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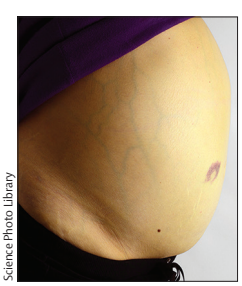
Deaths from alcohol-related liver disease in the UK: an escalating tragedy



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In 2013, the UK National Confidential Enquiry into Patient Outcome and Death (NCEPOD) published *Measuring the Units*.[1] This report on UK hospital deaths from alcohol-related liver disease in 2011 highlighted the avoidable nature of many of these deaths and found that care was less than good in more than half of the cases reviewed; basic omissions in patient care and missed opportunities were common, including the identification of patients with decompensated liver disease and initiation of simple urgent investigation and treatment.[1] There was also failure of referral to gastroenterologists and hepatologists and challenges to get people with alcohol-related liver disease admitted to critical care, despite the potentially reversible nature of their condition. The 2013 NCEPOD report underlined 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".[1] This report contained 28 recommendations for improving structures and processes to reduce avoidable deaths.[1]

Remeasuring the Units,[2] a new NCEPOD report published on Dec 15, 2022, describes a 2021 survey of admissions in 2019 to National Health Service (NHS) Trusts in England, Wales, and Northern Ireland and shows that, although there have been some improvements in the care of patients with alcohol-related liver disease, there is still widespread failure to implement the recommendations of 2013. These findings come in the context of worsening alcohol-related liver disease in the UK. The latest Office for National Statistics data for 2021 show the highest number of alcohol-specific deaths on record in the UK; of these 9641 deaths, 7518 (78%) deaths were due to liver disease.[3]

Liver disease kills young people: in 2020 it was the second most common cause of years of life lost in England among people of working age (16–64 years) after "self-harm and undetermined intent".[4] Since 2011, in England, the number of premature (<75 years) deaths from alcohol-related liver disease has increased by 23% (4300 in 2011 and 5285 in 2020).[5] On average, women die of alcohol-related liver disease 1 year younger than men (mean age 55·7 *vs* 57·0 years) and this difference is widening.[2] The increase in mortality has been mirrored by an increase in hospital admissions for alcohol-related liver disease—15 596 in 2010–11 rising to 24 544 in 2020–21.[5] Of 17 604 inpatient admissions for alcohol-related liver disease in 2020-21, 16 207 (92%) were emergencies (unpublished, Verne J). Not only does alcohol-related liver disease kill many young adults, but it is also a condition of stark inequalities; in 2020, the premature mortality rate (<75 years) was 4·8 times higher in the most deprived areas of England than the most affluent.[5]

The 2013 NCEPOD report highlighted that "admission with decompensated cirrhosis is a common medical presentation with high (10–20%) in-hospital mortality".[1] The 2022 NCEPOD survey found that of the 20 876 such patients admitted to hospital 2481 (11·9%) died.[2] A study from England and Wales from 2004 to 2012 showed 60-day mortality of 23·4% after acute admission for alcohol-related liver disease and 35·4% for those with hepatic failure at that time; such deaths were significantly lower among patients who were seen by consultant hepatologists and gastroenterologists or admitted to transplant centres or larger hospitals than among those who did not receive such care.[6] An updated analysis to 2017, for England, found the high 60-day mortality unchanged.[7] A study of 25 887 patients who died from liver disease in hospitals in England between 2013 and 2017 found that 7533 (29·1%) died without any previous hospital 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.[8] This study also found substantial differences in rates of referral to gastroenterologists and admission to intensive care units between the types of hospital.[8] In 2018, the fifth report of the *Lancet* Standing Commission on Liver Disease in the UK showed the substantial variation across NHS Trusts in relative risk of inpatient deaths from liver disease.[9] Variation in the ratio of deaths to admissions in different NHS Trusts was also noteworthy in the 2022 NCEPOD survey.[2]

Remeasuring the Units[2] found persisting deficiencies in disease detection and care of patients with alcohol dependence, inadequate implementation of simple management guidelines for patients with decompensated cirrhosis,[10] and a failure in some hospitals to ensure all such patients are routinely under the care of gastroenterologists or hepatologists. The survey data also show considerable variations in care at all stages in the pathway, highlighting the importance of addressing these aspects of care 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 2009 NCEPOD report, *Adding Insult to Injury*, examined hospital deaths among patients with acute kidney injury and highlighted deficiencies in care.[11] This report led to the development of a national algorithm to be used across the NHS to ensure identification and appropriate treatment of acute kidney injury to prevent avoidable harm.[12] Given the high mortality among patients admitted to hospital with decompensated cirrhosis, one must ask why there has been so little progress since the 2013 *Measuring the Units*[1] report? Unlike acute kidney injury, no such process for detection and standardisation of management in alcohol-related liver disease and of data collection by NHS Trusts is mandated. One key factor could be the stigma associated with a condition generally perceived to be self-induced.[13] The 2013 NCEPOD report proposed that such stigma and attitudes could explain some of the variation seen in admission to intensive care units.[1] The 2022 *Lancet* Commission into ending stigma and discrimination in mental health described the impacts of stigma and discrimination in many societies and cultures and approaches to tackle it and urged that "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] Stigma associated with alcohol use disorder and alcohol-related liver disease feeds into care provision at multiple levels.[13,15] Approaches to tackle societal barriers to care and improve appropriate training of health-care professionals are urgently required to address such societal and professional stigma.

