WHAT IS THE COST OF PUBLIC HOSPITAL CARE AT THE END-OF-LIFE?

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CANDIDATE'S DECLARATION

I, Christopher H. McGowan certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university; and to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Christopher H. McGowan

16th December 2015

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SUMMARY

This program of research asked the question: what is the cost of public hospital care associated with end-of-life? The research included a retrospective cohort study to examine Australian public hospital costs associated with end-of-life care and specifically addressed:

- the proportion of total public hospital costs comprised of end-of-life care
- the proportion of total public hospital costs related to end-of-life care attributable to ageing
- Do public healthcare costs changes over time?
- factors that impact on hospital costs at the end-of-life
- variations in hospital costs at end-of-life among selected States

A unique database comprising population-wide health data was created containing all deaths in NSW, Qld, WA and SA for 2005 and 2010, and 1995 and 2000 decedents for WA. Decedents' public hospital records were linked with births, deaths and marriage records to form a longitudinal public hospital utilisation record for each decedent. These linked, routinely collected administrative health data were examined to establish the proportion of public hospital resources consumed in the last 12 months and last five years of life. The proportion of these resources consumed by older patients, and changes over time, were examined together with factors that might influence public hospital costs of end-of-life care, including age of death, and cause of death. Examination of patterns of hospital utilisation by cause of death and distribution of hospital resources by patient type was also undertaken. Variations among the four jurisdictions were also examined.

The findings indicate that the last year of life accounts for 10 percent of total state expenditure on public hospitals; an amount comparable to other research in the Australian context and other developed countries. Further, these costs for end-of-life care were rising significantly faster than inflation.

The findings also indicated that while the cost of ageing, excluding the higher proportion of deaths occurring for older people, is substantial, projecting future hospital utilisation demand, after excluding the cost of dying, represents a significant discount to current projections. The research also found that public hospital costs of end-of-life care decrease as decedents' age, for all causes of death except sudden death. The results indicate that cause of death

influences the cost of end-of-life care, ranging from neoplasm related deaths (\$26,303) to frailty related deaths (\$10,763). Further, the age of death and cause of death remained stable between 2005 and 2010.

A comparison of the four jurisdictions found that public hospital utilisation for end-of-life care was largely consistent. The pattern of hospital admissions preceding death varied by cause of death, but a higher proportion of resources were consumed by a relatively small number of decedents.

Conclusions

Costs of end-of-life care in public hospital are rising faster than health inflation and, as such, require attention from policy makers for the future. While to some degree the costs of an ageing population are offset by reduced hospital costs for older decedents, this exchange is not sufficient to mitigate the healthcare costs of an ageing population. Moreover, it was found that a large percentage of end-of-life hospital costs is concentrated on a relatively small percentage of decedents and, as such, might guide policy makers to address healthcare for this group.

CHAPTER 1 CONTEXT AND INTRODUCTION

In a developed society, along with the provision of a judicial and an education system, the provision of healthcare to the population is amongst the highest priorities of an organised state. Across the globe, government expenditure on healthcare is generally rising and therefore receives considerable attention from policy makers (Commonwealth of Australia, 2003; Australian Institute of Health and Welfare, 2010). Government expenditure on healthcare is usually measured both in terms of real (normalised) dollars and as a percentage of gross domestic product (GDP) reflecting the relative prioritisation of healthcare in a given economy.

The most common method for evaluating the 'effectiveness' of healthcare expenditure is by measuring life expectancy at birth. While this does not capture all dimensions of healthcare value, it is useful in that it reflects many of the consequences of subordinate dimensions to healthcare service delivery such as access to care, quality of physicians, access to pharmaceuticals and preventative care, and infant mortality. All these dimensions are arguably necessary to achieve the goal of extending life expectancy at birth. However, life expectancy does not measure the experience of the years lived and can lack sensitivity to the inequity in health outcomes between sub-populations.

Over time, life expectancy has increased markedly across developed countries. Changes in life expectancy in Australia between 1888 and 2013 are illustrated in Figure 1.1 where average age of death increased from 46 and 48 (M; F) to 79 and 81 (M; F) (Commonwealth of Australia, 2015). Similar increases have occurred across most developed countries.

Consistent with demographic trends in other developed countries, the Australian population is ageing (Australian Institute of Health and Welfare, 2007, 2014). This is largely due to low fertility and increases in life expectancy (Australian Institute of Health and Welfare, 2007, 2014). Between 2010 and 2050 it is estimated that the number of Australians aged 65 to 84 years will double and those aged 85 and over will quadruple (Australian Institute of Health and Welfare, 2010). A case in point: in 1950 life expectancy for male was 65 years and for a female 70 years. In 2015, a male aged 65 years can now expect to live to 84 years and a female to 87 years (Australian Institute of Health and Welfare, 2014).

The ageing of the Australian population is already having an effect on the Australian health care system. In 2004–05, 2.5 million hospital separations were recorded for persons aged 65 years and over, representing 35% of all separations (Australian Institute of Health and Welfare, 2006). If the current situation continues, the number of hospital separations is projected to significantly increase over the next 15 years. For instance, it is expected that the number of public hospital separations will increase from a total of 7 million separations in 2004–05 to around 11 million in 2030, with a corresponding increase from around 24 million to 42 million patient days (Australian Institute of Health and Welfare, 2007).

Where life expectancy has increased markedly it is largely attributable to reductions in infant mortality. A reduction in infant mortality has disproportionate effects on life expectancy at birth compared to the additional one or two years of life at the end. Furthermore, social disharmony and war tend to rob life years from the young disproportionately and so too have a disproportionate effect on life expectancy. Western societies have transitioned from the early part of the 20th century, where diseases and catastrophic infections which affect the young as well as the aged, were substantially arrested by the early 1950s (Fries, 1980). These diseases have been largely replaced by lifestyle diseases which manifest in chronic conditions that are frequently discussed in the health policy arena (Fries, 1980; Lubitz et al., 2003; Fries, 2005; Goetzel et al., 2005; Graves et al., 2006; McNamara & Rosenwax, 2006; Fassbender et al., 2009; Gandjour, 2009; Rosenwax et al., 2011). It is these lifestyle diseases, or chronic conditions, that will define the nature of healthcare provision in the future.



Figure 1.1 Expected length of life at birth, by sex, Australia, 1888 to 2013 Source: ABS 2014a; ABS 2014b (Table S1).

Consideration of the concept of "value" might usefully be determined therefore as life expectancy per dollar spent on healthcare or percentage of GDP. Figure 1.2 shows that in 2013, once healthcare spending per capita reached approximately \$2,000 across numerous countries, the return in terms of additional life expectancy gained diminished markedly. It might reasonably be assumed that as a country's GDP per capita increases, the affordability of healthcare concurrently rises and investment in normalised dollars for healthcare spending per person increases.



Figure 1.2 Life expectancy at birth by GDP per person. (OECD Health Statistics 2013).

The propensity for governments to continue to spend on healthcare services in spite of diminishing returns, as illustrated in Figure 1.2, raises the question of what constitutes "value for healthcare" as the state's resources are challenged by other priorities such as infrastructure, education and other policy matters. When there is such competition for resources, the question arises regarding the most appropriate "health" expenditure priorities relative to other investment opportunities.

To establish health expenditure priorities it is important to be able to accurately quantify how current health care expenditure is distributed (Tanuseputro et al., 2015). For example, what proportion of health resources are consumed by older people and has this changed over time? More precisely, what proportion of public health care costs is consumed by older patients overall and by older patients in their last years of life? To date, relatively little research has been directed to this question in Australia (Goldsbury et al., 2015).

In examining the potential impost on the provision of health care services and their associated costs various theories have been developed. In 1980, James Fries described a phenomenon termed 'the Compression of Morbidity' whereby the lifetime trajectory of illness for the average, standardised person, is characterised by: higher health care utilisation for infants followed by a long period of relatively low utilisation and healthy life years. For women, this is slightly interrupted by the use of healthcare during child birthing years which, while not considered an illness as such, does use healthcare resources. At the later stages of life, the theory speculates that the onset of age related disease and disability begins to encroach on quality of life and increases healthcare consumption which, as death approaches, increases rapidly (both cost and morbidity) preceding death (Fries, 1980) (Figure 1.3).



Figure 1.3 Fries' lifetime acute health care costs (illustrative only)

Fries also contends that while life expectancy for the individual is largely determined by one's genes, changes in lifestyle may defer the onset of age related disease and disability but only have a small impact on ultimate life expectancy. He further speculated that as the deferment of age related disease and disability occurred faster than the extension of life years, the period of morbidity preceding death is compressed.

Therefore, he argued, that investment in healthcare that deferred the onset of age related disease and disability, more than it extended life, would result in an increase in quality life years (time preceding the onset of age related disease and disability) and reduce the morbid pre-death phase and, as total morbidity decreased, it was likely to result in less healthcare expenditure over the life of a citizen (Figure 1.4).





Fries early work helped stimulate discussion and exploration of the relationship between health innovations, patterns of morbidity, quality of life and the overall impact of these changes on the total cost to society of healthcare expenditure and the consumption of healthcare resources. More recent research has demonstrated that the Fries' morbidity compression effect has been taking place in the US (Fries, 2003, 2005; Mor, 2005). However, this effect appears to operate, or to have been assessed, independently of a range of other variables that impact overall health care costs as healthcare expenditure continues to rise in real terms and as a percentage of GDP (Commonwealth of Australia, 2003). So while morbidity compression among ageing populations may occur, it is likely to be only part of the picture in terms of factors that influence the upward cost of healthcare provision.

Numerous cross-sectional studies on healthcare expenditure have highlighted the cost of ageing, forecasting that as populations live longer and the percentage of people in the old and very old categories increases, both in real terms and as a percentage of the population, healthcare expenditures becomes an increasing financial challenge for governments (Commonwealth of Australia, 2003; Alemayehu & Warner, 2004; Commonwealth of Australia, 2010). These cross-sectional studies draw attention to the relative percentage of healthcare expenditure consumed by various age cohorts and in particular the older cohorts. For example, total health expenditure on people aged 75-84 years divided by the population of 75-84 year olds is high compared to younger population cohorts. This led to speculation, therefore, that as the population of 75-84 year old citizens increases, health care expenditure will also increase as a direct result of this demographic change alone (Commonwealth of Australia, 2003).

From as early as the 1960's, researchers began to pay particular attention to the relationship between age of death and healthcare expenditure. Attention was directed toward additional healthcare costs as a function of ageing, as it related to end-of-life care, rather than ageing *per se* (Van Vliet & Larmers, 1998; Felder et al., 2000; Felder, 2001; Seshamani & Gray, 2004; Stearns & Norton, 2004; Calver et al., 2006; Forma et al., 2007). Hence, two different, but related issues emerged. The first was the potential impact on health care costs of the phenomenon of ageing *per se*. The second was the impact of the cost of end-of-life care on healthcare costs. Often, these two different, but related, issues were conflated thereby making it challenging to disentangle the different effects and their implications for funding policy and service provision planning.

From one perspective, the healthcare costs associated with dying were essentially deferred with a population with greater life expectancy. As those end-of-life costs were relatively constant regardless of whether or not the patient died young or elderly they were not adding a significant burden to the healthcare budget. The corresponding argument was that the older person who was not in near proximity to death was unlikely to consume significantly more health resources than a middle aged citizen. That is, ageing per se was not creating a greater impost on the cost of health care provision. Therefore, having a proportionally larger elderly

population does not confer additional healthcare costs to the state but simply defers those costs until a later time.

An additional argument is that whether end-of-life healthcare costs are deferred or not there is also a decrease in the costs of end-of-life care as patients get older. If this were the case, it would potentially further reduce healthcare costs incurred by an ageing population (Van Vliet & Larmers, 1998).

Conversely, others have speculated that as the frailty associated with ageing becomes more disabling, the non-health related costs of older people are significant drivers of state expenditure more so than healthcare (McGrail et al., 2000). While the public hospital component of the total healthcare sector may not experience substantial increases in cost due to larger proportions of older people, there may in fact be increased costs that are defrayed to other elements within the healthcare system overall. Also, as the "baby boomer" cohort age, larger numbers of people in older age groups will likely increase outright resource consumption.

Understanding future health care utilisation patterns of older populations is clearly a critical issue for policy makers for whom predicting future demand and cost of hospital care is an issue of central economic concern.

Fries' compression of morbidity concept is useful in that it, arguably, provides a framework for the conceptualisation of "value" to the public of healthcare investment. Deferring the onset of age related disease and disability, to optimally manage life limiting illnesses predeath and to enhance end-of-life care, would increase "quality life years" while potentially reducing costs. A corresponding framework for healthcare purchasing could be as follows:

- *Invest in preventative healthcare to defer the onset of age related disease and disability.* These investments might focus on services which, for example, promote early childhood development which has a lifetime effect on the social determinants of health, reduced smoking, healthy eating, positive exercise and generally good lifestyles.
- *Effective management of the onset of age related disease and disability.* The objective is to defer the decreasing quality of life and symptoms associated with the inevitable

onset of disease and disability. (For example, services that promote evidence based medicine, positive self-management, effective use of pharmaceuticals, early detection and monitoring of problems and the use of only effective treatments.)

- Provision of effective healthcare services that adopt the lowest cost modalities.
 Provision of information through technology, the avoidance of high cost health services where for example, home care might substitute and the avoidance of futile care.
- Finally, efforts to deliver these services could be *equally distributed across all populations such that health outcomes (quality of life years) are provided equally to all population sub-groups.*

There is a view that healthcare expenditure in the last year of life consumes significantly more resources than in all preceding years of an individual's life and some health policy commentators have identified the cost of dying as an area that warrants health policy attention and potentially reform (Lubitz & Riley, 1993; Emanuel & Emanuel, 1994; Hogan et al., 2001; Gray et al., 2002; Hoover et al., 2002; Bolnick, 2003).

Estimates of the cost of health care provided in the last year of life vary from two to three times up to 28 times the national average healthcare consumption level (Van Vliet & Larmers, 1998). However, there remains limited research into the nature of the end-of-life care, other than descriptive analyses that provide details of segmentation by gender or with a predominant focus on palliative care (Dumont et al., 2010; Chastek et al., 2012; Bremner et al., 2015; Cheung et al., 2015).

Some modelling of forward estimates of healthcare expenditures by policy makers has taken into account the cost of end-of-life care and have discounted the effect of ageing of the population (Calver et al., 2006). However, these models hold the actual cost of dying as a constant – and have not analysed whether the relative cost of dying has increased or decreased. Furthermore, the cost of end-of-life care may vary depending on the cause of death; such as predictable death associated with cancers versus less predictable deaths associated with, for example, chronic diseases or organ failures. Rosenwax *et al.* for example, suggested that palliative care approaches can be increasingly applied to people with organ

failure, thereby changing the provision of end-of-life care resource consumption and improving quality of care (Rosenwax, McNamara et al., 2011).

The evolution of the research plan

Hospital expenditure accounts for approximately 30 percent of total State government expenditures in Australia. The Australian population is ageing and it is commonly assumed that age related and end-of-life hospital costs are both major and growing contributors to the overall expenditure on hospital-based care. However, to-date a detailed examination of the cost burden to public hospital care, associated with ageing and end-of-life, has not been undertaken, notwithstanding recent work undertaken on pre-decedents' healthcare in NSW (Goldsbury, O'Connell et al., 2015). Goldsbury et al. (2015) using population-wide linked health data collections examined end-of-life utilisation in public and private hospitals, EDs, ICUs, palliative care-related admissions and place of death, but did not address costs. This recent work will allow for some valuable comparisons with the present program of work reported here.

A detailed examination of age and end-of-life public hospital costs is required and has yet to be undertaken. Such an examination will provide a much needed evidence base to inform decision making in regard to how resources might be best deployed to deliver value to the community. Policy debates regarding end-of-life care make the assumption that there are significant costs, and moreover, that these costs are not the best use of valuable resources (Emanuel & Emanuel, 1994).

Using a retrospective cohort design, a series of studies was therefore developed for this program of research to establish the percentage of health care expenditure that is associated with end-of-life. Quantifying these expenditures will help inform this policy debate. It is also important to know whether costs of end-of-life care are stable overtime. If costs are rising, for example, then it is important to understand why they have risen and if the previous cost trajectories are likely to continue into the future.

With a population experiencing increasing life expectancy, it follows that statistically individuals will live more years as older citizens. However, as Fries asks, does this lead to more healthy years of life or at least years with little hospitalisation (Fries, 1980). If age of

death is deferred, does this impact on the cost of each death? Is, for example, there less cost associated with death the older one dies? If so, to what degree is any reduced cost discounted by the costs incurred by the preceding increase in "healthy" years.

The distribution of end-of-life costs may also vary within and between different causes of death. It may also be the case that hospital utilisation is not distributed equally amongst decedents or it is disproportionately consumed with some decedents using little while others consume a lot.

It is feasible that costs associated with death are relatively fixed and not amenable to change. This question may be better understood through examination of variations between health systems. In Australia, hospital care is provided by State governments and each state has its own history and nuances. It is possible that expenditure on end-of-life care is different between States. If so, this may present an opportunity to implement policy changes to emulate the features of the better performing states. State comparisons of end-of-life care may also help elucidate policy options that might result in improved clinical outcomes.

However, to ensure comparisons are comparing like with like, whether between jurisdictions or over time, it is also crucial to understand the reasons populations die. If for example, there is a changing mortality rate of cancer, and the cost of a cancer related death varies significantly from other deaths, this may also influence costs. Cause of death is therefore a critical consideration and understanding the changes in costs associated with cause of death, and changes in causes over time, will also help to address the issue concerning better management of resources at the end-of-life.

Conclusion

To explore these questions, the program of research presented here was developed. The purpose was to establish an empirical evidence base that might inform policy decisions with respect to the costs of public hospital services at the end-of-life. Before presenting the studies undertaken in this program of research, the next Chapter first further examines the extant literature and the broader conceptual frame within which these important epidemiological investigations were set. At the end of Chapter 2, the specific research questions undertaken are outlined. Chapter 3 provides detail of the methodology applied throughout the program of

work, and then the five studies undertaken are presented in Chapters 4-8. Chapter 9 provides a summary overview of the studies and their key findings and Chapter 10 explores their implications for policy and practice, identifies limitations and caveats, and highlights options for future research in this area.

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CHAPTER 2 LITERATURE REVIEW AND CONCEPTUAL FRAME

A key issue of interest to policy makers, service providers and clinicians is the percentage of total healthcare expenditure dedicated to the final year(s) of life. There are various reasons that justify a closer examination of this issue. Among these reasons is the potential for cost savings or efficiencies. Questions of allocative efficiency also arise. That is, are the limited healthcare resources available to a community being used in the most appropriate and judicious manner possible. Todate there has been little examination of population-wide data to identify the relative contributions of older patients and end-of-life patients to the impost on public hospital care, and the cost of such care (Tanuseputro et al., 2015).

There is growing interest and concern about this issue. Public commentary on the rising cost of healthcare often invokes the ageing of the population as a cost driver (Commonwealth of Australia, 2010a). Other factors are also important in planning and predicting future health care costs. For example, emerging technologies, community expectations and defensive practice to mitigate legal damages contribute to increasing costs. This program of research specifically addresses the contribution of ageing on rising health care, and specifically, the costs associated with end-of-life. Using this approach, the projection of an ageing demographic brings with it a prediction of significantly higher healthcare demand in the future. This contributes to a sense of urgency in the public political debate to address the rising cost of aged care (Alemayehu & Warner, 2004). As outlined above, this perception reflects a simplistic cross-sectional understanding of populations and health consumption. For example, the amount of healthcare typically consumed by the populations aged in their 30s or 40s.

The use of healthcare resources in the last years of life has been studied by researchers since the early 1960's. As death and age are positively correlated, the costs associated with death are also correlated with age. The realization that proximity to death may account for some of the health costs associated with age has increasingly become an assumed artefact in health economic discussions (Felder et al., 2000; Felder, 2001; Calver et al., 2006; Forma et al., 2009).

Since the mid-1960s, researchers have examined the role of end-of-life costs and its relationship to ageing as a contributor to age related healthcare expenditure. That is, once researchers realised that healthcare utilisation increased markedly as patients approached death, and that this expenditure was limited to proximity to death, then proximity to death was able to explain a high percentage of healthcare costs that would otherwise relate to ageing. As Carlver states:

"Remaining lifetime is a significant predictor of inpatient costs. Failure to account for proximity to death over emphasises the impact of population ageing on health care expenditure because older people have a higher probability of dying" (Calver, et al., 2006 P. 143).

So, proximity to death has become an accepted variable in the projection of healthcare costs based on population age structures (McGrail et al., 2000; Dormont et al., 2005; Calver, et al., 2006; Menec et al., 2007; Payne et al., 2007; Forma, Rissanen et al., 2009).

It is important to note that the debate continues with respect to the 'non-end-of-life care' healthcare costs for the ageing. Zweifel et al. contend that the non-pre-decedent cost of ageing, excluding end-of-life costs, still contribute markedly to projected health care expenditures (Zweifel et al., 1999). However, while the cost of healthcare related expenditures as people age is greatly mitigated when end-of-life care costs are taken into account, the social costs and aged care related costs are of equal and possibly even greater concern to economies (McGrail, Green et al., 2000; Payne, Laporte et al., 2007).

