Sickle Cell Experience: a Survey

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Abstract

Comprehensive care is required to prevent long-term sequelae from sickle cell disease (SCD); such care may not be accessible to all with the condition . Providers often lack experience managing SCD, a condition associated with frequent painful episodes. This convenience sample-based survey aims to evaluate knowledge of SCD among patients, health care providers, and the general public and to assess health-care related experiences of those with SCD.

Introduction

Sickle Cell Disease (SCD) is an inherited disorder of hemoglobin that impacts nearly 100,000 Americans, occurring in approximately 1 of every 365 births in those of African heritage and 1 of every 16,300 births in those of Hispanic heritage[1]. The US has made great strides in reducing mortality among children with SCD, with an average 3% reduction per year between 1979 and 2005[2]. Access to specialized care is often lacking in rural areas[3], which are often deeply impacted by the opioid crisis[4]. Patients with SCD are living longer in an era that prompts health care providers to view adults seeking pain relief suspiciously[5,6]. Further, those who live in rural areas tend to use complementary and alternative medicine more frequently that their urban counterparts[7]. This mixed-methods convenience sample-based survey seeks to identify qualitative experiences of patients with SCD and seeks information about botanical treatments that patients with SCD may use.

Quantitatively, the following hypothesis will be tested:

Ho: Rural patients with SCD report the same level of health promotions-related education from their provider as urban patients.

Ho: Attention to appropriate pain management for those with SCD has not been impacted by the opioid crisis.

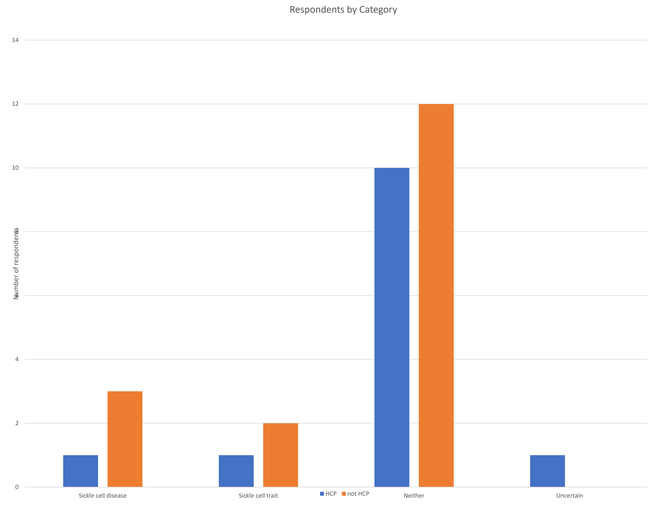
Ho: Rural providers have the same familiarity with standards of care for SCD patients as urban providers.

Methods

A Qualtrics-based survey was designed to capture responses of four groups: lay persons with sickle cell disease or trait, health care providers, health care providers with sickle cell disease or trat, and those who are neither. Rurality will be determined by zip code using the Rural Health Information Hub Am I Rural? Tool[10]. Knowledge-based questions for health-care providers were derived from the most recent American Society of Hematology guidelines[8,9]. Open-ended questions seek qualitative input on experiences and concerns of persons with SCD, botanicals used/sources of information about botanicals used by those with SCD, and botanicals recommended/sources of information about botanicals recommended by health care providers. The survey was reviewed as exempt by LMU institutional review board. The survey has been launched through social media and through flyers distributed at facilities that specialize in the management of sickle cell disease.

Preliminary Results

The survey is underway, with thirty responses to date.



Discussion

Despite the great strides made in reducing mortality from Sickle Cell Disease in the United States, specialized care may be lacking in rural areas. This study aims to evaluate the experiences of rural sickle cell patients and providers as they compare to urban counterparts. The use of a non-probability sample is a major limitation to the study design, with great potential impact on external validity.

References

1. Centers for Disease Control and Prevention. (2020). Data & statistics on sickle cell disease. *National Center on Birth Defects and Development Disabilities, Centers for Disease Control and Prevention*.
2. Nowogrodzki, A. (2021). No adult left behind: bridge the health-care gap for sickle-cell disease. *Nature*, *596*(7873), S13-S15.
3. Telfair, J., Haque, A., Etienne, M., Tang, S., & Strasser, S. (2003). Rural/urban differences in access to and utilization of services among people in Alabama with sickle cell disease. *Public health reports*, *118*(1), 27.
4. Schalkoff, C. A., Lancaster, K. E., Gaynes, B. N., Wang, V., Pence, B. W., Miller, W. C., & Go, V. F. (2020). The opioid and related drug epidemics in rural Appalachia: A systematic review of populations affected, risk factors, and infectious diseases. *Substance abuse*, *41*(1), 35-69.
5. Ruta, N. S., & Ballas, S. K. (2016). The opioid drug epidemic and sickle cell disease: guilt by association. *Pain Medicine*, *17*(10), 1793-1798.
6. Uwaezuoke, S. N., Ayuk, A. C., Ndu, I. K., Eneh, C. I., Mbanefo, N. R., & Ezenwosu, O. U. (2018). Vaso-occlusive crisis in sickle cell disease: current paradigm on pain management. *Journal of pain research*, 3141-3150.
7. Adams, J., Sibbritt, D., & Lui, C. W. (2011). The urban-rural divide in complementary and alternative medicine use: a longitudinal study of 10,638 women. *BMC Complementary and Alternative Medicine*, *11*, 1-7.
8. Liem, R. I., Lanzkron, S., D. Coates, T., DeCastro, L., Desai, A. A., Ataga, K. I., ... & Mustafa, R. A. (2019). American Society of Hematology 2019 guidelines for sickle cell disease: cardiopulmonary and kidney disease. *Blood advances*, *3*(23), 3867-3897.
9. Brandow, A. M., Carroll, C. P., Creary, S., Edwards-Elliott, R., Glassberg, J., Hurley, R. W., ... & Lang, E. (2020). American Society of Hematology 2020 guidelines for sickle cell disease: management of acute and chronic pain. *Blood advances*, *4*(12), 2656-2701.
10. Rural Health Information Hub. Am I Rural? Tool. Accessed at https://www.ruralhealthinfo.org/am-i-rural

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