What doctors wish immunocompromised patients knew during COVID-19

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Mask mandates have been rolled back, as have restrictions on large indoor gatherings. And many people are eager to return to a new normal, protected by the safe and highly effective COVID-19 vaccinations that vastly reduce the risk of severe outcomes for patients who acquire SARS-CoV-2.

Yet the threat of COVID-19 remains elevated for the millions of Americans with compromised immune systems. That’s because patients who are immunocompromised are still at higher risk for severe infection from SARS-CoV-2. For too many of these patients, it can feel as though the date on the calendar hasn’t budged much from March 2020.

The AMA’s What Doctors Wish Patients Knew™ series provides physicians with a platform to share what they want patients to understand about today’s health care headlines, especially throughout the COVID-19 pandemic.

In this installment, three AMA members took time to discuss what patients should know about being immunocompromised during the pandemic. They are:

- Omar Atiq, MD, a medical oncologist at the Winthrop P. Rockefeller Cancer Institute at the University of Arkansas for Medical Sciences in Little Rock. He also is president-elect of the American College of Physicians.
- Erin Schwab, MD, a hematologist-oncologist in Breckenridge, Colorado. She is also an alternate delegate in the AMA House of Delegates for the American Society for Clinical Oncology.
- Monique Spillman, MD, PhD, a gynecologic oncologist and clinical associate professor of obstetrics and gynecology at Texas A&M College of Medicine.
Some patients are more susceptible

“As a gynecologic oncologist, we consider people who are immunocompromised to be both those who have a current cancer, as well as those who are undergoing therapy for that cancer—particularly chemotherapy or other types of immune therapies,” said Dr. Spillman.

“I have patients with colon cancer who are going through treatment who have the ups and downs of their blood counts and their white cells will drop. But overall, they stay pretty healthy,” said Dr. Schwab. “Then I have the patients with leukemia who get terribly sick and are very immunocompromised.”

“It’s almost a spectrum in terms of trying to manage these patients because some are much more susceptible than others,” she said.

Mask up in public indoor spaces

“We do recommend that they wear masks even if they have been vaccinated,” said Dr. Spillman. “We know that just because of their therapies—including chemotherapies—their immune systems can be lowered, and they are more at risk of not just COVID-19, but other infectious diseases as well.”

“Every time we think we are out of the woods, we are not, so I would rather side with caution than be cavalier,” said Dr. Atiq. “We all know that wearing masks doesn’t just mean any mask. It means a good quality, well-fitting mask, especially if you’re going to be in an area where people are closer than six feet radius from you.”

Close contacts should mask up too

Dr. Spillman urges patients “to initiate that conversation with their friends and family,” acknowledging that it can sometimes “be a very difficult conversation for our patients to have, but oftentimes family and friends will act to protect their loved ones.”

“People who come in close contact with those who are immunocompromised should try to make sure that their loved ones who are immunocompromised do not get the infection by minimizing that risk,” said Dr. Atiq. “And you minimize that risk by being vaccinated yourself, by washing your hands, by keeping a distance of six feet and by wearing masks.”
On masking, disregard judgment from others

Many patients with compromised immune systems “choose to wear a mask and continue to wear a mask, so those people who you see in the grocery store, many of them may be cancer patients, and you don’t even realize it,” said Dr. Schwab, noting that many are continuing to mask up to protect a loved one.

For example, Dr. Schwab told of a woman friend who “was going through fertility treatments and she had been vaccinated, but she hadn’t had her booster yet. When she came over, she chose to wear a mask in my house,” she said. “That’s her own personal choice.”

It’s still important to get vaccinated

“We strongly urge our patients to be vaccinated and I have that conversation with every single one of my patients, whether they’re on active chemo or immunotherapy or not,” said Dr. Spillman. “We urge them to get vaccinated because even if your immune system is slightly lowered because of chemotherapy or immunotherapy, you can still respond somewhat to the vaccine.

“And it does give you some level of protection, particularly against the more severe forms of the disease,” she added.

“The ideal timing of vaccination in post-transplantation patients is not known,” said Dr. Atiq. “In those situations, one has to weigh the risk of infection against the probability of mounting a protective response to vaccination.

“When possible, delaying vaccination for a month post solid organ transplant and three months after hematopoietic cell transplant and chimeric antigen receptor T-cell transplant is advisable,” he added. “However, all patients should be offered vaccination prior to the initiation of transplant therapy, if feasible. In general, there is no harm in getting vaccinated sans a history of an allergic reaction to it.”

