

# Issues using linkage of hospital records and death certificate data to determine the size of a potential palliative care population

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## Abstract

**Background:** Studies aiming to identify palliative care populations have used data from death certificates and in some cases hospital records. The size and characteristics of the identified populations can show considerable variation depending on the data sources used. It is important that service planners and researchers are aware of this.

**Aim:** To illustrate the differences in the size and characteristics of a potential palliative care population depending on the differential use of linked hospital records and death certificate data.

**Design:** Retrospective cohort study.

**Setting/participants:** The cohort consisted of 23,852 people aged 20 years and over who died in Western Australia between 1 January 2009 and 31 December 2010 after excluding deaths related to pregnancy or trauma. Within this cohort, the number, proportion and characteristics of people who died from one or more of 10 medical conditions considered amenable to palliative care were identified using linked hospital records and death certificate data.

**Results:** Depending on the information source(s) used, between 43% and 73% of the 23,852 people who died had a condition potentially amenable to palliative care identified. The median age at death and the sex distribution of the decedents by condition also varied with the information source.

**Conclusion:** Health service planners and researchers need to be aware of the limitations when using hospital records and death certificate data to determine a potential palliative care population. The use of Emergency Department and other administrative data sources could further exacerbate this variation.

## Keywords

Palliative care, death certificates, hospital records, medical record linkage

### What is already known about the topic?

- Linked hospital records and death certificate data can be used to estimate the size of a potential palliative care population.

### What this paper adds?

- This study demonstrates how estimates based on data from the death certificate and hospital records can vary depending on the data sources and variables used.

### Implications for practice, theory or policy

- The method of estimating the palliative care population must be carefully considered as it can have a large effect on the size and demographics of the population estimate.

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## Background

The lack of a clear definition for identifying potential palliative care patients has long been a problem in palliative care research and a hindrance in comparing the results of studies.<sup>1–3</sup> Borgsteede et al.<sup>1</sup> noted that differing inclusion criteria can result in very different palliative care patient populations. Van Mechelen et al.<sup>3</sup> undertook a systematic review of palliative care randomised controlled trials (RCTs) with the aim of proposing minimum characteristics to define a palliative care patient and found that even these RCTs did not use clear definitions or descriptions of palliative care patient populations. One method to estimate the size of a population requiring palliative care is to use population-based administrative data to look at the number of deaths in a given year and to assume that people who did not experience a sudden or trauma-related death may have benefited from some form of palliative care. These people can be identified using cause of death data from their death certificate. Some researchers have further refined this method to include only specific underlying causes of death<sup>4</sup> and in some cases the cause of death information has been expanded upon to include diagnostic information for those who were admitted to hospital in their last year of life.<sup>5</sup> A number of studies using these methods are now being published in the literature.<sup>6,7</sup> They rely on linked hospital and death data which, in addition to the United Kingdom and Australia, is also available in other countries, such as Denmark, Finland, Israel, Korea, France, Canada and the United States.<sup>8</sup> We thought it timely and important to compare the differences in the size and characteristics of a potential palliative care population, depending on the specific data sources used. This issue arises as a result of multiple cause of death coding on death certificates<sup>9</sup> together with the coding of multiple diagnoses (principal diagnoses and additional diagnoses) on hospital admission records and multiple hospital admissions during the last year of life.

To understand the origins of multiple causes of death data, we first describe the death certificate. The Medical Certificate of Cause of Death is recommended by the World Health Organization for international use and this is used in Australia.<sup>10</sup> Information about cause of death on the death certificate is divided into parts 1 and 2. The direct cause of death, that is, the disease or complication which led directly to death is listed on part 1, line a of the death certificate. If the direct cause of death listed on line 1a arose as a consequence of another disease or injury, this disease/injury is entered on line 1b. Likewise, if the disease on line 1b arose as a consequence of another disease/injury, this should be listed on line 1c and so on for line 1d. Thus, part 1 of the death certificate contains the sequence of events leading to death and the cause listed as 1a should be of the shortest duration. Part 2 of the death certificate lists conditions that did not directly cause death

but which may have unfavourably influenced the cause of illness, for example, chronic diseases such as diabetes, dementia or chronic obstructive airways disease. Following death registration, the information is sent to the Australian Bureau of Statistics (ABS) who code and validate causes of death. ABS staff assign and code all conditions on the death certificate and also assign an ‘underlying cause of death’ according to the coding rules of the International Classification of Diseases.<sup>10</sup>

