NHS BLOOD AND TRANSPLANT

LIVER ADVISORY GROUP

How should patients awaiting a liver transplant who are disadvantaged by a National Allocation System based on UKELD be allocated a donor organ?

Recommendations of a LAG Fixed-Term Working Unit

Terms of Reference:

1. How should patients with chronic liver disease whose clinical need is not appropriately reflected by the main allocation system be defined and managed (disadvantaged patients)?
2. How should patients with exceptional indications be prioritised?
3. Do patients requiring elective retransplantation need to be considered as different to patients within the backbone of the allocation system?

Introduction

For patients awaiting liver transplant in the UK, priority is determined by their risk of death, currently calculated using the UKELD scoring system. Some patients who benefit from liver transplant are disadvantaged by this system, either because their UKELD score underestimates their risk of dying on the list (or of being removed from it) or because their risk of dying is low and they are being considered for transplant to improve their quality of life . Some belong to the current "variant syndromes". Some have chronic liver disease for whom the UKELD system is appropriate but require additional points to restore equity. Some receive a transplant to treat non-liver disease, for whom the UKELD score is irrelevant.

Section A. <u>Who is disadvantaged?</u>

The following categories were judged to be <u>definitely</u> disadvantaged:

1. Hepatocellular Carcinoma (HCC): These patients are removed from the list if their tumour(s) progress beyond the agreed maximum size and number. This is independent of UKELD. A separate FTWU are considering this.

2. Hepatopulmonary Syndrome (HPS)*: Patients can benefit from transplant even at low UKELD. The suggested threshold is PaO2 <60 mmHg or 7.8 kPa.

3. Portopulmonary Hypertension (PPH): Patients can benefit from transplant if they have pulmonary hypertension (mean PAP > 25 mmHg) which demonstrates reversibility by pulmonary vasodilator therapy.

4. Polycystic Liver Disease (PCLD)*: The suggested additionamarker of disease severity is the degree of malnutrition (objectively assessed).

5. Familial hypercholesterolaemia*: **6. Porphyria**: **7. Glycogen storage disease**: These 3 conditions can benefit from transplant to cure metabolic diseases whose consequences are non-hepatic illness, so UKELD does not reflect their risk.

8. Primary Hyperoxaluria: This metabolic condition can benefit from combined liver and kidney transplant. UKELD is irrelevant, but a donor liver should be allocated when the kidney donor is identified.

9. Hepatic Epithelioid Haemangiendothelioma (HEHE)*: The prognosis of this tumour is independent of UKELD.

The following categories were also felt to be disadvantaged, but <u>not</u> because of increased risk of death or removal from the list:

10. Chronic hepatic encephalopathy*:
11. Intractable pruritus*:

Very rarely patients can have disabling encephalopathy or intractable pruritus despite preserved liver function with a low UKELD.

The following categories were thought to be <u>probably</u> disadvantaged:

12. Diuretic Resistant Ascites (DRA)*: A minority of patients with DRA have a low UKELD and are unsuitable for TIPSS. Further NHS BT data is required to confirm whether or not they have a higher mortality than their UKELD indicates. If so, malnutrition could be the additional weighting factor.

13. Cholangiopathy with refractory cholangitis or intrahepatic sepsis: Patients with various cholangiopathies may require transplant for recurring cholangitis of increasing severity and resistance to antibiotics, or intractable intrahepatic sepsis. This includes patients with ischaemic cholangiopathy requiring retransplant due to late HAT or DCD damage. Further NHS BT data is required to confirm whether or not they have a higher mortality than their UKELD indicates.

The following categories were not felt <u>not</u> to be disadvantaged:

14. Retransplants: Patients requiring retransplantation for ischaemic cholangiopathy due to DCD damage or late HAT may fall into category 13 above. For other retransplant indications, their degree of graft failure should be indicated by their UKELD score.

15. Familial Amyloid Polyneuropathy: these patients livers can be re-transplanted into another recipient on the waiting list ("domino transplant"), and can be prioritised according to the UKELD of the selected domino recipient.

16. Sickle Cell Hepatopathy*. Their indication for transplant is severe jaundice with or without liver failure so UKELD should adequately prioritise.

(* existing variant syndromes)

Section B. <u>How should these disadvantages be corrected?</u>

<u>System 1: Award extra UKELD points</u>.
In a numerical national allocation system such as UKELD the allocation of additional numerical points to disadvantaged categories could correct these disadvantages. The number of points should be based on the additional risk of death or removal from the list and on the degree of advantage that such additional points confer. This will require

modelling by NHSBT. The principle is similar to the US system. The French system was initially considered too complex. Following its introduction, any additional points system would require regular adjustments.

- Some categories would receive additional points when their condition crossed an agreed threshold:
  - **HPS -** PaO2 < 7.8 kPa
  - **PPH** - MPAP >25mmHg + reversibility
  - **PCLD -** agreed malnutrition indicator
- This would also apply to 2 further categories <u>if NHSBT data confirms their disadvantage</u>:
  - **DRA** - agreed malnutrition indicator
  - **Cholangiopathy with sepsis (including re-transplants) -** possible triggers: >1 episode of sepsis with MOF; sepsis with multiple antibiotic resistance; dependence on external biliary drainage
- For other categories, the number of additional points awarded would increase with time:
  - **HCC**
  - **HEFE**
- For categories without chronic liver disease, their risk of death from their disease should be matched to an equivalent UKELD score:
  - **Porphyria**
  - **Hypercholesterolaemia**
  - **Glycogen storage disease**
- For categories not at risk of dying, their low chance of being transplanted could be adjusted by awarding additional points after they had been waiting longer than, say, 2 years:
  - **intractable pruritus**
  - **chronic encephalopathy**

<u>System 2: “Proportional allocation”.</u>
For categories where UKELD is not relevant, the percentage of registrations which fall into these categories could be calculated, and this percentage of donor offers could be set aside from national allocation for individual units to offer transplants to these categories.

- This could be used for patients not at risk of dying:
  - **Intractable pruritus**
  - **chronic encephalopathy**
- Or for patients without chronic liver disease:
  - **porphyria**
  - **hypercholesterolaemia**
  - **glycogen storage disease**
  - **HEHE**

Fixed-Term Working Unit members: Mark Aldersley, James Ferguson, Bill Griffiths, Alastair MacGilchrist*, James O’Beirne*.
(* co-chairs)

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