Interestingly, Gandjour et al. point out that preventative care for older citizens is, in the context of the health insurance payer, a cost burden (Gandjour, 2009). Every additional quality adjusted life year created costs the insurer US\$14,000 yet, after the proximity to death mitigation is taken into account, this cost is reduced to US\$11,000 per quality adjusted life year. Such micro economic studies examine the healthcare expenditure of individuals by using life league tables and consumption of healthcare by individual decedents.

When a macroeconomic perspective is taken into account, and after the proximity to death adjustment is adopted, age is negatively related to healthcare expenditure (Palangkaraya & Yong, 2009). This may infer that end-of-life care is consuming available capacity and thereby deny access to non-end-of-life patients. This view is consistent with the Productivity

Commission Report (2005) which noted that, "Age explains little or none of the differences in the growth of healthcare expenditure between OECD countries" (Commonwealth of Australia, 2010a).

A possible contributor to such an unexpected observation may be related to the cost of endof-life care relative to the age of death. Considerable research now substantiates the perspective that the older one dies, the fewer healthcare resources consumed in the period immediately preceding death (Van Vliet & Larmers, 1998; Calver, Bulsara et al., 2006; Palangkaraya & Yong, 2009). It may be possible therefore, that the decreasing costs associated with dying as people age might (partially) offset the non-pre-decedent cost of ageing.

Breyer and Felder (2006) argue that both the cost of ageing and the cost associated with dying explain a relatively small proportion of future healthcare expenditures regardless of ageing (Breyer & Felder, 2006). Rather, clinical practice and the attribution of expanding medical technology require more attention from policy makers than age related issues.

Corresponding effort is also direct toward reducing the healthcare care cost impost of an ageing population. However, it has been argued that the traditional pursuits of cost savings in the last year of life would ultimately be unsuccessful. In particular, Emanuel and Emanuel (Emanuel & Emanuel, 1994) have argued that many of the strategies that might be employed to reduce end-of-life costs are unlikely to realise cost savings. They cite evidence that use of advanced care directives; a strategy often mooted to reduce costs, show little, if any, cost savings. Emanuel and Emanuel also argued that advanced care directives are already employed where appropriate and as such, do not provide opportunity for further cost savings.

Emanuel and Emanuel have criticised the use of comparisons with low cost hospital alternatives, such as home based hospice care, citing flaws in the research that purportedly indicates lower costs. They argued that these programs are biased towards people who are seeking less aggressive care and if applied to all eligible patients would not necessarily be as successful (Emanuel & Emanuel, 1994).

In a further attempt to locate the source of healthcare costs, Fassbender (2009) disaggregated the various categories of hospital expenditure, and found inpatient costs were the most significant contributor to healthcare expenditure and varied markedly depending on the cause

of death. Sixty-five percent of predictable deaths, 56% of organ failure related death and 45% of other frailty related deaths were hospital related costs (Fassbender et al., 2009).

Similarly, in an effort to identify the proportion of patients that were in their end-of-life phase, Clark *et al.* undertook a prevalence cohort study of 10,743 patients in 25 Scottish hospitals in March 2010 and followed up to ascertain how many had died within the following 12 months. In all, 28.8% of patients who were in hospital on the census day were deceased in the 12 month period, indicating roughly the percentage of hospital resources that may have been devoted to treatment in their last year of life (Clark et al., 2014). Clark et al.'s research however stands counter to other methods and results which increasing rely on more sophisticated techniques using linked data.

Other studies have focussed on hospital utilisation rather than the cost of such utisilation. O'Connell et al. (2014) for example described healthcare utilisation in the last year of life to help inform health services planning using routinely collected administrative health data for all people who died in NSW that comprised linked death records, hospital admissions and emergency department presentations and cancer registrations (O'Connell et al., 2014). They addressed the utilisation of hospital-based services at the end-of-life, including number and length of hospital admissions, emergency department presentations, intensive care admissions, palliative-related admissions and place of death.

While the O'Connell et al. study is among the first in Australia to provide an information-rich census of end-of-life hospital-based experiences it did not examine cost of care, as did the program of research presented here. Nonetheless, it does highlight how linked administrative datasets can inform the development of relatively inexpensive, timely and reliable approaches to the ongoing monitoring of acute hospital-based care utilisation near the end-of-life and inform whether service access and care are optimised.

Studies on end-of-life health costs

A review of relevant literature was undertaken to examine patterns of healthcare utilisation and expenditure in the last year of life. This literature and is presented below (see Table 2.1). Sixteen studies were identified, of which five were undertaken in the US, six in Canada, two in Australia, and one in each of the UK, Netherlands and Denmark. With two exceptions, the studies were undertaken within the past 10 to 15 years, suggesting an emerging and growing interest in this issue. Variable measures and criteria were used across the studies to estimate costs, making comparisons and generalisations across the studies difficult.

Author(s)	Country (jurisdiction ²)	Study Design	Time Period until Death	Expenditure Type	Costs	Percentage of total health expenditure related to the end-of- life	Ratio of expenditure of decedents to survivors where available
	Australia	Data-linkage Hospital inpatients N= 70,384	12 months	In-patient hospital costs	Total Costs: Not Available	8.9% of all hospital inpatient costs, falling with age	
Kardamanidis et al. (2007)				In-patient hospital costs x age group	Average Costs: 65-74yrs: \$17,927 95yrs≤:\$7,028		
				In-patient hospital costs x condition	Average Costs: CardioVD ³ : \$11,069 Cancer: \$16,853 GSD ⁴ : \$18,948		
Moorin & Holman (2008)	Australia (WA) Data-linkage Hospital inpatients N=49,663	Data-linkage Hospital inpatients N=49,663	12 months	In-patient hospital costs	Total Cost: A\$ 177.5 million (total cost of last 3 years of life: A\$ 298.7 million)	Of the last 3 years of life, 59% of costs occur in the last 1 year of life Least expensive year: 3 rd year prior to death (17%).	
					Total Cost x condition: Cancer: \$78.5 million IHD ⁵ : \$72.5 million CerebroVD ³ : \$26.8 million		
Dumont, et al (2010)	Canada	Longitudinal N=160	5 months	In-patient care	Average Cost: 5 th Mth: \$580±\$3014 4 th Mth: \$926±\$2507 3 rd Mth: \$792±\$2583		

Table 2.1 Studies reporting in-patient hospital costs for the last 12 months of life

					2 nd Mth: \$2282±\$5332	
					1 st Mth:\$ 4565±\$8095	
Yu et al. (2014)	Canada (Ontario)	N=186	Total costs of palliative care (four months on average)	Public & Private Costs	Public Hospitalisation Costs: \$4558.61 Total Public Costs: \$15,976.00 Total Private Costs: \$18,221.73 Total Costs: \$34,197.73	
Cheung et al. (2015)	Canada (Ontario)	Cancer patients N=107,253 Data linkage	1 month	Publicly funded acute institutional care or chemotherapy administration	Total Average cost of care: \$13,903 Hospital Average cost of care: \$8998 Average cost per patient for aggressive care: \$18,131 Average cost per non-aggressive care: \$12,678	
Tanuseputro et al. (2015)	Canada (Ontario)	Retrospective cohort study identified all deaths in Ontario from April 1, 2010 to March 31, 2013. N=264,755	12 months		Average cost: \$53,661 (Quartile 1- Quartile 3: \$19,568-\$66,875). The total captured annual cost of \$4.7 billion represents approximately 10% of all government-funded health care. Inpatient care, incurred by 75% of decedents, contributed 42.9% of total costs (\$30,872 per user). Physician services, medications/devices, laboratories, and emergency rooms combined to less than 20% of total cost. About one-quarter used long-term- care and 60% used home care (\$34,381 and \$7,347 per user, respectively). Total cost did not vary by sex or neighbourhood income quintile, but were less among rural residents. Costs rose sharply in the last 120 days prior to death, predominantly for inpatient care. Interpretation	

Centers for Medicare & Medicaid Services (2004) ^a	USA	12 months	Medicare	26.5% (1994) 27.9% (1999)	
Emanuel & Emanuel (1994)	USA	12 months	Total	10-12%	
Gray (2004) ^a	UK	12 months	Hospital	28.9%	
Hogan et al. (2001)	USA	12 months	Total (for elderly)	27.2%	
Hoover et al. (2002)	USA	12 months	Total Medicare Non-Medicare	22% 26% 18%	4.98 6.29 3.86
Lubitz & Riley ¹ (1993)	USA	12 months	Medicare	28.2% (1976) 30.8% (1980) 27.4% (1985) 28.6 (1988)	7.1 7.8 6.55 6.9
Menec et al. (2004) ^a	Canada (Manitoba)	12 months	Total	21%	
Pollock et al. (2001) ^a	Canada	12 months	Total	33.3%	
Wickstrøm et al. (2002) ^a	Denmark	12 months	Hospital		9.4 (women) 13.3 (men)
Stooker et al. (2001)	Netherlands	12 months	Total Long-term Care Acute Care	10% 5% 10%	

^a Sources: (Pollock, 2001; Wickstrøm et al., 2002; Centres for Medicare & Medicaid Services, 2004; Gray, 2004; Menec, 2004; ANHHR Commission, 2009)
 ¹ Incorporates results from Lubitz & Prihoda (1984)
 ² If applicable
 ³ VD = vascular disease
 ⁴ GSD = genitourinary system diseases
 ⁵ IHD = Ischaemic heart disease
 ⁶ Department of Veteran Affairs
In interpreting the findings from these studies, it is important to note the limitations and unique parameters involved, and the particular features of the different healthcare delivery systems in various parts of the world that may colour the findings and their potential for application in other contexts. Cost comparisons across countries therefore are undertaken with caution.

In the USA, for example, where several studies have been conducted to-date, the analysis of expenditure in the last years of life as a proportion of total expenditure is complicated by the prevailing financing system. Medicare, available to citizens over 65 years, disproportionately funds decedents and therefore a high proportion of their expenditure is associated with last year of life. These estimates tend to be in the vicinity of 25-30 percent of total healthcare expenditure (noting that the total only refers to Medicare outlays). Where wider population hospital costs are accounted for, such as studies in the UK and Canada, costs ranged from 21% to 33.3%. The Netherlands outlays 10% of all health care in the last year of life which is consistent with the Emmanuels' estimate of the total US costs of 10-12%.

In some studies, end-of-life (final year) healthcare expenditure has been found to constitute approximately 10% of all healthcare expenditure and approximately 30% of healthcare expenditure for persons over 65 years old (Lubitz & Riley, 1993; Emanuel & Emanuel, 1994; Hogan et al., 2001; Hoover et al., 2002; Cartwright & Parker, 2004). However, in other studies the costs are substantially higher and more variable.

Both policy makers (Australian Productivity Commission, 2005) and researchers (Breyer & Felder, 2006; Calver, Bulsara et al., 2006; Fassbender, Fainsinger et al., 2009) have progressively disregarded the cross-sectional analytical methods that lead to the assumption that age alone, or primarily, drives hospital expenditure. Increasingly, the research literature has indicated that proximity to death (rather than age per se) is a much stronger predictor of healthcare expenditure for an ageing population. When compared to cross sectional methods of analysing healthcare expenditure, it significantly discounts expected costs associated with an ageing population. Armed with this new insight, projections for healthcare expenditure that take into account proximity to death have been used from a policy and planning perspective to predict budget expenditure.

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It has been standard practice for policy makers and researchers to assume that the percentage of healthcare spent in the last year of life remained constant relative to overall healthcare expenditure (Lubitz & Riley, 1993; Lubitz et al., 2003; Commonwealth of Australia, 2010b). However, technology and clinical practice also plays an important role in determining healthcare expenditure both now and into the future (Barnato et al., 2007) and are likely reflected in changing cost structures.

If end-of-life care expenditure or proximity to death is an important discounting variable in predictive modelling for healthcare expenditure and if clinical and technological changes are also influencing practice then it is important to examine the assumption that end-of-life care, as a percentage of expenditure, remains constant over time. Failure to account for the technology and changing practice may have the effect of under (or over) estimating projected expenditures. This notwithstanding, it does not necessarily follow that end-of-life care costs remain constant for the purposes of economic modelling. Both complexity of presentations to hospital and rate of admissions to hospital also influence cost of care.

What factors impact on end-of-life healthcare costs

The changing causes of death require appropriate research attention. If decedents, for example, live long enough to increase the mortality rate associated with cancers and, noting the higher cost of end-of-life care associated with cancer then this may offset the potential benefits of increased longevity.

In this program of research, the ages at which people died and the causes of their death overtime were analysed. Four causes of death were considered: cancer, organ failure, frailty and sudden death. (A typography to categorize cause of death was adopted using Lunney's research and is detailed further below.) Further, changes in cause of death overtime were examined: specifically, Western Australia over two decades and in New South Wales, South Australia, Queensland, over a five-year period. The cost of dying by age cohorts over time was also estimated. Similarly, the question of whether the cost of end-of-life care, controlling for age, has increased relative to the rate of health inflation was also examined. This is important as modelling the future healthcare expenditure generally holds the cost of end-of-life care as a constant in predictive models (Australian Productivity Commission, 2005).

Comparison by Cause of Death

The process of dying was described in terms of *trajectories to death* by Lunney et al. (Lunney et al., 2003) (see Figure 1.3, Chapter 1). These trajectories to death provided a useful categorisation of death to enable further analysis of the public hospital costs associated therewith. Lunney et al. described four trajectories to death categorised as frailty, predictable death (e.g., cancer, neurodegenerative conditions), organ failure related deaths and sudden death.

In the frailty trajectory, the decedent experiences a progressive decline in their ability to function until their body deteriorates to a point where some small event causes them to ultimately die. Fries also described this process whereby all of the body's main organ systems essentially declined at the same rate, in a synchronised way (Fries, 2005). Fries posited that this pathway to death was characterised by no single organ system failing in advance of the others. The patient slowly loses function, both physically (gross motor) and systemically (the major organ systems). The high care nursing home patient who is barely able to achieve their most modest functions exemplifies this category.

Lunney et al.'s second trajectory was the predictable death, that was often, but not always, related to cancer. Other conditions could include degenerative conditions affecting, for example, the central nervous system. Such deaths, Lunney et al. suggested, are characterised by a structured curative care period, followed by a relatively rapid pre-mortal comfort care period. Essentially, this 'palliative' care phase infers that death is imminent and cure is now excluded from the treatment regime. Comfort and care are the goal and are reflected in care plans.

Third, Lunney et al. described the organ failure trajectory that included failing lungs, heart, renal systems and so on. In Fries' terms, this trajectory is caused by one or other of the organ systems failing in advance of the other organ systems. In such cases, the 'resilience' of the other systems carries the patient forward while the acute intermittent failing system recovers. For example, cardiac infarcts would cause death in the frail patient where, in the younger one, the resilience of the organ systems allows recovery and life to continue.

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Lunney et al.'s description of the organ failure category is that it is characterised by frequent acute health events with an underlying chronic cause. These patients are assumed to be "frequent flyers" that use the hospital system at ever increasing rates as their vulnerable organ system deteriorates.

Finally, sudden death is a distinctly different trajectory and, as its nomenclature suggests, is not preceded by any predictable events. For example, suicide (which may well be associated with an underlying mental health disorder) or motor vehicle accidents, or the unanticipated catastrophic cerebral haemorrhage, myocardial infarct, or aortic aneurism fall into this category. While these are essentially failures of organ systems, they are catastrophic at presentation and distinctly impact on the data from an analytical point of view. For the purposes of this research, such "organ system" related causes of "sudden death" are considered as organ failure while the non-organ related causes are categorised as sudden deaths and does not, therefore, cloud analysis. These four trajectories are graphically depicted in Figure 2.1 where the 'Y' axis represents functional health status and the 'X' axis represents time (Lunney, Lynn et al., 2003).



Figure 2.1 Lunney et al.'s 4 trajectories to death

These 'intuitive' trajectories are regarded as the major end-of-life patterns. Lunney et al. delineated these patterns based on measures of Activities of Daily Living (ADL) capacity rather than hospital use as a proxy for morbidity as one approaches death. Fassbender provided frequency data on the incidence of death using the trajectories to death categories over a three year period with little variation in causes of death (Fassbender, Fainsinger et al., 2009) over that time frame.

Fassbender (Fassbender, Fainsinger et al., 2009) and Lunney et al. are among the few researchers who have undertaken empirical research investigating the trajectories to death.

The present body of research was informed by Fassbender and Lunney et al.s' work and involved examination of public hospital utilisation over a 15 year period using Western Australian data and over 10 years for three other jurisdictions (New South Wales, South Australia and Western Australia). The average costs, changes over time, among various health systems, and for different groups within health systems, were examined.

The patterns of utilisation within and across various patient cohorts were also examined. It was hypothesised that some patients use disproportionately more resources than others. This is particularly important given Emmanuel and Emanuel's argument that end-of-life care does not present significant opportunities for resources remediation, however they did not consider the possibility that if some patients disproportionately use more resources while others use few, those who use greater resources may be better served and resources saved by improved management and/or clinical practice (Emanuel & Emanuel, 1994). While cost savings was not the focus of this thesis, the examination of costs associated with various patterns of healthcare utilisation and so called "futile care" at the end-of-life is relevant and the subject of extensive research elsewhere.

Contextual variations: by country, region, jurisdiction

It is reasonable to expect that culture, clinical behaviours and history of practice may also contribute to variations in utilisation at the end-of-life. A study across seven countries (mostly European plus Australia) found significant variations across clinicians' beliefs and behaviours with respect to end-of-life care and in particular, preserving life. There was a significant variation between countries in terms of behaviours and beliefs. The major explanation of variance was "country"; indicating that it may be the networks of physicians and cultures and dynamics of health systems that lead to variation in respect to end-of-life care (Miccinesi et al., 2005).

Barnato et al. (2007) undertook research of Medicare beneficiaries (patients) and their attitudes towards end-of-life care. Referencing patients' attitude towards: receiving too little treatment, too much treatment, for life-prolonging drugs that made them feel worse, access to palliative drugs even if they might be life shortening and access to medical ventilation if it would only extend their life by one month, were all reasonably consistent between states after adjusting for factors such as age, sex, ethnicity, education, financial strain, health status etc.

(Barnato, Herndon et al., 2007). Their findings indicate that, at least within cultures, variations in hospital utilisation and clinical service provision that may occur between states is not necessarily attributable to the preferences of the patients.

It is logical to expect that where there is variation in practice and/or health service utilisation, not explained by a difference in outcomes or patient preferences, that an opportunity may exist to adopt the lower cost service benchmarks that represent improved value to the community. Therefore, examining the differences in utilisation patterns between the states in Australia may provide an opportunity to identify ways to improve the performance of the higher cost jurisdictions.

Australia has a hybrid health system that includes a national system in respect to primary specialist and pharmaceutical systems, but a loosely federated secondary and public hospital system. These two systems work in lose alignment, together with a profit driven private hospital system. One might reasonably expect, within the context of the national system and the underlying economic and social contexts of the nation, that end-of-life care patterns would be largely consistent across jurisdictions. Equally, with marginal economic differences and natural variations in clinical practice, one might also expect inconsistent utilisation patterns of care among states.

The inter-jurisdictional variations in raw admission rates, weighted admissions rates and costs were examined. Further, what led to these variations in the relative resource utilisation profiles? Are end-of-life cost variations among states explained by examining the distribution of costs within cohorts for each state? If variation exists, it provides an opportunity to adopt the practice of the better performing jurisdictions and thereby increase value.

Conclusion

Hospital costs associated with end-of-life care represent a period of elevated hospital utilisation. These costs can be explored having regard to cause of death, place of death (jurisdiction), time and age of death. To address these end-of-life care issues a retrospective cohort study was undertaken that involved the use of population level linked administrative data from WA decedents over four periods (1995, 2000, 2005, 2010) and from decedents in SA, NSW and Qld for 2005 and 2010. The studies were designed to investigate hospital

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expenditure in the last year and last five years of life. By using Australia's diagnostic related groups (DRG) admission weighting methodology (casemix or activity based funding), case weights were applied to all admissions for decedents in their last year of life and multiplied by the standard national benchmark price to estimate the cost of admissions. These cost estimates reflect the mean cost of any given diagnostic group. Full details of the methodology are outlined in Chapter 3.

To address the range of issues outlined above the following questions were examined:

- 1: What proportion of total hospital cost does end-of-life care comprise? (Chapter 4)
- 2: What proportion of total hospital cost related to ageing is attributable to end-of-life care? (Chapter 5)
- 3: Has the cost of public hospital end-of-life care changed over time? (Chapter 6)
- 4: What factors impact on hospital costs at end-of-life? (Chapter 7)
 - a. Does end-of-life care vary with patient age?
 - b. Has age of death changed over time?
 - c. Does end-of-life care hospital cost vary by cause of death?
 - d. What is the relationship between age of death and cause of death?
 - e. Is there any difference in the level of services used by decedents by cause of death?
 - f. What is the pattern of hospital utilisation for different causes of death?
- 5: Are there variations in hospital cost at end-of-life between selected States of Australia? (Chapter 8)
 - a. Does age, cause of death vary by states?
 - b. Does the distribution of resources vary by decedent between states?

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CHAPTER 3 METHODOLOGY

Introduction

To address the research questions proposed in this program of work a unique database was created that allowed the variables of interest to be investigated. The database contained detail of the hospital utilisation by decedents in New South Wales (NSW), Queensland (Qld), South Australia (SA) and Western Australia (WA), over a sufficient time period to enable a comprehensive analysis of end-of-life care hospital utilisation patterns. This Chapter details how the database was created. Strengths and limitations of the database are also described. The statistical methods used are discussed in each of the Chapters as they relate to the specific analyses in question. Detailed technical specifications are included in relevant appendices.

