National Model of the Need for Palliative Care

Hospice NZ
4 August 2016
Outline

- Methodology
- Historic Need for Palliative Care
- Projections of Need for Palliative Care
- Projections of Need for Hospice Care
- Projections of Place of Death and Policy
Methodology
Estimating the Need for Palliative Care
Health Needs Assessment
Phase 1

- **Phase 1**: Assessment of Palliative Care Need

- It establishes, for the first time, the number of people who might benefit from palliative care in New Zealand.

- In 2006, mid-range estimate that **56.3%** of all deaths were amenable to palliative care.

- Report prepared for Palliative Care Council by Wayne Naylor. Published June 2011.
Need to Revise Methodology

- **Period of Projection**: projected to 2016 and 2026.
  - Period now too short for effects of longevity and the “Baby Boomers” coming through the population.

- **Projected using Population not Deaths**:
  - Used proportion of population needing palliative care, expressed as a rate per 100,000 of population. Thus is an explicit assumption that the proportion of deaths to population will remain constant in the future, which is not the case in the Statistics NZ projections.
  - Calculations of minimal and maximal only shown at national level.

- **Separate Adult and Child Lists of Conditions**:
  - Anomalies between child (under age 20) and adult list, with nearly half of congenital deaths excluded.

- **Pattern at Older Ages**
  - Adult estimate based on ten disease groups with frailty/dementia not fully represented.
The median projection from Statistics New Zealand is that deaths will rise from around 30,000 a year to 55,500 a year by 2068.

The graph begins in 1979, the year the first hospice in New Zealand opened.
The crude death rate has declined historically. We are currently at a low point for the crude death rate and the rate is expected to rise by the 2050s to levels last seen in the 1940s and 1950s. This is NOT a failure of medicine!

Source: Palliative Care Council, Working Paper No. 1, July 2013
Drawn using data from Statistics New Zealand
Work on perinatal and congenital conditions shows that 45.4% (nearly half) of all deaths from congenital conditions occur over age 20. In the previous estimates of need, only congenital deaths under age 20 were included. The revised methodology to include all congenital deaths.
HNA1 Minimal 40.2%, HNA1 Maximal 93.6% of total deaths.

HNA1 Minimal shape declines rapidly at lower ages. Thus as the population ages, we would get a lower need for palliative care, which is counter-intuitive and is the core reason for revising the methodology.

**Data Source:** Ministry of Health MORT data 2000-2013
Methodology and New Papers

- **Australia:** Rosenwax (2005) and McNamara (2006).
  - Was the basis for adults in the HNA Phase 1 report
  - **Updated study ten years later, published 2016**
- **UK:** Cochrane (2007) for children and young people
  - Was the basis for under 20s in the HNA Phase 1 report
- **UK:** Murtagh (2013)
  - Compared Rosenwax, Higginson and Gómez-Batiste, then developed revised approach. Produced much higher estimates.
  - **Studies using same methodology in Ireland and Germany.**
- **England and Wales:** Hain (2013)
  - New Paediatric Directory of Life-Limiting Conditions
- **World:** WPCA and WHO Global Atlas (2014)
  - Uses early Higginson approach, with updated assumptions
- **Spain:** Gómez-Batiste (2014)
  - Testing tools for identification of palliative care need
- **French Observatory, based on work in Québec.**
National and Regional Need for Palliative Care Model

**National and Regional Need for Palliative Care Model**

**Statistics NZ**
Projections of deaths 2014 - 2068

**Statistics NZ**
Projections of deaths for MOH 2016 - 2038

**MOH MORT data**
Historic patterns 2000-2013

**MOH MORT data**
Historic patterns 2000-2013

**Period for historic patterns for model is 2009-2013**

**Historic Patterns of Need for Palliative Care**
Refined by Clinical Panel

**Projections at national level to 2068; National, DHB and regional level to 2038.**

**National and Regional Need for Palliative Care Model**
Combines historic patterns with future projections
Spreadsheet model, choice of region and DHB, produces tables and graphs

**Refined with PCAP and PC Review team**
There are strong patterns by age and gender. The peak for deaths from neoplasms occurs earlier and is proportionally higher for women. External causes of death are significant for young men.