Medical records generated as a result of hospital admissions generally have a principal diagnosis and other co-occurring diagnoses. These additional diagnoses are defined as conditions that affect patient management by requiring (1) commencement, alteration or adjustment of therapeutic treatment; (2) diagnostic procedures; or (3) increased clinical care and/or monitoring.<sup>11</sup>

The information most readily available to researchers requiring population-level information on cause of death is the ‘underlying cause of death’ although it should be noted that there remains a number of countries around the world where such vital statistics are not available.<sup>12</sup> In recent years, multiple cause of death data have also become available and are being increasingly reported. Multiple cause of death data are available in Australia from 1997 onwards.<sup>9</sup> The availability of record linkage in many jurisdictions means that hospital morbidity information can be considered along with cause of death information for a defined period prior to death. This adds further dimensions to the methods by which conditions potentially amenable to palliative care can be identified, leading to the need for this comparison of methods.

## Methods

### Study design

The design is a retrospective cohort study using administrative databases. In this study, we compared the number of people identified with at least one of 10 conditions considered amenable to palliative care: cancer, heart failure, renal failure, chronic obstructive pulmonary disease (COPD), Alzheimer’s disease, liver failure, Parkinson’s disease, motor neurone disease, HIV/AIDS and Huntington’s disease<sup>5</sup> from five different information sources: (1) underlying cause of death from the death certificate, (2) any condition on part 1 of the death certificate, (3) any condition on part 1 or part 2 of the death certificate, (4) primary diagnosis for a hospital admission in the last year of life and (5) the diagnosis recorded in any diagnostic field for a hospital admission in the last year of life.

The International Classification of Diseases, 10th Revision, Australian Modification (ICD-10-AM) codes<sup>13</sup> for the conditions studied are given in Table 1. ICD-10-AM is a slightly modified version of ICD-10 to ensure relevance to clinical practice in Australia.

**Table 1.** Palliative care amenable conditions and their ICD-10-AM codes.

Palliative care amenable condition	ICD-10-AM code
Neoplasms	C00.0–D48.9
Heart failure	I50.0, I50.1, I50.9, I11.0, I13.0, I13.2
Renal failure	N18.0, N18.8, N18.9, N19, E10.23, E11.23, E13.23, I12.0, I13.1
Liver failure	K70.4, K71.1, K72.1, K72.9
Chronic obstructive pulmonary disease	J40, J41.0, J41.4, J41.8, J42, J43.0, J43.1, J43.2, J43.8, J43.9, J44.0, J44.1, J44.8, J44.9, J47
Alzheimer's disease	G30.0, G30.1, G30.8, G30.9
Motor neurone disease	G12.2
Parkinson's disease	G20
Huntington's disease	G10
HIV/AIDS	B20, B21, B22, B23, B24

ICD-10-AM: International Classification of Diseases, 10th Revision, Australian Modification.

Mortality data for this cohort were linked to their hospital admission records for the last year of their life. In addition to the total number of people with each condition, we have also compared their median age, age range and the sex distribution.

### Setting/participants

This study used de-identified linked death records and hospital admission data obtained from the Data Linkage Branch at the Western Australian Department of Health. The data were processed to remove duplicate records. Hospital admission records for the same person which overlapped in time were converted to one record. Variables on the death records included age at death, sex, date of death, underlying cause of death and all contributing causes of death listed on the death certificate. Variables on the hospital admission record included age and sex, date of admission and discharge, the principal diagnosis code and up to 20 additional diagnosis codes.

Our study cohort consisted of 24,836 people aged 20 years and over who died in Western Australia between 1 January 2009 and 31 December 2010. After excluding 984 people because of deaths related to pregnancy, childbirth or the puerperium (ICD-10-AM O00-O99); deaths originating during the perinatal period (ICD-10-AM P00-P96); deaths resulting from injury, poisoning and certain other external causes (ICD-10-AM S00-T98); or deaths resulting from external causes of morbidity and mortality (ICD-10-AM V01-Y98), there remained 23,852 people in the cohort.

Data management and statistical analysis was conducted with Stata version 13.1, StataCorp, Texas, USA. Ethics permission was granted by the Department of Health, Western Australia (2012/76) and Curtin University Human Research Ethics Committee (HR53/2012). Percentages in the tables have been formatted to zero decimal places, and as a result, any values of less than 0.5% are shown as 0%.

