Satisfactory project example

Title: What happens to where people die when two palliative care services are amalgamated?: an analysis of the socioeconomic and symptom burden factors that impact on site of death.

Abstract

The SA Health Palliative Care Services plan (2009-2016) called for amalgamation of Modbury (MH) and Lyell McEwin (LMH) services into the regional level 6 service, Northern Adelaide Palliative Service (NAPS).

This study investigated the change in patient demographics, site of death and impact of the move of inpatient palliative care beds to MH in 2013, compared with the independent MH and LMH hospital based palliative care beds in 2009.

Data were collected from a client management engine (CME) database for 1237 patients who died under palliative care in the NAPS catchment in 2009 and 2013. Socioeconomic suburb status was obtained from the Australian Bureau of Statistics 2011 Census and distance from hospital to home was plotted for the patients. These data were analysed utilising Chi Square analysis and Mann-Whitney U tests.

The growth in the service was 14.6% between the two years; patient demographics were similar and referral of non-malignant disease increased. Time from referral to death decreased between 2009 and 2013. General hospital death rates increased while inpatient palliative care bed deaths decreased. Community death rates across the NAPS increased from 31 to 37%, reflecting increased resourcing and home support resulting from the merger of the services.

The second aspect of this study identified end-of-life site of preference, Palliative Care Outcomes Collaborative (PCOC) scores and qualitative data for 68 patients reviewed in the community. This data showed the importance of making a conscious decision to die in the home setting. Pain and carer distress were the dominant reasons patients changed their preference to die in the hospital setting. Patients whose preferred site of care was the hospital setting showed increasing symptom burden during the terminal phase of their illness.

Five Key Words.

palliative care, site of death, socioeconomic, symptom burden, health service merger.

Introduction

The South Australian (SA) Health Palliative Care Services plan (2009-2016) highlighted two primary issues for the state. First, the issue of an aging population with fewer family carers, and second, the financial pressure imposed by an aging workforce.[1] This plan also identified a need to rationalise palliative care from individual hospital based services to integrated regional services.[2] The result was the amalgamation in 2012 of five adult SA palliative care services into three new specialised services which provide support to local providers of palliative care in urban and rural areas.

The Lyell McEwin Hospital (LMH) is a hospital located in the northern peri-urban fringe of Adelaide. LMH expansion has seen bed numbers increase by 60 beds to 396. It is now designated to be equipped as one of three tertiary hospitals in Adelaide. The population demographic demonstrates significant problems with low socioeconomic status, unemployment, and substance abuse. The LMH palliative care service, before 2010, was located within the LMH. There were two palliative medicine physicians and advance trainees and junior medical staff. There was an extensive nurse-focused community outreach program with medical and social work support, outpatient clinic, social work and bereavement programs and volunteer groups in addition to an inpatient unit. Country outreach was to Gawler, Barossa and Yorke Peninsula.

Modbury Public Hospital (MH) is 17 kilometres from the LMH. It has a strong community focus and had various models of care including public/private collaboration. There was a palliative community nursing outreach team and social work support. In 2009, LMH had nominally 10 and MH 14 palliative care beds. In 2010-2012 LMH had no specifically designated palliative care beds but were utilising beds under general medical and other hospital specialty bed cards still providing some direct care.

By 2013, the Lyell McEwin Hospital (LMH) and Modbury Public Hospital (MH) palliative care services and inpatient palliative care beds were amalgamated to a single service, the Northern Adelaide Palliative Service (NAPS), which offers service to similar geographical area as its predecessors, with 18-20 designated palliative care inpatient beds based at MH.[1]

Post amalgamation, there was increased junior medical staffing with more advanced trainees in palliative medicine. The community teams containing administration, outreach community nursing, social work and bereavement programs were amalgamated and located at MH. The staffing profile was enhanced to include advance practice roles including nurse practitioner candidates, specialist occupational therapy, physiotherapy, psychology and pharmacy as part of the team. NAPS provides inpatient care, consultation liaison services and community services to the urban northern Adelaide catchment area of 350,000 people, as well as to rural areas of Gawler, Barossa, Port Pirie Regional, Yorke Peninsula, Clare Valley and Lower North areas of South Australia.[3]

Pre and post merger, specialist palliative care medical advice was available to patients by telephone outside of service hours. In addition, extended care paramedics (ECP) were utilised after hours to assist in assessing and controlling symptoms in the home setting, with specialised medical backup via telephone. This service had grown in capacity between 2009 and 2013.[4]

Previous studies demonstrated that 70% of the population of South Australia would prefer to die at home when asked when well or with a low symptom burden.[5] Dying at home is seen as almost a right or at least an expression of personal autonomy. It also may be seen as beneficial in reducing hospital bed pressure and cost of health care. There is no consistent evidence identifying the factors that support patients dying in the community setting.[5,6]

This research was constructed as two distinct studies that provide complementary information. A literature review was conducted to ascertain

current knowledge of socioeconomic and geographical factors influencing site of death (Appendix 1). The first study investigated changes in site of death for the geographical catchment area of NAPS and the influence of shifting inpatient palliative care beds to a single site. It compared patient and service demographic factors for a total 1237 patients dying in the service; in the years 2009 prior to the merger in comparison to 2013, after the merger was complete. The research question was; Did changing the palliative care service model result in a change in where people died? The second study considered factors that influenced choice and actual site of death for 68 consecutive patients seen by a single palliative medicine advanced trainee. These reviews were undertaken across the breadth of the NAPS community area.

