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Overcoming the Stigma of Sickle Cell Disease

Thursday, January 28, 2021

People living with sickle cell disease (SCD), an inherited blood disorder that primarily affects African Americans in the U.S., have to deal with constant fatigue and severely painful episodes that can last for a few hours or as long as a week. Adding to these daily challenges, family, friends, and the general public can sometimes view people with SCD as weak, lazy or faking their symptoms. These stigmas even exist in healthcare settings, making it more difficult for people living with SCD to get the care they need and the support to help them cope with it.

To help overcome these stigmas, we as a society can start by becoming better educated about SCD, and have compassion for people living with the condition.

What is sickle cell disease?

Sickle cell disease is a group of genetic disorders that affect red blood cells, causing them to become shaped like crescents, or sickles. The sickle-shaped cells travel through the bloodstream where they can get stuck and cut off blood flow, causing intense pain and organ damage.

What is health-related stigma?

Health-related stigma refers to the rejection of people with certain health conditions that is based on a negative stereotype, and usually within a healthcare setting. With SCD, health-related stigma can be compounded by racism (actual or perceived) and can pose significant barriers to getting appropriate care. For example, the standard of care for SCD patients with chronic or acute pain is to receive opioids. But some patients seeking medication for chronic or acute pain may be misperceived as drug addicts. Or people who need to rest from fatigue caused by SCD may be falsely thought of as malingers (those who pretend to be sick to get out of their responsibilities).

Unfortunately, not all healthcare providers always believe that people with SCD are suffering; some may think that SCD patients are exaggerating their pain or are seeking painkillers to satisfy an addiction. Several studies show how stigma from healthcare providers may impact a patient's physical well-being: People with SCD reported being mistaken as drug seekers or drug addicts and say their pain wasn't taken seriously by healthcare providers.

Why stigma is a problem in SCD

There are many factors that can contribute to stigma in SCD. Some of the most common reasons include:

- **People with SCD experience mistrust from healthcare providers about their pain levels.** The fact that people with SCD often experience chronic pain and have experience managing frequent, acute pain crises may often lead (emergency room or private) providers to the wrong idea that they are addicts, rather than simply being knowledgeable about their health needs.
- **People with SCD often suffer from extreme pain and fatigue.** The frequent pain episodes and extreme fatigue can lead to absenteeism from both school and work. This may cause create a false impression that the person with SCD is "lazy."

The overall effect of SCD-related stigma may leave some sufferers feeling mistrustful of the healthcare system.

What you can do about it

There are many strategies that may help reduce the impact of stigma including: counseling, therapy, support groups, empowerment and self-help, and advocacy. There are also several things you, as a person with SCD, can do to discourage SCD-related stigma and to help manage your condition. Here are some tips:

- Stay up to date with your medical care and keep yourself informed about your condition.
- Work together with your hematologist and your regular healthcare team.
- Create a 'pain plan' with your healthcare team and either carry a validated copy with you at all times or have easy access to an electronic version.
- Carry a document with you at all times that summarizes previous hospitalizations or emergency room visits. The individualized pain plan from your doctor can also be included here.
- If having acute pain, document the symptoms and location of the pain before and during attempts to manage pain with therapy.
- Find ways that help to reduce and/or manage your pain before it becomes an emergency. The National Heart Lung Blood Institute has some very good ideas to get you started.

For people with SCD, these tips may help you to avoid bias and stigma on an individual level. But you shouldn't go it alone. We also need the support of family members, healthcare providers and society to better understand this condition.

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Originally published, Thursday, January 28, 2021