### Results

A total of 10,445 (44%) people had a condition potentially amenable to palliative care as an underlying cause of death out of the eligible cohort ( $n=23,852$ ). This increased to 15,064 (63%) people when one of these conditions was present anywhere on either parts 1 or 2 of their death certificate (Table 1). When having any one of these conditions listed on a hospital admissions record during the last year of life or anywhere on a death certificate, this increased to 17,384 (73%) people. Overall, this equated to an increase in the potential palliative care population by a factor of 1.7.

These proportions also varied within each disease condition. Of the 10 conditions, neoplasms were the broadest category and the most common condition identified across all information sources, ranging from 32% of underlying causes of death to 41% of all 10 conditions identified using all sources of information (Table 2). Using all information sources, 23% of the cohort died with heart failure, 14% with renal failure and 14% with COPD. When stratified by disease condition, of those who died with heart failure as identified using all information sources, only 8.6% (483/5585) had it recorded as the underlying cause of death whereas 77.5% (4330/5585) were identified using hospital records. The increase in the potential palliative care population of those with heart failure was 11-fold between underlying cause of death alone and all data sources combined. For people who died with renal failure and COPD, 13.6% and 26.2% of people had it recorded as the underlying cause of death, respectively. This is contrast to neoplasms where 79% of people who died had it recorded as the underlying cause of death. In addition, 17% of people who had a condition recorded on their death certificate did not have the condition recorded on a hospital admission record during the last year of life. This ranged from less than 1% of people with motor neurone disease, Huntington's disease and HIV/AIDS to 7% of people with renal failure. In all, 22% of people had a

**Table 2.** Number of people identified with specified conditions and percentage relative to total cohort (n = 23,852).

	Death certificate						Diagnoses on hospital record				All sources combined		Condition on death certificate only		Condition on hospital records only			
	Underlying cause		Part 1		Part 1 or Part 2		Principal		Principal or additional		N	%	N	%	N	%	N	%
	N	%	N	%	N	%	N	%	N	%								
Neoplasms	7671	32	7693	32	8752	37	7361	31	8573	36	9707	41	1134	5	834	4		
Heart failure	483	2	2408	10	3197	13	1771	7	4330	18	5585	23	1255	5	2690	11		
Renal failure	437	2	1341	6	2390	10	69	0	1478	6	3224	14	1746	7	777	3		
COPD	874	4	1220	5	2145	9	1206	5	2505	11	3336	14	832	3	962	4		
Alzheimer's disease	594	2	617	3	1006	4	200	1	906	4	1618	7	712	3	561	2		
Liver failure	62	0	331	1	365	2	166	1	552	2	706	3	155	1	292	1		
Motor neurone disease	126	1	138	1	148	1	89	0	128	1	170	1	42	0	26	0		
Parkinson's disease	180	1	183	1	431	2	82	0	343	1	572	2	230	1	154	1		
Huntington's disease	12	0	13	0	21	0	2	0	12	0	21	0	9	0	2	0		
HIV/AIDS	6	0	4 <sup>a</sup>	0	12	0	1	0	23	0	25	0	2	0	11	0		
Total	10,445	44	12,817	54	15,064	63	10,276	43	14,110	59	17,384	73	3949	17	5231	22		

COPD: chronic obstructive pulmonary disease.

<sup>a</sup>Two of the six HIV/AIDS cases which were identified as the underlying cause of death came from part 2 rather than part 1 of the death certificate.

**Table 3.** Age distribution (median and range in years) by data source and specified condition amenable to palliative care.

	Death certificate						Diagnoses on hospital record				All sources combined	
	Underlying cause		Part I		Part I or Part 2		Principal		Principal or additional			
	Median	Range	Median	Range	Median	Range	Median	Range	Median	Range	Median	Range
Neoplasms	74	20–104	74	20–104	75	20–104	74	20–105	75	20–105	76	20–105
Heart failure	88	38–105	85	20–107	85	20–107	84	31–103	83	24–103	84	20–107
Renal failure	84	35–104	83	22–104	83	22–104	81	38–99	82	21–104	83	21–104
COPD	81	33–105	80	35–105	81	32–105	79	20–101	80	20–101	80	20–105
Alzheimer's disease	86	57–106	86	57–106	87	57–106	84	60–98	85	55–104	86	55–106
Liver failure	61	31–89	65	29–98	65	29–98	59	31–91	65	22–96	66	22–98
Motor neurone disease	71	35–96	71	35–98	72	35–98	70	37–89	72	37–96	73	35–98
Parkinson's disease	81	41–101	81	41–101	82	41–101	81	41–100	82	41–100	82	41–101
Huntington's disease	61	39–74	60	39–75	60	34–81	54	39–68	56	34–75	60	34–81
HIV/AIDS	45	30–67	51	30–67	57	30–67	36	36–36	50	30–72	50	30–72
Total	77	20–106	78	20–107	79	20–107	76	20–109	78	20–105	80	20–107

COPD: chronic obstructive pulmonary disease.

