

Transition process in children with chronic liver diseases: what is the challenging point?

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Comment on: Joshi D, Nayagam J, Clay L, *et al.* UK guideline on the transition and management of childhood liver diseases in adulthood. Aliment Pharmacol Ther 2024;59:812-42.

Keywords: Chronic liver diseases; children; transition; adult

Submitted Jun 29, 2024. Accepted for publication Jul 30, 2024. Published online Sep 06, 2024. doi: 10.21037/hbsn-24-354 View this article at: https://dx.doi.org/10.21037/hbsn-24-354

Pediatric chronic liver diseases encompass a wide spectrum of hepatopathies with a relevant health medical and financial burden (1,2). In addition to inherited disorders (e.g., Alagille syndrome, metabolic disorders, etc.), there are numerous chronic liver conditions including metabolic dysfunction-associated steatotic liver disease (MASLD) and autoimmune liver diseases affecting morbidity, quality of life, and life expectancy of these young patients (3,4). To complicate matters, the exact prevalence of childhood chronic liver diseases is still unknown since their asymptomatic course especially in the early stages but increasing rates are reported worldwide (1,5,6). Moreover, management of these chronic conditions represents a great challenge for clinicians as it requires a lifelong multidisciplinary approach (1). Worthy of note, advances in the knowledge of pathophysiological mechanisms underlying liver diseases greatly improved their natural history with increased survival rates into adulthood (1,3). Given that, adult hepatologists are increasingly dealing with most of these conditions (3).

Therefore, pediatric chronic liver diseases are currently considered as a growing public health issue (7) with an urgent need not only for early diagnosis, prevention, and treatment but also for standardized transition programs development (1,3).

Recently, UK guidelines on the transition and

management of pediatric liver diseases in adulthood have been released (8). This great scientific effort is closely related to the urgent need for an adequate transition care process of pediatric patients with chronic conditions, as confirmed by studies from experts in different medical fields (9-11).

Transition from childhood to adulthood care represents a challenging process for youths with chronic physical and mental diseases and their families since the relevant involvement of various medical and psychological aspects (12,13). Indeed, adolescence represents a sensitive transitional stage including dynamic changes across multiple systems (13). Due to the concurrent rapid physical, cognitive, social, and emotional growth during this period, a heightened sensitivity to both positive and negative experiences has been described in adolescents (5). However, most professionals have no expertise in the field, thus requiring guidance to facilitate the transition of these highly burdened patient to adult care (8,13).

Based on these premises, it is understandable how transition from pediatric to adult care deserves a special medical attention as the uniqueness of needs of adolescents than children and adults (12,13). In February 2024, Joshi *et al.* published the first nationally developed UK guideline on the transition care of children with chronic liver diseases (8). Authors provided a detailed overview on the overall management of the main pediatric chronic liver diseases (ranging from autoimmune

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HepatoBiliary Surgery and Nutrition, Vol 13, No 5 October 2024

diseases, specific rare genetic and neonatal conditions to inherited metabolic disorders and MASLD), suggesting also specific models and provision of care (8).

Overall, numerous key questions on the medical and psychosocial challenges related to the disease and its treatment burden need to be addressed for patients requiring lifelong multidisciplinary care such as those with chronic liver diseases (8). Indeed, it should be noted that young patients often experienced greater fragility and vulnerability during the transition process from pediatric to adult care (13).

Firstly, a multidisciplinary and individualized approach represents a key element for the optimal management of these young patients (8). Indeed, a successful transition needs to overcome numerous barriers related to patient, caregiver, and healthcare provider potentially affecting this process (3,8). Among these, poor adherence and inadequate/lack of knowledge of healthcare services and of communication, protocols, and guidelines between the pediatric and adult systems need to be considered (8). In particular, the struggle in living pediatric setting has emerged as one of the major barriers for an effective transition (8), as further demonstrated in children with other chronic diseases (9-11). Besides, poor youth and caregiver readiness and inadequate coordination care underscoring specific differences between pediatric and adult approach, lack of expertise in managing complex childhood-onset diseases, and healthcare policies heterogeneity also act as significant barriers (8).

To ensure the best transition from a parent-supervised to a patient-centered adult health care, mental health monitoring through the use of standardized screening questionnaires should be also included in the routine clinical practice (8), as the negative impact of psychosocial circumstances and stressors on health outcomes in young patients with liver diseases (6,8). In an attempt to foster the transition process, an ideal model of care should provide for joint clinics including a multidisciplinary expertise with flexibility and continuity of care from pediatric to adult setting, as suggested by the Chronic Care Model (8).

In this perspective, the decision-making process should include, where possible, the patient (8). Given also the cruciality of caregivers, their early and individualized involvement in the transition process needs to be considered for a more supportive role (8).

