Seeking Excellence in End of Life Care UK (SEECare UK): A UK multi-centred service evaluation

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Key Messages:

1. **What is already known on this topic?**
    i) Patients dying in hospital have variable access to and input from specialist palliative care (SPC) services.
    ii) Little is known of the care provided in the absence of such support.
2. **What this study adds?**
    i) SPC would intervene in the care of more than half of those dying inpatients not referred for their services
    ii) End of life care plans appear to be a powerful support to non-specialists in providing end of life care in hospital
3. **How this study might affect research, practice or policy**
    i) This study may encourage non-specialists in palliative care to consider whether their dying patients may benefit from SPC input
    ii) Researching the most effective structure and function of end-of-life care plans should improve the care received by patients managed by non-specialists

Abstract:

Objective:

To evaluate the care of patients dying in hospital without support from specialists in palliative care (SPC), better understand their needs and factors influencing their care.

Methods:

Prospective UK-wide service evaluation including all dying adult inpatients unknown to SPC, excluding those in Emergency Departments/Intensive Care Units. Holistic needs were assessed through a standardised proforma.

Results:

88 hospitals, 284 patients. 93% had unmet holistic needs, including physical symptoms (75%) and psycho-socio-spiritual needs (86%). People were more likely to have unmet needs and require SPC intervention at a District General Hospital (DGH) than a Teaching Hospital/Cancer Centre (Unmet need 98.1%v91.2% p0.02; Intervention 70.9%v50.8% p0.001) and when end-of-life-care-plans (EOLCP) were not used (Unmet need 98.3%v90.3% p0.006; Intervention 67.2%v53.3% p0.02). Multivariable analyses demonstrated the independent influence of teaching/cancer hospitals (aOR0.44 CI0.26-0.73) and increased SPC medical staffing (aOR1.69 CI1.04-2.79) on need for intervention, however, integrating the use of EOLCP reduced the impact of SPC medical staffing.

Conclusion:

People dying in hospitals have significant and poorly identified unmet needs. Further evaluation is required to understand the relationships between patient, staff and service factors influencing this. The development, effective implementation and evaluation of structured individualised EOLCP should be a research funding priority.

Background:

The 2022 Health and Care Act requires adequate provision of specialist palliative care (SPC) across England, in community, hospice and hospital settings[1]. In the UK it is estimated that one in three adult hospital inpatients is in the last year of life, with one in ten likely to die while admitted[2]. In UK hospitals, specialist palliative care (SPC) teams often function as a consult service, relying on referral from the managing team to support with holistic assessment and management of multidimensional care needs. However, complexities around recognising dying and stigma associated with palliative care mean patients are often not referred to SPC, living with unmet needs until they die[2].

Meeting the holistic needs of dying people in UK hospitals has been challenging, with previous attempts such as the Liverpool Care Pathway causing public and professional upset[3]. Baroness Neuberger's review 'More Care, Less Pathway', highlighted the need for greater involvement of patients and those important to them in the development of individualised end-of-life care plans (EOLCP)[3]. The review also noted a paucity of evidence to guide the effective structure and implementation of EOLCP and their impact on care delivered[3]. The Leadership Alliance for Dying People offered 'Five Priorities of Care for the Dying Person' outlined in 'One Chance to Get it Right' to guide and support the delivery of individualised care at the end-of-life[4]. These reports have triggered the development of local individualised EOLCP, to support non-SPC healthcare professionals in the complexities of caring for the dying [5]. However, the gaps in research largely remain.

Retrospective evaluation of care at the end-of-life is undertaken by NHS Benchmarking's National Audit of Care at the End of Life[6]. Due to delays in reporting associated with large national audits, attempts at contemporaneous reporting to support quality improvement, such as the Hospital Deaths Dashboard, have also been trialled[7]. These evaluations include deaths with and without SPC involvement without differentiation. Furthermore, both rely on retrospective case-note reviews and questionnaires of loved ones and staff, limiting their ability to capture the care delivered to what was documented, or what can be remembered.

There is a need to explore other methodologies in evaluating care to ensure services are meeting the standards and requirements outlined in the Health and Care Act[1].

In response to the perceived unmet needs of people dying in hospitals, a collaborative of 4 acute UK NHS Trusts undertook a pilot evaluation (SEECare) against set standards[8]. They prospectively reviewed the care of patients dying in hospital without SPC involvement and found that this group often had unmet care needs where 56% required immediate intervention from the SPC reviewer[8]. This present study's aim was to expand this pilot across the UK and prospectively evaluate the holistic care of dying people unknown to SPC and the factors influencing their experiences.

