



Correspondence



Evaluating psychosocial stressors in families of children with inborn errors of metabolism

Families of individuals with inborn errors of metabolism (IEMs) often experience many physical, social, and emotional challenges. These challenges can make it difficult to provide care and may negatively affect the health of people with IEMs. Since the well-being of the family can impact the well-being of patients, excellent care for patients must include recognition and support for the family [1]. In their recent study, Rajasekar et al. [2] provide an important description of several psychosocial stressors experienced by parents of children with IEMs; however, some additional questions and implications must be considered.

Rajasekar et al. [2] reported that several parents experienced anxiety, emotional distress, decreased social contact, and other psychosocial stressors. However, the authors did not quantify the specific stressors identified in the study. While qualitative research offers many benefits, a mixed methods approach with quantitative analyses could help us better understand the prevalence of these stressors and help prioritize the development of future supportive interventions [3,4].

Although Rajasekar et al. [2] interviewed parents of children under the age of ten, they did not specifically note the ages of the children. How old were the children at diagnosis, and how much time elapsed between diagnosis and data collection? Around the time of diagnosis, parents may experience anxiety, confusion, and uncertainty regarding their child's illness and may need resources for informational and emotional support [5]. In later years, parents may be responsible for providing a significant amount of care at home, which may lead to severe physical and psychological distress and necessitate resources for respite, residential support, and future planning [6,7]. Since the experiences of parents can change over time [5–8], future studies must specifically investigate the relationship between age and psychosocial stressors in order to fully understand the perspectives and support needs of parents.

While Rajasekar et al. [2] sought to identify common challenges associated with various metabolic disorders, the considerable heterogeneity of IEMs may cause psychosocial outcomes to differ significantly between conditions [9]. Certain factors, such as neurobehavioral issues and complex care needs, may contribute more heavily to emotional distress than other factors. Reporting conclusions about multiple IEMs collectively may guide future interventions to adopt a one-size-fits-all approach to treatment and support, which may benefit some families but not all. Accordingly, further studies are needed to investigate how disease severity, as indicated by visceral and neurocognitive manifestations, affects the experiences of families.

Furthermore, while Rajasekar et al. [2] provide important information about parents in Canada, their results may not be fully generalizable to parents in other locations. For example, financial support for medical bills and access to care, particularly at centers of excellence, can vary significantly between countries which may affect outcomes for the entire family [5,7]. Such factors should also be taken into consideration

in future studies.

Interestingly, although Rajasekar et al. [2] interviewed only parents, they found that siblings may also experience serious psychosocial challenges. As siblings often serve important roles for their brothers and sisters with IEMs [10], researchers must specifically include siblings in future studies to better understand their unique perspectives.

We appreciate the important and much-needed information that Rajasekar et al. [2] provided and encourage additional studies to delve further in identifying the overall impact of IEMs, which may ultimately help improve outcomes for patients and their families.

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Nathan Grant: Conceptualization, Writing – Original draft preparation, Writing – Review and Editing. **T. Andrew Burrow:** Conceptualization, Supervision, Writing – Review and Editing. All authors approved the final manuscript as submitted.

Declaration of Competing Interest

NG serves in a non-paid capacity as the President and Founder of Siblings with a Mission, a support group for siblings who have brothers and sisters with inborn errors of metabolism and other complex health conditions. NG also serves in a non-paid capacity on the Board of Directors of the Sibling Leadership Network and on the Sibling Resource Committee of the National MPS Society. NG has a twin brother who has Hunter syndrome. TAB has no conflicts of interest to disclose.

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