Journal of Primary Care & Community Health
2017, Vol. 8(1) 37–40

DOI: 10.1177/2150131916662969
jpc.sagepub.com
SAGE

Attitudes of Primary Care Physicians Toward Sickle Cell Disease Care, Guidelines, and Comanaging Hydroxyurea With a Specialist

Joseph Lunyera[1], Charles Jonassaint[2], Jude Jonassaint[2], and Nirmish Shah[1]

Abstract

Background: Sickle cell disease (SCD) is a complex chronic disease requiring multidisciplinary care that involves primary care physicians (PCPs) working with a hematologist or SCD specialists. However, PCPs often lack access to SCD specialists and are unaware of SCD guidelines or efficacious treatment. **Methods:** We partnered with Community Care of North Carolina (CCNC) to identify assigned PCPs for SCD patients with Medicaid across North Carolina. CCNC network administrators distributed a web-based questionnaire for completion. The questionnaire involved 12 self-reported items on a yes-no or a 1 to 5 Likert-type scale that assessed PCP attitudes toward SCD care, awareness of recent guidelines, and comanaging hydroxyurea. **Results:** Of the 53 PCPs who completed the electronic survey, 73% felt they were comfortable with the number of SCD patients in their practice. Most PCPs reported having infrequent communications with an SCD specialist (67%) and most were also not aware of the 2014 SCD guidelines (66%). Many reported that they would frequently use the new SCD guidelines if provided to them (76%). Furthermore, 51% of PCPs expressed comfort with using mobile apps to access SCD guidelines and provided email contact to receive further information. The majority also reported being comfortable comanaging hydroxyurea with an SCD specialist (65%). **Conclusion:** Few PCPs in North Carolina were aware of the new SCD guidelines or had regular communication with an SCD specialist. The majority of PCPs, however, demonstrated a favorable attitude toward receiving the SCD guidelines and comanaging hydroxyurea with a specialist. In response to this gap in care, we have developed a mobile-based SCD toolbox specifically for PCPs to provide guidelines, algorithms, and a method to communicate with local SCD specialists. With the interest in receiving these guidelines, we are confident the toolbox will provide an easy to use platform to assist PCPs to utilize the SCD guidelines.

Keywords

sickle cell disease, hydroxyurea, primary care, co-management, guidelines, mHealth

Background

Sickle cell disease (SCD) is a complex chronic disease requiring care from a multidisciplinary team, including a hematologist, other specialists, and primary care physicians (PCPs). SCD affects nearly 70 000 to 100 000 individuals in the United States, with nearly one-tenth of that population receiving their care in North Carolina.[1] Nationally, emergency department and hospital utilization charges for SCD is estimated at $2.4 billion annually.[2,3] Given the significant financial burden for SCD, it is imperative to utilize strategies to improve access to SCD care, which have been largely underutilized.[4-6]

Because PCPs serve as the major point of contact between patients and the health care system, they are integral to management of SCD.[7] As such, understanding their perspectives, availing educational resources to them, and leveraging meaningful work relations between PCPs and SCD specialists is critically important in formulating a comprehensive and coordinated SCD care system.[7-14] Therefore, we sought to better understand regional PCP attitudes toward SCD care, and comfort with comanagement of hydroxyurea, which is the standard of care for SCD. We also assessed PCPs' awareness and use of the new (2014) SCD guidelines, for which dissemination has remained a

[1]Duke University Medical Center, Durham, NC, USA
[2]University of Pittsburg Medical Center, Pittsburg, PA, USA

Corresponding Author:
Joseph Lunyera, Division of Hematology, Department of Medicine, Duke University Medical Center, 315 Trent Drive, Durham, NC 27710, USA.
Email: josephlunyera@gmail.com

Table 1. Survey Responses Concerning Attitudes of Primary Care Providers Toward Sickle Cell Disease Care.

