Do screening tools assess palliative care needs and 12-month mortality in patients admitted to hepatology in-patient wards?

Short running title: Screening for palliative care needs

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Declarations

Ethics approval and consent to participate: This study was conducted as a part of Quality Improvement project for the Royal Free NHS Foundation Trust and registered with the Royal Free Quality Governance Department (RF265-19/20) and, as such, no Research Ethics Committee (REC) approval was required.

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ABSTRACT

Background: Many liver patients have unmet palliative care needs, but liver clinicians are unclear whom to refer to specialist palliative care (SPC). The Supportive and Palliative Care Indicator Tool (SPICT) and the Bristol Prognostic Screening Tool (BPST) could help identify suitable patients, but neither has been tested for this role. This study evaluated their role as screening tools for palliative care needs and for predicting 12-month mortality.

Methods: A case notes review of hepatology in-patients who were not peri- and post-transplant status, was conducted in one tertiary unit. Main outcomes were: clinical judgement of need for SPC referral, BPST scores, SPICT attribution of caseness, and 12-month survival status. Discriminatory ability of tools were assessed using sensitivity, specificity, positive predictive value (PPV), negative predictive value (NPV) and area under the Receiver Operating Characteristic (AUROC) curve.

Results: 117 medical notes were reviewed for survival analysis, 47 of which were additionally assessed for suitability for SPC referral, using clinical judgement. SPICT (Sensitivity=93%; PPV=93%; AUROC= 0.933) and BPST (Sensitivity=59%, PPV=79%, AUROC=0.693) demonstrated excellent and good performance respectively in predicting patients' need for SPC referral. SPICT and BPST only had moderate ability at predicting death at 12 months (PPV: 54% and 56% respectively).

Conclusion: SPICT and BPST show potential as screening tools for identifying patients for referral to SPC. Further work is needed to determine how to implement these tools in a clinical setting.

Key words: advanced liver disease, screening, palliative care, health service research, cirrhosis

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Key messages

What is already known about this subject?

- Many people with liver disease have significant symptom burden and unmet psychosocial which would benefit from specialist palliative care input.
- Liver clinicians are unclear on which patients would benefit from referral to SPC.
- Two screening tools (SPICT and BPST) are available which may be able to identify individuals with unmet palliative care needs.

What are the new findings?

- The SPICT and the BPST show good ability to screen for individual patients who would be considered appropriate referrals to specialist palliative care.

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

- Liver clinicians, working in conjunction with specialist palliative care, can use these screening tools to identify suitable patients attending Hepatology in-patient wards who are not peri and post-transplant status, and who would benefit from input from specialist palliative care.
- Discussions about future preferences for care should be initiated for individuals identified as a positive case on these screening tools.

INTRODUCTION

Liver disease is a growing international public health problem (1-4) and a leading cause of mortality in many high-income countries (5, 6). End stage liver disease (ESLD) represents the point when severe liver scarring has occurred, commonly known as cirrhosis. Although ESLD is synonymous with decompensated cirrhosis, a person may initially show no symptoms, a state known as compensated cirrhosis, where the liver is still able to function. Decompensated cirrhosis occurs at the point of liver failure, leading to serious complications and increased mortality (7). People with ESLD have significant symptom burden, high levels of psychological distress and unmet psychosocial and informational needs (8). Liver clinicians feel unable to deliver appropriate support for this group to manage their symptoms or to communicate with them effectively about prognosis (8-10). They recognise that specialist palliative care (SPC) play a role in caring for patients with ESLD. Limited research has suggested that early palliative care input to this patient group (11) is acceptable, with its potential to improve both symptom management and psychological distress (12). However, liver clinicians are unclear about when to refer to SPC, partly due to the uncertain prognosis. (13).