Aim:

To pilot a UK-wide prospective one day snapshot evaluation of holistic care provided to hospital inpatients unknown to SPC.

Objectives:

1. To assess the acceptability of a prospective outreach service evaluation
2. To report the level of unmet need in hospital inpatients dying unknown to SPC
3. To explore the patient and service factors influencing whether a dying inpatient unknown to SPC is unlikely to have their needs met or require SPC intervention following review

Methods:

A Seeking Excellence in End-of-life Care working group was convened by the Association for Palliative Medicine of Great Britain and Ireland (APM) bringing expertise from consultant, trainee, research, and clinical governance backgrounds. The processes and documents of the prior project were reviewed and refined (See appendices 1-3 – SEECare data collection guide, excel database and paper collection tool).

Design

A prospective multi-site cross-sectional study with evaluations completed on a single day. All evaluations took place between 25/4/2022 and 01/05/2022.

Site recruitment:

UK NHS hospital SPC services were recruited via the membership networks of the APM and UK Palliative Trainees Research Collaborative (UKPRC). Sites registered the project following local clinical governance processes.

Participant identification:

The SPC representative (nurse or doctor) visited every adult ward in their hospital on the same day and identified eligible patients against the following criteria.

Inclusion criteria:

All hospital inpatients recognised as being in the last days of life, identified through discussion with the clinical staff on the ward.

Exclusion criteria:

Patients under 18 years old, those in Emergency Departments or Intensive Care Units and those currently known to SPC.

Data collection:

At registration, sites provided data on country of service, hospital type (District General vs Teaching Hospital/Cancer Centre), team staffing (from each professional group including the presence of a dedicated end-of-life care team), working patterns (7-day service and referral systems), geography (urban, rural, mixed) and estimated population served.

Included patients were assessed by the SPC nurse/doctor using an anonymised standardised proforma (See appendices 1-3). This proforma recorded the ward specialty, patient demographics (age, gender, ethnicity, diagnosis (cancer/non-cancer), presence and severity of physical symptoms at the point of review; whether psychological, spiritual and social needs were being addressed; and whether a plan for hydration and nutrition was in place. A review of medical and nursing notes was conducted for evidence of elements of an individualised EOLCP addressing the identified needs. “Unmet need” was identified as an unaddressed issue on the collection tool. If the SPC reviewer suggested an immediate intervention to better serve an identified area of unmet need this was also recorded and considered as "SPC intervention”

A proforma was completed for each patient and transcribed, or directly entered, into an excel database by teams. These databases were cleaned and anonymity assured by site leads prior to forwarding to the central project team via dedicated secure email. At central collation all sites were assigned an anonymous coded identifier, held password protected by the project lead and administrative support lead.

On return of sites’ databases, they were invited to provide feedback on the process of registration, planning for, staff experience and the tools provided.

Analysis:

Data extracted underwent univariable and multivariable analyses to understand which factors were associated with presence of unmet need (defined as unaddressed issue identified on collection proforma) and need for SPC intervention following review. Continuous data was analysed for normality using the D’Agostino and Pearson tests. All data were non-normally distributed and analysed using Mann Whitney *U* tests with results reported as median (interquartile range (IQR)). Categorical data were analysed by Fisher’s exact tests and results reported as number (%). For ease of interpretation, data on staffing levels were presented per 100,000 population served and categorised as above or below mean staffing of the sample for further analysis. Where multiple categories existed, the predominant category was analysed against the remainder (DGH vs Teaching Hospital/Cancer Centre; white vs all non-white ethnicity; referrals only (reactive) vs all proactive methods of patient identification; Medicine and specialties vs all other ward types).

Multiple logistic regression was utilised to identify site and patient variables independently associated with unmet need or need for intervention following review. Variables with a p value of <0.2 were included in each model and backwards elimination was performed until all variables within the model achieved a p value of <0.05. An r^2 threshold with other variables within the model was set at <0.50 to reduce co-linearity. Goodness of fit was assessed using

Hosmer-Lemeshow (HL) test, log-likelihood ratios and pseudo r^2 values. Results were recorded as odds ratio (OR) with 95% confidence intervals (CI) and p values. A $p<0.05$ was considered statistically significant and signified by *. All univariable and multivariable analyses were performed using Prism V9.2.0 (GraphPad, San Diego, USA).

Results:

In total, 69 sites representing 88 hospitals across the 4 UK nations registered for the study (76 England, 6 Northern Ireland, 4 Scotland, 2 Wales). The estimated population served by these hospitals was 35,782,123 (mean 526,000, range 100,000-3,000,000). 65%(57/88) were teaching hospitals/cancer centres. SPC staffing per 100,000 population ranged from 0.38-11.45 doctors, 1.01-30.23 CNSs and 0.35-10.6 AHPs. 45% (40/88) provided 7-day in-person cover. 38.6%(34/88) of teams used proactive measures of patient identification (such as daily focused ward outreach and electronic flagging from patient records). 8 hospitals withdrew due to staffing and service challenges.

