

Special Article - Hospice Care

Translating Performance Level to Clinical Frailty Scale Category Simplifies Scoring and Indicates Length of Stay and Outcome: A Longitudinal Observational Study

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- Understanding how to provide palliative care to the growing number of people with frailty is an international priority.
- Patients who currently access SPC may subjectively be described as frail; however, frailty is not routinely measured in hospice settings.

What are the new findings?

- Hospice populations are likely to include:
 - Those with mild frailty, moderate lengths-of-stay, and high rates of discharge.
 - Those with moderate frailty, long lengths-of-stay and equal discharges and deaths. Rate of frailty change may provide more accurate prognostication.
 - Those with severe frailty, short lengths-of-stay and high rates of death.

What is their significance?**A) Clinical**

- Models of care could vary depending on frailty level with medically led short stay units and nurse led longer stay units or hospice at home.
- Frailty level could indicate when discharge from hospices to nursing care is appropriate (a source of anxiety and distress amongst patients, families, and healthcare professionals alike).

B) Research

- More research evaluating simultaneous scoring of AKPS and CFS by healthcare professionals, patients and carers is needed to validate the translation used in this paper.
- Regular recurrent measurement of AKPS and CFS are also needed to further explore if trajectory of scores using one or both measures might better predict outcome particularly in those with moderate frailty.

Background

Improved understanding of how to provide palliative care to

the growing number of people living and dying with frailty is an international priority and a key strategic area highlighted by the National Institute for Health Research (NIHR) and the Care Quality Commission (CQC) [1].

Frailty has received increased consideration in recent Specialist Palliative Care (SPC) literature [2-6]. Patients with life-limiting illnesses who currently access SPC, including those admitted to hospices, may subjectively be referred to as frail regardless of age or diagnosis [2,4,7]. Defined as age related decline across multiple systems, increasing vulnerability to health stressors [8,9], frailty is common amongst older adults. Approximately 11% of people >65 years and 25%–50% of those >85 years are frail [10], but in Specialist Palliative Care (SPC), frailty may be endemic across all age groups [2,4,7].

There is some evidence that frail older people commonly experience high levels of under-treated symptoms and poorly recognised and managed dying [11]. However, there are limited data on frailty in hospices. Association between frailty, sociodemographic characteristics, diagnoses, and outcomes in this setting are also unclear. It is not yet known which models of palliative care should be provided for those with frailty (regardless of diagnosis) in specialist palliative care settings. This may be partly because frailty is not routinely measured in hospices, and therefore it is unknown if current care provision effectively manages those with frailty or if measurement of frailty could make a positive impact on patient care.

The Clinical Frailty Scale (CFS), part of the Comprehensive Geriatric Assessment (CGA) is a recognised method of summarising the overall level of frailty in geriatric medicine [12]. The CFS is widely used in hospital settings (including during the COVID-19 pandemic), and increasingly in primary care [13-15]. Specific measures of frailty are not routinely documented in SPC. Performance Status is recorded primarily using the AKPS (UK and Australia) and the Palliative Performance Scale (PPS) (Canada, America and rest of the world) [16]. Previous work has summarised the available evidence on translating between palliative performance scales and frailty measures [17].

We aimed to subdivide performance level scores of hospice inpatients using the clinical frailty scale to describe relationships between performance, frailty, demographics, diagnosis, length-of-stay, and outcome (death/discharge).

Methods

Setting

Three independent hospices in the North of England with between 10 and 15 bed adult in-patient units. These hospices admit patients with life limiting illnesses for symptom control or end-of-life care and represent both rural and urban, deprived affluent populations.

Participants

All people age 18+ admitted to hospices over one year between April 2017 and April 2018.

Data Collection

Data were extracted from medical and nursing notes by clinicians with knowledge of local note keeping systems and palliative care experience.

Exposure Information and Confounders

Staff at the study sites routinely record information on patient performance using Australia-modified Karnofsky Performance Status (AKPS) scores. The scores were recorded at patient admission, and then longitudinally for the duration of each inpatient admission. Frequency of and time between assessments varied. Some healthcare professionals just complied with the Outcome Assessment and Complexity Collaborative (OACC) Suite of Measures recommendations, “the AKPS should be used at least twice: once on admission and then after 3–5 days for inpatients” where others also performed measurements weekly and when a change of phase occurred [18].

