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Hospitalised patients with palliative care needs: Spain and Sweden compared

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ABSTRACT

Objectives This study aimed to describe and compare symptoms, care needs and types of diagnoses in hospitalised patients with palliative care needs in Spain and Sweden.

Methods A cross-sectional, population-based study was carried out at two hospitals in both Spain and Sweden. Using a questionnaire, we performed 154 one-day inventories (n=4213) in Spain and 139 in Sweden (n=3356) to register symptoms, care needs and diagnoses. Descriptive analyses were used.

Results The proportion of patients with care needs in the two countries differed (Spain 7.7% vs Sweden 12.4%, p<0.001); however, the percentage of patients with cancer and non-cancer patients was similar. The most prevalent symptoms in cancer and non-cancer patients in both countries were deterioration, pain, fatigue and infection. The most common cancer diagnosis in both countries was lung cancer, although it was more common in Spain (p<0.01), whereas prostate cancer was more common among Swedish men (p<0.001). Congestive heart failure (p<0.001) was a predominant non-cancer diagnosis in Sweden, whereas in Spain, the most frequent diagnosis was dementia (p<0.001). Chronic obstructive pulmonary disease was common in both countries, although its frequency was higher in Spain (p<0.05). In total, patients with cancer had higher frequencies of pain (p<0.001) and nausea (p<0.001), whereas non-cancer patients had higher frequencies of deterioration (p<0.001) and infections (p<0.01).

Conclusions The similarities in symptoms among the patients indicate that the main focus in care should be on patient care needs rather than diagnoses. Integrating palliative care in hospitals and increasing healthcare professional competency can result in providing optimal palliative care.

BACKGROUND

Several factors determine the place of care in the of end of life, such as characteristics of community-based care, presence of informal caregivers, illness factors, overall health and complexity of care needs.¹ Moreover, if a diagnostic procedure is a prerequisite for a care intervention, this may also affect place of care. Many patients receive palliative care in an institution despite a wish to stay home.² Gomes *et al*³ found that most people prefer the home environment even if their illness progresses. However, this is not always a realistic option and hospital care remains an alternative.

Despite efforts to offer palliative care in primary care and at nursing homes, admissions to acute hospitals still occur. Therefore, a considerable proportion of patients are cared for and die in acute hospital environments.^{4 5} A high percentage of palliative care patients continue to be cared for in hospitals, which theoretically are designed for curative and life-prolonging measures, not primarily for palliative care. Vogl *et al*⁶ also argue that patients with palliative care needs differ from acute patients regarding the care they need, as does the complexity of their unique situation.

Earlier research focused on symptoms and care needs in patients with cancer in the context of specialised palliative care at hospice and palliative care units^{7–10} and focused less on acute care hospitals and reasons for hospitalisation.^{11–13} More knowledge is needed regarding the extent of palliative care needs and prevalence and characteristics of symptoms in acute care hospitals, especially in regions with limited availability to specialised palliative care 24/7. Moens *et al*¹⁴ argue that research is also needed to compare

palliative care and associated problems between patients with cancer and non-cancer patients using the same measuring tools.

It is important to determine the symptoms and care needs of patients and assess whether the needs differ across various types of patients and sociocultural contexts in different countries. The unique aim of this study was, therefore, to describe and compare symptoms, care needs and types of diagnoses among hospitalised palliative patients in Spain and Sweden.

METHODS

Design and setting

This cross-sectional, population-based study was conducted at the departments of Oncology, Surgery and Medicine in two Spanish and two Swedish hospitals. Those in Spain served almost 200 000 individuals on all levels, and served as specialised hospitals (tertiary care hospitals) for 650 000 inhabitants. The two hospitals in Sweden served almost 194 000 individuals, in a medium-sized county in southern Sweden. The counties in Spain and Sweden had no 24 hours specialised palliative care services but had access to a palliative advisory team during daytime hours, from Monday to Friday. These teams affiliated with the hospitals and supported healthcare professionals in the home healthcare. In Spain, the advisory team consisted of 3 physicians, 13 registered nurses and 13 nurses assistants. In Sweden, the team consisted of 3 physicians (halftime), 6 nurses and one social worker. In one of the internal medicine wards in Spain, 10 beds were reserved mainly for patients with palliative care needs. The counties in Sweden had no such reserved beds.

