



# FEAR

# FACTOR

DELAYING  
HEALTH  
CARE  
DURING THE  
COVID-19  
PANDEMIC

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Institute for  
Patient Access

# FEAR FACTOR

*noun.* A feeling of apprehension or fear, usually viewed as a reason not to do something.

“People stay home, telling themselves ‘I’m okay for now.’

They’re not always right about that.

*Dharmesh Patel, MD*



# INTRODUCTION

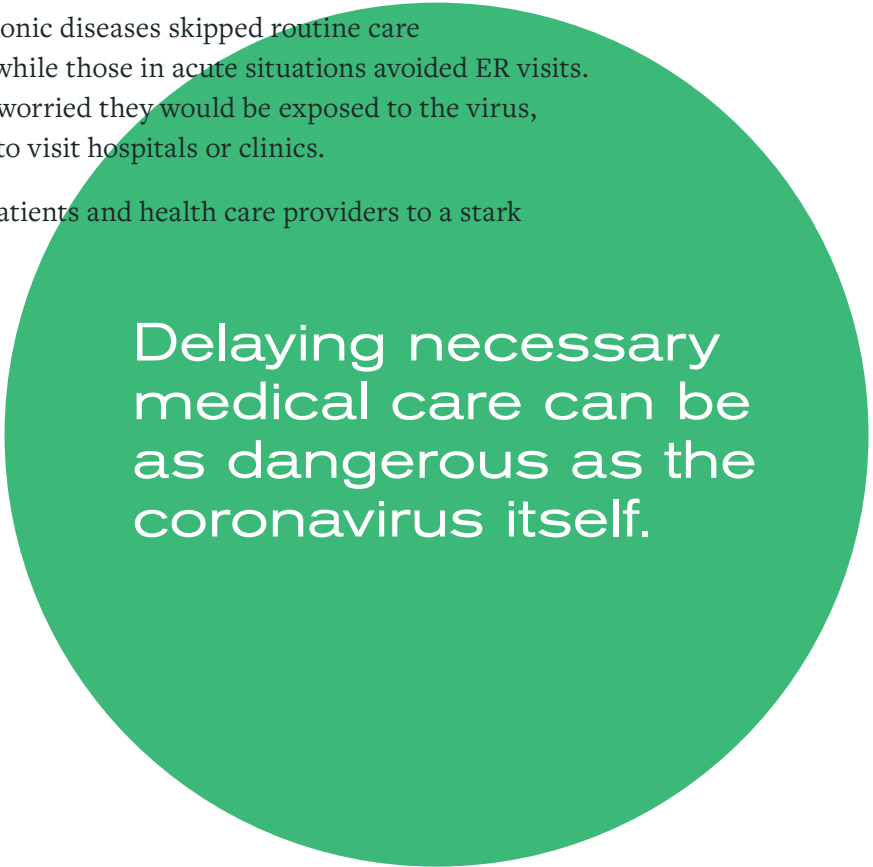
As the pandemic took hold, public health experts advised social distancing and issued stay-at-home orders. People who could work from home began to do so. Schoolchildren transitioned to virtual learning. Restaurants moved to take-out only. Air traffic ground to a virtual halt.

These and other measures helped to minimize Americans' exposure to the novel coronavirus.

But as the pandemic captured the nation's attention, caution morphed into something more. Fear of exposure to the coronavirus led people to avoid nearly all contact with the outside world – even necessary medical care.

People with chronic diseases skipped routine care appointments, while those in acute situations avoided ER visits. Some patients, worried they would be exposed to the virus, simply refused to visit hospitals or clinics.

The trend led patients and health care providers to a stark realization:



Delaying necessary medical care can be as dangerous as the coronavirus itself.

*Part 1*

# LAPSES IN CARE





## DISRUPTIONS IN ROUTINE CARE

From asthma to high cholesterol, diabetes to migraine, chronic diseases affect millions of Americans. These conditions typically can be managed through a combination of routine health care provider visits, a stable medication regimen, and a commitment to a lifestyle of healthy eating and exercise. When one of these elements falters, however, patients may suffer.

That reality became clear from the onset of the COVID-19 pandemic, as gaps in care overtook patients with chronic diseases.

