

## Community Leaders as Educators: Mobilizing for Sickle Cell Disease Reduction

\*Emmanuel Ifeanyi Obeagu<sup>1</sup> and Getrude Uzoma Obeagu<sup>2</sup>

<sup>1</sup>Department of Medical Laboratory Science, Kampala International University, Uganda

<sup>2</sup>School of Nursing Science, Kampala International University, Uganda

\*Corresponding author: Emmanuel Ifeanyi Obeagu, [Department of Medical Laboratory Science, Kampala International University, Uganda, emmanuelobeagu@yahoo.com, ORCID: 0000-0002-4538-0161](#)

### Abstract

Sickle Cell Disease (SCD) poses a significant health challenge globally, particularly affecting marginalized communities with limited access to healthcare resources. Community leaders, including religious figures, grassroots organizers, and advocacy groups, play a pivotal role in mobilizing efforts to reduce the burden of SCD. This review examines the crucial role of community leaders as educators in raising awareness, promoting early detection, and advocating for improved care and support for individuals living with SCD. By analyzing existing initiatives, challenges, and best practices, this article highlights the impact of community-led education and advocacy efforts and provides recommendations for enhancing community engagement in SCD reduction. The findings underscore the importance of leveraging community leadership and networks to address the challenges associated with SCD and advance efforts to improve outcomes for affected individuals and families.

**Keywords:** *Sickle Cell Disease, Community Leaders, Education, Awareness, Advocacy, Mobilization*

### Introduction

Sickle Cell Disease (SCD) stands as a significant health concern, affecting millions globally, with a pronounced impact on marginalized communities. Among these communities, community leaders wield considerable influence, serving as trusted figures who can mobilize resources, disseminate information, and catalyze change. This review aims to explore the pivotal role of community leaders as educators in the context of SCD reduction efforts. From grassroots organizers to religious leaders and advocacy groups, these leaders play a vital role in raising  
**Citation:** Obeagu EI, Obeagu GU. Community Leaders as Educators: Mobilizing for Sickle Cell Disease Reduction. Elite Journal of Health Science, 2023; 1(1):37-43

awareness, promoting early detection, and advocating for improved care and support for individuals living with SCD. Community leaders serve as linchpins in disseminating accurate information about SCD within their respective communities. Leveraging their credibility and influence, they organize educational workshops, community forums, and outreach programs to educate community members about SCD, its symptoms, treatment options, and available support services. By providing culturally sensitive and linguistically appropriate education, community leaders empower individuals and families affected by SCD to make informed decisions about their health and well-being, thus bridging gaps in knowledge and reducing misconceptions.<sup>1-10</sup>

However, community leaders encounter various challenges in their efforts to mobilize for SCD reduction. Limited resources, stigma, and cultural barriers often hinder outreach efforts and impede access to care and support services. Overcoming these challenges requires collaborative efforts between community leaders, healthcare providers, policymakers, and other stakeholders. Furthermore, capacity building, partnerships, and advocacy for policy changes and increased funding for SCD research and services are essential to enhance community engagement and address disparities. Despite the challenges, opportunities exist to strengthen community-led education and advocacy efforts for SCD reduction. By leveraging existing community networks and resources, providing training and support for community leaders, and fostering partnerships between community organizations and healthcare providers, the impact of community-led initiatives can be amplified. Additionally, promoting culturally appropriate messaging and addressing stigma are crucial for reaching underserved populations and reducing disparities in access to care.<sup>1-20</sup>

### **The Role of Community Leaders as Educators**

The role of community leaders as educators in the context of Sickle Cell Disease (SCD) reduction is multifaceted and pivotal. Community leaders, encompassing religious figures, grassroots organizers, and advocacy groups, serve as trusted sources of information and support within their communities. Through their influence and networks, they play a crucial role in raising awareness, promoting early detection, and advocating for improved care and support for individuals living with SCD. Firstly, community leaders serve as educators by disseminating accurate information about SCD and its impact within their communities. They organize educational workshops, seminars, and community forums to provide community members with knowledge about the disease, its symptoms, treatment options, and available support services. By delivering culturally sensitive and linguistically appropriate education, community leaders empower individuals and families affected by SCD to make informed decisions about their health and well-being, thereby bridging gaps in knowledge and dispelling misconceptions.<sup>21-25</sup>