Questionnaire

A questionnaire with 14 items was used. The questionnaire included organisational and healthcare aspects (clinic wards, number of beds, number of palliative patients, etc), demographic data (age, sex, main diagnosis, etc), and a list of a total 21 different symptoms and/or interventions during the hospitalisation. An optional comments section was provided. The detailed WHO's definition of palliative care was printed on the back of the questionnaire and used as an aid for the identification of patients as being in a palliative phase. WHO defines palliative care¹⁵ as an approach 'that improves the quality of life of patients and their families facing the problem associated with life-threatening illness'. The comprehensive and detailed definition also underlines (among other issues) the importance of '...early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'. The questionnaire was pilot tested in 2002 for face and content validity by a panel of palliative care experts¹⁶ and has been used in earlier studies.^{13 16}

Data collection

On a specific day every month, the nurses in cooperation with the physicians, assessed all inpatients regardless of their primary reasons for admission, and those who were assessed as palliative were registered in the questionnaires. In order to get comparable assessments, it was of utmost importance that each nurse knew how to assess patients as palliative and how to complete the questionnaire. We therefore met with the nurses in charge of the different wards to discuss how to assess a patient as being in a palliative phase in accordance with the WHO's definition of palliative care.¹⁵ A patient whose disease was not responsive to curative treatment and where the prognosis was limited, was defined as a patient being in a palliative phase. The patient could be in either an early or a late palliative phase. To get comparable assessments of how to identify right patients, we discussed the palliative care definition and how to perform assessments by discussing different patient cases. We also explained that the reasons for hospitalisation could be different symptoms (such as pain and nausea) and/or interventions (such as diagnostic procedure and palliative radiotherapy).

In Spain, data were collected in 16 wards in 2015: 1 oncology ward (22 beds), 4 surgical wards (127 beds) and 11 medical wards (296 beds). In Sweden data were collected in 12 wards in 2012: 1 oncology ward (17 beds), 4 surgical wards (85 beds) and 7 medical wards (162 beds). In Spain, there were 154 one-day inventories (data missing for 5 days, ie, 3.1%) and in Sweden, there were 139 one-day inventories (data missing for 5 days, ie, 3.5%). In both Spain and Sweden, all inpatients on the involved wards were assessed once a month during 1 year. In total, 4213 patients were assessed in Spain and 3356 patients in Sweden.

Statistical analysis

A descriptive analysis of demographic and clinical variables was performed. Qualitative variables are presented as frequency and percentages. In the quantitative variables, the mean, median and SD were calculated. The variables were compared using bivariate analyses. Pearson's χ^2 test was used for comparison of proportions, and Mann-Whitney U test was used after applying the Kolmogorov-Smirnov normality test. Values of $p < 0.05$ were considered statistically significant. IBM SPSS statistics V.24 (IBM) was used to perform the analyses.

RESULTS

Regarding hospitalised patients with palliative care needs, there was a significant difference between Spain (325/4213) and Sweden (354/3356), with 7.7% and 12.4%, respectively ($p < 0.001$). Of those, 76.6% and 74.6% of the Spanish and Swedish patients had cancer diagnoses (data not shown). The patients were significantly younger in Spain ($p < 0.001$) and more than half

Table 1 Characteristics, situational data and prevalence of symptoms and care needs for all palliative patients

