

RESEARCH LETTER

High Error Rates in Coding Causes of Death in Adults With Congenital Heart Disease



Mortality statistics calculated from death certificates are vital for health systems planning, informing strategic priorities, and funding. Despite this, the cause of death coding is often done by junior nonspecialist doctors unfamiliar with the decedent, under significant time pressure and using decades-old coding systems lacking in detail. Congenital heart disease (CHD) affects hundreds of thousands of children and adults worldwide.¹ CHDs are often multiple, complex, and comorbid. This study aimed to determine the error rate in coding causes of death in adults with CHD.

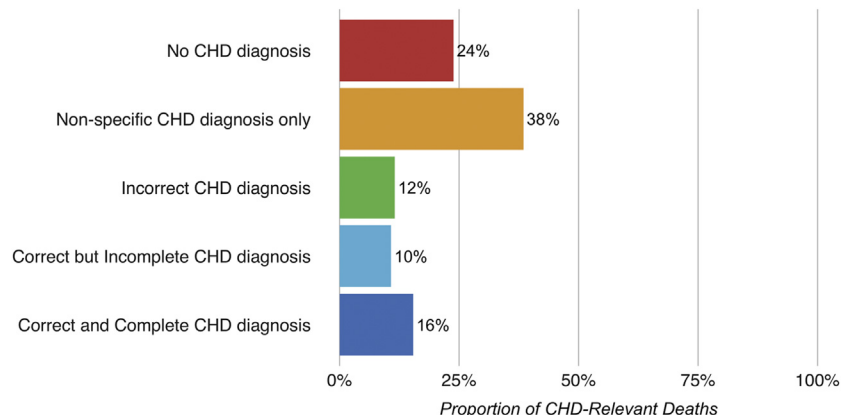
We studied 171 consecutively deceased adult CHD (ACHD) patients from our ACHD center. We excluded those who had heart transplantation ($n = 3$), with isolated patent foramen ovale ($n = 6$), a very minor ventricular septal defect ($n = 1$), or insufficient information to determine relevance of CHD to death ($n = 7$), leaving 154 eligible patients. Average age at

death was 42 years (interquartile range 30-57); 56% were male. Causes of death listed in the National Death Index (NDI) were compared to the actual causes of death as assessed by ACHD specialists, familiar with each decedent. Patients who died of causes unrelated to their CHD ($n = 24$) were excluded. This study was approved by the Institutional Review Board at the Royal Prince Alfred Hospital, Sydney (Protocol X18-0189).

We considered any CHD diagnosis to be “nonspecific” if a more specific International Classification of Diseases, Revision 10, code existed but was not used. All CHD-relevant deaths ($n = 130$, 84% of cohort) were separated into 5 groups.

1. No CHD diagnosis included in the NDI cause of death list;
2. Nonspecific CHD diagnosis only;
3. Incorrect CHD diagnosis (if any incorrect CHD code was found, the patient’s diagnosis as a whole was considered incorrect);
4. Correct but incomplete CHD diagnosis (if any CHD diagnosis in the NDI matched the ACHD database and there were no incorrect CHD diagnoses, but relevant diagnoses were missing); or
5. Correct and complete CHD diagnosis.

FIGURE 1 Accuracy of CHD Cause of Death Coding in the Australian National Death Index



The nationally registered cause of death codes for 130 consecutively deceased CHD patients seen at the quaternary ACHD center in Sydney, Australia, were compared to the true causes of death. CHD = congenital heart disease.

Cause of death records were incomplete and/or incorrect for more than 80% of CHD-relevant deaths (Figure 1). One-quarter had no CHD recorded at all. When CHD was listed as a cause of death, half the time, a nonspecific diagnosis code was used where a more specific diagnosis code was available. More than 10% of patients had an incorrect CHD diagnosis.

Patients were much more likely to have a nonspecific CHD diagnosis listed than a specific one, reflecting the difficulty of appreciating the full spectrum of CHD for nonspecialists unfamiliar with the decedent. While the rate of incorrect CHD coding is similar to previous literature on all causes of death,²⁻⁵ the rate of nonspecific coding reported here far exceeds previous estimates.⁴

While the sample size for this study was relatively small, personal knowledge of patients and extensive, regularly audited clinical records allowed us to determine the relevance of CHD and confidently classify more than 95% of the study cohort. Highly centralized care of CHD in Australia ensures that our cohort is representative of the urban and rural CHD population. Furthermore, the Australian setting allows the use of the Australian NDI: a comprehensive database of all deaths, nationwide.

Future studies are needed to understand current pressures on junior doctors and hospital systems that lead to inaccuracies and nonspecific coding of CHD, as well as the precise impact that underestimated prevalence and lack of specificity have on health systems planning. In the meanwhile, researchers using mortality data must beware of prevalence underestimates and low accuracy.

In conclusion, CHD is substantially underrepresented in death certificates, and where it is recorded, it is usually nonspecific, incomplete, or inaccurate.

The completeness and accuracy of mortality information, especially for CHD, needs to be improved.

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The authors attest they are in compliance with human studies committees and animal welfare regulations of the authors' institutions and Food and Drug Administration guidelines, including patient consent where appropriate. For more information, visit the [Author Center](#).

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