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What happens at the end of life? Using linked administrative health data to understand healthcare usage in the last year of life in New Zealand

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ABSTRACT

The end of life is often associated with increased use of healthcare services. This increased use can include over-medicalisation, or over-treatment with interventions designed to cure that are likely futile in people who are dying. This is an issue with medical, ethical, and financial dimensions, and has implications for health policy, funding and the structure of care delivery.

We measured the annual use of nine pre-defined public healthcare services between 1 January 2008 and 31 December 2012 by elderly New Zealanders (65–99 years old) in their last year of life and compared it with that of the cohort of elderly New Zealanders who used healthcare in the period but did not die. We used linked, encrypted unique patient identifiers to reorganise and filter records in routinely collected national healthcare utilisation and mortality administrative datasets.

We found that, in New Zealand, people do seem to use more of most health services in their last year of life than those of the same age who are not in their last year of life. However, as they advance in age, particularly after the age of 90, this difference diminishes for most measures, although it is still substantial for days spent in hospital as an inpatient, and for pharmaceutical dispensings.

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1. Introduction

Since Ivan Illich developed his critique of the medicalisation of dying in the mid-1970s [1] technologies and interventions to maintain and preserve life have rapidly developed, particularly in fields such as critical care. Inevitably this has led to an increasing role for public health services to provide medical interventions and treatment until the end of life.

“Over-medicalisation” implies an over-reliance on interventional treatments aimed at cure that may prolong dying rather than easing suffering and focusing on the quality of patients’ remaining life. Over-medicalisation is a contentious issue, with a burgeoning literature, particularly in the United States (US) [2–7]. Ever-increasing intensity of treatment has been associated with concerns about the quality, costs, and sustainability of medical treatment near the end of life [8–13]. In the New Zealand context, commentators have noted “adverse outcomes such as physical

distress can be associated with aggressive management in individuals whose prognosis is poor” [14]. Furthermore, care designed to prolong life at all costs, which is pursued in the absence of established goals of care reflecting patient preferences, may not in fact be what patients want [2,15,16].

Over-medicalisation of end-of-life care is an issue with medical, ethical, and financial dimensions, and has implications for health policy, funding and the structure of care delivery, particularly in the context of ageing populations. The financial implications of providing overly interventional care at the end of life are real and raise fraught ethical issues around the capacity for autonomous decision making in very sick patients, withholding and withdrawing sometimes very expensive but futile treatment in end-of-life situations and accusations of “rationing” of healthcare in such cases [17]. In line with many countries [18–20], in New Zealand, individuals’ health costs over their lifetimes appear skewed to the last year of life—one study finding around 25% of costs were incurred in the last year of life of a 70-year-old [18]. Furthermore, provision of end-of-life care is not distributed equitably [21–23].

New Zealand, like other jurisdictions, has an ageing population and a workforce under strain. For both policy and practice we must

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understand current patterns in the nature and distribution of end-of-life care so that we can assist funders, researchers, policy makers and decision makers to identify priorities and opportunities for improvement work and for the future allocation of finite resources [14,24].

Internationally, retrospective studies of administrative data have sought to analyse patterns in care use near the end of life [25], but there has been little previous investigation of such use in New Zealand [18,26,27]. In this study we used linked, encrypted unique patient identifiers to interrogate routinely collected national administrative datasets to identify use of nine healthcare services (general practitioner visits, laboratory tests, pharmaceutical dispensing, emergency department visits, inpatient public hospital discharges and length of stay, public outpatient consultations, aged residential care length of stay, and mental health events). We compared the frequency of healthcare use of those aged 65–99 years of age who died between 2008 and 2012 (the study period) against an age-matched cohort of those who did not die during this period. We aimed to better understand what care we provide to patients in their last year of life and how it differs, if at all, from the care provided to patients of the same age not in their last year of life.

2. Materials and methods

We aimed to assess and compare use of healthcare services by two cohorts: elderly New Zealanders who died within the study period and elderly New Zealanders who did not die (the control population) within this period. Our source population was identified from administrative use data and then separated into those deceased or surviving during the study period, 2008–2012.