A brief tool identifying which individual patients with ESLD could benefit from SPC would be useful in supporting liver clinicians to make referrals. The Bristol Prognostic Screening Tool (BPST)(14) and the Supportive and Palliative Care Indicators Tool (SPICT)(15), both developed in the United Kingdom (UK), may be suitable for this role. Some work has evaluated their role in predicting mortality one year post-index admission (14, 15), but none has evaluated whether these tools enable liver clinicians to make appropriate referrals to SPC.

A screening tool would be helpful for identifying individuals with unmet palliative care needs from among the wider group of liver inpatients (who may or may not have ESLD). A health improvement project initiated by the Royal Free palliative care and hepatology teams aims to improve the integration of the SPC team with the hepatology team. One of its key goals was to explore which tool would be most useful for identifying patients for multi-disciplinary team (MDT) discussion. To explore

this, we evaluated BPST and SPICT as tools: to identify which hospital in-patients with liver problems admitted under hepatology services, were in need of referral to specialist palliative care; and to predict mortality at 12 months. This paper reports on findings from the analysis conducted using data from patients who were neither peri-transplant nor post-transplant.

METHODOLOGY

Study setting and participants

Patients admitted to the hepatology ward at a tertiary liver unit in London (UK) between April 2018 to February 2019, were eligible. Our study sample included all patients with liver disease (e.g. those with alcohol-related liver disease, hepatitis) under the care of the hepatology and whose medical notes were present on the days where the case note review was being conducted. Those with or without a diagnosis of cirrhosis were included in the sample. We excluded all peri- or post-transplant patients, those were not under the care of the hepatology team, or whose notes were not available on the ward at the time of the case note review

Evaluation of the screening tools

We evaluated both the BPST and SPICT as screening tools to determine if patients required referral to SPC, and as prognostic tools to predict survival at 12 months.

There is no gold standard for assessing whether a patient would benefit from SPC input. For this study, the performance of the screening tools was compared against clinical judgement by one of three SPC team members (CC, JW, RC). Team members used a *pro forma* to review patients' notes and determine whether they had: a life-limiting disease, a potentially life changing/limiting diagnosis, a need for a holistic assessment (Appendix I).The pro-forma was specifically created for this review as a way of recording the opinion of specialist clinicians about patients' suitability for a palliative care referral. In developing this 'gold standard', the three members of the specialist palliative care team (a palliative

medicine consultant - RC, a palliative care nurse consultant - JW and a hepatology/palliative care clinical nurse specialist – CC) used both their specialist knowledge and guidance from the document 'Ambitions for palliative and end of life care: a national framework for local action: 2015–2020 (16), in identifying the criteria for referral. Survival status at 12-months post-screening was used to evaluate the ability of the screening tools to predict prognosis.

Screening / prognostic tools

BPST (14).

BPST assesses five criteria (Child Pugh Grade C; >2 liver-related admission over the last 6 months; ongoing alcohol use for patients with alcohol-related liver disease; unsuitable for transplant work-up; and WHO performance status 3-4). Patients score one point if they meet any of these criteria. Scores range between 0 – 5, with higher scores representing more severe disease and poorer prognosis. For patients fulfilling at least 3 of these criteria (i.e. cumulative score of ≥3) a specific supportive care package should be triggered. This score was recommended by the authors of this tool as the best cut-off score in predicting mortality one year post-assessment, taking into account PPV 81.8%, sensitivity 75.0% and specificity 83.8%.(14)(Appendix II).

SPICT (15).

SPICT is a two-tier screening system in which each patient is first screened using the top section looking at 'general indicators of poor and deteriorating health'. If no items on this section apply to the patient, that patient is considered a negative case and would not be referred for SPC. If any items on this section applies, the patient is further screened using the 'clinical indicators of one or multiple life-limiting conditions' section (covering clinical issues related to eight types of chronic diseases). If the patient additionally scores positively on at least one item from this section, the patient is considered

a positive case for referral to SPC. A pragmatic approach was used by the assessment clinical team in assessing this section, taking into account co-morbidity from the different organ dysfunctions in addition to liver disease. The SPICT tool does not claim to be a prognostic indicator tool (Appendix III).

