



## The need for paediatric palliative care in New Zealand

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### Abstract

**Aim** To estimate the incidence of life-limiting conditions requiring palliative care in New Zealand children.

**Methods** Mortality data was obtained for all children who died aged 0-17 years during the period 1996-1998. Based on the cause of death and hospitalisation data, cases were classified as either 'palliative' or 'not palliative'. A separate analysis was performed to allow comparison with overseas estimates of paediatric palliative care need.

**Results** Of a total of 2,122 deaths during the study period, 348 cases (16%) were assessed as potentially having required palliative care, giving a rate of 1.14 per 10 000 children per year. 37% of these deaths were due to cancer, 11% cardiac conditions, 24% congenital anomalies, and 28% other conditions. 29% of these children died in hospital.

**Conclusions** The findings of this study are consistent with estimates from overseas studies and will be valuable in planning paediatric palliative care services in New Zealand.

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Paediatric palliative care has firmly established itself as a worthwhile and essential service for children and their families.<sup>1</sup> There is, however, a distinct lack of data available for assessing the prevalence of life-limiting conditions in children in New Zealand.<sup>2</sup> This study aimed to estimate the incidence of death in children in which palliative care prior to death may have been appropriate. By estimating the frequency of children requiring palliative care, the study provides a basis for planning paediatric palliative care services.

### Methods

Mortality records were obtained from the New Zealand Health Information Service (NZHIS) for all children who died aged 0-17 years between 1 January 1996 and 31 December 1998. Hospitalisation data for these children were obtained from NZHIS for the period 1995-1998, using linkage via encrypted National Health Index (NHI). These data include any inpatient discharges from public hospitals and publicly-funded discharges from private hospitals. Each case was then classified as requiring palliative care or not using two separate analyses.

**Analysis 1** For the primary analysis, a subjective methodology was used to estimate the frequency of children aged 0-17 years requiring palliative care. Information about cause of death was supplemented with hospitalisation data to provide additional clinical information.

All children who died under the age of seven days were excluded, as were those who remained in hospital from birth until death. The following causes of death were excluded: motor vehicle accidents; injuries and poisonings (International Classification of Disease (ICD) codes 800-999); and SIDS (ICD 7980). However, exceptions were made for cases in which there was evidence of sustained brain injury and palliative care may have been required. Deaths due to infection (ICD 001-139) were also excluded, except one case of herpetic meningoencephalitis and one case of aspergillosis. Mental disorders (ICD 290-319) were also excluded after first checking the hospital admission records for any evidence of co-morbid life-limiting conditions.

The remaining cases were assessed on an individual basis, guided by the UK definitions for life-limiting conditions and palliative care<sup>3</sup> (Table 1). Provisional judgments were made by the research team; in equivocal cases the final decision was made by a paediatrician with experience of paediatric palliative care. Assessment was based on a summation of all the available evidence, including death registration information, any other conditions identified from hospital admission data, and information about any procedures undergone in hospital.

**Table 1. Definitions used for classification of children<sup>3</sup>**

<p><b>Life-limiting conditions</b> Life-limiting conditions are those for which there is no reasonable hope of cure and from which children will die. Many of these conditions cause progressive deterioration, rendering the child increasingly dependent on parents and carers.</p> <p><b>Palliative care</b> Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement. It is provided for children for whom curative treatment is not (or is no longer) appropriate and may extend over several years.</p>
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Cases were considered in four broad disease categories using death registration ICD codes:

1. **Cancer** (ICD 140–239), this included benign and malignant neoplasms;
2. **Cardiac** (ICD 390–459 and 745–747), this included general diseases of the circulatory system as well as congenital conditions of the heart and circulatory system;
3. **Congenital** (ICD 740–744 and 748–759), this included conditions due to chromosome anomalies (eg Edward's syndrome) and congenital conditions affecting various body systems (eg microcephalus, renal dysplasia);
4. **Other**, consisted of diseases of body systems (other than circulatory), perinatal conditions (eg severe birth asphyxia) and endocrine, nutritional or metabolic disorders (eg cerebral lipidoses).

Two of these groups presented considerable difficulty in assessing need for palliative care – cancer and cardiac conditions. After consultation with a paediatric oncologist, the records of children with cancer who died in hospital were examined in more detail, in view of the fact that some of these children may have died of an acute, unexpected complication. This resulted in the exclusion of 24 children: 21 with acute lymphoid leukaemia, two with benign neoplasms and one with a neoplasm of uncertain behaviour. It was also decided to exclude six children who died after receiving a bone marrow transplant.