Domain and Items	All, n (%)	Likert-Type Scale Ratings		
		Mean	Standard Error	95% Confidence Interval
Awareness of SCD guidelines		—	—	—
Yes	16 (34)			
No	31 (66)			
Use of SCD guidelines		3.45	0.15	3.15-3.75
Never, rarely	11 (24)			
Always, often, sometimes	35 (76)			
Communicating with a specialist		2.04	0.14	1.76-2.31
No, not sure	30 (67)			
Yes, possibly, occasionally	15 (33)			
Comfortable comanaging HU		3.49	0.20	3.09-3.89
No, not sure	16 (35)			
Yes, possibly, occasionally	30 (65)			
Would use mobile app for SCD guidelines		2.80	0.18	2.43-3.16
Never, rarely	23 (49)			
Always, often, sometimes	24 (51)			
Would use app to communicate with specialist		2.46	0.16	2.14-2.79
Never, rarely	29 (62)			
Always, often, sometimes	18 (38)			

Abbreviation: SCD, sickle cell disease; HU, hydroxyurea.

concern.[15,16] Subsequently, we introduced an electronic toolbox to assist PCPs in providing SCD care.

Methods

We partnered with Community Care of North Carolina (CCNC), a managed care solution to Medicaid in North Carolina, which maintains an active directory of PCPs practicing across North Carolina,[11] to identify PCPs who were assigned 5 or more SCD patients with Medicaid across North Carolina. CCNC network administrators distributed a web-based questionnaire for completion to eligible PCPs by email between October and December 2015. At least 2 follow-up reminder emails were sent to those who did not respond within 2 weeks.

The questionnaire (Supplementary Material available at http://jpc.sagepub.com/content/by/supplemental-data), which comprised 12 self-reported items with a yes-no or a 1 to 5 Likert-type scale, was developed as part of a collaboration between CCNC and providers (specialists and PCPs) at academic medical centers and community-based settings across the state of North Carolina.[17-20] We designed the questionnaire focusing on 4 broad domains relevant for understanding PCPs' attitudes toward SCD care: awareness of the recent (2014) SCD guidelines, communication with SCD specialist, comanaging hydroxyurea with an SCD specialist, and use of a mobile application to assist clinical care.

Survey was conducted using Qualtrics survey software then exported to STATA v.14 software (Stata Corp, College Station, TX) for analyses. Likert-type scale ratings for PCP responses were summarized by their frequencies and percentages, and means and standard errors. We dichotomized selected questionnaire items, and we summarized the subsequent binary responses to these items by their crude counts and percentages.

Results

Of the 131 PCPs in the CCNC directory with at least 5 patients with SCD, 53 completed the survey. Of these, 45% cared for the pediatric population, 15% adults, and 40% of them cared for both pediatric and adult patients. Most PCPs (73%) reported being comfortable with their load of SCD patients, and only 27% of them reported being less than comfortable with their SCD patient load.

Although the majority of PCPs reported being unaware of the most recent 2014 SCD guidelines (66%), many stated that they would use SCD guidelines if availed to them (76%). Many PCPs reported having infrequent communication with an SCD specialist (67%), including 37% who reported that they "never" communicate with an SCD specialist (Table 1).

Most PCPs also reported being comfortable comanaging hydroxyurea with an SCD specialist (65%). Although 51% of PCPs expressed comfort using an iOS-based mobile app to access SCD guidelines, only 38% of them expressed comfort regarding using mobile apps to communicate with an SCD specialist.

Discussion

Our study examined attitudes of PCPs toward SCD care, awareness and use of the new guidelines, and comfort with comanagement of hydroxyurea. Most PCPs reported having infrequent communications with a specialist and not being aware of the 2014 SCD guidelines. However, many PCPs reported that they would frequently use the new SCD guidelines if provided to them.

