ORIGINAL ARTICLE

Burden of Palliative Care in a Public General Hospital Setting

A Chang[1], RP Maharaj[2, 3], TAR Seemungal[2]

ABSTRACT

Objective: *The number of palliative care patients in Trinidad and Tobago is unknown. The purpose of this study is to estimate the prevalence of palliative care patients on a public general medical ward.*

Methods: *A retrospective cross-sectional study was undertaken to collect information on patients' diagnoses, symptoms and Palliative Performance Scale (PPS) scores. Patients who would benefit from palliative care services and satisfied inclusion criteria were referred to as palliative-care-appropriate patients.*

Results: *The one-month prevalence of palliative-care-appropriate patients was found to be 23.47% on an acute medical ward of a public hospital. Most of these patients had diagnoses that were either neurologic or cardiac in nature. Pain (46.8%) and dyspnoea (51.1%) were the most common symptoms documented for palliative-care-appropriate patients. Seven (14.95%) palliative-care-appropriate patients died while in hospital.*

Conclusion: *There is a significant palliative care burden in this pilot study as evidenced by the high prevalence of palliative-care-appropriate patients on a general medicine ward. A larger prospective study should be undertaken to elucidate the number of patients who could benefit from hospice and palliative care services. Palliative performance scale scores may be considered for more widespread use in the Caribbean.*

Keywords: Palliative, Palliative Performance Scale, prevalence of palliative-care-appropriate patients, Trinidad

INTRODUCTION

The World Health Organization defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness with a particular focus on the patient as a whole, taking into account not only the medical aspects of care, but psychosocial and spiritual needs of the patient and their family (1). The need for comprehensive palliative care services is a global problem. An ageing population in conjunction with increasing rates of cancer and chronic disease is creating a situation that may conceivably overwhelm even the best prepared healthcare systems (2, 3).

These problems are magnified in developing countries where healthcare services must vie with numerous other governmental priorities for resources and support (4, 5). Given the increasing rates of all major chronic diseases and cancer in the developing world, the need for palliative care in developing nations could be considered to far exceed the need in developed nations where there is better cancer screening, disease prevention and management of chronic illness. However, even in resource-poor settings, patients can still receive excellent palliative care, once the will exists to establish and maintain programmes (3, 5).

Correlates can be drawn between many of the barriers written about in the literature and the accessibility of palliative care in Trinidad and Tobago. Palliative care in Trinidad and Tobago is in its infancy, with only one new established palliative care inpatient unit, two charity-funded hospices, limited coverage of the country's major hospitals and two outpatient clinics.

From: [1]Caura Hospital, North Central Regional Health Authority, Trinidad and Tobago, [2]Department of Clinical Medical Sciences, The University of the West Indies, St Augustine Campus, St Augustine, Trinidad and Tobago and [3]National Radiotherapy Centre, North West Regional Health Authority, Trinidad and Tobago.

Correspondence: Professor TAR Seemungal, Department of Clinical Medical Sciences, The University of the West Indies, St Augustine Campus, St Augustine or National Radiotherapy Centre, North West Regional Health Authority, Trinidad and Tobago. Email: Terence.Seemungal@sta.uwi.edu

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Anecdotal reports from healthcare practitioners in Trinidad and Tobago suggest that there is a great need for palliative care with a heavy burden amongst the general medical population. However, the feeling is that few patients in the acute medical services require palliative care (Jan 2014, T. Seemungal, personal correspondence). Thus, we sought to determine the burden of palliative care in the acute medical service of a busy public hospital.

SUBJECTS AND METHODS

Study design

A retrospective cross-sectional chart review was undertaken. For four weeks from January to February 2014, all admissions to a selected acute medical inpatient service in a public hospital in Northwest Trinidad were reviewed. Patient charts were accessed after the medical team had reviewed the patients and written a care plan in the notes.

An instrument was developed that collected patient demographic information, diagnoses and medical illnesses, burdensome symptoms, whether the patient no longer desired curative care, and whether the patient was too ill to receive curative care and the Palliative Performance Scale (PPS) score (6). The main life-limiting diagnosis was considered to be the diagnosis that would most likely be the eventual cause of death for a given patient. When information was not clearly stated in the chart, medical staff were questioned to gather further information about the patients, especially with regard to the patient's ability to ambulate and self-care.

PPS score

The PPS is a validated scale that provides a framework for measuring palliative patients' gradual physical decline and speaks to prognosis and functional status (6). It was chosen because it is easy to administer, and is widely used in the palliative care field. The PPS gives a percentage score from 100 (normal) to 0 (death) in decrements of 10, taking into account the domains of ambulation, activity level, evidence of disease, the ability to do self-care, oral intake, and level of consciousness (7). A PPS score of less than 70% is taken as an indicator of the need for a referral to a hospice, palliative care programme (8).