We sub divided AKPS scores using the CFS (Table S1). We also extracted information on sociodemographic characteristics (age, sex, and ethnicity), primary diagnosis (cancer vs non cancer) and reason for referral (end stage care, symptom control, and respite care).

Outcome Information

Our outcomes of interest were length of stay (defined as the time between admission and discharge or death), reason for admission (symptom control, respite care, or end stage care), and whether the person was discharged or died in the hospice.

Statistical analysis

We used descriptive statistics to calculate the degree of frailty on admission and associated sociodemographic characteristics. We also described the reason for admission and outcome by frailty level. We used Kaplan-meier curves to visualize survival probabilities, stratified by frailty severity, with separate analyses for people who were discharged, and people who died. We used locally weighted smoothing to visualize longitudinal change in frailty scores, stratified by admission status and outcome. Logistic regression was used to model the relationship between the 14 day length of stay outcome and other confounders, a final minimally adjusted model included only variables with clinically significant effect sizes in the univariate analyses. All data management and analyses were carried out in R (R core team, Austria 2021).

Results

Patient Characteristics

520 discharges or deaths (from 455 patients) occurred in the three hospices between April 1st, 2017 and March 31st 2018. AKPS scores were available for 406 individuals across 419 admission episodes. (Table 1) contains demographic information of patients with AKPS scores.

Across all sites, most patients were aged 65 or over, white British, admitted with a primary diagnosis of cancer, and referred for symptom control.

Frailty at Admission

Moderate frailty was the largest group (35.6% of all people in the study). People admitted for end-of-life care (Table 2) had higher levels of frailty than people admitted for symptom relief, and people admitted with non-malignant disease had higher levels of frailty than those admitted with malignancies. (Figure 1 & Table 2) shows the proportion of people who died was higher in the more severe frailty categories in people with malignant and non-malignant disease.

Table 1: Demographic characteristics.

	Cancer (N=334)	Non cancer (N=82)	Total (N=419)
Gender			
Female	181 (54.2%)	34 (41.5%)	217 (51.8%)
Male	153 (45.8%)	48 (58.5%)	202 (48.2%)
Age (years)			
Mean (SD)	68.6 (13.1)	70.2 (12.7)	69.0 (13.1)
Median [Min, Max]	70.0 [21.0, 99.0]	71.5 [36.0, 100]	70.0 (21.0, 100)
Ethnicity			
Any other ethnic group*	41 (12.3%)	20 (24.4%)	62 (14.8%)
White British	169 (50.6%)	47 (57.3%)	218 (52.0%)
Missing**	124 (37.1%)	15 (18.3%)	139 (33.2%)
Frailty/Performance status			
Fit (CFS ≤4/AKPS 70-100)	34 (10.2%)	3 (3.7%)	38 (9.1%)
Mild (CFS 5/AKPS 60)	65 (19.5%)	9 (11.0%)	74 (17.7%)
Moderate (CFS 6/AKPS 40-50)	111 (33.2%)	37 (45.1%)	149 (35.6%)
Severe (CFS 7/AKPS 30)	40 (12.0%)	6 (7.3%)	47 (11.2%)
Very severe (CFS 8/AKPS 10-20)	84 (25.1%)	27 (32.9%)	111 (26.5%)
Reason for referral			
End stage care	66 (19.8%)	18 (22.0%)	84 (20.0%)
Symptom control	262 (78.4%)	56 (68.3%)	321 (76.6%)
Respite care	6 (1.8%)	8 (9.8%)	14 (3.3%)
Outcome			
Died	210 (62.9%)	50 (61.0%)	263 (62.8%)
Discharged	124 (37.1%)	32 (39.0%)	156 (37.2%)

*Multiple ethnic groups were combined to 'any other ethnic group' to suppress low numbers. **One site did not record any information about ethnicity.

Discharges versus Death in the Hospice

Discharge was most common in those who were “fit” at the time of admission with 78.9% of patients surviving to discharge. Survival rates progressively declined with increasing frailty. 83.3% and 90.1% of those with severe and very severe frailty died during the hospice

admission. Admission reasons and outcome amongst those with moderate frailty demonstrates that prognostication and outcome prediction is most difficult for these patients. Around 80% of people with moderate frailty were referred for symptom control however 60% went on to die.

