INACCURATE DEATH CERTIFICATES CAN KILL YOU

Underreporting of Alzheimer's Disease
Deprives Medical Researchers
of Critical Funding

The significance of accurate cause of death information on death certificates cannot be overemphasized. Analyses of reported causes of death form the backbone of vital national health statistics. Death certificates are used by governments worldwide to set priorities for healthcare funding and to appropriate money for critical medical research of diseases in specific categories.

My mother had severe Alzheimer's dementia for over a decade. In 2017, she passed away from Alzheimer's disease in a nursing home, unable to move, speak, or even track objects with her eyes. Aside from the effects of Alzheimer's disease, she was physically healthy. A brain autopsy confirmed the diagnosis of advanced Alzheimer's dementia, yet the term "Alzheimer's" or "dementia" does not appear anywhere on her death certificate. Instead, "cardiopulmonary arrest" was her stated cause of death. In addition, her death certificate incorrectly states that no autopsy had been performed.

I have been a pathologist for over three decades and am well versed in determining causes of death. When I questioned my mother's physician, who had cared for her for years, why he omitted the diagnosis of dementia from her death certificate and used the term "cardiopulmonary arrest"—an incorrect term for a cause of death on a death certificate, as will be discussed, below—his reply was, "I've been using that term for over 40 years and nobody ever told me there was any problem with it," and he would not amend it. This physician wrote the exact same inaccurate cause of death on my father's death certificate, three years later, and tried to dissuade me from requesting autopsies after my parents died, questioning why I would want to subject their remains to such a procedure.

Dementia is a global health challenge and the number of people living with dementia is predicted to double by 2030.[1] It is estimated that, worldwide, 50 million people have dementia. Alzheimer's Disease is the most common cause of dementia, likely accounting for 60–70% of cases.[2] More than 6 million Americans reportedly are living with Alzheimer's Disease, and this number is projected to rise to nearly 13 million by 2050. It is estimated that one in nine people age 65 and older (11.3%) has Alzheimer's dementia. But Alzheimer's is not just memory loss. Alzheimer's kills. Alzheimer's dementia kills more people than breast cancer and prostate cancer combined, and 1 in 3 seniors dies with Alzheimer's or another dementia.[3] Dementia and Alzheimer's

Disease usually occur in older patients, and more people are surviving other illnesses and living longer. According to a World Health Organization report in 2015, estimated worldwide prevalence of dementia and the estimated total number of new cases of dementia each year globally (nearly 7.7 million) imply one new case every four seconds.[4]

Accuracy of Cause of Death information on death certificates is of paramount importance, because cause of death statistics guide how public health resources are allocated, e.g., to direct public health projects and to fund medical research and hospital-based programs. However, several studies have demonstrated that death certificates are often completed incorrectly, leading to inaccurate mortality statistics being ascertained from death records. Unfortunately, the use of death certificate data to monitor patterns of mortality from dementia has been significantly limited by well-documented underreporting of Alzheimer's Disease on death certificates.[1,5,6] A 2014 National Institute on Aging (NIA)-funded study of 2566 people aged 65 and older concluded that deaths attributable to Alzheimer's Disease far exceed the annual numbers reported by the Centers for Disease Control and Prevention (CDC), possibly 5 to 6 times higher. [7] According to mortality data from the CDC, there were 121,499 deaths in the United States due to Alzheimer's Disease in 2019, making Alzheimer's Disease the 6th leading cause of death in this country.[8] However, these data were based on death certificates, and the CDC also acknowledges that the number of reported deaths due to Alzheimer's Disease actually is much greater. Data in the 2014 NIA study suggest that Alzheimer's Disease may be the 3rd leading cause of death, after heart disease and cancer. Citing more than 20 years of previously reported research, authors of this study echo that dementia often is omitted as an underlying cause of death on death certificates.[7]

The complications that can arise from inaccurate data on a death certificate are far-reaching. Records of death are part of the vital statistics that governments utilize to plan for health care, including setting national, regional, statewide, and local priorities for health care funding and medical research. In addition, death certificates can have significant impacts on knowledge of family medical history, settling estates, determining insurance and pension benefits, providing evidence in court cases, and providing outcome data for major research studies.[9]

When a person dies, the death certificate, containing the cause or causes of death, are filed with the state's Bureau of Vital Statistics. This information is then forwarded to the National Center for Health Statistics of the CDC, which compiles and reports the data yearly as the official U.S. mortality numbers and leading causes of death. The individual responsible for completing the medical portion of the death certificate, typically a physician, is called the "Medical Certifier of Death." If the Medical Certifier does not complete or fill out the death certificate properly, the document should be rejected by

the official public registrar of vital statistics in the jurisdiction in which the document was completed.[10] However, my mother's erroneous death certificate—containing inaccurate terminology—was not rejected or even questioned, nor had any of the death certificates improperly completed by her physician, a geriatrician who had been using incorrect terminology on death certificates over the course of 40+ years.