Data Source: Ministry of Health MORT data 2000-2013
There are strong patterns by age and gender. Deaths in public hospital are highest under 1 year old and decline at the oldest ages. There is an expanding “funnel” of deaths in residential care at older ages.

Data Source: Ministry of Health MORT data 2000-2013
### Conceptual Need for Palliative Care

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>Public Hospital</th>
<th>Residential Care</th>
<th>Hospice Inpatient Unit</th>
<th>Private Residence</th>
<th>Other</th>
<th>Proportion by Cause of Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neoplasms</td>
<td>All deaths</td>
<td>All deaths</td>
<td>All deaths</td>
<td>All deaths</td>
<td>All deaths</td>
<td>100.0%</td>
</tr>
<tr>
<td>Circulatory System</td>
<td>Clinical panel</td>
<td>All deaths</td>
<td>All deaths</td>
<td>Clinical panel</td>
<td>Clinical panel</td>
<td>Derived</td>
</tr>
<tr>
<td>Other Conditions</td>
<td>Clinical panel</td>
<td>All deaths</td>
<td>All deaths</td>
<td>Clinical panel</td>
<td>Clinical panel</td>
<td>Derived</td>
</tr>
<tr>
<td>Maternity</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>0.0%</td>
</tr>
<tr>
<td>Perinatal and Congenital</td>
<td>As agreed with Starship</td>
<td>All deaths</td>
<td>All deaths</td>
<td>As agreed with Starship</td>
<td>As agreed with Starship</td>
<td>Derived</td>
</tr>
<tr>
<td>External Causes</td>
<td>Sequelae only</td>
<td>All deaths</td>
<td>All deaths</td>
<td>Sequelae only</td>
<td>Sequelae only</td>
<td>Derived</td>
</tr>
<tr>
<td>Proportion by Place of Death</td>
<td>Derived</td>
<td>100%</td>
<td>100%</td>
<td>Derived</td>
<td>Derived</td>
<td>Derived</td>
</tr>
</tbody>
</table>

Only some of the deaths in light blue and purple are included, based on the underlying cause of death as summarised in the **NZ COD Minimal** lists by the Clinical Panel. The outer proportions of the table (x%) are then calculated.

**Data Source:** Ministry of Health MORT data 2000-2013
Palliative Care Council Studies

- Palliative Care in Residential Care
  - Kate Gibb, Nursing Director, Older People - Population Health, Canterbury District Health Board
  - Dr Michal Boyd, Senior Lecturer and Nurse Practitioner, School of Nursing, University of Auckland

- Paediatric and Adolescent Palliative Care, Perinatal and Congenital Conditions
  - Dr Ross Drake, Paediatric Palliative Care and Pain Medicine Specialist, Clinical Lead, Paediatric Palliative Care Service, Starship Child Health
  - Karyn Bycroft, Nurse Practitioner, Paediatric Palliative Care Service, Starship Child Health
Clinical Panel

Clinical Panel and Palliative Care in Public Hospitals

- **Dr Jonathan Adler**, Palliative Medicine Consultant and Clinical Leader, Palliative Care Service, Wellington Regional Hospital
- **Dr Simon Allan**, Director of Palliative Care, Arohanui Hospice, and Consultant Medical Oncologist and Palliative Care Physician, Palmerston North Hospital
- **Dr Kate Grundy**, Palliative Medicine Physician and Clinical Director, Canterbury Integrated Palliative Care Services
- **Professor Rod MacLeod**, Senior Staff Specialist, HammondCare, and Conjoint Professor in Palliative Care, University of Sydney
- **Dr Carol McAllum**, Palliative Medicine Specialist and Associate Dean Undergraduate Studies Hawke’s Bay, Hawke’s Bay District Health Board
- **Wayne Naylor**, Director of Nursing, Hospice Waikato
Proportional Need for Palliative Care in New Zealand, 2000-2013