Other data collected

Data were also collected on gender, age, and cause and severity of liver disease (MELD score). To calculate the MELD score, the following data were collected on the dates when the assessments were conducted: serum bilirubin, serum creatinine, International normalised ratio for prothrombin time (INR).

Data collection

A case-note review of medical notes was conducted on eligible patients who were on the hepatology ward on 14 days during April 2018 – February 2019 (these 'census' dates were chosen for convenience).

On census dates, data were collected on SPICT and BSPT from eligible patients' notes and survival statuses were checked at 12 months. On the last six census dates, notes were additionally scrutinised by expert clinicians to determine suitability of referral to specialist palliative care. The decision to evaluate the ability of the two screening tools to identify which patients were suitable for specialist palliative care referral evolved after the initial review (on survival prediction) had started, hence the delay in collecting these data. A hepatology clinical fellow (SC) and a junior doctor (SV) extracted demographic and clinical data for all patients retrospectively.

Evaluating the ability of BPST and SPICT in identifying specialist palliative care need

Three SPC clinicians (CC, JW, RC) first met to discuss the key criteria for referring patients to specialist palliative care. They then reviewed medical notes for all eligible hepatology inpatients present on the wards on six 'census' days (July 2019 to February 2020). Each clinician reviewed one third of the notes independently to determine whether patients had specialist palliative care needs, using a *pro forma* (Appendix I). Once the clinical assessment was completed, relevant information were extracted from the medical notes, to calculate BPST scores and to determine whether patients were identified as in need of SPC referral according to SPICT. To ensure validity and reliability of clinical assessments about specialist palliative care need, at least 10% of medical notes were independently reviewed by a different assessor.

Evaluating the ability of the BPST and SPICT in predicting 12 month mortality

A clinical nurse specialist (CC) reviewed medical notes for all eligible hepatology inpatients present on the wards on 8 census days (April 2019 to September 2020). CC extracted relevant information from medical notes to calculate BPST scores and to determine whether patients were identified as in need of SPC referral according to SPICT. For patients present on wards on the remaining six census days, we used BPST scores and the SPICT rating assessed by the three palliative care clinicians (see previous section). CC followed up survival status of all these patients at 12 months.

Statistical analysis:

All data were entered into an Excel spreadsheet and checks were performed to identify which patients had repeated observations over different time-points. Data entries were double-checked to ensure accuracy. If patients were present on the ward on more than one of the census dates, only the first observation was used for analysis. Data were analysed using Stata version 14.

1. Discriminatory ability was assessed using sensitivity (ability to recognize those suitable for referral to SPC/dying in specific timeframe), specificity (ability to recognize those not suitable for referral to SPC/dying in a specific timeframe), positive predictive value (PPV; proportion of those who were referred/died during the timeframe when referral/dying was predicted) and negative predictive value (NPV; the proportion of those who were referred/survived when referral/surviving was predicted). The area under the Receiver Operating Characteristic (ROC) curve (AUROC) was used to assess:

    a) The performance of SPICT and BPST in predicting need for SPC referral when compared with clinical judgement from SPC clinicians.
    b) The performance of SPICT and BPST in predicting 12 month mortality.

    AUROC, values of between ≥ 0.7 and < 0.8 are considered to represent good discrimination, values of between ≥ 0.8 and < 0.9 are considered excellent, and values ≥ 0.9 are considered outstanding (17).

Ethical approval

This study was conducted as a part of Quality Improvement project for the Royal Free NHS Foundation Trust and registered with the Royal Free Quality Governance Department (RF265-19/20) and, as such, no Research Ethics Committee (REC) approval was required.

RESULTS

The notes of 117 patients were collected on all 14 census days and reviewed for evaluation of SPICT and BPST for survival prediction. The notes of a subsample of 47 patients, collected on the last 6 census days, were also evaluated to determine suitability for referral to SPC (Figure 1). In the 13% (n=6) of 47 notes that were evaluated by two clinicians independently, there was excellent agreement on the need or otherwise for SPC (Agreement =5/6 (83%)).

