J R Coll Physicians Edinb 2018; 48: 293–8 | doi: 10.4997/JRCPE.2018.402 ORIGINAL RESEARCH PAPER

NCEPOD and alcohol-related liver disease, what are the views of those who deliver the service? A survey of consultants and trainees in North Eastern England

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Abstract

Background National Confidential Enquiry into Patient Outcome and Death (NCEPOD) 'Measuring the Units' (June 2013) identified significant organisational and attitudinal deficits in hospital care of patients with alcohol-related liver disease (ARLD), care being recognised as good in less than 50% of patients.

Method We surveyed over 700 consultants and trainees in acute medical and intensive therapy specialties to examine their perceptions of the NCEPOD findings.

Results A total of 178 responded. In keeping with the NCEPOD findings, their perception was of lack of 24-hour access to specialty advice for patients with liver disease and inequity of access to high-dependency units. Their explanations include lack of resources, therapeutic nihilism and prejudicial judgements that would not be made of other patient groups.

Conclusion There is an urgent need for robust mechanisms to ensure equity of access to specialist liver advice and intensive therapy unit resources, and to counter negative and prejudicial attitudes to these patients.

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Introduction

There is a widely acknowledged increase in the prevalence of chronic liver disease, of hospital admission and of liver-related death within the UK.[1–5] There has been a fivefold increase in liver deaths since 1971[1] and there are sevenfold differences in years of life lost across England, which correlate with indices of deprivation.[2] There is also a more than twofold difference in mortality rates for liver disease or cirrhosis within acute Trusts suggesting variation in the standard of care provided for inpatients.[1] The Lancet Commission[1] noted the comment by the All Party Parliamentary Hepatology Group that expressed, 'grave concerns about patchy service provision across the country, the late diagnosis of patients and a lack of the necessary central drive and prioritisation'. The rising burden of cirrhosis means that liver disease is becoming an increasing part of inpatient care. In 2004 decompensated alcoholic liver disease was thought to account for 37% of gastroenterology workload,[6] but the most recent figure suggests that in 2011 liver disease accounted for 46% of gastroenterology inpatient admissions in England.[7] The Lancet Commission[1] has described their recommended staffing for the provision of hepatology services across all types of acute hospital and, more recently, recommendations on the provision of acute liver services in secondary care.[8] However, there is little or no guidance for clinicians concerning the allocation of scarce and costly hospital resources for patients with acute on chronic liver disease and no guidance on the appropriate ceiling of care for those with alcohol-related liver disease (ARLD) where attitudes to self-inflicted disease and recidivism might be expected to be important.

In 2013 the National Confidential Enquiry into Patient Outcome and Death (NCEPOD)[9] looked at the outcome of patients admitted to hospital with ARLD and highlighted shortcomings in the care of this group of patients. In this survey NCEPOD found that less than 50% of patients had care considered to have been good, and in 44% there was room for improvement in clinical or organisational care. There were resource limitations identified, such as the presence of hepatologists in only 28% of hospitals, the problem of staffing of out-of-hours gastroenterology services in small hospitals and variable access to endoscopy out of hours. There were

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clinical deficits; in particular, there were delays in these patients being seen by gastroenterologists/hepatologists, and 25% of patients were not seen by a specialist at all. There were failures to escalate care, inappropriate limitation or withdrawal of treatment and avoidable deaths. Approximately one-third of patients did not have care escalated. Treatment limitation was felt to have been inappropriate in 17% of cases, and 32 deaths were thought to have been possibly preventable.

NCEPOD concluded that, 'hospitals are missing opportunities to save the lives of people with ARLD by failing to provide early intervention and specialist consultant input'. The NCEPOD survey relied solely on case note review. Although inequalities in resource allocation may well be of relevance to their conclusions, NCEPOD was not able to consider how attitudes towards those with alcohol-related problems influence how ARLD patients are treated. This survey was undertaken to see if clinicians involved in the care of these patients in the North East of England agreed with the NCEPOD comments about organisational and clinical care deficits for ARLD patients and their perceptions of the reasons underlying these deficits.