One-third of patients missed or canceled an appointment with their health care provider,<sup>1</sup> while about one in 10 skipped or delayed filling a prescription.<sup>2</sup> Health care providers across specialty areas reported major drops in patient visits. Chicago-based cardiologist Dinesh Kalra, MD, recalled that *office visits initially sank to about 25% of the clinic's normal patient load.*<sup>3</sup>

News coverage of coronavirus outbreaks drove a public perception of all medical facilities as germ and overrun with highly contagious COVID-19 patients. But, as Alabama allergist Allen Meadows, MD, explained to his patients, "It's safer to come to the allergy office than it is to make a weekend trip to Home Depot. Or to browse the produce aisle at your local grocery store."<sup>4</sup>

### *Nevertheless, patients held back.*

Meanwhile, as gyms and community centers temporarily closed, some patients also lapsed in their commitment to healthy lifestyles. Tennessee internist John Anderson, MD, recalled a patient with Type 2 diabetes who struggled with weight. "I'd encouraged her to stay active," Dr. Anderson explained. "Last time we talked, she told me her grown son wouldn't let her leave the house for fear of the coronavirus. I told her in no uncertain terms: Get outside."

"There's no reason," Dr. Anderson went on, "that people shouldn't be gardening, mowing their lawns and going for walks in open areas."<sup>5</sup>

In some cases, in-person visits are necessary not only to monitor symptoms but also to administer patients' medication. Infused and injected medications are a treatment mainstay for diseases

ranging from rheumatoid arthritis to refractory gout to chronic migraine.

Yet maintaining access to these medications proved to be a challenge even for some providers. As Washington, DC-based neurologist Carrie Dougherty, MD, recalled,

**We had to fight to continue providing botulinum neurotoxin injections for migraine patients who rely on those. The heads of our facility saw the injections as elective procedures, which hospitals [had] stopped due to COVID concerns.<sup>6</sup>**

Patients taking infused or injected medications understood that missing appointments with their health care provider meant forfeiting treatment as well as routine check-ups. And for some patients, fear of losing control of their disease outweighed concerns about contracting the coronavirus. As California rheumatologist Wesley Mizutani, MD, explained, "That's part of the reason [patients are] committed to continuing the infusions, even during COVID. They know the alternative isn't good for them."<sup>7</sup>



Carrie Dougherty, MD

## CONUNDRUMS IN CANCER CARE

For cancer patients, disruptions to care during COVID-19 were particularly difficult.

Like patients with certain chronic diseases, cancer patients are at higher risk due to their weakened immune systems. This left cancer patients and their families with a painful choice. Some patients opted to delay cancer care, either to avoid the clinic setting for fear of contracting the coronavirus, or to avoid suppressing their immune system as a side effect of some cancer treatments. Delaying care was a trade-off, however, that potentially allowed their cancer to grow or spread.

Ohio oncologist Jeffrey VanDeusen, MD, PhD, reflected that,

The pandemic has forced difficult conversations about what's essential and what's non-essential.



Jeffrey  
VanDeusen,  
MD, PhD

...Oncologists have to consider who goes to surgery versus who gets chemo. When is the risk of tumor growth bigger than the risk of starting a patient on cytotoxic chemotherapy?"

"Some oncolytics can be taken at home," Dr. VanDeusen explained, "but there's a risk of allergic reaction that you don't want a patient facing alone, or other changes that we worry may be under-monitored."

For cancer patients, the pandemic posed yet another roadblock in an already uphill battle. ***One study found that 50% of cancer patients experienced delay or disruption to their health care.*** The same study found that 27% of patients being actively treated at the onset of the pandemic experienced a delay, with one in eight not knowing when their treatment might resume.<sup>8</sup>

## GAPS IN IMMUNIZATION

Few factors could complicate the pandemic like a co-occurring outbreak of another infectious disease. Yet routine immunizations for young children are among the medical services delayed or canceled during the COVID-19 pandemic.

Children across the country have fallen behind schedule for critical immunizations, such as measles,

according to recent reports from the U.S. Centers for Disease Control and Prevention.<sup>9</sup> From mid-March to mid-April alone, health care providers administered about 2.5 million fewer doses of non-flu vaccines than in the same period in 2019.<sup>10</sup>

This drop in vaccination rates poses a threat not only to immuno-compromised children but also to people, regardless of age, who have been previously vaccinated, because the effect of some immunizations wanes over time.<sup>10</sup>

"Young parents today have no experience with the devastating effects of polio, measles, mumps, and rubella," explained California neonatologist Mitchell Goldstein, MD. "But vaccine-preventable diseases maim and kill people. That's why staying on the immunization schedule is so important."