Ethics Approval

These studies were approved by the Human Research Ethics Committees of The Queen Elizabeth Hospital (TQEH), LMH and MH (Protocol Number HREC/14/TQEHLMH/24).

Study 1

Method – data collection

SA Health maintains a client management engine (CME) database for palliative care services within the state. The CME database was used to collect data on patients within the same geographical boundaries dying under the care of MH and LMH palliative care services in 2009 and NAPS in 2013.
The 2009 LMH geographical area divided into northeast (NE) and northwest (NW) and MH geographical area, divided into central (C) and east (E), continued within NAPS in 2013.

Data were collected for 'date of referral', 'date of death, 'age at death', 'sex', 'referral source', 'main diagnosis', 'site of death', 'marital status', 'living arrangements', 'suburb' and 'postcode'. Geographical distance from home to palliative care bed was measured from the centre of each suburb to the relevant hospital while population demographics considering relative socioeconomic advantage and disadvantage were collected from the Australian Bureau of Statistics 2011 Census Socio-Economic Indexes for

areas report (SEIFA).[7] Decile data in the ABS SEIFA report identified the census population as divided into 10 equal rankings based on socioeconomic data. Identifying data including address and case number were deleted. 'Length of referral' was calculated by using 'date of death' and 'date of referral'.

Statistical analyses

'Length of referral' and 'age at death' population comparisons were analysed utilising Mann-Whitney U tests. The discrete data sets: population number, sex, marital status, living arrangements, diagnosis and site of death were analysed via Chi square analysis.

Results (Appendix 2)

Seventy-four per cent of referrals to NAPS occurred while the patient was a hospital inpatient. The total number of deaths in the NAPS catchment was 668 in 2009 and 753 in 2013. However, 36 urban patients were geographically out of area for NAPS and 150 patients were country patients supported by NAPS in conjunction with the local palliative care services. The data for these patients were excluded from analysis leaving a total of 1237 patients.

The East/Central (E/C) and Northeast/Northwest (NE/NW) areas grew comparably between the years 2009 and 2013 (p=0.64) with the urban death rate increasing from 576 to 661 patients (14.6%, Table 1). Country patients increased additionally in this time period from 67 in 2009 to 83 in 2013 in line with the state-wide palliative care plan (23.9%).[1] There was no significant difference in gender distribution within each geographical area. (E/C p=0.14, NE/NW p=0.07). However, across the entire NAPS population gender differences were apparent (p=0.02), with women under-represented compared to men in 2009 (45% v 55% respectively) and over-represented in 2013 (52% v 48%, Table 2).

There was no significant difference in distribution of patient age at death between 2009 and 2013, with a median age of 76.0 in 2009 and 76.2 in 2013 (p=0.39, Table 3).

The time from initial referral to death decreased in both geographical areas between 2009 and 2013 (Table 4). The median referral decreased from 51 days in 2009 to 38 days in 2013 (p<0.01). During this time period, patients with periods of palliative care less than 28 days increased from 37.4% in 2009 to 43.7% in 2013. When excluding these patients with an initial referral within 28 days of death, the difference between median referral times remained significantly different with a median of 109 days in 2009 compared with 88 days in 2013 (p<0.01, Table 5).

There was no significant difference in marital status between the two cohorts (p=0.97, Table 6). Living arrangements changed between the cohorts with greater numbers of patients living in residential aged care facilities (RACF) in 2013. Decreasing patients lived alone during this period (p<0.01, Table 7, 8).

Recorded diagnosis is shown in Table 9, and also as collapsed variables of malignant and non-malignant disease in Table 10. Non-malignant disease incidence increased between 2009 and 2013 for E/C (26 v 36% respectively, p=0.05) and for NAPS overall (24 v 26%, p=0.03). This increase was not reflected in NE/NW. However, the number of non-recorded diagnoses excluded from analyses in 2013 was high (82) compared to 2009 (7), which may weaken the accuracy of these findings.

The SEIFA data applied to each suburb in the geographical areas revealed that suburbs within the east area were of higher socio-economic advantage with median decile ranking of 6-7. The central suburbs had moderate socio-economic advantage, with median decile 4.0, while both northeast and northwest suburbs were relatively disadvantaged with both NE and NW decile 2-3 (Table11).

Moving the site of palliative care beds did not impact travel distance from home for the E/C areas, while it doubled the travel distance for the outer suburbs, N/E, N/W (Table 12).

In NAPS overall, home and RACF (community) death rate increased from 31% in 2009 to 37% in 2013. There were marked differences in site of death across the total NAPS area between 2009 and 2013 (p<0.01). However site of death in NE/NW areas was unchanged despite palliative care beds being moved from LMH to MH (p=0.78, Table 13). In 2009, 98 patients from NE/NW died under a palliative care bed card at LMH. In 2013, 103 NE/NW patients died at MH after either being admitted directly or transferred from the LMH. Analysing NE and NW independently, where distance to palliative care bed was doubled, showed no significant differences in site of death between 2009 and 2013 in either geographical area (NE p=0.31, NW p=0.60, Table 14). Results were similar when 'referral to death' time periods of less than 28 days were removed (NAPS p=0.01, E/C p<0.01, NE/NW p=0.94, Table 15). The significant changes in NAPS site of death overall arose from C and E areas (MH) and three main contributions to this significance were identified: (i) Home deaths increased between the two years. (ii) Palliative care inpatient deaths fell over the same period. (iii) Greater public hospital general bed deaths occurred over this period (Table 16, 17).

