End-of-life Care Needs of People Dying from Stroke in Australia, New Zealand and Singapore: a space for palliative care

M O’Connor, J Beattie, E Wing Hong, R McKechnie and K Keow Lee

Abstract

Aims:
1. Investigate the illness pathway of people dying of stroke in Singapore, New Zealand and Australia; and
2. Undertake a comparison of the needs of people dying of stroke between these countries.

Methods: A pilot retrospective medical record review was conducted with patients who died of stroke aged 18 years and over during 2008 to 2011 within acute care hospitals in Australia (n=10), New Zealand (n=10) and Singapore (n=7). This sample was designed to identify significant issues in the treatment and care of people who die of stroke, and will be used to inform a larger study. Sites chosen represented the key hospital for the treatment of people with stroke for a population of 200,000.

Medical record data were collected using an agreed template and concerns of patients, relatives and health professionals were also extracted. One researcher led the analysis, which included descriptive statistics and thematic analysis. Electronic and telephone discussions between researchers ensured consistency of data.

Principal findings: The majority of patients in Australia and New Zealand were transferred to stroke wards for care; those in Singapore were transferred to intensive care and lived longer. A stroke care pathway was followed in all countries, with a palliation pathway identified in two records (Australia and New Zealand). Palliative care was documented in the majority of Australian and New Zealand records.

Concerns related to impaired consciousness and deterioration in patients’ conditions. There was a lack of documented advance care plans and care directives; where present, staff had difficulty following them. Palliative care referral could make a difference to these patients and families.

Conclusion: Stroke happens suddenly. Time to death is often short. This pilot indicates there is space for palliative care in the management of stroke patients to assist in end-of-life decision-making and symptom management. A larger study on this issue is justified.

Abbreviations: DHB – District Health Board; ED – Emergency Department; EOL – End-of-Life; HP – Health Professional; ICU – Intensive Care Unit; MoH – Ministry of Health; NFR – Not-for-Resuscitation; PC – Palliative Care.

Key words: end-of-life care; stroke; care pathway; research; palliative care.

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Introduction

Stroke is a leading cause of death in Australia, [1] New Zealand [2] and Singapore. [3] In the acute phase of stroke, accurately predicting prognosis can be difficult. [4] Australian figures show that greater than 20% of patients diagnosed with their first stroke will die within 28 days. [5] and that by five years, 60% have died. [6] It is predicted that these figures will worsen as the population ages. [4] Following the acute phase of hospitalised care, United Kingdom figures show that as many as 19% of patients who survive hospitalisation after stroke require transfer to nursing or residential homes to manage ongoing care needs. [7]

The World Health Organisation defines stroke as: 'rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin'. [8]

While patients with cancer constitute the largest proportion of patients seen by Palliative Care (PC) services in most parts of the world, [9] the provision of End-of-Life (EOL) care services to patients who have had a stroke and their families remains challenging and unclear. [4, 10, 11] Some physicians regard stroke as a condition not appropriate for referral to PC, [12] leaving many patients and their families with unmet PC needs. [13]

In the three participating countries, there is little health policy connection between stroke and EOL care. However, the National Stroke Foundation in Australia has developed Clinical Guidelines for Stroke Rehabilitation and Recovery, which endorses that people with stroke who are dying, and their families, should receive care consistent with the principles of PC. [14, 15] Implementing these guidelines and determining the PC requirements for these patients can be a major challenge for managers of health services. [4, 16] Care delivery needs to be patient-centred, address stroke symptoms and immediate needs, ensuring that the patient’s and family views on life and living are taken into account, with PC as a part of care planning offered to every patient. [17]

Compared to other diseases such as cancer, the onset of stroke and death can be short, with little time for family to adjust, often leaving them feeling unsupported. [18, 19] Communication, where families are invited to share in decision-making, is crucial. [17] Family meetings can have a positive effect on care for the dying patient with stroke as these ensure that clinicians and family are informed and in consensus, and better placed to make decisions about care. [19]

