

End-stage organ disease–Healthcare utilisation: Impact of palliative medicine

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ABSTRACT

Objectives Although patients living with end-stage organ disease (ESOD) suffer unmet needs from the physical and emotional burdens of living with chronic illness, they are less likely to receive palliative care.

The aims of the study were to determine if palliative care referrals reduced healthcare utilisation and if impact on healthcare utilisation was dependent on the timing of the referral.

Methods Patients with ESOD who received palliative care support were matched with those who did not using coarsened exact matching and propensity score matching, and compared in this retrospective cohort study. Primary outcomes of interests were reduction in all-cause emergency department (ED) visits and costs, reduction in all-cause tertiary hospital admissions, length of hospital stay and inpatient hospital costs.

Results Patients with ESOD referred to palliative care experienced a reduction in the frequency of all cause ED visits and inpatient hospital admissions. Significant impact of a palliative care referral was at 3 months, rather than 1 month prior to death with a greater reduction in the frequency of ED visits, inpatient hospital admissions, length of stay and charges (p all <0.05). The most common ESOD referred to palliative care for 1110 matched patients was end-stage renal failure (57.7%), and least commonly for respiratory failure (7.6%).

Conclusion Palliative care can reduce healthcare utilisation, with reduction greatest when the referral is timed earlier in the disease trajectory. Cost savings can be judiciously redirected to the development of palliative care resources for integrated support of patients and caregivers.

INTRODUCTION

With exponential population growth and global ageing, death secondary to non-cancer diseases will increase.^{1,2} Despite significant contribution to worldwide mortality from non-cancer illnesses,

Key messages

What was already known?

- Patients with end-stage organ disease (ESOD) have a symptom burden as significant as those suffering with end-stage cancer.
- Yet, they are afforded less access to palliative care resources and support.

What are the new findings?

- There is differential access to palliative care support even within different disease groups in ESOD.
- Earlier involvement of palliative care resulted in greater reduction in healthcare utilisation.

What is the significance?

- Palliative care is beneficial for the patient and also for the justification of healthcare resource allocation in the promotion of care of patients with ESOD within the community.
- More research is needed to understand the barriers limiting access to palliative care for patients with ESOD.

patients with end-stage organ disease (ESOD) have differential access to palliative care although physical suffering and psychosocial needs increase in prevalence in the last year of life.^{3–5} Individuals with advanced chronic obstructive airway disease were more likely to fare significantly worse for activities of daily living, physical, emotional and social functioning compared to patients with lung carcinoma, yet were less likely to receive access to support care services.⁵

Palliative care referrals for non-cancer diseases still trail behind support for end-stage cancer and do not accurately reflect the proportions of individuals dying with non-cancer. Furthermore, delivering cost-effective care in end-stage organ diseases is challenging given their protracted



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duration of illness and pattern of decline characterised by 'entry–re-entry' disease trajectories.⁶

As in end-stage cancer, suffering in ESOD is significantly burdensome, with evidence of the beneficial effects of palliative care on symptom burden and quality of life.⁷ However, less well documented is the impact of palliative care in ESOD in relation to health resource utilisation. The last year of life is characterised by an increase in hospitalisations and aggressive interventions in the mistaken belief that survival will be prolonged.⁸ Conversely, early integration of palliative care, including discussions of advance care plans, equips patients to better manage their illnesses, potentially reducing unnecessary hospitalisations and time spent away from loved ones. Overall, this translates to improved quality of life and reduced healthcare costs.⁹

Therefore, the main objectives of this study were to determine if palliative care referrals reduced healthcare utilisation, and if the impact on healthcare utilisation was dependent on the timing of the referral.