Discussion

This study compared two demographically similar populations between 2009 and 2013, during which the number of urban deaths in the service grew by 14.6%.

There was statistically significant increased referral for non-malignant disease across NAPS. Medical units increased referrals to palliative care to facilitate provision of equipment in the community and symptom management. With inpatient beds at MH, where most non-malignant referral had increased, the increased hospital presence and growth of NAPS, combined with bed pressure resulted in many dying patients being managed in the palliative care unit, even with low symptom burden. This decision was based on nursing care as well as

medical need and was reflected by the relatively low public general hospital bed deaths in the E/C areas in both years. The impact of increased non-malignant disease raises the problem of less predictable disease trajectory. Many of these patients in 2013 were opened and closed by the service based on symptoms requiring specialised palliative care input at that time.

However, despite less predictable disease trajectory, the interval of patient care between initial referral and death decreased. The decreasing 'length of referral' from initial review to death represents the changing nature of palliative care delivered in NAPS. This represents, in part, a data management practice with the closure and subsequent reopening of palliative episodes for patients with minimal symptoms. Patients with low symptom burden were discharged from the service and reopened when clinical need increased. Referrals in the last week of life had increased. This was most evident at LMH, which had increased oncology, respiratory, cardiovascular and general medical services between the cohorts. However, median referral time decreased even with the removal of late referrals.

The risk of shorter palliative care episodes of care is identified in the literature. Earlier referral to palliative care in community, intensive care unit (ICU) and general ward hospital settings is associated with greater rates of home death and greater family satisfaction and survival. Complicated bereavement is more common with late referrals. [8,9,10] There is always a tension between service provision and budget and the question raised by the shorter episodes of care is whether the service was more efficient or has decreased its standard of care.

Similar to the results of previous studies, this study demonstrated that the preferred site of death in the home setting was 68%.[5,11] Desired place of care and place of death are not identical, and patient preferences change over time.[12,13,14] The involvement of specialised palliative care and symptom management is shown to increase likelihood of dying at home.[15] However, as demonstrated in this study, less than 40% of palliative care patients die in the home setting.

Although the number of patients living in RACFs had increased between the cohorts, numbers of patients dying in RACFs did not increase. This study showed that despite increasing resources, many RACF patients were still referred to hospital for end of life care.[16] Studies have shown 40% of people who die in the hospital setting have no direct medical reason, such as symptom management, requiring inpatient care but rather nursing requirements or patient or family choice. Hospitalisation, unnecessary investigations and medical treatments at the end of life have been shown to reduce quality of life and increase risk of complicated bereavement.[1,11,16,17] The importance of advanced care directives (ACD) and planning for end-of-life care to enable death in a RACF is shown in the literature.[18]

It is difficult to identify common community factors influencing preferred site of death. Gill et al identified a lack of a consistent framework to assist in predicting the location of death.[6] Ethnic, socioeconomic, and geographical variables have been shown to have an impact on site of death but these factors are site specific and not broadly applicable.[2,19,20,21,22,23,24,25,26,27]

This study demonstrated that increasing geographical distance from palliative care inpatient beds for the most socioeconomic disadvantaged patients made no difference to the number of these patients dying in the community or hospital setting. The death rate for the geographical areas serviced by LMH showed no statistical significance despite the distance to palliative care beds being doubled. This is in part due to inter-hospital transfers from LMH to MH as well as direct admissions to MH palliative care inpatient beds.

What was demonstrated, as in the literature, is the importance of the availability of inpatient beds at the end of life. Studies identify the importance of proximity to home to allow friends and families easy access to support the patient.[2] Shifting the palliative care beds from LMH, did not significantly alter the number of patients dying under general medical bed cards at LMH. Hospital deaths remained similar across the cohorts for palliative and general beds. This mirrors Cassel et al who demonstrated introducing palliative care beds in the hospital setting did not increase overall hospital death rates, but did

change the intra-hospital site and improved the quality of patient deaths.[28] This study of one service operating at two sites has shown similar numbers of palliative care bed card deaths; but moved from LMH to MH. This result was discussed with consultant and nursing staff employed at the LMH in 2013. They identified the ethos of LMH, had always focused strongly on education and consultation liaison palliative care. While there was provision for inpatient palliative care beds in 2009, the service predominantly ran as a consultation liaison service with the inpatient beds utilised for only the patients with most severe symptom management. At that time the hospital instituted end of life pathways based on the Liverpool Care Pathway (LCP)[29] and actively promoted end of life decision-making. As such, with the continuation of the consultation liaison service, the impact of shifting beds in 2013 was lessened.

Transfers incurred costs, both financially in ambulance transfer, additional medical and nursing costs in repeating admission documentation and patient and family costs in travel time. There were patients who would have benefitted from transfer, but who were too unwell and died in the acute hospital setting at LMH.

The E/C areas underwent the largest change in site of death, with markedly increased home deaths, moderately increased general hospital deaths and decreased palliative care inpatient deaths. This reflected the merger of the two services that increased the resourcing of the E/C areas. It added occupational therapy, physiotherapy and community pharmacy services. Social work and community nursing continued with greater support. There was increased consultant and junior medical support for the community patients. The care emphasis shifted from reactivity to proactivity with greater emphasis on patient goals of care. This is consistent with research identifying patient and family factors favouring home death. These include availability of carers, being married, younger age and a perception of responsive community nurses. Service factors include equipment resourcing and 24 hour responsiveness to perceived family need. [12,13,26,30,31,32,33, 34] This responsiveness was enhanced by the consolidation of the ECP service between the cohorts assisting 'out of hours' care plus the greater 'within hours' palliative care staffing available to

families. This greater resourcing supported families and achieved higher rates of home deaths.