Methods

In 2014, on behalf of The North East and Cumbria (NENC) hepatology network we undertook a survey of medical specialists involved in the acute care of ARLD patients in North East England. The survey was designed following a brainstorming session based on the key themes highlighted in the NCEPOD survey by the authors. The survey was uploaded electronically on Survey Monkey and included a mixture of yes/no questions and multiple choice questions with free-text responses. The survey was emailed to all participants and the request to complete it made only once.

Participants included consultants and trainees in three broad categories: those in acute medicine including those in a medical specialty (but not gastroenterology) participating in acute medical reception (AM), those in gastroenterology and hepatology (gastroenterology), and those in intensive care medicine (intensivists).

Physicians were contacted using the regional Royal College of Physicians office database of northern region physicians, intensive therapy unit (ITU) consultants were contacted via the regional ITU network. Trainees were contacted via the relevant educational training officers for the programs.

Results

A total of 774 doctors were emailed the survey (300 consultants, 474 trainees), 178 responded (23%). Of 178, 100 were consultants and 77 were trainees (six described themselves as core trainees and the rest as specialist registrars). One person (gastroenterology) did not clarify his status.

Table 1 outlines the specialty breakdown of the respondents and their grades for the three groups outlined above. The ITU medics were asked to confirm that their work was largely on ITU to avoid including anaesthetists doing little ITU work. There were higher proportions of consultant respondents from the gastroenterology and intensivist groups.

A total of 73% gave their place of work as secondary care, 27% as tertiary care. There are two Trusts within the North East of England that deliver substantial amounts of tertiary care within the region with the regional liver unit in one of these.

Respondents were given a scenario to create the picture of a sick ARLD patient to consider in their responses to the questions that followed:

> **Scenario:** A 32-year-old with cirrhosis due to alcohol related liver disease is admitted via A&E to your Medical Admissions Unit (MAU) on Friday midday with a GI bleed. The patient is hypothermic, hypotensive, acidotic and in renal failure with evidence of ascites and encephalopathy. The Hb is 6 gm/dl and the patient is oliguric. The patient is transfused and actively warmed.

The following concerns were identified from the NCEPOD report and formed the focus of the survey.

Access to high-dependency unit for sick patients with ARLD

Although almost all respondents (97%) thought that a sick ARLD patient *should* be nursed on a high-dependency unit (HDU), only 77% thought that this would actually happen in their hospital, 16% thought the patient would be on a general medical ward and 7% on a gastroenterology ward. In tertiary care this patient was more likely to be in a HDU (90%) than in a district general hospital (DGH; 77%).

The survey offered respondents the option to comment upon the discrepancy outlined in the previous paragraph. Four possible explanations were offered and respondents could select more than one explanation. Thirty-two respondents made a total of 45 responses (lack of beds: n = 16; resistance by the owners: n = 11; lack of senior decision-making early on: n = 11; lack of a decision about ceiling of care: n = 7). AM and gastroenterology respondents concentrated on lack of beds and resistance from HDU (26 out of 36 responses), whereas intensivists concentrated on lack of early senior decision-making (seven out of nine responses).

Access to specialist input within first 24 hours

When asked who (at consultant level) should see the sick ARLD patient within the first 24 hours 71% felt that an AM physician should see the patient, 92% felt that a gastroenterologist should do so and 91% felt an intensivist should do so. When asked which specialist would *actually* see the patient, the percentage who felt that an AM physician would do so remained little changed at 74%, but there was a considerable fall in the percentage who thought that a gastroenterologist would be involved (from 92% to 60%). For intensivists the figure fell to 80%. There were 51 free-text