In addition to lack of awareness of SCD guidelines, many PCPs also lack comfort in providing SCD care.[7,21] As such, strategies to address the gaps in SCD care should aim at informing the practice of PCPs, for example, developing innovative strategies for disseminating SCD guidelines to PCPs, and incorporating SCD management in primary care residency training curricular.[7,22] Furthermore, to address the gaps in SCD care more broadly, effort should be made to establish coordinated care systems in order to maximize appropriate referrals to SCD specialists.[22]

In response to the gaps in SCD care, we have introduced an iOS-based SCD toolbox to assist PCPs in providing SCD care. Built on Apple's CloudKit framework, registered users of the toolbox have full access to built-in functions of the application, including SCD guidelines and algorithms, and a network of PCPs and specialists caring for patients with SCD. The latter functionality of the application provides a platform to facilitate communications between providers caring for patients with SCD. By utilizing contacts available through this network, PCPs, for example, can reach out to SCD specialists to communicate regarding a patient in their care, or to make general queries regarding SCD care. On the other hand, SCD specialists can also reach out directly to a PCP caring for a patient to coordinate care for the patient. We aim to beta-test the feasibility and acceptability of the SCD toolbox among providers in North Carolina. Subsequently, we hope to introduce the SCD toolbox to iTunes.

We noted a few limitations. Because our study sought to understand PCP's attitude toward using an iOS-based application to access guidelines, these findings may have underestimated the willingness of providers to access guidelines electronically across all mobile operating systems.

In conclusion, PCPs in North Carolina demonstrated a favorable attitude toward receiving the SCD guidelines and comanaging hydroxyurea with a specialist, yet few of them currently were aware of these guidelines or had regular communication with an SCD specialist. In response to this gap in care, we have now developed a mobile-based SCD toolbox specifically to assist PCPs to utilize SCD guidelines, algorithms, and a method to communicate with SCD specialists.

Acknowledgments

We thank Dr Marian F. Earls, Maria Dover, and all the network administrators at Community Care of North Carolina (CCNC) for identifying assigned primary care providers in the CCNC network, and for distributing the web-based questionnaires to eligible providers for completion. We also give special thanks to primary care providers who willingly shared their attitude toward sickle cell disease care, guidelines, and comanagement of hydroxyurea with specialists.

Authors' Note

The data supporting the conclusions of this article are available on the Duke University secure data server managed by the Duke Office of Clinical Research. The data can be provided on requests sent to the corresponding author.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

References

1. Brousseau DC, Panepinto JA, Nimmer M, Hoffmann RG. The number of people with sickle-cell disease in the United States: national and state estimates. *Am J Hematol*. 2010; 85:77-78.
2. Lanzkron S, Carroll CP, Haywood C Jr. The burden of emergency department use for sickle-cell disease: an analysis of the national emergency department sample database. *Am J Hematol*. 2010;85:797-799.
3. Daras LC, Chong N, Ingber M, et al. Technical Expert Panel Summary Report: Development of potentially preventable readmission measures for post-acute care deliverable 14. RTI International, February 2016. https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Post-Acute-Care-Quality-Initiatives/Downloads/Potentially-Preventable-Readmissions-TEP-Summary-Report.pdf. Accessed June 6, 2016.
4. Brawley OW, Cornelius LJ, Edwards LR, et al. National Institutes of Health Consensus Development Conference statement: hydroxyurea treatment for sickle cell disease. *Ann Intern Med*. 2008;148:932-938.
5. Charache S, Dover GJ, Moyer MA, Moore JW. Hydroxyurea-induced augmentation of fetal hemoglobin production in patients with sickle cell anemia. *Blood*. 1987;69:109-116.
6. Lanzkron S, Haywood C Jr, Segal JB, Dover GJ. Hospitalization rates and costs of care of patients with sickle-cell anemia in the state of Maryland in the era of hydroxyurea. *Am J Hematol*. 2006;81:927-932.
7. Whiteman LN, Haywood C Jr, Lanzkron S, Strouse JJ, Feldman L, Stewart RW. Primary care providers' comfort levels in caring for patients with sickle cell disease. *South Med J*. 2015;108:531-536.
8. DeBaun MR, Telfair J. Transition and sickle cell disease. *Pediatrics*. 2012;130:926-935.
9. Kuhlthau K, Ferris TG, Beal AC, Gortmaker SL, Perrin JM. Who cares for Medicaid enrolled children with chronic conditions? *Pediatrics*. 2001;108:906-912.

