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Original Article

# Assessment of adult patients with cerebral palsy

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***ABSTRACT***

**Objectives:** The aim of this study was to evaluate health problems, accommodation, and mobility of adult patients with cerebral palsy (CP).

**Patients and methods:** Between September 2018 and September 2019, a total of 70 adult CP patients (37 males, 33 females; mean age 29.4±10.2 years; range, 19 to 68 years) who were admitted to our clinic were included. Accommodation, education status, mental state, comorbidities, spasticity, contracture, deformity, and mobility of the patients were evaluated.

**Results:** Of the patients, 24.3% were diplegic, 21.4% were hemiplegic, 32.9% were tetraplegic, 15.7% were dyskinetic, and 5.7% had mixed form of CP. Among the patient, 38.6% had normal mental ability and 21.4% had severe mental retardation. A total of 92.9% of the patients were living with their family, 85.7% were unemployed, 10% were illiterate, and 21.4% had no health problems. Speech disorder was the most common health issue in 52.9% of the patients. Other health concerns included sensory problems, epilepsy, bladder/intestinal problems, nutritional problems, and respiratory and skin problems. The ratio of pain was 31.4%. Mild deformity was present in 54.3% of the patients, 43.7% were wheelchair-dependent, and 25.7% were Gross Motor Function Classification System (GMFCS) Level V.

**Conclusion:** Recognition and understanding health problems and living conditions of adult patients with CP would be useful both in determining the treatment goals of pediatric CP patients and in improving the quality of life of adult CP patients.

***Keywords:*** Adult, cerebral palsy, function, locomotion, social.

Cerebral palsy (CP) encompasses a group of disorders that affect the development of movement and posture, causing limitation of activity due to a non-progressive lesion in the developing fetal or infant brain. In CP, motor disability may be accompanied by epilepsy, communication difficulties or sensory, perceptual and behavioral problems. Cerebral palsy is the most common motor disability of childhood.[1] Although it is a lifelong condition, it is considered as a pediatric problem by many researchers.[2] In developed countries, its prevalence is estimated at 2 to 2.5 per 1,000 live births.[3] In Turkey, CP has a prevalence of 4.4 per 1,000 live births.[4] Many individuals with CP reach adulthood.[5] Globally, there are more than 17 million individuals diagnosed with CP, and one-fourth of CP patients will never be able to walk and 50% of them with severe intellectual disability will become adults.[6] Cohen and Kohn[7] and Evans et al.[8] reported a survival rate of over 60% in affected children who survived the first year of life, even among those with the most severe disabilities. Survival rates of more than 90% have been reported for mild cases.[9]

In the light of the fact that symptoms may affect patients throughout their lives and knowing that there is no cure for CP patients and almost all children with CP survive into adult life, management approach for adult CP patients requires an understanding of their needs and specific problems. Adult CP patients have limited participation in social, family, and work-related activities and experience several health problems such

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as functional impairment, pain, fatigue and sedentary lifestyle in addition to comorbidities associated with increasing age.[10-12]

In the literature, there is no study in adult CP patients in Turkey. In the present study, we, for the first time, aimed to evaluate lifestyle, demographic characteristics, general health condition, and locomotion skills of adult CP patients and to identify their problems.

## PATIENTS AND METHODS

Between September 2018 and September 2019, a total of 70 adult CP patients (37 males, 33 females; mean age 29.4±10.2 years; range, 19 to 68 years) who were admitted to Istanbul Medeniyet University Göztepe Training and Research Hospital, Physical Medicine and Rehabilitation outpatient clinic were included in this cross-sectional study. Patients under 18 years of age and patients who did not agree to participate in the study were excluded. Patient data were collected from the patients themselves and/or from their family members for those with speech disorder. Locomotor system examination was performed by a single physiatrist for all patients.

Mental state was retrieved from their Health Board reports as assessed by the Porteus and Kent tests and defined as normal or mild, moderate or severe mental retardation (MR).[13] The education status was recorded as illiterate, literate, primary, secondary, high school or university graduate. Accommodation status was questioned whether they lived alone, with their family, their spouse or caregiver. The CP type was categorized based on the Swedish classification.[14] The patients were classified in five levels using the Gross Motor Function Classification System (GMFCS).[15] Deformity was assessed based on the presence and type of the deformity:[16] *(i)* no deformity; *(ii)* mild deformity; foot deformity (e.g. equinus); knee or upper extremity deformity; no more than two deformities; *(iii)* severe deformity; hip subluxation or dislocation; scoliosis >30 degrees; and *(iv)* severe multiple deformities; hip subluxation or dislocation; scoliosis >30 degrees together with more than two deformities and prior orthopedic interventions.