Table 1 Respondents by specialty and training status

Grouping	Total number	Subdivision	Consultant : trainee number
Acute medicine (AM)*	80	AM, n = 16 General medicine, n = 64	39 : 41
Gastroenterology	34	Gastroenterology, n = 30 Hepatology, n = 4	20 : 13 1 grade not stated
Intensive care (intensivists)	64	Solely intensivists, n = 28 Anaesthetists also working on intensive care units, n = 36	41 : 23

*Clinicians either in AM alone, or in a medical specialty (but not gastroenterology) participating in acute medical reception (general medicine)

comments. Twenty-six of these were on the lack of availability of gastroenterologists especially out of hours, for example, 'If it is a weekend with no gastroenterologist available then acute care physician and intensivist will be the only ones available to see patient', 'Depends which physician is on take, not always a gastro physician'. This concern is acknowledged by the gastroenterologists. Of the 10 gastroenterologists who made comments, half commented on the lack of availability of gastroenterologists. These comments came from secondary rather than tertiary care.

In respect of where hepatology advice would be sought during working hours, for those working within the Trust hosting the regional liver unit (and with a number of gastroenterology specialist registrars) referral to the unit was favoured. Two large district general hospitals made use of a system of ward-based gastroenterology consultants available during working hours. Regionally, there was some use made of the regional liver unit (6%, 9/157). However, 25% (23/92) of the responding consultants felt either that there was no formal process for seeking advice (n = 16) or that they were unaware of one (n = 7). Amongst trainees this figure was 23% (15/65) of whom seven (five on ITU) were unaware of any process for seeking advice (Table 2).

For out-of-hours hepatology advice 25% (40/159) knew of no formal route or were unaware of any route – this figure includes 25 consultants, of which 13 were intensivists (Table 2). The proportion using the regional liver unit rose to 30% (47/159). Comments indicated that the regional liver unit was the default option out of hours as, often, there is no local 'in house' gastroenterology opinion available. It is clear that on some sites the endoscopist on call is regarded as only on call for bleeders and not to provide a liver opinion – although that person may in practice be approached, 'I have used the physician endoscopist on call for varices in this instance to good effect', 'if it was not specifically related to a GI bleed then we would phone the regional liver unit', 'there is on call gastroenterology consultants for bleeders … however, there is no formal hospital protocol for decompensated cirrhotic patients with no bleed and stable Hb', 'We have a gastro consultant on for variceal bleeders who will often double up as a liver opinion even in the event of no bleeding'. The feeling that there is no formal route for seeking advice exists does not, of course, mean that people do not know where to turn. However, it is concerning that a significant proportion of trainees and even consultants reported that they were unaware of any process for seeking advice.

Escalation of care of ARLD patients

NCEPOD stated that the care of ARLD patients was not escalated enough. A total of 40% (59/149) agreed that they were not escalated *often* enough and 54% (80/149) agreed that they were not escalated *promptly* enough. In relation to frequency of referral, there was a tendency for AM and gastroenterology (49%) to agree with the statement more than intensivists did (22%), in relation to promptness of referral there was little difference between specialties.

Free-text comments from those who agree with the statements suggested that limitation of escalation occurred both because of lack of beds and because of attitudes to ARLD patients, 'negative and non-evidence-based attitudes exist regarding prognosis and whether patients are "deserving"', 'sometimes written off', 'reluctance in some centres due to

Table 2 Referral process for alcohol-related liver disease patient in and out of hours

Grouping	Routine working hours				Out of hours			
	No formal process		Unaware of process		No formal process		Unaware of process	
	Consultants	Trainee	Consultants	Trainee	Consultants	Trainee	Consultants	Trainee
Acute medicine	4	5	1	2	2	4	3	2
Gastroenterology	5	3			7	2		1
Intensivists	7		6	5	8	1	5	5
Total	16	8	7	7	17	7	8	8

prioritisation of beds according to "deserves" rather than "needs"', 'nihilism of ICU staff'. One comment suggests that attitudinal issues may not simply be on ITU, 'ignorance of the admitting team to refer, and the "get out" clause of a label of ALD. Escalation usually only occurs once seen by gastroenterology. ITU are open to referrals and don't appear biased – they are just usually constrained by lack of beds'. And 'nihilistic attitude to this group of patients by non-GI medical consultant colleagues'. However, those working at the hospital hosting the regional liver unit did not feel that escalation was delayed for ARLD patients and a specific comment is of relevance, 'often ITU don't seem to realise how sick these patients are. In hospitals where the gastro consultants are more gastro than liver specialists this is particularly hard. Having been an SHO on liver unit it is clear that patients with ARLD at this hospital are more likely to be treated on ITU than at some DGHs'.

