7-1-2016

Improving Sickle Cell Transitions of Care Through Health Information Technology.

Jennifer R Frost

Rebecca K Cherry

Suzette O Oyeku

Elissa Z Faro

Lori E Crosby

See next page for additional authors

Follow this and additional works at: https://hsrc.himmelfarb.gwu.edu/smhs_peds_facpubs

Part of the Other Medical Specialties Commons, and the Pediatrics Commons

Authors

Jennifer R Frost, Rebecca K Cherry, Suzette O Oyeku, Elissa Z Faro, Lori E Crosby, Maria Britto, Lisa K. Tuchman, Ivor B. Horn, Charles J Homer, and Anjali Jain

Improving Sickle Cell Transitions of Care Through Health Information Technology

Jennifer R. Frost, MPA,[1] Rebecca K. Cherry, BA,[1] Suzette O. Oyeku, MD, MPH,[2,3] Elissa Z. Faro, PhD,[3] Lori E. Crosby, PsyD,[4,5] Maria Britto, MD, MPH,[4,5] Lisa K. Tuchman, MD, MPH,[6] Ivor B. Horn, MD, MPH,[7,8] Charles J. Homer, MD, MPH,[9] Anjali Jain, MD[1]

Introduction: Transitions between inpatient and outpatient care and pediatric to adult care are associated with increased mortality for sickle cell disease (SCD) patients. As accurate and timely sharing of health information is essential during transitions, a health information technology (HIT)-enabled tool holds promise to improve care transitions.

Methods: From 2012 through 2014, the team conducted and analyzed data from an environmental scan, key informant interviews, and focus groups to inform the development of an HIT-enabled tool for SCD patients' use during care transitions. The scan included searches of peer-reviewed and gray literature to understand SCD patient needs, transition concerns, and best practices in mobile health applications, and searches of websites and online stores to identify existing transition tools and their features. Eleven focus groups consisted of four groups of SCD patients of varying ages ($\geq$9 years); three groups of parents/caregivers of SCD patients; three groups of providers; and one with IT developers.

Results: In focus groups, patients and caregivers reported that the transition from home to the emergency department (ED) was the most challenging; the ED was also where transitions from pediatric to adult care usually occurred. Patients felt they were not taken seriously by unfamiliar ED providers, and their inability to convey their diagnosis, pain regimen, and detailed medical history while in significant pain hindered care.

Conclusions: The environmental scan did not reveal an existing suitable transition tool, but patients, parents, providers, and IT experts saw the potential and appeal of creating a tool to meet ED health information needs to improve care transitions.
(Am J Prev Med 2016;51(1S1):S17–S23) © 2016 American Journal of Preventive Medicine. Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

Introduction

Sickle cell disease (SCD) is a serious, inherited, life-long condition characterized by recurrent vaso-occlusive episodes that cause pain and widespread organ damage.[1] Treatment of these episodes typically requires care in both inpatient and emergency settings in addition to primary care.[1] As a result, SCD patients often experience multiple transitions in care settings between self- and primary care at home and urgent care in an acute care setting. Because of recent medical advances, individuals living with SCD in the U.S. can now expect to live well into adulthood,[2] necessitating additional transitions from pediatric to adult SCD care that also require significant preparation and coordination.

Care transitions can be challenging for all patients with chronic medical conditions, given the complexity of many diseases and need for multiple medications and communication among primary care providers and specialists. Transitions may be particularly fraught for individuals with SCD because of the subjective nature of clinical findings in many acute pain and vaso-occlusive crises along with high and increasing levels of concern by

From the [1]The Lewin Group, Falls Church, Virginia; [2]The Children's Hospital at Montefiore/Albert Einstein College of Medicine, Bronx, New York; [3]National Institute for Children's Health Quality, Boston, Massachusetts; [4]Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio; [5]University of Cincinnati School of Medicine, Cincinnati, Ohio; [6]Children's National Health System, Washington, District of Columbia; [7]Seattle Children's Hospital, Seattle, Washington; [8]University of Washington School of Medicine, Seattle, Washington; and [9]Office of the Assistant Secretary of for Planning Evaluation, DHHS, Washington, District of Columbia

Address correspondence to: Jennifer R. Frost, MPA, The Lewin Group, 3130 Fairview Park Drive, Falls Church VA 22042. E-mail: jennifer.frost@lewin.com.

