

Paediatric to adult liver transition services: the state of play in the UK

The transition of young adults (YA) from paediatric to adult health services is a challenging time for patients, parents / care providers and health care professionals. This period has a higher prevalence of mental health problems and is associated with high rates of non-adherence.¹ These factors can have a deleterious impact on physical health and in transplant recipients, on graft survival. Strengthening the continuity of transition care from paediatric to adult services was a key recommendation of the Lancet commission² and yet there are no UK guidelines for the transition of YAs with liver disease. A US survey among adult liver transplant physicians reported that less than a third of YAs arrived at their first adult clinic appointment with adequate knowledge about their condition and poor adherence was found to be a frequent barrier to successful transition.³

We performed a national survey of paediatric to adult transition liver services in the UK using a questionnaire adapted from the US study.³ The questionnaire was distributed electronically to 26 secondary and tertiary liver centres in the UK between 22 October 2017 and 12 February 2018. In total, eighteen centres (69%) responded: nine centres had a dedicated liver transition service while 12 had an affiliation with a paediatric centre. Nine centres received more than five referrals/year. The availability of transition services resulted in YAs having adequate knowledge about their condition (76% vs 50%), better adherence and less patient/family dependence on the paediatric provider.

Compared with the USA, UK centres were more likely to have a formal transition programme (61% vs 16%) but YAs attending clinic were less likely to have adequate knowledge about their condition and were more likely to attend with a parent or guardian. In the UK, there appeared to be adequate communication with paediatric providers. The main barriers to a successful transition in the UK were poor adherence and ongoing dependence on the paediatric providers. YAs in the UK appeared to be more likely to discuss the impact of their condition independently, ie without their parent or guardian. Similarities were noted between the USA and UK with regard to parents/guardians managing the YA's condition without engaging the YA.

Transition services were available in half of secondary/tertiary adult liver centres who responded to an online questionnaire and, within these centres, nearly two-thirds have a documented formal transition programme. However, the constituents of the multidisciplinary team varied hugely among the centres and a more standardised approach would be of benefit to YAs. Neurodevelopment and higher brain executive functions continue to develop in YAs well into their twenties and therefore, transition services can be an important resource for YAs diagnosed with *de novo* liver disease.⁴

Table 1. Comparison of UK and US surveys.

	USA (n=236)	UK (n=18)
Formal transition programme	16 %	61 %
No transition strategy	32 %	22 %
Characteristics of YA attending clinic appointment		
Have adequate knowledge about their condition	70 %	62 %
Arrived to the appointment with parent/guardian	66 %	76 %
Barriers to transition		
Inadequate communication with paediatric provider	61 %	11 %
Patient/family dependence on paediatric provider	46 %	67 %
Poor adherence	72 %	56 %
Patients lack the capability to discuss the impact of their condition independently without the help of their parent/guardian	54 %	28 %
Parents/guardians manage their child's condition without engaging their child	49 %	44 %

YA = young adult

The importance of transition services for YAs with liver disease is clearly recognised in the UK but the infrastructure is still lacking. It is time to consolidate and improve current services given the marked deficiencies highlighted by this survey. Adherence remains key and was identified as a significant barrier to transition. Self-management remains an important management strategy to try to improve adherence. Self-management programmes sensitive to the needs of YAs need to continue to develop. In addition, peer support programmes are a unique opportunity to reach out and support YAs. Engagement and support of parents/guardians with the transition process remains critical but this has to be with the engagement of the YA. A national collaborative approach is needed and this work must continue to be a priority for the UK hepatology community. ■

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