Deaths from alcohol-related liver disease in the UK

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Alcohol Related Liver Disease deaths – an escalating tragedy

In 2013 NCEPOD published 'Measuring the Units' reporting on a case note audit of patients with Alcohol Related Liver Disease (ArLD) who died in hospital in 2011 (1). This highlighted the '*avoidable nature of many of the deaths from alcohol related liver disease*'. (1). It found that '*the care was less than good in more than half of the cases reviewed*' and basic omissions in patient care and missed opportunities were prevalent, including the identification of patients with decompensated liver disease and initiation of simple urgent investigation and treatment. There was also failure of referral to gastroenterologists/hepatologists either at all or in a timely way and challenges to get people with ArLD admitted to critical care despite the potentially reversable nature of their condition. NECPOD highlighted then that '*early intervention with evidence-based treatments for patients with the complications of cirrhosis can save lives*' and that there was a '*failure to use appropriate protocols*'. The report contained 28 recommendations for improving structures and processes designed to reduce avoidable deaths (1). A new report from NCEPOD describing a survey of Trusts conducted in 2021 based on admissions in 2019 has shown some improvements in the care of ArLD patients but still widespread failure to implement the recommendations of 2013 (2). This is against a background of a worsening picture for ArLD, consistent with the recently published ONS data for 2021 demonstrating the highest number of alcohol-specific deaths on record, of which liver disease constitutes 78% (3).

Liver Disease kills young people - in 2020 it was the 2nd commonest cause of years of life lost in people of working age after Self harm and Undetermined intent (4). Since 2011, in England, the number of premature (<75 years) deaths from ArLD has increased by 23% (4,300 in 2011, 5,285 in 2020) (5). On average women die of ArLD a year younger than men (mean age 55.7 vs. 57.0 years) and this difference is widening (6). Not only does ArLD kill many young adults, it is a condition of stark inequalities. In 2020, the premature mortality rate (<75 years) was 4.8 times higher in the most deprived decile of Lower Super Output areas than the most affluent (5). The increase in mortality has been mirrored by an increase in hospital admissions from 15,596 in 10/11 to 24,544 in 2020/21 (5) 92% of in-patient admissions are emergencies (6).

The original NCEPOD Report highlighted that '*admission with decompensated cirrhosis is a common medical presentation with high (10-20%) in hospital mortality*' and the recent NCEPOD Survey found that 11.9% of the 20,876 admitted patients died. A study from England and Wales from 2004 to 2012 showed 60 day mortality rates of 23·4% following acute admission for alcohol-related liver disease and 35·4% for those with hepatic failure at that time, seven times higher than for acute admissions with stroke and eight times higher than for acute myocardial infarction. Mortality was significantly lower for patients seen by consultant hepatologists and gastroenterologists and for patients admitted to transplant centres or larger hospitals. (7,) An updated analysis to 2017, for England, found the very high 60-day mortality unchanged (8). A study of ~26,000 patients who died of liver disease in hospital between 2013-17 found that 29.1% died without any previous admission in the preceding year and this varied from 30.2% in hospitals not regarded as a Liver Unit to 25.9% in a Regional or Transplant Centre. This study also found significant differences in rates of referral to Gastroenterologists and admission to ITU between the types of hospital (9). The fifth report of the Lancet Standing Commission on Liver Disease in the UK, 'Gathering momentum for the way ahead', highlighted the significant variation across Trusts in relative risk of liver in-patient mortality (10). Variation in ratio of deaths to admissions in different Trusts was also noteworthy in the latest NCEPOD survey (2).

'Remeasuring the Units', while noting some improvements, found persisting deficiencies in the detection and care of patients with alcohol dependence, the implementation of simple management guidelines for patients with decompensated cirrhosis (11) and this patient group not being routinely under the care of gastroenterologists or hepatologists in some hospitals. It also found significant variations in care at all stages in the pathway, highlighting the importance of addressing these as a priority, including linking all hospitals to regional liver units and transplant centres and appropriate access to critical care support, as well as palliative care input where required.

A previous NCEPOD Report in 2009, 'Adding insult to injury', looking at patients dying in hospital with acute kidney injury (AKI) (*12*) highlighted deficiencies in care in patients with an AKI. This resulted in NHSE overseeing the development of a national algorithm to be used

across the NHS to ensure identification and appropriate treatment of AKI in order to prevent avoidable harm (13). Given the high mortality of patients, often young, admitted to hospital with decompensated cirrhosis, one must ask why so little progress has been made since 'Measuring the Units'? Unlike AKI, and despite the NCEPOD Report 9 years ago, no such process for detection and standardisation of management in this condition and of data collection by Trusts is mandated. One key factor may be the stigma associated with a condition perceived to be 'self-induced'. The 2013 NCEPOD Report suggested this explained some of the variation seen in admission to ITU(1). The Lancet Commission into ending stigma and discrimination in mental health described the stigma and discrimination in many societies and cultures and approaches to tackle it, starting the Executive Summary with "It is time to end all forms of stigma and discrimination against people with mental health conditions, for whom there is double jeopardy: the impact of the primary condition and the severe consequences of stigma" (14). Societal stigmatisation of alcohol-use disorder (AUD) is higher than other mental health conditions (15) and the stigma associated with AUD as well as ArLD feeds into care provision at multiple levels (16). Approaches to tackle societal barriers to care as well as training of healthcare professionals are urgently required to address this.

In hospital mortality amongst ArLD patients remains very high. It is now time for the NHS to systematically apply rigorous approaches to the care of patient with ArLD including provision of care by appropriately trained specialists and access to critical care support and specialist Liver Units where indicated. More widely, societal and professional stigma needs to be tackled to ensure AUD and ArLD patients get access to evidence-based interventions through opportunities to identify all patients in hospital with alcohol dependence with referral to appropriate support and improving earlier diagnosis in primary care. Finally, as mortality in hospital is so high, palliative care should be engaged early to support patients' understanding of their poor prognosis and options for choices in care (17).

What is clear is that we cannot be looking at further data in a few years' time showing that little has changed – now is the time to change the way this condition is viewed, and addressed, in healthcare systems.

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