age-matched peers because of other impacting factors. This highlights the idea that none of these factors can be taken as the only one when assessing young adults with CP readiness in health care management. It has been previously revealed that assessing the person, e.g., by age is not the only determinant of person's readiness to be transited to adult health care [48].

To find out which of the factors have the most significant impact on independency in health care management we divided the TRAQ scores in two groups: ≤ 3.00 (rather passive phase, less independency) and ≥ 3.01 (rather active phase, more independency). It was detected that level of GMFCS, MACS, MMSE, having or not having severe speech problems or the need for an assistant and having income that exceeds the average have an impact on the participant's presents in one of the groups. The more capable the participant was in terms of gross motor or manual function, the less cognitive deficit and severe speech problems he/she had, and the more his/her income exceeded the average, the more he/she was likely to be present in group with TRAQ score ≥ 3.01 . Almost all domains of RTP (except

for Rehabilitation services) and the total score of RTP had an impact on the participants' presence in one of the groups. Respectively, the higher score of RTP domains and the total score of RTP the more likely for the participant to be in a rather active phase of independency in health care management. For the overall readiness to adult life for persons with CP and normal cognitive status it has been proven that there are associations with participant's age, gross motor functioning (GMFCS), manual abilities (MACS) and level of education [43]. We did not find the participants' gender, age, having or not severe problems with vision or hearing, having or not epilepsy, the place of living, being brought up by one or both parents, coming or not from a large family as an impacting factor on participants' presence in one of the groups.

The most correlating factors for the independency in health care management were found to be level of MMSE, level of leisure (social activities), independency in transportation and the total score of RTP. Suggesting that if the person has higher levels of cognitive status, ability to participate in leisure activities, arrange transportation and has higher level of overall readiness to adult life, he or she can achieve greater independency in health care management. After the binary logistic regression equation, the most impacting factor on whether the participant will receive TRAQ score ≥ 3.01 , was detected to be the level of cognitive status (MMSE). Cognitive status has been found as an impacting factor also for other aspects of life for persons' with CP, e.g., employment [49], communication, receiving support and accessing services [50].

Limitations of this study include not having an able-bodied control group as a reference and the fact that RTP and TRAQ are similar in their aim of an assessment, therefore some results were overlapping. This is planned to be taken into account in the future research.

5 Conclusions

Young adults with cerebral palsy show low levels of participation in almost all domains of transition to adult life. Regardless of the fact that persons with CP need throughout life health care, the level of attendance of rehabilitation services is not sufficient. Even though young adults with CP seem to take part in decision-making and the increase of independency has been strongly highlighted, the level of independency for young adults with CP in health care management is between phases of preparation and action. The most impacting factor for independency in health care management was found to be the cognitive status, which should be considered when assessing person's readiness for transition to adult health care.

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