The median length of stay was 14 days (interquartile range 7 - 24). Median time to discharge was lower than median time to death, but variability in time to death was greater. Median length of stay is lowest for those with severe frailty at 5 days; patients were most likely to die shortly following their admission to the hospice. Those with “no” or mild frailty have moderate lengths of stay and hospice intervention is likely to result in them being discharged home. The highest LOS was observed in those with moderate frailty, and variation in length of stay was greatest here too.

14 Day Length of Stay in the Hospice

In the minimally adjusted model (table 4), severe (OR=2.43, 95% CI: 0.94 -6.47) and very severe frailty (OR=5.66, 95% CI: 2.29 to 14.53) were associated with a length of stay under 14 days. The impact of diagnosis and referral reason was attenuated, likely due to collinearity between these predictors (table S2).

Changes in Frailty over Time

Group frailty trajectories are displayed in figure 2. The first two graphs demonstrate the average frailty trajectories for patients who died (Figure 2.1) and who were discharged (Figure 2.2). In the former there is a rapid decline in frailty status for patients with both malignant and non-malignant disease in the 14 days prior to death whereas in the latter their discharge is preceded by a slight improvement or plateau in frailty status. This is particularly useful in those with moderate frailty (in both malignant and non-malignant disease) (Figure 2.3) where outcome can be predicted by frailty trajectory. Death is preceded by a rapid decline in frailty level whereas discharge effectively occurs in those with a plateau in their frailty status.

Discussion

This study assessed hospice inpatient’s performance level and subsequently grouped performance scores using clinical frailty scale categories. This demonstrated that there is a significant burden of

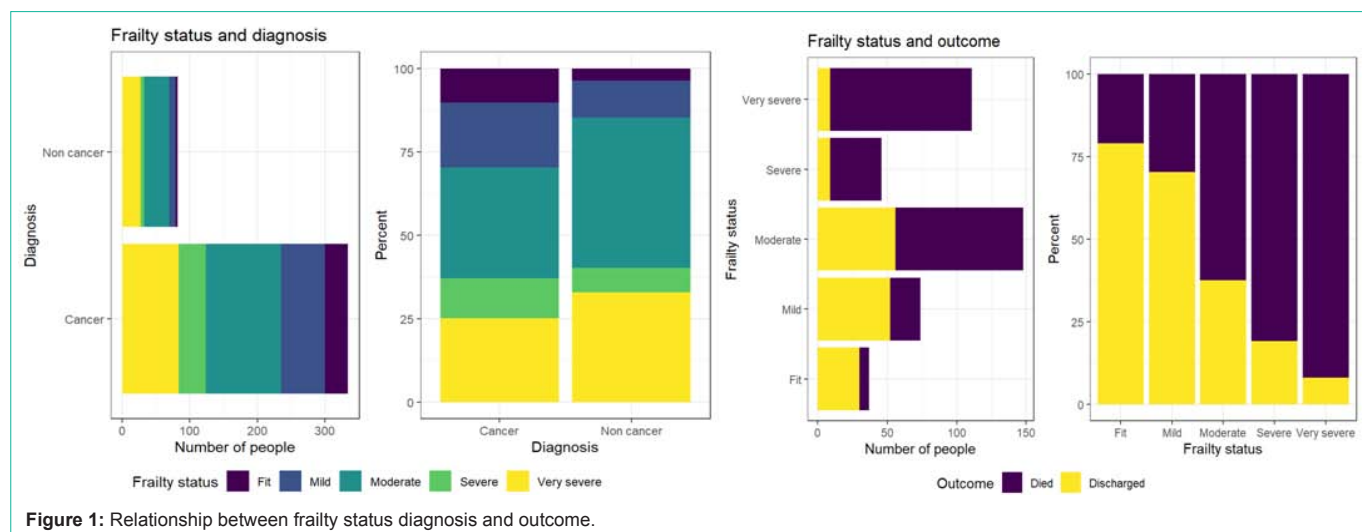


Table 2: Relationships between frailty level, demographics, diagnosis and outcome.

