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## **Extent of palliative care need in the acute hospital setting: a survey of two acute hospitals in the UK.**

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Keywords: palliative care; acute hospital; generalist palliative care

**Background:** In common with international health policy, The End of Life Care Strategy for England has highlighted the delivery of high quality palliative care in the acute hospital setting as an area of priority.

**Aim:** To explore the extent of palliative care need in the acute hospital setting, and to explore agreement between different sources in the identification of patients with palliative care need.

**Design::** A cross-sectional survey of palliative care need was undertaken in two UK acute hospitals. Hospital case notes were examined for evidence of palliative care need according to Gold Standards Framework (GSF) prognostic indicator criteria. Medical and nursing staff were asked to identify patients with palliative care needs. Patients (or consultees) completed assessments of palliative care need.

**Participants:** Of a total inpatient population of 1359, complete datasets were collected for 514 patients/consultees.

**Results:** 36.2% of patients were identified as having palliative care needs according to GSF criteria. Medical staff identified 15.5% of patients as having palliative care needs, and

nursing staff 17.4% of patients. Patient self-report data indicated that 83.2% of patients meeting GSF criteria, had palliative care needs.

**Conclusion:** The results reveal that according to the GSF prognostic guide, over a third of hospital in-patients meet the criteria for palliative care need. Consensus between medical staff, nursing staff and the GSF was poor regarding the identification of patients with palliative care needs. This has significant implications for patient care and draws into question the utility of the GSF in the hospital setting.

## **Background**

The majority of deaths in developed countries now occur in the acute hospital setting. Whilst countries such as the US, Australia and Canada have been successful in reducing the numbers of patients dying in hospital<sup>1</sup>, in England around 58% of people currently die in acute hospitals. Whilst recent evidence suggests a slow increase in the proportion of deaths at home in England and Wales<sup>2</sup>, other predictions based on past trends estimate that only one in ten people in the UK will die at home by 2030, and an expansion of inpatient facilities by one-fifth may be required.<sup>1</sup> The End of Life Care Strategy for England has highlighted the delivery of high quality palliative and end of life care in the acute hospital setting as an area of priority, acknowledging that a significant proportion of patients dying in acute hospitals receive very poor care.<sup>3</sup> A recent UK report has highlighted shortcomings in the care received by some patients dying in acute hospitals, including issues with the identification of patients approaching the end of life, and in the implementation of good end of life care.<sup>4</sup>

The identification of patients who may benefit from palliative care is recognised as problematic. Health professionals have reported differing understandings of what constitutes a ‘palliative care’ patient,<sup>4-6</sup> and have reported difficulties with recognising when a palliative

care approach may be appropriate.<sup>7</sup> This was evident in a study conducted in an English acute hospital in 2001 which aimed to identify the proportion of inpatients with palliative care needs, according to medical and nursing staff. Whilst 23% of the inpatient population were identified as having palliative care needs, there was a lack of concurrence between medical and nursing staff regarding which patients had palliative care needs<sup>8</sup>. Difficulties have also been recognised within primary care, with a lack of any validated tools that predict the optimal timing to initiate palliative care services in general practice, despite a wealth of international research on the prediction of mortality, survival, and prognostication for patients with advanced disease<sup>9,10</sup>. A recent systematic review identified a lack of validated criteria for identifying patients who would benefit from a transition to a palliative care approach, and highlighted that inconsistencies in the identification of patients with palliative care needs may have a negative impact on care delivery.<sup>11</sup> There are significant implications of a lack of consensus in identifying which patients have palliative care needs. Poor continuity of care, inadequate service provision and support, and excess economic cost have all been suggested as consequences of inconsistent identification of patients with palliative care needs.<sup>7,11</sup>