METHODS

This was a retrospective cohort study using coarsened exact matching (CEM) and propensity score matching (PSM) to compare patients with ESODs who received palliative care support with those who did not.^{10–12} It is common in retrospective analyses to use matching methods to select a control group that had the same probability of receiving the treatment as the treatment group. This enables the analysis to approximate that of a randomised control trial by directly comparing outcomes between individuals who received the treatment of interest against those who did not, using methods that account for the paired nature of the data. Both CEM and PSM are commonly used matching methods.¹³ However, PSM may not always result in a perfect match between both groups of patients. Hence, CEM was used in this study to ensure that patient characteristics were perfectly matched between both groups of patients. Since the strict matching criteria in CEM may result in only a small number of patients being matched, potentially reducing the statistical power during the analysis, PSM was applied after CEM. This is to achieve a balance between finding as close a match in patient characteristics between the two groups of patients being studied, while meeting the need to achieve a sufficient number of patients for analysis.

Patients with ESOD, specifically advanced dementia, Parkinson's disease, end-stage heart, respiratory, renal and liver failure, who accessed palliative inpatient and/or outpatient care in a university-affiliated hospital between 2014 and 2017 but died between 2015 and 2017 were included in the study. Access to care was defined as the point of initial review by the palliative care team in either the inpatient or outpatient setting. A team of 25 medical and nursing clinicians provide palliative care support to its own inpatient unit, consult

service and outpatient clinics in the 1700-bed tertiary care hospital. An average of 2000 new patients were reviewed by the palliative care team in each year of the study period. In both settings, other multidisciplinary team members, including allied health and community hospice teams became involved as needed based on assessment of the patient and caregiver needs.

Study variables and outcomes

Study variables included demographic information such as age, gender, ethnicity and socioeconomic status. Clinical variables were of the ESOD, comorbidity burden using the Charlson Comorbidity Index (CCI) and frailty, evaluated using the Electronic Frailty Index (eFI).^{14 15} Primary outcomes of interests were reduction in all-cause emergency department (ED) visits and costs, reduction in all-cause tertiary hospital admissions, length of hospital stay and inpatient hospital costs.

The study period was from index referral to the palliative care team with follow-up until study completion which was at patient death. For patients not referred to palliative care, their study period was adjusted to be similar to their matched patient referred to the palliative care team.

Identifying matched patients for those referred to palliative care

A two-step matching process was used to identify patients with ESOD who were referred for palliative support against patients with ESOD who were not referred. The first step of the process involved 1:1 CEM. Patients were matched exactly using the ESOD, gender, race, socioeconomic status and eFI category. For age, the match was coarsened to categories of below 45, 45 to 54, 55 to 64, 65 to 74, 75 to 84, and 85 years and above. For CCI, the match was coarsened based on Sturges rule.¹⁰ Patients referred to palliative care who were not matched by CEM were subjected to step 2. In step 2, 1:1 propensity score matching using a calliper of 0.2 was used. For each ESOD, the same set of variables used in CEM was used for the match, except CCI which was used as a continuous variable instead of binning into groups.

Statistical analyses

The reduction in all-cause ED visits and costs, all-cause tertiary hospital admissions, length of hospital stay and costs were analysed using paired t-test. Subgroup analyses were performed for each ESOD and for different referral periods (0–13 days before death, 14–30 days before death, 31–90 days before death, 91–180 days before death, 181–365 days before death). For all tests, a p value <0.05 was used to define a statistically significant result.

All statistical analyses were performed using Stata V.16.0. CEM was done using Stata module

cem, and PSM was performed using Stata module PSMATCH2.34.

RESULTS

Overall, 1110 patients with ESOD referred for palliative care were matched to 1110 patients with ESOD who were not referred for palliative care. There was no match found with CEM or PSM for 268 patients with ESOD with palliative care and 1813 patients with ESOD without palliative care. In total, 523 patients with ESOD were CEM matched, while 587 patients were matched by PSM. The most common ESODs referred to palliative care for matched patients overall were end-stage renal failure (57.7%), advanced dementia (24.3%), heart failure (17.6%), Parkinson's disease (12.6%), severe liver disease (12.5%) and respiratory failure (7.6%).