Additionally, community leaders act as advocates for SCD reduction efforts, leveraging their influence to raise awareness and mobilize resources. They advocate for increased funding for SCD research, access to quality healthcare services, and the implementation of supportive policies at local, national, and international levels. By amplifying the voices of affected individuals and communities, community leaders ensure that SCD remains a priority on the public health agenda and advocate for the needs of those living with the condition. Moreover, community leaders play

**Citation:** Obeagu EI, Obeagu GU. Community Leaders as Educators: Mobilizing for Sickle Cell Disease Reduction. *Elite Journal of Health Science*, 2023; 1(1):37-43

a crucial role in fostering a supportive environment for individuals living with SCD and their families. They provide emotional support, connect individuals with resources and support networks, and advocate for inclusive policies and practices that promote the well-being of those affected by the disease. By creating a culture of understanding, empathy, and support, community leaders help reduce stigma and improve the quality of life for individuals living with SCD.<sup>26-28</sup>

## **Challenges and Opportunities**

### **Challenges**

Community leaders often operate with limited financial and organizational resources, which can constrain their ability to effectively educate and mobilize their communities around SCD. Lack of funding may limit the scope and reach of educational initiatives and hinder efforts to provide support and advocacy for individuals living with SCD. Stigma and misconceptions surrounding SCD persist in many communities, leading to discrimination and barriers to care. Community leaders may encounter resistance or reluctance to engage in discussions about the disease due to cultural beliefs, fear, or misinformation. Addressing stigma and misconceptions requires sensitive and culturally appropriate approaches to education and advocacy. Cultural and linguistic diversity within communities can present challenges in delivering effective SCD education and support services. Language barriers may hinder communication and understanding, while cultural differences in beliefs and practices related to health and illness may influence perceptions of SCD and willingness to engage in educational initiatives.<sup>29-30</sup>

### **Opportunities**

Community leaders have the unique ability to engage directly with their communities, leveraging their trust and influence to raise awareness and mobilize support for SCD reduction efforts. By organizing community forums, workshops, and events, community leaders can facilitate open discussions, share information, and address questions and concerns about SCD. Opportunities exist to build the capacity of community leaders and organizations to effectively educate and advocate for SCD reduction. Training programs, workshops, and resource materials can provide community leaders with the knowledge, skills, and tools they need to deliver accurate information, engage their communities, and advocate for change. Collaboration between community leaders, healthcare providers, government agencies, and non-profit organizations can amplify the impact of SCD education and advocacy efforts. By working together, stakeholders can pool resources, share expertise, and coordinate initiatives to address the multifaceted challenges of SCD and promote holistic solutions. Community leaders can play a powerful role in advocating for policy changes and increased funding for SCD research, treatment, and support services. By raising awareness of the needs of individuals living with SCD and mobilizing community support, community leaders can influence policymakers and drive legislative action to improve access to care and support for affected individuals.<sup>31-33</sup>

## **Best Practices and Recommendations**

**Citation:** Obeagu EI, Obeagu GU. Community Leaders as Educators: Mobilizing for Sickle Cell Disease Reduction. *Elite Journal of Health Science*, 2023; 1(1):37-43

Develop culturally tailored educational materials and programs that resonate with the cultural beliefs, values, and languages of diverse communities. By incorporating culturally sensitive messaging and addressing specific cultural norms and practices related to health and illness, community leaders can enhance the relevance and effectiveness of SCD education initiatives. Employ community engagement strategies that prioritize the active involvement of community members in SCD education and advocacy efforts. This may include organizing community forums, focus groups, and storytelling sessions to facilitate dialogue, share personal experiences, and address misconceptions about SCD. By engaging community members as active participants in the process, community leaders can foster ownership and sustainability of initiatives. Provide training and capacity-building opportunities for community leaders to enhance their knowledge, skills, and confidence in delivering SCD education and advocacy. Training programs may cover topics such as SCD basics, communication strategies, advocacy techniques, and resources for accessing healthcare services and support. By investing in the capacity of community leaders, organizations can strengthen the effectiveness and sustainability of SCD reduction efforts.<sup>34-40</sup>