Description of the patient cohort:

284 patients were identified. The majority were between the ages of 75 and 94 (216/284, 76%). Most had non-cancer diagnoses (240/284, 85%). See Table 1 for patient demographics.

	N	(%)
Age range		
18-74	40/284	14
75-84	101/284	36
85-94	115/284	40
95+	27/284	10
Gender		
Female	153/284	54
Ethnicity		
White/white other	271/277	98
Primary Diagnosis		
Cancer	44/284	15
Ward specialty		
Medicine	170/284	60
Frailty	57/284	20
Admissions	20/284	7
Surgical	37/284	13

Table 1 – Demographics and clinical characteristics of identified patients

Acceptability:

8/64 sites withdrew due to difficulties with staffing and service provision during the collection window. Feedback from remaining sites was that data collection was straightforward and acceptable to patients and other clinical teams. Proactive support was “warmly welcomed” by ward teams and “reviews have triggered educational intervention”, “review of policies” and helped team functioning (e.g. “improving Administrator’s insights into team’s work in clinical areas”). 19 of the 35 sites returning qualitative feedback stated they would be keen to repeat the exercise regularly through the year. 7/35 felt that for significant ‘extra’ work the patient numbers were small and wondered about more efficient methods of identification.

Evaluation findings:

75% of patients(213/284) had physical symptoms (pain 24%, 67/284; dyspnoea 24%, 68/284; respiratory secretions 21%, 61/284; agitation 23%, 66/284; nausea/vomiting 8%, 22/284), with 31% (88/284) experiencing moderate to severe physical symptoms. Mouthcare was poor in 56% (159/284). There were further unmet holistic care needs in 86% (244/284) (spiritual needs 67%, 190/284; psychological needs 60%, 170/284; social needs 18%, 51/284, no plan for hydration/nutrition 28%, 80/284). A locally agreed EOLCP was in place for 57% (162/284), communication with relatives that the patient was dying had occurred in 85% (241/284), and anticipatory prescribing was present in 82% (233/284). Overall, an overwhelming majority of 93% (264/284) of patients reviewed had demonstrable unmet need.

Interventions were required from the SPC reviewer in 57% (162/284) of cases. 39% (63/162) of changes made focused on prescribing, 15% (24/162) on psychosocial or spiritual care, 12% (19/162) on mouthcare, 11% (18/162) on engaging with EOLCP and 10% (16/162) on immediate administration of symptom focused medication. Other interventions included stopping therapies that were no longer appropriate, advance care planning and rapid discharge.

Factors associated with unmet need:

Patients' needs were significantly less likely to be met at a DGH compared with a Teaching Hospital/Cancer Centre (98.1% v 91.2% p0.02). Whilst a high proportion of patients with EOLCPs in place had unmet needs, this was significantly fewer than when an EOLCP was not in place (EOLCP 90.3% v No EOLCP 98.3%, p0.006). The Negative Predictive Value of an EOLCP on all needs being met was 0.98 (CI 0.94-0.997) meaning for those who did not have an EOLCP, needs were very unlikely to be met.

Factors associated with the need for intervention from SPC team:

Patients were significantly more likely to require intervention in a DGH compared with a Teaching Hospital/Cancer Centre (70.9% v 50.8% p0.001), where there was higher than average SPC staffing/100,000 (65.9% v 51.6% p0.02), where there was a 7-day SPC service (67.1% v 54.0% p0.03) and where there was no EOLCP in place (67.2% v 53.3% p0.02) (see table 2).

		Outcomes			
	N	Unmet needs%	P value†	Intervention%	P value†
Site					
District General Hospital	103	98.1	0.02*	70.9	0.001*
Teaching Hospital/ Cancer Centre	181	91.2		50.8	
Geography					
Rural	19	84.2	0.1	57.9	>0.999
Mixed / Urban	265	94.3		57.7	
Staffing					
CNS < avg/100,000	155	94.8	0.5	58.6	0.1
CNS > avg/100,000	129	92.3		41.4	
Drs < avg/100,000	161	92.6	0.5	51.6	0.02*
Drs > avg/100,000	123	95.1		65.9	
No EOLC team	169	95.9	0.08	53.3	0.7
EOLC team	115	90.4		55.7	
Service provision					
< 7-day service	126	96.0	0.2	54.0	0.03*
7-day service	158	91.8		67.1	
Reactive referrals	127	96.1	0.2	53.5	0.1
Proactive referrals	157	91.7		63.1	
Ward					
Medicine and specialties ward	148	93.2	0.7	55.9	0.7
Other ward	36	97.2		61.1	
Patient characteristics					
Gender					
Female	154	94.2	0.8	57.8	0.8
Male	130	93.1		59.2	
Ethnicity					
White/white other	271	94.1	0.3	55.0	0.7
Non-white	6	83.3		66.7	
Primary diagnosis					