Am J Prev Med 2016;51(1S1):S17–S23 **S17**

providers about use of narcotic analgesics. Exacerbating this problem further is widespread perception by individuals with SCD of significant racial bias from healthcare providers[3] and the documented low quality of the interpersonal aspects of health care provided for adults with SCD.[4] Moreover, adolescence and young adulthood, when transitions usually occur, is a high-risk time for clinical complications and progressive SCD-related organ damage. These challenges occur at a time when normal developmental and life changes can also lessen effective engagement with healthcare systems.[5,6] During these transitions of care, timely and accurate sharing of health information among patients, families, and providers is critical. Preliminary evidence supports the use of health information technology (HIT), including technology-based tools and applications, to facilitate communication of health information for patients with other chronic diseases, and may also be fruitful for individuals with SCD.[7–9] This research aligns with broader efforts of the HIT community to move beyond use of electronic health records alone to broader applications of HIT in care delivery and for patient engagement.[10]

This project aimed to better understand the experience of SCD patients, their caregivers, and providers during care transitions to determine whether and how their needs could be met through HIT. The team hypothesized there would be opportunities to address challenges related to healthcare transitions using HIT. The team also sought to determine the current use of technologies by patients and caregivers to guide the design and development of a patient-centered HIT-enabled tool. Detailed recommendations for the development of the HIT-enabled tool are found in the publicly available final report, "Improving Sickle Cell Transitions of Care through Health Information Technology: Recommendations for Tool Development."[11] This article summarizes the research methods in two sections according to the main study tasks—the environmental scan, and the focus groups and key informant interviews—followed by integrated results that inform development of such a tool.

Methods

Environmental Scan

An initial environmental scan was conducted between October and December 2012, and updated between January and February 2014. The scan was guided by three overarching goals:

1. to better understand problems that occur during different types of care transitions for SCD patients;
2. to identify successful transition practices and care coordination approaches for patients with SCD and relevant similar chronic conditions; and

3. to ascertain current best practices and advances in HIT and mobile health that may be relevant to tool design and development.

To conduct the scan (Appendix Figure 1, available online), the team

1. compiled a list of sources;
2. conducted an initial broad search using medical subject headings in combination with other complementary keyword or text terms, such as *SCD*, *transition to adult care*, and *HIT*;
3. developed a targeted search strategy, including search terms relevant to source material;
4. completed title/abstract review and applied inclusion/exclusion criteria (e.g., articles must be available in English) to identify tools/literature;
5. conducted detailed data abstraction for a subset of highly relevant materials; and
6. synthesized data and summarized findings pertaining to tool content and functionality.

The scan included two tracks: The first searched for existing tools in the market (both for sale and freeware), whereas the second identified literature (peer reviewed and gray) focused on SCD, patient needs, transitions of care, and best practices in mobile health applications. Tools and articles were examined if they were

1. relevant to SCD or other relevant chronic health conditions (e.g., cystic fibrosis) and
2. targeted for or applicable to non-professional audiences (i.e., patients and caregivers).

Tools that were mentioned by focus group participants or key informants also were studied.

Research Electronic Data Capture (REDCap™), a web-based application designed to support data capture for research studies, was used to complete data abstraction for each of the tools identified in the first track. The data elements included tool description, purpose, end user, cost, type of technology, data source(s), sponsoring/producing organization, release date, evidence of impact or effectiveness, and evidence of stakeholder input in development.

Tools were organized into five areas of relevance for better identification of themes:

1. pediatric to adult care transitions;
2. care setting transitions (e.g., between hospital and home);
3. management or monitoring of a specific disease or condition;
4. personal health records and facilitators of collection and storage of general health information; and
5. community builders for those who share a common condition.

For each of the articles selected for full-text review in the second track, a two-step data abstraction process was conducted. First, reviewers catalogued bibliographic information using EndNote. Second, reviewers entered key elements of each article into a sortable data abstraction table built in Microsoft Excel. The data elements included bibliographic information; detailed description of item, study design, and methodology; study findings and conclusions relevant to tool content and functionality; study population; studied clinical condition; study limitations; content

category (e.g., design, functionality); related search goal; and funding source.