The database created for this program of research is the most comprehensive of its type in Australia or internationally to the candidate's knowledge that contains linked detail of end-of-life public hospital inpatient care. It provided details of over 192,000 decedents and linked over 1,000,000 hospital inpatient records. It covered four jurisdictions over two time periods, 2005 and 2010, and in the case of Western Australia, over four time periods: 1995, 2000, 2005 and 2010.

Overview

The jurisdictions of NSW, Qld, SA and WA were asked to provide linked hospital records of admissions, and corresponding mortality and morbidity data, for all people who died in those states in 1995, 2000, 2005 and 2010. As data linkage techniques have been developed only relatively recently, the states of NSW, Qld and SA were unable to provide data for the 1995 and 2000 decedents.

State Departments of Health provided data as follows:

• NSW linked data was provided by the Centre for Health Record Linkage (CHeReL), Cancer Institute NSW (2005 and 2010)

- QLD linked data was provided by the Health Statistics Centre, Queensland Health (2005, 2010)
- WA linked data was provided by the Department of Health, WA Data Collections and the Data Linkage Unit (DLU) (1995, 2000, 2005 and 2010). A number of data collections from the WA Department of Health and other agencies are routinely linked using best practice protocols. The DLU maintains a set of 'core' linkages which are updated on a regular basis, including the Deaths Registration Collection (which contains records of all deaths registered in WA since 1969) and the WA Hospital Morbidity Data Collection (which includes separations data from all public and private hospitals in WA)
- SA linked data was provided by SA Health, Epidemiology Branch (2005 and 2010).

Hospital admission data for the five years preceding the death of each decedent were extracted and subsequently combined with the corresponding death records. After deidentification, deaths data were also included in the study data base. Details of the linking methodology for each jurisdiction are provided in Appendix D.

Ethics

Ethics approval was obtained from the following ethics committees:

- The Department of Health WA Human Research Ethics Committee (DOH HREC)
- SA Health Human Research Ethics Committee (HREC)
- Flinders University Social and Behavioural Research Ethics Committee¹
- The NSW Population and Health Services Research Ethics Committee.

All data was unidentified so consequently no significant issues were raised by the various ethics committees. As detailed in Appendix D, some data custodians limited access to data to prevent identification of individuals.

¹ Queensland Health Statistics Centre accepted the Flinders University Social and Behavioural Ethics Committee approval.

Mortality data collections

In analysing end-of-life care, it is necessary to have a high level of confidence that as many deaths that occurred in a given jurisdiction are identified as possible. The Registrar of Births, Deaths and Marriages (RBDM) data is the most comprehensive source of data on deaths available in Australia. To ensure that all deaths, including those that occurred outside of hospital, were included RBDM death certificates in each state were used to establish the overall study cohorts.

Accordingly, death certificates from the four designated jurisdictions were sought for each of the study periods 1995, 2000, 2005 and 2010. NSW, Queensland, and SA did not have the capability to provide the data requested for 1995 and 2000 but were able to provide data for the 2005 and 2010 periods.

Table 3.1 Number of decedents by state and year of death (Source: Registry of Births,Deaths and Marriages Data)

State	1995	2000	2005	2010	Total
SA			12,010	12,858	24,868
NSW			44,629	47,282	91,911
Qld			16,241	13,124	29,365
WA	10,613	10,778	11,624	12,892	45,907
Total	10,613	10,778	84,504	86,156	192,051

The Registry of Births, Deaths and Marriages (RBDM) in each state is required to register all births and deaths. In the event of a death, a medical certificate stipulating the cause of death is forwarded to the RBDM which transcribes the information. This information is then uploaded on to a computer in an encoded format and a death registration number assigned.

ABS Mortality Data

The Australian Bureau of Statistics (ABS) codes all data that is received from the RBDM including unidentified, un-coded text information from the medical certificate forwarded by the RBDM. Cause of death is coded according to the International Statistical Classification of Diseases and Related Problems; ICD 9-CM for 1995 and ICD-10-AM for 2000 and 2005 respectively. The ICD codes provide the prerequisite data to later recode the hospital admissions to Diagnostic Related Group (DRGs) which define reason for admission and which are able then to be associated with cost of admissions. After data is complete and

cleaned, the ABS removes personal identifiers, such as names and addresses, from the data sheet that may lead to identification of a particular individual. The death registration number is retained. At the time of preparing the database, coded "cause of death" was not available for decedents who died in 2010. Consequently, an alternative method to code cause of death to ICD-10-AM was necessary. The way in which these un-coded deaths were treated is described in Appendix C.

Defining Cause of Death

Major categories of death, or more accurately, trajectories to death, for decedents were categorised according to Lunney's (Lunney, 2003 #140) four categories of organ failure, frailty, sudden death and cancer. These categories have been used previously as 'a useful schema' for depicting trajectories to death. To achieve this, a panel of clinicians was assembled, along with a qualified Medical Coder, who reviewed the DRG codes and associated each DRG group to a specific cause, or 'trajectory' to death. The Coder provided advice on mapping of ICD-9-CM to ICD-10-AM codes to DRGs to enable determinations of cause of death and costs of admissions. Details of the method of coding cause of death is provided in Appendix E.

For people who died in 2010, where ABS coding was not available, a probabilistic matching algorithm was developed for the purposes of this research. To achieve DRG codes for deaths where the hospital code was not available (i.e., 2010 deaths) a computer matching program was developed that identified words (and combinations of words) in death certificates in 2005 RBDM death records that matched hospital death records. For example, "heart attack" had a high probability to be present in RBDM records where the hospital DRG code also included Myocardial Infarction. This program was then tested on random selection of RBDM records where hospital records were available to test the failure rate. Agreed DRGs were then used to code the RBDM data to match a DRG (see Appendix C).

Morbidity data collection

Decedents' hospital morbidity data was extracted for the five years prior to death for the state in which the death occurred and linked to the corresponding death records. These linked records were then de-identified and provided for analysis. No attempt was made to link

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public hospital morbidity data beyond the state in which the death was recorded as it was deemed logistically impractical to do so. However, it is acknowledged that in some cases decedents may have moved from one state to another, or incurred hospital admission in a state other than that in which they died.

Nor was non-admitted hospital care linked in the data extraction process. Non-admitted, or out-patient records vary substantially between hospitals and jurisdictions. Hence these data were omitted to avoid confounding the results and, as a result, this is a limitation of the findings that requires further consideration.

Morbidity data for NSW & SA was only available from 1/7/2000 due to the unavailability of the decedent's name data prior to July 2000. This reduced the completeness of morbidity data for 2005 decedents to 4.5 years prior to death. However, as decedents' hospital use was likely to be very low in the "excluded" period (as evident in the more complete WA data set), this exclusion was unlikely to have had a substantial impact on the results of research involving the 5 year pre-death period.

Place of death (hospital vs non-hospital) was derived according to whether "death" was recorded as the final mode of separation in the hospital morbidity dataset.

NSW, Qld and SA have poor linkage for private hospital morbidity data sets compared to public data. WA has comprehensive data for private hospitals activity, however, to ensure that data was interpreted consistently this program of research only included public hospital data across all four jurisdictions. This approach, to only include public hospital data, had the effect of under-reporting admission and cost results. That is, the findings from the present research are conservative and may under-estimate costs and impacts on the public hospital system. However, as the private hospital system responds to economic drivers in a different manner to the public system, and the financial consequences of the private system only marginally effect the public purse, it was considered a more reliable and rigorous approach to exclude private hospital data.

Decedents without any identified morbidity records were excluded from the database.

Obtaining morbidity data from each of the jurisdictions required different data accessing processes. These are outlined in Appendix D.

Length of stay

Different states use different methodologies to measure length of stay in hospitals. These methodological variations impacted on calculations for length of stay of specific admissions up to \pm 15 days, and therefore effected the calculation of occupied bed days (a measure of resource utilisation). However, as the number of admissions is large, and these variations occurred non-systematically within the data set, the analyses undertaken in this program of research were not substantially affected.

The length of stay measures used by the different states are summarised below.

NSW	Whole days for inpatients/ hours for same day patients (divided by 24 to aggregate to Occupied Bed Days)
SA	Whole days
Qld	Whole days - capped at 60 days (capping LOS at 60 is an administrative practice of Qld)
WA	Whole days

ICU days

Measures of ICU utilisation by state are summarised below:

NSW	NSW provided total length of stay (days). Where Bed Unit Type was General Intensive Care Unit or Neonatal Intensive Care the total length of stay was considered total ICU days.
SA	ICU Days divided by 24
Qld	Total length of stay (days) was used as a proxy for ICU Days (for episodes flagged as having an ICU component) – capped at 60 days.
WA	Actual ICU days (whole days)

Same day medical separations

An initial examination of the morbidity data identified that a substantial proportion of episodes of care comprised same day medical separations. For example, same day separations for renal dialysis and chemotherapy separations represented 31% of all public hospital separations for 2010 NSW decedents. Treatment of same day medical separations admission

data also varied by state. Chemotherapy and renal dialysis was variously treated as an outpatient service or inpatient admission depending on local administrative protocols.

Given this, it was considered potentially misleading to include same day medical patient numbers when examining activity trends as such a large proportion of same day separations for renal dialysis and chemotherapy cases would act as a confounder and impede identification of inpatient public hospital utilisation trends over time.

State	1995	2000	2005	2010
SA	-	-	7,886	9,452
NSW	-	-	87,801	130,664
Qld	-	-	39,969	80,475
WA	4,655	21,511	42,869	50,152

Table 3.2 Renal dialysis separations by jurisdiction

Table 3.3 Chemotherapy separations by jurisdiction

State	1995	2000	2005	2010
SA	-	-	9,210	6,413
NSW	-	-	18,651	20,391
Qld	-	-	14,102	40,083
WA	5,901	11,698	23,004	25,692

The exclusion of dialysis and chemotherapy separations has the effect of under-estimating resource consumption for both neoplasm and organ failure related death. Conclusions from this program of research and any speculations about future service demand should be considered in light of this.

Casemix cost estimation

Overview

To establish the cost of hospital care in the five years prior to death the procedure outlined below was followed. Estimated casemix costs were derived by applying public sector estimated Diagnostic Related Group (DRG) cost weights and Benchmark Prices from the National Hospital Cost Data Collection (NHCDC) to each Australian Refined Diagnostic Related Group (AR-DRG) for each hospital morbidity record in this study's purpose-built database. Historical health inflation rates, sourced from the Australian Institute of Health and Welfare (AIHW), were used to calculate net present values for the data related to the study time periods (1990 – 2010). This method assumes present values are adjusted for health inflation which is higher than general inflation.

National Hospital Cost Data Collection

The National Hospital Cost Data Collection (NHCDC) contains component costs per DRG based on patient-costed and cost-modelled information. The purpose of the collection is to produce the national public and private sector cost weights for Australian Refined Diagnosis Related Group (AR-DRG) and associated analytical tables contained in the AIHW Cost Report. The data is used for outcomes measurement, performance information and policy development. It provides the health care industry with a nationally consistent method of classifying all types of patients, their treatment and associated costs.

The scope of this uniquely developed data set was all public hospitals with more than 200 acute separations in the financial year. Hospitals with less than 200 admissions per year are not usually funded on an activity basis and do not have the capability to code and recode data adequately. Further, such hospitals are not likely to be admitting truly acute hospital patients.

AIHW, using the data provided by the various states, derives an overall mean cost per standard admission. The total hospital costs divided by total number of admissions (adjusted for complexity of admissions) equals mean admission cost. The derived mean admission cost determines the benchmark price for each specific period of calculation, referred to as a cost round. Details of the benchmark prices for the relevant cost rounds are outlined below (Table 3.4).

Cost estimation steps

The present program of research adopted the following steps to determine cost of hospital admissions:

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- National Public Sector Estimated DRG Cost Weights were obtained from the National Hospital Cost Data Collection (NHCDC). These costs are inclusive of all hospital costs, such as training and research, undertaken in public hospitals.
- National Public Sector Estimated Benchmark Prices were obtained from the NHCDC.
- Relevant DRG specific cost weights were applied to morbidity data to derive weighted separations.
- Weighted Separations were then multiplied by the Estimated National Benchmark Price (see Table 3.4) to derive the estimated cost for each DRG as well as the Total Cost.

Examples of the methodology outlined above are provided in Table 3.5 below.

Cost Round	Date Range	DRG Versions	AIHW Benchmark Price
N/A	2010/11	AR-DRG 6.0	\$4,507.52 ²
14	2009/10	AR-DRG 6.0	\$4,500.00
		AR-DRG 6.0	
13	2008/09	AR-DRG 5.2	\$4078.57
		AR-DRG 5.1	
12	2007/08	AR-DRG 5.1	\$3879.66
11	2006/07	AR-DRG 5.1	\$3690 44
11	2000/07	AR-DRG 4.2	\$3070.44
10	2005/06	AR-DRG 5.0	\$3510.46
9	2004/05	AR-DRG 5.0	\$3339.25
8	2003/04	AR-DRG 5.0	\$3176.39
		AR-DRG 4.2	\$5170.57
7	2002/03	AR-DRG 4.2	\$3021.48
6	2001/02	AR-DRG 4.2	\$2874.12
5	2000/01	AR-DRG 4.1	\$2733.95
4	1999/00	AR-DRG 4.1	\$2600.61
3	1998/99	AR-DRG 4.1	\$2473.78
2	1997/98	AR-DRG 4.0	\$2353.13
1	1996/97	AN-DRG 31	\$2238.37
N/A	1995/96		\$2129.2
N/A	1994/95		\$2025.36
N/A	1993/94		\$1926.58
N/A	1992/93		\$1832.62
N/A	1991/92		\$1743.24
N/A	1990/91		\$1658.22

Table 3.4 Estimated benchmark prices by cost round

² Benchmark prices for years where cost round data were not available were estimated using exponential regression.

AIHW benchmark prices are determined on a financial year basis. To align the financial years to calendar years, the bridging preceding financial and the following year were averaged to provide an estimate of the calendar year cost. As the financial years prior to 1996/97 were not available an exponential regression of later years was used to estimate cost prior to 1996/97. This process is outlined in Figure 3.1 below.



Figure 3.1 Benchmark Price Estimation Process

ARDRG	Description	Seps	National Cost Weight	Wtd Seps	Bench- mark Price	Average Price	Total Cost
A06B	Trach W Vent >95 hours W/O Cat CC or Trach/Vent >95 hours W Cat CC	153	20.12	3,078	\$4,398	\$88,488	\$13.54 M
B63Z	Dementia and Other Chronic Disturbances of Cerebral Function		2.71	710	\$4,398	\$11,919	\$3.12 M
B66A	Nervous System Neoplasm W Catastrophic or Severe CC	252	2.65	668	\$4,398	\$11,655	\$2.94 M
B66B	Nervous System Neoplasm W/O Catastrophic or Severe CC	178	1.12	199	\$4,398	\$4,926	\$.88 M
B70A	Stroke and Other Cerebrovascular Disorders W Catastrophic CC	176	4.38	771	\$4,398	\$19,263	\$3.39 M
B70B	Stroke and Other Cerebrovascular Disorders W Severe CC	120	2.39	287	\$4,398	\$10,511	\$1.26 M
B70D	Stroke and Other Cerebrovascular Disorders, Died or Transferred <5 Days	253	0.54	137	\$4,398	\$2,375	\$.60 M
C16Z	Lens Procedures	183	0.58	106	\$4,398	\$2,551	\$.47 M

Table 3.5 Example of cost calculations for selected DRGs (DRG x national weight of sepx benchmark price = average sep price x number of seps = total cost of DRG)

The Australian Institute of Health and Welfare (AIHW) publish data on which to base health inflation and general inflation adjustments to calculate, among other things, net present values of the Australian dollar over time. From time to time, these are revised and republished. For the purposes of this program of research, where there was more than one publication on either a general inflation or health inflation rate for a particular year, the mean of the published rates was used (see Table 3.6 and Table 3.7).

Time period	2000/01 AIHW Pub	2010 AIHW Pub	2011 AIHW Pub*	Mean Rate
1990/91 to 1991/92	4.7			4.700
1991/92 to 1992/93	2.2			2.200
1992/93 to 1993/94	0.8			0.800
1993/94 to 1994/95	1.1			1.100
1994/95 to 1995/96	2.3			2.300
1995/96 to 1996/97	2.2			2.200
1996/97 to 1997/98	1.9			1.900
1997/98 to 1998/99	2.1	2.5		2.300
1998/99 to 1999/00	2.6	2.4		2.300
1999/00 to 2000/01	3.9	3.9	3.5	3.767
2000/01 to 2001/02		3.3	3.3	3.300
2001/02 to 2002/03		3.5	3.1	3.300
2002/03 to 2003/04		3.5	3.3	3.400
2003/04 to 2004/05		4.2	3.7	3.950
2004/05 to 2005/06		4	4.1	4.050
2005/06 to 2006/07		3.3	3.5	3.400
2006/07 to 2007/08		2.9	2.3	2.600
2007/08 to 2008/09			2.1	2.100
2008/09 to 2009/10			3.2	3.200
2009/10 to 2010/11				

Table 3.6 Health inflation trends*

* Source: Australian Institute of Health and Welfare 2011. Health Expenditure Australia 2009–10. Health and Welfare Expenditure Series no. 46. Cat. no. HWE 55. Canberra: AIHW.

Time period	2000/01 AIHW Pub	2010 AIHW Pub	2011 AIHW Pub*	Mean Rate
1990/91 to 1991/92	1.9			1.900
1991/92 to 1992/93	1.1			1.100
1992/93 to 1993/94	1			1.000
1993/94 to 1994/95	1.3			1.300
1994/95 to 1995/96	2.4			2.400
1995/96 to 1996/97	1.6			1.600
1996/97 to 1997/98	1.4			1.400
1997/98 to 1998/99	0.1	0.1		0.100
1998/99 to 1999/00	2	2.1		2.050
1999/00 to 2000/01	4.8	4.9	4.6	4.850
2000/01 to 2001/02		2.8	3	2.900
2001/02 to 2002/03		3	2.6	2.800
2002/03 to 2003/04		3.5	3.3	3.400
2003/04 to 2004/05		3.8	4	3.900
2004/05 to 2005/06		4.6	4.9	4.750
2005/06 to 2006/07		4.6	5.3	4.950
2006/07 to 2007/08		4.4	4.6	4.500
2007/08 to 2008/09			4.4	4.400
2008/09 to 2009/10			0.1	0.100
2009/10 to 2010/11				

Table 3.7 General inflation trends*

* Source: Australian Institute of Health and Welfare 2011. Health Expenditure Australia 2009–10. Health and Welfare Expenditure Series no. 46. Cat. no. HWE 55. Canberra: AIHW.

Linked data calculations

Days until death calculation

All separations that fell within the five year period prior to death (i.e., less than 1,826 days) and the date of death were calculated to establish the eligibility for inclusion of an identified decedent's hospital record in the database.

South Australia and Queensland did not provide the day of death (only month), while Queensland did not provide the day of separation (for confidentiality reasons). For these jurisdictions it was necessary to estimate a midpoint for the day of death/separation in the identified month. This introduced an unavoidable error in the calculation of days until death. The following example illustrates a scenario where up to a 30 day difference could result due to the use of midpoint dates (Table 3.8).

Type of Date	Date Range	Calculation Result
Exact Dates:	Separation Date 01/03/2010, Date of Death 31/05/2010	91 days until death
Midpoint Dates:	Separation Date 15/03/2010, Date of Death 15/05/2010	61 days until death

Table 3.8 Example of mid-point calculation variation

Calculation of 5 years costs

When calculating decedents' costs over 5 years the issue arose of the overlapping of costs from decedents who died in subsequent years. For example, in 2009 public hospitals would not only have incurred costs from decedents in the 12 months prior to their death in 2010, but also the costs incurred by decedents who died in 2011, and 2012, and so on. In 2009, the costs of the 2011 decedent cohort were assumed to be equivalent to the 2009 hospital costs of the 2010 decedents and so on. To calculate the cumulative cost of all five year pre-decedents overlapping in a given year, the estimated cost of each overlapping cohort were summed to establish the cost for all five year pre-decedents for the designated year. These calculations were based on two assumptions:

- That the number of decedents in 2011 (and 2012 etc.) was the same as the sentinel year 2010.
- The cost incurred by future decedents (i.e., in 2011, 2012 etc.) were the same as the costs incurred by the seminal decedents in their penultimate, second and third (and so on year) year prior to death.

An example is displayed in Table 3.9.

 Table 3.9 Sample calculations of five year public hospital expenditure five years prior to

 death for decedents in 2010 with estimates of future decedents' costs (\$)

Year of Death	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
2010		3,159	4,305	5,482	8,854	29,606					
2011			3,159	4,305	5,482	8,854	29,666				
2012				3,159	4,305	5,482	8,854	29,606			
2013					3,159	4,305	5,482	8,854	29,606		
2014						3,159	4,305	5,482	8,854	29,606	
							3,159	4,305	5,482	8,854	29,606
Total five											
years						51,406					
cost (\$) in 2010						,					

Each decedent's hospital utilisation was calculated for 365 days (12 months) and 1826 days (five years) prior to death.

