

Community End-of-Life Care for Older Non-Cancer Patients: A Pilot Study

Dear Editor,

In Singapore, a majority of patients in established end-of-life (EOL) care programmes are suffering from cancer. But there are patients, typically of advanced age, suffering from a combination of frailty, disability and multiple chronic diseases who will benefit from palliative care. In 2013, 69.3% of deaths in Singapore were unrelated to cancer. A total of 49.7% of all deaths were at age 75 and older. Only 26.8% of deaths occurred in the home.¹ These patients tend to die in pain, not in their place of choice which tends to be the home, but often after frequent visits to the emergency department.² To improve the delivery of EOL care for the homebound, non-cancer elderly patients, the Tsao Foundation Hua Mei EOL Care Pilot Programme was introduced. This study describes the pilot programme.

Discussion

Tsao Foundation is a non-profit organisation incorporated in 1993 to improve the overall experience of ageing in the community. There are several Hua Mei clinical programmes within the Tsao Foundation.

There were 51 patients in the pilot programme. Patient recruitment was non-random. A total of 75% of patients were selected from existing frail and homebound elderly in the Hua Mei Mobile Clinic, and the remaining 25% were hospital referrals. Patients were selected based on a prognosis of more than 50% probability of death within 6 months. This was based on the American Medicare Local Coverage Determination (LCD).³ Patients selected were eligible for nursing home care based on the Resident Assessment Form (RAF) categories 3 or 4, and they were also at high risk of nursing home placement. Once the patient satisfied the LCD for hospice eligibility, the Karnofsky Performance Scale (KPS)⁴ was used to fine-tune the prognosis. This scale showed the strongest association with basic activities of daily living (BADL), instrumental activities of daily living (IADL), and other functional measures. As such, this scale can be used for patients diagnosed with dementia.

Over the 24-month period of the pilot programme from 1 October 2010 to 30 September 2012, patients received team-managed home-based primary care, advanced care planning, caregiver support, and spiritual care. Patients received care from a multidisciplinary team of a family

physician, 2 nurses, a social worker, an assistant social worker and an administrative staff member. All were trained in basic geriatrics and gerontology. Frequency of home visits by different members of the team was based on the patient's clinical stability using KPS. Advance care planning was provided to all patients and it involved their families. To ensure that the experiences of the terminally-ill patient and caregiver were supported, counselling and spiritual care were provided. For patients who lived alone, volunteers within close proximity organised visits to the patient's home. Volunteers provided assistance with BADL and medication use. They complemented the home medical visits and phone consultations.

Grief support was provided to the caregiver and family members prior to and after death. Initial support was provided in the first and second week after the patient's death. Longer periods of grief support were also available. One of the limitations of this study was that the pilot programme was unable to use the Good Death Inventory (GDI) scale⁵ which measures the patient's death from a bereaved family member's perspective. Within a year after a patient's death, social workers would interview the deceased's family members. They were asked to respond with either a "Yes" or "No" to the question of whether the patient had a good death.

The mean age of elders at enrolment was 87 years. The most frequent diagnosis types were dementia (76%) and stroke disease (60%). Table 1 provides information on patients upon enrolment and patients at death.

Over the 24 months, there were 36 deaths; 77% of these actual deaths were in the home and this percentage is higher than the national average of 26.8%. Given the various disease trajectories of the patients, deaths occurred on an average of 172 days after enrolment in the programme. Patients did not appear to have a high level of acute care (AC) utilisation. The rate of AC admission per patient per year of enrolment in the EOL programme was 1.47. Across all AC events, average length of stay was 9 days. This is arguably a low number in AC and implies low healthcare utilisation costs.

Another limitation of this study is that there is no comparative group that can provide information on the

Table 1. Patient Characteristics

Patient Characteristics Upon Enrolment	Mean (Standard Deviation, SD)	Total (n = 51)	%
Age		87 (6.8)	
Gender			
Male		19	37
Female		32	63
BADL			
Independent		1	3
Assisted		10	19
Total dependence		40	78
Number of diagnosis	4.7 (1.9)		
Diagnosis type			
Dementia		42	76
Stroke disease		33	60
Hypertension		27	49
Osteoporosis		22	40
IHD		14	25
Anaemia		19	35
DM		17	31
Hyperlipidemia		10	18
Cataract		14	25
Depression		11	20
Malnutrition		10	18
Cancer		5	9
CRF		10	18
COPD		3	5
Parkinson's disease		8	15
Epilepsy		5	9
CCF		6	11
Hypothyroidism		3	5
OA knees		4	7
Preferred place of death			
Home		46	90
Places other than the home		5	10
Patient Characteristics At Death	Mean (SD)	n = 36	%
Time to death after enrolment	172 (193)		
Actual place of death			
Home		28	77
Hospital		8	23

BADL: Basic activities of daily living; CCF: Congestive cardiac failure; COPD: Chronic obstructive pulmonary disease; CRF: Chronic renal failure; DM: Diabetes mellitus; IHD: Ischaemic heart disease; OA: Osteoarthritis
 Note: Each patient had at least one diagnosis upon programme enrolment

terminally ill who are without community-based care and has access only to acute care. Also, there is no information available on AC utilisation in the last year of life at the national

level. From the 36 deaths, 92% died while leaving family behind while 3 patients died alone without any family. A total of 72% of family members perceived that the patient had a good death, which was interpreted as a peaceful death at home.

Conclusion

This paper has attempted to disseminate knowledge on community-based EOL care for elderly patients with non-malignant chronic disease in Singapore. Access to EOL care can be provided to all and this can be effectively carried out within the community. This will enable more terminally ill elders to die in their place of choice – the home – and reduce AC hospitalisation.

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