Focus Groups and Key Informant Interviews

Between October and December 2013, the team conducted 11 focus groups: four groups of SCD patients aged 9–13, 14–17, ≥18 years and mixed ages; three groups with parents and caregivers of adolescents with SCD; three with healthcare providers; and one group with IT developers. Focus groups were conducted at Cincinnati Children's Hospital Medical Center in Cincinnati, OH; Children's National Medical Center in Washington, DC; Nemours Children's Specialty Care in Jacksonville, FL; and the National Institute for Children's Health Quality in Boston, MA (Table 1). The three clinical research sites were selected as each had an SCD center and represented geographically diverse patient populations.

Each site obtained local IRB approval in addition to Office of Management and Budget approval obtained by the Agency for Healthcare Research and Quality. Onsite staff conducted purposive sampling, a form of non-probability sampling in which decisions concerning the individuals to be included in the sample are taken by the researcher, based on defined criteria,[12] from SCD patients at each center within the prescribed age ranges of each focus group and their parents/caregivers. Provider participants were required to have clinical experience caring for SCD patients and were purposely chosen to vary by time in healthcare practice, gender, specialty, and HIT experience. IT developers were targeted who represented diversity in technology platform expertise as well as academic and private sector experience. Focus group participants received $50 cash or cash equivalent for compensation.

At the start of each focus group, participants completed a short demographic questionnaire. Moderator guides were developed for each group that contained questions designed to elicit actionable feedback for tool design, content, and functionality. All focus groups were co-moderated. The lead moderator facilitated the group. The co-moderator clarified vague responses and encouraged participation. One author (AJ) acted as lead or co-moderator for the majority of the focus groups, which enabled her to weave and probe insights and experiences from each focus group into the others.

Each focus group was audio recorded and supplemented by written notes. Moderators and observers met after each focus group to discuss and confirm major themes and findings. Data analysis occurred between November 2013 and March 2014. Each site summarized results and analyses, including key findings, supporting evidence, and illustrative quotations. Key themes across focus groups were identified and discussed across sites and investigators.

During March 2013, the team also conducted four interviews with key informants whose knowledge and areas of expertise did not lend themselves to the focus group setting. The key informants were a state government representative, an attorney with expertise in privacy and security issues, a representative from the Office of the National Coordinator, and a patient advocate/SCD researcher (same person). Interviews were 1 hour in length and conducted via telephone by two experienced phone interviewers (AJ and JF), using semi-structured guides. Summary notes were analyzed in conjunction with focus group data.

Results

The sample of focus group participants included 94 participants: 34 patients, 31 parents/caregivers, 22 healthcare providers, and seven IT developers. Patient and caregiver focus group participants were predominantly black/African American (65 of 67, 97%) with two also reporting as American Indian/Native American or

Table 1. Focus Group Participants by Site and Focus Group Type

Research site	Location	Focus group	Participants
CCHMC	Cincinnati, OH	Patients 9–13 years old	9
CCHMC	Cincinnati, OH	Parents/caregivers	12
CCHMC	Cincinnati, OH	Providers (pediatric–adult transitions)	8
CCHMC	Cincinnati, OH	Providers (pediatric–adult transitions)	5
NICHQ	Boston, MA	IT developers	7
CNMC	Washington, DC	Patients ≥18 years old	6
CNMC	Washington, DC	Parents/caregivers	10
CNMC	Washington, DC	Providers (care setting transitions)	9
CNMC	Washington, DC	Patients—mixed ages	9
Nemours	Jacksonville, FL	Patients 14–17 years old	10
Nemours	Jacksonville, FL	Parents/caregivers	9
		Total	94

CCHMC, Cincinnati Children's Hospital Medical Center; CNMC, Children's National Medical Center; IT, Information Technology; NICHQ, National Institute for Children's Health Quality.

Alaskan Native (2 of 67%, 3%). All but one of the provider participants were white or black/African American (21 of 22, 95%). Patient focus groups were evenly divided between male (16 of 34, 47%) and female (18 of 34, 53%) participants, whereas provider focus groups were predominately female (17 of 22, 77%) as were the parent/caregiver focus groups.

Patient participants described relatively frequent—about once every 3 months—pain crises and acute visits for their SCD; many reported at least one "hospitalization in the previous year." All patients in the age ≥18 years focus group reported having attended medical appointments alone, though some indicated they still rely on parents to communicate details about medical histories and medication names and doses. Participants described difficulties communicating with healthcare providers about the extent of their pain. Some noted they rely on family or caregivers to "speak for them" while they are in pain. Patients of all ages, but particularly those aged >18 years, reported they often do not feel respected and believed by providers about the severity of their pain because it is not visible and, instead, subjectively assessed. Compared with patients with cancer, patients with SCD felt they were taken less seriously or dismissed. Some patients described using their phones or music for distraction when in pain, which they reported providers misperceived as their pain being less severe.