Cancer	44	95.4	>0.999	59.1	>0.999
Non-malignant	240	93.3		57.0	
EOLCP in place					
No	119	98.3	0.006*	67.2	0.02*
Yes	165	90.3		53.3	

ǂ 2 sided Fisher's exact

Table 2 – Univariate analyses of variables against intervention required

Multivariable analysis:

Multivariable analysis demonstrated that need for intervention was independently associated with site type, (Teaching Hospital/Cancer Centres (site type aOR 0.44 CI 0.26-0.73 p 0.002)) and SPC medical staffing, (higher-than-mean SPC doctors (SPC doctor numbers aOR 1.69 CI 1.04-2.79 p 0.04)) (See Figure 1a). When presence of an EOLCP was included the number of SPC doctors did not remain independently significantly associated with the need for intervention (Site type aOR 0.45 CI 0.27-0.79 p 0.005*, SPC doctor numbers aOR 1.61 CI 0.98-2.67 p 0.06, EOLCP aOR 0.65 CI 0.39-1.08 p 0.09) (See Figure 1b). No other variables were found to be independently significantly associated with the need for intervention including nursing staffing levels, 7-day service, proactive referral seeking and cancer diagnosis.

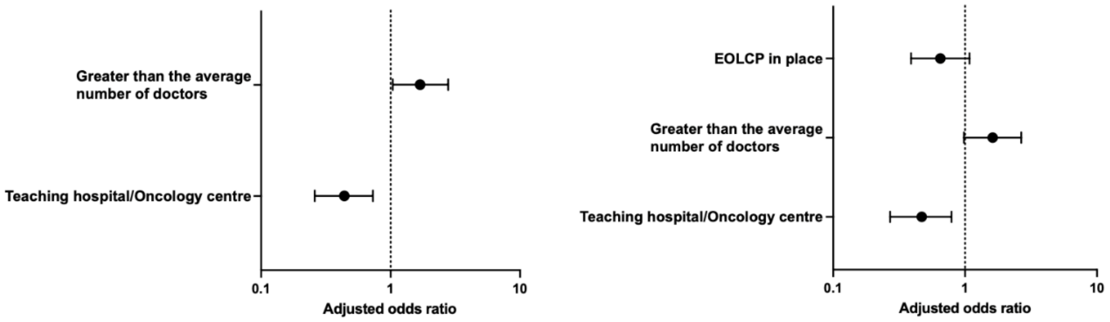

Figure 1: Comparison of models for SPC medical staffing, site type and presence of an EOLCP against need for intervention following review. Figure 1a (left) n=284, AUC 0.637, CI 0.57-0.70 Hosmer-Lemeshow 5.091, Figure 1b (right) n=284, AUC 0.651, CI 0.59-0.72 HosmerLemeshow 6.948

Discussion:

Key findings:

This is the first prospective UK-wide evaluation of care provided to people dying in hospitals without the support of specialists in palliative and end-of-life care. Nearly all identified patients (93%) suffered unmet needs, with more than half (57%) requiring immediate intervention from SPC. Inequity was demonstrated in the care provided to patients, with those in DGHs requiring higher rates of SPC intervention even when accounting for all other measured variables. SPC medical staffing and working patterns demonstrated significant relationships with need for intervention but this was mitigated in the multivariate model by the presence of an EOLCP. EOLCP were associated with significantly fewer unmet needs and significantly lower rates of intervention but were not enough to independently guarantee the provision of holistic care.

Strengths & weaknesses:

The multi-site, multi-setting involvement across county and country borders allows for interrogation of the data to demonstrate local and overall trends. The cross-sectional design and minimal exclusion criteria maximise representative data. The convenience sampling outreach approach was acceptable to SPC and wider hospital teams.

The convenience sampling methodology used to identify patients relied upon the senior ward nurse/doctor's ability and openness to identify patients dying on the ward. The varying culture and ability to recognise dying across specialties/hospitals/regions will have been in some way accounted for in the multi-site nature of this evaluation, however the suggested differences in this ability between nurses and doctors has not been accounted for in this study[9]. This study did not attempt to evaluate the differences in outcome dependent on profession of SPC reviewer (e.g. nurse vs doctor), nor day of week of data collection.