Costs reported and analysed are derived from a statistical process based on average cost across the Australian public hospital system. These may differ from the cost of a particular hospital, and therefore of a particular patient who receives care in any given hospital. As the numbers of patients are large in these analyses, the results are representative for the purposes of policy making.

Analyses

To address the specific research questions posed in this program of research, various analyses were undertaken using the unique purpose built linked data base. The analyses undertaken are described in more detail in the respective Chapters, but included:

- Descriptive statistics, including the median, standard deviation, minimum and maximum were calculated for length of stay, occupied bed days, costs and weighted separations (Chapters 4,5,6,7 &8).
- Lorenz curve with corresponding Gini coefficients were generated to describe the concentration of resource utilisation within cohorts. Lorenz curves were selected as they lend themselves to the calculation of Gini coefficients which quantify what other distribution models, for example histograms, might only indicate (Chapters 7 & 8)
- A graphical presentation of the timing of hospital admissions, and length of stay, by cause of death, is presented in Chapter 7.
- The final analyses conducted were inferential statistics including multiple regression and ANOVAs (Chapters 4,5,6,7 & 8).
- As the data has a skewed distribution, the Welch statistic and corresponding post hoc Games-Howell statistic were reported. Welch statistic ensures that variations in means are not likely to have occurred by chance (Chapters 6,7 & 8).
- In most analyses the data contained outliers. Cases greater than 2.5 standard deviations (SD) from the mean were excluded, except in relation to the examination of hospital utilisation patterns where 1 SD was applied as the exclusion criterion. While this has the effect of understating variations, it also minimises the likelihood of extreme cases influencing the statistical inferences. The exception to 2.5 SD being

used as exclusion criteria was for reference data depicting patterns of hospitalisation by cause of death where 1 SD was applied as the exclusion criteria for outliers.

- Unless otherwise stated, if a specific year of death is not identified in the calculations, both 2005 and 2010 were included in analysis (2005 adjusted for 2010 dollars using health inflation). Also all causes of death are included in calculations unless an analysis was specifically addressing a specific cause of death. All four states were included in all analyses unless stated otherwise.
- All recorded admissions to public hospitals are included in the year prior and five year prior analyses, even when nor apparently relevant to end-of-life care.

This Chapter has outlined the key methodological approaches applied in this program of research, including the development of a unique linked database that provided access to deidentified patterns of public hospital utilisation for four states (NSW, SA, QLD and WA) for two cohorts of decedents (i.e., from deaths that occurred in 2005 and 2010, plus decedents from 1995 and 2000 in WA). The database formed the basis on which all the studies involved in this program of research were executed.

The first study undertaken is presented in Chapter 4 and involved quantifying the percentage of overall public hospital funding that is attributable to end-of-life care. This question sets the context for the broader program of research that follows by establishing the quantum of overall public hospital resources used in the last 12 months and last five years of life. Subsequent Chapters then report the investigations undertaken of patterns and correlates of end-of-life care in greater detail and specificity.

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CHAPTER 4 WHAT PROPORTION OF TOTAL PUBLIC HOSPITAL CARE DOES END-OF-LIFE CARE COMPRISE?

Introduction

Very little research has been undertaken in regard to the proportion of total public hospital expenditure in Australian associated with the last year of life, and no research has examined public hospital costs consumed in the last five years of life. Establishing the proportion of total public hospital care that end-of-life care constitutes is the first step in this overall program of research. To address this question the unique linked database of decedents' deaths, as detailed in Chapter 3, was interrogated to identify the history of hospital utilisation of a specified cohort of decedents prior to death. Analyses were undertaken to examine the public hospital costs of end-of-life care as a percentage of total public hospital costs across four states for the last 12 months and the last five years of life.

Methodology

The data base created for this program of research identified the number of decedents, the number and DRGs associated with admissions to public hospitals experienced by those decedents and was able to associate those admissions with AIHW determined costs. By aggregating the admissions and multiplying them by the AIHW costs it was possible to determine public hospital expenditure on care for patients who were in their last year/s of life (for details of how AIHW costs are derived see Chapter 3).

This calculation was carried out as per the following example:

- In NSW there were 47,945 decedents in 2010.
- Each decedent experienced a number of public hospital admissions and each admission was identified by a particular DRG.
- As each DRG is associated with a weight, to account for its complexity, the sum of the weights for a decedent over their pre-death period represented their total public hospital utilisation (for either 12 months or five years prior to death).

- The sum of each decedent's weighted admissions was multiplied by the AIHW costs to yield the cost of hospital care per decedent. In this case example, it was established to be \$29,568.
- 47,945 decedents multiplied by \$29,568 equals \$1,417,678,942.
- The mean of AIHW reported total expenditure for NSW public hospitals in 2009/10 and 2010/11 was \$12,335,500,000.
- \$1,417,678,942/(\$12.335.500.000/100) equals 11.5% of total NSW hospital expenditure that was attributable to public hospital care provided to decedents in the 12 months prior to their death.

A similar analysis was undertaken in regard to public hospital costs for the five years preceding death. For example, in a state with 10,000 decedents in 2010, public hospital use would be calculated for these 10,000 individuals for each of the five years prior to their death.

The purpose of these analyses was to calculate public hospital costs being incurred by patients in the 12 months preceding their death and in the last five years of life. This analysis was conducted for decedent cohorts in 2005 and 2010 using the same methodology.

Results

As state expenditure on hospital care is reported in the AIHW publications by financial year (Australian Institute of Health and Welfare, 2011), the average of the 2009/10 and 2010/11 years was calculated to establish estimates for public hospital expenditure in 2010 for New South Wales, Queensland, Western Australia and South Australia (see Table 4.1). Similar calculations were also carried out for 2005/06 and 2004/05 hospital expenditure and adjusted to reflect 2010 dollars using health inflation (Australian Institute of Health and Welfare, 2007).

Table 4.1 Total public hospital expenditure 2009/2010 and 2010/2011 by State(\$Millions)

State	2009/10	2010/11	Averaged expenditure for 2010
NSW	\$12,024	\$12,629	\$12,336
Qld	\$7,134	\$7,360	\$7,247
WA	\$3,446	\$3,831	\$3,639
SA	\$2,904	\$3,059	\$2,982

The database created for this program of research was able to identify all admissions for each decedent and associate the admissions with a cost weight to determine the total cost of public hospital services consumed by decedent (for methodology details see Chapter 3). This cost calculation per decedent could then be executed for any pre-selected cohort (for example, a particular age group or year of death). By multiplying the number of known decedents in each state in 2010 by the average cost incurred in their last year of life, the total expense of public health care for the public hospital population who were in their last year of life could be calculated and expressed as a percentage of total hospital expenditure (see Table 4.2).

Table 4.2 Number of decedents, average hospital cost per decedent, total cost and percentage by state of public hospital costs in the last year of life for 2010 decedents by State

State	N Decedents 2010	Average hospital cost per decedent 12 months prior to death	Total cost of all decedents 12 months prior to death (\$m)	Total State Expenditure (\$m)	% of total state expenditure
NSW	47945	\$29,609.53	\$1,419.63	\$12,335.50	11.5%
Qld	27289	\$26,050.64	\$710.90	\$7,247	9.8%
WA	12957	\$23,106.87	\$299.40	\$3,638.50	8.2%
SA	12720	\$20,176.90	\$256.65	\$2,981.50	8.6%

Similar calculations were carried out for decedents in 2005 (see Table 4.3).

Table 4.3 Number of decedents, average hospital cost per decedent, total cost andpercentage by state of public hospital costs in the last year of life for 2005 decedents byState

State	N Decedents 2005	Average hospital cost per decedent in last 12 months of life	Total cost of all decedents 12 months prior to death (\$m)	Total State expenditure (\$m)	% of state expenditure
NSW	44629	\$22,802.55	\$1,017.66	\$11,641.02	8.7%
Qld	25202	\$21,222.14	\$534.84	\$5,769.09	9.3%
WA	11624	\$19,049.78	\$221.43	\$3,357.94	6.6%
SA	12010	\$19,878.26	\$238.74	\$2,557.58	9.3%

Overlapping Pre-decedents

It is likely that a similar number of deaths would occur in each state as occurred in the sentinel year 2010. For example, 2011 decedents would be in their penultimate year of life in 2010 and in 2009 they would be in their second year of life before death and incurring public hospital costs similar to the 2010 decedents who were in their last year of life. Based on the assumption that equal numbers of decedents were in their penultimate year, third last, fourth last and fifth last year of life, as were in their last year of life in 2005 or 2010, it was possible to calculate the percentage of expenditure on public hospital care for the overlapping decedent cohorts in their last five years of life that were concurrent with the 2010 decedents (the method for calculating the cost for the last five years of life were provided in Chapter 3) (see Table 4.4 and Table 4.5).

State	N Decedents 2010	Mean Cost last 5 years	Total cost last 5 years (\$m)	Total State Expenditure (\$m)	% Expenditure
NSW	47945	\$51,411.12	\$2,464.91	\$12,335.50	20.0%
Qld	27289	\$46,249.41	\$1,262.10	\$7,247	17.4%
WA	12957	\$44,709.26	\$579.30	\$3,638.50	15.9%
SA	12720	\$35,511.43	\$451.71	\$2,981.50	15.2%

Table 4.4 Number of decedents, total public hospital cost, mean cost per decedent and total cost of decedents for the five years of life prior to death in 2010

5 years 2005	N Decedents	Mean Cost last 5 years (\$m)	Total cost last 5 years (\$m)	Total State Exp (\$m)	% Exp
NSW	44629	\$ 41,029.60	\$1,831.11	\$11,641.02	15.7
Qld*	25202	\$ 32,999.73	\$831.66	\$5,769.09	14.4
WA	11624	\$ 37,150.07	\$431.83	\$3,357.94	12.9
SA	12010	\$ 34,499.10	\$414.33	\$2,557.58	16.2

Table 4.5 Number of decedents, total public hospital cost, mean cost per decedent andtotal cost of decedents for the last five years of life in 2005 (2010 dollars)

* Low data cost reliability in 2000 & 2001

The percentage of total hospital costs attributable to end-of-life care for both 2005 and 2010 decedents, in each state, was established for the last year prior to death (see Figure 4.1) and for the last five years of life (see Figure 4.2).



Figure 4.1 Percentage of public hospital resources consumed in the last year by decedents (by year and state)

As can be seen from Figure 4.1 and Figure 4.2 the total public hospital utilisation impost of pre-decedents in the last five years of life, was approximately 1.5 to 2 times greater than that incurred in the last 12 months of life.



Figure 4.2 Percentage of state hospital resources consumed in the last five years by decedents (by year and state)

Discussion

This study examined public hospital expenditure in the last year of life in four Australian states for decedents from two time periods, 2005 and 2010. The proportion of overall public hospital expenditure that end-of-life care comprised was then calculated. These analyses were conducted for two time periods: 12 months and five years prior to death.

It was found that the average cost of 2010 decedents' public hospital care in the 12 months prior to death ranged from \$20,176 (SA) to \$29,609 (NSW). This represented 8.6% and 11.5%, respectively, of the total public hospital expenditure of SA and NSW in 2009. Across the four states examined, the average proportion of public hospital costs attributable to 2010 pre-decedents' care in the 12 months prior to their death was 9.5%. For 2005 decedents, the average proportion of public hospital costs for care 12 months prior to death across the four states was lower at 8.5%.

The percentage of total public hospital expenditure devoted to pre-decedents appears to be similar in Australia than that identified in international literature for countries such as USA (10-12%) (Emanuel & Emanuel, 1994; Stooker et al., 2001) and the Netherlands (10%) (Stooker, Van Acht et al., 2001) (Refer Table 2.1).

The variations in expenditure found between the four jurisdictions examined may be a function of differences in age of death, cause of death, or the relative cost of hospital care in the different jurisdictions. A closer examination of the variations in costs of dying among the states is provided in Chapter 8.

As would be expected, hospital costs associated with the last **five** years of life are greater than the final year alone. The four years preceding the final year of life approximately equate to the cost of the final year's expenditure. For 2010 decedents, the state with the lowest mean public hospital consumption by pre-decedents' average annual percentage of total hospital expenditure five years prior to death was South Australia with 15.2% of total public hospital expenditure; the highest was NSW with 20%. These jurisdictional variations are examined in more detail in Chapter 8.

For 2005 decedents, hospital expenditure was lower, as a percentage of total hospital expenditure than for 2010 (after adjusting for health inflation). For the 2005 decedent cohort, WA had the lowest average annual expenditure on pre-decedent care at 12.9% of total expenditure, and South Australia expended the highest percentage of its public hospital resources on end-of-life public hospital care at 16.2% of total expenditure.

After adjusting for health inflation, a marked increase in pre-decedent public hospital care was identified between 2005 and 2010. This finding indicates that end-of-life care expenditure rose as a percentage of overall public hospital healthcare expenditure. Moreover, these findings indicate that these increases are not consistent among states. The cost of five year pre-decedent care in NSW, after adjusting for health inflation, rose from 15.7% of state public hospital expenditure in 2005 to 20% in 2010. Conversely, South Australia reduced its pre-decedent hospital expenditure from 16.2% in 2005 to 15.2% in 2010.

Conclusions

The proportion of public hospital care devoted to those in their last 12 months or last five years of life was examined. This was examined in relation to two cohorts of decedents across four different states. For the first time, Australian data has been able to provide an accurate indication of the proportion of hospital care that is consumed by those approaching death. It was identified that the cost of care in the last 12 months prior to death is approximately

double that of the cumulative total for care in the five years preceding death. These costs were slightly lower than available international comparisons, had increased over time and varied by state.

However, this examination of the proportion of public hospital care consumed by those approaching death did not address the patterns of hospital utilisation by the age of the patient.

It is important to know what proportion of end-of-life care provided in public hospitals is consumed by older patients. Moreover, what proportion of public hospital care by older age groups is consumed by those who are proximal to death compared to those who are not approaching death.

While this chapter examined the public hospital cost attributable to end-of-life for 2005 and 2010, it is noteworthy that as the so called "baby boomer" ages, the absolute number of both non-pre-decedents and pre-decedents will increase and put demand pressure on State resources.

End-of-life hospital costs are relevant to policy makers charged with anticipating future expenditure relating to the cost of end-of-life care. In Chapter 5, the costs incurred by older patients are examined, and changes over time are then examined in Chapter 6.
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CHAPTER 5 WHAT PROPORTION OF TOTAL PUBLIC HOSPITAL COSTS RELATED TO AGEING IS ATTRIBUTABLE TO END-OF-LIFE CARE?

Introduction

The cost of health care in general and hospital care in particular, incurred by the growing population of older Australians, is an issue of topical concern. Similarly, the question of the proportion of public hospital costs that are attributable to end-of-life care for older people is also one of growing relevance to health policy planners.

In the previous Chapter, the total number of public hospital bed days used by two cohorts of decedents (2005 and 2010) in the 12 months and five years prior to death were to establish the cost of end-of-life care. This then allowed the proportion of this care to be calculated as a percentage of the total public hospital expenditure for the stipulated year. However, the previous estimates of impost and cost did not differentiate end-of-life hospital usage by age. In this Chapter, the question of public hospital costs incurred in the end-of-life period by older patients is examined. This question has important implications for future policy development and the provision of cost efficient and clinically effective health care into the future.

The study database allowed for the available hospital utilisation data and associated cost data to be examined by patients' age. Hence, it was possible to identify the proportion of public hospital care (in terms of bed days and DRGs) provided to patients in given age groups who were in their last 12 months and/or five year pre-decedent period of life compared to patients in the same age group who were not pre-decedents. In this way, it was possible to determine the costs incurred by end-of-life patients by age, compared to the costs incurred by non-end-of-life patients in the same age group, using public hospital care over the same time period. Little research has been carried out on this subject.

End-of-life care is positively correlated with age. That is, the older one is, the more likely it is that one is in their last years of life. As such, it would be expected that a greater proportion of

end-of-life care costs is incurred by older patients. However, to-date this issue has not been empirically examined and quantified.

Commentary on healthcare costs commonly ascribes increasing hospital costs to "an ageing population" (Commonwealth of Australia, 2015). The current study was undertaken in view of a general concern about the costs of ageing. In the present context, an attempt was made to distinguish between the costs incurred by older patients (i.e., >55 years of age) 12 months and five years prior to their death and to compare this to the cost of public hospital care for all people aged >55 years.

In this Chapter three distinct groups of patients and the cost of their public hospital care were examined:

- Non-differentiated patients: this included all members of a given age group and the total public hospital expenditure on their care. This establishes the mean cost of public hospital care for all citizens in a given aged group. For example, total expenditure on people between 75 and 84 years divided by the total population of 75 to 84 year olds.
- **Pre-decedents**: the proportion of the non-differentiated population who will die in the 12 months to next five years. This research was able to identify the number of pre-decedents and the cost of public hospital resources consumed by them regardless of whether they had or did not have admissions in any given year. decedents who had no admissions in any of the five years prior to death were excluded from the database.
- Non-pre-decedents: Patients who will not die in the subsequent five years. These were calculated by subtracting the known number of pre-decedents from the non-differentiated population. Non-pre-decedents includes people who had admissions and those who had no admissions.

Examination of the cost of pre-decedents compared to no-pre-decedents is important as it will help inform the broader issue of whether a population that is likely to live longer, and therefore die older, is likely to impose a greater cost burden on society than if life expectancy was not extended. From one perspective, the "healthy ageing" of a population may well mean that the years immediately preceding the "last years of life" might draw on the public purse to no greater extent than a population with a less extended life expectancy. In this scenario, the costs associated with dying are simply deferred and therefore pose a "virtually" static cost exposure. If, on the other hand, as people age they incur significantly higher healthcare costs, regardless of whether they are in their last years of life or not, then an ageing population may expose governments to significantly higher public hospital costs. While this study did not fully explore this issue (a fuller examination of hospital patterns of use by all age groups and over time is needed to do this), it does go some way to start to explore the issue of public hospital costs incurred by older age groups overall and to differentiate these costs from those incurred by older pre-decedent patients.

This study first involved an examination of the average cost of public hospital care for older aged patients (i.e., >55 years) compared to the average cost per person in the WA population. This initial step addressed the question of whether older people per se incurred more public hospital costs than the overall WA population on average. A comparison of the public hospital costs incurred by two different groups of older patients was then undertaken. The first group where those in their five year pre-decent years and the second group were older people who were not pre-decedents. This allowed the question of whether public hospital costs incurred by older patients varied according to whether they were approaching death or not.

Methodology

Although a large and comprehensive database was created for this program of research that included data from four states (i.e. NSW, Qld, WA and SA) only the more complete and comprehensive data available for WA was appropriate to address the research question examined in this chapter.

The Western Australian Department of Health data linkage unit (the most well-developed of all the jurisdictional data linkage units within Australia) was asked to create a data set that could identify all public hospital costs for four age groups: i.e., patients aged 55-64, 65-74, 75-84 and 85+ years. By summing the costs of public hospital utilisation by the 2010

65

decedents for each of the five years preceding their death, an estimate could be made of *all* hospital care consumed by the cohort of 2010 decedents.

To establish the proportion of public hospital costs used by pre-decedents compared to their age cohort equivalents, who were not pre-decedent, the following procedure was followed. The total hospital costs of decedents who were in their final five years of life were calculated and then subtracted from the total hospital expenditure for the overall matched age group (the formula for the latter is shown below). In this way, the total hospital expenditure could be established for patients, who were *not* in their last five years of life and compared with patients who were in their last five years of life.

$$TD\$a1 = NDa1(\$Y1,a1 + \$Y2,a1 + \$Y3,a1 + \$Y4,a1 + \$Y5,a1)$$
$$\frac{HC\$a1 - TD\$a1}{Na1 - 5(NDa1)}$$

- HC\$a1 = Public hospital expenditure for Western Australia for age category 1
- TD\$a1 = Total decedent expenditure for Western Australia for age category 1
- Na1 = Total population for Western Australia in age category 1
- \$Y1a1 Sum public hospital expenditure in the five years prior to death for age category 1
- NDa1 = Number of decedents in age category 1
- Y1 to Y5 refers to years before death

Age category 1 refers to a given age category (e.g. 55–64 years old). Calculations were carried out for the four specified age categories.

The calculations were carried out as follows:

- The database created for this research provided details of the number of decedents in 2010 for a given age group and the cost of their public hospital use (as detailed in Chapter 3).
- The number of decedents was multiplied by the mean public hospital expenditure for the five years prior to death to give the cost of all decedents in their last five years of life.

- The total public hospital expenditure by age group was provided by the WA Department of Health Data Linkage Branch
- Census Data was used to establish the number of citizens in WA in each age group in 2010.
- The total cost of decedents was subtracted from the total hospital expenditure (as provided by WA DoH DLU)
- The number of decedents (multiplied by 5) was subtracted from the census data to establish the estimated number of citizens who were not in their last five years of life (i.e. survivors)
- The total state public hospital expenditure (minus the decedent expenditure) was then divided by the survivor population to establish the average public hospital costs for the non-decedent populations in each age group.

The non-pre-decedents' costs were also compared to the population cost determined by dividing the total state expenditure on public hospital care by the total population.

Results

Base line population health costs in WA for the 2010 year were:

- WA Public Hospital total expenditure \$ 3,638,500,000
- WA population 2,535,000
- Mean public hospital cost per person per annum \$1,435

Table 5.1 displays the number of Western Australians in each age group, the state government calculated total costs for each age group (as outlined in the method section in this Chapter), the number of the surviving population, the number of decedents, and the average total cost of decedents in the last five years of life.