Harness the power of technology and social media platforms to reach broader audiences and amplify SCD education and advocacy efforts. Create online resources, webinars, and social media campaigns to disseminate information, raise awareness, and engage community members in discussions about SCD. By utilizing digital platforms, community leaders can overcome geographical barriers and connect with individuals across diverse communities. Foster collaborative partnerships between community leaders, healthcare providers, government agencies, and non-profit organizations to maximize the impact of SCD reduction initiatives. Pooling resources, sharing expertise, and coordinating efforts can enhance the reach, efficiency, and sustainability of educational programs, advocacy campaigns, and support services for individuals living with SCD. Empower individuals and families affected by SCD to become advocates for themselves and their communities. Provide opportunities for peer support, mentorship, and leadership development to help individuals build resilience, self-efficacy, and advocacy skills. By empowering affected individuals to share their stories, advocate for their needs, and drive change within their communities, community leaders can create a culture of empowerment and solidarity. Regularly evaluate the effectiveness of SCD education and advocacy initiatives through surveys, assessments, and feedback from community members. Use evaluation data to identify strengths, areas for improvement, and opportunities for innovation, and adjust strategies accordingly. By prioritizing evaluation and continuous improvement, community leaders can ensure that SCD reduction efforts remain responsive to the needs of communities and individuals affected by the disease.<sup>41-44</sup>

## Conclusion

Community leaders play a vital role in driving Sickle Cell Disease (SCD) reduction efforts through education, advocacy, and community engagement. Despite facing challenges such as limited resources, stigma, and cultural barriers, community leaders have significant opportunities to make a positive impact by leveraging their influence, engaging their communities, and fostering partnerships. By implementing best practices such as culturally tailored education, community engagement strategies, capacity building for community leaders, leveraging technology, **Citation:** Obeagu EI, Obeagu GU. Community Leaders as Educators: Mobilizing for Sickle Cell Disease Reduction. Elite Journal of Health Science, 2023; 1(1):37-43

collaborative partnerships, empowering individuals and families, and prioritizing evaluation and continuous improvement, community leaders can enhance the effectiveness and sustainability of SCD reduction initiatives.

## References

1. Ata F, Rahhal A, Malkawi L, Iqbal P, Khamees I, Alhiyari M, Yousaf Z, Qasim H, Alshurafa A, Sardar S, Javed S. Genotypic and phenotypic composition of sickle cell disease in the Arab population-a systematic review. *Pharmacogenomics and Personalized Medicine*. 2023;133-144.
2. Piel FB, Williams TN. Sickle cell anemia: history and epidemiology. *Sickle Cell Anemia: From Basic Science to Clinical Practice*. 2016;23-47.
3. Aneke JC, Okocha CE. Sickle cell disease genetic counseling and testing: A review. *Archives of Medicine and Health Sciences*. 2016;4(1):50-57.
4. Bitoungui VJ, Pule GD, Hanchard N, Ngogang J, Wonkam A. Beta-globin gene haplotypes among cameroonians and review of the global distribution: is there a case for a single sickle mutation origin in Africa? *Omics: a journal of integrative biology*. 2015;19(3):171-179.
5. Obeagu EI, Ochei KC, Nwachukwu BN, Nchuma BO. Sickle cell anaemia: a review. *Scholars Journal of Applied Medical Sciences*. 2015;3(6B):224422-52.
6. Obeagu EI. Erythropoietin in Sickle Cell Anaemia: A Review. *International Journal of Research Studies in Medical and Health Sciences*. 2020;5(2):22-28.
7. Obeagu EI. Sickle Cell Anaemia: Haemolysis and Anemia. *Int. J. Curr. Res. Chem. Pharm. Sci*. 2018;5(10):20-21.
8. Obeagu EI, Muhimbura E, Kagenderezo BP, Uwakwe OS, Nakyeyune S, Obeagu GU. An Update on Interferon Gamma and C Reactive Proteins in Sickle Cell Anaemia Crisis. *J Biomed Sci*. 2022;11(10):84.
9. Obeagu EI, Bunu UO, Obeagu GU, Habimana JB. Antioxidants in the management of sickle cell anaemia: an area to be exploited for the wellbeing of the patients. *International Research in Medical and Health Sciences*. 2023;6(4):12-17.
10. Obeagu EI, Ogunnaya FU, Obeagu GU, Ndidi AC. Sickle cell anaemia: a gestational enigma. *European Journal of Biomedical and Pharmaceutical Sciences*. 2023;10(9): 72-75
11. Obeagu EI. An update on micro RNA in sickle cell disease. *Int J Adv Res Biol Sci*. 2018; 5:157-8.
12. Obeagu EI, Babar Q. Covid-19 and Sickle Cell Anemia: Susceptibility and Severity. *J. Clinical and Laboratory Research*. 2021;3(5):2768-0487.
13. Obeagu EI. Depression in Sickle Cell Anemia: An Overlooked Battle. *Int. J. Curr. Res. Chem. Pharm. Sci*. 2023;10(10):41-.
14. Obeagu EI, Obeagu GU. Evaluation of Hematological Parameters of Sickle Cell Anemia Patients with Osteomyelitis in A Tertiary Hospital in Enugu, Nigeria. *Journal of Clinical and Laboratory Research*. 2023;6(1):2768-0487.
15. Obeagu EI, Dahir FS, Francisca U, Vandu C, Obeagu GU. Hyperthyroidism in sickle cell anaemia. *Int. J. Adv. Res. Biol. Sci*. 2023;10(3):81-89.
16. Njar VE, Ogunnaya FU, Obeagu EI. Knowledge And Prevalence of The Sickle Cell Trait Among Undergraduate Students Of The University Of Calabar. *Prevalence*.;5(100):0-5.