A particularly challenging time for patients with SCD is during the transition from pediatric to adult care. Providers noted that parents/caregivers are often the ones to seek transition support. Patients of all ages reported their parents/caregivers are highly involved in their care, such as reminding them to take their medications or accompanying them to appointments. Participants in the provider focus group expressed concerns that parental involvement can hinder the transition process as it keeps the patient from acting and advocating on his or her own behalf. Although they believed patients should be independent, providers also reported that patients still benefit from ongoing familial support. Adult providers expressed beliefs that pediatric providers coddle SCD patients, whereas pediatric providers believed their adult colleagues were not supportive enough.

Patients reported feeling anxious and hesitant about transitioning from adolescent to adult care. Specific fears discussed in the literature and in the focus groups included loss of familiar and trusted providers, concern that adult care providers may not meet their needs, and fear about being treated as adults without adequate preparation, skills, or support.[13–17] The literature noted these fears are common and well founded for individuals with SCD for a range of reasons, including the dramatic

increase in life expectancy for SCD patients in the last several decades[18] and the ongoing dearth of adult providers with specialized SCD knowledge and experience.[13] Furthermore, patient focus group participants of all ages expressed anxiety about some of the differences between pediatric and adult healthcare settings. Patients reported feeling a sense of being wanted by their pediatric providers, and potentially unwanted by adult clinicians. They also expressed concerns about not being prioritized in emergency situations, citing longer wait times in adult emergency departments (EDs) as an example. Providers echoed patients' concerns, noting long wait times are commonly encountered and should be expected. Adult providers also described—with some frustration—that it is not uncommon for patients assigned to a regular adult provider—whom they do not yet know—to miss outpatient clinic appointments and turn instead to the ED when in need of care.

Patients, parents, and providers identified the ED as the site where most difficult transitions occur. This finding was confirmed by the environmental scan. The literature showed that young adults with SCD (aged 18–30 years) have increased ED utilization, and the majority of these transitions are unplanned and urgent.[19,20] Long wait times and delayed or insufficient treatment of pain during an SCD pain crisis in the ED can lead to increased morbidity (or mortality) and long-term end organ damage.[21–23] An interview with a patient advocate revealed that personnel in EDs rarely initiate a discussion or ask about a patient's SCD status—the onus usually falls on the patient to broach the topic. Unfamiliar providers in the ED may be skeptical of a patient's disease status and thus cautious about dispensing medications in high enough doses to relieve pain. Treatment can also be delayed while diagnoses are being confirmed. Transitions to the ED are further complicated by the inability of patients in pain and other crises to convey their medical histories with the level of detail required by providers to optimize care.[24] Even among familiar providers and settings, patients reported that severe pain makes it challenging to communicate about their disease and may instead rely on family or caregivers to speak for them.

Providers, patients, and caregivers all agreed that care transitions would improve if patients and families have clear expectations, the patient functions independently, and communication among providers occurs. Participants discussed current efforts that ease transitions, including familiarizing adolescents with adult care providers and settings prior to a crisis, improving communication between pediatric and adult providers, and involving community health workers or patient navigators in care coordination.

Patients and parents reported using technology extensively, though they indicated they may use it differently (e.g., parents to locate health-related information; patients as a means of distraction during pain crises).[9,25] Research has shown that minority populations more readily adopt new technology, and African-American and Hispanic adolescents and young adults are more likely than peers to own smartphones and access health information on their phones and online.[26] These literature findings were confirmed by the focus groups, where the majority of patient participants (from all age groups) reported using smartphones, most often for social media, games, texting, and to help with school scheduling. Though patients regularly use technology, few reported using their phone for medical purposes (e.g., calendar of appointments, medication reminders). Some patients noted they do not need to use technology to communicate with their healthcare providers or look up health information because their parents still primarily manage their disease. Although patients themselves did not confirm this use, some parents reported that their children use technology to look up symptoms and keep track of their own appointments and medications. Some parents also described using online portals to access personal health information posted by their child's physician.