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>Place of Death</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Proportion by Cause of Death</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Public Hospital</td>
<td>Residential Care</td>
<td>Hospice Inpatient Unit</td>
<td>Private Residence</td>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>Neoplasms</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Circulatory System</td>
<td>80.5%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>48.5%</td>
<td>50.3%</td>
<td>78.4%</td>
</tr>
<tr>
<td>Other Conditions</td>
<td>55.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>53.2%</td>
<td>56.4%</td>
<td>73.9%</td>
</tr>
<tr>
<td>Maternity</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Perinatal and Congenital</td>
<td>91.2%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>96.4%</td>
<td>94.0%</td>
<td>92.6%</td>
</tr>
<tr>
<td>External Causes</td>
<td>3.5%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>1.4%</td>
<td>0.3%</td>
<td>10.0%</td>
</tr>
<tr>
<td>Proportion by Place of Death</td>
<td>73.5%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>64.9%</td>
<td>38.4%</td>
<td>79.4%</td>
</tr>
</tbody>
</table>

Only some of the deaths in light blue and purple are included, based on the underlying cause of death as summarised in the **NZ COD Minimal** lists by the Clinical Panel.

In total, **79.4%** of all deaths met the definition of need for palliative care over the period 2000-2013.

**Data Source:** Ministry of Health MORT data 2000-2013
The pattern for the NZ Need for Palliative Care and the NZ Maximal Need for Palliative Care are shown using the full historic data, 2000 to 2013.

**Data Source:** Ministry of Health MORT data 2000-2013
NZ Need for Palliative Care

The pattern for the NZ Need for Palliative Care and the NZ Maximal Need for Palliative Care are shown using the full historic data, 2000 to 2013.

Data Source: Ministry of Health MORT data 2000-2013
The pattern for the NZ Need for Palliative Care is compared to the previous HNA1 methodology (based on Rosenwax), the Murtagh methodology and the French Observatory methodology.

Data Source: Ministry of Health MORT data 2000-2013
Historic Patterns of Need for Palliative Care
MORT data 2009-2013
As the population ages, so the need for palliative care increases. The need has increased from 78.1% of deaths in the year 2000 to 80.7% of deaths in 2013. The fluctuations in the “not included” category are largely due to fluctuations in numbers of deaths from external causes.

**Data Source:** Ministry of Health MORT data 2000-2013
The summary proportions are a consequence of the different age structures and causes of death in each group. Note also that these are the historic values, not the proportions to be used in future.

**Data Source:** Ministry of Health MORT data 2000-2013
This does NOT mean that women have a higher need or that Māori have a lower need for palliative care. The summary proportions are a consequence of the different age structures and causes of death in each group.

Data Source: Ministry of Health MORT data 2000-2013
The patterns for women and men are similar, with proportionately lower need for palliative care at higher levels of NZDep. This is a function of the ages and causes of death, which are not identical across the categories.

Data Source: Ministry of Health MORT data 2000-2013
By total numbers, there are more deaths needing palliative care in Dep 7&8 than in any other quintile. The numbers needing palliative care in areas with Dep 7&8 are roughly double those in areas with Dep 1&2.

Data Source: Ministry of Health MORT data 2000-2013
100% of deaths from neoplasms are included, with 78.4% of circulatory system deaths and 73.9% of deaths from other conditions. Only 10.0% of deaths from external causes are included.

**Data Source:** Ministry of Health MORT data 2000-2013
All deaths in hospice IPU and residential care are included (other than deaths in childbirth). **73.5%** of deaths in public hospital and **64.9%** of deaths in private residence are included.

**Data Source:** Ministry of Health MORT data 2000-2013
NZ Need for Palliative Care
Cause and Place of Death

Combining cause of death and place of death. The effects on the circulatory system conditions and other conditions are most noticeable.

Data Source: Ministry of Health MORT data 2000-2013
Deaths in public hospital and residential care are mutually exclusive. The balance of deaths under the NZ Need for Palliative Care is shown as being in the community, excluding residential care.

NB: This is place of death and not place of care.

