Mortality due to liver disease is increasing more than any other chronic condition in the UK. 7% of England’s deaths are attributable to liver disease. Early deaths from liver disease have increased by 250% in the past four decades and constitutes the third most common cause of premature death in England.1 Across England's Clinical Commissioning Groups (CCGs), liver disease mortality rates vary 7.7 fold.2 Cirrhosis is the end stage of liver disease. Cirrhosis progression to chronic liver failure can take months or even decades. Predicting when a patient with advanced liver disease might need end of life care presents particular challenges for clinicians as the duration of liver disease development is more difficult to anticipate than other terminal illnesses.3 It is difficult for clinicians to know when to start discussions around palliative care with the patient. End of life complications include ascites, variceal bleeding, multiple hospital admissions and days spent in hospital. As the disease progresses, patients often experience psychological stress, social stigma and family worries.4 Liver disease patients are more likely to die in hospital (>70%) than cancer patients (< 50%). In 2015, 78.0% of liver non-cancer deaths occurred in hospital compared to 38.6% of liver cancer deaths. While most liver disease patients may want to die in hospital, some may want to die at home or at another place of care. The ‘Aimments for Palliative and End of Life Care: A national framework for local action 2015-2020’ set out a number of ambitions one of which was ‘Maximising comfort and wellbeing’.1 1 This study aims to look at the degree of geographical variation across England of 5 Proxy Quality Indicators (PQI) for quality of end of life care in liver disease.

RESULTS

PQI 1: Hospital admissions in NALYOL

In England, 52.7% (5,151) liver disease patients died without being admitted to hospital in the last year of life (Figure 2a), this ranged from 10.1% to 16.1% between SCN areas (Figure 2b). Among patients with at least one admission of for paracentesis, a third are admitted only once, with a fifth having five or more admissions (Figure 2c).

PQI 2: Mean number of bed days in MDLYOL

On average, patients with liver disease spend 13.8 bed days in hospital with a 1.7-fold difference between SCNs (Figure 3a). With significantly higher average number of bed days in London and Northern compared to England value (Figure 3b).

PQI 3&4: Place of death: liver cancer HDPLC and non-cancer HDNLCL

The proportion of liver cancer patients dying in hospital is 38.6% ranging from 29.3% to 45.5% across SCNs. Among those with non-cancer liver disease, this figure is 78.3%, ranging from 73.3% to 82.1% across SCNs (Figure 4).

DISCUSSION

The variation in deaths with NALYOL need to be examined. It does not necessarily represent good end of life care planning and may relate to case mix or quality of care and potential cost savings. Overall this is a measure of service need and provision across England. The wide variation in proportions of deaths in hospital between HDPLC and HDNLCL patients may reflect palliative care involvement and choice. Prevention of ascites involves good management of liver disease, including aspects of self management and service planning to reduce emergency admissions.

CONCLUSIONS

These indicators highlight some of the variation in liver disease mortality and admissions across England. They reflect patient characteristics and type of liver disease. Indicators need consideration locally.

Patients, for whom curative options have been exhaustive, may stand to benefit from end-of-life care planning, in particular an exploration of their choices for place of care and death once they are made aware that their condition is likely to be fatal.

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