Inclusion criteria

Patients over the age of 18 years, with anyone of the following criteria, were included in the study: (a) they were too ill to undergo curative treatment, (b) they were no longer desirous of curative care, (c) they had a PPS score of less than 70% (8), (d) they had a diagnosis of end-stage disease, or (e) irreversible end organ damage would shorten life span. For purposes of this study, all the patients included in the study were defined as *palliative-care-appropriate patients*. Although the case notes of all patients admitted to the selected medical service were reviewed, data were collected only from the case notes of the palliative-care-appropriate patients.

Exclusion criteria

Patients who were younger than 18 years, pregnant and non-English speakers were excluded from the study.

Symptoms: With regard to the patient's symptoms, bleeding was taken to be documented bleed from any site, such as haemoptysis, haematemesis or haematochezia.

Ethical considerations

Ethical approval was obtained from the University of the West Indies Ethics Committee and the Ethics Committee of the North West Regional Health Authority.

Statistical analysis

Data were analysed using SPSS version 22. Prevalence was calculated using the total number of patients admitted to the selected medical service. Descriptive statistics were performed on demographic variables of the study population, along with the examination of the diagnosis and the absence or presence of symptoms known to be burdensome to palliative patients. At the time the study was completed, four patients had not yet been discharged from the hospital, and were considered to be alive when a count was made of patients who died in hospital.

RESULTS

The total number of patients admitted to the medical service over the one-month period was 202, with 47 (23.47%) being found to be palliative-care-appropriate patients (see Table 1). The graph shows that the number of palliative care patients varied from 14.81% to 36.36% of all acute medical admissions (Figure). Seven of the 47 palliative-care-appropriate patients died in hospital.

Palliative-care-appropriate patients had a mean PPS score of 49.57% (SD = 18.992, range: 10–80). There was only one patient with a PPS of 80% and this was a known hypertensive with atrial fibrillation, with previous ischaemic stroke and heart attack, and non-compliant with his medications, who presented to hospital with

Table 1: Main life-limiting diagnosis by system, for palliative-care-appropriate patients

Main life-limiting diagnosis	n (%)
Neurologic	17 (36.2)
Stroke	7 (14.9)
Alzheimer's disease/dementia	7 (14.9)
Traumatic brain injury	1 (2.1)
Schizophrenia	1 (2.1)
Paraplegic	1 (2.1)
Cardiac	14 (29.8)
Congestive cardiac failure	8 (17.0)
Ischemic heart disease	5 (10.6)
Atrial fibrillation	1 (2.1)
Oncologic	6 (12.8)
Prostate cancer	2(2.1)
Brain cancer	1 (2.1)
Mandibular cancer	1 (2.1)
Breast cancer	1 (2.1)
Leukaemia	1 (2.1)
Renal	4 (8.5)
Chronic renal disease	4 (8.5)
Endocrine	3 (6.4)
Diabetes mellitus	2 (4.3)
Refractory hypoglycaemia	1 (2.1)
Respiratory	2 (4.3)
COPD	2 (4.3)
Other	1 (2.1)
HIV positive	1 (2.1)
Total	47 (100)

COPD = chronic obstructive pulmonary disease.

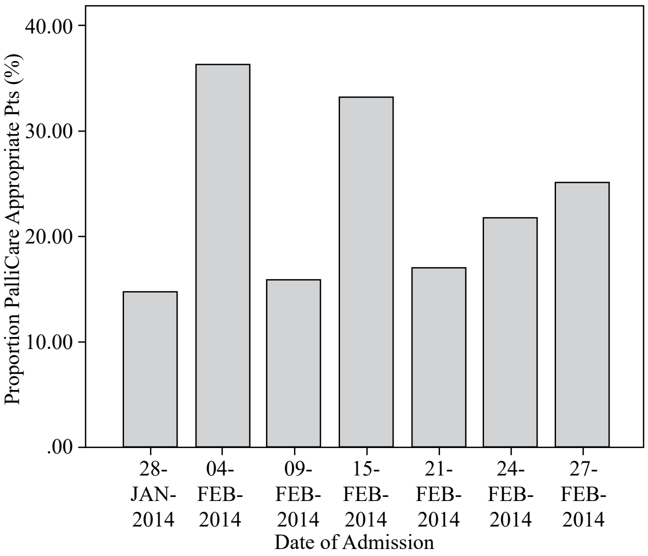

Figure: The proportion of palliative-care-appropriate patients, per day of admission over seven call days.