Research suggests that while medical and nursing staff have identified that patients with stroke might have PC needs, referral to PC services is not always considered appropriate in many countries. [20] However, this lack of referral is considered detrimental to the relationship between stroke and PC services, as working together would facilitate better understanding in both areas, resulting in improved patient care. [21] Incorporating a care pathway for the dying patient with stroke has been found to improve documentation of care delivered as well as ensuring appropriate care of dying patients. [16] In a United Kingdom stroke unit the care pathway for the dying patient provided guidance for aspects of EOL care such as comfort measures, medication prescribing, cessation of inappropriate interventions and psychological and spiritual care, including care of the family before and after death of their loved one. [16]

An Asia-Pacific regional workshop on PC research revealed that the provision of PC for people with non-malignant illnesses was problematic in many countries. As stroke is a major cause of death in most countries, agreement was reached to undertake a research project on people dying of stroke. The chosen sites were agreed to represent the key acute health services for the treatment of people with stroke for a population of approximately 200,000.

Aim

The aims of this pilot study were to validate a data collection instrument in order to:

1. Investigate the illness pathway of people dying of stroke living in Singapore, New Zealand (Otago) and Australia (Melbourne); and
2. Undertake a comparison of the needs of people dying of stroke between these countries.

The results of this pilot study will be used to inform a larger study of 300 records to pursue clinical aspects that emerge as significant in the treatment and care of people who die of stroke. The numbers chosen for the pilot represent approximately ten per cent of a total number of 300 records of all people who died from stroke over all three sites.

Each site gained approval from their human research ethics committees and the lead researchers also gained ethical approval from the Monash University Human Research Ethics Committee to conduct the study.

Method

A retrospective medical record review of patients who had died of stroke aged 18 years and over during 2008 to 2011 in Australia, New Zealand and Singapore was conducted. Because it was a pilot study, an agreed small sample of five
female and five male patient records were sought from each site (n=10). With assistance from neurologists or medical records staff, the records selected were those that first met the above inclusion criteria (Australia n=10, New Zealand n=10, Singapore n=7).

Data were collected by the researchers in each country, using one template with items developed and agreed by them and then reading each medical record accordingly. Demographics; Admissions and Emergency Department (ED) presenting problems; primary diagnosis, co-morbidities, medications and cause of death; provision of care and treatment, including Health Professionals (HPs) and services used; as well investigations, treatments and clinical pathway were recorded. Any concerns of patients, relatives or next of kin, and HPs that were documented in the records were also collected. The common template enabled each researcher to collect the same data and no identifying data such as medical record number, name, or address was collected. One researcher (JB) managed the data as it came in from each site. She was involved in preliminary analysis of the descriptive statistics and led electronic and telephone discussions with each researcher regarding the consistency of the data.

Quantitative data were entered into SPPS software (version 18.0) and descriptive analysis conducted. Qualitative data were thematically analysed for common patterns of concern for patients, relatives and HPs. [22]

Results

Demographics
Twenty-seven records (Australia n=10; New Zealand n=10; Singapore n=7) were examined (Table 1). The Australian sample was older (median age=87.5) than the New Zealand and Singapore samples (median age=70); however, the greatest age range was New Zealand (20-95). In Singapore and New Zealand, most patients had lived at home with family carers (spouses and children); for one person in Singapore, a maid assisted in care. In contrast, half of the Australian sample had lived in a nursing home with staff as their primary carers. Living arrangements varied from one person who lived alone with no carer, to others who lived with family. All patients in all countries had died in a public hospital.

Admission and emergency department presenting problems
Most patients in Singapore (100%) and Australia (80%) were transported to the ED by ambulance. In contrast, 38% of patients used an ambulance in New Zealand. The number of admissions per patient in the study period, ranged from one to ten (Australian mean=4.4; New Zealand mean=8.5; Singapore mean=3.5). The most frequent presenting problem on last admission in all countries was ‘altered conscious state’/’unresponsive’/’collapse’ (16/27; 59.3%), followed by stroke/stroke symptoms (9/27; 33.3%).