	Spain			Sweden		
	All (n=325)	Male (n=201)	Female (n=124)	All (n=354)	Male (n=181)	Female (n=173)
Age; mean, (range) SD	68.6, (21–101) 14.4	69.9, (21–94) 12.8	66.8, (21–94) 16.6	74.9, (38–102) 12.2***	75.6, (38–98) 11.5***	74.2, (45–102) 12.8***
Connected to palliative team; %	52***	52.7***	50.8***	17.5	16.6	18.5
No of symptoms and care needs per patient; mean, median (range)	3.0, 3 (1–8)	3.0, 3 (1–8)	3.1, 3 (1–6)	2.8, 3 (1–9)	2.8, 3 (1–8)	2.9, 3 (1–9)
Symptoms/care needs; %						
Blood transfusion	6.5	7.0	5.6	10.5	11.0	9.8
Congestive heart failure treatment	4.0	3.5	4.8	11.0**	9.9*	12.1*
Deterioration	68.6***	67.7***	70.2***	42.4	38.1	46.8
Diagnostic procedure	11.7	13.4	8.9	18.4*	16.6	20.2**
Fatigue	24.6	22.4	28.2	28.0	28.7	27.2
Infection	20.3	18.4	23.4	26.0	29.8**	22.0
Infusion	11.1*	8.0	16.1**	6.8	7.2	6.4
Nausea	17.5	14.9	21.8	12.7	10.5	15.0
Nutrition	18.2	18.4	17.7	20.3	19.3	21.4
Obstipation	11.7**	10.9	12.9*	5.6	6.1	5.2
Pain	45.5*	44.8	46.8*	35.9	37.0	34.7
Pleuracentes	1.8	1.5	2.4	5.1*	5.5*	4.6
Palliative radiotherapy	0.9	–	2.4	12.7***	13.3***	12.1**
Psychosocial issues	9.2***	9.0*	9.7***	1.7	2.8	0.6
Social problems	14.8***	16.4**	12.1	6.5	6.1	6.9
Palliative surgery	5.8	6.0	5.6	8.5	8.8	8.1

Significant difference between the countries (indicated with * at the higher value).

*P<0.05, **p<0.01, ***p<0.001.

Table 2 Characteristics, situational data and prevalence of symptoms and care needs for non-cancer patients

	Spain			Sweden		
	All (n=76)	Male (n=39)	Female (n=37)	All (n=90)	Male (n=46)	Female (n=44)
Age; mean, (range) SD	78.5, (21–101) 11.8	79.8, (40–101) 10.1	77.1, (21–94) 13.4	84.7, (56–102) 8.4***	85.1, (56–96) 7.8**	84.3, (66–102) 9.0**
No of symptoms and care needs per patient; mean, median (range)	3.3, 3 (1–7)***	3.5, 3 (1–7)**	3.2, 3 (1–6)*	2.4, 2 (1–6)	2.3, 2 (1–5)	2.6, 2 (1–6)
Connected to palliative team; %	18.4**	20.5**	16.2**	3.3	4.3	2.3
Symptoms/care needs; %						
Blood transfusion	6.6	7.7	5.4	5.6	2.2	9.1
Congestive heart failure treatment	9.2	10.3	8.1	34.4***	32.6*	36.4**
Diagnostic procedure	13.2	10.3	16.2	12.2	8.7	15.9
Deterioration	90.8***	87.2***	94.6***	48.9	41.3	56.8
Fatigue	32.9	28.2	37.8*	21.1	23.9	18.2
Infection	31.6	33.3	29.7	34.4	39.1	29.5
Inhalation	5.3	10.3	–	10.0	10.9	9.1
Infusion	18.4**	10.3	27.0**	3.3	4.3	2.3
Nausea	9.2*	12.8	5.4	1.1	2.2	–
Nutrition	26.3	25.6*	27.0	18.9	8.7	29.5
Obstipation	9.2*	12.8	5.4	1.1	2.2	–
Pain	30.3	35.9	24.3	22.2	23.9	20.5
Psychosocial issues	11.8**	10.3	13.5*	1.1	2.2	–
Social problems	17.1***	25.6***	8.1	1.1	–	2.3

Significant difference between the countries (indicated with * at the higher value).