Age Group	WA Population per age group 2010	Costs of public hospital for all patients (\$m) ⁽¹⁾	Population Survivors ⁽²⁾	N Decedents	Total mean cost last 5 years ⁽³⁾
55-64	225,465	\$ 577.7	224265	1200	\$ 60,382
65-74	153,748	\$ 576.7	151761	1987	\$ 59,631
75-84	188,561	\$ 519.4	185126	3435	\$ 51,738
85+	32,934	\$ 241.4	28544	4390	\$ 41,225
Total	600,708	\$ 1,915.2	589696	$11012^{(4)}$	

Table 5.1 WA population and decedent numbers and public hospital costs for 2010

(1) Total expenditure on public hospital care for all patients by age group as provide by the WA Dept. Health Data Linkage Unit.

(2) Total population in WA, by age group, minus 5 times the annual number of decedents.

(3) The database created for this research link each decedent's hospital record for the 5 years prior to death and attributes costs by multiplying each admission weight by the relevant benchmark price. This total for each decedent was then averaged to provide the mean five year cost by age category.

(4) Excludes decedents under the age of 55 years.

Using the formula above, the non-pre-decedent hospital cost of ageing were estimated (that is, excluding the cost associated with the cohorts who were in their last **five** years of life) (see Table 5.2).

Table 5.2 Public hospital costs incurred by older patients who were approaching death(pre-decedents) and older persons who were not approaching death

Age Group	Non-pre- decedent cost of ageing ⁽¹⁾	Percent difference greater than WA mean health costs (\$1435) PP/PA ⁽²⁾	Mean cost for each of last 5 years ⁽³⁾	Cost of public hospital care for average person in aged group ⁽⁴⁾	Difference ⁽⁵⁾
55-64	\$2,253	156%	\$12,076	\$2,562	12%
65-74	\$3,019	210%	\$11,926	\$3,751	19.5%
75-84	\$1,846	129%	\$10,347	\$2,754	33%
85+	\$2,117	148%	\$ 8,245	\$7,330	71%

- (1) Using the formula outlined in the method section, total health care costs for the aged group were averaged excluding the costs associated with pre-decedents and the number of patients in the cohort of pre-decedents.
- (2) Cost of non-pre-decedents as a percentage of the mean population health care use in WA (\$1,435 per person per annum).
- (3) Total public hospital cost for the 5 year prior to death divided by 5 (Average cost per year of decedents).
- (4) Mean public hospital cost per person for the age group. Total public hospital expenditure divided by the total age population (inclusive of pre-decedents).
- (5) Percentage difference (discount) of the cost of ageing after excluding the cost of predecedents from the population calculations.

The public hospital utilisation costs of non-pre-decedent older patients is a discount to the non-differentiated age cohort's estimates of cost of ageing (range 55-64 years 12%, 85+ years 71%) (see Table 5.2). However, the cost of care for older non-pre-decedent patients (>55 years) is greater than the state average cost of hospital care (\$1,435). As such, the cost of an ageing population presents significant challenges to the state. In the case of 55-64 year olds, the average cost of their public hospital care was \$2,253 or 12% greater than expected if an undifferentiated calculation of the mean population cost of health care was adopted.

Among 65-74 year olds, the cost of public hospital care for non-pre-decedents increased to \$3,019 (210% of the WA average). However, it decreased for decedents aged 75-84 years old to \$1,846 (129% WA state average) and rose again for decedents aged 85 years and older to \$2,117 (148% WA average).

In all age groups, the cost of non-pre-decedents represented a substantial discount to the undifferentiated cohort's cost of public hospital care. In the case of patients aged 55-64 years, the cost of care, excluding pre-decedents, was \$2,253 compared to an average for all patients of \$2,562 (when pre-decedents were not excluded), representing a 12% discount. The discount increased to 71% for non-pre-decedents over 85 years of age.

Discussion

This Chapter examined the cost of public hospital care for older people relative to the cost for the WA population overall. It then examined the costs of public hospital care for older people who were five years pre-decedent compared to older people who were not pre-decedents. This study therefore allowed for an examination and quantification of the extent to which end-of-life care contributed to the total public hospital costs for older people.

The average public hospital costs of patients aged >55 years was \$3,609 (\$3,425 excluding chemotherapy and dialysis) compared to the WA state average cost per person in 2010 of \$1435.

When the costs associated with pre-decedents were excluded from the calculations of the mean cost of older age groups, it was found that the cost estimates for public hospital care reduced substantially. In the case of 55–64 year olds, the cost ranged from \$2,562 to \$2,253 (12% discount). For 65–74 year olds it ranged from \$3,751 to \$3,019 (19.5% discount), and for 75–84 year olds from \$2,754 to \$1,846 (33% discount) and for those over 85 years from \$7,330 to \$2,117 (71% discount). Factors contributing to the reduction in cost for 75-84 years old people warrant investigation. Further research is necessary to understand why the population aged 75-84 would show a decrease in the non-pre-decedent cost of ageing.

These figures represent substantial discounts to forward estimates of hospital costs when using a non-differentiated age cohort analysis of the cost of ageing. While it appears evident that older patients cost significantly more than the mean WA population, these results indicate that an ageing population may not present the cost burden hitherto anticipated by state governments. If these findings can be replicated and proved to hold constant in similar rigorous analyses a strong case may be developed to argue that the ageing population may not constitute a major financial threat to the healthcare system that is sometimes supposed.

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Alternatively, if these data hold true there will not be a substantial increase on healthcare costs as a result of the ageing of the population.

This Chapter has compared the public hospital costs associated with an non-pre-decedent aged population after excluding the hospital costs associated with those within the defined age groups who were in their last five years of life. The next Chapter presents a study undertaken to examine changes in the public hospital costs associated with end-of-life care over time for four states (NSW, Qld, and SA) between 2005 and 2010 and for WA between 1995 and 2010.

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CHAPTER 6 HAS THE COST OF END-OF-LIFE HOSPITAL CARE CHANGED OVER TIME?

In establishing the cost of hospital care associated with the end-of-life it is also important to examine the stasis of these costs. That is, it is important to establish whether these costs are increasing (in real terms) or static. Information about the trajectory of end-of-life hospital costs can assist policy makers to estimate and predict resource needs into the future more accurately.

To investigate whether hospital expenditure in the last year of life has changed over time decedents' data from NSW, Qld and SA for 2005 and 2010, and from WA for 1995, 2000, 2005 and 2010, were examined. The average length of stay that decedents experienced for hospital admissions in their last year of life was analysed to investigate key factors that might impact on change over time. For example, have the number and type of admissions related to end-of-life care changed over time? If so, did these changes involve shorter lengths of stay? If shorter lengths of stay for public hospital admissions exist, what factors might be contributing to this and what implications would this have for future resourcing?

By using Australia's diagnostic related groups (DRG) admission weighting methodology (casemix or activity based funding), case weights were able to be applied to all admissions for decedents in their last year of life and these were multiplied by the standard national benchmark price to estimate the cost of admissions. These cost estimates reflect the mean cost of all admissions for a given DRG. If the cohort in question experienced a significant variation from the mean of the whole population who was admitted for the same DRG, the cost weights would over or under estimate true costs. Both the cost weight of the admissions themselves, the type of the DRG and the complexity of the admission and the net present value after adjustment for health inflation after the price weights were examined. The cost weights are 'blind' to price and simply represent the nature and complexity of the admissions, and frequency thereof, whereas the cost takes into account the net present value using the annual health inflators as issued by the Australian Institute of Health and Welfare [45].

Method

To examine the raw admission rate, data was extracted for decedents who died in each of the four States (NSW, Qld, WA and SA), in each of the years 2005 and 2010 and for WA, also for the years 1995 and 2000. As there was significant variation in the number of raw admissions for each decedent, admissions that were more than 2.5 SD from the mean were excluded. Mean scores were compared using Welch tests to account for the highly skewed distribution. The Welch test serves to establish the likelihood that variations in means between groups are due to chance.

Using the diagnostic related group (DRG) cost weights, both admission rates were compared taking into account complexity of each admission, or weighted admissions (sourced from AIHW), and applying the Welch test to compare means.

Length of stay (LOS) was calculated by subtracting the admission date from the discharge date, as outlined in Chapter 3. Average length of stay (ALOS) was calculated by aggregating the total occupied bed days (the sum of the LOS) for a particular period and dividing it by the number of admissions. This was carried out for the last year of life for decedents in each state for 2005 and 2010 (see Table 6.10).

Costs were estimated for each admission using the AIHW published benchmark prices (multiplied by the admission weights) and adjusting for Health Inflation as published each year by AIHW. This method allowed for the cost to the public hospital system of decedents in their last year of life to be calculated. Caution should be taken to note that these cost estimates are "pricing tools" used to predict costs and are not actual costs. If for example, the cohort selection (last year of life patients) are not representative of the whole population who experience a given diagnosis, then these estimates may over or under represent actual resources consumed.

Analysis of the variation in raw admission rate, weighted admissions and adjusted net present value were carried out for the four states for the periods 2005 and 2010. As data was available for Western Australia for four periods (1995, 2000, 20105 and 2010) it was possible to undertake a more detailed analysis over time focussing on adjusted net present value. Again, excluding outliers (greater than 2.5 SD above the mean, or greater than \$56,780),

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correlations between years and mean costs were calculated. The distribution of occupied bed days, admissions, weighted admissions and public hospital costs were highly skewed (to the left) so the adoption of Spearman's correlation coefficient was preferred over Pearson's correlation coefficient statistic.

Statistical analysis was performed using the Breusch Pagan test to determine whether the data were heteroscedastic. That is, were variables randomly distributed or was there evidence of sub-populations within the group. The results of the Breusch Pagan test are outlined in Table 6.1 with a significant value of P<0.0001 indicating that it can be assumed that there are sub-populations in the variables and that variations in the means are unlikely to be a consequence of chance.

Table 6.1 Bresch Pagan Test Results

BP	11,707	
Df	2	
P - value	< 0.0001	

Next Spearman's correlations were conducted for the adjusted costs (after excluding outliers) and the year in which the death occurred. A significant difference was found between the year of death and the cost of death (see Table 6.2). A Spearman's test was conducted for the year in which the death occurred (1995, 2000, 2005, 2010) and the years until death, that is, the year preceding death, the two years preceding death and so on until five years before the year in which the death occurred. A weak correlation was found for year of death and cost (significance p<0.0001), and a moderate to strong negative correlation was found for the number of years preceding death and cost (see Table 6.2). That is, hospital costs increase as death approaches.

Table 6.2 Correlation coefficients year of death (2005 and 2010) and public hospital cost (2010 dollars)

	Spearman's Correlation Coefficient (Rho)	P-Value
Death Year and NPVG	0.16	< 0.0001
Years Until Death and NPVG	-0.38	< 0.0001

Analysis of variance using Welch tests were performed on the means of each of the years in which death occurred and years prior to death (see Table 6.3 and Table 6.4). In both cases, a

statistically significant relationship was found for year of death (F:2,094) and proximity to death (F:7,039) (p < 0.0001).

Table 6.3 Welch test public hospital costs (2010 dollars) and year of death (2005 and2010)

F	2,094
num df	3.0
denom df	113,903
p-value	< 0.0001

Table 6.4 Welch test public hospital cost (2010 dollars) and years preceding death

F	7,039
num df	4.0
denom df	101,121
p-value	< 0.0001

Total raw admissions by state show that decedents had an average of 2.5 admissions in their last year of life (see Table 6.5), and the mean number of admissions varied significantly between states (2010 range 2.0 - 2.9) (F:390.2; p<0.0001) (see Table 6.6).

	Table 6.5 Rav	v admissions	by state	by year	during t	he year	preceding	death
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Admits Excluding Outliers					
States 2005 2010					
NSW	2.5	2.9			
Qld	2.5	2.5			
SA	2.2	2.0			
WA	2.1	2.3			
Total	2.4	2.6			

Table 6.6 Welch test state by raw admissions during the year preceding death

F	390.2
num df	3
denom df	65,315
p-value	< 0.0001

When factoring in the complexity of the raw admissions, it became apparent that the complexity of the decedents' hospital presentations increased over time. Changes in complexity over time (i.e., from 2005 to 2010) between states varied significantly (F: 509.4; p<0.0001). Complex admissions in NSW and WA increased, Qld remained constant while SA decreased (see Table 6.7 and Table 6.8).

Weighted Admissions Excluding Outliers	Weighted admissions	Weighted admissions
States	2005	2010
NSW	4.9	5.6
Qld	4.6	4.6
SA	4.4	4.0
WA	4.0	4.2
Grand Total	4.6	5.0

Table 6.7 Weighted admissions by State by year for the 12 months prior to death

 Table 6.8 Welch test: State and number of weighted separations in the year prior to

 death

F	509.4
num df	3
denom df	53,441
p-value	< 0.0001

Application of the benchmark hospital prices to the weighted admissions indicated that for all states, except South Australia, prices increased significantly in the period 2005 to 2010 after health inflation was applied (F:519.6; P<0.0001) (see Table 6.9 and Table 6.10).

 Table 6.9 Cost of end-of-life care after adjusting for health inflation (2010 dollars) by

 state by year

Net Present Value (Adjusted for Health Inflation) (excluding outliers)					
States	2005	2010	Change		
NSW	\$20,180	\$24,613	21.97%		
Qld	\$18,741	\$20,364	8.66%		
SA	\$17,418	\$17,491	0.42%		
WA	\$16,571	\$18,552	11.96%		
Grand Total	\$19,046	\$21,919	15.09%		

 Table 6.10 Welch test: State and inflation adjusted cost of public hospital care in the year prior to death

F	519.6
num df	3
denom df	53,402
p-value	< 0.0001

Mean length of stay represents a measure of efficiency of hospital performance. As occupied bed days are a major determinant of hospital admission cost, a shorter average length of stay (ALOS) indicates improved patient management. Table 6.11 shows a decrease in ALOS by an average of 1.1 OBD across states for the periods 2005 and 2010.

ALSO	2005	2010	Difference	%
NSW	9.5	8.5	-0.9	9.9
Qld	6.7	6.5	-0.2	3.3
WA	10.1	8.2	-1.9	18.9
SA	9.9	8.8	-1.1	10.8
Mean	9.1	8.0	-1.1	10.7

Table 6.11 Average length of stay (days) of hospital admissions in the year prior to death, by state in 2005 and 2010

Discussion

This study examined the question of whether end-of-life public hospital costs were increasing over time. The findings indicated that between 2005 and 2010, the cost of end-of-life care in the last year of life increased overall but the degree of difference varied among states. In some instances, the differences among states were significantly different.

Overall, evidence was found of an increase in the cost of public hospital end-of-life care. However, this increase was not found for South Australia. For Western Australia, where data were available for examination over a longer period of time, there was also evidence that endof-life care costs had increased over two decades at a rate greater than health adjusted inflation rates.

Most economic models assume that end-of-life care costs are fixed in line with health inflation, and as a result, the future cost of end-of-life care is likely to be under-estimated. This is an important issue as much health policy is concerned with the cost of ageing and, as stated elsewhere in this thesis, as the cost of ageing incorporates the cost of dying, policies that do not account for the cost of dying will not adequately predict future public hospital financial exposure.

While a relationship exists between age and likelihood of death, the cost of ageing and the cost of dying are not proven to be a function of each other. The findings from the present study provide definitive evidence that the cost of dying has not held constant over time. This

finding has important implications for the provision of healthcare resources into the future and the planning of appropriate care services. Further research is warranted to examine the potential drivers of these increasing costs. In addition, there is a need for the development of appropriate statistical models which can account for predictable variations in the cost of dying in the future.

This Chapter has established that public hospital costs associated with end-of-life are increasing over time at a rate in excess of health inflation. These findings both provide useful and meaningful data for policy makers as well as posing challenges for public resource management and health policy makers. The next Chapter examines factors that contribute to public hospital costs for end-of-life care. For example, does age at death effect hospital cost at end-of-life? Does the cause of death influence costs and is there a relationship between the age at death and the cause of death?

While this Chapter examined the cost of end-of-life care costs for whole populations, the following Chapter explores cost distributions within decedent cohorts to determine if there was a differential pattern of resource consumption among patients (that is, do some patients use significantly more resources than others).

CHAPTER 7 WHAT FACTORS IMPACT END-OF-LIFE PUBLIC HOSPITAL COSTS?

Introduction

In this Chapter, the effects of a range of factors that may impact end-of-life care hospital costs are examined. International evidence indicates that the older one dies, the fewer hospital resources are consumed in the last year of life (Van Vliet & Larmers, 1998). Limited Australian research has also identified a similar pattern of hospital utilisation (Calver et al., 2006). The findings presented in Chapter 5 reported results consistent with this literature. As 'proximity to death' is increasingly recognised as a key contributor to health care costs associated with an ageing population (Breyer & Felder, 2005; Fassbender et al., 2009; Rosenwax et al., 2011), the cost of healthy ageing may to some degree be offset by a lower cost of death for older decedents.

If, as shown in previous research (Lubitz et al., 2003; Calver, Bulsara et al., 2006), the older the decedent the fewer hospital care resources consumed the question arises as to whether this may be related to cause of death relative to age. For example, do cancer related deaths typically occur among a younger cohort of decedents than, for example, organ failure? As outlined in Chapter 2, Lunney et al. defined a range of trajectories to death (Lunney et al., 2003). These were:

- frailty,
- sudden death,
- organ failure, and
- cancer.

While Lunney's trajectories are based on the experience of the patient, the present research was interested in how these particular causes of death might impact hospital use in the last year of life. A further question of interest was whether there were variations in the cause of death between jurisdictions?

The cost structure of public hospitals is largely determined by fixed costs. These fixed costs include capital, staff (doctors, nurses, service and administrative staff) and are proportional to the size of the hospital as measured by the number of beds provided. Therefore, the potential bed days available determines the efficiency of a given hospital. As Australian hospitals are funded on a 'weighted activity' basis (that is, per admission adjusted for the complexity of the admission) it follows that an increase in weighted admissions per available hospital bed represents an efficiency increase (efficiency equals output divided by inputs, or weighted admissions per available bed).

This research examined length of stay in order to identify potential scope for improvements in technical efficiency of public hospital care at the end-of-life. Analyses were undertaken to quantify the cumulative cost of all admissions over the last 12 months and last five years of life. Age, cause of death and length of stay are critical variables associated with hospital costs of end-of-life care. The relationship between these variable are important and are examined in this Chapter.

A comprehensive analysis of the cost of end-of-life care necessarily takes into account variations in costs among decedents. It was unknown whether there was a general similarity in hospital costs for all decedents, or if some classes of patients used disproportionately more resources than others. In this Chapter, a range of factors that may potentially influence the cost of end-of-life care, including causes of death, and their cost in relation to end-of-life care hospital utilisation and costs are examined. While Lunney's trajectories to death aimed to describe patients' experiences of morbidity, the present research applied them as a typology to describe utilisation patterns and costs of public hospital resources at end-of-life. Lunney, for example, suggested that end-of-life experiences for cancer involved a rapid deterioration in health proximal to day of death (Lunney, Lynn et al., 2003). This Chapter examines whether Lunney's suggested trajectories of end-of-life morbidity are reflected in contemporary public hospital utilisation patterns and costs.

Method

The database created for this program of research contained detail of 'raw' separations for all decedents in 2005 and 2010 in four states (NSW, Qld, WA and SA). The distribution was skewed with some decedents experiencing very high admissions rates in their last year of life.

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To minimise any potential bias from these extreme cases, decedents whose separations rate was greater than 2.5 SD were excluded from these analyses.

Descriptive statistics of raw separations for all decedents in 2005 and 2010 are outlined in Table 7.1.

Table 7.1 Public hospital separations for all decedents (NSW, Qld, WA and SA) in 2005
and 2010 in the 12 months prior to death

	Raw Separations
Mean	2.5
Variance	11.37
Standard Deviation	3.37
2.5 standard deviations from mean	12

All hospital records are coded and able to be associated with standardised Diagnostic Related Group (DRG). By multiplying the weighting allocated to each DRG by the standard benchmark price (as determined by the Australian Institute of Health and Welfare), the cost of each hospital separation is attributed to each DRG. These cost estimates form the basis on which the calculation of the cost of end-of-life care for the cohorts of patients examined in this research were established. It is possible, however, that a particular cohort (decedents or near death patients) might not be reflective of the mean cost weight. For example, if people approaching death spend, on average, longer in hospital than people who would otherwise be healthy if not for the condition for which they were admitted, then the cost may be underrepresented. To investigate this, the following analysis was undertaken:

- The database created for this program of research contained admission and discharge dates, and DRG codes for every public hospital admission by each decedent.
- Decedents were categorised by their cause of death as outlined in Chapter 3.
- By aggregating the cumulative sum of all admitted bed days (discharge day minus admission day) it was possible to calculate the total occupied bed days per decedent.
- As each admission was coded by DRG, it was also possible to calculate the average casemix price of hospital care consumed by decedents, based on DRG weighted activity prices.
- AIHW weights and benchmark prices represent the average of all hospital activity. That is, both pre-decedents and non-pre-decedents.

- Therefore, by dividing the total casemix price by the total occupied bed day, a 'price per occupied bed day' result was be derived.
- The degree to which this occupied bed day price varies from a standard bed day price is indicative of longer or shorted average length of stay of the cohort in question.

