

Burdens and Difficulties Experienced by Parental Caregivers of Children and Adolescents with Idiopathic Nephrotic Syndrome in Mainland China: A Qualitative Study [Letter]

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Dear editor

We are writing in response to the article “Burdens and Difficulties Experienced by Parental Caregivers of Children and Adolescents with Idiopathic Nephrotic Syndrome in Mainland China: A Qualitative Study” by Xinmiao Hu et al, published in the Journal of Multidisciplinary Healthcare. Hu et al’s qualitative study sheds light on the difficulties faced by parents in mainland China who are caring for children and adolescents with idiopathic nephrotic syndrome (INS). The study identified five major themes, including persistent emotional burden, neglected physical burden, overwhelming financial burden, absence of a social support system, and burden related to the loss of a normal life. The findings underscore the significant impact of INS on parental caregivers and the need for targeted support and interventions to alleviate their burdens.¹

The study’s findings have important implications for healthcare professionals, policymakers, and support organizations. It highlights the need for stage-by-stage, targeted health education and psychological support services for parental caregivers of INS youth in China. Additionally, the financial burden on parental caregivers, including the high cost of disease treatment, calls for government subsidies and support to minimize the financial strain on families. Furthermore, the study emphasizes the importance of addressing the social isolation and stigma experienced by parental caregivers, as well as the need for improved communication and information sharing between healthcare providers and caregivers. Overall, the study provides valuable insights into the lived experiences of parental caregivers of INS youth and underscores the need for comprehensive support systems to address their challenges.

Despite the excellent contribution we have comments on the article. One of the weaknesses in the article is the limited representation of the patient’s perspective. While the article provides valuable insights from the perspective of caregivers, it does not include direct patient perspectives. This may reduce the comprehensiveness of understanding the daily lived experiences of patients with INS.² In addition, the majority of caregivers interviewed were female, so the results may not fully reflect the experiences of male caregivers. In addition, the limitation in geographical representation is also a weakness, as the study was only conducted in mainland China. This may limit the generalizability of the findings to INS caregivers in other regions.³ Finally, the article also has limitations in social and economic representation, so the findings may not be fully relevant for INS caregivers from different social and economic backgrounds.

To improve the quality of this study and future research, it is recommended to complete the representation of the perspectives of patients with INS. Research involving interviews with patients themselves may provide a more comprehensive understanding of the daily life experiences of patients with INS. In addition, it is important to broaden the scope of participation of male caregivers in this study, so that the results can reflect experiences from different gender perspectives. Another recommendation is to include caregivers from diverse geographical regions, not just mainland

China, so that the findings can be more globally relevant.^{2–4} In addition, further research that expands the social and economic scope of caregivers may provide more comprehensive insights into the challenges faced by INS caregivers from different backgrounds. As such, this article may provide more holistic and relevant recommendations for INS caregivers in different contexts.

Disclosure

The authors report no conflicts of interest in this communication.

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