

Missed and Delayed Diagnoses of Non-COVID Conditions — Collateral Harm from a Pandemic

By Susan Carr, Senior writer

In addition to having killed more than 130,000 Americans and afflicted millions of others, the coronavirus pandemic has caused an unknown number of missed or delayed diagnoses for non-COVID conditions.¹⁻⁶ An interventional cardiologist at Columbia says this collateral damage, which constitutes a parallel epidemic of harm, is “one of the yet-to-be-told stories of the Covid-19 pandemic.”^{1(p2369)}

The pandemic has interrupted normal patterns of health care in the United States, including temporary suspension of some medical services beginning in March, leading to missed and delayed diagnoses. The pandemic also triggered economic recession, unemployment, and loss of health insurance, causing some patients to avoid seeking medical care altogether. And for many, fear of the new coronavirus recast healthcare facilities as places of peril, not assistance.

A new typology for classifying diagnostic errors in the context of COVID-19 includes collateral harm as an effect of the pandemic.⁷ Each category of error reflects situations related to COVID-19, such as problems with diagnostic testing, lack of knowledge, clinicians and systems stressed by a “surge” of critically ill COVID-19 patients, and preoccupation with the new disease that results in anchoring on that diagnosis. Under “collateral harm,” authors Tejal Gandhi, MD, and Hardeep Singh, MD, include diagnoses missed or delayed because patients are unwilling or unable to access medical attention due to fear of COVID-19.

Leading Indicators in Emergency Medicine

Although hospitals expected COVID-19 would interrupt routine medical care, many were surprised to see a sudden, dramatic decline in the number patients presenting to emergency departments (EDs). In “Where Are All the Patients?” a hospital in California’s Central Valley reported that ED volume fell by 50% in March, after shelter-in-place was mandated.⁴ The hospital welcomed the decline to a degree, as it anticipated a surge COVID-19 patients, but it noticed “alarming statistics”^{4(p2)} as the trend continued. The hospital could see in admissions data that the decline included both high- and low-acuity emergencies. Data from emergency medical services (EMS) confirmed that patients who really did need emergency service were staying home:

...EMS reported the highest-ever number of cardiac arrests in the field — 45% more than the previous month — suggesting that patients were waiting too long to seek cardiac care. Of note, all of these EMS heart patients tested negative for Covid-19.^{4(p3)}

Other health systems across the country reported similar patterns:

- EMS teams in Newark, New Jersey, made four times as many “on-scene death pronouncements”^{2(p18)} in April 2020 compared with April 2019.

- Kaiser Permanente Northern California, which provides care for 4.4 million people, reported the weekly rate of hospitalization for acute myocardial infarction “decreased by up to 48% during the COVID-19 period.”^{8(np)}
- In June, the U.S. Centers for Disease Control and Prevention (CDC) reported that ED visits nationally were 42% lower for a 4-week period (late March – late April) in 2020 than a similar period in 2019. ED volumes subsequently increased, moderating the decline to 26% compared to 2019 for the last week of May. CDC noted that the steepest drop off in ED visits occurred in pandemic hotspots.⁹
- The Department of Veterans Affairs (VA) compared hospital admissions data for 5-week periods before and after the declaration of a national emergency for the pandemic. It found an overall decrease of 42% following the declaration, including 52% fewer admissions for stroke and 40% fewer for myocardial infarction.¹⁰

Other countries also noted changes in emergency care during COVID-19 outbreaks. In Spain, 40% fewer emergency procedures were performed for heart attacks in late March compared with the same period in 2019¹¹, and a study of hospitals in Northern Italy showed a decline in hospitalizations for acute coronary syndrome (ACS) in the early phase of the outbreak.¹² The authors reported that mortality during the period, among other data, “raise the question of whether some patients have died from ACS without seeking medical attention during the Covid-19 pandemic.”^{12(p89)}

Emergency medicine was not alone in this trend. A poll performed by the Kaiser Family Foundation in May found 48% of U.S. adults sampled reported that they or someone in their household had postponed or skipped medical care due to the coronavirus outbreak.¹³

The US National Cancer Institute (NCI) studied pandemic-related delays in screening and treatment for breast and colorectal cancer and projected there will be approximately 10,000 “excess” deaths over the next 10 years. The model NCI used estimates a 1% increase over the expected one million deaths. Norman Sharpless, MD, director of NCI, suspects the estimate is conservative; among other factors, the model optimistically assumes the pandemic will cause “a moderate disruption in care that completely resolves after 6 months.”^{6(p1290)} Further, Sharpless fears that “...ignoring life-threatening non-COVID-19 conditions such as cancer for too long may turn one public health crisis into many others.”^{6(p1290)}

Contributing Factors

The pandemic seems to touch all aspects of daily life; it also affects all aspects of health care and contributes to missed and delayed diagnoses in myriad ways:

- Having heard that hospitals and emergency departments expected to be overwhelmed with COVID-19 patients,^{14,15} many people avoided going so as to reduce pressure on health systems and because they feared catching the virus.
- Medical facilities of all kinds prohibited visitors, including family members, friends, and other care partners. This policy added another dimension to fear associated with COVID-19 and removed a crucial source of information, especially for patients too ill to communicate on their own.
- Physician offices and ambulatory services put non-emergency appointments on hold to avoid spreading the virus and overtaxing health systems. Despite a dramatic shift to telehealth,¹⁶ some diagnoses were still missed or delayed; the effect on outcomes is unknown at this time.
- Patients who seek medical care for respiratory symptoms are likely to be considered “patients under investigation” for COVID-19. The time involved in waiting for test results or for symptoms

to resolve and related isolation of the patient contribute to diagnostic delay of non-COVID conditions.

- With millions of people laid off or furloughed from their jobs, the number of patients unable to afford medical care has ballooned.⁵ Loss of income and health insurance force many people to prioritize paying for food, lodging and medical care.
- The pandemic inspires fear that is multidimensional and lasting. In addition to rational concern about COVID-19, the pandemic also triggers irrational fear or “dread risk” that contributes to collateral harm.¹⁷

Dread Risk

In “Do Not Stay Home: We Are Ready for You,” executives at RoMed, a regional hospital in Germany, introduce the concept of “dread risk” to help explain fewer patients than expected in the emergency department.¹⁷ Dread risk is a psychological reaction to “low-probability, high-damage” events, such as plane crashes, terrorist attacks, tsunamis, and pandemics.¹⁷⁻¹⁹ Knowledge of an uncontrollable, apparently random shock, reinforced with vivid imagery viewed repeatedly through the media, can prompt irrational fears and avoidance behaviors.

Gerg Gigerenzer, PhD, director of the Harding Center for Risk Literacy at the Max Planck Institute for Human Development in Berlin, studied transportation patterns following 9/11, an example of a dread risk-inducing event. After airplanes were involved in causing nearly 3,000 deaths on 9/11, many people avoided flying and chose instead to drive. Passenger miles in automobiles and fatal crashes increased in the United States for the following 12 months and then returned to normal rates. Gigerenzer estimates that this dread-risk effect caused a “secondary death toll”^{18(p350)} of 1,595 lives.

In late May, *New York Times* reporter Katie Hafner spoke with patients who, fearing COVID-19, avoided medical attention despite knowing they needed it. In many cases, they were aware that their choices were based on irrational fears they were not able to surmount at the time. Hafner spoke with Lance Hansen, who turned down a liver transplant in late April. He dreaded catching COVID-19 at the hospital, feared dying there, and could not face being there alone. Hafner reports that Hansen now regrets his choice and is back on the waiting list. He says that in April, “I just freaked out...I should have gone, but I just freaked out.”^{2(np)}

Risk and Uncertainty

In the pandemic, decisions about what to do or avoid are not simply rational or irrational. SARS-CoV-2 is a novel coronavirus we are just beginning to understand. Diagnosis and treatment of COVID-19 are evolving daily. It may not be possible to know how much risk is associated with certain choices, which makes the task of reassuring patients and the public that it’s safe to “come back” all the more challenging. John Brush, MD, author of *The Science of the Art of Medicine: A Guide to Medical Reasoning*, reflects:

The uncertainty itself becomes pandemic as we try to reopen society and restart the economy. As we feel our way along, every decision is a choice between gambles. Is it safe to congregate at church? Go to the beach? Should I wear a mask? (Yes!)^{20(np)}

Sebastian Walsh, a public health registrar in England and academic clinical fellow at the University of Cambridge, says that asking “Is it safe?” is a misguided approach to decision-making, especially now.²¹ Nothing is purely “safe”; everything involves a degree of risk. People often underestimate or simply avoid thinking about risks inherent in familiar, everyday activities. Risk assessment is personal and, these days, political; we each must evaluate risks and benefits according to our own circumstances and values.

Mark L. Graber, MD, founder and president emeritus of the Society to Improve Diagnosis in Medicine, notes that viewing risk on a relative scale is something academics are familiar with, but most patients and clinicians view the world “in more simplistic terms – safe vs unsafe. It may be misguided, but that’s what most of us do” (written communication, July 2020).

For hospitals and clinicians trying to reengage with patients and the public, societal fear of COVID-19 complicates the already challenging task of prioritizing and rescheduling delayed care. Rebuilding trust and counteracting the dread people have developed over the past months will take time.