The cost per day output indicated substantial variations among states and for different causes of death as outlined in Table 7.2. Therefore, two approaches to costing were possible:

- multiply admission weight by benchmark price
- assume cost per bed day was approximately constant, and use occupied bed days as a proxy for cost.

This research adopts the first approach as it provided a more relevant indicator of pricing for policy considerations.

	Qld	SA	WA	NSW
Neoplasms OBD*	25.9	29.3	23.6	36.5
Neoplasm Estimated cost	\$32,663	\$28,330	\$28,041	\$36,594
Estimated cost per day	\$1,262	\$967	\$1,187	\$1,001
Neurodegenerative OBD*	23.9	50.5	18.4	35.5
Neurodegenerative Estimated Cost	\$23,967	\$14,811	\$16,216	\$ 20,536
Estimated cost per day	\$1,003	\$293	\$880	\$578
Organ Failure OBD*	19.3	25.1	25.0	32.2
Organ Failure Estimated Cost	\$24,028	\$17,600	\$21,186	\$27,486
Estimated cost per day	\$1,243	\$700	\$846	\$854

Table 7.2 Average DRG cost divided by occupied bed days to test consistency of cost per day (2005 and 2010)

*OBD signifies Occupied Bed Day

Analyses were also undertaken of the *pattern* of hospital utilisation in the years prior to death. In doing so, the timing of death, ALOS and proximity of admissions to death in the last 1000 days of life were calculated. The last 1000 days were chosen as it depicts a longer period than a single year but was shorter than the five year period used elsewhere in this research. Extending the period to five years would over-represent the rate of admissions in the 4th and 5th year prior to death where admissions were less frequent and many decedents did not experience admissions. Only the last 15 admissions were considered necessary as these provided a sufficient pattern of utilisation within a 1000 day period.

Patterns of utilisation prior to death were calculated by taking the proximal admission and discharge days (in order to calculate length of stay and date of admission) relative to the day of death. The median discharge date was used to determine the discharge dates' proximity to death for the final admission. The mean length of stay was used to determine the admission date for all admissions. By utilising the average length of stay of the final admission for all decedents, the mean admission day for the final discharge could be calculated. The median discharge day was then calculated for the penultimate admission date and the mean length of stay for the penultimate admission was used to calculate the proximity to death and the length of stay for the penultimate admission.

The distribution of resource consumption of decedents within each cause of death cohort was analysed by calculating Lorenz curves and associated Gini coefficients. Lorenz curves are used to statistically determine the equality of within group distributions. If 10% of patients use 10% of resources, and 20% of patients use 20% of resources and 50% of patients 50% of resources and so on, then there is an even distribution of resources which results in a straight line and a Gini coefficient of 0.0. Alternatively, if 10% of patients use 1% of resources, 30% of patients use a total of 10% of resources, and the final 10% of patients consume, for example, 50% of resources then a plot of resource consumption would be curvilinear.

Results

A correlation between age of death and the cause of death was performed. Organ failure was found to have a weak positive correlation with age of death and neoplasms a weak negative correlation with age of death. This may indicate that neoplasms (i.e., cancers), are more likely to contribute to death for any age group; whereas, organ failure tended to occur more often among older age groups (see Table 7.3). As death from cancer is avoided there is an increased likelihood that one will die from organ failure. The other causes of death were not significantly correlated.

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Table 7.3 Correlation coefficients for cause of death and age for 2005 and 2010decedents in NSW, Qld, WA and SA

	Spearman's Correlation Coefficient (Rho)	P-Value
Neoplasm and Age	-0.237	< 0.0001
Neurodegenerative and Age	-0.010	0.0001621
Organ Failure and Age	0.231	< 0.0001
Sudden Death and Age	-0.136	< 0.0001

Using the Spearman correlation statistic, an analysis was performed for all causes of death and specific causes of death to examine relationships between weighted separations (the main contributor to public hospital costs) and age group. A correlation across all cause of death cohorts (Rho= -0.14, P<0.0001) and a negative correlation between the weighted separations by age for neoplasms, organ failure and neurodegenerative conditions (-0.18, -0.1, and -0.16, respectively) was found (see Table 7.4). However, sudden death was positively correlated with weighted separations, indicating that when older patients died from sudden death, these deaths involved more weighted separations than for younger decedents (although younger decedents were more likely to die a sudden death (see Table 7.14)) (Rho 0.36, P < 0.0001).

	Spearman's Correlation Coefficient (Rho)	P-Value
All Cohorts	-0.14	<0.0001
Neoplasm	-0.18	<0.0001
Organ Failure	-0.10	<0.0001
Neurodegenerative	-0.16	<0.0001
Frailty	-0.07	0.0394
Sudden Death	0.36	<0.0001

 Table 7.4 Correlation of weighted separation by age (2010)

While frailty, as a cause of death, was not significantly correlated with age (as the age values for frailty in the database were almost exclusively for patients over 85 years) thereby eliminating meaningful correlation results. A Welch test was carried out to determine whether the means for the cause of death cohorts were independent of each other (Table 7.5). This was confirmed for all causes of deaths, however, not in the case of the frailty.

Welch tests						
	All Cohorts	Neoplasm	Organ Failure	Neuro- degenerative	Frailty	Sudden Death
F	597.28	187.28	153.43	3.74	2.317	34.92
num df	7	7	7	7	3*	7
p-value	< 0.0001	< 0.0001	< 0.0001	0.001486	0.0988	< 0.0001
Critical F Value		2.1	2.01	2.12	3.07	2.01

 Table 7.5 Welch test of weighted separations by age (2010)

* As almost the whole population of frail decedents were very old, and therefore occupied the single age category (85+ years), this had the effect of reducing the degrees of freedom for age analyses with the frail cohort.

Similar tests were carried out for the net present value by cohort, including a subsequent Welch test to examine differences in separations by mean cost of last year of life for each cause of death group (see Table 7.6 and Table 7.7). These findings confirm previous research (Calver, Bulsara et al., 2006) that indicated the older a person dies, the fewer public hospital resources that are consumed in the last year of life. A negative correlation between cost of public hospital care in the last year of life and age was found. That is, as age of death increased the cost of hospital care in the last year of life reduced, with the exception of sudden death in which case it increased significantly.

	cur of me (net present value) and m	50 (2010)
Spe	arman's Correlation Coefficient (Rho)	P-Value

Table 7.6 Correlation of cost of last year of life (net present value) and Age (2010)

	Spearman's Correlation Coefficient (Rho)	P-Value
All	- 0.13	< 0.0001
Neoplasm	- 0.18	< 0.0001
Organ Failure	- 0.10	< 0.0001
Neurodegenerative	- 0.16	< 0.0001
Frailty	- 0.07	0.0424
Sudden Death	0.37	< 0.0001

Table 7.7 Welch Test cost of last year of life public hospital care by age

	All Cohorts	Neoplasm	Organ Failure	Neuro- degenerative	Frailty	Sudden Death
F	569	179.64	143.44	4.34	2.12	35.81
num df	7	7	7	7	3	7
p-value	< 0.0001	< 0.0001	< 0.0001	0.004013	0.1274	< 0.0001
Critical F Value	2	2	2	2	3	2

Spearman's correlation was performed on year of death (2005 or 2010) and age by jurisdiction. Results indicate that there is no meaningful relationships as Spearman correlation coefficients were less than 0.1.

 Table 7.8 Correlation coefficients between years of death (2005 and 2010) and age of death

	Spearman's Correlation Coefficient (Rho)	P-Value
Death Year and Total Raw Separations	0.070	<0.0001
Death Year and Raw Separations WA	0.014	0.003251
Death Year and Raw Separations NSW	0.090	< 0.0001
Death Year and Raw Separations QLD	-0.010	0.0369
Death Year and Raw Separations SA	-0.059	< 0.0001

The relationship between the year of death (2005 and 2010) and cause of death was also examined (see Table 7.9). Analysis of correlations between the year of death and cause of death was performed. While some P values suggested significant relationships the size of the correlations were negligible. That is, between the years 2005 and 2010, the age of death did not vary substantially by cause of death (see Table 7.9).

Table 7.9 Correlation coefficients death year (2005 and 2010) and age by cohort

	Spearman's Correlation Coefficient (Rho)	P-Value
Neoplasm	0.034	< 0.0001
Neurodegenerative	-0.092	< 0.0001
Organ Failure	0.041	< 0.0001
Sudden Death	0.103	< 0.0001

Analyses were undertaken to identify whether any increased costs in the last year of life for a particular cause of death may be masked by the overall cost patterns. The relationship between cause of death and cost of public hospital cost was examined (see Table 7.10). A meaningful correlation was found for neoplasm related death and health inflation adjusted costs in 2010 (Rho 0.22 (p<0.0001)). Other causes of death, i.e., neurodegenerative, organ failure, sudden death and frailty, were weakly negatively correlated (-0.03, -0.1, -0.04 and - 0.05, respectively) (p < 0.0001).

These results indicate variability in the public hospital costs by cause of death. A Welch test (see Table 7.11) was undertaken to identify independence of the mean cost and causes of death.

Table 7.10 Correlation coefficients for cause of death and public hospital cost of lastyear of life (NPV Health inflation) (2010)

	Spearman's Correlation Coefficient (Rho)	P-Value
Neurodegenerative and Cost of end-of-life hospital care	-0.03	< 0.0001
Neoplasm and Cost of end-of-life hospital care	0.22	< 0.0001
Organ Failure and Cost of end-of-life hospital care	-0.10	< 0.0001
Sudden Death and Cost of end-of-life hospital care	-0.04	< 0.0001
Frailty and Cost of end-of-life hospital care	-0.05	< 0.0001

 Table 7.11 Welch test for state and inflation adjusted cost

F	519.6
num df	3
denom df	53,402
p-value	<2e-16

A series of chi square analyses were undertaken to examine the relationship between cause of

death and a range of variables. The chi square analyses included the following:

Cause of death and state:	X-squared = 3942.308, df = 15, p < 0.0001
Cause of death and year (2005 and 2010):	X-squared = 871.5908, df = 5, p < 0.0001
Cause of death and age:	X-squared = 22267.16, df = 40, p < 0.0001
Age group and state:	X-squared = 318.7666, df = 16, p < 0.0001
Age group and year of death:	X-squared = 407.4399, df = 8, p < 0.0001

While all chi square results showed significant P values, the relationship strength was measured by the calculation of a Cramer's V test. The results presented in Table 7.12 indicate a strong relationship between cause of death and age group.

Table 7.12 Cramer's V	test on age of death	, cause of death, s	state and year o	of death (2005
and 2010)				

Variables	Cramer's V score
Cause of death and state	0.09017579
Cause of death and year (2005 and 2010)	0.07343982
Cause of death and age group	0.1891629
Age of death and state	0.03578574
Age of death and year	0.05721638

The relationship between the various cohorts and age was examined. Spearman's correlation was performed and significant relationships were observed between age and organ failure (Rho = 0.231; p<0.0001) and neoplasm (Rho=-0.237; p<0.0001) (see Table 7.13). Neoplasms were found to be related to an increased likelihood of death at a younger age, whereas organ failure was likely to occur at an older age. Similarly, sudden death was also found to be significantly associated with younger age (Rho = -0.136; p<0.0001).

	Spearman's Correlation Coefficient (Rho)	P-Value
Neoplasm and Age	-0.237	< 0.0001
Neurodegenerative and Age	-0.010	0.0001621
Organ Failure and Age	0.231	< 0.0001
Sudden Death and Age	-0.136	< 0.0001

Results indicated that there was a weak correlation between the cost of dying for all causes of death with the exception of neoplasm where there was a significant and positive correlation (Rho=0.22 p<0.0001). To ascertain the degree to which the mean costs of public hospital care in the last year of life and the various causes of death varied, the mean cost was calculated for all decedents by cause of death (see Table 7.14).

Table 7.14 Mean c	ost of last year	of life by cause	of death (202	10 dollars adjuste	ed for
health inflation)					

	Mean Inflation Adjusted Cost Last Year of Life per decedent (2010 dollars adjusted for health inflation)
Neoplasm	\$26,303
Organ Failure	\$18,151
Frailty	\$10,763
Sudden Death	\$14,462
Neurodegenerative	\$15,504

The costs of care for the various causes for death are relevant in respect to variations in costs. Neoplasm costs were higher than other causes of death and frailty less than the other causes. Lunney's trajectories to death provide a typology of the 'experience' of end-of-life care. This program of research analysed public hospital utilisation patterns using Lunney's trajectories to ascertain if the cost consumption matched the trajectories. This analysis allows cost of endof-life to be considered in terms of proximity to death. In Figures 7.1a-e below, the X-axis represents days preceding death and the y-axis represents the last day of life and the white bars on the chart the proximity to death and duration of admissions prior to death (see Figure 7.1).



Figure 7.1 Description of end-of-life utilisations graphs



Figure 7.1a Admission pattern for Neoplasm



Figure 7.1b Admission pattern for Neurodegenerative



Figure 7.1c Admission pattern for Organ Failure



Figure 7.1d Admission pattern for Frailty



Figure 7.1e Admission pattern for Sudden Death
Thus far, this Chapter has examined factors affecting end-of-life hospital costs in broad categories. A further important consideration was to understand whether utilisation evenly distributed within such categories. To do so, Lorenz curves and associated Gini coefficients were calculated for the five causes of death for all decedents. Lorenz curves display the degree to which variables are evenly distributed within a data set. Gini coefficients measure this evenness with a score of 0 representing a perfectly distributed set and 1 representing a maximally skewed data set. For the purposes of ascertaining to what degree decedents who die from a particular cause use an equal amount of public hospital care as other decedents who die from similar causes, Lorenz curves and Gini coefficients provide a means to quantify the distribution in comparison to alternative causes of death. Figures 7.2a-e display Lorenz curves and Gini coefficients for each of the five causes of death.



Figure 7.2a Neoplasms - All States - 2005 & 2010



Figure 7.2b Neurodegenerative - All States -2005 & 2010





Figure 7.2d. Sudden Death - All States – 2005 &

Figure 7.2c Organ Failure - All States - 2005 & 2010



Figure 7.2e Frailty - All States - 2005 and 2010

Death that occurred as a consequence of neoplasms show the most evenly distributed cost per decedent with a Gini coefficient of 0.52 and frailty related deaths the most maldistributed with a Gini coefficient of 0.8 indicating approximately 10 percent of decedents consumed 65 percent of end-of life public hospital expenditure for al frailty related deaths.

2010

Discussion

This Chapter examined factors that might affect the public hospital costs associated with end-oflife care. Analyses of length of stay over time, the relationship between age and cause of death, public hospital costs by cause of death, years of death and state were undertaken. Results indicated that age had a significant and meaningful impact on costs associated with end-of-life care. In terms of the relationship between age of death and cause of death, it was found that age was positively correlated with organ failure. However other causes of death were negatively, though weakly, correlated with age. Correlations with public hospital costs also showed a negative relationship with age for all causes of death, except sudden death. That is, the older people died the fewer public hospital resources they consumed.

The exception to the above pattern with the 'sudden death' cohort appears somewhat counter intuitive. Sudden death cohorts include a range of diagnostic groups that would classify decedents in the sudden death group (a full list of causes of sudden death is provided in Appendix E) such as:

- Injuries to the head
- Injuries to the abdomen, lower back, lumbar spine and pelvis
- Injuries to the wrist and hand
- Injuries involving multiple body regions
- Injuries to unspecified part of trunk, limb or body region
- Burns
- Poisoning by drugs, medicaments and biological substances
- Toxic effects of substances chiefly non-medicinal as to source
- Other and unspecified effects of external causes
- Certain early complications of trauma
- Complications of surgical and medical care, not elsewhere classified
- Other complications of trauma not elsewhere classified
- Transport accidents
- Intentional self-harm
- Event of undetermined intent
- Complications of medical and surgical care.

Noting the detailed causes of death which define the 'sudden death' cohort, the present results would suggest that deaths caused by such factors may be preceded by other admissions to public hospitals as decedents age, thereby, increasing their overall hospital utilisation prior to death.

An analysis of the age at which death occurs showed weak a relationship over time, although statistically significant (with no state indicating a Rho value greater than 0.09).

Results of the analysis of the relationship between cause of death and cost of public hospital services found that public hospital resource use varied significantly. Neoplasm related deaths were correlated with higher public hospital costs (Rho 0.22 P < 0.0001). Other causes of death were found to have a weak negative relationship with public hospital costs, the highest being organ failure (Rho -0.1, P<0.0001).

In addressing the question of the relationship between age of death and cause of death, the results indicated that organ failure was positively correlated with age, suggesting that organ failure related deaths are more common in older patients (Rho 0.231, P<0.0001). Conversely, neoplasm deaths were negatively correlated with age (Rho -0.237, P<0.0001).

Age of death was found to be positively correlated with organ failure, indicating an increased likelihood of dying of organ failure as decedents aged. Other causes of death showed weak relationships with age.

Analysing the relationship between public hospital costs and cause of death this research found that cancer related deaths result in higher public hospital costs (mean of \$26,303 in the last year of life) compared to organ failure deaths (mean \$18,151 in the last year of life). This finding may partially explain the reduction in costs associated with ageing which were found to be negatively correlated with neoplasm and positively correlated with organ failure.

Age at death and age by cause of death remained stable over the 2005 to 2010 period in each of state. Accordingly, it is reasonable to conclude that age of death has generally not significantly changed over time and that there is no significant relationship between year of death (2005 vs 2010) and cause of death. The exception was in relation to neurodegenerative conditions in Western Australia where the age of death fell from 81.95 years to 73.78 years between 2005 and

2010. However, the number of deaths for neurodegenerative conditions is relatively low and this finding may be a product of chance. Further research might identify whether this pattern was sustained between 2010 and 2015. In Western Australia, the age of death of organ failure also fell from 79.93 years of age in 2005 to 76.01 in 2010.

The findings from the present study are consistent with an assumption there is a significant relationship between age of death and cause of death, as a significant increase in the likelihood of dying of organ failure as one ages was found, with cancer more likely to be fatal at a younger age.

The trends reported in the literature (Lubitz, Cai et al., 2003; Calver, Bulsara et al., 2006) where the cost of end-of-life care decreases with age, particularly for patients over 65 years of age, is supported. This study also found that older decedents were associated with an increased likelihood of cancer and frailty related deaths which consume fewer public hospital resources. It was also found that a negative correlation existed between age and public hospital costs. It was established in Chapter 6 that end-of-life public hospital costs were rising more quickly than health inflation. In addition, Chapter 5 showed that non-pre-decedents incurred significantly more public hospital costs than the average citizen although substantially less than pre-decedents of similar ages.

While older decedents were found to be less costly than younger decedents, the escalation in price overall was outstripping health related CPI, and while non-pre-decedents were incurring more costs in their ageing years, those costs were substantially less than would be expected if pre-decedents were not excluded from cost calculations.

Nevertheless, the cost of end-of-life care is rising more quickly than the cost of healthcare consumption generally (assuming health related CPI is an appropriate adjuster for the cost of healthcare consumption over time). Again, it is important to note that the cost estimates reported here are based on cost weight multipliers of benchmark healthcare prices and may overstate actual costs, but more realistically they are likely understate the healthcare costs associated with end-of-life care. However, this methodology was consistently applied over the periods under review and it is therefore unlikely that this would affect the veracity of the cost estimations.

This study also found that organ failure was positively correlated with age and neoplasm was negatively correlated with age (Rho 0.321 and Rho -0.237 respectively P<0.0001). Other causes of death were not significantly correlated with age. As the correlations of neoplasm and organ failure are almost reciprocals of each other it might be assumed that one offsets the other. That is, as deaths from cancer are averted more deaths from organ failure are likely to occur.

The findings also indicated that neoplasm deaths were significantly more costly than other causes of death. It was demonstrated that older age is correlated with lower costs of end-of-life care and, as such, the likelihood that a more costly neoplasm death is negatively correlated with age, appears logical.

In the organ failure representation of the trajectory to death, in contrast to the expectation that might be assumed from Lunney et al.'s [2003] research, patients experienced a series of increasingly longer admissions evenly distributed at approximately 4-5 month intervals. As death approached, slightly more frequent and longer admissions were apparent.

The presentation of neoplasm related deaths showed, again in contrast to Lunney et al.'s [2003] morbidity description, that decedents experienced more and increasingly frequent admissions as they approached death.

For patients suffering neurodegenerative conditions, the pattern of utilisation was one of far less frequent admissions but longer lengths of stay. It is also noteworthy that it is more likely that those with neurodegenerative conditions died outside of a hospital, as the median discharge date for these decedents' finale admission was some days before death.

Frailty related deaths were characterised, unsurprisingly, by relatively extended periods of stay in hospital. This possibly reflects the extreme age and frailty of these patients in that once admitted to hospital they were likely to be very complex patients and so experienced longer lengths of stay. There is also a low probability that these patients would die in hospital.

In order to examine resource utilisation within cause of death cohorts, Lorenz curves and Gini coefficients were undertaken to describe the utilisation of occupied bed days to determine the equality/inequality of resource utilisation for the different causes of death (Figures 7.2a-e). For the purposes of this Chapter, the distribution of resources relative to the cause of death needed to

be analysed. Figures 7.2a-e show that in all cases resources were consumed disproportionately to the numbers of patients. The most equally distributed resources were for people dying with neoplasms (Gini coefficient of 0.52) and the most unevenly distributed resource utilisation was for people dying of frailty with a Gini coefficient of 0.8. In the case of people dying with frailty, 10% of the patients consumed approximately 65% of all resources used this cohort of people dying with frailty. While this contrasts sharply with people dying of neoplasms, it is still the case that 10% of people dying with neoplasms consumed approximately 37% total all neoplasm public hospital bed days used by neoplasm related deaths.