Respondents were asked if the threshold for escalation of a sick ARLD patient was higher than for other equally unwell patients. Overall, the gastroenterologists felt this to be the case (62%), but those in other specialties did not feel this (38%). Comments of those who felt the threshold was different suggested a perception of negative attitude to active drinkers.

The respondents were further asked if specialties had differing thresholds for escalation of an ARLD patient to ICU. A total of 78% (117/150) agreed with this, and 63% (65/104) felt that intensivists had the highest threshold, and AM physicians the lowest threshold.

Decisions on ceiling of care

The respondents were then asked their response to a number of statements that compared the care of ARLD patients with other 'equally' sick patients, in terms of timely and appropriate decisions about 'ceiling of care'. A total of 21% (29/139) agreed there was a deficit in timely decision-making, 79% felt this was sometimes true. Comments supported a view that ARLD patients were disadvantaged, 'it's a bit of a lottery depending on which physicians and intensivists are on call', 'reluctance to make decisions in unfamiliar cases and given ARLD patients are often younger and the case is less clear cut compared to other patients', 'the assumption that ICU won't accept them can be prevalent'. The comments come from across the specialties.

Respondents were asked whether the decision about the ceiling of care for such a patient should always be made by a gastroenterologist. A total of 80% (118/148) thought this correct. The respondents indicated that the appropriate specialists (and the patient) should be involved. However, many comments identify lack of availability of gastroenterology, 'all very well in theory but in the real world they aren't there or don't come to see the patient', 'not always available in the hospital let alone at the bedside', 'we don't have sufficient on-site gastro'. Indeed, a proportion of those who did not think that a gastroenterologist should always be the one making a decision about ceiling of care made it clear that this was partially because of lack of availability of gastroenterologists. A number of respondents commented to the effect that there were occasions when other physicians actually knew the individual patient much better and that one could not, therefore, prescribe that the decision had to be made by a gastroenterologist.

The respondents were asked if the escalation of a sick ARLD patient to ITU should be influenced by whether this is the first presentation or a recurrent admission. A total of 115 of 168 (68%) agreed that this was reasonable. The percentage of those who agreed was lowest amongst AM (57%) and higher across the other specialty groups (75–77%). Free-text comments from those who agreed mostly emphasised either that other people could be deprived access to ITU if recidivist drinkers were admitted, or that multiple admissions are an adverse prognostic factor that should limit further access. Those who disagree included comments from those unwilling to entertain the idea that active drinking might be a factor in escalation to ITU ('the question beggars belief') and those who feel that continued drinking was only one factor to consider, 'the threshold should be the same independent of the frequency of presentation. The decision about whether it is an appropriate admission to ICU should be the thing that should vary depending on functional status/comorbidities and patient preference'.

To explore the role of active drinking in the decision to escalate care, respondents were then asked if 'a history of active drinking, despite documented advice to stop, could rightly influence the decision about ceiling of care'. A total of 69% of 148 agreed that active drinking could be a legitimate factor in determining ceiling of care. Amongst the gastroenterologists an even higher proportion (90%) thought so. Some free-text comments identified the need for an active plan for these patients. A small number of others commented that the patient was not taking responsibility for their own health, with the implication that this might reasonably influence decisions about the ceiling of care. Conversely, there was at least one comment about prejudicial behaviour, 'we don't refuse to escalate the obese and smokers'. There were comments on a feeling of futility and limited resource. Specific comments stated, 'very difficult, this. Ideally should have same level of care regardless of patient's previous choices, with care based on patient's needs and potential for recovery', 'recidivism despite advice and previous significant decompensations should impact upon the level of care considered especially when this is a finite expensive resource'.