The National End of Life Care Programme in England has recently published recommendations for improving end of life care in acute hospitals.<sup>12</sup> The recommendations acknowledge that much end of life care in hospitals is provided by generalist clinicians, who provide care and work in partnership with specialist palliative care providers. Increasing emphasis is being placed on the role of the generalist in the provision of palliative care, however a national consultation on generalist care concluded that more needs to be known about the context of generalist provision and the influence of competing priorities.<sup>13</sup> More recent research has identified challenges in the implementation of generalist palliative care provision. Whilst generalists are recognised as having the requisite skills to provide palliative

care, the provision of this care can be complicated by conceptual issues and differing understandings of what constitutes palliative care.<sup>14</sup>

Within the context of increasing hospitalisations at the end of life, recognised challenges in the identification of patients who would benefit from palliative care input, and increasing emphasis on the role of the generalist in palliative care, it is imperative that research is undertaken to further explore palliative care in the acute hospital setting. A better understanding of the extent of palliative care need in the hospital setting is crucial in order to more appropriately map services to patient need, and define priorities for care.<sup>15</sup> The aim of this study was to explore the extent of palliative care need in the acute hospital setting, and to explore agreement between medical professionals, nursing professionals, and Gold Standards Framework (GSF) prognostic indicator criteria in the identification of patients with palliative care need.

### **Methods:**

A comprehensive survey of hospital in-patients was undertaken in two UK hospitals selected for socio-demographic diversity. Sheffield's Northern General Hospital (SNGH) has over 1100 beds and serves a largely urban, economically disadvantaged and ethnically diverse area. In contrast the Royal Lancaster Infirmary (RLI) has approximately 400 beds and serves a predominantly white Caucasian semi-rural / remote rural population.

The survey of SNGH was undertaken over an 11 day period in May 2010 and the survey of RLI over a 5 day period in Nov 2010. All in-patient wards, with the exception of children's wards and mother and baby units were included. Each ward was visited by two members of the data collection team at some point during the survey period. Inclusion criteria were

patients aged 18 years and over resident on the ward at 9am on the day the ward was surveyed. Non-English speaking patients, and deaf patients were excluded due to a lack of translation facilities. The approach to the inclusion of patients lacking capacity to consent for themselves was developed in line with Mental Capacity Act (2005) guidance.<sup>16</sup> Senior medical and nursing staff, and relatives (where available) were consulted to identify any patients lacking capacity to consent. Personal consultees (relatives or close friends) were identified and, where available, were invited to participate on behalf of patients lacking capacity. For patients/consultees who consented to participate, the following data were collected:

1. Collection of data from patients' hospital case notes comprising: evidence of palliative care need according to Gold Standards Framework (GSF) prognostic indicator criteria (the GSF prognostic indicator guide provides 11 diagnostic criteria categories which provide an indication of patients who might benefit from palliative care input)<sup>17</sup>; reason for admission; socio-demographic and diagnostic information; details of co-morbidities; evidence of adoption of a palliative care approach using a list of predefined indicators (see table 2 for indicators); number of previous hospital admissions in last 12 months; discharge plans.
2. For each consenting patient a member of medical staff and a member of nursing staff known to the patient were interviewed. Staff were asked to provide diagnostic and admission information for the patient. They were also asked whether they believed the patient to have palliative care needs according to a standardised definition (a broad and inclusive definition of palliative care was purposively selected in order to maximise potential for patient identification);<sup>18</sup> whether they would have been surprised if the patient died within 12 months; appropriateness of the admission to hospital; and whether prognostic discussions had taken place. Nursing staff were,

where possible, the designated 'named nurse' for the patient and medical staff the junior (FY1&2) or senior (ST1&2) house officer, or registrar.

3. Patient/consultee completed questionnaires comprising: socio-demographic information; a service use questionnaire developed for use with a palliative care population,<sup>19</sup> and the Sheffield Profile for Assessment and Referral to Care (SPARC).<sup>20</sup> SPARC is a validated holistic self assessment tool to identify patients who would benefit from palliative care input. It provides scores across a range of physical, psychological, and social domains. In cases where a consultee participated, they were asked to answer questions as they believed the person they were acting as consultee for would have done.