In a recent essay reviewing actions hospitals can take to reengage with patients at this stage in the pandemic, David Asch, MD, executive director of the University of Pennsylvania Medicine Center for Health Care Innovation, points out that patients will have the last word regarding the safety of healthcare going forward:

I am not sure when we can replace the new normal with the old normal we long for, or when it will be safe to fully open up clinical care again. But I do know that when it is, the judges will not be the politicians, scientists, or clinicians. The judges will be the patients.^{22(pe2)}

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WomenHeart Receives \$100,000 PCORI Engagement Award

Last month, WomenHeart received a \$100,000 grant through the Eugene Washington PCORI Engagement Awards program, an initiative of the Patient-Centered Outcomes Research Institute (PCORI). Working with the Society to Improve Diagnosis in Medicine (SIDM), [WomenHeart](#) will use the funds to develop a convening to address missed and delayed diagnosis of heart disease in women. WomenHeart is a member of SIDM's [Coalition to Improve Diagnosis](#).

For decades, heart disease has been considered a “man’s disease,” [which has greatly contributed to higher rates](#) of misdiagnoses and delayed diagnoses in women. This discrepancy in diagnosis is also greater in women of color. Why? Part of the reason is that the [majority of heart disease studies have been done on white men](#), which leads to a lack of understanding of the symptoms and treatments that are unique to women with heart disease.

Suz Schrandt, Senior Patient Engagement Advisor to SIDM, shared that “This project will provide a perfect platform for SIDM to partner with WomenHeart, as we can contribute insights from both our diagnostic quality and safety focus and our ongoing work in patient engagement.”

The convening will bring patients and diverse stakeholders together to discuss missed and delayed diagnosis of heart disease in women, as well as support the creation of research recommendations to improve health outcomes and quality of care for women with heart disease. WomenHeart and SIDM will assemble a Steering Committee of female patients who suffer from heart disease, cardiologists, nurses, researchers, policy makers, industry representatives, and others to lead the planning process.

“We are thrilled to be awarded this funding so we can center women’s experiences as we bring together experts to build a plan for addressing this inequity and, ultimately, improve the care journey for women with or at risk of heart disease,” said Celina Gorre, CEO of WomenHeart, in a [press release](#).

The “Convening to Address Missed and Delayed Diagnosis of Heart Disease in Women” is part of a portfolio of projects that PCORI has funded to help develop a community of patients and other non-clinician stakeholders equipped to participate as partners in comparative clinical effectiveness research (CER) and disseminate PCORI-funded study results.

WomenHeart’s project was selected through a highly competitive review process in which applications were assessed for their ability to meet PCORI’s engagement goals and objectives, as well as program criteria. Through the [Engagement Award Program](#), PCORI is creating an expansive network of individuals, communities, and organizations interested in and able to participate in, share, and use patient-centered CER.

SIDM Proud to Announce 2020-2021 Fellows in Diagnostic Excellence

The Society to Improve Diagnosis in Medicine (SIDM) welcomes seven individuals to this year's [Fellowship in Diagnostic Excellence](#) program. The new Fellows will work on innovative projects focused on improving diagnostic quality and safety during the 2020-2021 academic year. The new SIDM Fellows are Justin Choi, MD, from Weill Cornell Medical College; Yasaman Fatemi, MD, from University of Pennsylvania; Ayodele McClenney, BSCE, JD, from Johns Hopkins University; Rajasekhara Mummadi, MD, from Northwest Permanente PC; Varun Phadke, MD, from Emory University; Lisa Schwartz, MD, MS, from NYU Langone; and Viralkumar Vaghani, MBBS, MPH, MS, from Baylor College of Medicine.

“We are thrilled to welcome the next class of future leaders in the fields of diagnostic quality and safety,” said Paul Bergl, MD, fellowship director and 2017 Fellow. “As a former Fellow, it has been gratifying to see the Fellowship in Diagnostic Excellence program evolve and continue to support researchers, educators, and others interested in improving the diagnostic process and innovating change.”

Since graduating from the program, SIDM Fellows have published more than 150 articles in peer-review publications. The Fellowship in Diagnostic Excellence is made possible, in part, with support from the Gordon and Betty Moore Foundation.

“We are proud of the work of our current and past Fellows. The Fellowship program has helped scholars shape new research on diagnosis and diagnostic errors, which in turn has highlighted key opportunities for diagnostic improvement,” said Paul L. Epner, MBA, MEd, CEO of SIDM.

Each SIDM Fellow is assigned a personal mentor in their area of study who provides guidance and mentorship for their projects (on-site or remotely). The Fellows regularly participate in webinars and [Journal Club](#) sessions. Fellows conduct research and present their projects and participate at the annual Diagnostic Error in Medicine Conference and are encouraged to submit their work for review and publication in [Diagnosis](#) and other peer-reviewed journals. Applications for the 2021-2022 Fellowship program will open in the Fall.

Full biographies and descriptions of the new Fellows' proposed projects can be found on the [SIDM Fellowship webpage](#).



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