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INTEGRATION OF PALLIATIVE AND SUPPORTIVE CARE IN THE MANAGEMENT OF ADVANCED LIVER DISEASE - DEVELOPMENT AND EVALUATION OF A PROGNOSTIC SCREENING TOOL AND SUPPORTIVE CARE INTERVENTION

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Abstract

Background & Objectives:

Patients with decompensated cirrhosis rarely receive palliative and supportive care interventions which are routine in other life-limiting diseases. We designed and evaluated a screening tool to routinely identify inpatients with decompensated cirrhosis at high risk of dying over the coming year, alongside development of a palliative and supportive care intervention.

Design:

Clinical notes from consecutive patients admitted as an emergency to University Hospitals Bristol NHS Foundation Trust with a diagnosis of cirrhosis over two distinct 90 day periods were scrutinised retrospectively for the presence or absence of five evidence-based factors associated with poor prognosis. These were analysed against their ability to predict mortality at one-year post admission. 'Plan-Do-Study-Act'(PDSA) methodology was used to incorporate poor-prognosis screening into the routine assessment of patients admitted with cirrhosis, and develop a supportive care intervention.

Results:

73 admissions were scrutinised (79.5% male, 63% ArLD, Median age 54). Overall one-year mortality was 49.3%. The presence of three or more poor prognostic criteria at admission predicted one-year mortality with a sensitivity, specificity and positive predictive value of 72.2%, 83.8% and 81.3% respectively, and was utilised as a trigger for implementing the supportive care intervention. Following modification from six PDSA cycles, prognostic screening (with provision of the supportive care intervention when appropriate) was integrated into the assessment of all patients admitted with decompensated cirrhosis.

Conclusions:

We describe a model of care which identifies inpatients with cirrhosis at significant risk of dying over the coming year, and describe development of a supportive care intervention which can be offered to appropriate patients in parallel to ongoing active management.

Summary Box

What is already known about this subject:

What are the new findings:

How might it impact on clinical practice in the foreseeable future:

INTRODUCTION

In the UK liver disease causes approximately 2% of overall deaths and is the 3rd commonest cause of death in people of working age [1]. Antiviral therapy or abstinence from alcohol can result in significant improvements in liver function, and transplantation offers the potential of cure for some patients, however the risk of death amongst patients with decompensated cirrhosis remains high.

Advanced liver disease is associated with a significant symptom burden, and extensive palliative and supportive care needs in this group have been demonstrated [2-5]. Palliative care interventions have been shown to improve symptoms, quality of life, and mood in patients with advanced liver disease [6], and allow patients to be involved in advance care planning and decisions (potentially prior to the onset or deterioration of hepatic encephalopathy when capacity is likely to be compromised). End stage liver disease has significant associated healthcare costs. Appropriately timed advance care planning has the potential to curtail futile and expensive interventions and is likely to be cost effective [7]. Despite evidence of clinical and economic benefit, supportive and palliative care services are seldom accessed by patients with advanced liver disease, with interventions typically limited to inpatient end of life care [8].

A high proportion of patients with liver disease die in hospital (73% in England [9]), with the terminal admission commonly preceded by multiple inpatient episodes [10] [11]. In parallel with consideration of a patient's therapeutic options, these admissions afford the opportunity to assess disease stage and discuss prognosis.

The end of life care strategy, published by the Department of Health in 2008, noted that many patients do not die in a place of their choosing, and that difficulties amongst medical professionals in identifying the dying process mean that patients are often unable to make plans for the end of their life, and to discuss their preferences with loved ones [12]. Such difficulties are compounded in liver disease by the typically young age of patients, the potential for disease reversibility, and an often unclear prognostic trajectory. Whilst there are numerous models that predict mortality statistically, the individual uncertainties pertaining to each patient mean confident prediction of the disease course is often difficult. Such factors may contribute to the problems in identifying patients who stand to benefit from supportive and palliative care. The Gold Standards Framework, one of the guidelines for care of patients with end-stage illnesses including cardiac, pulmonary, renal, and neurologic diseases, omits prognostic criteria for liver disease [13].

This study describes the design, validation, and implementation of a prognostic screening tool for use amongst inpatients with decompensated cirrhosis, with the aim of identifying patients at high risk of dying over the coming year. We describe the development of a supportive care intervention, which can be offered to appropriate patients in parallel with their ongoing active disease management.

METHODS

Design

The tool was designed for use amongst patients admitted to hospital with a pre-existing diagnosis of cirrhosis. Based on the Gold Standards Framework criteria, we aimed to accurately identify patients in whom death was likely to occur within 12 months. We intended criteria to be simple, objective and reproducible.