All data were collected by a team of 30 researchers with previous experience in health care research as either academics or clinicians. Data collected from hospital case notes were collected by researchers with a clinical background in medicine or nursing. All researchers attended a full day training session prior to the study commencing, with training in approaching patients/staff, correct use of data collection tools, and procedures for problem situations. Ethical approval for the study was granted by Nottingham 1 Research Ethics Committee. Research Governance approval was granted by the relevant NHS Trusts.

All data were recorded onto anonymised paper proformas and were subsequently transferred onto an SPSS database for data cleaning. Descriptive analyses were used to describe the data and Cohen's Kappa measure of chance corrected agreement was used to assess agreement between medical staff, nursing staff, and GSF criteria regarding identification of patients with palliative care needs.

## **Results**

A total of 1359 in-patients were eligible for inclusion in the survey (1009 patients in Sheffield and 350 patients in Lancaster). Of the total eligible patient population, 654 (48.1%) patients agreed to participate in the study. Patient response rates were similar for the two hospitals (SNGH 46.9%, RLI 52.9%). Figures for recruitment are given in figure 1.

Of the 654 consenting patients/consultees, complete datasets are available for 514 patients (final response rate 37.8%). A complete dataset is defined as containing a patient/consultee questionnaire, a case note review and a questionnaire completed by a member of either medical or nursing staff, but not necessarily both. Whilst the intention was to collect data from both medical and nursing staff for each patient, in practice this was difficult to achieve due to time demands on medical staff. For purposes of completeness it was therefore decided to include all cases where either medical or nursing staff had responded. For the 514 included patients, staff questionnaires were completed by nurses alone in 217 cases, by medical staff alone in 41 cases, and by both medical and nursing staff in 256 cases. The analyses presented in this paper relate to the 514 patients with complete datasets.