	Fit (CFS ≤4) (N=38)	Mild (CFS 5) (N=74)	Moderate (CFS 6) (N=149)	Severe (CFS 7) (N=47)	Very severe (CFS 8) (N=111)	Total (N=419)
Gender						
Female	23 (60.5%)	43 (58.1%)	77 (51.7%)	22 (46.8%)	52 (46.8%)	217 (51.8%)
Male	15 (39.5%)	31 (41.9%)	72 (48.3%)	25 (53.2%)	59 (53.2%)	202 (48.2%)
Age (years)						
Mean (SD)	59.3 (15.0)	67.6 (12.4)	68.9 (12.1)	72.1 (12.8)	72.1 (12.5)	69.0 (13.1)
Median [Min, Max]	62.0 [21.0, 87.0]	68.0 [42.0, 100]	70.0 [25.0, 99.0]	72.0 [27.0, 95.0]	74.0 [36.0, 97.0]	70.0 [21.0, 100]
Diagnosis						
Cancer	34 (89.5%)	65 (87.8%)	111 (74.5%)	40 (85.1%)	84 (75.7%)	334 (79.7%)
Non cancer	3 (7.9%)	9 (12.2%)	37 (24.8%)	6 (12.8%)	27 (24.3%)	82 (19.6%)
Missing	1 (2.6%)	0 (0%)	1 (0.7%)	1 (2.1%)	0 (0%)	3 (0.7%)
Reason for referral						
End stage care	2 (5.3%)	3 (4.1%)	18 (12.1%)	13 (27.7%)	48 (43.2%)	84 (20.0%)
Symptom control	34 (89.5%)	67 (90.5%)	126 (84.6%)	33 (70.2%)	61 (55.0%)	321 (76.6%)
Respite care	2 (5.3%)	4 (5.4%)	5 (3.4%)	1 (2.1%)	2 (1.8%)	14 (3.3%)
Outcome						
Died	8 (21.1%)	22 (29.7%)	93 (62.4%)	38 (80.9%)	102 (91.9%)	263 (62.8%)
Discharged	30 (78.9%)	52 (70.3%)	56 (37.6%)	9 (19.1%)	9 (8.1%)	156 (37.2%)

Table 3: The relationship between frailty and length of stay.

	Died					Discharged				
	Fit (CFS≤4) (N=8)	Mild (CFS 5) (N=22)	Moderate (CFS 6) (N=93)	Severe (CFS 7) (N=38)	Very severe (CFS 8) (N=102)	Fit (CFS ≤4) (N=30)	Mild (CFS 5) (N=52)	Moderate (CFS 6) (N=56)	Severe (CFS 7) (N=9)	Very severe (CFS 8) (N=9)
Length of stay (days)										
Mean (SD)	44.4 (38.8)	35.2 (22.8)	23.7 (22.6)	16.1 (18.1)	9.01 (13.5)	19.3 (14.4)	19.2 (13.0)	22.8 (16.8)	22.7 (21.0)	22.8 (21.4)
Median [Min, Max]	23.5 [10.0, 109]	28.0 [4.00, 81.0]	19.0 [1.00, 133]	11.5 [1.00, 87.0]	5.00 [0, 91.0]	15.0 [3.00, 62.0]	16.0 [3.00, 75.0]	20.0 [6.00, 93.0]	15.0 [7.00, 69.0]	15.0 [2.00, 68.0]

Table 4: Logistic regression for 14-day length of stay outcome.

	Term	Odds Ratio	95% CI		p value
			Low	Up	
Frailty Status	Fit [12]	-	-	-	-
	Mild	0.88	0.38	2.05	0.76
	Moderate	0.82	0.37	1.85	0.62
	Severe	2.43	0.94	6.47	0.07
	Very severe	5.66	2.29	14.53	<0.001
Diagnosis	Cancer (ref)	-	-	-	-
	Non cancer	1.35	0.77	2.39	0.29
Referral reason	End stage care (ref)	-	-	-	-
	Symptom control	0.70	0.38	1.28	0.25
	Respite care	13.09	2.21	252.06	0.02
Outcome	Death (ref)	-	-	-	-
	Discharged	0.94	0.56	1.58	0.82

frailty in hospices and therefore managing patients with frailty is already routine practice. It also showed that in the hospice frailty is seen amongst the elderly and the non-elderly [2,4,7].

Grouping performance status according to frailty level allows

three distinct patient groups to be identified: Those with mild frailty, moderate lengths-of-stay, and high rates of discharge. Those with severe frailty, short lengths-of-stay and high rates of death. Those with moderate frailty, long lengths-of-stay and similar rates of discharge and death. Admission reasons and outcome amongst those with moderate frailty demonstrates that prognostication and outcome prediction is most difficult for these patients. Around 80% of people with moderate frailty were referred for symptom control however 60% went on to die. Rate of performance or frailty change may provide more accurate prognostication amongst this population which may offer a solution to the clinical conundrum of whether patients should be discharged or remain in the hospice for terminal care. Objective scoring rather than subjective viewpoints may aid justification of decision making in these circumstances.