Deaths from alcohol-related liver disease among patients admitted to hospital in the UK remain unacceptably high. The NHS needs to systematically apply rigorous approaches for the care of patients with alcohol-related liver disease, including the 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 must be addressed to ensure patients with alcohol use disorder and alcohol-related liver disease are afforded opportunities to get access to evidence-based interventions by identifying all patients in hospital with alcohol dependence and referring them for the appropriate support. Efforts must also be made to ensure earlier diagnosis of both conditions in primary care. Finally, palliative care should be engaged early to support patients with advanced liver disease and their families.[16] Now is the time to change the way alcohol-related liver disease is viewed and addressed in health-care systems.

We are all members of the Stakeholder Group that reviewed, edited, and commented on the NCEPOD report *Remeasuring the Units*[2] that is discussed in this Comment; the report is written by the NCEPOD with input from MEDA and JV. JF, GF, IG, and JV were all members of the Standing *Lancet* Commission on Liver Disease. MEDA reports grants to his institution from GSK and Takeda Research Grant and is the National Services Lead for the British Association for the Study of the Liver (BASL) (unpaid). JV is a member of the *Lancet* Commission on Liver Disease in Primary Care and a member of the Liver Section of the British Society of Gastroenterology (BSG) and the UK Liver Alliance (unpaid). WB reports consulting fees from Versantis and Flagship Pioneering. MC is the Chair of the British Liver Nurses' Association. JFD is the Vice-President for Hepatology of the BSG. JF reports consulting fees for advisory board from Mirum Pharma. GF reports consulting fees, speaker's fees, or travel fees from Abbvie, BioMarin, UniQure, Gilead, MSD, and GSK and is NHS England Clinical Lead for hepatitis C virus. IG reports medicolegal consultancy for the Medical Defence Union, travel support from the Medical Council on Alcohol, the Alcohol Health Alliance, the Royal College of Physicians, and Royal College of General Practitioners, and is a trustee of the Foundation for Liver Research, the Chair of the Alcohol Health Alliance, and President of the Medical Council on Alcohol (all unpaid). RJ reports accommodation support from the BASL and is President of the BASL. SM is the Clinical Alcohol Lead for the BSG. BO reports support for attending a conference from the BSG, is the National Clinical Lead for Gastroenterology for the NHS England Getting it Right First Time (GIRFT) Programme (NHS England reimburse hospital trust for GIRFT work), and is the Honorary Treasurer of the BSG (unpaid). PR reports grants from National Institute for Health and Care Research's Health Technology Assessment Programme and speaker's fees from Kyowa Kirin. JS is a Trustee of the Society for the Study of Addictions. JW reports travel and accommodation support to attend meetings from the ISICEM and is a member of the Faculty of Intensive Care Medicine Board (unpaid). DW reports grants from the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) and the United Nations Office of Drugs and Crime (UNODC); travel, accommodation, and subsistence costs to attend meetings from the EMCDDA, the UK Advisory Council on the Misuse of Drugs (ACMD), the UNODC, and the European Association of Poisons Centres and Clinical Toxicologists (EAPCCT); and is a member of the Scientific Committee of the EAPCCT and the Council of ACMD (unpaid). SC, AD, and VH declare no competing interests.

**Michael E D Allison, Julia Verne, William Bernal, Michelle Clayton, Sam Cox, Ashwin Dhanda, John F Dillon, James Ferguson, Graham Foster, Ian Gilmore, Vanessa Hebditch, Rebecca Jones, Steven Masson, Beverley Oates, Paul Richardson, Julia Sinclair, Julia Wendon, David Wood*

michael.allison6@nhs.net

Liver Unit, Cambridge NIHR Biomedical Research Centre, Cambridge University Hospitals Foundation Trust, Cambridge CB2 0QQ, UK (MEDA); National Liver Disease Intelligence Network, Office for Health Improvement and Disparities, Department of Health and Social Care, UK Government, London, UK (JV); Liver Intensive Therapy Unit, Institute of Liver Studies, King's College Hospital, London, UK (WB); St James's University Hospital, Leeds, UK (MC); Addictions and Inclusion Directorate, Office for Health Improvement and Disparities, Department of Health and Social Care, UK Government, London, UK (SC); Faculty of Health, University of Plymouth, Plymouth, UK (AD); Division of Molecular and Clinical Medicine, School of Medicine, University of Dundee, Dundee, UK (JFD); University Hospitals Birmingham NHS Foundation Trust and University of Birmingham, Birmingham, UK (JF); Blizard Institute, Queen Mary University of London, London, UK (GF); University of Liverpool, Liverpool, UK (IG); British Liver Trust, London, UK (VH); Leeds Teaching Hospitals NHS Trust, Leeds, UK (RJ); Liver Unit, Freeman Hospital, Newcastle, UK (SM); Translational and Clinical Research Institute, Newcastle University, Newcastle, UK (SM); Wirral University Teaching Hospital, Birkenhead, UK (BO); Department of Gastroenterology, Royal Liverpool University Hospital, Liverpool, UK (PR); Faculty of Medicine, University of Southampton, Southampton, UK (JS); University Hospital, Southampton, Southampton, UK (JS); King's College Hospital, King's College London, London, UK (JW); London Critical Care ODN, London, UK (JW); Clinical Toxicology Department, St Thomas' Hospital, London, UK (DW)

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