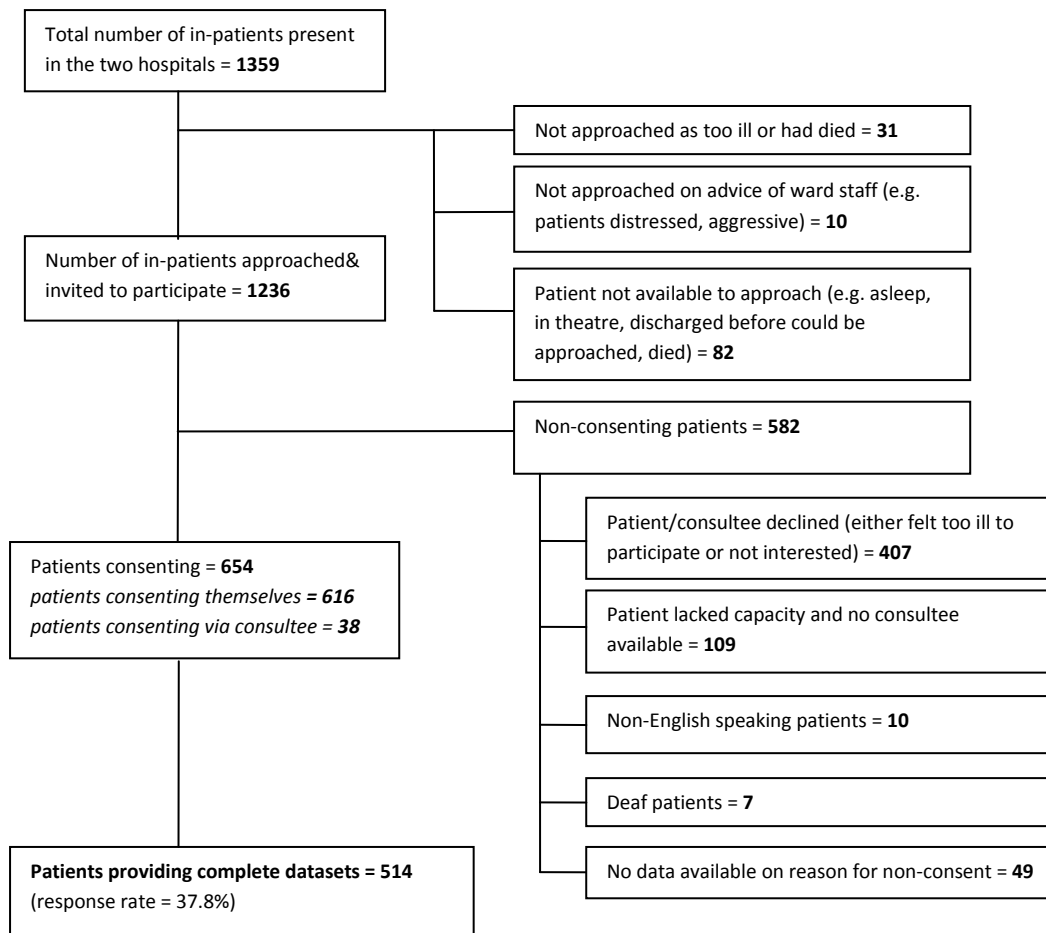


Figure 1: Details of patient recruitment at the two participating hospitals

Of the 514 patients in the sample, just over a third ( $n=185$ , 36.2%) met one or more of the GSF prognostic indicator criteria for palliative care need. The majority of the analyses presented herein relate to this sub-group. Guidance for the GSF indicators states that the indicators are intrinsically only a very approximate guide to prognosis, and should be interpreted with clinical judgement, therefore they are only used in this study as an indication that patients may have palliative care needs. Of the patients identified with palliative care needs according to GSF criteria, 53.8% were female and the median age was 78 years. The majority of patients were aged 65 or older (77.8%), with a considerable proportion aged 85 or

older (23.2%). Table 1 shows demographic information for the sample of patients with palliative care needs according to GSF criteria.

[table 1 about here]

The majority of patients (70.8%) met only one GSF criteria for palliative care need, however just under a third (29.8%) met two or more criteria (table 2). Figure 2 shows the breakdown of GSF prognostic indicators amongst the patient sample. The most common GSF prognostic indicator was frailty, with almost a third of patients (27%) meeting this criteria. Heart disease (20.5%), cancer (19.5%), chronic obstructive pulmonary disease (COPD) (18.4%), and dementia (17.8%) were the next most common GSF criteria, and were roughly equal in prevalence. Other indicators including stroke and renal disease were less common.

[figure 2 about here]

Table 2 provide admission and diagnostic information for the group of 185 patients with GSF defined palliative care needs. Reason for admission to hospital was ascertained in all but five patients. The most common reasons for admission were falls/confusion/general frailty (14.6%), complications relating to cancer (13%), and respiratory disease or exacerbation (13%). Patients had a median of two co-morbid conditions, with over a third of patients having three or more co-morbidities. Most patients had been admitted to hospital at least once in the 12 months prior to the survey. For the majority of patients (65.9%) there was no evidence of adoption of a palliative care approach. Around a third (28.6%) of patients had a Do Not Attempt Resuscitation (DNAR) order in place, but only a small number (8.1%) had been referred to specialist palliative care services.

[table 1 about here]

Medical and nursing staff were asked whether they believed patients to have palliative care needs according to the Canadian Palliative Care Association(1997) definition.<sup>18</sup> Nurse questionnaires were completed for 473 patients, of these nurses stated that 84 (17.8%) had

palliative care needs. However, data from patients hospital case notes indicated that only 174 (36.8%) of these 473 patients were identified as having palliative care needs according to GSF criteria (table 3). Nursing staff were also asked “would you be surprised if this patient died: (a) during this admission? and (b) in the next 12 months?”. Nursing staff would not have been surprised if the patient died during the current admission in 74 (15.6%) cases, and in the next 12 months in 180 (38.0%) cases. Medical staff questionnaires were completed for 297 patients, of these doctors stated that 46 (15.5%) had palliative care needs, whereas using the GSF criteria 108 (36.4%) were identified with palliative care needs (table 3). Medical staff would not have been surprised if the patient died during the current admission in 50 (16.8%) cases, and in the next 12 months in 123 (41.4%) cases.