The mean number of days to death from the first palliative care review (or from the start of the study period for matched patients not referred to palliative care) was 67.3. For unmatched patients referred to palliative care, this was 81.3 days compared with unmatched patients not referred to palliative care at 265.1 days. The majority of patients were above 55 years of age in all groups, with a near equal gender distribution between matched patients. More than 80% of the patient population were of Chinese ethnicity. The mean CCI was similar in all groups of patients with more than 50% of matched patients moderately to severely frail (table 1)

Patients with respiratory failure visited the ED and were admitted more frequently than patients with other ESOD. Patients with heart failure experienced the longest length of hospital stay, followed by patients with respiratory failure and advanced dementia (online supplemental table 1).

Reduction in healthcare utilisation with palliative care

Overall, patients with ESOD referred to palliative care experienced a reduction in the frequency of all cause ED visits, but this was only statistically significant for patients with heart and renal failure, advanced dementia and Parkinson's disease ($p < 0.05$). The frequency of inpatient hospital admissions was reduced for all ESOD studied, but only patients with heart failure experienced a statistically significant reduction in the length of hospital stay ($p < 0.05$). Overall, there was a statistically significant reduction in inpatient hospital charges for patients with heart, renal failure and advanced dementia ($p < 0.05$). Patients with end-stage liver disease experienced a reduction in ED gross charges [S\$198 (S\$44 to S\$351); $p < 0.05$] but did not have a significant reduction in the other elements of healthcare utilisation. For Parkinson's disease, although patients receiving palliative care were less likely to visit the ED [0.39 (0.04 to 0.74); $p < 0.05$], inpatient admission frequency [0.16 (−0.17 to 0.48)], length of hospital stay [1.6 (−0.17 to 0.48)]

and inpatient charges were not significantly reduced [S\$1764 (−S\$2500 to S\$6029)] (online supplemental table 1)

Reduction in healthcare utilisation based on timing of referral to palliative care

Reduction in healthcare utilisation differed based on the referral timing to palliative care before death for patients with ESOD. There was a greater reduction in the frequency of ED visits [0.85 (0.37 to 1.33); $p < 0.05$], ED gross charges [S\$356 (S\$171 to S\$541); $p < 0.05$], frequency of hospital admissions [0.55 (0.10 to 1.0); $p < 0.05$] and inpatient gross charges [S\$9828 (S\$2870 to S\$16 786); $p < 0.05$] when a palliative care referral for ESOD was made at 6 months rather than 1 month prior to death. However, there was no significant change to the length of hospital stay [3.8 (−3.2 to 10.7)]. A palliative care referral for ESOD at 3 months resulted in significant reduction in all health utilisation parameters studied but not at 1 year prior to demise. Most of the patients in the study were referred to palliative care 1 month before death. (online supplemental table 2)

DISCUSSION

The principles of palliative care are rooted in the judicious use of healthcare resources to improve and sustain the quality of life of patients living with life-limiting illnesses, with healthcare utilisation in the tertiary setting often used as a quality performance indicator of benefit.^{16–18}

Patients with ESOD in this study experienced a reduction in healthcare utilisation with palliative care support compared with patients who did not. However, the impact on healthcare utilisation was not the same across all the ESOD groups studied. Specifically, patients with advanced dementia, end-stage heart and renal disease experienced the greatest reduction in the frequency of all cause ED visits, inpatient hospital admissions and charges. However, end-stage respiratory failure patients did not have a reduction in any of the healthcare utilisation elements examined, possibly as they were the ESOD group least likely to be referred for palliative care although they had the highest frequency of inpatient hospital admissions and ED visits.

Such differences may reflect symptom characteristics unique to each organ system at the end stage and the trajectory of decline.¹⁹ 'Entry–re-entry' death trajectories are commonly witnessed in heart and respiratory failure where patients suffer acute exacerbations of breathlessness resulting in increased hospital admissions for stabilisation, leading to unplanned hospital admissions.^{20 21} In renal and liver failure, prevalent symptoms include fatigue, pruritus and constipation, associated with a poor health-related quality of life (HRQOL).^{22 23} Conservatively managed patients with renal failure may require increased support in the last

Table 1 Profile of matched and unmatched patients who were referred and not referred to palliative care