At the same time, with two referring hospitals, the inpatient waiting list and bed pressure increased at MH. This resulted in deteriorating palliative care patients admitted under general medicine whilst waiting for inpatient palliative care beds. Patients awaiting transfer from LMH took priority from patients on general wards in MH. This accounted for some of the fall in palliative care inpatient deaths and increase in general medical deaths across the service. The RACF death rate did not significantly change between the cohorts despite increased patients living in RACF facilities. This may reflect increased discharge from the service and usage of primary health care to support these patients. However RACF staffing levels may make timely symptom management difficult leading to acute hospitalisation. Improved symptom management, staff attitudinal change and utilisation of advanced directives has been shown to increase capacity for end-of-life care in RACFs. [16,35,36,37] Increasing RACF staff education, supporting ACDs and encouraging supported end-of-life may improve these figures.

Study 2 - Patient reviews
Method
In the second half of 2013, one palliative medicine consultant, two advanced trainees and two doctors not in a training program comprised the NAPS medical community service. The advanced trainees, with consultant support saw patients with greater symptom burden determined at multidisciplinary meetings and as requested by the community nurses and allied health practitioners.

Sixty-eight patients were reviewed consecutively in the community by a palliative medicine advanced trainee. These patients were not a homogenous representation of the service. They exhibited symptoms significant enough for specialised medical review, but not to the extent of requiring immediate admission. These patients were already known to the service and had received nursing and possible allied health and medical review. At each of these initial

advanced trainee medical reviews, prospective goals of care, end-of-life preferences and Palliative Care Outcome Collaborative (PCOC) data was collected.[39] Data was retrospectively collected from terminal admission data or final community review from Snapshot, a SA Health database and compared to the prospective data.

The collected PCOC data comprised:

1) a functional dependence assessment using Resource Utilisation Groups - Activities of Daily Living scale (RUG-ADL).

2) severity of symptoms utilising Problem Severity Scores (PSS).

3) performance status utilising Australia-Modified Karnofsky Performance Scale (AKPS, Appendix 3). [38]

In addition to collection of quantitative data, qualitative reasons for admission were drawn from case note and hospital discharge letters.

Results

From 68 assessed patients, eight remained alive and three died of complications from active treatment including repair of a fractured neck of femur, and two from complications arising from chemotherapy. From the remaining 57 patients, 38 patients had data at both initial review and at end of life/terminal admission (Table 18). The overall rate of home or RACF death of this patient subgroup was 50%.

All patients reviewed showed a decrease in AKPS, indicating decreasing function, and an increase in RUG-ADL, indicating increasing dependency on others for activities of daily living. These scores identified the increasing care required by the patients as their terminal disease progressed. Although limited nursing support was available, it indicated increasing responsibility and demands on patients' carers.

The data demonstrated the breadth of site of preference for terminal care in this population. Of the 57 patients at initial review, 28 wished to die in a private residence (49%) and 10 in a RACF (18%) comprising a total community death rate of 38 (68%). Twelve patients wished to die in hospital (21%), and seven had no preference or refused to discuss site of death (12%).

There were a total of eight patients who wished to die at home but died in hospital (14%). Their average PSS scores revealed an overall average increase for pain (PSS-pain=0.6) and carer distress (PSS-carer=0.4). In this group of patients, confusion and carer distress, and patient isolation featured most strongly in qualitative descriptions for admission. Although increased pain in PCOC scores was identified, pain was not qualitatively described as the precipitating factors for admission in this subgroup.

Residential aged care patients who died in the facility had an average total decreased PSS of 3.8, with most pronounced decreases in pain and carer distress. Patients who chose to, and died at home, showed reduced symptom severity across the all the PSS categories, averaging a reduction of 1.15 per patient, with a notable average reduction in carer distress of 0.54 per patient.

The subgroup of six patients who had no preference or refused to discuss site of death and died in hospital, showed averaged increased pain (PSS-pain=1) and carer distress per patient (PSS-carer distress=0.33). The qualitative descriptions of reasons for admission reflected symptom management for pain, fatigue and home stress. Only one patient died suddenly at home without previously identifying a preference for site of death.

The 12 patients who chose to die in hospital at initial advanced trainee review showed worsening symptoms overall with average increasing scores (PSS=1.5) with pain (PSS-pain=0.6) and carer distress (PSS-carer distress=0.8) featuring strongly. This patient group identified that their carer would not manage, or they wished to protect carer and children, or identified an absence of carer as main reasons to die in hospital. Although symptom control was identified of lesser importance, pain, delirium and general deterioration were the main admission diagnoses.

Discussion

As expected, patients had declining function and increased dependency on others in the terminal phase of their illness.