The American Academy of Pediatrics' Sean T. O'Leary, MD, emphasized, "Medical offices are among the safest places you can be right now given the really extensive measures they've taken to prevent spread of COVID-19," adding that "parents shouldn't be afraid to go to their doctor."

The impending flu season underscores the threat of immunization gaps. Children and adults who miss routine medical appointments may also miss their routine flu vaccine. The timing and severity of a COVID-19 wave in the fall and winter of 2020 are still uncertain, but past experiences with the 1918<sup>11</sup> and 1957<sup>12</sup> influenza pandemics point to the possibility of a resurgence.

Lack of widespread flu immunization could exacerbate communities' struggles with COVID-19, spurring a deadly combination of infectious disease outbreaks.



Part 2

# DESERTED EMERGENCY ROOMS





Patients didn't forego only routine care during the pandemic. The Centers for Disease Control and Prevention reported a jaw-dropping 42% decrease in emergency room visits by the end of April 2020.<sup>13</sup>

By some estimates, the measure reflected tangential benefits of quarantine. Less car travel meant fewer traffic accidents. In some cities, drops in violent crime resulted in fewer crime victims needing medical attention.<sup>14</sup>

There were also less rosy indications of lockdown's impact. ER visits for children were one of the few indicators that rose. Children spending more time at home led to higher incidents of poisoning from ingesting household cleaning products, while injuries from domestic violence against children also triggered an increase in ER visits.<sup>14</sup>

But, too often, adult patients who needed acute care held off.

Cardiovascular patients were one of the most noticeable patient groups absent from America's ERs. *Just 10 weeks after a national emergency was declared, ER visits for heart attacks had declined by 23%. For stroke, the decline was 20%.<sup>15</sup> Calls to 911 for stroke and heart attack symptoms dipped as well.<sup>16</sup>*

While absent patients are hard to tally, the experiences of other countries confirm U.S. physicians' fears. In Austria, for example, 86 people died in a single month from COVID-19, while 110 died from untreated heart attacks.<sup>17</sup>

Some health care providers share tragic stories. Tennessee internist John Anderson, MD, recalled, "I had a patient...in his 70s with heart disease and AFib. On Friday night he called our after-hours line complaining of chest pain. The nurse told him to go to the emergency room."

"On Saturday they talked again," Dr. Anderson continued. "She urged him again to go to the emergency room. He said he would just wait and see me on Monday. Monday morning, I got the death certificate."<sup>15</sup>

Patients experiencing accidents or injury also stayed away.

New Jersey orthopedic surgeon Jake Zarah, MD, explained, "People with severely broken bones who would typically present in the ER are instead showing up in my office." Dr. Zarah recalled one patient who nearly lost his leg because he refused to seek immediate care at the ER.

This is one of the biggest problems... really severe trauma situations that could have long-term effects if not tended to.<sup>18</sup>

## UNTIMELY CARE

As patients slowly have begun returning to ERs, some health care providers report seeing worse symptoms as a result of delayed care.

Chicago-area emergency rooms, for example, saw patients with dangerously high blood pressure and poorly controlled asthma, as well as "inadequately controlled" chronic kidney failure, the Chicago Tribune reported.<sup>19</sup> Local physicians relayed stories of patients whose chest pain had progressed to an acute heart attack and patients whose facial weakness had turned into a full-fledged stroke before they finally sought care at the local ER.



Jake Zarah, MD





Part 3

# RESTORING CARE & MINIMIZING IMPACT

During the summer of 2020, anecdotal reports suggested that patients were slowly resuming visits with their health care providers. Emergency rooms reported an uptick in visits for non-COVID conditions and concerns.<sup>19</sup> Whether due to declining COVID-19 infections, fatigue with pandemic isolation or realizing the impact of delayed care, the shift marked a positive trend.

Certain measures have empowered patients to resume or maintain care. They could prove critical to keeping patients committed to their health, even in the event of future COVID-19 resurgences.

## TELEMEDICINE

For some patients, telemedicine provided a vital link to care during the pandemic. Temporary changes in Medicare policy allowed reimbursement for virtual visits, making the service financially feasible for health care providers, many for the first time.

“Virtual visits are a prime example of patient-centered care,” explained Nashville-based neurologist David Charles, MD.

When circumstances don't allow for in-person visits, such as during the pandemic, we can tailor care for our patients, whatever their individual circumstances or comfort level. And we can still maintain that fundamental physician-patient relationship.