**Table 4.** The proportion and relative percentage difference of people with specified conditions who were male by the data source and relative to all sources combined.

	Death certificate						Diagnoses on hospital record				All sources combined
	Underlying cause		Part I		Part I or Part 2		Principal		Principal or additional		
	% male	% Δ of all	% male	% Δ of all	% male	% Δ of all	% male	% Δ of all	% male	% Δ of all	% male
Neoplasms	57	–1	57	–1	58	0	59	1	59	1	58
Heart failure	41	–9	47	–3	47	–3	53	3	52	2	50
Renal failure	48	–8	54	–2	55	–1	61	5	61	5	56
COPD	57	–3	59	–1	60	0	58	–2	60	0	60
Alzheimer's disease	33	–7	33	–7	35	–5	63	23	49	9	40
Liver failure	68	5	63	0	63	0	68	5	65	2	63
Motor neurone disease	64	–2	65	–1	65	–1	66	0	67	1	66
Parkinson's disease	64	2	64	2	62	0	83	21	70	8	62
Huntington's disease	75	4	69	–2	71	0	0	–	75	4	71
HIV/AIDS	67	–17	75	–9	83	–1	100	16	83	–1	84
Total	55	1	54	0	54	0	58	4	56	2	54

COPD: chronic obstructive pulmonary disease.

condition on their hospital record only, again less than 1% of people with motor neurone disease, Huntington's disease and HIV/AIDS, but 11% of those with heart failure.

The median age at death varied between information sources (Table 3), but there was no clear pattern. The difference in the median age between information sources was 3 years or less for neoplasms, COPD, renal failure, Alzheimer's disease, motor neurone disease and Parkinson's disease, but was 5 years for heart failure, 6 years for liver failure and 7 years for Huntington's disease. The median age at death for people who died with HIV/AIDS varied from 36 to 57 years between information sources; however, these results are skewed due to only one person being in the category 'principal diagnosis on

hospital admission'; otherwise, the range in median age at death would be from 45 to 57 years, spanning 12 years.

There were 271 hospital records with liver failure as the principal diagnosis and a median age at death of 59 years. When additional diagnoses were included, a further 604 (69%) records with liver failure were identified and the median age increased to 65 years. The principal diagnoses for these additional admissions included 129 digestive disorders (21%), 115 cancers (19%) and 76 circulatory diseases (13%). The median age at death for these additional records was only 66 years.

Within each of the 10 conditions considered amenable to palliative care, the distribution of sexes varied dependent on the data source, with some conditions showing more



variation than others (Table 4). Of all people who died with any record of cancer on death or hospital records in the last year of life, 58% were male. This percentage only showed a 1% variation (57%) when restricted to people with neoplasm recorded as the underlying cause of death. In contrast, the variation in the proportion of males with heart failure, renal failure and Alzheimer's disease was decreased by 9%, 8% and 7%, respectively, when analysed only by underlying cause of death compared to all data sources. When the principal diagnosis of hospital records in the last year of life was used to identify a palliative care population, it was observed that the relative proportion of males increased by 23% for Alzheimer's disease and 21% for Parkinson's disease when compared to the use of all data sources.

The 123 men who had a primary diagnosis of Alzheimer's disease on hospital admission had a number of different underlying causes of death including vascular or unspecified dementia ( $n=24$ , 20%), circulatory disease ( $n=32$ , 26%) and cancers ( $n=11$ , 9%). Only 26 (21%) had an underlying cause of death of Alzheimer's disease. A similar picture was seen with Parkinson's disease. In this case, there were 67 men with a primary diagnosis of Parkinson's disease, 22 (33%) of whom had an underlying cause of death of Parkinson's disease, 17 (25%) had an underlying cause of death of circulatory disease and 9 (13%) had an underlying cause of death of neoplasm.