Providers were highly concerned about the difficulty of monitoring or managing health information shared through social media and the risk of patients receiving inaccurate information through the Internet more broadly. Pediatric providers were also skeptical that patients would use a tool or an application while in pain, but patients described using their phones and applications as a distraction from pain. For example, some patients reported that listening to music and playing games were helpful strategies employed to distract themselves during pain crises or while waiting for treatment.

When prompted about potential uses for a tool, patients and parents appeared enthusiastic at the prospect of a tool that could help patients remember their medical histories and display it for clinicians so repeating information would be less necessary. Patients and parents were frustrated by having to answer the same medical questions repeatedly for each provider and setting. Patients did not, however, seem interested in using technology to track pain associated with SCD. Reasons given were that they did not want to think about their SCD regularly nor did they see tracking pain as helpful.

With regard to tool design, IT developer focus group participants suggested keeping the function of an HIT-enabled tool as simple as possible and that a tool should have a singular purpose. Developers identified bidirectional data exchange—the ability for patients and providers to access and share data—as a feature that would promote tool usefulness and uptake. Developers also indicated that a tool should not require users to manually input data (or only minimally) but produce actionable information.

The environmental scan found no existing tools that met all or most of the anticipated needs of patients with SCD who are undergoing care transitions. Only 5% (3 of 40) of identified tools were intended for use by patients with SCD, and these tools addressed some of the common issues that arise from living with SCD, such as pain management (i.e., Wireless Pain Intervention Program for At Risk Youth with SCD); accessibility of personal health information during routine healthcare encounters and in emergencies (e.g., SiKL); and the need for social and familial support and connections (i.e., Sickle Cell Warriors). Only one tool was identified, a paper-based curriculum, that specifically addresses transition for SCD adolescents.[26] Sixteen tools (40%), however, were identified that address transitions from pediatric to adult care or care setting transitions for the general population (e.g., Healthy Transitions, Journey to Adulthood: A Transition Travel Guide) that might be adapted for the SCD population.

Discussion

Information from an environmental scan, focus groups, and key informant interviews was combined to identify gaps and opportunities for an HIT-enabled tool to improve care transitions for patients with SCD. Patient and caregiver input confirmed and amplified findings in the literature: they experienced challenges in provider familiarity with SCD, skepticism about patient levels of pain, and insensitivity in interpersonal care, especially in adult ED settings.[13] These experiences led patients to delay seeking and obtaining care. Patients, caregivers, and adult and pediatric providers all viewed the pediatric to adult system transition as suboptimal, although each had dramatically different perceptions of the underlying causes and potential solutions.

All providers, patients, and caregivers agreed that HIT tools could address some, but not all, care transition challenges. An HIT-enabled tool could be one mechanism to convey to diverse ED providers accurate medical and medication histories as well as clinician-endorsed, patient-specific acute plans. Although such a tool would not fundamentally address the complex issues of racism and discrimination,[3,23] it could lessen the opportunity for such biases to interfere with provision of high-quality care. Similarly, HIT-enabled tools could help patients and families be more effective in patient

self-management practices (e.g., maintain appointments, adhere to medication goals), ultimately enhancing success navigating the adult care system. It is possible that an HIT-enabled tool for pain management could align with other related applications (i.e., health service management tools like calendars to track appointments and medications) within an overall portfolio or "ecosystem," with each application focusing on a critical need of SCD patients.

The environmental scan identified a few tools with some direct relevance that could be adapted for use within SCD. It is unknown, however, the extent to which these tools are available on different smartphone platforms, interoperable with HIT and exchange systems used by healthcare institutions, and how they meet health information security standards. An HIT-enabled tool to facilitate communication (i.e., share medical history and medications, document diagnosis) in the ED or during acute pain episodes would have the greatest impact or value. Similar functionality could also be useful for patients engaging with new physicians as they transition to adult care.

Limitations

Although this study addresses an important gap in the literature and uses qualitative and quantitative descriptive methods to gather and synthesize data from a variety of stakeholders, the authors recognize that the approach has some limitations. The study included a relatively small sample of patients, parents/caregivers, providers, and IT developers. Additionally, sampling bias may have affected the findings because participants who were willing to participate in a focus group or interview may differ from the general population of patients with SCD, their parents, or providers. Furthermore, focus groups did not fully capture the perspectives of patients of different racial and ethnic populations (e.g., Latinos with SCD), or those with more severe SCD (most participants had SCD without cognitive impairment). These populations may have different experiences of care and have different needs for HIT tools. Critical stakeholder groups, such as ED staff and older adults with SCD, were also not included in the present study. Although a particular area of interest for this research, neither the focus group participants nor the IT developers discussed details about the specific types of functionality they would like to see in an HIT-enabled tool despite specific inquiries about such features.