Data Source: Ministry of Health MORT data 2000-2013
Comment on Community

- The community, excluding residential care is NOT equal to the coverage of hospice care.
- For hospice patients, deaths occur in hospice IPU, in private residences, in public hospitals and in residential care, with a few in other settings.
- Important to remember that this analysis uses place of death and not place of usual care:
  - People moving between residential care and hospital.
  - People moving between private residence and hospice IPU.
  - People moving between private residence and hospital.
  - Other more complex trajectories.
- Hence estimate NZ Need for Hospice Care using a different approach, as used in the Hospice NZ Demand Model (used to consider new collaborations between hospices and residential care).
Conceptual Need for Palliative Care

Hospice Care

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<tr>
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<td>All deaths</td>
<td>All deaths</td>
<td>100.0%</td>
</tr>
<tr>
<td>Circulatory System</td>
<td>None</td>
<td>All deaths</td>
<td>All deaths</td>
<td></td>
<td>None</td>
<td>46.2%</td>
</tr>
<tr>
<td>Other Conditions</td>
<td>None</td>
<td>All deaths</td>
<td>All deaths</td>
<td></td>
<td>None</td>
<td>50.1%</td>
</tr>
<tr>
<td>Maternity</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
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</tr>
<tr>
<td>Perinatal and Congenital</td>
<td>Congenital only</td>
<td>All deaths</td>
<td>All deaths</td>
<td>Congenital only</td>
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<td>53.0%</td>
</tr>
<tr>
<td>External Causes</td>
<td>None</td>
<td>All deaths</td>
<td>All deaths</td>
<td>Sequelae only</td>
<td>None</td>
<td>9.0%</td>
</tr>
</tbody>
</table>

Hospice care might be in a supportive role to residential care or in some cases might be direct care - models of collaboration are evolving. This gives a lower need for Hospice Care of 36.6% and an upper need of 60.7% of all deaths. The lower estimate has only neoplasms and congenital deaths in residential care, while the latter has all deaths in residential care.

**Data Source:** Ministry of Health MORT data 2000-2013
The need for hospice care is shown relative to the overall NZ Need for Palliative Care. Two versions are shown, the lower line with only cancer deaths and congenital deaths in all settings (close to existing practice) and the upper line adding support to all deaths in residential care.

**Data Source:** Ministry of Health MORT data 2000-2013
Projected Need for Palliative Care

National with scenarios: 2016-2068
National, Regional, DHB: 2016-2038
The median projection from Statistics New Zealand is that deaths will rise from around 30,000 a year to 55,500 a year at a national level by 2068.

The more detailed national, regional and DHB projections are to 2038.

**Data source:** Statistics New Zealand. Historic estimates and National population projections, 2014(base)-2068.
Projected Deaths 2016-2068

Statistics NZ use a stochastic (probabilistic) approach to projections. The median projection is the 50th percentile (half the projections are larger and half smaller than this number). The graph illustrates the range of uncertainty from the 5th to the 95th percentile and the expanding “funnel of doubt” in the projections.

Source: National Model of the Need for Palliative Care
Projected Deaths 2016-2068

Statistics NZ also produce projections using five defined scenarios. Three of these are for estimates of migration (none, cyclic and very high). The very high fertility scenario has little impact on deaths compared to the median projection. Of interest is the very low mortality projection. 

Source: National Model of the Need for Palliative Care
Projected Need 2016-2068

This illustrates the NZ Need for Palliative Care, the NZ Maximal Need for Palliative Care and the deaths not included in the definition of need, projected from 2016 to 2068.

Source: National Model of the Need for Palliative Care
The number of deaths needing palliative care is projected to increase from 24,680 in 2016 to 37,286 by 2038, an increase of 51.0%.
This compares to an increase in the total number of deaths of 47.5%.

Source: National Model of the Need for Palliative Care
Projected Need 2016-2038 Regions and New Zealand

Note the x-axis does not start at zero. The proportion of deaths needing palliative care is a function of the age and gender of each region and how this is projected to change over time. Important to use the spreadsheet model and not simply apply a flat percentage of need.

Source: National Model of the Need for Palliative Care
Over the period to 2038, the projected need for palliative care increases by **51.0%** for New Zealand, **64.5%** for Northern, **45.1%** for Midland, **41.3%** for Central and **47.3%** for the South Island region.

