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Knowing When Our Patients Are Deceased: Why Is It So Important?

Thank you for this opportunity to discuss how vital records can provide value to patients by making information available to their doctors and other care providers. I know there is interest and much discussion in next generation vital records registration infrastructure, but I wanted to highlight a relatively simple challenge, that if solved, would create significant value for patients and their care providers.

It may surprise you to know that today, in 2017, there is no national file that doctors and care providers can use to determine which of their patients is deceased. It is not that such a file does not exist. A national file with this information exists and is electronically available – but not in a way that allows healthcare professionals to systematically match those records against their electronic patient records to have the correct vital status of the patients for whom they rendered care. As a care provider myself, this is a disappointing situation.

I have practiced Internal Medicine in an academic medical institution in California for 25 years. I have also had the privilege of working with the California Department of Public Health to evolve a 150-year old paper-based death registration process to a fully electronic process for 250,000 death registrations annually. My team developed and currently manages the California Electronic Death Registration System. The system enables the fully electronic registration of one in every 10 deaths in the US. We are also one of the first jurisdictions in the US to integrate an electronic death registration system and an electronic health record (EHR) systems. We recently demonstrated the ability to submit data electronically to the National Center for Health Statistics (NCHS), and to do so immediately upon state registration of a death, dramatically decreasing the time from death event to data submission to NCHS.

I am proud of the collaborative relationship between the University of California, the California Department of Public Health and the National Center for Health Statistics -- we accomplished what some thought was impossible.

However, as a physician, I am disappointed that despite having an advanced electronic health record system, and having my state with a broadly used electronic death registration system, I do not have access to an electronic national file to know which of my patients have passed away. The EHR I use can perform speech-to-text conversion of dictations, electronic prescribing to any of thousands of pharmacies, and medical record exchange with hospitals across the US. It gives me a myriad of metrics, but the one important statistic it cannot provide reliably is mortality.

The death of a patient is a key event for them, their family, and their friends. It is also important to their doctor. My practice of medicine benefits when I, as a physician, am aware of the passing of my patients.

Among many, there are two benefits that come from this knowledge that I would like to highlight today. It is important to know a patient passed away to avoid distressing family with poorly timed healthcare related communication. Additionally, the ability to accurately determine mortality rate for a patient populations is fundamental to improving quality of care.

I hope many of you understand how physicians feel when our office sends a medical appointment reminder to a patient for whom we have cared for many years, only to have a distressed mourning spouse call you not understanding why you don't know of the passing of their loved one. Imagine how that spouse feels when their doctor office sends a medical bill for their deceased spouse yet never sends a card or letter expressing condolences. After all, their bank knew within days. Why not their doctor?

When my patients pass away, our relationship does not end, it only changes. It changes from one in which I am helping them, to one in which they are helping me practice better medicine. Knowing about a patient's death is a critical piece of data in helping me be a better doctor for others. Medical practice is not static, it is a process of continuous improvement, and mortality rate is fundamental in understanding the quality of the care I deliver to my patients.

The mortality rate of patients in my practice and across our University's medical practice is a key to quality measures. For example, 30-day re-admission is an important quality measure. 30-day post-discharge mortality is even more important. Some patients return to our hospital but many will go to other hospitals in the area or not come to the hospital at all. For those who unfortunately pass away, I have no way of knowing an accurate count. They don't all pass away in my hospital. This issue is the same for every quality metric that involves survival (or mortality) as a statistic. It affects every aspect of care. For example, we have no way of knowing which of our patients on opiates has passed away – most do not pass away in our hospital. How are we to learn to optimize our prescribing of narcotics without access to that information?

If we, as healthcare providers, have no way of accurately measuring mortality of our patient population after discharge from the hospital, how can we optimally decrease 30-day mortality?

In the recent past, the Social Security Administration (SSA) made available a "death master file" (DMF), which could be used to determine vital status of patients. However, on Nov 1, 2011, the SSA had to remove protected state death records, resulting in the removal of 5% of old record and exclusion of 40% of new death records from the file. Before this, the DMF provided an accessible source of national vital status data and was routinely used to monitor post-discharge outcomes [1]. The NAPHSIS EVVE Fact of Death (FOD) service is a step in the right direction, however, it does not have data from 17 jurisdictions, and would cost over $120,000 annually for monthly checking of the 2.4 million records in my hospital's EHR [2]. This is substantially more than the cost of the DMF in the past. Starting in 2016, California began providing a monthly non-comprehensive death file to healthcare organizations for $120/year, or $12/month. This file only contains California deaths and does not include social security number, making matching less complete and more difficult. Having a national file would be ideal.

The Centers of Disease Control National Death Index is a complete mortality file that could be made available to healthcare organizations to match against their electronic health records to determine vital status – but that is currently not an allowed use. Although I recognize it is not an easy nor quick process, and that it involves dealing with heterogeneous jurisdictional privacy laws, my experience in implementing an electronic vital records system in California has taught me nothing is impossible. We just need to set the goal, be patient, and be persistent. It can happen.

[1] Graca B, Filardo G, Nicewander D. Consequences for Healthcare Quality and Research of the Exclusion of Records from the Death Master File. Circ Cardiovasc Qual Outcomes. 2013;6:124-128.
[2] NAPHSIS Electronic Verification of Vital Events (EVVE) Fact of Death (FOD) service. https://www.naphsis.org/evve-fod