Conclusions

This study sought to identify health information needs using existing tools, relevant literature, and focus groups to inform the content and functionality of HIT-enabled tools to improve transitions of care for patients with SCD. Results from this study endorse the recommendation that an HIT-enabled tool to support SCD patients should facilitate the most challenging care transition for patients and families affected by SCD: home to the ED. Even as comprehensive medical home models of care are being developed for patients with SCD that would improve pediatric to adult care transitions,[27] the ED will likely continue to be a challenging setting. These results suggest that a focused technology-based tool that presents a summary of a patient's important health information and includes static and dynamic information with limited requirements for patients to input data holds promise to deliver crucial information appropriate to the situation in the ED and to the patient and providers. Further detailed recommendations about this potential tool are outlined in "Improving Sickle Cell Transitions of Care through Health Information Technology: Recommendations for Tool Development."[11] Future studies should include developing and testing such a tool among a larger and more diverse group of patients with SCD, parents, and providers to ensure that these stakeholders' perspectives and needs are represented in tools and applications that have the greatest impact.

References

1. Kliegman R, Stanton B, St. Geme J, Schor N, Behrman R. *Nelson Textbook of Pediatrics.* 20th ed., Philadelphia, PA: Elsevier, 2016.
2. Hassell KL. Population estimates of sickle cell disease in the U.S. *Am J Prev Med.* 2010;38(4 suppl):S512–S521. http://dx.doi.org/10.1016/j.amepre.2009.12.022.
3. Nelson SC, Hackman HW. Race matters: perceptions of race and racism in a sickle cell center. *Pediatr Blood Cancer.* 2013;60(3):451–454. http://dx.doi.org/10.1002/pbc.24361.
4. Lattimer L, Haywood Jr., Lanzkron S, Ratanawongsa N, Bediako SM, Beach MC. Problematic hospital experiences among adult patients with sickle cell disease. *J Health Care Poor Underserved.* 2010;21(4):1114–1123. http://dx.doi.org/10.1353/hpu.2010.0940.
5. Ballas SK, Kesen MR, Goldberg MF, et al. Beyond the definitions of the phenotypic complications of sickle cell disease: an update on management. *ScientificWorldJournal.* 2012;2012:949535. http://dx.doi.org/10.1100/2012/949535.
6. Ballas SK, Lieff S, Benjamin LJ, et al. Definitions of the phenotypic manifestations of sickle cell disease. *Am J Hematol.* 2010;85(1):6–13. http://dx.doi.org/10.1002/ajh.21550.

7. Forjuoh SN, Reis MD, Couchman GR, Ory MG, Mason S, Molonket-Lanning S. Incorporating PDA use in diabetes self-care: a central Texas Primary Care Research Network (CenTexNet) study. *J Am Board Fam Med*. 2007;20(4):375–384. http://dx.doi.org/10.3122/jabfm.2007.04.060166.

8. Mosa AS, Yoo I, Sheets L. A systematic review of healthcare applications for smartphones. *BMC Med Inform Decis Mak*. 2012; 12:67. http://dx.doi.org/10.1186/1472-6947-12-67.

9. Fox S, Duggan M. *Mobile Health 2012*. Washington, DC: Pew Research Center, 2012. www.pewinternet.org/2012/11/08/mobile-health-2012/.

10. The Office of the National Coordinator for Health Information Technology (ONC). *Federal Health IT Strategic Plan 2015-2020*. www.healthit.gov/sites/default/files/federal-healthIT-strategic-plan-2014.pdf. Published 2015. Accessed August 24, 2015.

11. Jain A, Frost J, Cherry R, et al. *Improving Sickle Cell Transitions of Care Through Health Information Technology: Recommendations for Tool Development*. Prepared under Contract 290-2010-00033I-1. AHRQ Publication No. 15-0017-EF. http://healthit.ahrq.gov/sites/default/files/docs/citation/improving-sickle-cell-transitions-of-care-through-health-it-final-action-report.pdf. Published 2015. Accessed July 13, 2015.