This study did not include evaluation of patients known to SPC, nor a measure of the actual count of those dying in hospitals. The lack of representative diversity in our ethnicity data with only 6 patients identified from non-white backgrounds and 6 with incomplete data is difficult to interpret, though may represents reduced recognition of dying in patients of non-white ethnic groups as is reported elsewhere[10].

The use of population served as an indicative measure for staffing was an intentional choice, as opposed to reporting by number of inpatient beds[6]. This was an attempt to account for some hospitals offering specialist services, however, it's likely that to truly capture the staffing relative to service need, future studies will need to consider services offered, bed base, population served and other variables.

In context:

These findings sit within a wider literature describing significant unmet need in the population of patients dying in hospital and the findings from the original SEECare pilot[8]. Our findings demonstrate less frequent use of EOLCP (NACEL 73%, SEECareUK 57%), communication with relatives (NACEL 98%, SEECareUK 85%) and anticipatory prescribing (NACEL 89%, SEECareUK 82%) for our patient cohort when compared with the population as a whole[11]. With the included consideration of broader holistic aspects of care, the level of unmet need demonstrated is significantly higher than the SEECare pilot and highlights the often-reported medicalisation of death in inpatient settings[8,12].

Individualised and structured EOLCP are recommended as one of the Five Priorities of Care for the Dying Person and we have found their use to be lower when SPC are not involved[4]. Though absence of an EOLCP has been demonstrated to predict unmet need (NPV EOLCP on all needs met 0.98), there remains significant need where they are in use. Nearly ten years after Baroness Neuberger's report, still, little is known about the elements of EOLCP that are most effective in supporting care and how they might best be implemented to ensure care provided meets the needs of patients whether they are referred to SPC or not[3].

The impact of SPC working patterns (e.g. 7-day working) and behaviours (e.g. proactive seeking of referrals) is poorly described in the literature though certain practices are called for in multiple reports and policies[1,6,13]. This project did not seek to evaluate the direct impact this has on patients reviewed by SPC, but to investigate any cultural impact this may have on the care of dying people in their hospitals. That increased medical staffing and 7-day working was significantly associated with increased need for SPC intervention (though not with unmet need), must be interpreted with caution. One might infer a level of reliance on SPC that deskills the generalist, alternatively, that increased SPC and medical presence drives higher standards and therefore increased likelihood to intervene.

With the Health and Care Act legislating access to palliative care wherever and whenever needed, these findings raise significant questions about the methods of delivery best suited to meeting the complex needs of dying people[1].

Future research:

In future iterations of SEECare, repeated sampling or extending the sampling window may allow for higher patient numbers to increase the utility of data on a local level and improve validity nationally. Requesting that sites provide mortality data for the collection period may allow for better understanding of the issues non-specialists face in recognition of dying.

Attempts to formally investigate the impact of EOLCP have relied on retrospective case-note review and bereaved interview-based measures, and focused on specific patient groups[14]. As such, our findings again emphasise the need for prioritisation of research funding here to more robustly understand and guide the development, implementation and evaluation of EOLCP for all people dying in hospitals.

The lack of variance and low levels of ethnicity data reported is important to explore further. Patterns in ethnicity representation in mortality data which do not match those identified prospectively may prompt further investigation into the recognition of dying and whether unconscious bias, access issues or other factors influence care received.

This evaluation focuses on acute inpatient care excluding Emergency and Intensive Care Departments. It may be appropriate to include these clinical areas in future iterations for further insights into the way in which hospitals care for those that are dying. Furthermore, expansion into intermediate care, residential care environments, patients' homes and other potentially underserved environments is likely to reveal significant unmet specialist palliative care needs.

Conclusion:

This first multi-centred prospective evaluation of care of those dying in hospitals without SPC input has demonstrated almost universal multidimensional unmet need. Given the 2022 Health and Care Act's legislation for access to palliative care services wherever and whenever needed, these findings should prompt further research and give service leads and commissioners stimulus to revisit their specialist palliative care strategic planning[1].

Contributorship statement:

ST, OM, SF-D, SC conceived the project
ST, YT, ES, SB, CS-J, SB, MT, AB, SC, OM designed the project plan and resources
ST, OM oversaw the collection and collation via the APM Office
ST, OT, NW, OM performed statistical analyses
ST, YT, ES, OT, SB, NW, CS-J, SB, MT, AB, SF-B, SC, OM contributed to the manuscript

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Conflict of interest statement:

No conflicts of interest are declared for any authors of this manuscript

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