Nurses get proactive about sickle cell disease awareness

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Sickle cell disease is an often deadly condition that affects approximately 100,000 Americans, most of whom are black. But even with these fatal odds, SCD is still alarmingly underreported. DNI staff know first-hand the consequences of not bringing awareness to this significant illness.

If you saw someone wearing a purple and fuchsia wristband, you probably wouldn't know what cause it was associated with. Wearing colors to draw awareness for sickle cell disease (SCD) doesn't have the same popularity as pink bands do for breast cancer or red bands do for HIV/AIDS. There is no celebrity social media challenge for SCD nor was there a vocal celebrity face until Tionne "T-Boz" Watkins of the R&B group TLC discussed her struggles with the disease in her 2017 book A Sick Life and why age matters.

The median age of death for those who have sickle cell disease is 42 years old for males and 48 years old for females. T-Boz is 47.

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About one in 13 African-American babies is born with sickle cell trait (SCT), although they may never actually get the disease. But what happens to those who do?

Rajni Chaudhry

"On top of there being only one medication, Hydroxyurea, which decreases the sickling effect, the trait is not prevalent in every culture," says Rajni Chaudhry, who has been teaching at DNI for 10 years. "Other groups may never go in for a diagnostic test to see if they have the trait because of its rarity among non-blacks and non-Hispanics. Additionally, it's an autosomal recessive disorder. So even though you have a trait, if you have a child, he or she will not have symptoms unless your partner also has the trait, or abnormal gene as well. If only one of the parents has the trait, then none of their children suffer from SCA."

How nurses can best treat patients with SCD

"Pain issues are the number one complaint for patients," says Dr. Iris Hobson, an ADN instructor for Dallas Nursing Institute. "Nurses should know the signs of SCD and first be concerned with the underlying cause of the pain. Once the SCD is known, nurses should be teaching their patients how to be able to help themselves with the disease, and keeping themselves well hydrated is a good start."

Dr. Iris Hobson

Chaudhry points out that anxiety and depression symptoms can also creep up in people with SCD because of the constant pain. Temporary relief, such as morphine, is available via the hospital, but unfortunately they often head back home to deal with the exhaustion, weakness, and pain all over again. While there is no surefire way to get the pain to stop for good, or to even know when it'll creep up beforehand, a well-informed patient may take proactive steps in an attempt to decrease the odds.

"We definitely shouldn't ignore elderly people with sickle cell disease," Chaudhry says. "But when trying to find a medication that could work in the long run and possibly become a cure, it's simply easier to work with a younger crowd before the complications that usually occur in later years. I also think we need to look into researching alternatives."

CDC confirms that the only cure for SCD is bone marrow or stem cell treatment. But not only does the bone marrow have to be a close match—usually a biological brother or sister—but the risky stem cell transplant can be fatal for the donor. The donor would allow him or herself to have soft, fatty tissue extracted from inside the center of the bones where blood cells are made. Then have the tissue inserted into the SCD patient whose bone marrow is not working properly. This procedure is reportedly only done for severe SCD cases focused on small children

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This procedure is reportedly only done for severe SCD cases focused on small children who have minimal organ damage.

While bone marrow transplants are not set in stone as the way all hospitals should treat those with SCD, there are other less stringent takeaways that patients can use in their everyday lives.

"In Nigeria, lime juice has been linked to reducing recurrent bone pain," Chaudhry explains.

In a recent study among 113 children who have sickle cell anemia (SCA), 58 of them that are receiving lime treatment had lower rates of significant painful episodes than the 57 who are not receiving the treatment. Significant painful episodes in the first group did a nosedive from 92.7 percent to 50 percent.

Lime juice treatment is still in its testing stages. However, there are more surefire ways to treat oneself in the meantime, including a healthy diet, more exercise to avoid decreased circulation, and protecting against harsh winters and cold weather.

"Risky weather can be especially dangerous and increase the risks of leukemia for people with SCD," Chaudhry says. "Be careful with some sports too. While swimming is a great way to exercise, for those with SCD, the temperature of the water definitely matters."

Peer pressure while growing up with SCD

For an unsuspecting eye, outsiders may not even recognize a child with sickle cell disease. As the child with SCD grows up, teachers and students may notice the child's attendance record more than others. Or, maybe that child won't participate in physical education classes as much, especially on particularly exhaustive days. But it may be easier to misread this child as not athletic or antisocial.

"Their peer group probably won't have the same kind of problems they do on an everyday basis," Chaudhry says. "Sporadic pain and school absences can be the reason they miss out on monumental moments in their younger years. They will have to make lifestyle changes in order to cope with the disease. And that can make them feel like outcasts."

By the time that child hits his or her teenage years, there's another level of peer pressure that will have to be conquered. Teenagers dealing with SCD may be at risk for lower self-esteem. For this reason, Chaudhry recommends cognitive behavioral therapy for the younger crowd.

"The obvious damages of sickle cell disease tend to be hidden," Dr. Hobson says. "Young people really don't discuss it as much because the complications aren't as glaringly obvious as, say, someone with an eye disease. With sickle cell, you have exacerbations. But you physically don't see the damage until later in life."

Famous faces: How "the cool kids" may help bring awareness

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"A lot of younger people don't want to advertise that they have a disease," Dr. Hobson says. "But using Michael J. Fox as an example for Parkinson's, when famous people are vocal and open about diseases such as this makes others take notice. Famous people put money into diseases that they know of and even those that run in their families."

Actor Larenz Tate did just that with a former foundation called Tate Brothers Foundation. Tate has SCD and created a campaign in the past called "Be Sickle Smart: Ask About Iron," educating people on iron overload. Late rapper Prodigy (one-half of Mobb Deep) passed away from complications with sickle cell disease. Other famous celebrities include late singer Paul Williams of The Temptations; late jazz musician Miles Davis; and Tiki Barber, who retired from the New York Giants. Ruben Studdard, an "American Idol" winner and singer, is also active in raising funds to help with the SCD fight due to his mother's ongoing humanitarian work.

But even an everyday person such as Anthony Senerchia, the inspiration behind the Ice Bucket Challenge to raise money for ALS, can help to leave an impact. Although Senerchia passed away at the age of 47, USA Today reports that within that eight-week period in 2014 when the Ice Bucket Challenge was at its most popular, it raised $115 million, with $89 million going into research for a treatment and cure. The ALS Association also announced $71.5 million on specific projects and initiatives out of the $115 million.

Whether it's a famous face to bring awareness, a trending topic on social media, more donations put into curing the disease, or being more open about the disease in a peer-to-peer setting, those with SCD may do themselves a service by being more open about the illness. With more attention being brought to any disease—from breast cancer to ALS to SCD—that can lead to more people paying attention. And with increased advocacy from both non-medical and medical professionals, nurses can use the teaching aspect to help treat the mental and physical symptoms in a way that makes those with SCD feel like they're not fighting the fight alone.