In addition, the improved survival and treatment of pediatric patients with chronic liver diseases impose to consider sexual health and pregnancy (including prepregnancy counselling) as a part of the multidisciplinary approach (8). As the profound change of the landscape, a guided and structured transition care process is of paramount importance. To improve the overall quality of transition to adult care for patients and their families, a key set of standardized quality indicators for healthcare processes and outcomes needs also to be provided (8,14).

On the other hand, all these gaps are reflected by the scarce existing literature in the field (1,7). Increased knowledge and education on the chronic condition affecting the young patient as well as multidisciplinary expert clinical networks development are essential for all healthcare professionals facing with these unmet needs (8).

Therefore, transition care process to adult care for children with chronic diseases should be considered as a top priority area for health policies (8). As a matter of fact, benefits achieved by a successful transition in various chronic conditions (e.g., diabetes, congenital heart and pulmonary disease, etc.) have been largely documented (9-11,15), whereas similar evidence for chronic gastrointestinal diseases is still more sparse but promising (5,7).

In this perspective, future research in the field must address several key concerns to significantly improve longterm health-related outcomes in young patients with chronic liver diseases. This might be attained through an effective cooperation between pediatric and adult care systems; therefore, the development of standardized and structured transition programs represents a challenge but essential need for these young patients.

Acknowledgments

Funding: None.

Footnote

Provenance and Peer Review: This article was commissioned by the editorial office, *HepatoBiliary Surgery and Nutrition*. The article did not undergo external peer review.

Conflicts of Interest: All authors have completed the ICMJE uniform disclosure form (available at https://hbsn.amegroups.com/article/view/10.21037/hbsn-24-354/coif). The authors have no conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are

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appropriately investigated and resolved.

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References

- Della Corte C, Mosca A, Vania A, et al. Pediatric liver diseases: current challenges and future perspectives. Expert Rev Gastroenterol Hepatol 2016;10:255-65.
- Hadžić N, Baumann U, McKiernan P, et al. Long-term challenges and perspectives of pre-adolescent liver disease. Lancet Gastroenterol Hepatol 2017;2:435-45.
- Brooks AJ, Smith PJ, Cohen R, et al. UK guideline on transition of adolescent and young persons with chronic digestive diseases from paediatric to adult care. Gut 2017;66:988-1000.
- Zou YG, Wang H, Li WW, et al. Challenges in pediatric inherited/metabolic liver disease: Focus on the disease spectrum, diagnosis and management of relatively common disorders. World J Gastroenterol 2023;29:2114-26.
- Huang JS, Terrones L, Tompane T, et al. Preparing adolescents with chronic disease for transition to adult care: a technology program. Pediatrics 2014;133:e1639-46.
- 6. Brahmania M, Rogal S, Serper M, et al. Pragmatic strategies to address health disparities along the continuum

Cite this article as: Di Sessa A, Capasso G, Tirelli P, Miraglia Del Giudice E, Marzuillo P. Transition process in children with chronic liver diseases: what is the challenging point? HepatoBiliary Surg Nutr 2024;13(5):854-856. doi: 10.21037/ hbsn-24-354

of care in chronic liver disease. Hepatol Commun 2024;8:e0413.

- Chen F, Huang Y, Huang Z, et al. The epidemiological characteristics of liver disease in hospitalized children: a 10-year single-center retrospective study. Front Pediatr 2024;12:1344714.
- 8. Joshi D, Nayagam J, Clay L, et al. UK guideline on the transition and management of childhood liver diseases in adulthood. Aliment Pharmacol Ther 2024;59:812-42.
- Pohunek P, Manali E, Vijverberg S, et al. ERS statement on transition of care in childhood interstitial lung diseases. Eur Respir J 2024;64:2302160.
- Shaikh MG, Barrett TG, Bridges N, et al. Prader-Willi syndrome: guidance for children and transition into adulthood. Endocr Connect 2024;13:e240091.
- Schultz AT, Smaldone A. Components of Interventions That Improve Transitions to Adult Care for Adolescents With Type 1 Diabetes. J Adolesc Health 2017;60:133-46.
- White PH, Cooley WC; , et al. Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. Pediatrics 2018;142:e20182587.
- Crowley R, Wolfe I, Lock K, et al. Improving the transition between paediatric and adult healthcare: a systematic review. Arch Dis Child 2011;96:548-53.
- Toulany A, Khodyakov D, Mooney S, et al. Quality Indicators for Transition from Paediatric to Adult Care for Youth with Chronic Conditions: Protocol for an Online Modified Delphi Study. JMIR Res Protoc 2024;13:e60860.
- Bredy C, Werner O, Huguet H, et al. Efficacy of a Transition Program in Adolescents and Young Adults With Congenital Heart Disease: The TRANSITION-CHD Randomized Controlled Trial. J Adolesc Health 2024;75:358-67.