Symptom management was shown to be a significant factor in site of death. This study showed patients dying at home and in RACF's generally showed reduced symptom burden (PSS) between their two reviews. The greatest reduction in PSS in these community patients was in pain and carer distress. For urban areas, it has been shown in this and other studies that the symptoms associated with terminal disease rather than location plays a greater role determining actual site of death.[39] In rural and semi rural areas, geography may be significant as timely resourcing and responsiveness is more difficult. Despite this, many patients choose to die in the home setting.[33,40,41]

During disease progression, patients and families have been shown to change their minds for preference of site of death.[12,13,14,42] Symptom management, carer support and perceived responsiveness of service are demonstrated to have an impact on this decision making.[26,30] The 14% of patients in this study who died in hospital despite their previously expressed wish to die at home demonstrated increased burden of symptoms. Their admission was often precipitated by an unexpected acute deterioration; pain, delirium, breathlessness or inability of carers to manage terminal care. Pain and decreased function were described as admission reasons. This partially reflects a biomedical rationale for admission.

The importance of a plan to die in the community demonstrated by Pekmezaris was reinforced in this study.[18] Patients who did not wish to discuss, or had no fixed ideas regarding site of death in this study died in hospital with increased PSS scores in pain and carer distress. The increasing carer distress may reflect the unwillingness or ambivalence of the patient and family in planning for end-of-life, resulting in less preparedness when deteriorating and entering the terminal phase. This too emphasises the importance of patients making a conscious choice to die in the community.[30] Supporting the group of ambivalent patients in regards to site of death did not reduce admission rates, but may have reduced length of stay by supporting the patients longer in the community. Repeated clarification of site of end-of-life care during the episode of care may have been useful in preparing patients and families.

Patients who elected to die in hospital showed increasing overall PSS scores, particularly in pain and carer distress. This was anticipated at the original interview, with patients identifying families and carers at risk of not managing and/or wishing to protect them from death at home. This subset of patients wished to manage at home as long as possible but die in the hospital setting. Many features of inpatient palliative care beds actually make them a preferred site for dying, such as increased resourcing and meeting cultural community needs.[9,43] Palliative care in this setting can reduce length of stay and enable planned admissions for end-of-life care.

Although the palliative model in NAPS is increasingly moving towards acute palliative care beds, there is still a community perception that NAPS provides hospice care. It raises the broader community question of where the aging northern Adelaide population should die. There are less health costs associated with a community death. But patient and family autonomy should be taken into consideration. Some patients will always elect to die in the hospital setting and this is increasingly difficult with hospital bed pressure.

Overall, providing community resources for carers, anticipating symptoms and providing help on demand had the most positive impact for dying in the community setting. Developing an end of life plan was crucial. However, many patients still chose to die in the hospital setting.

Limitations/Further Research

The databases for the geographical areas within NAPS were incomplete for 2009 and 2013. They did not fully capture the case-mix, (excluding living patients and closed episodes) and they were analysed retrospectively. Similarly, the data for the community patients was incomplete with comparable PCOC data for only 38 of the 68 patients. Although the initial goals of care and PCOC data were collected prospectively, the subsequent comparisons were collected retrospectively eight months later. This meant some of the subgroups were very small and statistical analysis was not performed. The qualitative description for reason for terminal admission was also varied depending upon

the composition of the medical team at the time. Similarly, patients dying in the community setting had less detailed qualitative descriptions.

Length of stay and total hospital days was not captured in these studies, nor were the total number of community visits and cost of community resources. The impact on quality of life of patients and carers from consolidating palliative care services was not evaluated. Involvement of general practitioners and non-specialised palliative care services was also not captured. General hospital services were not reproduced at both hospital sites and patients required transfer for investigations and treatment such as MRIs, radiotherapy etc and the associated costs were not captured.

The impact of additional travel time and strain on the low socioeconomic families was anecdotally described as significant for some families. Although NE/NW patients were transferred to MH for inpatient palliative care demonstrating the regionalisation of services did not detract from inpatient palliative care, the patient and carer experience of this changed care needs exploration.

Finally, the merger of the service had a significant impact on staff, which is not addressed in this study. Outpatient, consultation liaison and community services were still provided, but at the cost of increased travel time for staff to the NE/NW areas.

Conclusion

Overall, combining two pre-existing palliative care services resulted in better resourcing of one unit. In northern Adelaide, palliative care service uptake and site of death was largely unchanged through the consolidation of inpatient palliative care beds. The most significant change was the growth of home deaths in the E/C area due largely to better resourcing of the service in that area.

Despite studies showing better outcomes with early referral to palliative care, the length of time between referral to death in the palliative service decreased

significantly between the cohorts. This deserves further study to determine whether it reflects greater efficiency, decreased level of service or an administrative episodic closure of patients.

Symptom control and outreach support remain critical features in supporting people dying in the community setting. The decision to die in the community setting is an active decision and improved community death rates could potentially be realised with earlier discussions regarding goals of care and preferred site for end of life care. There is a subset of patients whose site of preference is the hospital setting and this group displays greater carer distress and patient symptom scores.

This study does not address changes in patient and carer satisfaction nor length of hospital stay. It highlights the importance of community services, and recognises the strength in consolidating resources. It also identifies the value in supporting end of life care under general medical units. Further RACF and community resourcing may potentially increase numbers of patients able to die in the community setting.

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Appendix 1: Literature Search

Medline, Embase, PsychInfo, CINAHL, Cochrane and Caresearch databases were searched for palliative care and site or place of death. The search was limited to English language, years 2004-2014, and incorporated hospice, palliative care, attitude to death, death and dying, site and place of death, death attitudes, geography and socioeconomic factors. An initial 41951 palliative care articles and 841 site or place of death articles were reduced to 171 articles. An additional 30 articles were included utilising geographical and socioeconomic search terms; 201 abstracts were reviewed and 50 articles downloaded.