## Discussion

The combined use of linked hospital and death data or death certificate data alone to estimate the prevalence of conditions potentially amenable to palliative care had a considerable effect on the size of the population identified. It is important that this is taken into account when planning health services.

Studies from England, Ireland and Australia have relied on the death certificate's underlying cause and contributory cause of death when estimating a palliative care population.<sup>4,6,7</sup> However, this could significantly underestimate the number of people dying with conditions that may benefit from palliative care, particularly the non-cancer conditions. The addition of hospital admissions data to death certificate data identified a further 10% of deaths as compared to death certificate data alone, increasing the estimate from 63% of eligible cases to 73%. When looking at individual conditions, the increase was in the order of 10%–110% and was most noticeable for heart failure, COPD, liver failure and HIV/AIDS. These are conditions identified as being underreported as the underlying cause of death.<sup>9</sup>

The age and sex distribution also varied by the data sources used with the variation more marked in some conditions compared to others. This may reflect differing comorbidity patterns that have different age and sex profiles as was described for liver failure and Alzheimer's disease. In the case of neurodegenerative disorders, specifically Alzheimer's disease and Parkinson's disease,

the proportion of men being hospitalised was considerably higher than the proportion dying from the condition and higher than expected based on hospitalisation rates for the population with the same condition regardless of whether they were in their last year of life. There is evidence that men with these conditions suffer a greater burden of disability than women.<sup>14,15</sup> It is also likely that these men are more likely to be admitted to hospital than women as a result of their living circumstances. It has been reported that a higher proportion of men with both dementia and Parkinson's disease live in a private dwelling compared to women who are more likely to live in cared accommodation and that men are more likely to live with others.<sup>16–18</sup> Thus, men may live with their families who recognise and arrange their need for health care while women tend to receive a greater level of nursing care in their care facility. These factors are likely to be compounded in the last year of life.

A review of death certification by Middleton et al.<sup>19</sup> cited a number of studies that looked at the accuracy of death certification and showed that conditions likely to have an effect on death may not appear on the death certificate. The Australian Institute of Health and Welfare (AIHW) in their report on multiple causes of death<sup>9</sup> show that deaths from colorectal, liver, lung, breast and prostate cancers as well as coronary heart disease and cerebrovascular disease are captured as underlying causes of death more than 50% of the time. For deaths from diabetes, dementia and Alzheimer disease, COPD, asthma and chronic and unspecified kidney disease, less than 50% are captured as the underlying cause of death and they are more likely to be listed as an associated cause of death. Zilkens et al.<sup>20</sup> report that of a population of 29,884 West Australian decedents identified with a lifetime history of dementia between 1990 and 2005, 56% had dementia coded as an underlying cause of death and 44% did not have dementia documented on their death certificate. They go on to say that the relatively short length of follow-up time from first hospitalisation until death indicates it is likely that the dementia contributed to death in many of the cases. Including hospital admissions data helps to counteract this problem.

The availability of coded multiple cause of death data, now available from a number of countries, highlights how death is frequently related to more than one disease.<sup>9</sup> Hospital admissions data also show that many people suffer from multiple chronic diseases.<sup>21,22</sup> Comorbidity can indicate the presence of more severe disease and the need for more intensive health care intervention.<sup>21</sup> The likelihood of co-occurring chronic diseases and the possibility that any could be fatal complicates the process of assigning the underlying cause of death and highlights the importance of including multiple causes of death data to ensure that all contributing factors are included.<sup>9</sup> The use of both hospital admission and death certificate data to identify comorbid conditions reduces the likelihood that conditions are missed because they were mistakenly excluded from one or other

source of information and gives a more complete picture of a person's chronic disease profile.

A limitation of this approach is that by including conditions identified through hospital admissions data, we have included some cases that were not severe and would not warrant palliative care. However, population-based estimates of those requiring palliative care are intended to be an approximate rather than a precise measure. Precise measures would require more detailed collection of information at the level of the individual and their carer and are unlikely to be feasible at a population level.

## Conclusion

The use of different administrative data sources to identify conditions potentially amenable to palliative care can paint a different picture with regard to the size of the population, the relative frequency of conditions and the age and sex distribution of the population. It is important to be aware of the potential variations in individual data sources in terms of identifying the population amenable to palliative care and their likelihood of producing lower or higher estimates of the population and to take this into account when the data are being used for service planning. In jurisdictions where linked hospital and death data are not available, our data will help to approximate the potential undercount from using death data alone.

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