Mobility was classified as walking unaided (without an assistive device), walking aided (with an assistive device), walking aided due to balance problem, previously ambulant but stopped walking-mobile with a wheelchair, and never walked-mobile with a wheelchair. Other problems including spasticity, contracture, epilepsy, pain, sensory problems, cardiac problems, respiratory problems, nutritional problems, bladder/intestinal problems, skin problems were also questioned.

A written informed consent was obtained from each participant and/or his/her legal guardian. The study protocol was approved by the Istanbul Medeniyet University Ethics Committee (No: 2018/0365). The study was registered in the ClinicalTrials.gov database (NCT03848936) and conducted in accordance with the principles of the Declaration of Helsinki.

### Statistical analysis

The size of the effect was interpreted based on the Cohen's classification.[17] After the study was completed, the post-hoc power analysis was performed using the G*Power version 3.1.9.2 software (Heinrich-Heine-Universität, Düsseldorf, Düsseldorf, Germany) and the power of the study was calculated as 0.33.

Statistical analysis was performed using the IBM SPSS version 22.0 software (IBM Corp., Armonk, NY, USA). Descriptive data were expressed in mean ± standard deviation or median (min-max) for continuous variables and in number and frequency for categorical variables. The Kolmogorov-Smirnov and Shapiro-Wilk tests were used for the normality of the distribution. Since the data did not follow a normal distribution, relations between variables were assessed using Spearman's rho coefficients. A two-tailed test was used for the evaluation of the results. P values of <0.05 and <0.01 were considered statistically significant at 95% confidence interval (CI).

## RESULTS

Age distribution of the patients is shown in Figure 1. The CP subtype distribution of the patients

