**Occupational Therapy and Sickle Cell Awareness**

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National Sickle Cell Awareness Month**

**September 2024 is Sickle Cell Awareness Month**, designated by Congress to spur research and treatment related to sickle cell disease (SCD), an inherited blood cell disorder causing deformed hemoglobin (sicklecelldisease.org, 2024). The crescent - or “sickle”-shaped red blood cells have decreased flexibility resulting blockages that impair blood flow and oxygen delivery throughout the body. When these unpredictable blockages (pain crises) occur, patients can experience a range of serious medical conditions including excruciating pain, infections, swollen limbs, fatigue, growth delays and varied complications with joints and organs (nhlbi.nih.gov, 2024) Bone marrow or stem cell transplants are high risk procedures used for SCD patients with the most severe cases; currently medication and blood transfusions are the most typical course of treatment (sicklecelldisease.org, 2024). Optimistically, according to the FDA, a cure for Sickle Cell is on the horizon, along with initiatives to better utilize available tools in the battle against this disease (curesickle.org, 2024).

Given the effects of SCD on the whole body, it’s impact on a person’s satisfaction with their occupational engagement are stark. Rarely does the care team of hematologists and pain specialists include occupational therapists. However there is an important role OTP’s can have in addressing meaningful and productive occupational participation to support those living with SCD across the lifespan. Occupational therapy is a major profession providing intervention addressing developmental milestones, cognition, task performance, pain management strategies, ADL independence and overall health and well-being (Dorvilien et al. 2024). Pediatric interventions have focused on issues of balance, ROM, ADL and mobility aids to address childhood conditions related to the SCD sequalae (nyulangone.org, 2024).

***U.S. Sickle Cell Disease Statistics***

* More than 100,000 people in the United States are affected by (SCD); 90% are Black (non-Hispanic), 3%–9% are Latino.
* SCD occurs in about 1 out of every 365 Black or African American births and about 1 out of every 16,300 Latino American births.
* About 8% of Black or African American babies are born with sickle cell trait (inheritance of a sickle cell gene from only one parent).
* Many people who come from Hispanic, Southern European, Middle Eastern, or Asian Indian backgrounds also have sickle cell disease (CDC.gov, 2024).

**Enter Occupational Therapy**

One qualitative OT study which examined the role of occupational therapy with SCD management analyzed a survey of 39 individuals living with SCD or caring for persons living with SCD (Henry, 2002). Results showed that ADLs were impacted for 50% of the subjects. Also participants noted hampered work activities (38%) and affected play/leisure activities (18%). The researcher recommended that a holistic approach be utilized by OTPs treating patients with SCD.

Preliminary results from another OT study reported SCD participants scored lower than expected on some cognitive measures of executive function, attention, working memory, and overall fluid cognition. Researchers noted these deficits and others can impact participation in productive daily occupations. They recommended that OTPs designing interventions for those with SCD, regularly assess cognition and task performance to enhance their client’s self-awareness and level of independent functioning (Varughese et al., 2019). Overall the limited OT research on those with SCD suggests more information is needed on pre-morbid or preventative, maintenance, and post morbid interventions (nyulangone.org, 2024).

#### **References**

CDC.Gov. (2024). Data and Statistics on Sickle Cell Disease. U.S. Centers for Disease Control and Prevention. https://www.cdc.gov/sickle-cell/data/index.html

Curesickle.org. (2024). Cure Sickle Cell. https://curesickle.org/

Henry, T. T. (2020). The role of occupational therapy for individuals living with sickle cell disease. (2002). ProQuest ETD Collection for FIU. AAI1409100.  
https://digitalcommons.fiu.edu/dissertations/AAI1409100

Nhlbi.nih.gov. (2024). What is Sickle Cell Disease? https://www.nhlbi.nih.gov/health/sickle-cell-disease

Nyulangone.org. (2024). Support for Sickle Cell Disease. NYU Langone Health. lhttps://nyulangone.org/conditions/sickle-cell-disease-in-children/support#:~:text=Physical%20and%20occupational%20therapists%20at,who%20have%20had%20a%20stroke.

Sicklecelldisease.org. (2024). National Sickle Cell Awareness Month. SCDAA. https://www.sicklecelldisease.org/get-involved/events/national-sickle-cell-awareness-month/#:~:text=September%20is%20National%20Sickle%20Cell,treatment%20of%20sickle%20cell%20disease.

Dorvilien, J., Hoyt, C., Lance, E., Dorvilien, C., Lois Williams, L., & Hurley, G. (2024). Improving Sickle Cell Care: The Role of Occupational Therapy. https://myaota.aota.org/shop\_aota/product/OL8681

Varughese, T., Varnum, M., Hull, E., Abel, R., & King, A., (2019). Cognitive and functional outcomes in adults with sickle cell disease. *The American Journal of Occupational Therapy*, 2019, Vol. 73(4\_Supplement\_1), 7311500032p1.

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Top of Form