*P<0.05, **p<0.01, ***p<0.001.

Table 3 Characteristics, situational data and prevalence of symptoms and care needs for patients with cancer

	Spain			Sweden		
	All (n=249)	Male (n=162)	Female (n=87)	All (n=264)	Male (n=135)	Female (n=129)
Age; mean, (range) SD	65.6, (28–92) 13.7	67.4, (32–92) 12.2	62.3, (28–91) 15.8	71.5, (38–98) 11.4***	72.3, (38–98) 10.8***	70.7, (45–94) 12.1***
No of symptoms and care needs per patient; mean, median (range)	2.9, 3 (1–8)	2.8, 3 (1–8)	3.1, 3 (1–6)	3.0, 3 (1–9)	3.0, 3 (1–8)	3.0, 3 (1–9)
Connected to palliative team; %	62.2***	60.5***	65.5***	22.3	20.7	24
Symptoms/care needs; %						
Abdominal surgery	4.0	3.7	4.6	5.3	6.7	3.9
Blood transfusion	6.4	6.8	5.7	12.1*	14.1*	10.1
Diagnostic procedure	11.4	14.2	5.7	20.5**	19.3	21.7**
Deterioration	61.8***	63.0***	59.8*	40.2	37.0	43.4
Fatigue	22.1	21.0	24.1	30.3*	30.4	30.2
Infection	16.9	14.8	20.7	23.1	26.7*	19.4
Infusion	8.8	7.4	11.5	8.0	8.1	7.8
Nausea	20.1	15.4	28.7	16.7	13.3	20.2
Nutrition	15.7	16.7	13.8	20.8	23.0	18.6
Obstipation	12.4*	10.5	16.1*	7.2	7.4	7.0
Pain	50.2*	46.9	56.3*	40.5	41.5	39.5
Pleuracentes	1.6	0.6	3.4	6.4**	6.7**	6.2
Palliative radiotherapy	1.2	–	3.4	17.0***	17.8***	16.3**
Psychosocial issues	8.4**	8.6*	8.0**	1.9	3.0	0.8
Social problems	14.1*	14.2	13.8	8.3	8.1	8.5
Palliative surgery	7.6	7.4	8.0	9.8	10.4	9.3

Significant difference between the countries (indicated with * at the higher value).

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

of the patients in Spain were enrolled in a palliative care team ($p < 0.001$) (table 1).

Symptoms and care needs

The number of symptoms and care needs per patient for the whole study group was similar in Spain (3.0) and Sweden (2.8) (table 1), whereas Spanish non-cancer patients had more symptoms and care needs, 3.3 compared with 2.4 ($p < 0.001$) (table 2).

The most prevalent symptoms causing hospitalisation in each country were deterioration, pain, fatigue and infection (table 1). However, the frequencies varied; deterioration ($p < 0.001$), pain ($p < 0.05$), obstipation ($p < 0.01$) were higher in Spain. In a subanalysis of patients with cancer (table 3), pain was a more frequent reason for hospitalisation in Spanish patients (50.2% vs 40.5%, $p < 0.05$), whereas fatigue was less frequent (22.1% vs 30.3%, $p < 0.05$). In non-cancer patients, deterioration was much more common (90.8% vs 48.9%, $p < 0.001$). Furthermore, nausea and obstipation were more frequent problems among Spanish non-cancer patients (< 0.05 and < 0.05 , respectively) (table 2). The differences between male and female patients within each country were minor.

Hospitalisation due to social problems ($p < 0.001$), psychosocial issues ($p < 0.001$) and need of infusions ($p < 0.05$) were more prevalent in Spanish patients, whereas the need for palliative radiotherapy ($p < 0.001$), congestive heart failure treatment

($p < 0.01$) or diagnostic procedures ($p < 0.05$) were more frequent in Sweden (table 1).