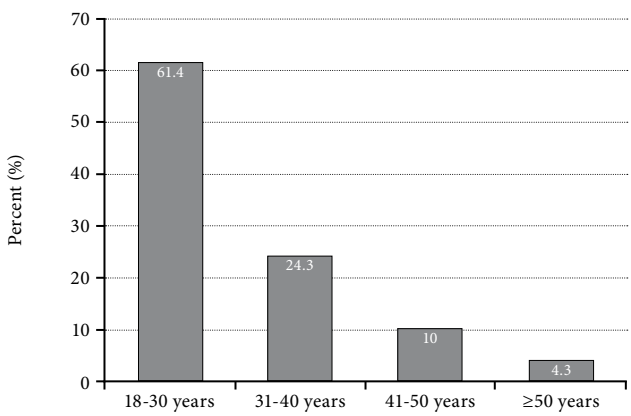


**Figure 1.** Age groups.

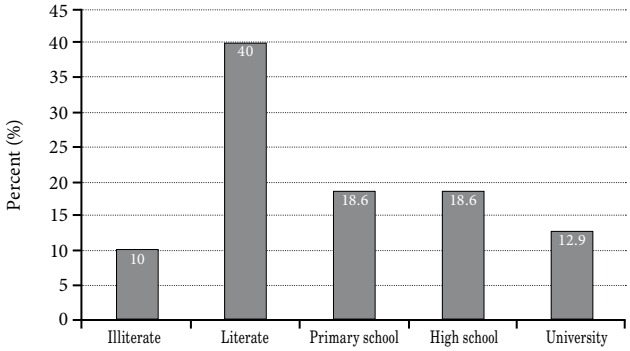


**Figure 2.** Education.

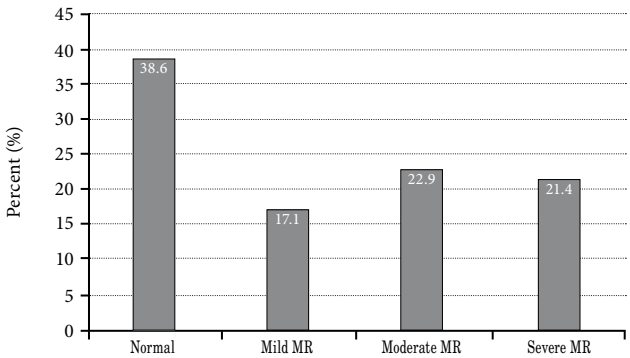


**Figure 3.** Mental state.
MR: Mental retardation.

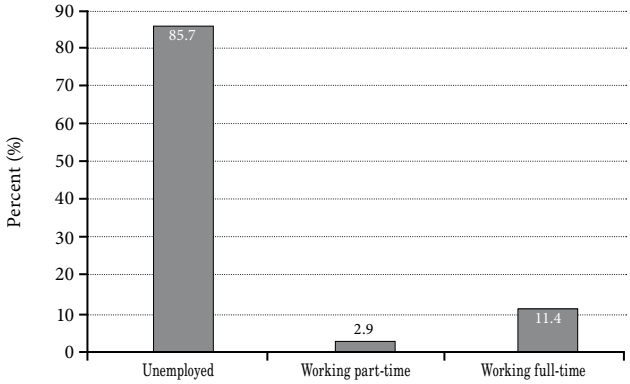


**Figure 4.** Employment status.

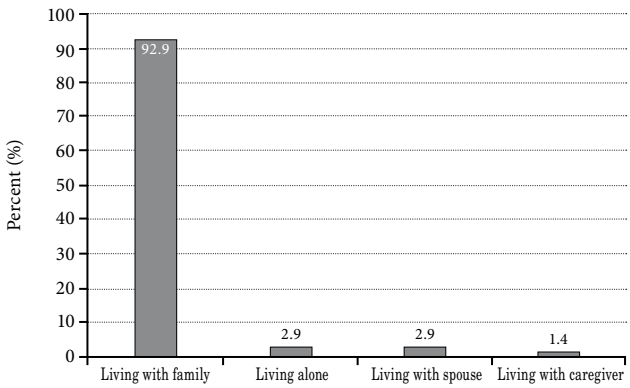


**Figure 5.** Accommodation.

was as follows: 24.3% diplegic, 21.4% hemiplegic, 32.9% tetraplegic, 15.7% dyskinetic, and 5.7% mixed form.

Mental status, educational status, accommodation, and employment data are shown in Figures 2 to 5.

Comorbid conditions are shown in Table 1. The spasticity rate was 92.9%. Deformity was absent in 10% of the patients and 54.3% had mild deformity, 22.9% had moderate deformity, and 12.9% had severe deformity. Contracture was seen in 37.1% of the patients and pain rate was 31.4% (Table 2). While mild deformity was most common among patients with spastic diplegic, spastic hemiplegic and dyskinetic CP subtypes, spastic tetraplegic CP had moderate or severe deformity (Table 3). Based on the GMFCS classification, 8.6% of the patients were Level I, 31.4% were Level II, 17.1% were Level III, 17.1% were Level IV, and 25.7% were Level V. Mobility status according to CP subtype is shown in Table 3.

Correlation analysis results are shown in Table 4. Education status, mental state, employment status, and comorbidity were all correlated with each other. Education status was strongly correlated with the mental state ($p<0.001$) and moderately correlated with the employment status and comorbidity ($p<0.001$). Mental state was moderately correlated with the employment status and comorbidity ($p<0.001$).

**TABLE 1**
Comorbidities of patients

| Number of health problems | | Epilepsy | | Speech disorder | | Sensory problems | | Respiratory problems | | Bladder/intestinal problems | | Nutritional problems | | Skin problems | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % |
| 15 | 21.4 | 15 | 21.4 | 37 | 52.9 | 20 | 28.6 | 1 | 1.4 | 9 | 12.9 | 6 | 8.6 | 1 | 1.4 |

**TABLE 2**
Distribution of spasticity, contracture, and pain among patients

| | Yes | | No | |
|---|---|---|---|---|
| | n | % | n | % |
| Spasticity | 65 | 92.9 | 5 | 7.1 |
| Contracture | 26 | 37.1 | 44 | 62.8 |
| Pain | 22 | 31.4 | 48 | 68.5 |