Get third mRNA dose and two boosters

Immunocompromised patients should get a third mRNA COVID-19 shot “as long as it’s not medically contraindicated,” said Dr. Spillman. That means, “if someone has had a vaccine reaction, has had difficulty with their heart after a vaccine or some sort of an allergic reaction, obviously they should avoid that.”

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“But, in general, we do ask that our patients consider a booster, and our specialty society does recommend that third dose,” she said, adding that patients with compromised immune systems are also eligible for two booster doses.

**Evusheld can offer powerful protection**

“We now have emergency use authorization for Evusheld, which is two monoclonal antibodies taken together in pre-exposure profiles,” said Dr. Atiq. “This is pre-exposure and there are two injections that are given at the same time.”

“Essentially, we have something that can prevent serious infection in patients who may be immunocompromised,” he said.

**Create rules for protection**

While some people may refuse to wear a mask or follow proper precautions, patients with compromised immune systems should set some rules to follow, said Dr. Schwab. “There are certain rules that certain patients made for themselves as we talked about what’s important to them and what their risk management was that they wanted to take with their family.”

For example, Dr. Schwab said that one patient “made some hard rules and if you’re not vaccinated, you don’t want to wear a mask, you don’t want to get tested, then you can’t see me.”

**Assess activities’ benefits, risks**

“Be cautious around those who have not been vaccinated and if anybody is sick, stay away from them,” said Dr. Schwab. “But I have to balance also the social side of stuff, because many of these patients may die from their disease and keeping them socially isolated in a time where they may not have much time left is very hard.”

That is why “we talk about the risks and benefits a lot, and many times they’re very open with me on what they’re planning on doing,” she said. “As long as you’re willing to take that risk and you understand that risk, then that’s fine.”

**Don’t rely on antibody testing**
“There are a lot of tests that purport to look at COVID-19 antibodies, but they don't necessarily correlate with one another or with the risk of the disease,” Dr. Spillman said. “At this point, I tell my patients that if they get one of those tests, it can be an important piece of information, but I still recommend vaccination.”

Dr. Atiq reinforced the point. “Outside of a clinical trial, I'm not sure that we should be running towards it or getting a false sense of security or anxiety from it,” he said.

Use caution with rapid test results

“If somebody is going to come in close contact with a person who is immunocompromised and therefore is at a high risk of serious infection and morbidity with COVID-19, it is helpful for them to get the rapid testing as close to the contact as possible,” said Dr. Atiq. “That certainly adds to the protection because you can have an infection even if you don’t have any symptoms.”

But, Dr. Spillman noted, rapid tests “can give some measure of confidence, but it is not absolutely predictive that you don’t have the disease.” She added that “tests can turn positive even 12 to 24 hours later, so caution is still appropriate.”

Gather outside to reduce risk

“We're not asking patients to do things like buy expensive equipment and have new fans installed and new types of filters on their air conditioning and heating systems. That’s largely impractical for our patients,” said Dr. Spillman. “But if you're in a gathering and it's possible to do that outside, of course that's a safer option.”

Being outside “is important protection that is needed not just for minimizing or reducing the risk of COVID infection, but also for healthy lifestyles,” said Dr. Atiq. “Going for a walk in a park is a natural way of not only protecting or minimizing the risk, but also of feeling better. Fresh air has a soothing effect on all of us.”

It’s OK not to feel OK

“All of us have the right not to feel OK. There’s nothing wrong with us. That’s totally normal, said Dr. Atiq. “It’s totally normal to feel down and depressed at times. It’s totally normal to be unhappy and upset.
“What we ought to do is to try to mitigate it because if that feeling persists for longer periods of time, it takes away from quality of life,” he added. “And just like it’s OK to be down, sad and not motivated, it’s in us to have a quality of life that we think we deserve.”

Keep seeing your physician

“As we continue to address COVID-19, one of the big takeaways from this is please don’t avoid your physician,” said Dr. Spillman. “We’ve had delayed cases of cancer diagnosis because people were simply too scared to come into the doctor’s office.”

“We need to encourage people to go out and start getting those screening tests again—get your mammograms, get your pap smears,” she said. “And if something isn't right, please do come in to see your physician because the earlier we can make a cancer diagnosis, the earlier we can intervene.”

Don’t let fatigue stop protective steps

“It's been tiring for everyone, but we are better off today than we were a year ago or two years ago,” said Dr. Atiq, acknowledging that it is especially hard on people with compromised immune systems who may feel left behind as society at large seems to move on.

“The ask still is—let's be careful. Let's keep doing what we can relatively easily do: physical distancing, hand-washing, wearing masks, having good ventilation, staying away from people who are obviously sick or who are positive from COVID-19,” he said. “We are going to get out of this and not too distant in the future, but we just have to hold tight for a little while longer.”