Appendix 2: Tables

Table 1: Geographical Area Distribution 2009, 2013

Area	2009	2013	Total
E/C	280	330	610
NE/NW	296	331	627
Year Total	576	661	1237

χ^2=0.21 (*df* =1, *N*=1237), p=0.64

Table 2: Sex Distribution 2009, 2013

Year	2009			2013		
Area	E/C	NE/NW	Total	E/C	NE/NW	Total
Male	155	160	315	163	155	318
Female	125	136	261	167	176	343
Total	280	296	576	330	331	661

NAPS Area 2009, 2013: χ^2=5.33 (*df* =1, *N*=1237), p=0.02
E/C Area 2009, 2013: χ^2=2.16 (*df* =1, *N*=610), p=0.14
NE/NW Area 2009, 2013: χ^2=3.26 (*df* =1, *N*=627), p=0.07

Table 3: Age Distribution 2009, 2013

	N	Median	Std Deviation	Range
2009	576	76.01	13.43	83.6
2013	661	76.18	13.92	100.7
Overall	1237	76.09		

Mann-Whitney U (U=185285, Z=0.856, p=0.39)

Table 4: Length of time between referral to death

	N	Median	Std Deviation	Range	M
2009	563	51	145.41	757	109
2013	653	38	122.59	797	81
Missing data	21				
Total	1237	43.50			

Mann-Whitney U (U=161233.5, Z= 3.699, p<0.01)

Table 5: Length of time between referral to death excluding referrals <28 days

	N	Median	Std Deviation	Range	M
2009	352	109	156.56	728	168.14
2013	367	88	139.55	797	138.02
Total	719				

Mann-Whitney U (U=56536, Z= 2.89, p<0.01)

Table 6: Marital Status

Marital Status	2009			2013		
Area	E/C	NE/NW	Total	E/C	NE/NW	Total
Divorced	15	21	36	18	20	38
Married	173	171	344	148	168	316
Never Married	17	14	31	15	14	29
Separated	7	8	15	8	19	27
Widowed	54	73	127	54	63	117
Unknown (excl)	14	9	23	77	57	134
Overall	280	296	576	320	341	661

NAPS Area 2009, 2013: χ^2=0.47 (*df* =4, *N*=1086), p=0.97
E/C Area 2009, 2013: χ^2=1.37 (*df* =1, *N*=553), p=0.85
NE/NW Area 2009, 2013: χ^2=5.25 (*df* =1, *N*=533), p=0.26

Table 7: Living Arrangements

Living Arrangements	2009			2013		
Area t	E/C	NE/NW	Total	E/C	NE/NW	Total
Alone	35	79	114	44	53	97
Other relative	41	47	88	38	57	95
RACF	23	16	39	55	44	99
Spouse	139	149	288	125	142	267
Unknown(excl)	42	5	47	68	35	103
Overall	280	296	576	330	331	661

NAPS Area 2009, 2013: χ^2=27.39 (*df* =3, *N*=1087), p<0.01
E/C Area 2009, 2013: χ^2=13.89 (*df* =3, *N*=500), p<0.01
NE/NW Area 2009, 2013: χ^2=19.27 (*df* =3, *N*=587), p<0.01

Table 8: NAPS living arrangements 2009, 2013: observed (expected)[Chi contribution]

Living Arrangements	2009 Observed(expected)[Chi square contribution]	2013 Observed(expected)[Chi square contribution]
Alone	114(102)[1.31]	97(108)[1.24]
Other relative	88(88.8)[0.01]	95(94.2)[0.01]
RACF	39(66.9)[11.7]	99(71.0)[11.0]
Spouse	288(270)[1.09]	267(287)[1.0]
Unknown	47	103

Table 9: Diagnosis

Diagnosis	2009			2013		
Catchment	E/C	NE/NW	Total	E/C	NE/NW	Total
Malignant	202	225	427	193	209	402
Cardiovascular	13	13	26	4	2	6
Respiratory	8	11	19	11	16	27
CNS	10	7	17	6	9	15
Renal	7	7	14	1	3	4
Haematological	11	6	17	15	7	22
Unspecified Non-malignant	25	24	49	64	39	103
Unknown	4	3	7	36	46	82
Overall	280	296	576	330	331	661

Table 10: Malignant/Non-malignant diagnosis

	2009			2013		
Area	E/C	NE/NW	Total	E/C	NE/NW	Total
Malignant	202	225	427	193	209	402
Unspecified Non-malignant	74	71	141	101	76	177
Unknown	4	3	7	36	46	82
Overall	280	296	576	330	331	661

Entire NAPS Area 2009, 2013: χ^2=4.72 (df =1, N=1148), p=0.03
E/C Area 2009, 2013: χ^2=3.80 (df =1, N=576), p=0.05
NE/NW Area 2009, 2013: χ^2=1.07 (df =1, N=578), p=0.3

Table 11: SEIFA* decile ranking applied to geographical area

Area	Mean SEIFA Decile Score	SEIFA Ranking	Socioeconomic Advantage
E	6.36	7-10	High
C	4.0	4-6	Moderate
NE	2.8	1-3	Low
NW	2.7	1-3	Low

* Australian Bureau of Statistics 2011 Census Socio-Economic Indexes for areas report

Table 12: Direct linear distance (km) to palliative care bed.