**Citation:** Obeagu EI, Obeagu GU. Community Leaders as Educators: Mobilizing for Sickle Cell Disease Reduction. *Elite Journal of Health Science*, 2023; 1(1):37-43



17. Swem CA, Ukaejiofo EO, Obeagu EI, Eluke B. Expression of micro RNA 144 in sickle cell disease. *Int. J. Curr. Res. Med. Sci.* 2018;4(3):26-32.
18. Obeagu EI. Sickle cell anaemia: Historical perspective, Pathophysiology and Clinical manifestations. *Int. J. Curr. Res. Chem. Pharm. Sci.* 2018;5(11):13-15.
19. Obeagu EI, Obeagu GU. Sickle Cell Anaemia in Pregnancy: A Review. *International Research in Medical and Health Sciences.* 2023 Jun 10;6(2):10-13.
20. Obeagu EI, Mohamod AH. An update on Iron deficiency anaemia among children with congenital heart disease. *Int. J. Curr. Res. Chem. Pharm. Sci.* 2023;10(4):45-48.
21. Edward U, Osuorji VC, Nnodim J, Obeagu EI. Evaluation of Trace Elements in Sickle Cell Anaemia Patients Attending Imo State Specialist Hospital, Owerri. *Madonna University journal of Medicine and Health Sciences.* 2022;2(1):218-234.
22. Umar MI, Aliyu F, Abdullahi MI, Aliyu MN, Isyaku I, Aisha BB, Sadiq RU, Shariff MI, Obeagu EI. Assessment Of Factors Precipitating Sickle Cell Crises Among Under 5-Years Children Attending Sickle Cell Clinic of Murtala Muhammad Specialist Hospital, Kano. *blood.*;11:16.
23. Obeagu EI. Vaso-occlusion and adhesion molecules in sickle cells disease. *Int J Curr Res Med Sci.* 2018;4(11):33-35.
24. Ifeanyi OE, Stella EI, Favour AA. Antioxidants in the Management of Sickle Cell Anaemia. *Int J Hematol Blood Disord:* <https://sybiosisonlinepublishing.com/hematology/hematology25.php>. 2018.
25. Inusa BP, Stewart CE, Mathurin-Charles S, Porter J, Hsu LL, Atoyebi W, De Montalembert M, Diaku-Akinwumi I, Akinola NO, Andemariam B, Abboud MR. Paediatric to adult transition care for patients with sickle cell disease: a global perspective. *The Lancet Haematology.* 2020;7(4): e329-341.
26. Buhari HA, Ahmad AS, Obeagu EI. Current Advances in the Diagnosis and Treatment of Sickle Cell Anaemia. *APPLIED SCIENCES (NIJBAS).* 2023;4(1).
27. Nnodim J, Uche U, Ifeoma U, Chidozie N, Ifeanyi O, Oluchi AA. Hepcidin and erythropoietin level in sickle cell disease. *British Journal of Medicine and Medical Research.* 2015;8(3):261-5.
28. Obeagu EI. BURDEN OF CHRONIC OSTEOMYELITIS: REVIEW OF ASSOCIATED FACTORS. *Madonna University journal of Medicine and Health Sciences.* 2023;3(1):1-6.
29. Aloh GS, Obeagu EI, Okoroiwu IL, Odo CE, Chibunna OM, Kanu SN, Elemchukwu Q, Okpara KE, Ugwu GU. Antioxidant-Mediated Heinz Bodies Levels of Sickle Erythrocytes under Drug-Induced Oxidative Stress. *European Journal of Biomedical and Pharmaceutical sciences.* 2015;2(1):502-507.
30. Obeagu EI, Bot YS, Opoku D, Obeagu GU, Hassan AO. Sickle Cell Anaemia: Current Burden in Africa. *International Journal of Innovative and Applied Research.* 2023;11(2):12-14.
31. Obeagu EI, Obeagu GU. Sickle Cell Anaemia in Pregnancy: A Review. *International Research in Medical and Health Sciences.* 2023; 6 (2): 10-13.
32. Obeagu EI, Ogbuabor BN, Ikechukwu OA, Chude CN. Haematological parameters among sickle cell anemia patients' state and haemoglobin genotype AA individuals at Michael Okpara University of Agriculture, Umudike, Abia State, Nigeria. *International Journal of Current Microbiology and Applied Sciences.* 2014;3(3):1000-1005.