	Matched patients		Unmatched patients	
	Referred to palliative care	Not referred to palliative care	Referred to palliative care	Not referred to palliative care
No of patients	1110	1110	268	1813
End-stage organ disease				
Heart failure	17.6%	17.7%	11.9%	13.2%
Respiratory failure	7.6%	7.7%	9.3%	4.4%
End-stage renal failure	57.7%	57.1%	31.3%	41.5%
End-stage liver disease	12.5%	12.7%	45.1%	5.3%
Advanced dementia	24.3%	25.0%	16.0%	33.9%
Parkinson's disease	12.6%	13.1%	9.3%	29.5%
Mean (median) days to death from start of study	67.3 (15)	67.3 (15)	81.3 (34.5)	265.1 (365)
Heart failure	64.8 (10.5)	64.8 (10.5)	95.5 (53.5)	247.9 (362)
Respiratory failure	79.4 (27)	79.4 (27)	93.8 (65)	260.1 (365)
End-stage renal failure	77.0 (17)	77.0 (17)	85.1 (42)	248.8 (365)
End-stage liver disease	40.0 (12.5)	40.0 (12.5)	63.4 (21)	203.7 (186)
Advanced dementia	56.4 (14)	56.4 (14)	97.2 (55)	265.8 (365)
Parkinson's disease	64.9 (12)	64.9 (12)	115.2 (36)	305.1 (365)
Mean age at death				
Below 45	0.4%	0.3%	1.1%	1.2%
45 to 54	3.2%	3.4%	6.7%	2.9%
55 to 64	11.4%	11.6%	17.9%	10.6%
65 to 74	20.9%	20.6%	29.1%	14.4%
75 to 84	36.7%	35.9%	29.9%	24.3%
85 and above	27.4%	28.2%	15.3%	46.6%
Gender				
Male	52.3%	53.5%	61.2%	52.8%
Female	47.7%	46.5%	38.8%	47.2%
Ethnicity				
Chinese	81.4%	80.0%	83.2%	80.3%
Malay	8.2%	8.7%	9.0%	8.6%
Indian	7.9%	8.6%	5.2%	6.7%
Others	2.5%	2.7%	2.6%	4.4%
Low socioeconomic status	58.6%	58.3%	64.6%	41.3%
Mean Charlson Comorbidity Index	9.0	9.1	10.9	8.0
Electronic frailty index				
Fit	10.3%	9.8%	27.2%	18.0%
Mild frailty	20.5%	20.9%	25.4%	27.6%
Moderate frailty	35.9%	35.8%	28.0%	33.0%
Severe frailty	33.3%	33.5%	19.4%	21.4%

1 to 2 months of life when functional decline becomes precipitously worse.²⁴ Patients at the end stage of dementia and Parkinson's disease suffer an increased incidence of dysphagia, infections and complications related to severely reduced function that results in increased healthcare utilisation and costs.^{25 26} Knowledge of the clinical characteristics of different ESOD and illness trajectories will help tailor palliative care response to the patient's needs, averting unplanned hospital reviews with palliative support integrated into community care.

Timeliness of palliative care referral also affected healthcare utilisation in this study. The greatest reduction in healthcare utilisation occurred with patients referred at least 1–6 months before death. However, the majority of patients were referred in the last month of life, reflecting a worldwide trend.¹⁸ In a population-based study of deaths conducted in Belgium, the median days between referral and death of patients was 10, 12 and 14 days for patients with chronic obstructive pulmonary disease (COPD), heart failure and severe dementia, respectively. Similar to findings reflected in

this study, patients with COPD in the Belgian-based population study were also less likely to be referred for palliative care compared with patients with heart failure, severe dementia and cancer.²⁷

Palliative care is traditionally associated with a cancer diagnosis. Implementation is less common, and initiated later in individuals living with ESOD although the unmet needs from physical suffering, psychosocial and emotional burdens of living with chronic illness are as prevalent as patients with advanced cancer.^{3 5 28 29} Patients with COPD were more likely to receive care consistent with prolongation of life with increased hospital admissions including intensive care in the last 6 months of their life, and were less likely to receive palliative medications compared to patients with lung cancer.³⁰