<table>
<thead>
<tr>
<th>GENDER (N)</th>
<th>AGE RANGE (MEDIAN)</th>
<th>PLACE OF RESIDENCE (%)</th>
<th>PRIMARY CARER (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>OWN HOME</td>
<td>FAMILY HOME</td>
<td>HOSTEL</td>
</tr>
<tr>
<td>Australia</td>
<td>Male (5)</td>
<td>78-86 (84)</td>
<td>2 (20)</td>
</tr>
<tr>
<td></td>
<td>Female (5)</td>
<td>9-92 (91)</td>
<td>2 (20)</td>
</tr>
<tr>
<td>New Zealand</td>
<td>Male (5)</td>
<td>56-88 (69)</td>
<td>9 (90)</td>
</tr>
<tr>
<td></td>
<td>Female (5)</td>
<td>20-95 (71)</td>
<td>9 (90)</td>
</tr>
<tr>
<td>Singapore</td>
<td>Male (4)</td>
<td>56-65 (63)</td>
<td>5 (71.4)</td>
</tr>
<tr>
<td></td>
<td>Female (3)</td>
<td>58-78 (77)</td>
<td>5 (71.4)</td>
</tr>
<tr>
<td>Total</td>
<td>27 (74)</td>
<td>16 (59.3)</td>
<td>3 (11.1)</td>
</tr>
</tbody>
</table>

*IDU = Independent living unit
Australian patients most frequently remained in ED (5/10; 50%), New Zealand patients were most frequently transferred to a general medical ward (8/10; 80%), and Singaporean patients to an Intensive Care Unit (ICU) (5/7; 71.4%).

Primary diagnosis, comorbidities and cause of death
Using the classifications identified in the patient records (haemorrhagic, ischaemic and non-specified stroke), the most frequently presenting primary diagnosis in Singapore was haemorrhagic stroke (100%). In New Zealand, both haemorrhagic (40%) and ischaemic stroke (40%) frequently occurred. However 50% of strokes were unspecified in Australia, making further analysis difficult. Patients presented with a range of cardiovascular, respiratory, musculoskeletal, gastrointestinal and psychological comorbidities and cancers. For many, this was not their first admission for stroke. Deaths from aspiration pneumonia (New Zealand n=2) and nosocomial pneumonia (Singapore n=2) as a complication of stroke were also identified.

Fifty per cent of Australian patients died on day of admission, with 40% living from one to two days, and up to 27 days (10%). In New Zealand, 20% of patients died on day of admission, with 60% living for one to five days and up to 27 days (20%). In contrast, in Singapore, 57.1% of patients lived for ten to 55 days.