Demographic details

Patients were predominantly male and white, with a mean age of 52 years. Patients had a mean MELD of 16.8. Most were had alcohol-related liver disease, auto-immune or mixed liver disease. A comparison between the full sample with the sub-sample of patients assessed for SPC referral, showed no major discrepancies in key demographic variables (Table 1).

BPST and SPICT as predictors of need for referral to specialist palliative care

Of 47 notes reviewed, 26 (55%) were deemed to have palliative care needs and likely to benefit from referral to SPC. SPICT scores correctly identified whether or not 44/47 (94%~~)~~ patients required SPC referral. BPST correctly identified 32/47 (68 %) of such patients (Table 2).

SPICT was outstanding (Sensitivity=~~-~~96%; PPV=93% and AUROC=0.933) and BPST was good (Sensitivity=58%; PPV=79% and AUROC=~~-~~0.693) at predicting need for referral to palliative care (Table 3).

Prognostic value of BPST and SPICT in predicting 12-month mortality

Of 117 patients, 61 (52%) had a positive indication on SPICT and 43 (36%) had a score ≥3 on BPST. Of the 117 patients, 41 (26%) had died within 12 months.

SPICT was 62% (73/117) accurate at predicting 12-month mortality and BPST was 67% (78/116) accurate (Table 2). Sensitivity scores of 81% and 59% and PPV scores of 54% and 56 % for SPICT and BPST respectively suggest that both tools had only moderate ability at predicting 12-month mortality. NPVs of 86 % and 77 % for SPICT and BPST respectively suggest that both tools were excellent at predicting which patients would be alive at 12 months. The AUROC of 0.718 and 0.660 for SPICT and

BPST respectively showed moderate to good discrimination at predicting which patients would be alive or dead at 12 months (Table 3).

DISCUSSION

This is the first study to investigate the prognostic value of BPST and SPICT in predicting need for referral to SPC in a population with liver disease admitted to hospital. In this study, we also assessed the ability of BPST and SPICT to predict mortality of patients with liver disease at 12 months. Our findings showed that SPICT and BPST demonstrated good ability to identify which patients would be suitable for SPC referral. SPICT appeared to perform better than BPST at identifying which patients would benefit from SPC referral. However further evaluation of these tools is needed, including studies to explore their implementation in clinical practice or larger scale studies to evaluate their ability to identify liver patients suitable for palliative care referral in more generalist settings. SPICT and BPST only had moderate accuracy at predicting mortality at 12-months. Both sensitivity and AUROC values suggest SPICT was better at detecting 12-month mortality than BPST.

Our evaluation had some limitations. This work was part of a quality improvement project aimed at improving referrals to SPC at a specific hospital in London, so may not be transferrable to other settings. Screening tool scores were calculated using data recorded routinely in medical notes, so relied on the accuracy of the written information. Our gold standard for SPC referral was based on the judgement of clinicians, and further work is needed for external validation of these findings as we assumed that all the information required to calculate the different scores for the clinical assessment, BPST and the SPICT were accurately recorded in the notes. As the BPST was specifically designed not to be used for patients on the transplant list, we excluded both peri- and post-transplant patients from the study analysis. However, these patients make up a significant proportion of in-patients in a liver tertiary specialist unit, who have unmet palliative care needs (18). Brief screening tools would be

useful to address this issue with this group of patients and further more detailed work is required to address this area.