Barriers to integration in ESOD include a misunderstanding that palliative care is only 'end-of-life' care, resulting in referrals in the last days of life and missed opportunities to reframe and honour patient wishes for their preferred place of care based on goals and values. ESOD with 'entry-re-entry' death trajectories are associated with clinical uncertainty and difficulty in prognostication. Referral to palliative care is all the more challenging compared with cancer in the context of current available technology and treatment.³¹ When faced with clinical ambiguity, the response is to resort to ordering more investigations, pursuing burdensome treatment, increased referrals and hospitalisation, thereby increasing overall healthcare costs.³² In the last 1 year of life, patients with heart or respiratory failure accumulated 1.6 times more healthcare costs compared to patients with advanced cancer.³³ Aside from a needs-based approach for palliative referrals, accurate prognostic tools need to be developed to ensure early identification of patients with ESOD.³⁴ Used synergistically with a clinician's estimate of survival, early access to palliative care ensures well-timed discussions about advance care plans, with opportunities for clinicians to plan and deliver care which aligns with realistic medical goals. Mobilising and channelling appropriate healthcare resources across care settings with integration of palliative and disease-specific models of care that extend support into the community have been shown to improve quality of life and also justify healthcare utilisation and costs for patients.^{35–37}

The disproportionately low referral to palliative care for ESOD may reflect the lack of training, education and palliative care awareness amongst healthcare professionals.³⁸ Reports from bereaved caregivers of loved ones who died of ESOD and frailty identified the lack of palliative care awareness among healthcare providers. Conversely, there was a lack of non-cancer disease-specific skills and knowledge among palliative care providers.³⁹ Care in the last week of life for patients with ESOD and frailty was rated poorer compared to patients with cancer, with less access to

spiritual counsellors. The quality of palliative care was not only different between patients with cancer and those without cancer, but the caregivers themselves felt less supported in the last week of the patient's life compared with caregivers of patients with cancer.⁴⁰ Interprofessional healthcare development is needed to improve the quality of palliative care in ESOD. Healthcare professionals in the various fields of medicine can be trained to identify and manage patients with symptoms, entering into discussions about patient's preferences for care, earlier rather than later in the disease trajectory. Palliative care professionals should also develop disease-specific skills to manage complex issues faced in non-cancer, increasing expertise in the provision of specialist palliative care for ESOD.

Our study is limited in its generalisability as it is a single-centre study with patients mainly of the Chinese ethnicity. We did not evaluate advance care plans and could not determine concordance between preferences and healthcare utilisation. The frequency of palliative reviews in the inpatient and outpatient setting were not measured and hence, the association between intensity of palliative care and healthcare utilisation was not assessed. As this is a retrospective review with observational data, these confounding variables which potentially affect quantification of healthcare utilisation could not all be measured. In retrospective studies, direct comparisons between patients with and without treatment could lead to biased estimates unless the control group were selected to have the same probability of receiving treatment as the treatment group.⁴¹ Hence, in this study, we used both CEM and PSM to assemble comparable study groups. This allowed a more accurate measurement of the relationship between palliative care and healthcare utilisation rather than direct comparison between unmatched control and treatment groups.

Implications

One of the first studies to evaluate healthcare utilisation between different ESODs, this study shows that palliative care can reduce healthcare utilisation, and reduction is greatest when the palliative care referral is timed earlier in the disease trajectory. Cost savings can be judiciously redirected from burdensome interventions in the hospital which neither improve HRQOL nor survival to the development of palliative care resources for integrated support of patients and caregivers.²⁶

The rising prevalence of patients living and dying with ESOD requires the healthcare community to be able to offer cost-effective options of care which are supportive and life affirming, even as their illnesses progress to the end stage. Hence, more research is needed to evaluate the cost-effectiveness of models of care where early intervention in ESOD is adopted. Early implementation of palliative care into ESOD may improve HRQOL, reduce caregiver burden, and help

establish resources and healthcare policies to integrate supportive care across different healthcare settings and the community, in alignment with efforts to improve end-of-life care for patients suffering with ESOD.

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