In Spanish patients with cancer, psychosocial issues and social problems were significantly more common reasons for hospitalisation, whereas interventions such as palliative radiotherapy, pleuracenteses, diagnostic procedures and blood transfusions were more prevalent in the Swedish settings ($p < 0.05$ – $p < 0.001$) (table 3).

Among non-cancer patients, psychosocial issues and social problems were more frequent reasons for admission in Spain than in Sweden. This was also true for the need of infusions, whereas congestive heart failure treatment was the most prevalent cause in all non-cancer patients in Sweden, and much more common than in Spain (34.4% vs 9.2%, $p < 0.001$). Details are presented in table 2.

All patients with cancer versus all non-cancer patients

When comparing all patients with cancer ($n = 513$) to all non-cancer patients ($n = 166$) regardless of country, patients with cancer had higher frequencies of pain ($p < 0.001$), nausea ($p < 0.001$) and obstipation ($p < 0.05$). However, non-cancer patients had higher frequencies of deterioration ($p < 0.001$) and infections ($p < 0.01$) (table 4).

Diagnoses in hospitalised palliative patients with cancer

In hospitalised palliative patients with palliative cancer, lung cancer was the most frequent cancer in both

Table 4 Prevalence of symptoms and care needs for all hospitalised cancer versus non-cancer palliative patients

	Patients with cancer			Non-cancer patients		
	All (n=513)	Male (n=297)	Female (n=216)	All (n=166)	Male (n=85)	Female (n=81)
No of symptoms and care needs per patient; mean, median (range)	3.0, 3 (1–9)	2.9, 3 (1–8)	3.0, 3 (1–9)	2.7, 3 (1–7)	2.8, 3 (1–7)	2.9, 3 (1–6)
Symptoms/care needs; %						
Deterioration	51.1	51.9	50	68.1***	62.4	74.1***
Diagnostic procedure	16	16.5	15.3	12.7	9.4	16
Fatigue	26.5	25.6	27.8	26.5	25.9	27.2
Infection	20.1	20.2	19.9	33.1**	36.5**	29.6
Nausea	18.3***	14.5	23.6***	4.8	7.1	2.5
Nutrition	18.3	19.5	16.7	22.3	16.5	28.4*
Obstipation	9.7*	9.1	10.6*	4.8	7.1	2.5
Pain	45.6***	45.1*	46.3***	25.9	29.4	22.2
Social problems	11.1	11.4	10.6	8.4	11.8	4.9

Significant difference between patients with cancer and non-cancer patients (indicated with * at the higher value).

*P<0.05, **p<0.01, ***p<0.001.

countries, although prevalence was lower in Sweden ($p<0.01$). In contrast, prostate cancer among men was significantly higher in Sweden ($p<0.001$). In women, the most prevalent cancer in both Spain and Sweden was gynaecological (NS) (table 5).

Diagnoses in hospitalised palliative non-cancer patients

The diagnoses of non-cancer palliative patients varied significantly between the countries. In Spain, dementia was the most frequent diagnosis and more common than in Sweden ($p<0.001$). Chronic obstructive pulmonary disease was common in both countries, although higher in Spain ($p<0.05$). Congestive heart failure was the most frequent diagnosis in Sweden and more common than in Spain ($p<0.001$). Parkinson's, liver failure and haemorrhage diagnoses were found

in Spanish patients, whereas there was minimal or no prevalence in Sweden (table 6).

