Q&A: Exploring COVID-19 Vaccine Hesitancy in Young Adults With Sickle Cell Disease

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Youth with sickle cell disease (SCD), a group of genetic red blood cell disorders that cause severe pain and anemia, face many challenges in managing their health care. In order to better support these vulnerable youth, a collaborative team of researchers across Children's Hospital of Philadelphia's (CHOP) Comprehensive Sickle Cell Center and PolicyLab, as well as Northwell Health's Cohen Children's Medical Center, are leading a study, referred to as the COMETS Trial, to identify best practices for helping youth with SCD transition from pediatric to adult health care. In our efforts to resume recruitment for this study during the pandemic, our team has heard some candid thoughts from our stakeholders, and we've seen firsthand some of the hesitancy around the COVID-19 vaccine among young adults with SCD.

It is important to note that patients with SCD experience pain crisis, which is one of the major symptoms of the disease. Pain develops when sickle-shaped red blood cells block flow through tiny blood vessels to the chest, abdomen and joints. A pain crisis can be triggered by many things, however, it remains unclear if the symptoms from the vaccine can trigger a pain crisis. This is one of the biggest concerns in the sickle cell patient community and may play a role in the decision-making process.

Our team of clinicians has been educating their patients on the benefits of the COVID-19 vaccine while also understanding the hesitancy among young adults deciding whether they will receive the vaccine. To learn more about these factors, I asked Isaac Williams, a young adult with SCD who recently joined our research team as a community health worker (CHW), to speak with me about the realities of vaccine hesitancy among young adults with SCD.



Tell me a little bit about yourself and your background.

I am a dancer, model and CHW living with SCD type SC. Since birth I've had various complications due to SCD, from retinopathy (disease of the retina that results in impairment or loss of vision) to multiple hospital admissions due to pain crisis throughout middle and high school. Over time I've grown to understand my body and manage my SCD with the help of medication, changing my eating habits, exercise and keeping up with my regularly scheduled doctor appointments. I received my SCD care at Cohen Children's Medical Center at Northwell, which is one of the recruiting sites for the COMETS Trial, and due to my knowledge and experience living with SCD, I was chosen to join the team as a stakeholder and more recently started in my new role as a CHW.

When I think about decision-making related to vaccines, I realize that there are many factors that contribute to someone's choice. To start, has your hematologist talked to you about getting the COVID-19 vaccine?

During one of our telehealth visits back in early winter, she mentioned it before it was released to the public. I told her of my history with vaccines that included symptoms such as fever and body aches, which would consistently lead me into a pain crisis. The last one I received in 2013 was so bad from the flu vaccine, I was admitted afterwards. She mentioned that they would be focusing on elderly people first, specifically those with preexisting conditions. At that time, my demographic wasn't really the focus, but more recently she recommended I get the vaccine as soon as possible when it is available to me.

Your medical history with vaccines seems to have a great impact on your decision. As you mentioned, you experienced a pain crisis after getting the flu vaccine in the past.

What additional factors do you think influence a young adult with SCD's decision when it comes to deciding whether to get the COVID-19 vaccine?

Honestly? Everything from Instagram, blog pages, tabloids, people in the grocery store or hair salon/barbershop and Tik Tok can all have an influence on one's decisions. The vaccine is such a hot topic wherever you go, you're likely to hear an opinion or two about it. At this point, it seems people fall into three categories as it relates to the vaccine, "I'm getting it," "I'm not sure if I'm getting it," and "I'm definitely not getting it"—all for different reasons.

In addition, this country's history with African Americans, unknown experiments such as the Tuskegee Experiment and one's trust in vaccines factor into decision-making. It hasn't been easy finding credible sources to help in the decision-making process. I feel that even at the beginning of the pandemic some sources have changed their stances on information and have back-tracked, therefore making it more difficult to deem them reliable. Platforms such as Instagram and Tik Tok are the most influential to people my age. If there are individuals they feel are trustworthy, they are most likely to believe whatever information is given to them.

Where do you stand right now in terms of getting the COVID-19 vaccine?

When the pandemic first started, I strictly quarantined with my immediate family. Professionally, I am a dancer and model so I am used to being around different groups of people often but that quickly changed. From March 2020 to February 2021, I only spent time at my house and my parents' home, therefore, I view myself as low risk for COVID-19. More recently, my life has resumed normal activity, I recently started booking gigs again and socializing with friends. However, strict safety measures are in place whenever interacting with others.

As of right now, I am still not interested in getting the vaccine. Personally, I want to wait for more information, mainly due to my personal history with triggered pain crisis due to vaccine symptoms. I am also hesitant due to the time frame of knowledge since the vaccine release. I have always been a reserved and patient person, so I tend to wait a few years even when a new phone comes out before getting it. I remember when the PS4 came out and I wanted to buy one right away, my dad told me to wait three or four years, because by then there would be a refined version out with way more games. I think that's where I received that approach to trying new things from, and why I would rather wait to have information that can only be received through an observation of time.

Now that you serve SCD patients as a CHW for the COMETS Trial, how do you see yourself supporting young adults in their decision-making process?

I would start by asking them questions to see what they currently know about the vaccine. What have they heard or where have they received information? I would also provide them with credible sources, but also not rule out sources they may see as reliable. Whether it's their doctor, a medical student on TikTok, or any online blogs— I would stress the importance of checking the sources they are receiving information from.

If you find yourself with questions, make sure you write them down for your next visit with your doctor. Compile a list of trusted sources and see if your questions can also be answered from those sources. The goal would be

to have all your questions answered before making your decision to get the vaccine. You want to be able to make the best decision for you, your family and your friends, because what you do could affect their decision making. Ultimately, I would want to provide them with information and resources that would lead to them making a decision they are comfortable with and confident in.

During a recent team meeting, Dr. Kim Smith-Whitley shared some of the work the sickle cell team at CHOP is doing to educate families on the COVID-19 vaccine, which included a town hall that provided families with an opportunity to ask questions in a safe space.

How do you think providers should approach their young adult patients with information or answer questions that may be brought to them?

I think it is important for them to approach it from a standpoint of individualism instead of as a collective. When information is presented from the CDC or other sources, it's presented with the notion "it's for the greater good" or "here is what the statistics say as to why or why not I should choose this decision." It detaches the patient. The more personal and specific the information provided is, the more comfortable the process will be for the patient. This may help the patient in being more receptive and even more inclined to listen with open ears. I personally think patients and their providers should come up with a pros/cons list together before the appointment is over. Being able to take a step back and look at this decision-making process through the lens of the patient can go a long way. After the year we have all had, we all have different stories and experiences that factor into our decision-making process.

Sickle cell providers have been recommending that young adults with SCD receive the COVID-19 vaccine and have been engaging with this population to answer any potential questions they may have in forums such as town halls and webinars. Young adults like Isaac feel that providers should offer patients individualized support in making their decision about the vaccine. Patients with SCD all have different experiences with the disease and managing their symptoms, therefore, providers should approach this conversation in the same manner. As Dr. Ifeyinwa Osunkwo shares, "the conversation about vaccine hesitancy should be held with patience and humility, acknowledging the past and validating patient concerns that will influence their decision." I hope my conversation with Isaac can offer providers a learning opportunity that allows them to better serve their patients.

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