



THE HANGOUT UPDATE

APRIL SESSION

4/27/2023



TAISHA MATHIEU

Health & Wellness Coordinator

In April, we completed our monthly session of **“THE HANGOUT - A support group for individuals impacted by Sickle Cell Disease.”** The topic was **“SCD & COMMUNITY HEALTH WORKERS”**. Thanks to everyone who joined in! If you were unable to participate in The Hangout this month, please enjoy this summary of the discussion.

GROUP NORMS

We want the Hangouts to be a safe, supportive space for all participants. We reviewed group norms briefly at the start of the session, and as always, if you have any questions or concerns about the norms, feel free to contact Taisha Mathieu at taisha@mythreesicklers.org.

TOPIC

This month’s topic focused on the impact that Sickle cell has on individuals and the importance of having community health workers. There are times when Sickle Cell Warriors begin to feel stressed, burdened, hopeless, and in solitude when the pain they feel is not taken into consideration and is being disregarded. There was a quote that a participant stated within the session that resonated with the emotions and the turmoil that members embark on every day in their daily lives as warriors. The participant stated, “Do not lose sight of the light that radiates from afar. Continue to fight back the rages of pain, trauma, depression, loneliness, and suffocation with peace advocacy education, and empathy. We are not known only by the disease and tribulations but by the power we fight and with the fortitude of our demeanors.

The power and recognition of hardship do not go unnoticed but are shown through the positive changes that one chooses to do in the spirit of living a life of homeostasis. Life has been given to every participant as a gift that should be used in having a balance. For instance, practicing self-care such as going on walks, and resting when it is needed and not when forced. In addition, practicing self-care individually also accepts that the challenges are not forever and that the day or days will get more forthright. The challenges may include missing days of work, missing events, and or celebrations of loved ones, etc. Because if a person does not want to believe that the day or days will get better, it can become more overwhelming and difficult in practicing how to be selfish for the sake of having stable health holistically for the body.

SCD warriors must understand that validation does not have to disrupt your vision of success. For example, participants have mentioned that families complain about having a member in the family constantly “popping pills, always fatigued, and being in pain. Learning to balance times of pain, and distress, but also having support and comfort from the grace of God and having the lending hands of community health workers will make having a healthy life more possible.

We had the opportunity to have a guest speaker, Dr. Tilicia L. Mayo-Gamble. She is an associate professor at Georgia Southern University. She provides education, guidance, and most importantly research on the importance of having community health workers for those who have Sickle disease. She is a true team player in bringing in the struggles and concerns of what the SCD participants need on an individual concern as well as overall. Dr. Mayo-Gamble quoted from Rumi saying, “You were born with potential. You were born with goodness and trust. You were born with ideals and dreams. You were born with greatness. You were born with wings. You are not meant for crawling, so don't. You have wings. Learn to use them and fly.” She believes in finding the best health solutions and proper care for those who have SCD. Additionally, she reminds the group and the organization that for change to happen we must ask those who are in need and how we can provide the need that will bring everyone to the utmost self in living a life full of support and access to caregiving.

Dr. Mayo-Gamble also provided the group with essential points that define the role of community health workers for those who have SCD. The reason entails allowing citizens to have frequent mental, and or emotional checkups on how one is doing or has been managing before doctors' visits as well for major life changes that individuals may experience. SCD warriors need to have access to resources and support the initiatives that community health workers are trying to provide are strategically funded programs that can help SCD warriors have what they need for basic needs. For instance, if an individual needs new eyeglass, heating pads, financial literacy and or guidance for daily expenses or even purchasing simple everyday health essentials the CHW tries to collect the information that the person provides and comes together to work with the person in finding the best

resources and accessibilities he or she can have to not feel overwhelmed and discouraged.

Moreover, a community health worker is a person who is not afraid of being proactive and persistent in helping citizens get the basic and essential items and mental support he or they may need to feel more at ease. Participants have mentioned that with the help of community health workers, they have been able to feel supported and have the proper knowledge and aid they need to manage life successfully. Community health workers provide people with individual support in discussing the physical ailments and medical concerns that one may experience. For example, individuals may simply just need someone to converse with about the daily hassles of living with Sickle cell and not being understood especially when having to take medication that perhaps may not fully alleviate the chronic pains. According to the participation in the group, the role that community health workers provide in their lives cannot be measured with a simple word other than Thank You.

Overall, SCD warriors, community health workers, and allies must come together in advocating for better strategies in providing outlets to live lives of wholeness. Sickle cell disease is not a death sentence, and it is not an illness that defines a person. Individuals choose how they want to live and how they want to be remembered and practicing self-love, self-care, and using their voices demonstrates the true definition of what it means to be a warrior in the eyes of obscurity and adversity.



SPECIAL GUEST

Dr. Tilicia L. Mayo-Gamble

Associate Professor - Georgia Southern University