Hospice healthcare professionals regularly make decisions about when to discharge from specialist palliative care, to nursing care or home. This may be particularly challenging for people with moderate frailty, where nursing care support would suffice. However, predicting the length of support needed is difficult, and discharging patients may be perceived as risky, unsettling, and only beneficial if there will be sufficient time remaining to adjust to new care providers/setting. Much of the literature surrounding hospice discharge decision making relates to live discharges from USA hospice programmes [19].

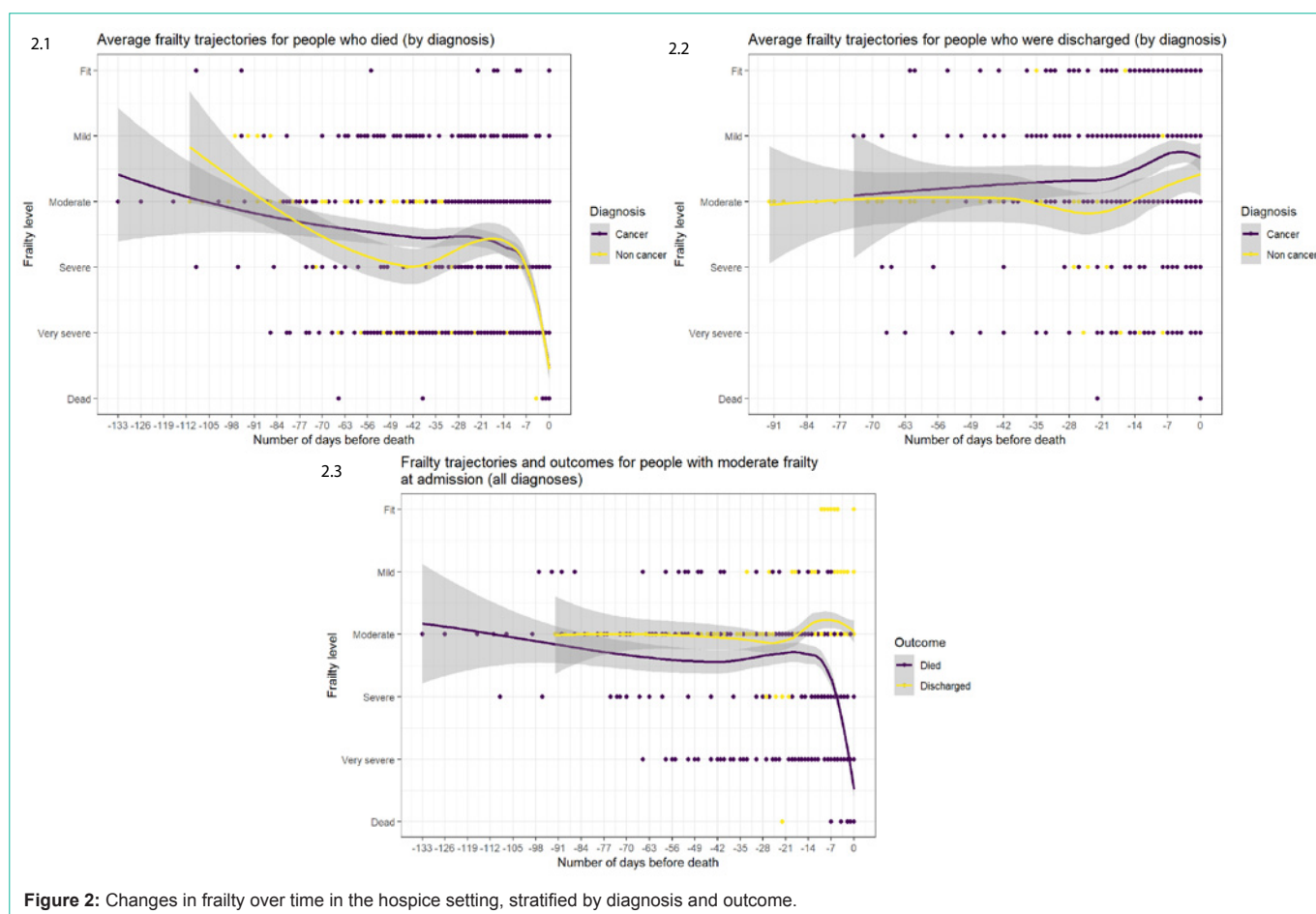


Figure 2: Changes in frailty over time in the hospice setting, stratified by diagnosis and outcome.