Area	2009	2013
E	2.57	2.57
C	6.0	6.0
NE	6.6	14.0
NW	7.1	11.7

Table 13: Site of Death: NAPS

Site Of Death	2009			2013		
Area	E/C	NE/NW	Total	E/C	NE/NW	Total
Home	26	54	80	68	70	138
RACF	45	46	91	48	47	95
Public hospital General bed	6	83	89	27	89	116
Palliative care bed	193	98	291	178	103	281
Private hospital	2	14	16	4	16	20
No Record	8	1	9	5	6	11
Overall	280	296	576	330	331	661

NAPS Area 2009, 2013: χ^2=12.3 (df =3, N=1089), p<0.01
E/C Area 2009, 2013: χ^2=28.6 (df =3, N=499) p<0.01
NE/NW Area 2009, 2013: χ^2=1.08 (df =3, N=586), p=0.78

Table 14: Site of Death: NE/NW geographical area

Site Of Death	2009			2013		
Catchment	NE	NW	Total	NE	NW	Total
Home	27	27	54	36	34	70
RACF	28	18	46	18	30	48
Public hospital general bed	32	51	83	35	54	89
Palliative care bed	40	58	98	39	64	103
Private hospital	7	7	14	8	8	16
No Record	0	1	1	2	3	5
Overall	134	162	296	138	193	331

NE Area 2009, 2013: χ²=3.60 (*df* =3, *N*=255), p=0.31
NW Area 2009, 2013: χ²=1.86 (*df* =3, *N*=336), p=0.60

Table 15: **Site of Death: NAPS: Removing referrals under 28 days**

Site Of Death Removing referrals under 28 days	2009			2013		
Area	E/C	NE/NW	Total	E/C	NE/NW	Total
Home	20	41	61	45	44	89
RACF	29	22	51	21	23	44
Public Hospital general bed	0	37	37	4	37	41
Palliative care bed	116	78	194	101	72	173
Private hospital	2	10	12	1	13	14
No Record	5	21	26	2	3	5
Overall	172	209	381	174	192	366

NAPS Area 2009, 2013: χ²=10.67 (*df* =3, *N*=621), p=0.01
E/C Area 2009, 2013: χ²=15.83 (*df* =3, *N*=289), p<0.01
NE/NW Area 2009, 2013: χ²=0.36 (*df* =3, *N*=332), p=0.94

Table 16: Site of death: NE/NW 2009, 2013: observed (expected)[Chi contribution]

Area	2009	2013
Home	54(59.1) [0.4]	70(65.0) [0.4]
Public hospital general bed	83(82.0) [0.01]	89(90.0) [0.06]
Palliative care bed	98(95.8) [0.05]	103(105.3) [0.05]
RACF	46(44.3) [0.07]	47(48.7) [0.06]

NE/NW Area 2009, 2013: χ²=1.08 (*df* =3, *N*=586), p=0.78

Table 17: Site of death: E/C 2009, 2013: observed (expected)[Chi contribution]

Area	2009	2013
Home	26 (42.9) [6.7]	68 (51.06) [5.6]
Public hospital general bed	6 (15.1) [5.5]	27 (17.92) [4.6]
Palliative care bed	193 (169.5) [3.3]	178 (201.5) [2.7]
RACF	45 (42.3) [0.15]	48 (51.1) [0.12]

E/C Area 2009, 2013: χ^2=28.6 (df=3, N=499) p<0.01

Table 18: Change in PSS between patient assessments.

	PSS-P	PSS-O	PSS-Psy	PSS-C	PSS Total	AKPS	RUG
Wished to die at home. Died at hospital. (Data 5/8 patients)							
	-1	0	-2	0	-3	0	4
	2	-2	-1	0	-1	-20	12
	1	1	0	1	3	-50	14
	1	0	1	0	2	-30	8
	-1	0	2	1	2	-30	0
Total	2	-1	0	2	3	-130	38
Mean	0.4	-0.2	0	0.4	0.6	-26	7.6
Wished to die in RACF. Died in RACF. (Data 5/10 patients)							
	-1	0	-1	0	-2	0	0
	-1	-2	0	-1	-4	0	0
	-2	-2	-1	-2	-7	0	0
	-1	1	-2	-1	-3	-30	14
	-2	0	0	-1	-3	0	0
Total	-7	-3	-4	-5	-19	-30	14
Mean	-1.4	-0.6	-0.8	-1	-3.8	-6	2.8
Wished to die at home. Died at home (Data 13/20 patients)							
	-1	1	0	0	0	-10	3
	0	0	-1	0		-10	4
	1	-1	1	-1	-1	-30	-6
	0	0	1	-1	0	0	0
	1	1	1	0	3	0	0
	1	0	1	0	2	-20	0
	0	1	0	-1	0	-50	4
	-3	-3	-3	-2	-11	-40	14
	-1	1	1	0	1	-10	3
	1	-1	-1	0	-1	-20	8
	-2	-1	0	0	-3	-20	10
	-1	1	0	0	0	-40	14
	-1	-1	-1	-2	-5	-30	14

Total	-5	-2	-1	-7	-15	-280	68
Mean	-0.38	-0.15	-0.08	-0.54	-1.15	-21.5	5.23

No preference for site of death. Died at hospital. (Data 3/4 patients)							
	1	0	-1	0	0	-40	14
	2	0	0	2	4	-60	11
	0	-1	-1	-1	-3	0	0
Total	3	-1	-2	1	1	-100	25
Mean	1	-0.33	-0.66	0.33	0.33	-33.33	8.33