Table 3 shows the level of agreement between medical staff, nursing staff and the GSF regarding the identification of patients with palliative care needs. The measure of chance corrected agreement Cohen’s Kappa indicates a poor agreement between nursing staff and GSF (n=473, Kappa: 0.22) in terms of identifying patients with palliative care needs. Agreement between medical staff and GSF is poor (n = 297, Kappa: 0.25). Agreement between medical and nursing staff regarding which patients had palliative care needs was moderate (n = 256, Kappa: 0.42).<sup>21</sup>

[table 3 about here]

Self-report questionnaires were completed for all 185 patients identified with palliative care needs according to GSF criteria. Questionnaires were completed by patients in 162 cases (87.6%), and by consultees in 23 cases (12.4%). The SPARC questionnaire provides a self assessment of palliative care needs and scores variables from 0 to 3, a score of 3 on any variable indicates that the patient merits ‘*immediate attention by the attending clinician*’. SPARC contains variables in six domains: physical symptoms; psychological symptoms;

religious and spiritual issues; independence and activity; family and social issues; and treatment issues. The majority of patients (n=154, 83.2%) scored 3 on at least one variable in one of the six domains. Physical symptoms were most troublesome with 74.6% of patients scoring 3 on one or more variable in this domain. Patients also reported high levels of psychological symptoms (43.2%), but fewer problems relating to the other domains (figure 3). Consensus between patients and medical staff (Kappa=0.20, n=107), and patients and nursing staff (Kappa=0.20, n=173) was poor regarding identification of palliative care need, when a SPARC score of 3 on >1 variable was used a proxy for self assessed palliative care need.

[figure 3 about here]

Sex	Male	85 (45.9%)
	Female	100 (54.1%)
Partnership status	Married	66 (35.7%)
	Single	19 (10.3%)
	Divorced	18 (9.7%)
	Widowed	59 (31.9%)
	Not stated	23 (12.4%)
Living Arrangements	Co-habits	89 (48.1%)
	Lives alone	78 (42.2%)
	Nursing home or residential care	18 (9.7%)
Median age		78 years

Table 1: Demographic information for patients with palliative care needs according to GSF criteria (n=185)

