Treatment of West Syndrome: From Clinical Efficacy to Cost-Effectiveness, the Juggernaut Rolls On

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West syndrome (WS) is an infantile-onset epileptic syndrome characterized by infantile spasms and hypsarrhythmia on electroencephalogram. In India, the underlying cause is mostly perinatal insult for which ACTH (adrenocorticotrophic hormone) and oral prednisolone are drugs of choice. Vigabatrin is the drug of choice for tuberous sclerosis-associated WS [1]. A recent meta-analysis has shown that high-dose prednisolone (4–8 mg/kg/d) is noninferior to ACTH in terms of electroclinical response and adverse effect profile [2]. However, WS is a chronic disease and in a developing country like India, the financial implications for a family are not just limited to direct medical expenditures (related to prevention, diagnosis, treatment, and rehabilitation), but include indirect (travel to healthcare facility, lodging, loss of livelihood) and intangible (psychosocial impact of the illness) facets as well. The current study is the first of its kind from India which has attempted to quantify the financial burden of WS on families [3].

In the current study by Raithatha et al. [3], around two-third of the expenditures were direct and rest were indirect. The direct expenditures included cost of drug, hospital visits (both in- and outpatient) and rehabilitation. In other chronic disorders like thalassemia and leukemia as well, direct expenditures predominate, and this fact has been highlighted by the authors in the current study. Majority of the patients in the current study (58/85, 68.2%) received ACTH as first-line therapy. Apart from being three times costlier than oral prednisolone, ACTH administration also requires hospitalization, further increasing both direct and indirect expenditures. Most of the children with WS, have associated developmental delay and thus require repeated hospital visits for both seizure-related follow-ups and multidisciplinary rehabilitation. Oral prednisolone costs one-third of ACTH; even then families of patients treated with prednisolone spent

more than 10% of their total income, suggesting indirect costs were significant. The expenditure was significantly less in families hailing from the adjoining states and those receiving financial assistance through various government schemes [3]. All these facts indicate that in a developing country like ours, in chronic diseases like WS, indirect expenditures form a considerable fraction of the economic burden faced by the family. The findings in the current study have also been echoed in a recent cohort of Nigerian children with epilepsy [4]. Moreover, with evidence emerging for high-dose prednisolone being more cost-effective for WS compared to ACTH [5], the treatment algorithms need to be looked at from this viewpoint as well in resource-limited settings like ours, for optimizing direct medical expenditures in WS.

A multicentric Indian study done two decades back highlighted the enormous economic impact of epilepsy [6]. The need of the hour is a similar study which can prioritize and guide decision-making in epilepsy, including WS. A cost-effectiveness analysis for ACTH and prednisolone needs to be done in resource-limited settings including India to guide therapeutic decision-making in WS. To cut down on indirect costs, empowering primary and secondary health facilities along with teleconsultation are promising options and should be studied systematically in various settings.

Declarations

Conflict of Interest None.

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