Respondents were asked if the decision about escalation to ICU happens at a senior enough level within their current place of work. The vast majority (93% of 147) felt that it did.

The final question was about the statement by NCEPOD that ICU teams often do not accept sick ARLD patients. A total of 85 of 141 respondents (60%) agreed with this statement, with little specialty difference in response. Those who agreed commented upon lack of resource, futility, lack of knowledge of potential treatments. There were comments

about prejudice, 'correct assumption that outcomes are poor (particularly for renal failure subgroup) and bias due to "self-inflicted" illness. Neither of which are relevant', 'they are less inclined to take ALD [sic] than other patients I find. I think the fact "they are still drinking" is more heavily weighted than it is for other groups of patients such as respiratory patients – "they are still smoking" rarely gets said!'.

Discussion

This survey has analysed responses from over 170 doctors involved in the care of sick ARLD patients, including both consultants and trainees. It confirms the conclusions of NCEPOD that there are deficits in the provision of care for these patients and, in addition, has sought to examine reasons underlying these deficits. However, it is at odds with a recent attitudinal survey undertaken in England in 2015 where a wide range of hospital doctors including physicians and intensivists were posited scenarios and asked to score them in relation to escalation of care.[10] The survey did not suggest particular therapeutic nihilism in relation to the management of ARLD patients. Reasons for such different results are not obvious but the authors of this paper were rather surprised by the findings. They had not offered the option of free-text responses.

A sick ARLD patient should be cared for in a HDU, yet nearly one-quarter of respondents felt that this would not happen in their hospital. Those outside the HDU felt that lack of beds and difficulty accessing HDU were the main reasons, those within ITU felt that the main obstacle was a lack of senior decision-making.

There was consensus among all the respondents that specialists (gastroenterologists or hepatologists) were important in the early assessment of such sick patients, yet the responses indicated that in practice this was not the norm. One likely explanation is that, in the majority of DGHs, there is no-one on call who is 'responsible' for providing a hepatology opinion. At the time of this survey all but one of our regional hospitals had an endoscopist available out of hours. However, it was clear that these people were not regarded as being required to provide hepatology advice. In some trusts the on-call endoscopist may be a surgeon rather than a gastroenterologist and, therefore, lack expertise to provide hepatology advice, in others gastroenterologists were available but asking them about hepatology patients was felt to be beyond the remit of their on-call responsibilities and, sometimes, felt to be outwith their usual daily practice. This is curious as, in nearly all DGHs, general gastroenterologists will be expected to look after inpatients with hepatology problems. However, the growth of pure 'endoscopist' consultants (whose daytime clinical commitments are confined to endoscopy practice), and who would be very likely to be on an endoscopy rota may encourage this perception.

Given that most respondents felt that decisions about place of care and ceiling of care of ARLD patients would be most appropriately made by a gastroenterologist, it is notable that it was felt that over half the time such a decision would be made by an intensivist. Free-text comments suggest that the gastroenterologists were not there to make the decision when it needed to be made.

Local gastroenterologists were accessed during working hours but, outside these, the regional liver unit became particularly important. This may reflect both the quality of their input but also the assumption already described that the on-call endoscopist was not there to provide liver advice. It is a cause for concern that a significant number of nongastroenterologist consultants within the region involved in the care of ARLD patients did not seem to have a clear idea of how to seek advice – including a proportion who seem to report having no route to advice in and out of hours. The need for access to appropriate advice for patents with liver disease is highlighted in The Lancet Commission report.[1]

Reflecting on the attitudes behind lack of escalation of sick ARLD patients, at the regional liver unit access to ITU is acknowledged to be easier and hepatology consultants are available to continue to support decision-making about care on ITU. In DGHs there is a perception of lack of escalation relating to a number of factors, including lack of resource, negative attitudes, therapeutic nihilism and a feeling that recidivism will make the trouble and expense fruitless (the 'revolving door'). Respondents are aware of negative attitudes. These and the absence of policy and guidance in this area contribute to inconsistent access to escalation for this patient group. The disparities between attitudes encountered at the regional liver unit and the DGHs suggest that there is a gap in service provision and that access to ITU should be more robust.

