

A survey on the utilization status of social welfare services for pediatric patients with epilepsy

Abstract

Objective: Social services are critical for children with epilepsy and their family, but details of their utilization status of social services are largely unknown. This study aims to clarify the utilization status of social welfare services for pediatric patients with epilepsy in Japan in order to obtain information on the social support for such children and their families.

Methods: A survey was conducted on 597 patients (aged 0–16 years) who visited the Department of Child Neurology at Okayama University Hospital and who were diagnosed with epilepsy from October 2015 to October 2016.

Results: The medical expense subsidy (MES) for children with specific pediatric chronic diseases (SPCD), MES for ambulant mental medical service, and MES for children/adults with severe motor and intellectual disabilities were utilized in 100 (16.8%), 67 (11.2%), and 63 (10.6%), of these patients, respectively. Patients using the MES for children with SPCD represented 13 of 114 (48.2%) children with West syndrome, 13 of 30 (43.4%) children with Lennox-Gastaut syndrome, and 6 of 13 (46.2%) children with Dravet syndrome, although these syndromes are included in this MES. Twenty-six of 66 patients with non-idiopathic epilepsy with frequent seizures could not use any of the 7 social welfare services related to MES.

Conclusions: A considerable proportion of patients did not apply for the available social welfare services probably because they chose other more easily applicable services such as the common MES covering all infants/children. On the other hand, no service was allowed for a group of patients with severe epilepsy not included in specific MES. The social welfare services were found to be difficult to apply for the patients and their families with pediatric epilepsy. Improvement of the application procedures of this service system is needed.