Refused to discuss. Died at hospital. (Data 1/2 patients)							
	-1	-1	0	-2	-4	-50	14

Wished to die at hospital. Died at hospital. (Data 8/12 patients)							
	1	-1	1	-1	0	-10	4
	1	0	-1	1	1	20	14
	1	1	-2	1	1	-50	8
	1	1	2	2	6	-30	13
	1	2	1	2	6	-50	14
	1	-1	-1	-1	-2	-30	2
	1	0	0	1	2	-60	14
	-1	1	-2	0	-2	-20	12
Total	6	3	-2	5	12	-230	81
Mean	0.75	0.375	-0.25	0.625	1.5	-28.75	10.12

Refused to discuss. Died at home (Data 1/1 patients)							
	-1	-0	-1	-1	-3	0	1

Still alive (Data 0/8 patients)

Died under active treatment (Data 0/3 patients)

Appendix 3: Palliative Care Outcome Collaborative data (PCOC)

Resource Utilisation Groups- Activities of Daily Living (RUG-ADL)
The RUG-ADL describes the level of functional dependence. It is a four-item scale measuring motor function with activities of bed mobility, toileting, transfer and eating.

Bed mobility: Ability to move in bed after the transfer into bed has been completed		
Bed Mobility	Score	Definition
Independent or supervision only	1	Able to readjust position in bed and perform own pressure area relief through spontaneous movement around bed or with prompting from carer. No hands-on assistance required. May be independent with the use of a device.
Limited physical assistance	3	Able to readjust position in bed and perform own pressure area relief with the assistance of one person.
Other than two persons physical assist	4	Requires the use of a hoist or other assistive device to readjust position in bed and provide pressure relief. Still requires the assistance of one person for task.
Two or more persons physical assist	5	Requires two or more assistants to readjust position in bed, and perform pressure area relief.

Toileting: includes mobilising to the toilet, adjustment of clothing before and after toileting and maintaining perineal hygiene without the incidence of incontinence or soiling of clothes. If level of assistance differs between voiding and bowel movement, record the lower performance.		
Toileting	Score	Definition
Independent or supervision only	1	Able to mobilise to toilet, adjusts clothing, cleans self, has no incontinence or soiling of clothing. All tasks are performed independently or with prompting from carer. No hands-on assistance required. May be independent with the use of a device.
Limited physical assistance	3	Requires hands-on assistance of one person for one or more of the tasks.

| Other than two persons physical assist | 4 | Requires the use of a catheter/uridome/urinal and/or colostomy/ bedpan/commode chair and/or insertion of enema/ suppository. Requires assistance of one person for management of the device. |
| Two or more persons physical assist | 5 | Requires two or more assistants to perform any step of the task. |

Transfer: includes the transfer in and out of bed, bed to chair, in and out of shower/tub. Record the lowest performance of the day/night.

Transfer	Score	Definition
Independent or supervision only	1	Able to perform all transfers independently or with prompting of carer. No hands-on assistance required. May be independent with the use of a device.
Limited physical assistance	3	Requires hands-on assistance of one person to perform any transfer of the day/night.
Other than two persons physical assist	4	Requires use of a device for any of the transfers performed in the day/ night. Requires only one person plus a device to perform the task.
Two or more persons physical assist	5	Requires 2 or more assistants to perform any transfer of the day/night.

Eating: includes the tasks of cutting food, bringing food to mouth and chewing and swallowing food. Does not include preparation of the meal.

Eating	Score	Definition
Independent or supervision only	1	Able to cut, chew and swallow food independently or with supervision once meal has been presented in the customary fashion. No hands-on assistance required. If individual relies on parenteral or gastrostomy feeding that he/she administers him/ herself then score 1.
Limited assistance	2	Requires hands on assistance of one person to set up or assist in bringing food

		to the mouth and/or requires food to be modified (soft or staged diet).
Extensive assistance/total dependence/tube fed	3	Person needs to be fed meal by assistant, or the individual does not eat or drink full meals by mouth but relies on parenteral/ gastrostomy feeding and does not administer feeds by him/herself.

Palliative Care Problem Severity Score (PSS)

PSS is a screening tool used to measure the severity of physical and psychological problems. The PSS has four domains. The first three are patient specific. The fourth domain measures family/carer problems associated with the patient's condition or palliative care needs. The score triggers a more in-depth assessment.

The PSS domains	
1	Pain
2	Other symptoms
3	Psychological/spiritual
4	Family/carer

The PSS score	
0	Absent
1	Mild
2	Moderate
3	Severe

The Australia-modified Karnofsky Performance Scale (AKPS)

The AKPS is a measure of the patient's overall performance status or ability to perform their activities of daily living. It is a single score between 10 and 100 assigned by a clinician based on observations of a patient's ability to perform common tasks relating to activity, work and self-care. A score of 100 signifies normal physical abilities with no evidence of disease. Decreasing numbers indicate a reduced performance status.

Score	AKPS Assessment Criteria
100	normal; no complaints; no evidence of disease
90	Able to carry on normal activity; minor sign of symptoms of disease
80	normal activity with effort; some signs or symptoms of disease
70	Cares for self; unable to carry on normal activity or to do active work
60	Able to care for most needs; but requires occasional assistance
50	Considerable assistance and frequent medical care required
40	in bed more than 50% of the time
30	Almost completely bedfast
20	totally bedfast and requiring extensive nursing care by professionals and/or family
10	Comatose or barely rousable
0	Dead