Most feel that it is appropriate to consider whether this is a first presentation or a recurrent admission when considering where to place the ceiling of care, and, similarly, that continuing alcohol ingestion is rightly part of that judgement (70% overall and 90% of the gastroenterologists).

In relation to the various specialists involved, intensivists were felt to have the highest threshold for escalation. Although some comments suggest attitudinal rigidity amongst the intensivists, others feel that ITU are constrained by bed availability and open to referral. Overall, this survey confirms the NCEPOD findings that ICU often does not accept sick ARLD patients. The reasons suggested are lack of resource, lack of knowledge of potential benefits, futility and that it is a 'self-inflicted illness'. People are aware of judgmental attitudes that might not be extended to others who have made other unwise lifestyle decisions.

There is a need for equity of access to hepatology advice 24 hours a day. The Lancet Commission[1,8] has made detailed recommendations about the staffing of DGH hepatology services. However, if local gastroenterologists are unable to deliver high-quality care themselves for ARLD patients, including decisions about the appropriate ceiling

of care for individuals at all hours, the local services need to adapt or adopt robust alternatives.

Given the rising inpatient burden of liver disease, all gastroenterologists should be formally and adequately trained in hepatology to enable them to manage this workload as outlined in The Lancet Commission recommendations.

However, beyond and above this, there is a need for clinical guidance and a national policy to guide all local clinicians in determining appropriate management pathways for sick ARLD patients and to counteract the negative attitudes and prejudice that many such patients seem to encounter.

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References

1 Williams R, Aspinall R, Bellis M et al. Lancet Commission on Liver Disease 2014. 2014. http://www.thelancet.com/commissions/crisis-of-liver-disease-in-the-UK (accessed 11/10/17).
2 NHS liver care. The 2nd atlas of variation in risk factors and healthcare for liver disease in England. *NHS Right Care* 2017: 1–192.
3 Thomson SJ, Westlake S, Rahman TM et al. Chronic liver disease–an increasing problem: a study of hospital admission and mortality rates in England, 1979–2005, with particular reference to alcoholic liver disease. *Alcohol* 2008; 43: 416–22.
4 A Time to Act: Improving Health and Outcomes in Liver Disease. https://eprints.soton.ac.uk/194669/1/National_Liver_Plan_2009.pdf (accessed 11/10/17).
5 Moreau R, Arroyo V. Acute on chronic liver failure: a new clinical entity. *Clin Gastroenterol Hepatol* 2015; 13: 836–41.
6 Hislop WS, Heading RC. Impact of alcohol related disease and inpatient workload of gastroenterologists in Scotland. *Scott Med J* 2004; 49: 57–60.
7 Lombard M. A Census of Medical Workforce & Infrastructure for Liver Disease Strategy. www.hcvaction.org.uk/resource/census-medical-workforce-infrastructure-liver-disease-strategy-summary-findings (accessed 11/10/17).
8 Williams R, Alexander G, Aspinall R. New metrics for the Lancet standing commission on liver disease in the UK. *Lancet* 2017; 389: 2053–80.
9 NCEPOD: Alcohol Related Liver Disease: measuring the units. 2013. 'A Review of Patients who died with Alcohol related Liver disease'. 2013. http://www.ncepod.org.uk/2013arld.html (accessed 11/10/17).
10 Berry PA, Peck M, Standley T et al. Do critically ill liver patients experience negative bias? A web-based survey examining doctors opinions to critical care escalation. *Frontline Gastroenterol* 2016; 7: 10–5.