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Psychological impact on parents of children with congenital adrenal hyperplasia: a study from Sri Lanka

Abstract

Introduction: Congenital adrenal hyperplasia (CAH) is a group of autosomal recessively inherited disorders with significant morbidity. The long-term implications result in immense psychological stress to the parents. This study assessing the psychological impact on the parents is a first in Sri Lanka and one of the few worldwide.

Objective: Document the presence of depressive symptoms in parents of children with CAH.

Design: Study participants were 37 parents of children diagnosed with CAH who were attending an endocrinology clinic of the largest children's hospital in Sri Lanka. Centre for Epidemiological Studies-Depression scale (CES-D), a psychometrically sound scale for assessing depressive symptomatology, was used.

Results: The study classified 59% of the parents as being affected, and the psychological impact on them did not reduce with time.

Conclusion: Parents of children with CAH demonstrated symptoms of depression that did not abate with the passage of time.

Keywords: congenital adrenal hyperplasia; depression; parents; Sri Lanka.

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Introduction and objectives

Congenital adrenal hyperplasia (CAH) is a group of autosomal recessively inherited disorders, the commonest type being due to deficiency of the enzyme 21-hydroxylase, resulting in either the salt-wasting form or the non-salt-wasting form (1, 2). CAH-affected girls are virilised at

birth with ambiguous genitalia. In addition, there is evidence of a lack of hydrocortisone, with or without fludrocortisone, which is also the manifestation in affected baby boys. CAH has many long-term implications such as the need for lifelong replacement therapy, meticulous clinical and biochemical monitoring, surgical interventions and fertility issues, to name a few (3, 4).

There have also been findings on the psychological dimension of those diagnosed with CAH. For instance, it has been indicated that they have significant difficulties with psychosexual identification, although they do adjust well to their illness and to receiving social support (5). Although there are some such studies on the psychological dimension of CAH, there is a dearth of research findings on the psychological impact on the parents of a child with this condition. The birth of a baby with CAH is a cause of immense psychological distress to the parents. In fact, most parents appear to be in perpetual doubt of the sex of the child, which is further compounded by chronic illness and attendant lifelong interventions (6). Indeed, this may be particularly so in traditional countries such as Sri Lanka, which tends to stigmatise such disease conditions more so than in Western countries. This stigma invariably leads to secrecy and the need to hide from family, friends and neighbors their child's condition. Having to conduct one's daily activities within such a context of stigma and secrecy, while also catering to the needs of the child, could have a tremendous psychological impact on the parents. Hence, the objective of the present study was to assess the prevalence of depressive symptomatology in parents of children diagnosed with CAH. It is envisaged that the results of this study may be used to plan appropriate psychological services to psychologically needy parents of children diagnosed with the condition.

Design and main outcome measures

All literate parents of children with CAH, receiving treatment at the University Paediatric Unit at Lady Ridgeway Hospital (LRH), Sri Lanka, were identified to participate