This is an important but distinct situation. USA hospice programmes have a financial incentive to discharge patients, and hospice profit margins are associated with the rate at which patients are discharged before death [20]. More research is required to explore links between profitability and patient-centeredness in hospice programmes, particularly the risk factors for live discharge [21].

A majority of UK hospices are not-for-profit, and appropriate use of scarce resources is a priority. UK based research has highlighted a need for multidisciplinary decisions about hospice admissions, that take an holistic view of the patient's experience [22,23]. Discharge from hospice and day hospice is a challenging area for decision-making [24]. Equitable access to support has to be balanced against potential deterioration in psychological and physical wellbeing of people no longer able to remain as an inpatient or attend day care [25]. Transfers are a common source of potential distress, particularly near the end of life. A recent review of the views and experiences of patients and their relatives undergoing transfer from hospice to care home reported that the UK literature was limited, despite such transfers being a common part of clinical practice and a source of concern. [26] The authors highlighted the need for clear communication with patients and their families and a consistent process to reduce distress. Prognostication tools may offer some support, and our study suggests that frailty level and trajectories may be helpful to decision making amongst for this group.

SPC has well developed services for people malignant disease [27,28], who made up the majority of patients in this. People with non-malignant disease often have higher levels of frailty and multimorbidity, but come into contact with SPC services later in their disease trajectory [28]. Our findings suggest that frailty predicts outcome and length of stay in both patients with malignant and non-malignant disease. As the reason SPC often fail to make an impact on the care of those with non-malignant disease, has been cited as uncertainty relating to illness trajectories and prognostication, we suggest that frailty may offer a solution. Defining and making serial measurement of frailty using the CFS may help SPC professionals feel more confident about when to get involved in the care of those with non-malignant disease. It may also aid conversations with families, other healthcare professionals and other specialists alike and go some way to bridge the malignant/non-malignant care divide, reducing the two tiered nature of current SPC provision [6,27-29].

Limitations

Conversion of the AKPS to the CFS may have introduced a degree of error and limit the conclusions that can be drawn from this data. More research is needed to validate the translation between AKPS and CFS used in this paper using simultaneous scoring by healthcare professionals, patients and carers. We also appreciate that using the AKPS or the PPS may enable rate of change to be picked up more easily, however using the CFS simplifies scoring and aids

conversations between specialties and non-specialists may feel more comfortable correctly scoring using the CFS as opposed to the AKPS/PPS [17]. This research has suggested that the defined cut offs of the CFS are likely to effectively divide up patients into categories that inform care provision, this clarity would not have been shown if looking at AKPS scores alone.

The collection of this large regional dataset required collaboration and utilised multiple personnel. Individuals all had palliative care experience and variance in entry requirements was reduced by a data entry guide.

Patient outcome was defined as whether they were died or they were discharged. Given the nature of hospice inpatient populations and patient preferences it may be that patients were discharged to die or died shortly after discharge. This information was not available from the dataset and therefore we have not been able to take this into account when interpreting the results.

More research is needed to explore if more frequent measures of AKPS and/or CFS and their trajectory might better predict outcome particularly in those with moderate frailty.

Future studies should explore if the routine measurement of frailty in specialist palliative care can aid inter specialty discussions and subsequently increase access to SPC for those with non-malignant disease and multi-morbidity.

Conclusion

This multi-site study suggests that there is a significant burden of frailty in hospices. Measuring frailty or dividing performance scores using frailty categories could support decision making. Frailty seems to divide cancer and non-cancer hospice-inpatients into three groups: Those with severe frailty, at high risk of dying with short LOS. Patients with mild/no frailty, moderate LOS and high discharge rates. Those with moderate frailty, long LOS and similar rates of discharge/death. However, the latter two groups are targets for future research as associations between frailty and length of stay were less clear. Improving SPC healthcare professionals understanding of frailty, its measurement and potential use in prognostication may improve SPC provision for patients with malignant and non-malignant disease.

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