Even beyond the pandemic, Dr. Charles noted, telemedicine offers a “convenient supplement to office visits.”

Telemedicine also offered a bridge to care for people with mental health conditions. For example, Florida psychiatrist Parikshit Deshmukh, MD, used video conferences or telephone calls to monitor the health and prescription medications of long-term care residents when facilities instituted COVID-19 limits on visitors and outside care providers.

David Charles, MD

This is a stressful time. Mental health, and access to mental health care for some of the most vulnerable among us, is more important than ever.<sup>20</sup>

## HOME INFUSION

The Centers for Medicare and Medicaid Services also loosened restrictions on home infusion during the pandemic. The agency began allowing for a trained medical professional to administer medication at a patient's residence, connecting with the prescribing health care provider as needed via phone or video conference.

The policy was a shift for Medicare, which historically has limited home infusion to only a few medicines. This rule expanded that list for the duration of the federal emergency declaration.

While not all infused medications were included, Medicare's expanded policy opened the door for more patients to continue treatment from the comfort and safety of their own home. *In a survey of Medicare patients with thyroid eye disease, for example, 94% agreed that home infusion could minimize treatment disruptions, while 100% agreed it would minimize their risk of exposure to COVID-19.*<sup>21</sup>

The increased flexibility could give clinicians another way to provide patient-centered care despite the limitations imposed by COVID-19. Access to home infusion also could alleviate pressure on sick and older Americans who feel they must choose between potential coronavirus exposure and continued treatment for their disease.

## FACILITY PRECAUTIONS

In addition to formal policy changes, individual clinics undertook creative measures to ensure continuity of care. For example, Alabama allergist Allen Meadows, MD, recalled a physicians' office in his area that used the parking lot as “a stand-up clinic for extra cautious or high-risk patients.” People remain in their cars while the providers, in masks and gloves, go “vehicle to vehicle to



Parikshit Deshmukh, MD



David Charles, MD

administer medications as needed,” Dr. Meadows explained.<sup>4</sup>

As patients become more comfortable with in-person care, hospitals and clinics strive to keep both patients and staff safe.

### ***Precautions may include:***

- Wearing gloves and requiring masks of both staff and patients
- Installing UV filtration lights and air purification systems to minimize airborne virus transmission
- Requiring temperature checks of patients and caregivers before they enter the facility
- Regularly cleaning office surfaces and offering hand sanitizer stations for visitors
- Screening patients with brief interviews or questionnaires about recent symptoms or potential COVID-19 exposure
- Limiting the number of patients in the waiting rooms, or having patients move directly to an exam room after they check in
- Asking patients to remain in their vehicle until they are called into the facility for their appointment
- Setting up triage booths to screen patients safely.

“Health care organizations are taking every precaution to ensure that neither employees nor patients become infected,

emphasized Atlanta-based Calli Cook, NP.



Calli Cook, NP

## **PATIENT EDUCATION & EMPOWERMENT**

Continued education can also empower patients to prioritize their health care. In some cases, that requires raising awareness about COVID-19 symptoms and instructing patients on what to do when they experience symptoms. For example, the World Health Organization released a “myth busters” paper to help patients distinguish truth from fiction in the information they encounter about COVID-19.<sup>22</sup>

In other instances, better awareness of the precautions taken by health care providers and local hospitals can embolden patients to maintain or resume care. While news headlines readily convey stories of exposure and contagion, few patients have balanced information about precaution and safety measures. Providers and clinics would do well to use their websites and regular communication with patients to highlight safety measures and reassure patients about the precautions they’ve adopted.

Above all, patients must be aware of the potential consequences of delaying or avoiding care. When fear of COVID-19 exposure leads to so-called “medical distancing,” the result can be avoidable deaths and far-reaching complications.<sup>23</sup>





# CONCLUSION

Concerns about COVID-19 exposure have led to widespread and dangerous disruptions to care and treatment. Some patients have even paid with their lives.

To restore continuity of care and minimize suboptimal health outcomes, policymakers, patients and health care providers must work together to address patients' fears and empower them to seek out the care they need.

That requires continued education and an ongoing commitment to safety measures for both patients and medical professionals. And, as the pandemic lingers on, policymakers would do well to make permanent the temporary changes to home infusion rules and telemedicine. These policies make continued care feasible for patients of all risk and comfort levels.

A pandemic can strike fear in even the most stalwart among us. But with the right policies and the proper mindset, patients and health care providers can keep access to medical care from becoming yet another casualty of the coronavirus.



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