

Insights

Sickle Cell Pain Protocol Reduces Wait Times for Meds and Eases Patient Frustration

When kids with sickle cell disease come to an emergency room (ER) asking for painkillers, the care can sometimes be less than ideal. In a busy ER, there can be long wait times, and, especially with an illness like sickle cell disease that has no visual signs of pain, doctors sometimes question whether a patient is really in a medical crisis or just drug seeking.

“It's a horrible feeling when the one person that is supposed to make you feel better doesn't believe you are in pain,” says Fatima Oyeku, who has had sickle cell disease all her life. “They ask the most annoying questions in order to figure out if I'm merely there for the pain killers.”

Oyeku says she has had countless experiences with hospital staff who question her need for meds, delay treatment or dole out the lowest possible dose until bloodwork comes back proving that she is in crises. The pain, she says, is “excruciating” and makes the wait for pain killers unbearable. Treating a crisis quickly is also important because it minimizes damage to internal organs.

To improve the care of its sickle cell patients, Boston Medical Center (BMC) developed a drug protocol that makes it possible to make quick, accurate decisions about acute care. As a result, the average time to first dose of medication for sickle cell patients experiencing a pain crisis dropped from nearly an hour to 22 minutes. ER staff also stopped second-guessing sickle cell patients asking for pain killers.

Getting Buy-In

“We brought all the stakeholders together in a very purposeful way,” says Patricia Kavanagh, MD, MS, a sickle cell disease expert and team lead for BMC's participation in the [Working to Improve Sickle Cell Healthcare](#) project. Nurses, doctors, pharmacists, hematologists, ER staff, and social workers from the hospital—which handles half of pediatric and most adult sickle cell cases in the city—were invited to discuss the issues of treating sickle cell disease in those people under the age of 22.

Instead of beginning the conversation by suggesting there were problems with the way kids were

being treated, despite hearing this from some patients and their families, Kavanagh first listened to staff concerns. This approach was key, she says, to getting staff off the defensive, which could slow change efforts.

In these conversations, some ER staff said the sickle cell patients didn't always seem to be in pain. They'd play games on their phone, or text friends. ER staff would later learn that playing on a phone is a distraction technique that sickle cell patients learn in order to better cope with a crisis. Oyeku says she often tries to distract herself from the pain to deal with it, which "makes me seem OK" when she's actually in terrible pain.

ER staff also expressed concerns that they were offering too much medication. Sometimes staff hesitated giving meds, thinking the child might become addicted. There were also questions about whether to give more medication to a child if they fell asleep after the first dose. Nurses voiced that they often received different answers from different doctors. It quickly became clear that a standard of care that would cover all situations in the ER was lacking. Similar protocols already existed for asthma attacks. Now one was needed for sickle cell crises.

Developing a Protocol

Pharmacy and hematology staff worked together to develop a dosing protocol for the ER.

"Giving staff the authority to use the protocol freed them from trying to make all these decisions," she says. "We also provided education to ER staff to cover the 'what ifs,'" such as how to deal with a sleeping child. The answer: continue administering pain meds as per the schedule.

Another critical piece of the puzzle: defining and communicating the role of the ER staff in sickle cell disease care. The emergency room team needed to know that they didn't need to assess children for long-term issues.

"The kids may have other things going on, but they have real pain that needs to get addressed quickly. We aren't going to fix the psychosocial issues in the ER," Kavanagh says.

Addressing the issue fully also required staff education about sickle cell disease. Kavanagh explained to the staff at BMC that many kids with sickle cell were taught and taught themselves coping skills, which they'd perfected over years of experience with the painful disease. These kids were already adept at remaining calm during a sickle cell crisis by distracting themselves from the pain with whatever they had on hand.

In the end, patient care improved by measurable metrics. The time to first dose of medication dropped substantially, with no increase in readmission.

"Pain management doesn't have to be hard," she says. "It just has to be agreed upon."