For the group with cardiac anomalies, it was often difficult to determine from the available information whether or not they would have been considered palliative prior to death or would still have been receiving active treatment. A paediatric cardiologist was consulted and reviewed 48 cases randomly chosen from the list of 85 children who died due to cardiac anomalies. There was disagreement on nine of these cases; our estimate of 43% of cardiac cases requiring palliative care compared to the cardiologist's estimate of 33%. The results presented here reflect our judgments rather than those of the cardiologist.

In order to further test the validity of our analysis, 50 cases were chosen at random from the 2122 mortality records and were reviewed by a general paediatrician. This resulted in agreement on 98% of the cases, providing support for the methodology.

Palliative care need was analysed by age, gender, ethnicity and NZDep96 deprivation decile.

Population rates were calculated using 1996 census data; 'prioritised' ethnic group was used to assign ethnicity. Other analyses examined seasonality, place of death (home vs hospital), and the proportion of children's lives spent in hospital. Place of death was determined from combined hospitalisation and mortality data. The time spent in hospital was calculated as a percentage of the time the child was alive during the period 1995 to 1998.

**Analysis 2** This analysis was performed in order to allow a direct comparison between New Zealand's paediatric palliative care requirement and overseas estimates. A recent UK study<sup>3</sup> examined deaths of children aged 1–17 years, with palliative care need assessed from the ICD code alone. Need for

palliative care was based on a proposed list of life-limiting incurable diseases developed by an expert advisory group. We used this list of disease ICD codes (ICD-9, to the level of three digits) for the purpose of this analysis. Cases in which the underlying cause of death was on the list were deemed to have required palliative care.

## Results

**Analysis 1** Of the 2122 deaths in children aged 0–17 years during the study period, 348 (16%) were classified as being appropriate for palliative care. This represents an incidence of palliative care requirement of 1.14 per 10 000 children per year. 37.4% of the deaths were due to cancer, 11% were cardiac, 23.6% were congenital and 10.6% were classified as other (Table 2).

**Table 2. Number of children (0–17 yrs) likely to have required palliative care during the period 1996–1998 by disease group, ethnicity and place of death**

		Disease				Place of death	
		Cancer (%)	Cardiac (%)	Congenital (%)	Other (%)	Home (%)	Hospital (%)
Ethnicity (%)							
Maori	91 (26)	32 (35)	10 (11)	24 (26)	25 (27)	64 (70)	27 (30)
European	207 (59)	81 (39)	22 (11)	48 (23)	56 (27)	148 (71)	59 (29)
Pacific Islanders	32 (9)	12 (38)	3 (9)	5 (16)	12 (38)	24 (75)	8 (25)
Other	18 (5)	5 (28)	2 (11)	5 (28)	6 (33)	11 (61)	7 (39)
<b>Total</b>	<b>348</b>	<b>130 (37)</b>	<b>37 (11)</b>	<b>82 (24)</b>	<b>99 (28)</b>	<b>247 (71)</b>	<b>101 (29)</b>
Place of death							
Home	247	89 (68)	23 (62)	53 (65)	82 (83)		
Hospital	101	41 (32)	14 (38)	29 (35)	17 (17)		

Fifty three per cent of the children were male and 47% were female. A large proportion (28%) of these children died under the age of one year (Figure 1). 59% of the children were European, 26% were Maori and 9% were Pacific (Table 2). The rate of palliative care requirement was similar for all ethnic groups. 29% of cases were from NZDep96 deciles 9 and 10 (the most deprived 20% of small areas in New Zealand), and the proportion of the total population of 0–17 years living in these areas was 24%.

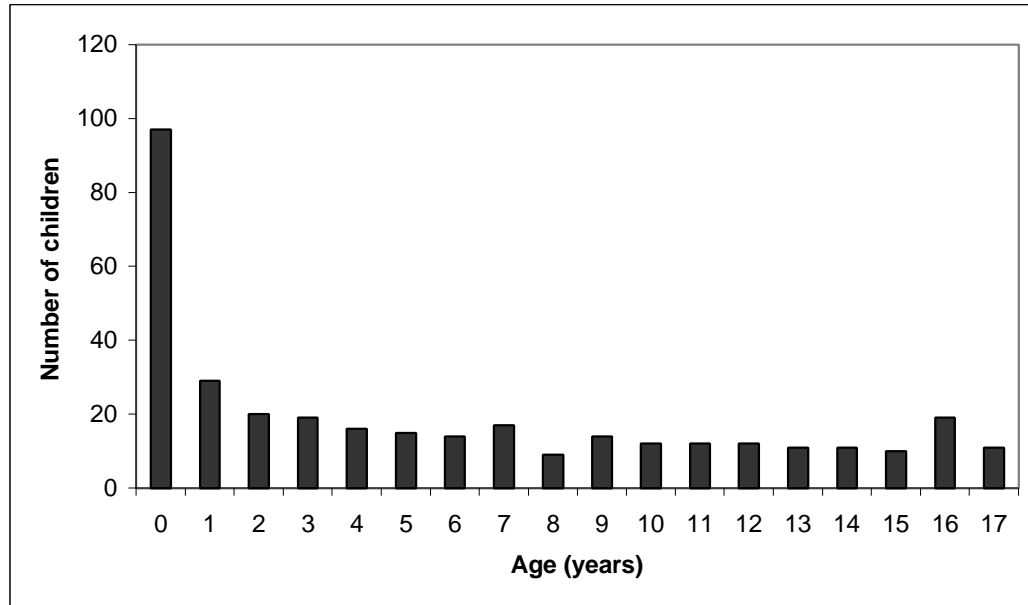
Twenty nine per cent of all children likely to have required palliative care died in hospital (Table 2). The percentage of children dying in hospital in each disease group was as follows: cardiac conditions, 37.8%; congenital conditions, 35.4%; cancer, 31.5%; and other conditions, 17.2%. The percentage dying in hospital by ethnic group was: European, 28.5%; Maori, 29.7%; Pacific, 25%; and Other, 38.9%.