When an autopsy is performed, some institutions have policies to ensure that the physician performing the autopsy consults the Medical Certifier of Death, and both assume responsibilities for signing the death certificate. The purpose is to prevent discordance between the autopsy report and the cause of death listed on the death certificate.[11] In my mother's case, not only did communication between the pathologist and Medical Certifier of Death not occur, her death certificate erroneously states that no autopsy was performed, despite the Medical Certifier of Death (her physician) approving the procedure.

Many studies have reported high rates of errors in the data reported on death certificates. In 2010, the New York City Health Department conducted a study of death certificates and found a 91% overreporting of coronary heart disease as the Cause of Death.[12] This means that overreported conditions, like heart disease, can be inaccurately weighted in public health decisions, while underreported diseases may be overlooked and disproportionately underfunded. Several other studies have estimated that errors are made on death certificates in at least 33% to 46% of cases.[13-16] A 2016 report of a study of 601 death certificates from the Vermont Electronic Death Registration System detected major errors in 51% of the certificates. Trained Medical Examiners reviewed the certificates and changed ICD-10 diagnostic codes in 93% of cases, of which 348 of 601 (60%) had a change in the underlying cause-of-death code. The conclusion was "Error rates on death certificates in Vermont are high and extend to ICD-10 coding, thereby affecting national mortality statistics."[17]

The Cause of Death section on a death certificate consists of two parts. Part I is a sequential list of conditions leading to the immediate cause of death. Part II is where other significant illnesses or conditions that may have contributed to the death, but may not have been direct causes of it, should be listed. More than one condition may be listed. Many patients have multiple illnesses and the physician should use knowledge of the patient and clinical judgment to best determine the most likely causes and sequences. In my mother's case, "dementia" was not listed in any of these Parts.

The immediate Cause of Death on a death certificate should be the final disease directly causing the death. It should not be the mode of dying. For example, terms such as "cardiac arrest," "cardiopulmonary arrest," and "respiratory arrest" should NOT be listed as a Cause of Death. These are highly overutilized terms erroneously listed as causes of death. Instructions for properly completing death certificates clearly state that these

phrases must not be used.[18,19] In fact, the CDC's formal U.S. Standard Certificate of Death contains these clear instructions: "DO NOT enter terminal events such as cardiac arrest, respiratory arrest, or ventricular fibrillation…." and "The terminal event (for example, cardiac arrest or respiratory arrest) should not be used."[20] This clearly is not being enforced, and it is not surprising that there is a significant over-representation of cardiovascular diseases as the primary cause of death on death certificates.[11,21,22]

When a person dies in a hospital, physicians unfamiliar with the person's medical history, for example, a hospitalist or emergency department physician, should make an effort to consult another physician who has more knowledge of that patient prior to completing a death certificate, yet this rarely happens. These busy physicians typically do not know the full stories behind patients' fatal illnesses. As a result, conditions related to dementia, e.g., aspiration pneumonia, may be listed as the primary cause of death while the underlying cause, dementia, may not be documented.[23]

In England and Wales, the number of reported deaths from dementia has increased in recent years.[24] In all probability, this largely was a consequence of initiatives put in place in 2013 to 2014, such as the Prime Minister's "Challenge on Dementia"[25] and the government's mandate to NHS England, which included a goal to more consistently formally document the diagnosis of dementia.[26] In addition, updates to the framework used to code causes of death took place in 2011 and 2014. In 2012, the reported three leading causes of death in England and Wales were circulatory (heart) diseases, cancer, and respiratory diseases.[27] In 2015, Alzheimer's Disease and dementia became the reported number one cause of death in England and Wales, replacing ischemic heart diseases.[28] In 2020, (January to November, prior to the COVID pandemic), the leading cause of death in both England and Wales continued to be Alzheimer's Disease and dementia.[24]

In addition, a study of death certificates in England and Wales led to a government announcement of a new system of medical examiners, beginning in 2019, with the intention of delivering more accurate and comprehensive documentation for deaths. This afforded an unprecedented opportunity to create a system to identify deaths due to problems in health care and to address avoidable deaths.[29] Perera *et al*.[1] concluded that this study provides evidence that changes in death certification practices regarding dementia likely contributed to the increase in the reported prevalence of dementia using mortality data.

