

要旨

【目的】福祉制度の利用は、てんかんを持つ小児が地域で安定して生活するための前提条件であるが、その利用実態は不明の点が多い。そこで本研究では、てんかんを持つ小児の福祉制度の利用実態を後方視的に明らかにすることとした。

【方法】岡山大学病院小児神経科を2015年10月～2016年10月の間に受診した当該時年齢0～16歳のてんかん患者597例を対象とした。

【結果】小児慢性特定疾病医療費助成（小慢）を100例（16.8%）、自立支援医療（精神通院医療）を67例（11.2%）、重症心身障害者医療費助成を63例（10.6%）が利用していた。小慢はWest症候群114例中55例（48.2%）、Lennox-Gastaut症候群30例中13例（43.3%）、Dravet症候群13例中6例（46.2%）が利用していた。一方、発作頻回の非特発性てんかん66例中26例（39.4%）は、7制度いずれも利用していなかった。

【結論】各種制度の該当対象者でも未申請の患者が相当数あり、その背景には乳幼児医療費助成等との重複が推定された。一方、てんかんが重症にも拘わらず制度対象に含まれない患者もいることが把握された。また新規申請や居住する県外での利用等患者・家族にとって福祉制度は必ずしも利用し易くないと思われたため、今後は手続きに係る負担を軽減する仕組みづくりを検討する必要がある。

「見出し語」 てんかん，福祉制度，実態調査，地域支援，社会福祉

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

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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.