DISCUSSION

In all healthcare systems, competent care is a goal. Generally, only symptoms or care needs that cannot be managed on other levels of care should be reasons for admission to an acute care hospital. Optimally developed primary care, and nursing homes with adequate resources should provide palliative care to patients. Our results reinforce this, indicating that 7.7% and 12.4% of the Spanish and Swedish patients at acute care hospitals were palliative patients for whom alternative care levels would have been desirable. These results are in line with the percentage of palliative patients found

Table 5 Prevalence of cancer diagnosis in hospitalised palliative patients in Spain and Sweden

	Spain			Sweden		
	All (n=249)	Male (n=162)	Female (n=87)	All (n=264)	Male (n=135)	Female (n=129)
Cancer diagnosis; %						
Bile duct	2.4	1.9	3.4	4.2	2.2	6.2
Breast	3.6	–	10.3	7.6	–	15.5
Cerebral	3.2	1.9	5.7	2.7	2.2	3.1
Colorectal	13.3	13.6	12.6	11.4	11.1	11.6
Gynaecological	4.8	–	13.8	8.7	–	17.8
Lung	21.7*	29.0***	8.0	11.4	10.4	12.4
Lymphoma	2.4	1.9	3.4	3.4	5.9	0.8
Melanoma	1.6	1.2	2.3	3.0	0.7	5.4
Pancreas	11.2	11.1	11.5	7.6	8.9	6.2
Prostate	3.6	5.6	–	11.4**	22.2***	–
Stomach/oesophagus	12.0	12.3	11.5	8.7	11.1	6.2
Unknown primary	2.0	3.1	–	4.9	5.2	4.7*
Urological	6.0	6.8	4.6	3.8	6.7	0.8

Significant difference between the countries (indicated with * at the higher value).

*P<0.05, **p<0.01, ***p<0.001.

Table 6 Prevalence of diagnosis (non-cancer) in hospitalised palliative patients in Spain and Sweden

	Spain			Sweden		
	All (n=76)	Male (n=39)	Female (n=37)	All (n=90)	Male (n=46)	Female (n=44)
Diagnosis (non-cancer); %						
Acute myocardial infarction	2.6	2.6	2.7	6.7	2.2	11.4
Chronic renal failure	6.6	7.7	5.4	10.0	15.2	4.5
Circulatory insufficiency	13.2*	12.8	13.5	4.4	6.5	2.3
Congestive heart failure	3.9	2.6	5.4	37.8***	39.1***	36.4**
Chronic obstructive pulmonary disease	18.4*	23.1	13.5	7.8	8.7	6.8
Dementia	26.3***	17.9*	35.1***	2.2	2.2	2.3
Haemorrhage	5.3 *	2.6	8.1	–	–	–
Intestinal inflammation	2.6	–	5.4	–	–	–
Liver failure	7.9	12.8*	2.7	2.2	–	4.5
Parkinson	7.9*	7.7	8.1	1.1	2.2	–
Pneumonia	1.3	2.6	–	4.4	6.5	2.3
Sclerosis	3.9	–	8.1	–	–	–
Septicaemia	3.9	2.6	5.4	–	–	–
Stroke	14.5	15.4	13.5	14.4	17.4	11.4

Significant difference between the countries (indicated with * at the higher value).

*P<0.05, **p<0.01, ***p<0.001.

in hospitals in Germany (6.7%),¹⁷ Belgium (9.4%),¹⁸ and in a New Zealand hospital (19.8%).¹⁹

Deterioration was the most frequent symptom in both countries, and for non-cancer patients the figures for Spain and Sweden were as high as 90.8% and 48.9%, respectively. The mean age was high for this subpopulation. The prevalence of deterioration was also found in other studies.^{13 20} Research has shown that frail patients at the time of hospital admission had poorer cognitive and physical functioning, with higher rates of delirium and cognitive impairment than those with cancer.²¹ Better developed care at nursing homes could prevent admissions for this group of patients. Obviously, different priorities in the expansion of care have an impact on the level of care. In Sweden, there has been a focus on dementia care in municipalities since the 1990s, which probably is the reason for the low number of dementia diagnoses in the Swedish hospitals in this study, 2.2% vs 26.3% in the Spanish hospitals.