Table 2: Health professionals and services providing care in each site

<table>
<thead>
<tr>
<th>HEALTH PROFESSIONALS/SERVICES PROVIDED</th>
<th>PATIENTS N=10 (%)</th>
<th>PATIENTS N=10 (%)</th>
<th>PATIENTS N=7 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>AUSTRALIA</td>
<td>NZ</td>
<td>SINGAPRE</td>
</tr>
<tr>
<td>Medical staff</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Registrar</td>
<td>10 (100)</td>
<td>10 (100)</td>
<td>7 (100)</td>
</tr>
<tr>
<td>Intern</td>
<td>0</td>
<td>10 (100)</td>
<td>0</td>
</tr>
<tr>
<td>Internal Medicine Consultant</td>
<td>0</td>
<td>6 (60)</td>
<td>0</td>
</tr>
<tr>
<td>Intensive Care Consultant</td>
<td>0</td>
<td>2 (20)</td>
<td>5 (71.4)</td>
</tr>
<tr>
<td>Neurologist/Neurosurgeon</td>
<td>0</td>
<td>1 (10)</td>
<td>7 (100)</td>
</tr>
<tr>
<td>Vascular Consultant</td>
<td>1 (10)</td>
<td>1 (10)</td>
<td>1 (14.3)</td>
</tr>
<tr>
<td>Endocrine Consultant</td>
<td>1 (10)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Orthopaedic Consultant</td>
<td>1 (10)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>General Practitioner</td>
<td>6 (60)</td>
<td>2 (20)</td>
<td>0</td>
</tr>
<tr>
<td>Radiologist</td>
<td>0</td>
<td>0</td>
<td>4 (57.1)</td>
</tr>
<tr>
<td>Anaesthetian</td>
<td>0</td>
<td>0</td>
<td>4 (57.1)</td>
</tr>
<tr>
<td>Nursing staff</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical Nurse</td>
<td>10 (100)</td>
<td>10 (100)</td>
<td>7 (100)</td>
</tr>
<tr>
<td>Stroke Nurse</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Palliative Care Nurse</td>
<td>3 (30)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Diabetes Clinical Nurse Consultant</td>
<td>0</td>
<td>1 (10)</td>
<td>0</td>
</tr>
<tr>
<td>Case Manager</td>
<td>0</td>
<td>0</td>
<td>4 (57.1)</td>
</tr>
<tr>
<td>Pain Management</td>
<td>0</td>
<td>1 (10)</td>
<td>0</td>
</tr>
<tr>
<td>Allied health staff</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pharmacist</td>
<td>0</td>
<td>0</td>
<td>6 (85.7)</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>4 (40)</td>
<td>3 (30)</td>
<td>3 (42.8)</td>
</tr>
<tr>
<td>Speech Therapist</td>
<td>4 (40)</td>
<td>3 (30)</td>
<td>0</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>3 (30)</td>
<td>2 (20)</td>
<td>3 (42.8)</td>
</tr>
<tr>
<td>Dietician</td>
<td>1 (10)</td>
<td>2 (20)</td>
<td>2 (28.6)</td>
</tr>
<tr>
<td>Social Worker</td>
<td>0</td>
<td>2 (20)</td>
<td>3 (42.8)</td>
</tr>
<tr>
<td>Podiatrist</td>
<td>0</td>
<td>1 (10)</td>
<td>0</td>
</tr>
<tr>
<td>Aged Care Assessment Team</td>
<td>1 (10)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Community care staff</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Help</td>
<td>2 (20)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Meals on Wheels</td>
<td>2 (20)</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
Of those records where a care pathway was identified, the stroke pathway was the most frequently followed (Australia 40%; New Zealand 30%; Singapore 42.4%). A palliation pathway was identified in only two records (Australia and New Zealand); however, palliative care was documented in 60% of Australian and 80% of New Zealand patient records. Not all care that is considered ‘routine’ care for severely ill patients was captured in the data. A ‘Dangerously Ill List’ (Singapore n=1) was also identified.

**Investigations and treatment**
The majority of patients had blood tests (Australia 80%; New Zealand 100%; Singapore 100%) and CT scans (Australia 60%; New Zealand 60%; Singapore 100%) to investigate their condition. All were prescribed multiple medications for multiple comorbidities, including stabilisation while in ICU (Australia m=9.6; New Zealand m=6.3; Singapore m=14). Morphine, benzodiazepines and antipsychotics were more frequently prescribed in the Australian sample, compared to no/little usage in New Zealand and Singapore. While most medications seemed appropriate for the presenting comorbidities, a detailed assessment for best practice was not undertaken.

Figure 1 shows the range of treatments, (other than medicines) received by patients. Palliative care (not further specified) was provided in Australia (n=6) and New Zealand (n=8), while intubation, ventilation, urinary catheterisation and enteral feeding were more prevalent in Singapore. This may be attributed to the fact that 71.4% of Singaporean patients were transferred to ICU. In comparing the qualitative data in each record, it was evident that care activities such as pain assessment, and oral and pressure area care which are considered to be routine nursing practice in each country, were not captured in the data for this study.

**Concerns of patients, relatives and health professionals**
In Australia, there was some evidence of patient, relative and HP concerns documented in medical records, however, little was documented in Singapore and New Zealand. Documented concerns are reported in Table 3 for all sites and concerns related to EOL decision-making and are outlined.