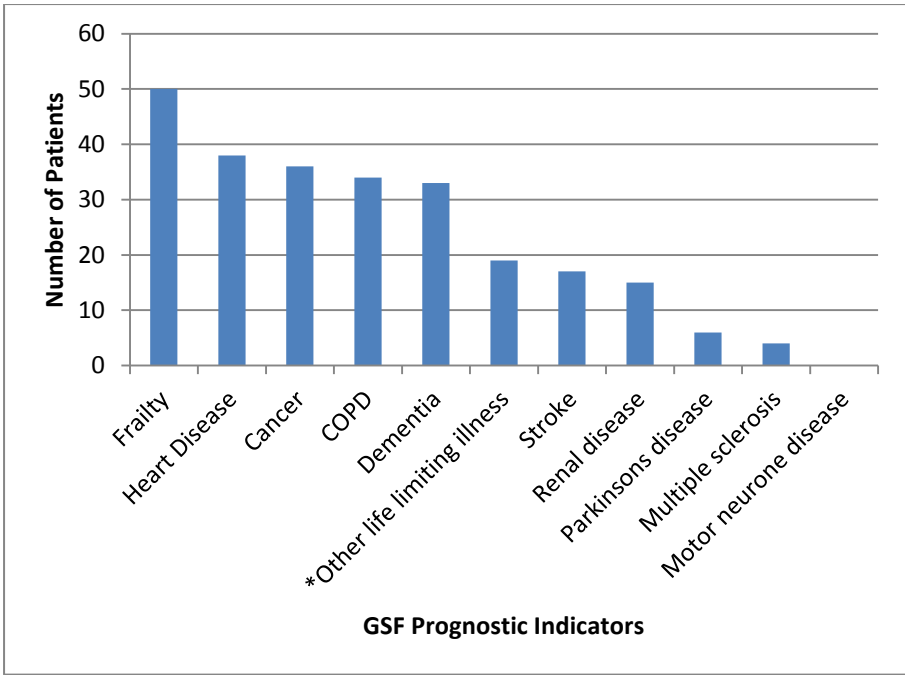


Figure 2: Numbers of patients (n=185) meeting each of the GSF prognostic indicators for palliative care need. \*Other life limiting illness included cystic fibrosis, Huntingtons disease, asbestosis etc.

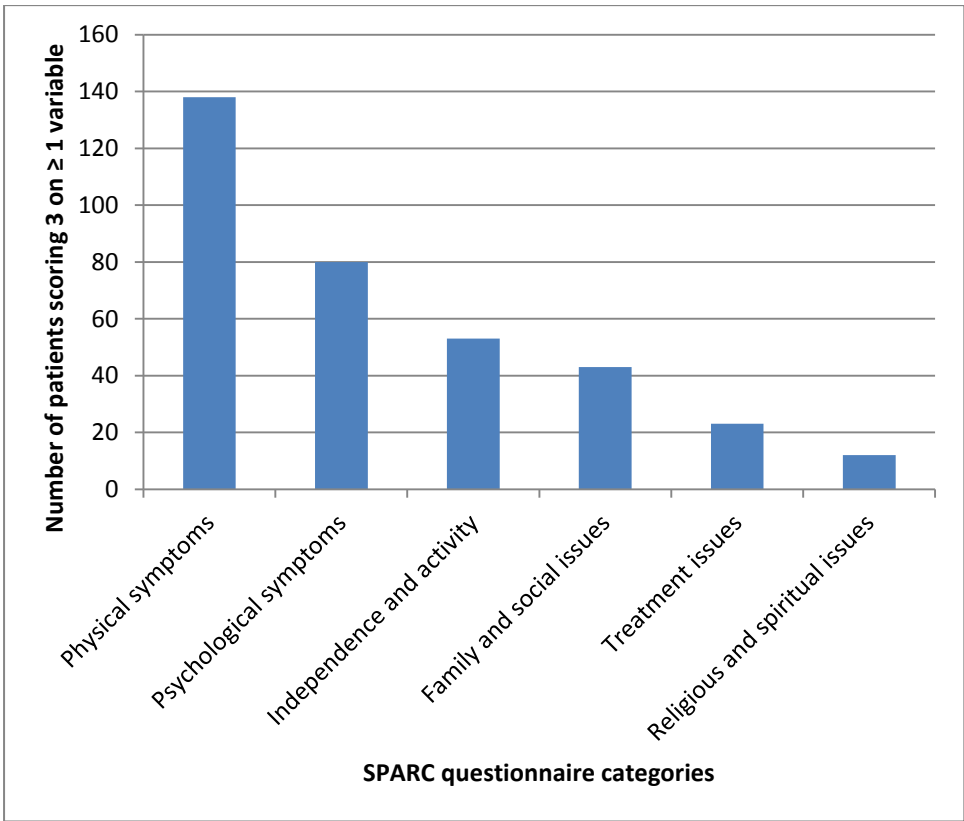


Figure 3: SPARC questionnaire responses for patients with palliative care needs according to GSF criteria (n=185).

