Consequences of a Health System Not Knowing Which Patients Are Deceased

Health systems accountable for patients need to know patients’ vital status. Yet the electronic health record (EHR) often does not reflect death.1 We investigated what proportion of active patients a health system is unaware are deceased and encounters after death.

Methods | This quality improvement study included all seriously ill, continuity primary care patients (aged ≥18 years, ≥2 primary care visits during the prior year) in 41 clinics across an academic health system.2 Patients were followed up for 2 years or until November 2022, whichever was earlier. Death was recorded in the EHR by the usual health system protocol. On December 19, 2022, we compared the seriously ill primary care cohort alive according to the EHR against the California Department of Public Health (CDPH) Public Use Death File. Matching used an algorithm that calculated a score of 0 to 24 based on name, gender, and birth date, including fuzzy logic and partial scores; 23 was required for a match. The matched cohort was validated by medical record abstraction on a random 10% of the matched cases using EHR documents, information from other health systems, and internet obituary search.

We identified medical record encounters (letters, notes, orders, portal messages, telephone outreach, appointments, and refills) that occurred after death until December 19, 2022 (mean [SD], 19.8 [12.9] months after death). Each encounter among the 10% random sample was reviewed to identify those related to the death or postmortem paperwork. The proportion of death-related encounters within each encounter category was applied to the full sample to estimate encounters unrelated to death.

Results | Among 11,698 seriously ill primary care patients (mean [SD] age, 75.1 [15.0] years; 51% male), 2,920 (25%) were recorded as deceased in the EHR, and 676 (5.8%) were deceased according to the CDPH death file but marked alive in the EHR. Among the 676 patients not known to be deceased, 541 (80%) had an encounter or appointment outstanding after death. Patients not known to be deceased received an estimated 221 telephone calls and 338 portal messages unrelated to death. Among these patients, 221 received 920 letters concerning unmet preventive care needs (eg, flu shots, cancer screening), 166 patients received 226 other mailed correspondence, 158 patients had 184 orders placed for vaccines and other clinical care, and 88 medications were authorized in 130 encounters. Among 145 patients, 310 appointments were active after death; in total, 7,469 days elapsed between the date of death and the date of cancellation or no-show (Table).

Discussion | Nineteen percent of deceased patients were marked alive in the EHR and 80% had outreach: a mean (SD) of 3.4 (3.8) encounters and 11 (36) elapsed appointment days per unknown decedent. Not knowing who is dead hinders efficient health management, billing, advanced illness interventions, and measurement. It impedes the health system’s ability to learn from adverse outcomes, to implement quality improvement, and to provide support for families.

Yet unawareness of patient death is remediable because each state maintains a death file. In California, this file is available to health care facilities only in a form that contains inadequate specificity to inform clinically about death. In contrast, a more complete file is available “for purposes of law enforcement or preventing fraud.”3 Furthermore, the National Association for Public Health Statistics and Information Systems maintains a real-time fact of death service,4 but health care organizations have not been able to use it.

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Table: Health System Outreach, Appointments, and Medications Refilled After Death

<table>
<thead>
<tr>
<th>Encounter type</th>
<th>No. of patients</th>
<th>No. of encounters</th>
<th>Estimated No. of death-related encounters</th>
<th>Estimated No. of encounters excluding death-related</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appointment</td>
<td>145</td>
<td>310</td>
<td>0</td>
<td>310</td>
</tr>
<tr>
<td>Health maintenance letter</td>
<td>221</td>
<td>920</td>
<td>0</td>
<td>920</td>
</tr>
<tr>
<td>Mailed letter</td>
<td>166</td>
<td>226</td>
<td>0</td>
<td>226</td>
</tr>
<tr>
<td>Physician notes</td>
<td>11</td>
<td>15</td>
<td>15</td>
<td>0</td>
</tr>
<tr>
<td>Orders placed</td>
<td>158</td>
<td>184</td>
<td>0</td>
<td>184</td>
</tr>
<tr>
<td>Patient portal messages</td>
<td>214</td>
<td>374</td>
<td>36</td>
<td>338</td>
</tr>
<tr>
<td>Refill</td>
<td>90</td>
<td>130</td>
<td>0</td>
<td>130</td>
</tr>
<tr>
<td>Clinical or administrative</td>
<td>267</td>
<td>460</td>
<td>219</td>
<td>2329</td>
</tr>
</tbody>
</table>

a The number of estimated encounters related to death is based on encounters in the 10% sample medical record abstraction aimed at clarifying whether a patient was dead. Death-related encounters included condolence calls and encounters and outreach related to completion of death certificates and other paperwork. The proportion of death-related encounters in each outreach category was calculated for the full sample and subtracted from the number of encounters in the electronic health record to estimate the number of encounters excluding death-related encounters.
Limitations include that the analysis was performed in a single health system and may not apply to nonacademic systems or states that share linkable death data with health facilities. The follow-up period was modest; encounters for deceased patients would grow with time. Better awareness of vital status is needed for health systems to provide accountable care.

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Accepted for Publication: September 12, 2023.

Published Online: December 4, 2023. doi:10.1001/jamainternmed.2023.6428

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Statistical analysis: Sanz Vidorreta.

Obtained funding: Wenger.

Administrative, technical, or material support: Sanz Vidorreta, Dudley, Walling, Hogarth.

Supervision: Walling.

Conflict of Interest Disclosures: Dr Hogarth reported being funded by the California Department of Public Health to manage the electronic vital record system for California. No other disclosures were reported.

Funding/Support: Research reported in this report was funded through a Patient-Centered Outcomes Research Institute (PCORI) Award (PLC-1609-36291). The views presented in this publication are solely the responsibility of the authors and do not necessarily represent the views of PCORI, its Board of Governors, or its Methodology Committee. This Research was supported by the Biomedical Informatics Program at UCLA CTSI and funded by the National Institutes of Health through the National Center for Advancing Translational Sciences Grant (UL1TR001881).

Role of the Funder/Sponsor: The funders had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication.

Data Sharing Statement: See the Supplement.

Additional Contributions: Victor Gonzalez, BA, UCLA Division of General Internal Medicine and Health Services Research, provided administrative support. He received salary support from the PCORI award as part of the study team.


