Speech: Inspiring Hope and Resilience for Sickle Cell Patients

By

David Adebayo Oluwole, PhD. University of Ibadan, Ibadan 08034105253

daoluwoledr@gmail.com

https://www.positivepsychology.org.ng/

Special Guests of Honour,

Ladies and gentlemen, friends, and cherished members of the sickle cell community,

I thank Bunmi Akinsola Sickle Cell Initiative for giving me the opportunity to be here today.

It is an honour to stand before you today as we come together in this space of hope, resilience, and unwavering strength. I want to begin by acknowledging the courage, determination, and perseverance that those living with sickle cell show every single day in their battle with sickle cell. For those living with it, for your families, and for those who stand beside you in this fight, you are the true heroes.

According to a 2023 article in The Lancet Haematology, 774 million people were living with sickle cell disease (SCD) in 2021. This is a 41.4% increase from 2000, when 546 million people were living with the disease. Sickle cell disease (SCD) is a hereditary red blood cell disorder of public health importance globally with Nigeria the epicenter zone in Africa with about 4-6 million people living with the disease (1 in every 4 Nigerians has a sickle cell trait) (Aygun & Odame, 2012).

Sickle cell disease is a chronic condition that has affected millions of lives globally, and while it brings with it immense challenges, it also brings stories of unbreakable spirit and resilience. Though sickle cell disease can make life difficult, it does not define who you are or limit your potential. It may be part of your journey, but it is not the destination. And I want to remind each of you today that hope is not lost.

To the brave individuals who endure the pain, the fatigue, and the constant medical appointments, I want to say this: You are not alone. The road you walk is not easy, and there may be times when you feel overwhelmed, but every step you take brings us closer to understanding, to treatment, and to a world where sickle cell is no longer a battle to fight, but a chapter in a shared history of triumph over adversity.

As we stand here today, I ask each of you to remember something deeply important: your resilience is more powerful than the disease. It is in the strength to get up every day, to keep moving forward despite the pain. It is in your voice, whether you are

speaking up for better healthcare, more support, or awareness. It is in your ability to hold onto hope, even when the road ahead seems uncertain.

What is Hope?

Hope is the belief or expectation that things can get better, even in the face of challenges, uncertainty, or adversity. It is a powerful, positive emotion that gives us the strength to persevere when times are tough. Hope is the driving force that helps us envision a better future, even when the present may seem overwhelming.

Hope is not just wishful thinking; it's a mindset that empowers us to take action and continue moving forward, even when the path ahead seems unclear. It can manifest in different ways: the hope of healing, the hope for change, the hope for a brighter tomorrow, or the hope that our efforts will lead to meaningful outcomes.

At its core, hope is about resilience and believing in the possibility of improvement. It is a light that guides us through dark moments, encouraging us to keep going, trusting that, with time, effort, and support, positive change is possible. Hope is deeply tied to the human spirit—an innate part of who we are—that keeps us moving forward, seeking solutions, and supporting each other through life's hardest moments.

Hope is a complex emotional and cognitive experience, and it involves some key components that work together to sustain and motivate us, especially during difficult times. These components include:

1. Goal Setting

- Hope involves having clear, meaningful goals that we aim to achieve.
- People who have hope often set goals for themselves—whether short-term or long-term—that give their life direction and purpose. These goals provide motivation and focus, helping individuals overcome obstacles.

2. Agency (The Willpower to Achieve Goals)

 Agency refers to the belief in one's ability to initiate and take actions toward achieving goals. This component is about the belief that you have control over your actions and that your efforts can lead to progress. Hopeful people believe they can influence their circumstances and are motivated to keep trying even when faced with setbacks.

3. Pathways (The Way to Achieve Goals)

- Pathways refer to the ability to identify multiple ways to achieve your goals, even when obstacles arise.
- Hopeful individuals are not deterred by challenges. They are resourceful and can think creatively, finding alternative ways to reach their goals. This component involves planning and problem-solving, which helps people stay on track when their original plans may not work out.