Reason for admission	General frailty/fall/confusion or deterioration	27 (14.6%)
	Cancer or cancer related problems	24 (13%)
	Respiratory disease or exacerbation	24 (13%)
	Chronic heart disease	12 (6.5%)
	Dementia	12 (6.5%)
	Infection	12 (6.5)
	Accidental injury	12 (6.5%)
	Renal failure	10 (5.4%)
	Stroke	10 (5.4%)
	MI/Acute cardiac event	10 (5.4%)
	Neurological conditions (exc dementia)	5 (2.7%)
Other	27(14.6%)	
Number of co-morbid conditions per patient	0	11 (5.9%)
	1	64 (34.6%)
	2	43 (23.2%)
	3	41 (22.2%)
	>3	26 (14.1%)
Number of GSF prognostic indicator criteria per patient	1	131 (70.8%)
	2	43 (23.2%)
	>3	11 (5.9%)
Number of hospital admissions in previous 12 months (excluding current admission)	0	31 (16.8%)
	1	52 (28.1%)
	2	26 (14.1%)
	3	18 (9.7%)
	>3	20(10.8%)
	Missing data	38(20.5%)
Number of days in hospital in last 12 months	1 – 20	65 (35.1%)
	21 – 40	27 (14.6%)
	41 – 60	15 (8.1%)
	> 60	28 (15.1%)
	Missing data	50 (27.0%)
Indicators of adoption of a palliative care approach	Do Not Attempt Resuscitation order in place	53 (28.6%)
	Evidence of referral to specialist palliative care	15 (8.1%)
	Placed on Liverpool Care Pathway	2 (1.1%)
	Prescription of long term opiates/syringe driver	9 (4.9%)
	Documented Advanced Care Plan	0 (0%)
	No indicators of palliative care approach	122 (65.9%)

Table 2: Participant admission and diagnostic data for patients with palliative care needs according to GSF criteria (n=185)

	Palliative care need according to GSF	No palliative care need according to GSF
Nursing staff assessment of palliative care need available (n=473)	174	299
- Palliative care need according to nurse	52 (30%)	32 (11%)
- No palliative care need according to nurse	122 (70%)	267 (89%)
	Kappa = 0.22, n = 473	
Medical staff assessment of palliative care need available (n=297)	108	189
- Palliative care need according to doctor	32 (30%)	14 (7%)
- No palliative care need according to doctor	76 (70%)	175 (93%)
	Kappa = 0.25, n = 297	

Table 3: Agreement between nursing staff, medical staff, and GSF regarding the identification of patients with palliative care needs.

## Discussion

This paper presents data from a survey of palliative care need in two acute hospitals in the UK. To our knowledge this is the first study which has attempted to profile the inpatient palliative care population of acute hospitals using a comprehensive dataset combining data from hospital case notes, a member of the clinical team, and patients. The results reveal that within our sample, according to the GSF prognostic indicator guide over a third of hospital in-patients (36.2%) meet the criteria for palliative care need. This figure is substantially higher than other estimates of palliative care need in the acute hospital population. A French survey in 1999 reported that only 13% of total hospital beds were occupied by palliative care patients.<sup>22</sup> In a census undertaken in the UK in 2001, 23% of hospital in-patients were

identified as having palliative care needs.<sup>8</sup> A more recent study in 2011 reported that just 9.4% of hospital patients in Belgium were identified as having palliative care needs.<sup>23</sup> All of these studies used the subjective judgement of generalist medical and nursing staff to identify patients with palliative care need, rather than an objective measure based on diagnostic criteria. Our results show that when using a systematic and objective measure, the percentage of patients with identified need is much higher and represents a substantial proportion of the inpatient population. Clearly a limitation that must be acknowledged is the low patient response rate (37.8%) and a probable response bias as a result of the self-selected nature of the patient sample. However as the overwhelming reason given for non-participation was that patients felt too ill, we believe that our sample constituted the ‘most well’ of the inpatient population. As such the findings presented here may under-estimate the true incidence of palliative care need in the acute hospital setting.