**Figure 1: Identified treatments for each site**
## Table 3: Concerns of patients, relatives and health professionals

<table>
<thead>
<tr>
<th></th>
<th><strong>CONCERNS DOCUMENTED</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PATIENTS:</strong></td>
<td></td>
</tr>
</tbody>
</table>
| Australia               | • Deterioration in condition; patient unable to verbalise concerns (n=4)  
                         | • Moaning and grimacing, stiffening when arm moved (n=1)  
                         | • Prepared to die (ID5); very open about not wanting resuscitation (ID7)  
                         | • Current NFR1 certificate used to determine wishes (n=1)  
| New Zealand             | • Became unsettled when turned (n=1); Used hand squeeze signals (n=1)  
                         | • DNRT (n=2); Advanced directive for health care (n=1)  
                         | • Unable to verbalise (n=1); Unable to recall fall (n=1)  
                         | • Remained unresponsive (n=3)  
| Singapore               | • Deterioration in condition; patient unable to verbalise concerns (n=7)  
|                         |                         |
| **RELATIVES:**         |                         |
| Australia               | • Agreed to NFR, including no cardiopulmonary resuscitation & intubation (n=7)  
                         | • Requested to be contacted when condition deteriorates (n=10)  
                         | • Advised no interaction that would cause suffering/no aggressive treatment (n=4)  
                         | • Requested patient be made comfortable (n=1), with no further assessments to be performed (n=1), and no enteral feeding (n=1)  
                         | • Concerned about deteriorating quality of life and frailty (n=1)  
                         | • Family wished to be present through palliation (n=2)  
                         | • Difficulty in making decision not to treat (ID7) (e.g. antibiotics, investigations)  
| New Zealand             | • Wanted explanation of cause of death and autopsy (n=1)  
                         | • Aware of severity of condition, watching and waiting (n=2); Present at death (n=1)  
| Singapore               | • Felt deprived of the opportunity to hear the patient’s last wishes because they were not allowed to be with the patient before she became comatose. (n=1)  
                         | • Financial concerns (n=2)  
                         | • Family requested that active treatment and ventilatory life support continue until the return of son from overseas (n=1).  
                         | • Despite being advised of poor prognosis, family requested active management and ICU re-admission (n=1).  
                         | • Family reluctant to reveal diagnosis and risk of deterioration to the patient because they thought this would cause them to be anxious and adversely affect their condition (n=1).  
|                         |                         |
| **MEDICAL STAFF:**     |                         |
| Australia               | • Too unwell to be transferred to a palliative care unit (n=1)  
                         | • Extensive discussion with family to arrive at NFR decision (ID6)  
                         | • Wean off oxygen, to palliate (n=1); Obesity made intubation difficult (n=1)  
                         | • Severe pre-morbid conditions (obesity, cheyne-stokes breathing) (n=1)  
| New Zealand             | • Visited several times to accurately assess advance directive (n=1)  
| Singapore               | • Patient’s wife intimidating & unaccepting the fact of low survival (n=1)  
|                         |                         |
| **NURSING STAFF:**     |                         |
| Australia               | • Difficulty with pressure area care (n=1)  
                         | • Awaiting medication order for management of symptoms (n=1)  
                         | • Aspiration - Concern that lack of swallowing reflex might lead to aspiration (n=1); vomiting and aspiration (n=1)  
                         | • Concern lack of spontaneous breathing & decision not to introduce fluids and antibiotics may lead to pneumonia (n=1)  
                         | • Ensure pain relief as necessary (n=2)  
                         | • Deterioration – malodorous urine, incontinence (treated with urinary catheter), hypothermia (n=1); Poor glycaemic control (n=1)  
                         | • Family had difficulty arriving at decision not to treat with antibiotics and further investigation (ID7); Pacemaker deactivated (n=1)  
                         | • Sacral pressure area sore present on admission (n=1)  
| Singapore               | • Stroke Nurse attempted to discuss Advance Care Planning with the family, who were initially keen, but then decided only to explore when patient condition was more stable (n=1)  
|                         |                         |
Challenges to advance care planning
Deterioration in patients’ conditions left many unable to verbalise their concerns, wishes and needs. In Singapore, relatives felt deprived of the opportunity to hear the patient’s wishes (n=1). In Australian records (n=2), patient wishes were followed in relation to Not-for-Resuscitation (NFR) because previously arranged NFR orders were available and confirmed. There was no detail documented however, of what care constituted ‘NFR’. In New Zealand records NFR orders were available for two patients. For one however, the advance directive witnessed by his general practitioner was continually challenged by an assortment of medical staff to ensure that this was still what he wanted, even though his family supported his directive. In one Singaporean record, there was evidence of the stroke nurse’s attempt to discuss advance care planning with the family; initially they were keen to do so, but changed their mind, hoping to discuss ongoing care with the patient when the condition stabilised.