In addition, deformity, contracture, GMFCS, and mobility were all strongly correlated with each other (p<0.001). Education status showed a moderate correlation with spasticity (p<0.05), strong correlations with deformity (p<0.001), GMFCS level (p<0.001), and mobility (p<0.001) and a moderate correlation with contracture (p<0.001). Mental state showed strong correlations with deformity (p<0.001), GMFCS level (p<0.001), and mobility (p<0.001) and a moderate

**TABLE 3**
Severity of deformity and mobility according to cerebral palsy subtype

| | Spastic diplegic | Spastic hemiplegic | Spastic tetraplegic | Dyskinetic | Mixed |
|---|---|---|---|---|---|
| | n | n | n | n | n |
| Deformity | | | | | |
| No | 0 | 5 | 0 | 1 | 1 |
| Mild | 13 | 9 | 5 | 10 | 1 |
| Moderate | 2 | 1 | 12 | 0 | 1 |
| Severe | 2 | 0 | 6 | 0 | 1 |
| Mobility | | | | | |
| Walking without an assistive device | 8 | 13 | 0 | 4 | 0 |
| Walking with an assistive device | 3 | 2 | 2 | 0 | 1 |
| Walking with help from others | 0 | 0 | 0 | 5 | 1 |
| Walked in the past but currently mobile with wheelchair | 1 | 0 | 1 | 1 | 1 |
| Never walked, mobile with wheelchair | 5 | 0 | 20 | 1 | 1 |

**TABLE 4**
Correlation analysis results

| | Spasticity | Deformity | Contracture | GMFCS | Mobility | Pain |
|---|---|---|---|---|---|---|
| Age | | | | | | |
| rho | -0.029 | -0.047 | 0.016 | 0.024 | 0.094 | 0.271* |
| p | 0.812 | 0.702 | .894 | 0.844 | 0.441 | 0.023 |
| Mental state | | | | | | |
| rho | -0.100 | -0.600** | -0.388** | -0.704** | -0.623** | 0.023 |
| p | 0.408 | 0.000 | 0.001 | 0.000 | 0.000 | 0.848 |
| Education status | | | | | | |
| rho | -0.305* | -0.648** | -0.497** | -0.760** | -0.729** | -0.013 |
| p | 0.010 | 0.000 | 0.000 | 0.000 | 0.000 | 0.914 |
| Accommodation | | | | | | |
| rho | 0.015 | -0.105 | -0.043 | -0.170 | -0.051 | 0.181 |
| p | 0.899 | 0.386 | 0.726 | 0.160 | 0.674 | 0.134 |
| Employment status | | | | | | |
| rho | -0.212 | -0.303* | -0.313** | -0.357** | -0.444** | -0.134 |
| p | .077 | 0.011 | 0.008 | 0.002 | 0.000 | 0.270 |
| Comorbidity | | | | | | |
| rho | -0.010 | 0.290* | 0.257* | 0.387** | 0.414** | 0.021 |
| p | 0.937 | 0.015 | 0.032 | 0.001 | 0.000 | 0.864 |

GMFCS: Gross Motor Function Classification System.

correlation with contracture ($p<0.001$). Employment status showed moderate correlations with deformity ($p<0.05$), GMFCS level ($p<0.001$), mobility ($p<0.001$), and contracture ($p<0.001$). Patients with low education status, employment status, poor mental state and the presence of comorbidities had greater deformity, poorer mobility, higher level of GMFCS, and more severe contracture. Pain was weakly correlated with only age ($p<0.05$).

## DISCUSSION

To the best of our knowledge, this is the first study to report demographic data and limitations of adult CP patients in Turkey conducted in a university rehabilitation clinic. The CP subtypes, accommodation, and difficulties of our adult CP patients were investigated. The majority of our patients were under the age of 30 years (61.4%). However, the mean age of adult CP patients was over 30 years in most studies.[11,18-20] The most common CP subtype among our patients was tetraplegic CP, while dyskinetic CP was the least common type. Our findings are consistent with the Murphy et al.'s findings;[21] however, the distribution of CP subtypes reported in other studies differs from our results.[11,20,21] Adult tetraplegic and dyskinetic CP patients cannot reach advanced ages.[22] This can be explained by the fact that most of our patients were tetraplegic and younger individuals with a low rate of hospital admission among patients without severe disability.

