

Can we tell what patients die of? Does it matter?

Matthew Anstey

In this issue of the Journal, Ridgeon and colleagues attempt to create a classification system for causes of death in critical care for research purposes.¹ Their article reminded me of a medical emergency team (MET) call that I attended recently. When I arrived, there was a frail, cyanosed elderly woman, curled up in bed, surrounded by buzzing nurses and doctors. She had been found unresponsive in bed, was making agonal gasps and had no palpable pulse, although the monitor showed a slow ventricular escape rhythm. Staff were uncertain how long she had been in this state, but she had been in hospital for 2 weeks after admission with heart failure. My assessment was that, despite the lack of a pre-existing treatment limitation order, the team should not perform cardiopulmonary resuscitation. It was extremely unlikely that it would be successful and allow this woman to return to a meaningful life, so she was moved to a quiet room and died peacefully a few minutes later. Afterwards, when the medical registrar rang his consultant to inform him of what had happened, a question that arose was, "What should we put on the death certificate?"

Entwined in our search to conquer death lies the possibility that understanding how someone died might give us clues as to what we could "fix" next time. The cause of death is dryly captured on the death certificate — a form that serves two purposes: as a legal document and to provide information for demographic and health purposes, giving insights into diseases and factors contributing to reduced life expectancy.²

The origin of the death certificate lies in the English Bills of Mortality. Their publication began in 1665 in London during the bubonic plague, when the weekly publishing of numbers of burials in the London parishes highlighted the areas that healthy citizens should avoid.³ In 1837, the General Register Office was set up to record births, deaths and marriages, as a response to increasing concern that poor registration of these events undermined property rights, and from the increasing recognition of the association between poor living conditions and life expectancy.⁴ The chief statistician, William Farr, developed a standardised list of causes of death, which were a great improvement on 18th century causes such as "overjoy, blasted, or king's evil".⁵ Several decades later, medical practitioners were required to complete the forms.

By 1910, the International Classification of Diseases (ICD) was used to attempt to further standardise the diseases recorded on the death certificate. In the early days of Australia, there were state-based death registers, which

were combined in 1964 to create the National Mortality Database.⁶ Every year, the Australian Bureau of Statistics produces a cheery top 20 causes of death and years of potential life lost, by ICD code, and the Australian Institute of Health and Welfare National Death Index is an opportunity for linking the death database for epidemiological studies.

Data linkage from death databases appears to provide amazing opportunities for understanding associations between mortality and various health-related factors such as diseases, treatments received and socioeconomic factors. However, one critical element in this relates to the quality of the information provided on the death certificate. There are guidelines to help doctors complete death certificates but research suggests that many doctors do not receive proper training to undertake this task correctly and distinguish between the *disease or condition directly leading to death* and the *antecedent causes*.^{2,7-9} Added to this is the complexity of assigning one of the 8000-odd ways one can die, as tabled in the ICD-10. Furthermore, doctors do not know the cause of death more often than we like to admit. Post mortem studies have shown significant disagreement on the cause of death between the autopsy and death certificate in up to 29% of cases.¹⁰ Researchers have called for training of clinicians in completing death certificates.^{11,12}

Several research articles have used the specific cause of death as an outcome measure, instead of using mortality, in an effort to obtain mechanistic insights into the processes occurring.^{13,14} Recognising the lack of validated systems being used in recording the specific cause of death, Ridgeon and colleagues have sensibly attempted to create one. Their article shows that the Intensive Care Unit Deaths Classification and Reason (ICU-DECLARE) system provides a simple and reproducible way for critical care researchers to reliably classify cause of death. The proximate cause of death has a systems approach, which is potentially useful in understanding the role of different treatments. Ridgeon and colleagues found substantial agreement between ICU specialists on the proximate cause of death, and moderate agreement on the underlying cause of death. This system is an important step forward, but it is important to note that there still was not "almost perfect" agreement between respondents — there are judgements being made and no gold standard exists (apart from a post mortem). One useful lesson from the study is that the ICU specialists had better agreement than the research coordinators, possibly because ICU specialists have had experience in determining cause of death previously.

As critical care clinicians, our role is not always to prevent death. Our priority for the patient I saw at my recent MET call was to provide a dignified death, not perform myriad tests to characterise the exact cause of death. That does not mean we cannot learn from death. A standardised classification of the mechanism of death could be a powerful tool for future research. The complexity of the ICD-10 makes it too difficult for routine use, but mapping the ICU-DECLARE model to the ICD-10 would provide opportunities for further standardisation and linkage in the future.¹⁵

Competing interests

None declared.

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