The time spent in hospital was calculated as a percentage of the time the child was alive during the period 1995 to 1998. There was considerable variation, but most children spent 5–20% of this period in hospital. Children with congenital conditions tended to spend more time in hospital.

The seasonal analysis showed a slight increase in deaths during the winter months with a peak in August (42 children; 12% of all deaths of children likely to have

needed palliative care). Death rates were at their lowest in February (21 children; 6% of the total).

**Figure 1. Age at time of death of children likely to have required palliative care for the period 1996–1998**



**Analysis 2** Based on ICD coding of deaths in the 1- to 17-year-old age group, 286 cases (28%) were classified as requiring palliative care. This gives a palliative care need rate of 0.99 per 10 000 population per year for 1- to 17-year-old children.

## Discussion

The palliative care requirement of the New Zealand child population was assessed in two different ways in this study. One method involved analysing available mortality and hospitalisation data for children aged 0–17 years. The other approach defined palliative care need simply using mortality ICD codes for the age range 1–17 years. The former analysis allowed the appraisal of more information on the clinical course of patients and hence likely need for community palliative care services; the latter provided a direct comparison with UK data.

Both these methods have their limitations. Using our more subjective methodology, it was often difficult to determine whether or not children would have required palliative care services based on the limited information available. This was highlighted by the difficulty in achieving consensus on cases of congenital heart disease in particular. The UK method also has its flaws; relying purely on ICD coding of the primary cause of death is a simplistic way of determining palliative care need.

The direct comparison with the UK showed that New Zealand has a rate of 0.99 per 10 000 population per year for 1- to 17-year-old children compared with the UK rate of 1 per 10 000. A rate of 1 per 10 000 children per year can be confidently used for palliative care planning purposes for the 1- to 17-year-old population in New Zealand.

The palliative care need rate for the 0- to 17-year-old population (ie including children under one year) using the combined mortality and hospitalisation data was 1.14 per 10 000 population. This higher rate reflects the substantial needs of the population under one year old. This group has the highest death rate from life-limiting conditions, and while they clearly do not have long-standing requirements, palliative care services remain an important consideration.

It is essential that all services have the capacity to address the specific needs of Maori whanau. The palliative care need rate for Maori children was similar to that of the total population, as was the distribution among disease groups and the proportion dying in hospital. Pacific children also had a similar palliation need rate to that of the total population. It must be recognised, however, that using 'prioritised' ethnic group denominators is likely to have underestimated Maori and Pacific mortality rates.<sup>4,5</sup>

Analysis by place of abode showed that all regions had comparable rates of palliative care need. The increase in deaths over winter was not unexpected and almost certainly reflects the increased rate of fatal complications, such as respiratory infections, during this time.

The current literature on support for families with a dying child indicates that home is considered to be the most appropriate place of care.<sup>6</sup> In New Zealand, a significant number of these children (29%) are dying in hospital. To what extent this finding represents a gap in current palliative care services is not known. This issue will be examined in a follow-up study involving qualitative research into the individual experiences of families. The relatively high proportion of time that these children spend in hospital means that palliative care services should be well integrated with both inpatient and outpatient services, which is currently not always the case.

In summary, this study has shown that New Zealand paediatric palliative care requirement is comparable to that of other developed countries. These findings can now serve as a valuable tool for planning of paediatric palliative care services in New Zealand. The New Zealand Palliative Care Strategy<sup>7</sup> recognises these needs and supports the implementation of the Paediatric Review recommendations.

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