In 2017, The Texas Department of State Health Services (DSHS) began partnering with Texas A&M University School of Public Health to develop online training for professionals responsible for completing death certificates. The DSHS Vital Statistics Section (VSS) reviewed literature, conducted focus groups, and led a panel of experts to assess the state of death data quality in Texas. As a result of these assessments, the

DSHS VSS determined there was a need for training, improved communications, and modern electronic systems for completing death certificates. The physicians' focus group showed little awareness among some physicians as to the importance of the death certificate and how to properly complete the cause of death section. Some physicians stated that lack of knowledge of how to use the electronic reporting system was an impediment to their signing death certificates.[30] This often leaves death certificates to be completed by junior medical residents who have minimal training and knowledge of the patient, a practice that I personally have witnessed. In Wexelman's study of NYC resident physicians, nearly half admitted that they knowingly reported an inaccurate cause of death, either because they didn't know the patient's medical history or they selected what they thought was the best of limited choices on the hospital's death certificate form.[12] In 2019, a new electronic system to document and create death certificates, TxEVER, replaced a decade-old system in Texas. The new TxEVER system allows DSHS to monitor and modify error messages that appear when Medical Certifiers fill out forms and provides a more user-friendly process for filling out death certificates, resulting in more accurate data.[31]

The lack of training of Medical Certifiers frequently is cited in the literature as a common barrier to accurately reporting death certificates.[22] Physicians are responsible for determining the cause and manner of death, yet they seldom are formally trained for this responsibility in medical school or residency. The consequence is frequent, yet avoidable, errors. Studies suggest that seminars and workshops teaching proper death certificate reporting procedures can significantly improve documentation accuracy.[11,16,21]

RECOMMENDATIONS:

Immediate Recommendation:

My immediate recommendation is to improve the accuracy of cause of death reporting on death certificates through Medical Certifier training and support.

Based on available data, I call for all medical students, residents, licensed physicians, and other medical professionals permitted to complete cause of death information to receive training on how to correctly fill out death certificates. Students and residents should learn this during their training and should be taught why death certificates are so important for national mortality statistics and medical research funding, and practicing physicians should complete a review of the death certificate process as a part of their ongoing commitment to continuing medical education (CME). To this end, I highly recommend a 50-slide online training module created by the CDC, National Center for Health Statistics, complete with useful examples and quizzes for self-assessment.[32] In

my opinion, this is an outstanding, straightforward tool that should become part of mandatory CME training.

Other excellent resources exist. The CDC, National Center for Health Statistics also published a handbook, “The Physicians’ Handbook on Medical Certification of Death,” that contains instructions on how to properly complete a death certificate.[33] The National Association of Medical Examiners has created a free cause of death mobile app that serves as a quick tool for clinicians filling out death certificates.[34]

Each state’s medical licensing board has its own set of licensure requirements for continued accreditation so that medical professionals remain in CME compliance. In New York State, physicians are mandated to complete a training course related to infection control every four years,[35] and prescribers licensed to prescribe controlled substances must complete at least three hours of training in pain management, palliative care, and addiction once every three years.[36] Adding a short, mandatory training/refresher course about death certificates, to be completed every few years, likely would have a profound positive impact on research funding and the accuracy of disease statistics and, possibly, prevention and/or treatment of dementia.

Additional Recommendations:

Improving the quality of cause of death information necessitates a broad approach. My recommendations for additional sources of improvement to this system include the following:

- Provide a user-friendly online system to file death certificates, including prompts that would provide immediate assistance and feedback during the data entry process.
- Enhance the capacity and expertise of the staff of states’ Bureaus of Vital Statistics offices to improve evaluation of cause of death reporting.

FINAL COMMENTS

Properly completed death certificates are as critical to public health as accurate medical charts are to the care of patients. Omitting the terms “Alzheimer’s Disease” or “dementia” on death certificates, even if only as a “significant condition” in Part ll of the document, has tremendous implications. According to the CDC, “Quality of mortality data is largely dependent on proper and thorough completion of death certificates by certifiers.” [37] In order to be considered as a cause of death in CDC mortality data,

Alzheimer's Disease MUST be listed on death certificates. If Alzheimer's Disease/Dementia were more accurately reported on death certificates, the National Institutes of Health (NIH) very likely would rank Alzheimer's Disease as a higher priority for research funding. Actual NIH **funding for Alzheimer's Disease reportedly was under $600 *million*** for fiscal years (FYs) 2012-2015, in contrast to NIH funding for the CDC's top two reported leading causes of death, heart disease and cancer: **research funding for heart disease topped $3 *billion* in each of those same 6 years, and cancer received more than $5 *billion*** for FY 2012-2015. Also, those totals are in addition to separate NIH funding of $600-$800 million for research in breast cancer and additional hundreds of millions of dollars in funding for other specific cancers in each of those same years.[38]

I can only imagine how much further along we might be in our understanding of the causes of Alzheimer's Disease and how we might treat it effectively, or possibly even prevent or cure it, if annual research funding for Alzheimer's Disease were at the same levels as annual research funding for heart disease and cancer. It's too late for my mother, but maybe not for you or those you love.

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