Reviewer's report

Title: Dying from cancer or other chronic diseases in the Netherlands: ten-year trends derived from death certificate data

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Reviewer: Robert Anderson

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I agree with the authors that death certificate data is generally underexploited for scientific research and applaud them for using the data to inform this important topic. That said, the issues associated with the use of death certificate data are somewhat more complex that I think the authors realize.

• Major Compulsory Revisions

1. The authors need to make a clear distinction between chronic diseases and chronic complications of diseases. A disease may be chronic, but its complications may be acute. The classic example is the acute myocardial infarction. The MI is an acute complication of ischemic heart disease, a chronic disease. Thus, a person who died from an acute MI would appropriately be said to have died from a chronic disease. The authors seem to be excluding these when they refer in the paper to “chronic diseases.” With regard to palliative care, the distinction that needs to be made is between acute and chronic complications of chronic diseases. It is those dying of chronic complications, of course, that are of most interest, because these are amenable to palliative care. The problem is in identifying those that died from a chronic complication of an underlying chronic disease. Generally, the complication should not be the underlying cause of death. Complications such as heart failure, renal failure and liver failure are all undesirable underlying causes because each can be caused by various underlying diseases. For example, heart failure is a common complication of ischemic heart disease, but may also be caused by other underlying conditions. If such a case is properly certified, heart failure would be reported as due to ischemic heart disease and ischemic heart disease would be selected and coded as the underlying cause. However, sometimes certifiers either do not know the underlying cause, or they fail to report it. In these cases, where only heart failure is reported, heart failure will be selected and coded as the underlying cause. The authors do include heart failure in their list of chronic diseases. However, they only include cases where heart failure was reported as the underlying cause. This will grossly underestimate the deaths due to heart failure as many will be assigned to underlying causes such as IHD, arrhythmias, hypertension, diabetes, etc. In the US, heart failure is reported as a complication about 5 times more often than it is assigned as the underlying cause. A better strategy is to look for any mention of the chronic complication on the death certificate. Of course, this is only practical if the Netherlands codes multiple causes from the death certificate in addition to the underlying cause. I do not know if this is the case. The authors should, in any case, think about these issues and how to deal with them in the
context of this study.

2. Page 5 – The authors divide cerebrovascular disease mortality into acute and non-acute deaths. I understand that the authors are trying to divide those who died from acute complications from those who died from chronic complications, although this needs to be better explained. They cite Hartmann et al to justify assigning one-third of the deaths as acute. However, after reviewing the Hartmann et al paper, I do not find evidence for this. I wonder if perhaps the authors meant to reference another article. I wonder also why the authors did not try to do this for ischemic heart disease as well given that some of the complications are acute and others chronic.

3. Page 4, methods section – I believe that cause of death is coded at the central statistics office, ie, CBS. The certifying physicians do not code cause of death and therefore, they should not be concerned about the WHO coding guidelines. In addition, while one disease or event is coded as the underlying cause (the authors should refer to this cause as the “underlying” cause rather than as the “primary” cause), the certifying physician is encouraged to report other complications and contributing conditions as well. On this same topic, on page 10, the authors seem to imply that ICD-10 is used as a template for physicians to certify the cause of death. And, on page 11, the authors state that “…ICD-10 is always used when death certificates are filled out…” This is not the case. While I am not exactly sure how things are done in the Netherlands, I doubt that physicians typically consult ICD-10 when filling out the death certificate. Physician certifiers are generally encouraged to use their own terminology to describe the cause of death. The coders then are tasked with assigning the appropriate ICD-10 codes based on the terminology provided.

4. I have some questions about the cause of death codes that appear in the supplemental table:
   a. Dementia – F00 and F02 are what are called “asterisk codes” and are not typically used for mortality coding, at least not for the underlying cause. My understanding is that the Netherlands does not code asterisk codes as the underlying cause. The asterisk flags codes that describe diseases that are also coded elsewhere. In this case, the important condition is Alzheimer’s disease which, for mortality, is coded to G30 (F00 is the asterisk code). If the authors are using F00-F03 for dementia, then they are only capturing F01 (vascular dementia) and F03 (unspecified dementia). They are missing Alzheimer’s disease, which I believe should be included in this category.
   b. Chronic kidney disease – why not include N05 (unspecified nephritic syndrome) and N19 (unspecified renal failure)? N12 is included, which is not specified chronic or acute (tubulo-interstitial nephritis). I would think one would want the unspecified as many of these will indeed be chronic renal diseases.
   c. Chronic liver disease – why not include K71 (toxic liver disease) or at least some of the subcategories, many of which involve chronic liver conditions? Also, K72.0 is clearly defined as acute and subacute hepatic failure and probably ought to be excluded.
   d. Other disorders of the central nervous system – G70 (myasthenia gravis and
other myoneural disorders and myopathies) and G71 (primary disorders of muscles) are neuromuscular diseases and not diseases of the central nervous system (which includes only the brain and spinal cord). The title needs to be revised to describe these properly – I suggest “Neuromuscular diseases” (or disorders).

e. Heart diseases – heart diseases (in addition to heart failure), including ischemic heart disease, valve disorders, cardiomyopathy, arrhythmias, etc., really should be included as a category on this list…or there should at least be a justification for not including them. Heart diseases result in both acute and chronic complications amenable to palliative care. These include most prominently, heart failure, as explained above. Of course, the problem is identifying how much of this category to assign to chronic complications. Most will probably be acute (acute MIs), but I suspect a significant proportion will be chronic (primarily heart failure). In any case, this should be discussed in the paper.

**Level of interest:** An article of importance in its field

**Quality of written English:** Acceptable

**Statistical review:** No, the manuscript does not need to be seen by a statistician.

**Declaration of competing interests:**

I declare that I have no competing interests.