*Source*: National Model of the Need for Palliative Care
NZ Model of Need for Palliative Care

Spreadsheet model with tables and graphs:

- **National planning from 2016 to 2068**
  - Range of results, using range of Stats NZ projections
  - Best used for policy and high-level planning of future workforce.

- **National, Regional and Local planning from 2016 to 2038**
  - Local is a whole DHB or combination/ proportion of DHBs
  - Can use historic patterns for New Zealand or region
  - Sections with information for planning for hospitals, residential care and hospice care.

- Recommend that the spreadsheet model be made freely available.

The number of deaths needing palliative care in public hospitals is projected to increase from 7,307 in 2016 to 10,045 by 2038, an increase of 37.5%.

Source: National Model of the Need for Palliative Care
The need for palliative care is projected to increase by **37.5%** in public hospitals and **84.2%** in residential care by 2038.

Important for discussions with DHBs and the residential care sector. This does not take capacity in the sector into account.

**Source:** National Model of the Need for Palliative Care
The number of deaths needing hospice care is projected to increase from 11,329 in 2016 to 13,867 by 2038, an increase of 22.4%. When support to residential care is included, the increase is from 19,295 deaths in 2016 to 29,296 in 2038, an increase of 51.8%. Some of these deaths may move into the community rather than be in residential care.

**Source:** National Model of the Need for Palliative Care
NZ Model of Need for Palliative Care

Spreadsheet model with tables and graphs:

- **National planning from 2016 to 2068**
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Projected Place of Death
New Zealand 2016 and 2038

Over the period of 22 years, deaths in residential care are projected to increase from **34.2%** to **42.6%** of total deaths.

Source: National Model of the Need for Palliative Care
Over this projection period, deaths in hospital continue to increase (42.2%), but not as fast as total deaths (47.5%). Deaths in private residence are projected to increase 15.6% and deaths in residential care 84.2%.

Source: National Model of the Need for Palliative Care
Projected Deaths 2016-2068
Place of Death – historic pattern

If the historic patterns persist, then deaths in residential care are projected to increase from around 10,000 a year to nearly 30,000 a year by 2068.

Source: National Model of the Need for Palliative Care
Deaths in public hospital and residential care are mutually exclusive. The balance of deaths under the NZ Need for Palliative Care is shown as being in the community, excluding residential care.

NB: This is place of death and not place of care.

Data Source: Ministry of Health MORT data 2000-2013
“All New Zealanders live well, stay well, get well”

No “dying well” in strategy

Theme 2: Closer to home

Ka aro mai ki te kāinga

How viable is this for end of life care?
Independent Life Expectancy, 1996–2013

- Female New Zealander at **65 years of age** in 2013 can expect to live:
  - another **10.6 years** independently, on average, which is 49.5% of her remaining life
  - a further **10.7 years** with functional limitations requiring assistance
    - non-daily assistance for **5.9 years**
    - daily assistance for final **4.8 years**.

- Male New Zealander at **65 years of age** in 2013 can expect to live:
  - another **10.2 years** independently, on average, which is 54.1% of his remaining life
  - a further **8.7 years** with functional limitations requiring assistance
    - non-daily assistance for **5.6 years**
    - daily assistance for the final **3.1 years**.

Impact on Whānau and Carers?

The Reality of Caring
Distress among the caregivers of home care patients

Let's make our health system healthier

Health Quality Ontario, 2016
Caveats and Updates

- **Projections are NOT predictions.**
  - StatsNZ: “projections and associated probability intervals should be used as guidelines and an indication of the overall trend, rather than as exact forecasts”

- Projections change as new information becomes available:
  - Annual update to StatsNZ projections for MOH – November 2016
  - StatsNZ national projections over long-term updated every two to three years. Important revision about 18 months after census, with next census due in 2018.
  - New national projection impacts medium-term assumptions used.

- Historic patterns of deaths should be updated every five years.
- Need for palliative care definitions change as practice evolves.
- Projections based on number of deaths, not whole period of care needed. Need to do work on trajectories of care.

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Adjunct Professor, School of Management Studies, University of Cape Town
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