There are other differences between the two countries: 34.4% of Swedish patients in palliative phases were hospitalised for acute treatment of congestive heart failure, vs only 9.2% in Spain. In comparison with other studies, heart failure is among the main diagnoses of non-cancer palliative patients.^{11 12 22} Treatment for congestive heart failure is an example of what preferably should be taken care of in primary care or in the home care setting, given adequate resources.²³ This has been recognised as a possibility in several Swedish county councils, where palliative care patients with severe symptoms of congestive heart failure are monitored and treated in home care settings by palliative care teams in co-operation with cardiologic consultants.

Two prominent symptoms, pain (45% in Spain and 36% in Sweden) and infections (20% and 26%) are additional examples of healthcare problems that are usually manageable in the primary or home care setting, given optimal conditions. Although pain was a problem in up to 45% of patients, these values are still lower than those found in other studies.^{24 25} One explanation could be that our study design had focused on reasons for hospitalisation, not on all experienced symptoms. Although majority of earlier studies have focused on the assessment of single or multiple symptoms, symptoms can occur together and be related to each other as part of a cluster. Symptom cluster research can increase our understanding of symptomatology, improving symptom management in palliative care.^{9 25} In this regard, identification of symptom clusters in palliative care is an area of special interest^{9 26} and research into this burden is required for this population.

Hospitalisation due to diagnostic procedures was very common for patients in this study, standing out in patients with cancer in Sweden. These results coincide with those obtained by Robinson *et al*¹² in New Zealand, where the majority of patients had tests and investigations as the reason for admission to palliative care. Moreover, for patients with cancer, this type of care was a top priority, compared with non-cancer patients. One possible explanation for this finding may be the perceived need for patients with cancer to want more information about their disease status because of the uncertainty of its progression and prognosis. In other studies,^{27 28} patients with cancer highlight the need for information on the diagnosis and future condition, sometimes even more than information about physical symptoms.

Social problems were more frequent reasons for hospitalisation in Spain than in Sweden. According to Fernández-López *et al*,²⁹ a social problem is a complex criterion in palliative care in Spain and it is questionable whether social problems are best dealt with at an acute care hospital. However, social problems were not the main problems of the patients studied, nor were they recognised as a priority by the palliative patients in other studies.^{20 27} At Swedish hospitals, a larger proportion of patients were hospitalised for well-defined care needs such as the need of palliative radiotherapy, pleuracenteses, diagnostic procedures and blood transfusions. Even if these seem to be relevant indications at first glance, these needs could be met in palliative home care, as palliative radiotherapy can be delivered on an ambulatory basis and measures such as pleuracenteses or blood transfusions are regularly provided in the home care environment in certain Swedish county councils, where medically advanced home care is offered around the clock, 7 days a week. Obviously, more palliative care training is needed in order to manage pain, infections and other symptoms outside the hospital. However, optimal organisations of palliative care are also important. In the catchment area for this study, the specialised palliative care teams only operated daytime, from Mondays to Fridays, which is not optimal. There are also different views on potentially avoidable admissions among hospitalised palliative patients. No doubt the development of specialised palliative care teams could help control the palliative patient at home.³⁰ For example, Pellizzari *et al*³¹ found that integrating palliative home cancer care reduced both the hospital deaths and the hospital stay in the end of life.

Early integrated palliative care

Integration of palliative care into health systems might be a strategy to offer quality care at different levels, thereby reducing the need of acute hospital care.³² Early integrated palliative care at hospitals, has shown to improve the symptom burden among patients with advanced cancer.³³ To provide palliative care, healthcare professionals need to identify patients as being in a palliative phase; however, there is still confusion regarding how to identify patients, especially those with non-cancer diagnoses.³⁴ Possible explanations for the differences in the provision of palliative care for patients with cancer and those without could mainly be related to differences in the trajectory of the disease, fluctuating more in the case of diseases such as organ failure and dementia, which makes accurate prognosis difficult. Bostwick *et al*³⁵ argue that non-cancer patients are less functional and may require more intensive care despite similar prognoses to patients with cancer.