Furthermore, about one-half of our patients had intellectual disability and the overall rate of patients with moderate and severe mental disability was 43%. Epilepsy was present in 21.4% of our patients. Intellectual disability (25%) and epilepsy (14%) were found at a lower rate in the Jonsson et al.'s study.[23] Motor and mental disturbances are closely related and we found correlations between mental state, deformity, contracture, GMFCS, and mobility.

In the present study, 10% patients were illiterate, 18.6% were primary school graduates, and 12.9% were university graduates. Our findings are consistent with those of Andersson and Mattsson[20] who reported that 15% of the patients completed compulsory education and 14% were university graduates. Mental disability was seen in almost 50% of our patients which precluded them receiving formal education, and education status was correlated with spasticity, deformity, contracture, GMFCS level, and mobility.

Speech disorder (37%) was the most common comorbidity in our cohort. While speech problems is mostly reported in dyskinetic syndrome, dyskinetic CP was found at a lower rate in our study.[16] Sensory problems including vision and hearing impairment were present in 28.6% of our patients. In a study investigating vision in CP patients, vision problems were detected in 12.5% of the patients.[16] Bladder and intestinal problems were evaluated together in the current study. Although we had a high number of tetraplegic patients, bladder problems occurred at a rate of 12.9% in our sample, which is lower than the rate (18.1%) reported by Bottos et al.[16] Nutritional problems were present in 12.9% of our patients, in contrast to 31.9% of the patients in the aforementioned study.[16] Patients with a comorbidity had greater deformities and contractures and higher levels of GMFCS and mobility.

Achieving social integration and independence is the major goal in CP. The majority of our patients were living with their family (92.9%) and did not have the capacity to work (85.7%). A very low number of patients were employed, despite the fact that nearly 40% were able to work unaided, almost one-half had normal or near-normal mental state, and 50% completed some forms of formal education. This may be related to current limited employment opportunities in Turkey. Employment status was correlated with mental state, education status, and comorbidity.

Epilepsy and physical and cognitive disorders affect independent living and cohabitation. In a study of adult CP patients without intellectual disability, 56.8% of the patients were living with their family, 13.5% were living alone, and 29.2% were sexually active.[19] In our study, only one patient was living alone and one patient was married. Half of our patients had poor mental state. Mental state was correlated with education status, lifestyle, employment status, and comorbidity. In another study evaluating mostly independent CP patients, 27% were cohabiting.[11]

In the current study, deformity, contracture, GMFCS level, and mobility were strongly correlated with each other. The patients with spastic hemiplegia, spastic diplegia or dyskinetic CP had mild deformity, whereas patients with spastic tetraplegic CP had moderate/severe deformity. Although there are studies supporting this finding,[20] Bottos et al.[16] found no association between deformity and motor disability.

In a study evaluating problems and needs of 363 adult CP patients, 24% of the patients worked full time.[20] In contrast, 11.4% of our patients had a full-time job. In the aforementioned study, 77% of the patients had spasticity, 80% had contractures,

and 18% had pain every day. When classified by mobility, 27% were unable to walk, 64% could walk with or without aid, and 9% walked in the past, but stopped walking. In another study, up to 65% of the patients could walk without any help and 22% with help.[11] In our study, the spasticity rate was very high (92.9%), while contractures were not common (37.1%). According to mobility status, 38.6% of our patients had never walked, 55.7% could walk with or without assistive devices, 5.7% stopped walking, and 43.7% were wheelchair-dependent. Patients stopped walking due to weight gain in later years, balance problems, and spasticity. In the study of Andersson and Mattsson,[20] 9% of the patients stopped walking. In the same study, muscle and joint pain was seen in 21% patients, whereas 31.4% of our patients had pain. Correlation analyses showed a correlation between age and pain, indicating that pain becomes worse by increasing age.

A limitation of our study is the relatively small sample size. Since the exact number of adult CP patients in our country is still unknown. Due to the low number of cases and the study being conducted in a single clinic, the results cannot be generalized to the overall population.

In conclusion, adults with CP experience difficulties in adult life due to progression of musculoskeletal disorders or other comorbidities. To ensure their integration into the adult life, it is important to recognize these problems and to reassess adult CP patients with reduced mobility to meet their changing needs and provide accessibility. Of note, since most of our CP patients who survived into adulthood have normal or minimal mental deficits and almost all of them live together with their families despite having some form of formal education, we should consider strategies for these patients to improve their social participation.

**Declaration of conflicting interests**

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