12. Jupp V. *The SAGE Dictionary of Social Research Methods*. London: SAGE Publications, 2006.

13. Telfair J, Ehiri JE, Loosier PS, Baskin ML. Transition to adult care for adolescents with sickle cell disease: results of a national survey. *Int J Adolesc Med Health*. 2004;16(1):47–64. http://dx.doi.org/10.1515/IJAMH.2004.16.1.47.

14. Lebensburger JD, Bemrich-Stolz CJ, Howard TH. Barriers in transition from pediatrics to adult medicine in sickle cell anemia. *J Blood Med*. 2012;3:105–112. http://dx.doi.org/10.2147/JBM.S32588.

15. Howard J, Woodhead T, Musumadi L, Martell A, Inusa BP. Moving young people with sickle cell disease from paediatric to adult services. *Br J Hosp Med (Lond)*. 2010;71(6):310–314. http://dx.doi.org/10.12968/hmed.2010.71.6.48435.

16. McPherson M, Thaniel L, Minniti CP. Transition of patients with sickle cell disease from pediatric to adult care: assessing patient readiness. *Pediatr Blood Cancer*. 2009;52(7):838–841. http://dx.doi.org/10.1002/pbc.21974.

17. Smith GM, Lewis VR, Whitworth E, Gold DT, Thornburg CD. Growing up with sickle cell disease: a pilot study of a transition program for adolescents with sickle cell disease. *J Pediatr Hematol Oncol*. 2011;33(5):379–382. http://dx.doi.org/10.1097/MPH.0b013e318211bb2e.

18. Doulton DM. From cradle to commencement: transitioning pediatric sickle cell disease patients to adult providers. *J Pediatr Oncol Nurs*. 2010;27(2):119–123. http://dx.doi.org/10.1177/1043454209350155.

19. Hemker BG, Brousseau DC, Yan K, Hoffmann RG, Panepinto JA. When children with sickle-cell disease become adults: lack of outpatient care leads to increased use of the emergency department. *Am J Hematol*. 2011;86(10):863–865. http://dx.doi.org/10.1002/ajh.22106.

20. Cibulskis CC, Giardino AP, Moyer VA. Care transitions from inpatient to outpatient settings: ongoing challenges and emerging best practices. *Hosp Pract (1995)*. 2011;39(3):128–139. http://dx.doi.org/10.3810/hp.2011.08.588.

21. Platt OS, Brambilla DJ, Rosse WF, et al. Mortality in sickle cell disease. Life expectancy and risk factors for early death. *N Engl J Med*. 1994;330 (23):1639–1644. http://dx.doi.org/10.1056/nejm199406093302303.

22. Tanabe P, Myers R, Zosel A, et al. Emergency department management of acute pain episodes in sickle cell disease. *Acad Emerg Med*. 2007;14 (5):419–425. http://dx.doi.org/10.1197/j.aem.2006.11.033.

23. Haywood Jr., Tanabe P, Naik R, Beach MC, Lanzkron S. The impact of race and disease on sickle cell patient wait times in the emergency department. *Am J Emerg Med*. 2013;31(4):651–656. http://dx.doi.org/10.1016/j.ajem.2012.11.005.

24. Todd KH, Green C, Bonham Jr., Haywood Jr., Ivy E. Sickle cell disease related pain: crisis and conflict. *J Pain*. 2006;7(7):453–458. http://dx.doi.org/10.1016/j.jpain.2006.05.004.

25. Mitchell SJ, Godoy L, Shabazz K, Horn IB. Internet and mobile technology use among urban African American parents: survey study of a clinical population. *J Med Internet Res*. 2014;16(1):e9. http://dx.doi.org/10.2196/jmir.2673.

26. Oyeku SO, Wang CJ, Scoville R, et al. Hemoglobinopathy learning collaborative: using quality improvement (QI) to achieve equity in health care quality, coordination, and outcomes for sickle cell disease. *J Health Care Poor Underserved*. 2012;23(3 suppl):34–48. http://dx.doi.org/10.1353/hpu.2012.0127.

27. Raphael JL, Rattler TL, Kowalkowski MA, Brousseau DC, Mueller BU, Giordano TP. Association of care in a medical home and health care utilization among children with sickle cell disease. *J Natl Med Assoc*. 2013;105(2):157–165. http://dx.doi.org/10.1002/pbc.24184.

Appendix

Supplementary data

Supplementary data associated with this article can be found at http://dx.doi.org/10.1016/j.amepre.2016.02.004.