

Problem

- When discussing chronic conditions in the school system the CDC highlights asthma, diabetes, epilepsy, oral health, food allergies, and epilepsy.
 - The common gap across these resources and several others is the failure to mention children with sickle cell disease, which primarily affects Black children.
- There is a lack of institutional leadership for education, outreach, and the spread of information on sickle cell.



Goals & Objective

The goal of this project was to develop a learning module for Tufts University students and diversify their understanding of different health conditions.

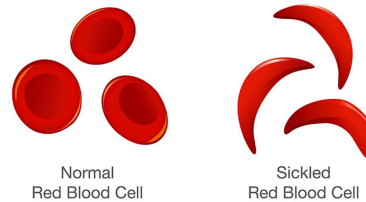
The goal of this module was to:

- Disseminate basic information on sickle cell disease prevalence, types, and the various symptom presentations.
- Sickle cell in the Boston Public School System
- Introduce students to personal testimonies and the familial experience
- Highlight gaps in care
- Spark conversations on the potential role of OT in working with children with SCD.

Module Development

Background Information:

- Sickle Cell Disease (SCD) is chronic condition that is the result of impaired blood circulation
- In this disease, the hemoglobin in the red blood cells is abnormal which distorts the blood cell from the normal circle to a c-shape, commonly referred as 'sickle'
- While travelling through the body the sickled cells often clog blood flow, resulting in pain and serious complications which may present throughout the lifetime



Sickle Cell Literature: Module with articles on the academic challenges and school service utilization of children with sickle cell.

Sickle Cell in BPS: Information on the 2015 complaint filed to the US Department of Education on BPS for violations of policies and practices on children with SCD.

Personal Interview: Interviews were conducted with a sickle cell disease survivor and her mother about their experience navigating services while in the school system.

Resource Dissemination: Provided supplemental resources on sickle cell handbooks implemented in various states, policies on sickle cell management in different school systems, supplemental videos, and helpful resources.

Assessment: Administered a short quiz as a content check for students.

Key Takeaways

From the Literature

- Karkoska et al. (2020) developed a study on children with sickle cell using the Brief School Needs Inventory (BSNI) and found that majority of parents were challenged in finding appropriate accommodations.
 - 60% of those children were found to have an elevated risk for facing academic challenges.
- Researchers Schwartz et al. (2009) recommended school-based interventions for students with SCD to better support the achievement of their academic goals and help manage chronic absenteeism.



Sickle Cell Survivor Testimonies:

- “I needed more support during a crisis, time extensions, comfort, medication management”
- “I wish that I had a space in school to deal with my crisis, since leaving school early can be complicated and disruptive

Sickle Cell Parent Testimony:

- “There needs to be a teacher support program to educate teachers on the diseases so that they can understand us”



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