Healthcare professionals' experiences in palliative care as well as their varying preconceptions of palliative care could also have an impact on how they identified patients as being in a palliative phase.³⁶

Competence in palliative care is, therefore, needed to integrate palliative care early in the trajectory.³⁷ A review of integrated palliative care in Spain shows that explanations of integrated palliative care exist, but with insufficient evidence of clinical impact.³² Though research has shown advantages of integrated palliative care, there is a paucity of how palliative care can optimally be implemented.^{37 38} One challenge is to use interprofessional communication to promote understanding and collaboration at different levels of care. The integration of palliative care at different levels of care could be a way of reducing the ambiguity of palliative care. We; therefore, believe that the integration of palliative care into the basic training of primary care teams, nursing homes and hospitals may be relevant in improving patient and family outcomes, providing emotional support and practical advice for patients and family members.

Methodological considerations

The assessment of patients as being in a palliative phase might differ between the countries; however, the definition was written on the questionnaire and also discussed with the persons responsible for the assessment. The symptoms and care needs were assessed by healthcare professionals and not by the patients themselves, which could have given a different spectrum of symptoms and care needs. However, the aim was to focus on symptoms and care needs related to hospitalisation, not all the experienced symptoms and care needs. Moreover, we only registered the occurrence of a certain symptom, for example, pain, not the intensity, which can be decisive when planning for an optimal level of care. The staff were only encouraged to address symptoms that were of clinical importance in the individual situation.

As we started our first registrations already in 2002 and have repeated them approximately every fifth year, we needed to create our own, study-specific questionnaire, as available questionnaires were lacking at that time. The detailed WHO's definition of palliative care from 2002 was printed on the back of the questionnaire and used as an aid. Today, there are specific instruments that can be used for the identification of patients that might have palliative care needs, for example, SPICT^{39 40} that originally was published in 2010 or NECPAL⁴¹ which was published in 2013. We have not used these instruments, which is a limitation. Our reason for not using them was that we wanted to be able to compare our results with our previous measurements from 2002, 2007 and 2012.

CONCLUSIONS

A significant proportion of patients with palliative care needs are cared for in acute care hospitals. Healthcare professionals need to be aware of the main reasons for hospitalisation of patients with palliative care needs to reduce unnecessary hospitalisations among this group, for whom alternative levels of care may be desirable.

High frequencies of symptoms such as deterioration, pain and fatigue were found in both patients with cancer and non-cancer patients in both countries, although patients with cancer had higher frequencies of pain and non-cancer patients had higher frequencies of deterioration.

However, the similarities were higher, which indicates that the main focus in care should be on patient symptoms and care needs, rather than the patient diagnoses. Symptom cluster research can increase our understanding of symptomatology, improving symptom management. In this regard, further studies exploring symptom clusters in this population will be carried out.

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Contributors The project leader (AS) developed the design along with PS; AS was also responsible for applying for research grants, monitoring the data, data collection and the administration of the questionnaire in Sweden, while FPGF and IMLM were responsible for this process in Spain. The analysis was conducted by AS with support from FPGF and DGS. Regular meetings involving the other authors were held throughout the analytical process. AS wrote the first draft of this manuscript, and FPGF, DGS, PS and IMLM contributed actively to the content and reviewed the text. All authors read and approved the final manuscript.

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Competing interests None declared.

Patient consent for publication Not required.

Ethics approval The study was conducted in accordance with the Declaration of Helsinki of the World Medical Association[42]. In Spain, the study was ethically approved by the Jaen Biomedical Research Committee. In Sweden, ethical approval was obtained from the operation managers and department heads at the hospitals. Swedish law and praxis consider this study - which used no identifiable patient data - as part of normal clinical improvement procedures[43] and approval by an Ethics Committee was thus not necessary. Written information about the study was sent to the head nurses of the participating wards who selected a responsible nurse for the data collection. The nurses - often in cooperation with the physicians - assessed all inpatients, and those who were assessed as palliative were registered in the questionnaires. As no identifiable patient data was registered, informed consent was not required.

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