Raising the profile of end of life care needs for patients dying from liver disease - using national mortality data

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INTRODUCTION

Liver disease is the underlying cause for 2% of all deaths. During a decade, deaths from liver disease increased 27% and will continue rising. Liver disease deaths are often associated with stigma. Many patients have complicated social circumstances with little family or social support.

The aim of the study was to use national mortality data to understand and publicise demographic characteristics of people dying from liver disease and place of death in order to improve care.

METHODS

Table 1: Definition of liver disease causes of death by ICD-10 code

Liver disease	ICD-10 codes
Alcoholic liver disease	K70
Liver cancer	C22
Other chronic liver disease	I81, I85, K71-K75, K761-K769, K77, T864
Fatty liver disease	K760
Viral liver disease	B15-B19

Analyses were performed on data on deaths registered 2003 to 2012 extracted from the National (England) Mortality Files from the Office for National Statistics (ONS). Analyses were performed by 'underlying' cause of liver death as defined by the WHO using a range of ICD-10 codes. Analyses were also performed for any 'mention' of liver disease on the mortality files. Place of death was categorised as: Hospital; Home; Care Homes; Hospice or Other places.

RESULTS

- the number of people who die with an underlying cause of liver disease has risen from 8,644 in 2003 to 10,948 in 2012 averaging 9,784 (2% of all deaths)
- on average14,217 people (3% of all deaths) die each year with a mention of liver disease on their death certificates
- the most common underlying causes of death are alcoholic liver disease and liver cancer (0.9% and 0.6% of all deaths)
- deaths from liver disease are more common in males (1.3%; females 0.8%) and age at death is younger than deaths from all causes
- 95% of deaths from alcoholic liver disease are under 75 years at death
- one in nine of all deaths in 40-49 year olds is from liver disease, 1 in 13 from alcoholic liver disease
- more (2.3 fold) people die of liver disease from the most deprived quintile than the least deprived quintile. For alcoholic liver disease the factor is 3.5, for viral liver disease 5.2, for all deaths from any cause 1.3
- 68% of people who died of liver disease (underlying cause) died in hospital compared with 55% for all deaths from any cause of death (most recent figures for 2012; 63% and 49% respectively)
- viral liver disease had highest hospital death rates (85%) and fatty liver disease lowest (39%)
- liver patients rarely died in hospices unless they died from liver cancer
- these results are being used to inform policy

Figure 1: The number of deaths from liver disease

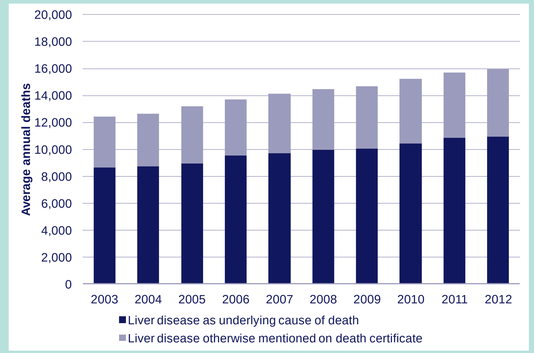


Figure 2: Average annual number of deaths with an underlying cause of liver disease, by sex

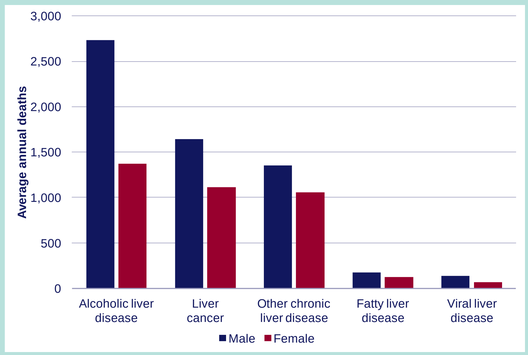


Figure 3: The percentage of deaths with an underlying cause of liver disease that occurred under the age of 75

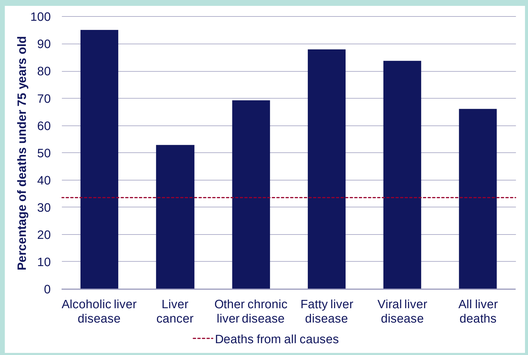


Figure 4: Distribution by quintile of income deprivation of deaths with an underlying cause of liver disease

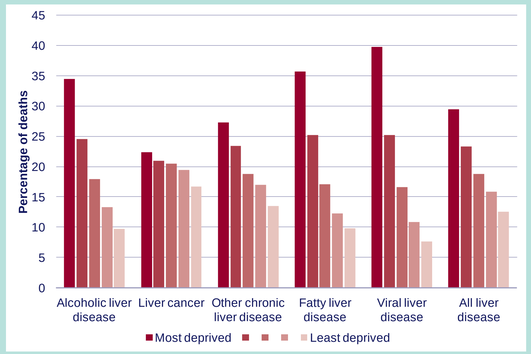
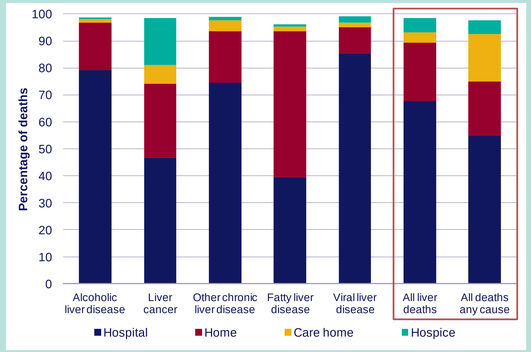


Figure 5: Distribution in place of deaths from an underlying cause of liver disease and deaths from any cause,



DISCUSSION

Death from liver disease is often associated with stigma. Many but by no means all of the people dying from liver disease come from deprived backgrounds. Those dying of alcoholic liver disease may have mental health problems or drug dependence problems which complicate their social circumstances such as they have little family or social support.

The course of advanced liver disease is complicated, with acute and sometimes near fatal exacerbations necessitating hospital admission but from which patients can make a good recovery.

CONCLUSIONS

Liver disease patients differ from the majority of dying patients due to young age, deprivation and hospital as a place of death. Life threatening, acute-on-chronic exacerbations, co-morbidities and psychosocial problems frequently complicate their end of life care.

More focus needs to be given in the hospital setting to recognition of and preparation for the possibility of death in liver patients as this is where most will end their lives.

REFERENCES

For more end of life care intelligence information see the website:
www.endoflifecare-intelligence.org.uk