The profile of this group is overwhelmingly frail older people, with multiple co-morbidities and multiple previous admissions to hospital. This finding has significant implications for the way in which we define and conceptualise palliative care need both in the UK and internationally. Specialist palliative care was developed around a cancer model, and whilst in recent years policy and practice has seen a shift away from a cancer focus, patients with non-malignant disease are still disadvantaged when it comes to equitable access to specialist palliative care.<sup>24,25</sup> Older people are also disadvantaged when it comes to access to specialist palliative care.<sup>6,26</sup> However our study shows that older people with non-cancer diagnoses constitute the majority of patients with palliative care need in the acute hospital population in the UK. Whilst specialist palliative care services must explore ways to better address the needs of this group, specialist resources are limited and may serve most effectively as a resource to support care by other clinical teams. There is a lack of clarity regarding the role of



the geriatrician in terms of responsibility for providing palliative care,<sup>27,6</sup> yet these professionals play a key role in the provision of palliative care for older people. Further research is needed to develop appropriately resourced and effective ways for specialists and generalists to work together to meet the needs of the growing population of frail older people with palliative care needs.

The most significant finding from this study is the lack of concordance between medical staff, nursing staff, and GSF prognostic indicators regarding the identification of patients with palliative care needs. Whilst it must be acknowledged that medical and nursing staff were using a different definition of palliative care need<sup>16</sup> than the GSF, the Canadian definition was selected on the basis that it is one of the broadest and most inclusive definitions, and is not restricted to particular diagnostic groups. Despite this, medical and nursing staff identified far fewer patients with palliative care needs than the GSF. Significantly, for the majority of patients who met GSF criteria for palliative care need, there was no evidence of adoption of a palliative care approach (table 2). Even amongst patients who were expected to die within 12 months, recognition of palliative care need was inconsistent. This is despite the '12 months' question constituting a key component of UK palliative care guidance.<sup>3,12</sup> Data from the SPARC questionnaire indicates that of the patients identified with palliative care needs according to GSF criteria, the majority had problems that warranted immediate attention by an attending clinician. Despite this, the level of agreement between medical and nursing staff, and patients, was poor regarding which patients had palliative care needs.

The identification of patients with palliative care needs presents a recognised challenge.<sup>5,7,11</sup> Recent policy recommends that health professionals should be trained to identify patients approaching the end of life, and to recognise when patients are dying.<sup>2</sup> However there is a

lack of consensus regarding how these patients should be identified and this has significant implications for patient care. A lack of recognition of palliative care need can result in unnecessary interventions, inappropriate hospitalisations with a potential economic impact, inappropriate treatments, and reduced patient and carer quality of life.<sup>28-31</sup>

The challenge in agreeing a consensus of definition and identification has additional implications for generalist palliative care providers. Recent policy and research has sought to engage more effectively with the generalist provider,<sup>13-14</sup> however our research shows that many generalists are struggling to identify patients who might benefit from palliative care input. Generalist palliative care is increasingly central to hospital based palliative care provision, particularly for the group of frail older people who appear to constitute the greater proportion of this population in the hospital setting.<sup>6</sup> It is crucial that generalists are provided with opportunities for greater partnership working with SPC colleagues, in order that palliative care resources can be used more effectively amongst a range of hospital based professionals. In addition there is a clear need for a consensus of definition, and for standardised validated criteria for the identification of patients with palliative care needs. Our data also suggest that patient completed questionnaires such as SPARC may be helpful in identifying patients with palliative care needs. Results indicated that SPARC scores show better agreement with the GSF than do either medical or nursing staff opinion, therefore the use of patient complete questionnaires should perhaps be considered more widely in order to assist in the identification of patients with palliative care needs.

### **Limitations**

Whilst this study provides important evidence relating to palliative care in acute hospitals, certain limitations must be acknowledged. The GSF was developed as a tool for use in

primary care, and has to date received no formal validation in the hospital setting.<sup>17</sup>

Criticisms of the GSF include that it is a poor predictor of mortality,<sup>32</sup> therefore its use as a tool for identifying patients with palliative care needs in hospital should be further explored..

In 23 cases consultees completed questionnaires on behalf of patients who lacked capacity to consent, and responses given via consultee may not be accurate. Therefore caution is required in interpreting findings from the questionnaire responses, and further research should seek to compare self-assessment and consultee-assessment measures to explore consensus.

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