Challenges to EOL care and decision-making
For those patients unable to communicate, there was recorded evidence of family members becoming their proxy decision-makers. While some relatives appeared ready to make these decisions, others found it a challenge, for example in agreeing to NFR orders (including no cardiopulmonary resuscitation, intubation, antibiotics, enteral feeding or further investigations). There was evidence that HPs spent considerable time with relatives to provide information to enhance the decision-making process.

There was also documentation in a number of Australian records identifying relatives’ requests that no action that caused harm or suffering be undertaken, and documentation in all countries requesting comfort care. In two Australian records, patients had stated that they were prepared to die (AIDS) and were ‘very open about not wanting resuscitation’ (AID7). Across all sites, there was documented evidence of relatives requesting to be notified when the patient’s condition deteriorated so they could be present at EOL. Other relatives were present throughout the dying process, while for one Singaporean family, regret was verbalised, because of not being allowed to be with the patient before the patient became comatose.

Further, deterioration in one Australian patient resulted in them being deemed too unwell to be transferred to a palliative care unit, and in other instances, concern that aspiration and pneumonia would occur due to lack of swallowing reflex and vomiting (Australia and New Zealand). One Singaporean family requested ongoing life support as necessary (n=1); Recommended no oral intake (n=1); Unsuitable for speech therapy due to deterioration of condition, recommended review as necessary (n=1); Patient unable to complete own activities, heavily reliant on wife (n=1); Patient’s wife verbalised acceptance of patient’s prognosis when medical social worker provided support to family (n=1); Social worker provided information on procedure for settling hospital bills, funeral management and gave written material as a reference (n=1).

Table 3: Concerns of patients, relatives and health professionals

<table>
<thead>
<tr>
<th>ALLIED HEALTH</th>
<th>CONCERNS DOCUMENTED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>• Occupational therapist noted depression &amp; poor insight into condition (n=1)</td>
</tr>
<tr>
<td></td>
<td>• Inability to swallow &amp; cough (n=1); Recommended no oral intake (n=1)</td>
</tr>
<tr>
<td></td>
<td>• Unsuitable for speech therapy due to deterioration of condition, recommended review</td>
</tr>
<tr>
<td></td>
<td>as necessary (n=1)</td>
</tr>
<tr>
<td></td>
<td>• Patient unable to complete own activities, heavily reliant on wife (n=1)</td>
</tr>
<tr>
<td>Singapore</td>
<td>• Patient’s wife verbalised acceptance of patient’s prognosis when medical social</td>
</tr>
<tr>
<td></td>
<td>worker provided support to family (n=1)</td>
</tr>
<tr>
<td></td>
<td>• Social worker provided information on procedure for settling hospital bills,</td>
</tr>
<tr>
<td></td>
<td>funeral management and gave written material as a reference (n=1)</td>
</tr>
</tbody>
</table>

* More than one concern was expressed in individual case records
† NFR and DNR: not for resuscitation and do not resuscitate

Discussion
Principal findings
The findings of this pilot study concur with previous stroke statistics for each country, [1-3] which showed that while stroke happens suddenly, and death can occur on the same day of admission for 20% (New Zealand) to 50% (Australia)
of patients, many had been admitted previously for stroke symptoms. Additionally, the majority of patients lived from one to five days (Australia 40%; New Zealand 60%), being transferred to stroke or general medical wards. The findings of this pilot study confer with what is known about the Asian population, namely, that haemorrhagic stroke was more prevalent in the Singaporean sample than Caucasian samples. [23, 24] Due to the severity of haemorrhagic stroke in the Singaporean sample, many patients were transferred to ICU, with about half of the sample living for ten to 55 days. The higher number of medications used in this Singapore sample are also likely to be due to the severity of stroke and active intensive care management. While there would seem an opportunity for palliative care expertise in EOL management of stroke patients in all countries, there was little evidence of formal service involvement. This study supports the work of others that patients and their families require care teams to abide by previously written advance directives, and assist those who do not have these, to make informed EOL care decisions so that requests for measures to reduce suffering and comfort care can be actualised. [13, 15]

In relation to investigations and treatments, patients in all countries were equally investigated with blood tests and CT scans, and multiple medications were prescribed for comorbidities. It was not the aim of this study to examine best practice in relation to investigations and treatments; however, this is also an area for further study. More invasive interventions were carried out in Singapore, where most patients went to ICU for ongoing care. However, the long-term use of technology and invasive treatments is an area for further study, particularly where relatives insist on such care when patients have poor prognoses.