4. Optimism

 Optimism is the positive outlook on the future, believing that good things are possible. Hope is closely related to optimism—the belief that the future holds potential
for positive outcomes. People who are hopeful are generally optimistic, trusting
that things will improve with time and effort.

5. Resilience

- Resilience is the ability to recover from setbacks and continue pursuing goals.
- Hope involves resilience because, in difficult times, it's easy to lose sight of your goals or feel overwhelmed. Hopeful people have the emotional strength to bounce back, stay committed, and keep working toward their objectives despite challenges.

The Defense Logistics Agency which is a combat support agency in the United States Department of Defense defined Resilience as how one "deals effectively with pressure, ambiguous and emerging conditions, and multiple tasks; remains optimistic and persistent, even under adversity or uncertainty. Recovers quickly from setbacks. Anticipates changes and learns from mistakes."

Resilience is the ability to function well in the face of adversity.

The DLA resilience model has four pillars: mental, physical, social and spiritual; balancing these four components help strengthen your life.

<u>Mental</u>: The ability to effectively cope with mental stressors and challenges. Pay attention to your needs and feelings. Our thoughts control our energy.

<u>Physical</u>: The ability to adopt and sustain healthy behaviors. Regularly work out and continually monitor physical stamina. Recognize the connection between mind and body: strong bodies help build strong minds

<u>Social</u>: The ability to network. Build and value interpersonal relationships and social networks. Social connections with others widen perceptions and grow character.

Spiritual: The ability to adhere to beliefs, principles, or values needed to persevere and prevail in accomplishing missions.

6. Belief in Support

- Hope can also involve a belief that you are not alone in your struggles and that others will support you.
- This component acknowledges the role of relationships and community. Having hope means not only believing in oneself but also in the importance of help and encouragement from others, whether family, friends, or support networks.
- There is so much hope in the world of medical research. Advances in gene
 therapy, improved pain management, and better treatments for sickle cell are
 on the horizon. While we may not have all the answers today, we are moving
 closer every day. Your strength fuels that progress. Every story shared, every
 voice raised in advocacy, and every act of kindness brings us one step closer
 to a brighter future.

7. Purpose

- Purpose is the deeper meaning or value behind pursuing one's goals.
- Hope is rooted in a sense of purpose or meaning that gives individuals a reason to strive forward. Whether the purpose is personal growth, helping others, or making a difference in the world, hope helps us stay connected to our "why" when challenges arise.

Together, these components create a framework for hope that enables individuals to face adversity with a belief that they can reach their desired outcome, no matter the difficulties they encounter along the way.

We cannot do this alone. It is critical that we come together as a community—patients, families, doctors, researchers, and advocates—to drive change. We must continue to fight not just for ourselves but for those who have yet to be diagnosed, for those too young to speak for themselves, and for future generations who will benefit from the advancements we make today.

To the caregivers, the loved ones, and the supporters of those with sickle cell disease, I want to express my deepest gratitude. Your love, your patience, and your unwavering support are invaluable. You are the foundation that so many of our warriors rely on. Your strength is the silent engine that powers the journey forward.

Above all, to every person here who is battling sickle cell, I want you to remember this: You are not defined by your illness. You are defined by your courage, by your heart, and by the way, you show up in this world. No matter how difficult the days may seem, you are building a legacy of hope and resilience, one that will inspire generations to come.

I appreciate Bunmi Akinsola Sickle Cell Initiative in their efforts in bringing succour to the society over time; having organised outreaches for over 5000 individuals including students and teachers.

Let us keep believing in each other. Let us keep pushing forward, united in the fight against sickle cell. Every effort matters. Every story is significant. Together, we will continue to make progress toward a world where sickle cell disease is no longer a barrier, but simply a part of our shared history—a history of overcoming.

Therefore, I leave you with this: Let your hope be stronger than your fear. Let your resilience shine brighter than the darkness of the challenges you face. And let the love and support of your community carry you when you need it most.

Thank you, and together, we will overcome.