Table 2: Documented symptoms of palliative-care-appropriate patients

Documented	Yes n (%)	No n (%)
Dyspnoea	24 (51.1)	23 (48.9)
Pain	22 (46.8)	25 (53.2)
Cough	18 (38.3)	29 (61.7)
Incontinence	17(36.2)	30 (63.5)
Nausea or vomiting	14 (29.8)	33 (70.2)
Hypoactive delirium symptoms	10 (21.3)	37 (78.7)
Hyperactive delirium symptoms	8 (17)	39 (83)
Diarrhoea	7 (14.9)	40 (85.1)
Death in hospital	7 (14.9)	40 (85.1)
Wound infection	6 (12.8)	41 (87.2)
Bleeding	5 (10.6)	42 (89.4)
Constipation	5 (10.6)	42 (89.4)
Depression or anxiety	2 (4.3)	45 (95.7)

chest pain. Patients who died in hospital had a mean PPS score of 35.71% *versus* 52.00% in those who survived to discharge, $p = 0.035$ (*t* test).

Of the study group of 47 patients, only one (2.1%) was documented as no longer being desirous of curative care, while four (8.5%) of the patients were identified as being too ill to undergo curative treatment. As seen in Table 2, the most frequently documented symptoms in the study group were pain and dyspnoea, with only two patients being documented as having psychiatric symptoms of depression or anxiety.

DISCUSSION

The prevalence of palliative-care-appropriate patients was 23.47% over the whole month, with no single call day having less than 14%. The prevalence of palliative care patients amongst the acute medical patients may seem high but correlates well with recent UK data that suggest a high proportion of unselected acutely ill inpatients (28.8%) enter the hospital within the last 12 months of life (9). Few patients in our palliative-care-appropriate group had an oncologic diagnosis as their main admitting diagnosis.

A lower PPS score correlates with greater inpatient mortality and has a role in prognostication for clinicians (10). Even though 13 (27.7%) patients had a PPS of 30% and less, and by definition would be bed-bound and appear very ill even to a lay person, few patients were considered too ill to undergo curative care, or no longer desired curative care (7). This may suggest ‘prognostic paralysis’, where doctors of patients with uncertain illness trajectories will avoid openly discussing end of life issues (11). These patients, afflicted with chronic medical conditions where the exact course is uncertain, but where their eventual demise can be foreseen, are precisely those who would benefit the most from early end-of-life planning. Patients and their families benefit from having these 'difficult conversations' because they can begin to have realistic expectations of the prognosis and plan for the future.

A systematic review of the literature found that palliative care patients had a median prevalence of depression of 15% (12). However, only 4% of our palliative-care-appropriate patients were noted to have psychiatric symptoms. A proper assessment for depression in this sample was not done. Psychiatric symptoms are common in the palliative population and the negative impact of unaddressed depression is well known by palliative care practitioners (13). Assessment of all psychological issues early in the disease course can tremendously improve patient outcomes and speaks to holistic, patient-centred care espoused by palliative care practitioners (14).

It is important to note that our inclusion criteria allowed patients into the study group even if their PPS score was 70% and greater. Although this could be viewed as a potential source of selection bias, it was felt that this was consistent with the present thinking; that palliative care should be introduced as early as possible in the disease trajectory (1). Relationships with healthcare providers and goals of care developed in the early stages of chronic disease lay the foundation for improved patient outcomes and holistic care at terminal stages of disease.

Limitations

This study is limited by the retrospective nature of the design. The number of patients was small, as it was just a pilot study. Given the study's retrospective design, questions could only be answered based on the medical record and recollections of the staff members. Family recollections and direct questioning of the patient may have been valuable in verifying information on functional status and symptoms. The PPS is best administered directly by the healthcare team involved directly in the care of the patient, not in a retrospective fashion by independent observers, as done in this study (6).

CONCLUSION

This study shows that there is greater need for palliative services within the public hospital system, as evidenced by the high prevalence of palliative-care-appropriate patients being admitted to an acute medical service. These patients have symptoms that overlap with those of the patients on the medical ward, but may have concerns particular to their deteriorating health that are not adequately met by the services offered on a busy inpatient acute medical ward. Specialized services need to be developed that cater to the physical, emotional and spiritual needs of patients and their families.

The PPS score may be a useful tool in predicting mortality amongst inpatients, and should be considered for routine use in prognostication. For patients who are expected to die in hospital, it may be prudent to have an inpatient hospice ward, more suited for the care of patients in terminal stages of life. A review of resource allocation may find these strategies cost saving and improving patient satisfaction.

It is imperative that education about palliative care take place amongst all levels of health care workers and the public, so that the parties involved will be receptive to the concepts of holistic, supportive care in situations where there is no cure. Many are unaware as to all that palliative care can encompass, and still hold the view that palliative care is limited to actively dying patients. Most importantly, this pilot study now paves the way for a well-powered, prospective study that can give a more accurate estimate of the palliative care burden in Trinidad and Tobago, and seek to address the particular needs of our patient population.

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