ELSEVIER

Journal of Clinical Epidemiology 67 (2014) 160−168

Journal of Clinical Epidemiology

Nationwide individual record linkage study showed poor agreement of causes of death and hospital diagnoses at individual level but reasonable agreement at population level

Bart Klijs[a,b,*], Wilma J. Nusselder[a], Johan P. Mackenbach[a]

[a]*Department of Public Health, Erasmus MC, University Medical Center Rotterdam, Dr. Molewaterplein 50, P.O. Box 2040, 3000 CA Rotterdam, The Netherlands*

[b]*Department of Epidemiology, University Medical Center Groningen, Hanzeplein 1, P.O. Box 30 001, 9700 RB Groningen, The Netherlands*

Accepted 31 July 2013; Published online 31 October 2013

Abstract

Objectives: To investigate to what extent underlying and multiple causes of death represent end-of-life morbidity in individuals and at population level.

Study Design and Setting: Cause of death and national hospital data were individually linked for all deaths at the age of 50−84 years, in 2005 in the Netherlands (n = 86,987). The individual agreement of diseases registered as a diagnosis of discharge in the last 2 years of life and underlying and multiple causes of death recorded was assessed. Cause-of-death ranking was compared with ranking of hospital diagnoses.

Results: The percentage of persons with a hospital diagnosis registered as the underlying cause of death was <30% for most diseases, except for cerebrovascular disease, chronic obstructive pulmonary disease and bronchiectasis, acute myocardial infarction (40−60%), and cancers (70−90%). Low Cohen's kappa values confirmed poor individual agreement between hospital diagnoses and underlying and secondary causes of death recorded. At population level, however, frequency rankings of underlying and multiple causes of death agreed reasonably well with frequency ranking of hospital diagnoses (Spearman ρ of 0.58−0.60 and 0.61−0.63).

Conclusion: Underlying and multiple causes of death poorly represent diseases present at the end of life in individuals but show reasonably well which diseases are most common at population level.

Keywords: Cause of death; Death certificates; Hospital records; Main diagnosis; Medical record linkage; Quality control

1. Introduction

Cause-of-death statistics are of major importance for quantifying burden of disease and are often relied on for policy decisions. Cause-of-death statistics originated in the era of infectious diseases, in which most persons died due to one major cause and at a relatively young age. It was therefore that the burden of disease in the population could validly be quantified by ranking according to the frequency of underlying cause of death. In this approach, the underlying cause of death was conceptualized as ''the disease or injury that initiated the train of morbid events leading directly to death'' [1]. Now, after completion of the epidemiologic transition, persons tend to die at older ages and, in most instances, in the presence of multiple co-occurring conditions [2−4]. To illustrate, it has been estimated that 55−98% of the elderly who have a chronic condition have at least one other disease [3]. Consequently, it is increasingly recognized that analysis of underlying causes of death alone might not be sufficient to represent the complex burden of multimorbidity at the end of life [5,6].

To enable analyses of multidisease patterns, ''secondary causes of death'' were conceptualized, which represent ''consequences or complications of the underlying cause of death or another disease present at the moment of death that may have contributed to death'' [7]. Recent multiple causes of death analysis for the United States among others revealed that diseases such as anemia, pneumonia, diabetes, and chronic lower respiratory diseases frequently occur at the end of life but are poorly represented as the underlying cause of death [8,9]. Using multiple instead of underlying

Financial support: This study was part of the project ''Living longer in good health,'' which was financially supported by Netspar.

* Corresponding author. Department of Epidemiology, University Medical Center Groningen, University of Groningen, Hanzeplein 1 (Room E3-25), PO Box 30.001, 9700 RB Groningen, The Netherlands. Tel.: +31-50-361-0937; fax: +31-50-361-4493.

E-mail address: b.klijs01@umcg.nl (B. Klijs).

0895-4356/$ - see front matter
http://dx.doi.org/10.1016/j.jclinepi.2013.07.017

What is new?

Key findings

- At individual level, strong discrepancies exist in diseases registered as a hospital diagnosis within 2 years before death and underlying and multiple causes of death recorded, except for cancers.
- At population level, however, causes of death represent reasonably well which diseases are most common at the end of life. Multiple causes of death performed only slightly better than underlying causes of death.

What this adds to what was known?

- Previous studies suggested that cause-of-death analysis may not sufficiently represent the complex burden of morbidity at the end of life. Our study confirms the expectation of a poor representation of diseases present in individuals but shows that the implications for cause-of-death statistics at the level of the population remain restricted.

What is the implication and what should change now?

- Causes of death, even multiple causes of death, appear unsuited for researchers aiming to investigate diseases present at the end of life in individuals. For policy makers requiring information on which diseases are most common in the population, however, frequency ranking according to the cause of death appears reasonably informative.

causes of death resulted in altered conclusions regarding the relative importance of specific diseases [9]. Similar results were found also for other countries [10,11].

What these studies show is that multiple causes of death provide more complete information on diseases present at the end of life in individuals than the underlying causes of death alone. Other studies showing variation in the accuracy of the reporting of secondary causes of death, however, suggest that also multiple causes of death may not provide a complete overview of diseases present at the end of life in individuals [11,12]. A study by Johansson et al. showed that for one-third of the persons who resided in hospital within 1 year before death, the main diagnosis was not mentioned on the death certificate as either an underlying or a contributing cause [13]. What has not been investigated is to what extent underlying and multiple causes of death represent diseases most common at the end of life at population level.

Our aim was to investigate to what extent underlying and multiple causes of death represent end-of-life morbidity in individuals and at population level. We used underlying and multiple causes of death data for all Dutch inhabitants who died in 2005 at the age of 50–84 years, linked at the individual level with information regarding hospital diagnoses. We assessed to what extent individual hospital diagnoses registered within the last 2 years of life are in agreement with diseases recorded in underlying and multiple causes of death. Prevalence and ranking of underlying and multiple causes of death are compared with those of hospital diagnoses.

2. Methods

2.1. Study population

For our analyses, we used nationwide individually linked data from the National Medical Registration and the Cause of Death Registration. We intended to use data as recent as possible, but as the coverage of the National Medical Registration strongly declined after 2005, we chose all persons who resided in the Netherlands and died in 2005 (n = 136,385) as our base population. From this base population, persons aged 50 years and older were selected (n = 128,049, 78%). Although the number of co-occurrences is generally expected to steadily increase with age, in our data, the number showed a decline at age 85 years and above (Fig. 1) [11,14]. As this decline was expected to reflect limitations of our data rather than an actual decline, the analysis was restricted to the age of 50–84 years. The study population consisted of 48,671 males and 38,316 females who on average died at the age of 72.0 and 73.6 years.

2.2. Data sources

Data from the Dutch Cause of Death registration and the National Medical Registration were linked on the basis of personal identification numbers contained in both sources. The Cause of Death registration is governed by Statistics Netherlands (www.cbs.nl). Data are collected through a legislative system in which a physician or an autopsist provides one underlying and up to three secondary causes of death on a death certificate for every decedent. Coding of causes of death is done by Statistics Netherlands according to World Health Organization coding rules given in the 10th revision of the International Classification of Diseases [1]. In our analysis, multiple causes of death data consisted of the underlying and secondary causes of death reported for each individual.

To investigate to what extent underlying and multiple causes of death represent end-of-life morbidity, information from the National Medical Registration was used as the reference. This registration is governed by Dutch Hospital Data (www.dutchhospitaldata.nl) and contains information on the main reason for admission as recognized at the end of hospitalization or responsibility period for both clinical and one-day admissions. Each disease present at the end of life of each individual was ascertained in accordance