The 2013 NHS document ‘Getting it right – improving end of life care for patients with liver disease’ highlighted specific, evidence-based “triggers” which could be used to prompt discussion of future care preferences [14]. Following departmental discussion with consultant and junior medical staff five of these criteria were selected and modified for use within the tool (Childs Pugh Score C, two or more admissions within the last 6 months, ongoing alcohol use in the context of known alcohol related liver disease, unsuitability for liver transplantation, WHO Performance status 3 or 4). For patients who had not undergone formal transplant assessment, the presence of ongoing alcohol misuse in the context of previously diagnosed ArLD, age >75, and the presence of untreated extra-hepatic malignancy were used as surrogates for a patient being unsuitable for transplantation

Validation

Using local databases, consecutive patients admitted to University Hospitals Bristol NHS Foundation Trust with a pre-existing diagnosis of cirrhosis (clinical, radiological or histological diagnosis) over two distinct 90 day periods were identified (periods commencing; 1st July 2013, 1st November 2014). Clinical notes and electronic records were scrutinised. Each patient was assessed for the presence or absence of the five criteria within the tool and scored independently

by two clinicians. Where scores were not consistent, or there was insufficient information in clinical records, patients were excluded from analysis. Mortality one-year from the date of index admission was determined through scrutiny of computerised patient records. For patients admitted more than once within the 3-month period, only the first admission was used. The ability to predict death one-year following index admission was calculated for each individual criteria, each cumulative prognostic score (CPS – eg total score of 3 or above), and various combinations of criteria, through determination of sensitivity, specificity and positive predictive value. Results from the two cohorts were compared to ensure the absence of any significant group effect.

Modification and Implementation

Prognostic scoring was integrated into the routine assessment of patients using principles of rapid-cycle change methodology (figure 1) [15]. Six PDSA (Plan-Do-Study-Act) cycles were completed. Opinions from junior medical staff, consultants, ward and specialist hepatology nursing staff, and allied health professionals were sought following each cycle of change.

RESULTS

Validation of tool and determination of trigger score

83 patients (51 - period a, 32 - period b) with a pre-existing diagnosis of cirrhosis were admitted over the 2 study periods, of which 10 were excluded from analysis due to insufficient information in clinical records. Patient demographics are shown in table 1.

Table 1 - Demographics

Patients included in analysis n (%)	73 (100)
Male n (%)	58 (79.5)
ArLD n (%)	46 (63.0)
Median age (IQR)	54.5 (47-66.25)
1-year mortality	36 (49.3)

Accuracy in predicting mortality one year following admission was a key criterion in design on the screening tool. Whilst not wanting to miss potentially suitable patients, the resource implications, and clinical appropriateness of including every patient admitted with decompensation also required consideration.

The proportion of patients meeting each of the individual criteria at index admission, alongside their positive predictive value, sensitivity, and specificity at predicting death at one year, are demonstrated in table 2. The same predictive statistical parameters are applied for cumulative

prognostic scores (CPS – total number of positive criteria at admission), and various combinations of commonly positive criteria.

Table 2 – Predictive capacity (mortality 1 year from date of admission) of individual prognostic criteria and potential combinations of scores.

Prognostic criteria/trigger	n (%)	Positive predictive value (%)	Sensitivity (%)	Specificity (%)
Childs Pugh C	36 (49.3)	77.8	77.8	78.4
Unsuitable for transplant	62 (84.9)	54.8	94.4	24.3
WHO Performance status 3 or 4	14 (19.2)	78.6	31.4	91.9
Continuing alcohol usage (in ArLD)	44 (60.3)	56.8	71.4	48.7
>2 admissions within last 6 months	7 (9.6)	57.1	11.1	91.9
Cumulative prognostic score ≥ 2	57 (78.1)	57.9	91.7	35.1
Cumulative prognostic	32 (43.8)	81.3	72.2	83.8

score \geq 3				
Cumulative prognostic	7 (9.6)	85.7	16.7	97.3
score \geq 4				
Childs C + continuing	24 (32.9)	87.5	58.3	91.9
alcohol				
Childs C + any other	34 (46.6)	82.4	77.8	83.8
prognostic criteria				

Childs Pugh C disease, a CPS of 3 or above, and the presence of Childs Pugh C disease in the presence of at least one other poor prognostic criteria all had excellent (and approximately equivalent) ability to identify patients at high risk of death over the coming year, and were considered equally acceptable triggers. Our model used a cumulative score of 3 or above as a trigger for intervention, however other units wishing to adopt the principle of prognostic screening might vary this. Inclusion of a Childs Pugh Score within prognostic screening did, however, appear to improve predictive ability significantly.

Modification and implementation

From the starting point of a simple list of criteria displayed on the ward, the quality improvement process described above led to full integration of prognostic screening into the routine assessment of inpatients admitted with decompensated cirrhosis. The format and content of the supportive care intervention offered to patients underwent a parallel process of quality

improvement. The key changes resulting from each cycle are demonstrated in figure 2. 4 months following implementation, audit demonstrated that PST use had become routine with completion rates of 88.9% for patients with decompensated cirrhosis (n=21). Figure 3 shows the weekly MDT discussion proforma, completed weekly for each hepatology inpatient, with the integrated PST.

DISCUSSION

References

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Figure legends

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