10. Treadwell M, Telfair J, Gibson RW, Johnson S, Osunkwo I. Transition from pediatric to adult care in sickle cell disease: establishing evidence-based practice and directions for research. *Am J Hematol*. 2011;86:116-120.
11. Okumura MJ1, Kerr EA, Cabana MD, Davis MM, Demonner S, Heisler M. Physician views on barriers to primary care for young adults with childhood-onset chronic disease. *Pediatrics*. 2010;125:e748-e754.
12. Freed GL, Hudson EJ. Transitioning children with chronic diseases to adult care: current knowledge, practices, and directions. *J Pediatr*. 2006;148:824-827.
13. Merrell RC, Doarn CR. Disease management in telemedicine and e-health. *Telemed e-Health*. 2014;20:679-680.
14. Woods K, Kutlar K, Adams L, Stachura ME. Primary care delivery for sickle cell patients in rural Georgia using telemedicine. *Telemed J*. 1998;4:353-361.
15. Yawn BP, Buchanan GR, Afenyi-Annan AN, et al. Management of sickle cell disease: summary of the 2014 evidence-basedreportbyexpertpanelmembers.*JAMA*.2014;312: 1033-1048.
16. Reeves SL, Fullerton HJ, Dombkowski KJ, Boulton ML, Braun TM, Lisabeth LD. Physician attitude, awareness, and knowledge regarding guidelines for transcranial Doppler screening in sickle cell disease. *Clin Pediatr (Phila)*. 2015;54:336-345.
17. Tilson EC. Dissemination and adoption of guidelines: the experience of Community Care of North Carolina. *N C Med J*. 2015;76:251-255.
18. Community Care of North Carolina. CHACC clinical guidelines. https://www.communitycarenc.org/emerging-initiatives/child-health-accountable-care-collaborative/chacc-clinical-guidelines/. Accessed March 4, 2016.
19. Community Care of North Carolina. CHACC hematology guidelines. https://www.communitycarenc.org/chacc-hematology-guidelines/. Accessed March 4, 2016.
20. Duke University. Emergency department sickle cell disease: crisis management and beyond. Treatment algorithms. http://sickleemergency.duke.edu/treatment-algorithms. Accessed March 4, 2016.
21. Okumura MJ, Heisler M, Davis MM, Cabana MD, Demonner S, Kerr EA. Comfort of general internists and general pediatricians in providing care for young adults with chronic illnesses of childhood. *J Gen Intern Med*. 2008;23:1621-1627.
22. Hoots WK, Shurin SB. Future directions of sickle cell disease research: the NIH perspective. *Pediatr Blood Cancer*. 2012;59:353-357.

Author Biographies

Joseph Lunyera, MBChB, MSc, is a research scholar at the Division of Hematology, Department of Medicine, at the Duke University Medical Center.

Charles Jonassaint, PhD, is a clinical psychologist at the University of Pittsburg Medical Center Adult Sickle Cell Disease Program. His research focuses on designing and implementing health IT interventions to address the chronic health care needs of patients with Sickle Cell Disease.

Jude Jonassaint, RN, is a research nurse at the University of Pittsburg Medical Center. A recipient of the Algernon Sydney Sullivan Award from Duke University, Jude's research seeks to leverage health IT to help patients and their providers to better manage disease symptoms and to improve health outcomes.

Nirmish Shah, MD, is an assistant professor of Medicine and Pediatrics at the Division of Hematology, Duke University Medical Center. As the Director of the Sickle Cell Transition Program at the Duke Comprehensive Sickle Cell Clinic, his research aims to increase engagement of patients with Sickle Cell Disease with their own care using mobile technology