Various patient, relative and HP concerns were identified in the records, many related to the impaired consciousness and deterioration in patients’ conditions. Of particular concern was the lack of documented advance care plans and directives, and where these were present, hospital staff appeared to have difficulty following them. Consequently, the role of family in decision-making was vitally important. This finding supports that of others where palliative care is seen as important in the care of stroke patients, [16, 17] where families require support with explanations about prognosis, surgery, withdrawal of technological support, and artificial nutrition. Thus there would seem to be a number of areas where PC referral could make a difference to this cohort and their families. Ensuring symptoms, in particular pain, are managed in an unconscious patient, is vital in good EOL care, and this is the PC services’ area of expertise.

Implications for health services managers and policy makers
In New Zealand stroke service provision is provided by the District Health Boards (DHBs) of which there are 20 throughout the country. These are funded by the Ministry of Health (MoH). Each DHB is responsible for its own area and is administered by a board of up to 11 members, four of whom (including the Chair and Deputy Chair) are Ministry appointments. The remaining seven are publicly elected through local government elections. DHBs are expected to plan and deliver health services in an ethical manner to provide effective care and support for those needing such services.

Stroke management in New Zealand is delivered according to the New Zealand Clinical Guidelines for Stroke Management (2010) where all DHBs are required to provide stroke services and that all those admitted to hospital with stroke should be managed in a dedicated stroke unit cared for by a multidisciplinary team with expertise in stroke and rehabilitation. However in an audit of DHBs carried out in 2009, only eight DHBs provided dedicated stroke units.

In the New Zealand system stroke patients are admitted to ED. Half die either on the same day or the following day and only those who are expected to survive are referred to a stroke pathway or stroke unit.

As highlighted in this study, EOL decision-making can be a challenge, even when advance care plans have been documented, [25-28] with hospital staff being unclear about the legal status of these plans/directives and NFR orders. [29, 30] It is therefore imperative for health service managers and policy makers to ensure advance care planning is discussed and documented early, that the position of such documentation is made clear within their organisations, so that patient wishes can be implemented where they have been made known.

In the New Zealand site, there was no interaction between stroke services and PC services although PC was documented in New Zealand patient records. Having this documented did not mean a referral to PC services, what it meant was that the patient received palliative of symptoms provided by the staff on the Neurology ward. However this may not be the case in other areas of the country.

In addition, formal communication channels need to be opened between those managing and delivering stroke services and those delivering PC services. However, given that PC has evolved around EOL care of people with cancer, [31, 32] there may be a resistance to engaging PC services
in the EOL care of people with non-malignant conditions. This may simply be that the PC team is not resourced to extend support beyond cancer care. This too is an area for further study. Engagement with PC services can assist with EOL decision-making and the provision of EOL care so that patients and their families can spend time together in a safe and dignified manner.

Study limitations
Caution needs to be taken in interpreting results and making comparisons between countries that have different health care systems and cultural contexts. In addition, the small sample for this pilot project may not be able to be generalised to all people admitted to hospital with stroke; however as noted, the care trajectory remained reasonably consistent before death.

Future research
This was a small pilot study; however it justifies a larger study to give a more comprehensive understanding of the EOL care needs of people dying from stroke, with the aim of informing the provision of PC for them. This study could also compare best practice in PC for stroke patients, including the appropriate use of medicines. In addition, interviews with carers and families about their concerns could be conducted to bridge the gap in documentation identified in this study. We suspect that a much broader discussion would have been conducted, but not documented; reasons for this could also be explored with HPs.

Conclusion
While stroke happens suddenly and time to death is often short, there is space for PC in the management of stroke patients to assist in EOL decision-making and symptom management.

References


