

Epidemiological and psychosocial outcomes of liver graft recipients transplanted during childhood

Clara Gautier^{1}, Mado Gautier², Jessica Almeida Sousa¹, Kiswendsida Sawadogo³, Catherine de Magnée⁵, Roberto Tambucci⁵, Giulia Jannone¹, Isabelle Scheers¹, Geraldine Dahlqvist⁴ & Xavier Stephenne¹*

¹ Pediatric Gastroenterology and hepatology division, Cliniques universitaires Saint-Luc, UCLouvain, Brussels, Belgium, ERN Transplantchild, ERN Rare Liver

² Louvain Experimental Psychopathology research group (LEP), Psychological Science Research Institute (IPSY), UCLouvain, Louvain-la-Neuve, Belgium

³ Statistical support unit, Cliniques universitaires Saint-Luc, Brussels, Belgium

⁴ Hepatology and gastroenterology unit, Cliniques universitaires Saint-Luc, UCLouvain, Brussels Belgium, ERN Rare Liver

⁵ Pediatric Surgery and Liver Transplantation division, Department of Surgery, Cliniques universitaires Saint Luc, UCLouvain, Brussels, Belgium.

Objectives and Study

While pediatric liver transplantation has markedly improved long-term survival, adult outcomes remain insufficiently explored beyond graft function, particularly regarding mental health and disease understanding, - key dimensions of meaningful survival. To this aim, we evaluated psychosocial, behavioral, and lifestyle outcomes of adults who received a liver transplant during childhood, using validated tools.

Methods

Among 195 eligible adults who underwent liver transplantation before age 18 at Cliniques Universitaires Saint-Luc, 50 completed a fully anonymous online questionnaire. Validated tools were used to assess anxiety (STAI-Trait), depression (BDI-SF), and alcohol use (AUDIT). Additional items covered sociodemographic status, lifestyle habits, treatment adherence, and disease knowledge.

Results

Participants (mean age 30.6 years, SD 8.19; mean age at transplant 4.48 years, SD 4.39) reported high rates of psychosocial distress: 49% displayed clinically relevant anxiety and 33% reported moderate to severe depressive symptoms. Problematic alcohol use (AUDIT >8) was found in 8% of respondents, and 24% indicated they had never received medical counseling regarding alcohol risks post-transplant; no association was found between alcohol use and anxiety or depression. Disease knowledge remained limited: only 31% could accurately describe the pathophysiology of their liver condition, and 36% were unaware of its transmissible genetic nature. Despite these challenges, 76% were professionally or academically active.

Conclusions

These findings highlight the persistence of high psychological distress and limited disease understanding into adulthood, supporting the integration of mental health screening and patient education into long-term post-transplant care

Acknowledgements: The authors have not received any funding or grants in support of the presented research or for the preparation of this work and have no declarations of potential conflicts of interest.