End of Life Care in Liver Disease

Dr Fiona Chiplen, Dr Lucy Cogdell, Dr Sally Lawton, Dr Gordon Linklater, Dr Santosh Salunke, Dr Balasubramaniam Vijayan, Dr Andrew Fraser

NHS Grampian

1495 UNIVERSITY OF ABERDEEN

Background

The key to delivering appropriate palliative and end of life care is the identification, assessment, monitoring and planning of care.[1] We wanted to know if this approach was being used for patients dying of chronic liver disease. The focus of care within liver disease has been on acute care and rescuing patients from complications, rather than on the uncertainties associated with the end of life phase.[2]

Aims

To audit the assessment, care planning and recording of palliative status in the Gastroenterology Department in Aberdeen
To identify whether any advanced care planning had occurred
To comment on the burden of illness

Audit standard

The audit standard was set that 90% of notes would include an entry about:
❑The patient's palliative status (stated in medical and nursing notes)
❑The review and discontinuation (where appropriate) of medications and interventions
❑Conversations with the patient and family about prognosis, care planning and their understanding
❑Anticipatory prescribing

Methods

Twenty patients who died of chronic liver disease between July 2011 and May 2012 were identified using a retrospective notes review approach. A data capture sheet was devised in consultation with Senior Medical staff from the Gastroenterology and Palliative Medicine Departments.

Findings

Gender	Male	12
	Female	8
Residence	Aberdeen City	11
	Aberdeenshire	8
	Other	1
Age	Mean	68
	Median (range)	69 (33 – 88)
Diagnosis	ALD	13
	Cryptogenic	3
	Autoimmune	2
	NAFLD	1
	PBC	1
Place of death	Home	3
	Community Hospital	3
	Secondary Care - GI Unit - Acute Medical Assessment Unit - ITU	 10 1 3

Table 1 – Demographic Data

	Palliative Status		Medications		Intervention review		Family discussion				
ID	Medical notes	Nurse notes	review	discontinued	Non essential medical interventions.	DNA CPR form	Any discussion	prognosis	Care plan	Understanding	Anticipatory prescription
5	Yes	Yes	No	No	No	Yes Hidden	Yes	Yes	Yes	No	Yes
6	Yes	Yes	Yes	No	No	Yes	Yes	No	Yes	No	Yes
7	Yes	Yes	Yes	Yes	Yes	Yes	No	-	-	-	Yes
9	Yes	Yes	Yes	Yes	Partial	Yes	Yes	Yes	Yes	Yes	Yes
10	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
11	Yes	Yes	No	No	No	Yes	Yes	Yes	Yes	Yes	Yes
13	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
15	Yes	Partial	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
16	Yes	Partial	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
20	Yes	Yes	No	No	No	Yes	Yes	No	Yes	Yes	Yes

Table 2 End of life care in the GI unit. Results of the audit for the 10 patients who died in the GI unit. The 90% audit standard was met in the following; dying recognised and recorded in medical and nursing notes; DNACPR in place; record of discussion with the family and agreed plan with the family; and anticipatory prescribing.

Burden of illness

All the patients who died in the acute sector had been admitted as unscheduled emergencies. Five patients died within 24 hours of admission. None had any evidence of pre-admission advance care planning.

Discussion

The audit has highlighted current good practice in the Aberdeen GI unit. Dying was recognised, discussed with families and appropriate decisions made regarding resuscitation and anticipatory prescribing. This shows that a palliative approach in combination with active medical management in an acute setting is possible.

Limitations of project

Retrospective notes review limited by the completeness of the record
Small number of patient records analysed

Recommendation

Re-audit of end-of-life care in the GI unit to maintain high standards

Questions for liver services

Is it possible to identify patients who are at risk of dying earlier in their disease trajectory?
Is advance care planning possible and helpful for patients with chronic liver disease?
What is the role of primary care?

References
1.Scottish Government *Living and Dying Well: A national audit plan for palliative and end-of-life care in Scotland* The Scottish Government Edinburgh September 2008
2.NHS Liver Care *Getting it right: Improving end of life care for people living with liver disease* National End of Life Programme , DOH, London (Feb 2013)

The authors would like to acknowledge support from the Shire Innovation award for registrars

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