The study presented in this Chapter has confirmed international and Australian research that indicated public hospital costs reduce as a function of decedents' age. It was found that end-of-life hospital costs are increasing at a rate faster than health inflation in NSW, Qld and WA although not in SA. Cause of death has a significant influence on public hospital utilisation in the end-of-life period with neoplasm related death being the highest cost in the final year of life (\$26,303 last year of life), organ failure second highest (\$18,151 last year of life) and frailty, sudden death and neurodegenerative deaths costing \$10,763, \$14,462 and \$15,504, respectively. Age of death had not changed significantly between 2005 and 2010. However, it was found that organ failure was correlated with age.

It was also found that the costs of public hospital services were unevenly distributed between decedents, even within similar causes of death. This Chapter also described patterns of utilisation that indicated that the morbidity typology provided by Lunney et al. is not reflected in Australian hospital admission patterns.

In the next Chapter, the extent to which public hospital utilisation in Australia is consistent or varies across states is examined. As each state largely functions independently of the others, in some respects each state is a different system. Therefore the study presented next examined similarities and variations among the four states in order to ascertain whether the costs of end-of-life public hospital care are uniform across different Australian jurisdictions.

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CHAPTER 8 JURISDICTIONAL COMPARISONS OF END-OF LIFE PUBLIC HOSPITAL UTILISATION

Introduction

In Australia, the public hospital system is administered at the jurisdictional level by the each respective state government. Each state and territory's health system is discrete in respect to public hospital services (see Appendix A). In reference to the primary question of this research, inter-state comparisons serve to determine whether the cost of hospital care at the end-of-life differs across these discrete systems. In Chapter 7, it was identified that public hospital costs of end-of-life care are increasing faster than health inflation. As this research is concerned with the cost of end-of-life care, consideration of variations in costs by state is also important.

Method

Using the database created for this research, the raw admission rate of each of the four states for the two patient cohorts (decedents in 2005, and decedents in 2010) were examined. Admissions were then adjusted to account for their complexity and subsequently compared across jurisdictions. Finally, after adjusting for health inflation and using the AIHW published national benchmark on cost determinations, the cost consumption rates by states, for the two decedent cohorts, were calculated.

As noted previously, the 'benchmark weighted activity' approach to estimating costs could result in skewed findings as not all admissions in the last year of life might be related to all designated diagnostic related admissions in the cost weight matrix. For example, a myocardial infarct in the last three months of life might be more complex (and therefore more costly) than a myocardial infarct experienced by a patient 20 years preceding their death. To establish the accuracy of the costing methodology the following steps were taken. The average number of occupied bed days experienced by decedents during their last year of life was divided by the estimated bed day cost (using the method outlined below). This provided an estimated cost per occupied bed day.

As indicated in Chapter 7 (see Table 7.2), the average cost per bed day for different conditions varied (range \$967 to \$1,262 per day). For example, the estimate of the cost of an occupied bed day for patients who died as a result of neoplasms varied by approximately 30% among states.

This variation was within reasonable tolerance of the actual occupied bed day costs of a tertiary hospital. Organ failure occupied bed daily rates were reasonably consistent for NSW, WA and SA (range \$700 to \$846 per day). Queensland, however, was substantially more expensive (\$1,243 per day).

The standard cost of an occupied bed day is derived by dividing the AIHW benchmark price for 2009/10, i.e., \$4,500 (see Table 3.4) by the national average length of stay in acute public hospitals in Australia (i.e. 3.4 days) (Australian Institute of Health, 2011) to establish the average occupied bed day cost in 2010. This is equal to approximately \$1,323. Since the occupied bed day cost appears lower than the national standard occupied bed day, it can reasonably be assumed that pre-decedent patients stay in hospital longer than the average patient. This assertion arises as a result of the total casemix cost divided by more occupied days derives a lower occupied bed day rate.

The cost per occupied bed day for neurodegenerative conditions varied substantially (\$1003.98 per day to \$293.24 per day). However, as neurodegenerative conditions were relatively infrequent among the decedent cohort, this should not substantially affect the inter-jurisdictional comparisons.

The cost of the last year of life by cause of death by state was extracted for each state and the case mix weighted price estimate methodology applied.

For the purposes of comparing states, it was relevant to consider variations in the cause of death, noting that cause of death is related to different cost factors (as discussed in Chapter 7).

Furthermore, the age at which people die, cause of death and any changes in the age of death over time are relevant to understanding the cost of end-of-life care as there are potential, but as yet unexamined, relationships between these variables. Therefore, the cause of death and the age at which decedents died were extracted for three states (Qld data was not suitable for inclusion in this analysis). Changes in age of death over the two cohorts (2005 and 2010 decedents) were also examined.

The relative distribution of resource consumption for each state was also analysed. This was undertaken using Lorenz curves and associated Gini coefficients. Lorenz curves are used for statistically determining the equality of within group distributions as opposed to between groups. As noted in Chapter 7, if 10% of patients' use 10% of resources, and 20% of patients use 20% of resources and 50% of patients 50% of resources and so on, then there is an even distribution of resources which results in a straight line and a Gini coefficient of 0.0. Alternatively, if 40% of patients use 5% of resources, 30% of patients use a total of 25% of resources, and the final 30% of patients consume the remaining 70% of resources then a plot of resource consumption would be curvilinear. The further the curve moves from the straight line (the blue shaded area in Lorenz curve graphs as seen in Figures 8.1a-d), the greater the coefficient change toward a maximum Gini coefficient of 1. Gini coefficient calculations were conducted (for estimated costs and occupied bed days) and results presented in Tables 8.8a and 8.8b for the various causes of death for each jurisdiction.

Results

Mean age of death by jurisdictions for all causes of death is displayed in Table 8.1. As can be seen, there was little variation in all cause age of death by jurisdiction.

Table 8.1 Mean age at death, all causes 2010*

	NSW	\mathbf{Qld}^*	WA	SA
Mean age at death	76.4	74.7	74.6	77.3

*Queensland data were averaged across 2008, 2009 and 2010.

Outliers were excluded for patients whose number of admissions in the year prior to death was greater than 2.5 SD above the mean (i.e. 12, see Table 8.2). On average, decedents experienced 2.5 separations in the year preceding their death.

Table 8.2 Mean, variance, SD and 2.5 SD for admissions for all decedents in their last year of life

	Raw Separations
Mean	2.5
Variance	11.37
Standard Deviation	3.37
2.5 standard deviations from mean	12

The relationship between the year of death (2005 or 2010) and the raw separation rate for each death for each of the four states was analysed using Spearman's correlation. The admission rate for each state did not vary significantly by jurisdiction. Although some relationships were statistically significant (see Table 8.3) this did not indicate a correlation f any consequence

(RHO range 0.014 to 0.09). A significant difference in the mean admission rates for each year by state was identified in a subsequent Welch test (see Table 8.3a).

	Spearman's Correlation Coefficient (Rho)	P-Value
Death Year and Total Raw Separations	0.070	< 0.0001
Death Year and Raw Separations WA	0.014	0.003251
Death Year and Raw Separations NSW	0.090	< 0.0001
Death Year and Raw Separations QLD	-0.010	0.0369
Death Year and Raw Separations SA	-0.059	< 0.0001

Table 8.3 Correlation coefficients of raw admission rate by state by year 2005 and 2010

 Table 8.3a Welch test raw separations by state by year (2005 and 2010)

F	390.2
num df	3.0
denom df	65,315
p-value	< 0.0001

Further analysis was undertaken using weighted separations rather than raw admission rates. Weighted separations have the effect of controlling for the complexity of each admission. No meaningful relationships were found between the year and the weighted separations, indicating that there does not appear to be any significant increase over time in the volume or complexity of separations for people in their last year of life (see Table 8.4 and 8.4a).

Table 8.4 Correlation coefficients for weighted separations by state by year 2005 and 2010

States	Spearman's Correlation Coefficient (Rho)	P-Value
All States	0.028	< 0.0001
WA	0.037	< 0.0001
NSW	0.065	< 0.0001
QLD	-0.009	0.07476
SA	-0.056	< 0.0001

Table 8.4a Welch Test Weighted separations by state by year 2005 and 2010

F	509.4
num df	3
denom df	53,441
p-value	<2.2e-16

In terms of variation between jurisdictions, published benchmark prices were applied to weighted separations and then adjusted for the published health inflation adjusters for the two periods (2005 and 2010). No clear correlation between public hospital costs in the last year of life and any of the four study states were identified (see Table 8.5).

Table 8.5 Correlation coefficients of cost of end-of-life public hospital care by stat	te by
Death Year 2005 and 2010 (2010 dollars)	

	Spearman's Correlation Coefficient (Rho)	P-Value
Death Year and Inflation Adjusted Cost	0.057	<2e-16
Death Year and Inflation Adjusted Cost WA	0.058	<2e-16
Death Year and Inflation Adjusted Cost NSW	0.097	<2e-16
Death Year and Inflation Adjusted Cost QLD	0.017	0.0007142
Death Year and Inflation Adjusted Cost SA	-0.024	0.000751

The high degree of consistency among mean ages of death by cause of death for decedents who died in 2005 and 2010 is evidence of a high level of consistency among jurisdictions (see Table 8.1). The exception was Western Australia, where an unexpectedly high age of death (81 years, 6 months) for neurodegenerative conditions in 2005 and a comparatively young age of death for organ failure decedents in 2010 was identified (see Table 8.6). These variations in the patterns across the three states warrant further investigation.

State	Year	Neoplasm	Neurodegenerativ	Organ failure	Sudden
NSW	2005	72.1	77.34	79.3	54.77
NSW	2010	72.94	75.54	80.42	60.98
WA	2005	71.38	81.59	79.93	50.56
WA	2010	72.3	73.78	76.01	53.83
SA	2005	72.24	72.46	79.93	59.04
SA	2010	72.98	75.45	80.78	62.15

 Table 8.6 Mean age of death by state, year and cause of death

To determine if statistical differences in the number of death and separation rates varied by particular cause of death further analyses were undertaken. For example, were increasing costs in the last year of life for particular causes of death affected by the overall utilisation patterns? A weak correlation for neoplasm related deaths for inflation adjusted costs between 2005 and 2010 (RHO 0.22, p=<0.0001) was found (see Table 8.7a and 8.7b).

Table 8.7a Cause of death by year of death (2005 and 2010) by cost of public hospital carein last year of life

	Spearman's Correlation Coefficient (Rho)	P-Value
Neurodegenerative and Inflation Adjusted Cost	-0.03	< 0.0001
Neoplasm and Inflation Adjusted Cost	0.22	< 0.0001
Organ Failure and Inflation Adjusted Cost	-0.10	< 0.0001
Sudden Death and Inflation Adjusted Cost	-0.04	< 0.0001
Frailty and Inflation Adjusted Cost	-0.05	< 0.0001

Table 8.7b Cause of death by cost in last year of life by year of death (2005 and 2010)

F	519.6
num df	3
denom df	53,402
p-value	<2e-16

Calculations were undertaken to determine the Lorenz curves and Gini coefficients by jurisdiction and cause of death for both adjusted cost and occupied bed days (see Tables 8.8a and 8.8b and Figures 8.1a-d). Gini coefficients of equally distributed resources are close to 0. Gini coefficients that are greater the 5 indicate disproportionate use of resources by groups within a cohort (a group of decedents in a particular state who died from a particular cause). A high degree of unequal resource consumption was found indicating that a small proportion of decedents are consuming a large percentage of resources (both occupied bed days and cost).

 Table 8.8a Gini coefficients of health inflation adjusted cost of last year of life by state by

 cause of death

	WA	NSW	QLD	SA	Total
Neoplasm	0.57	0.46	0.52	0.50	0.49
Neurodegenerative	0.73	0.58	0.53	0.63	0.63
Organ Failure	0.65	0.59	0.61	0.63	0.61
Sudden Death	0.72	0.67	0.72	0.66	0.69
Frailty	0.72	0.68	0.70	0.58	0.69
Total	0.63	0.56	0.59	0.61	

Table 8.8b Gini coefficients occupied bed days in last year of life by state and by cause of death

Gini coefficients based on - Occupied Bed Days	WA	NSW	QLD	SA	Total
Neoplasm	0.60	0.50	0.54	0.51	0.52
Neurodegenerative	0.81	0.67	0.68	0.62	0.71
Organ Failure	0.71	0.65	0.67	0.69	0.67
Sudden Death	0.78	0.75	0.76	0.74	0.76
Frailty	0.80	0.80	0.80	0.67	0.80
Total	0.68	0.61	0.64	0.66	

The Lorenz curves (see Figure 8.1a-d) show the distribution of occupied bed days for the four states. The findings indicate that 40 percent of decedents in each state use less than 5 percent of the total occupied bed days while 10 percent of the group use between 30 and 40 percent of total bed days. While these results indicate unequal resource consumption, for the purposes of the comparison of states, the mal-distribution of resources was similar for all states analysed. WA, however, was marginally more mal-distributed than other states.



Figure 8.1a Resource distribution in WA for all causes 2005 and 2010



Figure 8.1c Resource distribution in Qld for all causes 2005 and 2010



Figure 8.1b Resource distribution in NSW for all causes 2005 and 2010



Figure 8.1d Resource distribution in SA for all causes 2005 and 2010

Discussion

The study presented in this Chapter examined variations in public hospital costs associated with end-of-life care in public hospitals across four states NSW, Qld, WA and SA. Little, if any, variation was found between states for any of the factors considered; e.g., raw admission rate, weighted admissions and health inflation adjusted costs for 2005 and 2010 decedents in the year prior to their death. A high level of consistency was found in terms of end-of-life public hospital costs among these states.

From the findings of this study, it can be generally assumed that the states examined are similar in terms of patterns of public hospital utilisation in the last year of life. Given the consistency of the findings identified here and reported for the related studies presented in earlier Chapters it would not be unreasonable to assume that this pattern of public hospital utilisation in the 12 months prior to death may also apply to other states in Australia. Further research could be undertaken to analyse the variation in costs associated with neoplasms in the last years of life to better understand why public hospital costs have increased between 2005 and 2010.

Western Australia had a more un-even use of public hospital care between the highest and lowest users of hospital care (Gini coefficient 0.63) than other states. Western Australia also showed a highly skewed consumption by a small number of patients. It may be that the longstanding community palliative care services that exist in Western Australia may account for these findings. However, further research would be needed to establish a causal relationship.

It is also noteworthy that for NSW, Qld and WA, the Gini coefficients for frailty were highly skewed (Gini score 0.8). South Australia however, had a lower Gini coefficient of 0.67 indicating a less extreme skew but one that still represented a very unequal consumption of resources (10% of SA patients consume approximately 50% of all resources used by people dying of frailty).

Conclusions

This Chapter set out to examine variations between jurisdictions in the public hospital costs associated with end-of-life care. The findings indicate that variations in raw admissions rate, weighted admissions and adjusted cost of end-of-life care across jurisdictions, are not supported by the available data. It is therefore concluded that across the nation, in spite of localised clinical and economic, historical and social nuances, the national level of public hospital utilisation by people in their end-of-life period seems to be broadly similar. However, some differences are apparent: the distribution of care resources across patients, or the skewing of resource consumption between decedents is variable with WA being the most un-equally distributed. This does provide opportunity for system improvement and closer scrutiny to establish potential casual and contributing factors is required.

In spite of quite different jurisdictional environments (see Appendix A), the four states examined appear to experience similar rates of public hospital use in the last year of life. The available data did not provide sufficient indications about possible causal and contributory factors to be able to determine any underlying reasons for the lack of variation among states. The lack of significant jurisdictional variation also eliminated the opportunity to replicate practice from a higher performing outlier jurisdiction to a lower performing one.

Chapters 4 to 8 have interrogated the database created for this program or research to examine the utilisation of public hospital resources associated with end-of-life care. Specifically, the percentage of total state government hospital expenditure dedicated to end-of-life and the degree to which end-of-life hospital costs influence the projected cost of an ageing society. Variations in the public hospital cost of end-of-life over time were also examined followed by an analysis of the relationships of age at time of death, age with cost of death and age by cause of death. The pattern of hospital utilisation within groups of decedents was examined as was the pattern of admissions leading to death. In this Chapter, variations in public hospital utilisation between states was analysed as was the distribution of resource use by decedents within those states.

The next Chapter will summarise the findings from the overall program of research. This will be followed by the final Chapter that will discuss issues and implications arising from this research thus far, highlight its strengths and weaknesses, and indicate potential areas of

potential policy and practice application of the findings as well as flag areas for future related research.

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CHAPTER 9 SUMMARY OF FINDINGS

This program of research examined the cost of public hospital end-of-life care in Australia. This is an issue of topical concern and growing interest to funders, policy makers, aged care providers and clinicians. Various perspectives have been taken on this issue. In the present body of work, the specific issue of the impost on the public hospital system of care in the last 12 months and last five years of life was examined. This examination provided a unique insight into the proportion of public hospital care that is devoted to end-of-life patients, the nature of the admissions and patterns of presentations by age and diagnostic conditions. In addition, interstate comparisons, across four different states were also undertaken.

To carry out this research, a retrospective cohort study was undertaken using a purpose built linked database. The database identified all decedents for 2005 and 2010 for New South Wales, Queensland, Western Australia and South Australia. Because Western Australia's public hospital databases and data linkage capacity was more advanced than the other states, all WA decedents for 1995 and 2000 were also able to be identified. For all decedents in these respective years, public hospital admissions for the five years preceding their death were linked to the decedents' death records. Using AIHW published diagnostic related group weightings and costing benchmarks, analyses were undertaken for length of stay, complexity of admissions and cost of admissions to contribute to the examination of public hospital costs of end-of-life care. The database provided details of over 192,000 decedents and linked over 1 million inpatient public hospital records. The following series of research questions were examined.

What proportion of total hospital cost does end-of-life care comprise?

In order to examine public hospital costs associated with end-of-life care, the program of research first set out to understand what proportion of public hospital expenditure involved end-of-life care. To do so, total hospital annual expenditure for the four states in question were examined. Each state's public hospital expenditure for the financial years preceding and following the sentinel years 2010 and 2005 were averaged to provide a total public hospital expenditure figure that corresponded with the sentinel calendar years of 2005 and 2010. Next, as the database provides an average cost of public hospital care per decedent for the

12 months prior to death and the five years prior to death, the number of decedents in each state was multiplied by their average pubic hospital cost to determine the total costs associated with the last year of life and the last five years of life respectively for all decedents. The resultant figure was then used to calculate the percentage that end-of-life care comprised of the overall state public hospital expenditure in each respective state.

Results indicated that the public hospital costs associated with end-of-life care ranged from 15.2 to 20 percent in the five years prior to death. These percentage estimates of the public hospital costs incurred by pre-decedents are slightly lower than the levels identified in the international literature [26, 29, 69]. This research found that end-of-life costs, relating to public hospital use the last year of life for decedents in 2010, comprised approximately 10 percent of the total public hospital expenditure ranging from 11.5 percent in New South Wales and 8.2 percent in Western Australia.

When compared over time (i.e. 2005 versus 2010), end-of-life care costs were found to have increased at a rate higher than health inflation. That is, public hospital costs of the 2010 predecedents were generally higher than the costs, after adjusting for health inflation, for the 2005 pre-decedents where the percentage of public hospital expenditure ranged from 9.3 percent in Queensland and South Australia to 6.6 percent of public hospital expenditure Western Australia.

Expenditure for the five years preceding death ranged from 20 percent (New South Wales) to 15.2 percent of total hospital expenditure (South Australia) in 2010 and compared to the five years preceding the 2005 decedents which ranged from 16.2 percent (South Australia) to 12.9 percent (Western Australia).

It was identified that costs for end-of-life care in public hospitals in every state examined, except South Australia, were increasing at a rate faster than health inflation.

What proportion of total hospital cost related to ageing is attributable to end-of-life care?

While this program of research set out to analyse public hospital costs associated with end-oflife care, it was also important to consider the cost of end-of-life care for specific age groups. In doing so, it was also possible to compare the costs of cohorts of patients of similar age who were not in their end-of-life phase with the costs incurred by the cohorts of predecedents. The database developed for this study provided the hitherto not possible opportunity to examine this question.

Data was sourced from the Western Australia data linkage unit (WADLU) for public hospital costs in 2010 for decedents aged 55-64, 65-74, 75-84 and 85+ years at their time of death. Australian Bureau of Statistic (ABS) data was sourced to provide the total population for corresponding age groups in Western Australia for 2010. The number of, and costs associated with, each age cohort in their end-of-life phase were then calculated. These costs and numbers of the decedents were able to be extracted from the ABS population numbers and the WADLU cost of healthcare expenditure to determine the public hospital costs associated with the corresponding age groups who were **not** in their last five years of life, that is, were non pre-decedents.

This was then compared with the non-differentiated age cohort average cost of ageing which does not account for the differentiation between those in the population who were predecedents and who were not pre-decedents.