2.1. Data sources and measures of service use

Virtually all New Zealanders are assigned a unique code at the time of their first contact with the healthcare system – this is known as the NHI unique patient identifier number [28].

NHI patient identifier numbers are recorded in the routinely collected national administrative datasets seen below in Fig. 1 [29]. We used the linked, encrypted NHI of every individual 65–99 years old who appeared in these datasets in the study period to assemble two cohorts: those who died, and those who didn't die. For each individual we then created measures of their use of nine defined healthcare services from the databases. See Fig. 1 for the measures and datasets which contributed to them.

The study period was between 1 January 2008 and 31 December 2012. For those who died in the study period the measures were assembled for their last year of life. For the much larger control population the measures were for the latest calendar year each individual consumed a healthcare service. This was 2012 for the majority (95%) of the control group. Longitudinal measures of service use change used the entire study period. We excluded those who died in 2013, as 2012 healthcare use would be that of their last year of life.

2.2. Measures of healthcare service activity (per year per person)

1. Number of quarters per year with a consultation with a general practitioner (GP visits). This includes all those enrolled with a PHO, including ARC residents. Data are only extractable from quarterly collected PHO data using the last consultation date, therefore only one visit per quarter is counted (maximum four per year). See the limitations for further discussion of this measure.
2. Number of publicly funded laboratory tests received that were performed in community laboratories (lab tests). This measure

was by individual laboratory test, not per request of potentially multiple tests. No imaging data are available in the national data collections.

3. Number of pharmaceutical dispensings (pharmaceutical dispensings). This measure is of frequency of dispensing events, not the number of types of medications, packs, or multiple medications within one dispensing event.
4. Number of attendances at hospital emergency department (ED attendances). Any ED presentation that lasts longer than three hours is automatically admitted to hospital and recorded in the NMDS with a subsequent inpatient discharge (measure 6 below). However, many of these presentations are in fact true ED attendances and not hospital admissions that result in inpatient discharge and associated inpatient length of stay. Therefore, any ED presentation coded as emergency that because of the three-hour rule resulted in an NMDS record of hospital inpatient admission that was less than a day was counted only as an ED attendance, not as an inpatient discharge. Also, an ED attendance that resulted as an inpatient admission less than a day but was coded surgical or other than emergency was retained in the NMDS records and treated as an inpatient admission.
5. Number of outpatient consultations, including medical, surgical and nursing (outpatient consultations)
6. Number of inpatient discharges (inpatient discharges)
7. Total length of stay in hospital in days (inpatient length of stay)
8. Number of health service events coded as mental health in the PRIMHD database (mental health events). These include all contacts with mental health services including inpatient, outpatient, community and teleconference events
9. Total length of stay in an aged residential care (ARC) facility (ARC length of stay)

(Abbreviated phrases in brackets used below.)

2.3. Deriving the cohorts

The population of those who died during the study period (decedents) was derived from all those in the relevant age group in the relevant period whose deaths are recorded in the national Mortality Collection ($n = 115,163$).

The control population was assembled by combining the NHI numbers of two groups. Those in the age group 65–99 years old who didn't die in the study period who:

- used any health services recorded in any of the national administrative datasets in Fig. 1 during the study period.

Combined with those who may not have used any health services but who:

- appeared in the PHO Enrolment Collection and were thus enrolled with any PHO – not-for-profit organisations that provide primary health services in a specified region to an enrolled population either directly or through GP practices. (94% of the NZ population is enrolled with a PHO [30].)

This method thus afforded us a control group ($n = 646,303$) we consider to be a reasonable proxy of the actual New Zealand population in this age group. For comparison, the 2013 NZ national census reports 607,032 people above the age of 65 years [31]. See Fig. 2 for an overview of how the two populations were derived.

The control population's use of healthcare services was measured for each calendar year within the study period, from January 1 to December 31. The healthcare use of people who died was measured for the 365 days before their death. This was extended prior to the study period proper to 1 January 2007 for patients who died,

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