**Citation:** Obeagu EI, Obeagu GU. Community Leaders as Educators: Mobilizing for Sickle Cell Disease Reduction. *Elite Journal of Health Science*, 2023; 1(1):37-43

33. Ifeanyi OE, Nwakaego OB, Angela IO, Nwakaego CC. Haematological parameters among sickle cell anaemia... Emmanuel Ifeanyi1, et al. pdf• Obeagu. Int. J. Curr. Microbiol. App. Sci. 2014;3(3):1000-1005.
34. Obeagu EI, Abdirahman BF, Bunu UO, Obeagu GU. Obsterics characteristics that effect the newborn outcomes. Int. J. Adv. Res. Biol. Sci. 2023;10(3):134-143.
35. Obeagu EI, Opoku D, Obeagu GU. Burden of nutritional anaemia in Africa: A Review. Int. J. Adv. Res. Biol. Sci. 2023;10(2):160-163.
36. Ifeanyi E. Erythropoietin (Epo) Level in Sickle Cell Anaemia (HbSS) With Falciparum Malaria Infection in University Health Services, Michael Okpara University of Agriculture, Umudike, Abia State, Nigeria. Paripex - Indian Journal of Research, 2015; 4(6): 258-259
37. Ifeanyi OE, Nwakaego OB, Angela IO, Nwakaego CC. Haematological parameters among sickle cell anaemia patients in steady state and haemoglobin genotype AA individuals at Michael Okpara, University of Agriculture, Umudike, Abia State, Nigeria. Int. J. Curr. Microbiol. App. Sci. 2014;3(3):1000-1005.
38. Ifeanyi OE, Stanley MC, Nwakaego OB. Comparative analysis of some haematological parameters in sickle cell patients in steady and crisis state at Michael Okpara University of agriculture, Umudike, Abia state, Nigeria. Int. J. Curr. Microbiol. App. Sci. 2014;3(3):1046-1050.
39. Ifeanyi EO, Uzoma GO. Malaria and The Sickle Cell Trait: Conferring Selective Protective Advantage to Malaria. J Clin Med Res. 2020; 2:1-4.
40. Isa H, Okocha E, Adegoke SA, Nnebe-Agumadu U, Kuliya-Gwarzo A, Sopekan A, Ofakunrin AO, Ugwu N, Hassan AA, Ohiaeri C, Madu A. Strategies to improve healthcare services for patients with sickle cell disease in Nigeria: The perspectives of stakeholders. Frontiers in Genetics. 2023; 14:1052444.
41. Martinez RM, Osei-Anto HA, McCormick M, National Academies of Sciences, Engineering, and Medicine. Community Engagement and Patient Advocacy. In Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action 2020. National Academies Press (US).
42. Issom DZ. Digital Health Interventions to Empower People with Sickle Cell Disease: Toward Patient-Led Design. In Sickle Cell Disease 2022. Intech Open.
43. Obeagu EI, Obeagu GU. From Classroom to Home: Strengthening the Continuum of Sickle Cell Disease Knowledge. Elite Journal of Health Science, 2023; 1(1):23-29
44. Obeagu EI, Obeagu GU. Incorporating Sickle Cell Disease Curriculum in Schools: An Effective Approach. Elite Journal of Health Science, 2023; 1(1):30-36

**Citation:** Obeagu EI, Obeagu GU. Community Leaders as Educators: Mobilizing for Sickle Cell Disease Reduction. Elite Journal of Health Science, 2023; 1(1):37-43