- For the 55-64 year old age group, the cross-sectional cost of ageing for each citizen was \$2,562 per annum whereas the non-pre-decedent cost of ageing was \$3,253 per citizen per annum (12 percent discount to the cross-sectional age).
- For the 65-74 year old age group, the non-differentiated age cohort average cost of ageing was \$3,751 per citizen per annum compared to a non-pre-decedent cost of ageing of \$3,019 per citizen per annum (19.5 percent discount to the non-differentiated age cohort average).
- For the 75-84 year old age group, the non-differentiated age cohort average cost of ageing was \$2,754 per citizen per annum compared to a non-pre-decedent cost of ageing of \$1,846 per citizen per annum (33 percent discount to the non-differentiated age cohort average).
- For citizens older than 85 years, the non-differentiated age cohort average cost of ageing was \$7, 330 per citizen per annum compared to a non-pre-decedent cost of

ageing of \$2,117 per citizen per annum (71 percent discount to the non-differentiated age cohort average).

The reduction in the non-pre-decedent cost of ageing for citizens aged 75-84 years and its substantial discount to the non-differentiated age cohort average cost of ageing for cohorts over the age of 75 is particularly noteworthy.

Have end-of-life care hospital costs changed over time?

An important dimension to this research program was the question of whether public hospital costs were constant over time. To examine this question, public hospital admission rates, admission rates adjusted for complexity and public hospital costs were examined for 2005 and 2010 for each of the four study states. It was found that the length of stay per admission in hospital had reduced in all four states between 2005 and 2010. The average length of stay in 2005 was 9.1 days compared to 8 days in 2010.

In contrast, the admission rate per decedent had increased between 2005 and 2010. The average decedent in 2005 experienced 2.4 admissions in the 12 months prior to death whereas in 2010, 2.6 admissions were experienced. Three states (New South Wales, Queensland and Western Australia) experienced increases between 2005 and 2010 in their raw admission rates, however South Australia experienced a reduction from 2.2 admissions per decedent to 2 admissions. After adjusting for complexity of hospital admissions, by multiplying the raw admission rate by the AIHW published weights per identified diagnostic related group for all admissions, a similar pattern was apparent. Overall, an increase from 4.6 weighted admissions per decedent in 2005 to 5 admissions per decedent in 2010 was found. However, South Australia experienced a reduction in complexity related admissions from 4.4 weighted separations per decedent in 2005 to 4 admissions in 2010. By multiplying the weighted activity rates by the AIHW published benchmark price, after adjusting for health inflation, the four states were found to have an increase in public hospital costs for end-of-life care between 2005 and 2010. The overall cost of public hospital care 12 months prior to death was \$19,046 in 2005 compared to \$21,919 in 2010. While overall all states experienced an increase in end-of-life public hospital costs of approximately 15.1 percent, South Australia's increase was the lowest at a 0.4 percent increase.

These results show that the cost of end-of-life care for older Australians is increasing faster than health inflation.

What factors impact on hospital costs of end-of-life care?

Having established that the costs of end-of-life care represent approximately 10 percent of total public hospital expenditure in the last year of life, and approximately 18 percent of healthcare expenditure for the last five years of life, and that the cost of end-of-life care for older people constitutes a significantly higher cost than the cost incurred by matched age cohorts, and that these costs are rising over time faster than health inflation, further analysis was undertaken to examine what factors may impact public hospital costs associated with dying. Factors examined were age of death and cause of death. In addition, whether these factors were changing over time was also examined.

Cause of death was examined in terms of the following categories: neoplasm, organ failure, neurodegenerative conditions, frailty and sudden death. Results indicated that neoplasm and age were negatively correlated (Rho=-0.237, P<0.001), whereas organ failure had a positive relationship with ageing (Rho=0.231, P<0.001) indicating that neoplasm as a cause of death was more likely to occur among younger people and organ failure as a cause of death was more likely to be associated with older decedents. Other causes of death showed no significant correlation.

Spearman correlations were undertaken for the weighted separations by age. Results indicated that decedents who experienced a sudden death (Rho=0.36, P<0.001) had a higher number of weighted separations the older they were at the time of death. No other correlations indicated a strong relationship. Results also showed that public hospital costs increased as decedents who died a sudden death aged, however no other significant correlations were evident for other categories of death. There was not a strong relationship between the year of death (2005, 2010) and age of death. Nor was there a strong relationship between cause of death and age of death between the year of death (2005, 2010). However, in conducting a correlation of public hospital costs in the last year of life and the cause of death, a relationship was found between neoplasm related deaths (Rho=0.22, P<0.001) indicating that neoplasm related deaths are a higher public hospital cost than other causes of death.

The mean cost of public hospital utilisation in the 12 months prior to death for all decedents in 2010 was calculated. The results indicated that neoplasm related deaths were found to cost \$26,303 per decedent in their final year of life. Organ failure related deaths cost, on average, \$18,151, neurodegenerative deaths \$15,504, sudden death \$14,462 and frailty related deaths \$10,763.

Neoplasm related deaths showed a relatively frequent but short pattern of utilisation, becoming increasingly frequent and longer as death approached. Neurodegenerative conditions showed fewer admissions although of longer duration. Organ failure related deaths showed a pattern of utilisation of regular hospital admissions for a relatively long period of time evenly distributed relatively close to the day of death. Frailty admissions show relatively few but longer length of stay admissions.

Lorenz curves were calculated to examine the distribution of resources within each of the cause of death cohorts for 2005 and 2010. In all cases, an uneven level of resource consumption was experienced across the cohorts. Frailty related deaths (Gini co-efficient 0.8) were the most disproportionate consumers of public hospital resources, with approximately 50 percent of decedents using less than 5 percent of the total resources consumed by this group. Conversely, 10 percent of frailty decedents consumed approximately 60 percent of all resources. The most evenly distributed cause of death was neoplasm with a Gini co-efficient of 0.52.

Relationships between causes of death and age were found that indicated that neoplasm related deaths cost significantly more than other causes of death and that organ failure deaths were positively correlated with age, whereas neoplasm related deaths were negatively correlated with age.

Interjurisdictional comparisons of end-of-life care utilisation

To further examine the costs of public hospital resources at end-of-life, analyses were undertaken to examine variations between the respective state jurisdictions. First, the age of death by cause of death by state (i.e., for New South Wales, Western Australia and South Australia) was examined for 2005 and 2010. Results showed that age of death generally appeared to remain stable, however, some significant variations occurred for particular causes of death by state. For example, the age of death for neurodegenerative conditions in Western Australia reduced in 2005 from 81.59 years of age to 73.78 years of age in 2010. A reduction from 79.3 years of age for organ failure related deaths in Western Australia in 2005 to 76 years of age in 2010 was also found. These unexpected findings are worthy of further examination.

Correlations of raw admission rate and weighted separations were examined for the years 2005 and 2010 and comparisons made between states. Results indicated no strong relationships.

These findings indicate that there were no significant differences between the states in terms of utilisation patterns for the cause of death cohorts. Further analysis was undertaken to examine the distribution of resources within cause of death cohorts for each of the four states (New South Wales, Queensland, Western Australia and South Australia). All states showed a significantly uneven distribution of resources with Gini coefficients ranging from 0.56 (New South Wales) to 0.63 (Western Australia) for costs of end-of-life care by state and 0.61 (New South Wales) and 0.68 (Western Australia) for occupied bed days. In all cases, Western Australia showed a more unevenly distributed consumption of resources by decedents within each of the cause of death cohorts (neoplasm, neurodegenerative condition, organ failure, sudden death and frailty).

These results generally indicate a high level of consistency between the states in spite of variations in each of the state administered public hospital systems.

The next and final Chapter highlights the key findings, their implications for policy and practice and flags areas for future research.

CHAPTER 10 DISCUSSION

This program of research examined the public hospital costs associated with end-of-life care. Important economic and social questions have arisen in recent times in relation to factors that impact on the allocation of health care resources. One of these sets of questions pivots around the issue of end-of-life care.

As populations are living longer it is important to know what, if any, impact this may have on end-of-life hospital utilisation and whether this is changing in significant ways. To date, it has not been established whether older decedents cost less at the end of their life compared to younger decedents and, if so, whether their reduced end-of-life public hospital costs are offset by the hospital use in their pre-end-of-life additional years.

This program of research examined these, and related questions, for the first time in relation to the Australian public hospital system. The more specific questions about the costs associated with various causes of death, whether these causes changed over time and were consistent between jurisdictions were also addressed.

Australia spends approximately 9% of its Gross Domestic Product on health services, marginally over \$5,000 per person per annum (Commonwealth of Australia, 2015). This is in line with the OECD average and, in many respects, health outcomes are slightly better than OECD averages when measured in terms of infant mortality and life expectancy (Organization for Economic Cooperation Development, 2013). Evidence shows that investment in health services at the macro level is subject to the law of diminishing returns; that is, increasingly less benefit is afforded to the community for additional expenditure (Organization for Economic Cooperation Development, 2013). As noted in Chapter 1, the diminishing returns on investment start to have effect at the level of approximately USD \$2,000 (per person) invested in healthcare services. This notwithstanding, healthcare expenditure in Australia continues to rise faster than CPI and is rapidly outstripping revenue growth to government. The marginal cost utility question over healthcare expenditure is increasingly explored by policy makers at both state and commonwealth levels. Arguably, it is not unreasonable that in a wealthy, developed economy, when people were experiencing their ultimately fatal health conditions that a significant proportion of the communities' resources should be directed towards their care. Emanuel and Emanuel (Emanuel & Emanuel, 1994) highlighted the difficulties associated with prognosticating with respect to end-of-life care, and noted the risk of inappropriately rationing care to people who might otherwise gain from curative treatments. 'Do not resuscitate' orders, for example, are well used in Australia and the use of advanced care directives is increasing rapidly. Most states are actively pursuing increased home based palliative care services though their application to organ failure (a high percentage of deaths) is poorly adopted (with the exception of respiratory disease and renal failure).

In the introduction to this thesis, Fries' Lifetime Healthcare Model was used as a framework to understand individuals' patterns of healthcare consumption over time. Increased healthcare consumption towards the end-of-life appears intuitively to be an area where better resource utilisation and management of healthcare capacity might increase value to the consumer (where value is benefit over cost). To examine these questions, this research involved a retrospective cohort study using a purpose built linked database that identified all decedents in Western Australia for 1995, 2000, 2005 and 2010, and all decedents in New South Wales, South Australia and Queensland in the years 2005 and 2010, and linked their death records to hospital morbidity databases to include each individual for the preceding five years. The resulting database had the capacity to analyse end-of-life care over a significant period of time (two decades) and for four jurisdictions to better understand the opportunities for better resource utilisation and capacity management in the end-of-life phase of care.

By extracting additional Western Australia data from the linkage unit, the it was possible to examine the relationship between the cost of public hospital care for patients who were in their end-of-life phase versus the cost of hospital care for those of similar ages who are not in their last five years of life. The database afforded the opportunity to analyse the end-of-life care hospital utilisation patterns, having regard to numerous variables. For the purposes of this research, **age** of death and the **cause** of death were identified as particularly important determinants of public hospital utilisation. To address the cause of death, a panel of clinicians was assembled to categorise the ICD codes and textual references in death records and hospital codes to classify patients into five categories; neoplasm, neurodegenerative conditions, organ failure, frailty and sudden death. By no means has this research exhausted

the utility of the database that has been created. Many more variables and research questions remained open for analysis. These include, for example, gender, Aboriginality, rural versus remote, socio-economic status and place of death.

From the perspective of understanding the proportion of resources consumed by end-of-life care, this research identified that between 8.5% and 11.2% of the states' total hospital resources were devoted to hospital care in the last 12 months of life. This figure is less than or roughly equal to the percentage of hospital expenditure for end-of-life care in some other countries (Emanuel & Emanuel, 1994; Hoover et al., 2002). This finding raises the question of whether this percentage of public hospital resources is an appropriate amount. From many perspectives it would not be considered excessive. It can be argued that, in a wealthy society, it might reasonably be expected that such a proportion of a state's resources might be spent on people who are in their last year of life.

This research also identified that between 18% and 22.5% of the four state's entire hospital services are consumed by people in the last five years of their life. Furthermore, this percentage is rising significantly faster than health adjusted inflation indicating that for health resource increases (which are rising faster than CPI), the cost of end-of-life care is increasing faster than other parts of the health system. It is also noteworthy that the rate of increase is faster in some states (New South Wales) than in others (for example, South Australia). To some degree this may be explained by overall resource constraints in states such as South Australia and therefore suggests it may be possible to constrain growth through appropriate managerial disciplines.

As these costs are increasing at a rate faster than inflation, together with the projection of greater longevity for the Australian population into the future, it is evident that economic modelling is required to estimate the trajectory of future cost growth. Such modelling is required for both the populations of older people and for end-of-life care. The current program of work provides an important basis upon which future cost estimates and modelling can be further developed.

One of the more critically important outcomes of this research was that the consumption of public hospital resources is heavily skewed within cohort groups. That is, within each state, a small percentage of decedents consumed significantly more resources than other decedents.

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Similarly, within particular cohorts determined by cause of death, again a small number of decedents consumed a significant percentage of resources compared to other decedents. This program of research showed that public hospital resources are unevenly consumed by decedents. This finding was consistent when decedents' patterns and levels of utilisation were examined by state or by cause for death. Results of this research showed that 10 percent of decedents consumed between 30 percent and 40 percent of all resources while 40 percent of decedents used less than 5 percent of public hospital resources. This program of research was unable to not identify clinical or managerial causes for such an uneven utilisation patterns. Indeed, it was not possible to do so with the data available. However, these findings highlight the importance and need for further work to be undertaken that examines more closely and explicitly the issue of the uneven distribution of resources among older people and end-of-life care recipients. This will be a useful subject for further research.

This research brings to light the pattern of end-of-life causality. In Chapter 5, the research highlighted the likelihood of cancer related deaths being negatively correlated with age. Against the background of increasing survival rates for cancer (Australian Institute of Health and Welfare, 2012; Maxwell et al., 2014), it is still likely that the benefits of medical science are not deferring the mortality associated with cancer as quickly as it is deferring the mortality associated with other historic causes of disease (e.g. cardiovascular disease).

A corresponding, positive correlation between death by organ failure and age was found. This may indicate that as individuals avoid the mortality associated with cancer, they are increasingly likely to die of some other cause; this research indicates is likely to be organ failure. It was also highlighted that the public hospital cost of dying from cancer, excluding chemotherapy, is still significantly higher than other causes of death. The research also supported the general international literature that the cost of the last year of life is negatively correlated with age; that is, the older one dies, the less resources are consumed. In this respect it is noted that organ failure is less costly than cancer related deaths. However, it is unknown whether this is because among older age groups cancer is not treated, as it is not seen to be the imminent cause of death. Having established the overall healthcare expenditure for particular age groups, and extracting the number of, and the resources associated with, the last five years of life, this research was able to demonstrate the non-pre-decedent cost of ageing is substantial. That is, the older one dies, the fewer public hospital resources are

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consumed in the last year of life. However, this effect is partially offset by the additional nonpre-decedents' costs of ageing not associated with death.

Drawing together the observations in this research, it is not possible to conclude Fries' assertion that morbidity is compressed toward the end-of-life is supported. However, the data in this research are consistent with such an assertion in that public hospital use, being a proxy for morbidity, is apparent proximal to death but older non-pre-decedents used substantially less hospital care. From an economic policy maker's point of view, this would be the desirable outcome. This thesis has shown that differences in terms of the provision of public hospital end-of-life care between the states are marginal. Notwithstanding the variable histories and context of each state studied, the differences in terms of public hospital resources were marginal. New South Wales and Queensland spent slightly more than South Australia and Western Australia on public hospital end-of-life care. New South Wales in particular seemed to be increasing its cost structure more quickly than other states. Nonetheless, the causes of dying and ages of dying appeared to be reasonably consistent across the states with only small variations noted. The distribution of resources also seemed consistent across the states, with the exception of Western Australia in relation to neurodegenerative conditions. It could be concluded that the variations between states probably do not provide a substantial opportunity to model one state against another in terms of learnings about resource management (with the possible exception of Western Australia's neurodegenerative conditions).

This research produced important findings in respect to variations associated with cause of death. It demonstrated that significant capacity and resource consumption varies with cause of death and that the cause of death itself varied with age. It is apparent that the pattern and relative resource consumption by cause of death are not consistent with what might have expected if Lunney's trajectories to death accurately reflected resource utilisation. Neoplasm related deaths showed a regular pattern of resource utilisation that fell approximately four months apart for the five years preceding death. Organ failure conditions, unexpectedly, did not reflect the morbidity experience posited by Lunney *et al.* (Lunney et al., 2003). One might have expected increasingly frequent acute episodes of care while health status deteriorated; whereas, the data showed that the utilisation pattern as one approaches death is relatively infrequent but slightly longer than average hospital admissions.

It was also found that cause of death greatly affected the different levels of resource consumption between cohorts. For example, neoplasm related deaths, while still significantly skewed (Genie co-efficient of 0.52) reflect a relatively consistent utilisation pattern across the total cohort than did decedents whose death was related to other causes such as frailty, organ failure or neurodegenerative conditions. In the case of frailty, approximately 10% of frailty patients consumed nearly 65% of all resources; however, it is also noted that the criteria for determination the frailty cohort was a referral from nursing homes. These findings may provide a great opportunity to support nursing homes to better manage particular residents in situ rather than be admitted to hospital.

The Australian public hospital system delivers large volumes of high quality healthcare to people who are aged and increasingly larger amounts of care to people who are in their last five years of life and particularly the last year of life. Furthermore, among public hospital decedents a surprisingly smaller number of patients consume a disproportionately large amount of resources.

Limitations

As in all research this program of research contained a range of limitations. These are summarised below. Interpretation of the findings should be considered in this context. This program of research only included data for in-patient stays within public hospitals. As a result, various components of the public and private healthcare system were not included in the calculations of cost. This encompassed patients receiving day stay chemotherapy and dialysis. As the various jurisdictions treated chemotherapy and dialysis treatment differently for recording purposes, and were treated variously as community, outpatients and admitted procedures, the decision was taken to exclude these treatments from the database. As a consequence, an understatement of the costs for organ failure and neoplasm related deaths may exist. Excluded data also involved ED data, which has been recently used in a similar Australian study (Goldsbury et al., 2015). The collection and coding of private hospital data varied significantly between states, particularly in the early phases of the period considered in this research. For this reason, the data included in the analysis in this program of research exclude all private hospital data.

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Methodologically there were also several limitations. The analysis used a database created through probabilistic record linkage. It is feasible that there may have been a small proportion of incorrect or missed linkages. However, the CHeReL estimate that there error rate is approximately 0.4% for false positives and 0.5% for false negative linkages. In addition, there were a small number of hospital records that were found that could not be linked. Overall, however, this would result in a record error rate of <0.1%. In addition, casemix costs were used to establish the cost estimates. Casemix cost allocation is a statistical methodology based on the attribution of a cost rate to a weighted diagnostic related group (DRG). That is, the method used to apply costs in this research was a 'pricing tool' rather than actual costs of care. The method assumes a standard cost for all admissions in a given DRG. However, as the cohort examined in this program of research (pre-decedents) might not be typical of the whole population who comprise a particular DRG, and this might influence the results.

Queensland data for the years 2000 and 2001 were of comparatively poor quality for linking purposes. However, very little hospital utilisation occurred for decedents where it was necessary to link the fourth and fifth year prior to death in other states and in the subsequent 2005/06 period.

This program of research measured the utilisation of public hospital admissions which, in turn, reflected the admission and treatment practices of condition. This program of research provides no insight into variations in this clinical practice or quality of care provided.

Other than age, no other demographic characteristics of decedents, such gender, SES, rural location or place of death were included in the studies; thereby limiting any conclusions that can be drawn about patterns and costs of public hospital utilisation by population sub-groups.

Areas for further research

The database created for this research provides significant opportunity for further analysis for numerous phenomena associated with end-of-life care. The research reported in this thesis highlighted a number of significant unexpected issues which warrant further research. In particular, these concern the unexplained reduction in non-pre-decedent cost of ageing for survivors between the ages of 75-84 years. One might reasonably expect that the non-pre-

decedent cost of ageing would increase with age. For example, is it possible that survivors between the ages of 75-84 years progressively opt out of elective surgery? For each *cause* of death and each *jurisdiction*, the results showed a highly skewed pattern of resource use indicating a relatively small percentage of decedents use a high proportion of public hospital care. Further research might seek to analyse predictors of these "high using" decedents in order to develop more appropriate care programs. These, it might be hypothesised, may lead to better outcomes for the patients and better use of resources.

Conclusion

Results of this retrospective cohort study, which is one of very few to be undertaken nationally or internationally, found that Australian states expend approximately 10 percent of total hospital funding on end-of-life care and, approximately 20 percent on the last five years of life. These expenditures are rising faster than health inflation and might therefore be expected to exert financial stress on state governments. Conversely, as the population ages and tends to do so with relatively little or moderate impost on the public hospital system there is substantial discounting on end-of-life care.

Nonetheless, the findings from this examination of public hospital expenditure on older age groups indicated that change is required in the way that future estimates of public hospital expenditure are calculated. The provision of end-of-life care should be treated independently of hospital costs for the ageing, non-pre-decedent population overall. As every citizen will eventually die, it is possible to anticipate, at a population level, the likely expenditure that will eventually be associated with their death. This should be calculated independently for the cost of ageing of the population and exclusive of the cost of dying. The findings from this program of research also provide opportunity for targeting innovative interventions to address cost containment into the future, particularly for high resource using decedents, as well identifying further research opportunities that can be undertaken to extend the limited but growing knowledge base in this area.

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