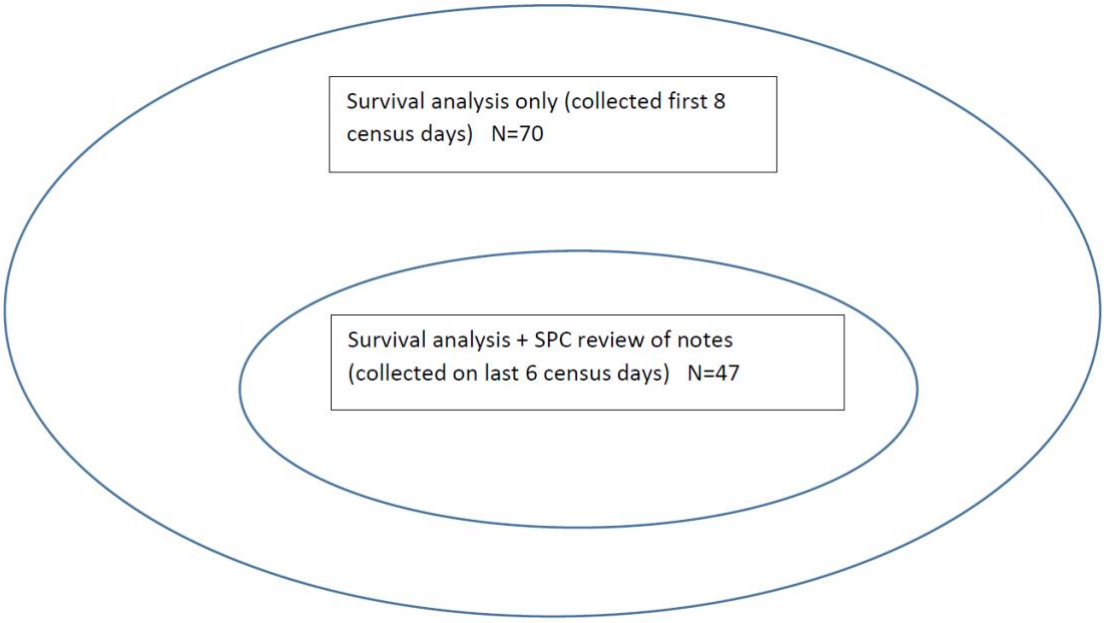
Our findings have several clinical implications. Previous studies have highlighted that liver clinicians are unclear about how to identify which patients would be suitable for SPC referral (8). Our findings provide evidence that patients with unmet palliative care needs at one specialist liver unit not eligible for transplantation could be identified using either SPICT or BPST. From the perspective of the SPC team, this is important as referral to SPC should not just be driven by a short prognosis, but by patients' needs for palliative care. We found that BPST and SPICT were more limited identifying individuals at risk of dying. Nevertheless, the mortality data may be helpful for liver clinicians to think about which patients may benefit from a discussion about their future wishes and advance care planning. Recommendations from United Kingdom (UK) NICE guidance, highlight the importance of identifying adults who may benefit from referral to SPC. Once appropriate patients are identified, this could act as a prompt for liver clinicians (with support from SPC if required) to begin having conversations about future preferences of care (19).

Our findings suggest that both SPICT and BPST can be used as a brief screening tool to identify people admitted as inpatients to a liver ward requiring SPC referral and in predicting 12-month mortality at one large tertiary liver centre in the UK, provided they are not peri- and post-transplant patients. In using the different screening tools in a clinical setting outside a quaternary centre, our own experience suggest that the SPICT was easier to use in a prompt manner, as it could be used more easily by nurses, therapists and doctors in the context of a multi-disciplinary team meeting with a SPICT assessment placed in front of patients' medical notes. In contrast, the BPST may be more appropriate in a medically led clinic where access to blood results, knowledge of ascites and presence of hepatic encephalopathy is readily more available. In addition to larger, prospective studies to confirm these results, co-design studies using mixed methodological or qualitative approaches and involving all

potential stakeholders are needed to explore which of these tools are easier to use and how clinicians should implement these tools in clinical practice.

