

Transition of Pediatric to Adult Healthcare in Patients with Cerebral Palsy

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Background: Longevity in patients with cerebral palsy (CP) is increasing, making this formerly childhood-associated diagnosis an adult matter, requiring resources and services from adult healthcare providers. During transition from pediatric to adult healthcare, patients often lose services needed or encounter barriers to access them. Although survival has increased, cerebral palsy is still thought to be a disease of childhood and as such, many patients continue to be cared for by pediatricians, child specialists and providers, including neurologists, physiatrists, physical and occupational therapists. After transition, these patients often experience sudden loss of services, feelings of abandonment during the process and sadness to leave the pediatric system.

Purpose: This study aims to describe the features of patients with CP who have undergone transition to adult care.

Participants: Patients with cerebral palsy ages 18-30 or, alternatively, their caregivers if the patient is unable to answer survey.

Design and Setting: Descriptive survey provided in paper at rehabilitation clinic or online through a REDCap link. We designed an original survey to gather data on demographics, education, and services received in both pediatric and adult healthcare services.

Results: 14 surveys were completed for analysis; 11 filled out by caregivers and 3 by patients. 11 patients (78.6%) are not currently enrolled in school while 3 (21.4%) are currently attending college, special education and another day program. Patients were enrolled in several services while in the pediatric healthcare system, including nursing, social work, case management, physical and occupational therapy. These services were provided at different settings, including home, school and clinics. After transition, patients describe a decrease of services in all settings, being nursing home services the most common maintained in 50% of the patients surveyed. Fifty percent of respondents did not participate in a transition clinic or formal process with their pediatric providers. Three respondents reported they were 18 years old when transition was first discussed, while other two reported discussions at age 12 and 21. Six patients (42.9%) reported being referred to an adult primary care provider by their pediatric provider, some were referred to specialists, and five patients were not referred to any specialists (35.7%). They also reported limitations to access medical care during transition, the most common being difficulty finding a physician that sees patients with cerebral palsy (50% of patients). Five patients reported not having any situations.

Conclusions: In a small sample of patients with cerebral palsy who have transitioned to adult healthcare, their experiences varied considerably. Services in the adult care setting are more limited compared to pediatric services, and transition is still being first discussed at a later age in adolescence. Although some patients are being referred to adult providers in their pediatric clinics, many of them still experience difficulties during the transition process, including finding physicians that see patients with cerebral palsy.