FIGURES:

Figure 1: Venn diagram illustrating the data collected from notes of 117 patients



TABLES

Table 1: Demographic results

Characteristics	Full sample (n=117) 6 & 12 month survival (n=117)	Sub-sample SPC needs assessment (n=47)
Gender (%)		
Female	39 (33)	16 (34)
Male	79 (67)	31 (66)
Age, mean (SD)	52.3 (15.9)	55.4 (16.1)
Ethnicity (%)		
White	60 (51)	24 (51)
Asian	15 (13)	4 (9)
Black	4 (3)	2 (4)
Mixed	3 (3)	1 (2)
Other	35 (30)	16 (34)
Liver diagnosis (n=117) (%)		
ARLD	45 (38)	17 (36)
Auto Immune	14 (12)	6 (13)
Mixed	12 (10)	8 (17)
Acute hepatitis (DILI,HAV,ALF)	11 (9)	3 (6)
Viral	10 (9)	3 (6)
Portal Hypertens + PV Thrombosis	7 (6)	4 (9)
Other	6 (5)	3 (6)
NASH/NAFLD	5 (4)	2 (4)
HCC	4 (3)	0 (0)
Cryptogenic	3 (3)	1 (2)
Prognostic tools		
MELD		
0-9	22 (19)	8 (17)
10-19	53 (46)	17 (37)
20-29	33 (28)	17 (37)
30-39	8 (7)	4 (9)
mean (SD)	16.8 (7.5)	17.9 (7.2)
Bristol score		
0-2	74 (63)	28 (60)
3+	43 (37)	19 (40)
Mean (SD)	1.7 (1.5)	2.02 (1.6)
SPICT		
Yes	61 (52)	20 (43)
No	57 (48)	27 (57)

Key: ARLD = Alcohol related liver disease, NASH = non-alcoholic steatohepatitis, NAFLD = non-alcoholic fatty liver diseases; MELD = Model for End Stage Liver Disease, SD = Standard deviation

Table 2: Accuracy of SPICT and BPST for predicting need for referral to specialist palliative care, and twelve month mortality for patients.

Need for referral to palliative care						
Palliative Care	SPICT		Total	BPST		Total
	N	Y		<3	≥ 3	
No referral	19	2	21	17	4	21
Referral required	1	25	26	11	15	26
Total	20	27	47	28	19	47
Twelve month mortality						
	SPICT		Total	BPST		Total
	N	Y		<3	≥ 3	
Alive	48	28	76	56	19	75
Died	8	33	41	17	24	41
Total	56	61	117	73	43	116

Table 3: Prognostic tests results for predicting need for referral to palliative care and twelve month mortality.

	Sensitivity (%)	Specificity (%)	Positive predictive value (%)	Negative predictive value (%)	AUROC (95% Confidence Interval)
Need for referral to palliative care					
MELD	-	-	-	-	*0.605 (0.434 to 0.775)*
SPICT	*96.2 (80.4 to 99.9)*	*90.5 (69.6 to 98.8)*	*92.6 (75.7 to 99.9)*	*95.0 (75.1 to 99.9)*	*0.933 (0.859 to 1.00)*
BPST ≥ 3	*57.7 (39.9 to 76.6)*	*81.0 (58.1 to 94.6)*	*78.9 (54.4 to 93.9)*	*60.7 (40.6 to 78.5)*	*0.693 (0.564 to 0.823)*
BPST (score 0 to 5)	-	-	-	-	*0.797 (0.656 to 0.938)*
Twelve month mortality					
MELD (score 6 to 40)	-	-	-	-	*0.512 (0.488 to 0.536)*
SPICT	*80.5% (65.1 to 91.2)*	*63.2% (51.3 to 73.9)*	*54.1% (40.8 to 66.9)*	*85.7% (73.8 to 93.6)*	*0.718 (0.636 to 0.800)*
BPST ≥ 3	*58.5% (42.1 to 73.7)*	*74.7% (63.3 to 84.0)*	*55.8% (39.9 to 70.9)*	*76.7% (65.4 to 85.8)*	*0.660 (0.575 to 0.757)*
BPST (score 0 to 5)	-	-	-	-	*0.755 (0.666 to 0.843)*

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