Research Article

Journal of Patient Experience
2020, Vol. 7(6) 1109-1114

DOI: 10.1177/2374373520956744
journals.sagepub.com/home/jpx
SAGE

Blood Transfusion: Knowledge, Perspectives, and Experience of Individuals With Sickle Cell Disease

Raymona H Lawrence, DrPH, MPH, MCHES[1], Ashley Singleton, MPH[2], and Jane Branscomb, MPH[2]

Abstract

Patient voice and perspective were needed to inform effective, comprehensive strategies for reducing preventable transfusion-associated complications. This report presents the results of interviews with sickle cell disease (SCD) patients and implications for strategies to reduce transfusion complications in this population. Twenty-two participants were recruited from 2 comprehensive SCD treatment centers in Georgia and interviewed regarding knowledge about transfusions and potential complications, attitudes about data storage and sharing, and the transfusion experience. Participants had general knowledge of physiology, blood products, and blood transfusions, including knowing the risk of complications, but varied in comprehension of complex health information and level of misinformation. Patients also varied in preferences for how they would like their transfusion information stored. They saw both advantages and disadvantages to wallet cards, smartphone applications, and registries. There is a need for a patient-centered approach that involves transfusion education and shared decision-making. Education should range from essential and simple to more in-depth to accommodate varying education and comprehension levels. Multiple tracking methods should be offered to store sensitive patient information.

Keywords

sickle cell disease, blood, transfusions, genetic disorder, community engagement

Introduction

Sickle cell disease (SCD) is a genetic blood disorder that frequently leads to complications (eg, extreme pain, organ damage, and pulmonary complications) that may affect physical and social well-being (1,2). It is estimated that up to 100 000 Americans have SCD (3,4). In the United States, SCD is most prevalent among African Americans. Sickle cell disease occurs in about one in every 365 African-American births, compared with one in every 16 300 Hispanic births, and one in every 100 000 non-Hispanic White births (5).

Under certain conditions, individuals with SCD may require a blood transfusion or a series of transfusions (6). These may be episodic or for treatment of acute, potentially life-threatening disease complications. For some individuals, a program of regularly scheduled, and often life-long, chronic transfusions is the optimal primary treatment for their disease (7).

Despite its therapeutic nature, blood transfusion carries its own risk of significant, potentially life-threatening complications. The most concerning of these is red cell alloimmunization, which can cause delayed hemolytic transfusion reaction upon subsequent transfusion, and iron overload. These complications can be prevented, minimized, or managed when patients and providers follow best practices, such as those published in 2014 by the National Institutes of Health's National Heart, Lung and Blood Institute (6).

The causes of preventable transfusion-associated complications are numerous and often occur because adherence to disease-management and transfusion best practices is inconsistent. Also, there is currently no unified system that provides ongoing, statewide education to health-care providers,

[1] Jiann Ping Hsu College of Public Health, Georgia Southern University, Statesboro, GA, USA
[2] Georgia State University, Atlanta, GA, USA

Corresponding Author:
Raymona H Lawrence, Jiann Ping Hsu College of Public Health, Georgia Southern University, PO Box 8015, Statesboro, GA 30460, USA.
Email: rlawrence@georgiasouthern.edu

blood banks, patients, and families about transfusion indications and the prevention and management of transfusion-related complications. Furthermore, there is no ready access to transfusion expertise, guidelines, individual patient transfusion histories (especially minor red blood cell antigen phenotypes or genotypes and previously documented alloantibodies); nor is there ongoing, statewide surveillance for transfusion utilization and complications.

The Georgia Registry and Education for Hemoglobinopathies and Hemovigilance/Transfusion Therapy project was developed to address these gaps and reduce transfusion-associated complications in individuals with SCD in the state. Patient voice and perspective were needed to inform effective, comprehensive strategies for the reduction of transfusion-related complications. Therefore, we conducted a series of interviews with individuals with SCD in Georgia to understand (a) patient knowledge of transfusion and potential complications; (b) patient attitudes and preferences about ways to store and share their transfusion history; and (c) patient perspectives on the transfusion experience. This article presents the results of interviews with SCD patients as well as strategies to reduce transfusion complications in this population.

Method

Setting

The prevalence of SCD in the United States is likely increasing; however, the exact number of people living with SCD is unknown (8). The Georgia Registry and Surveillance for Hemoglobinopathies surveillance project identified more than 7000 confirmed or probable cases of SCD in the state for the 5-year period from 2004 through 2008 (8).

Inclusion and Recruitment

Individuals eligible for inclusion in the current study had a SCD diagnosis and had received at least one blood transfusion in their lifetime as treatment for SCD complications. Individuals 18 or older could participate with no upper age limit and with written informed consent.

Participants were recruited at the comprehensive SCD treatment centers at Grady Health System in Atlanta, Georgia, and Augusta University Hospital in Augusta, Georgia. A member of the clinic staff or research team gave patients a recruitment flyer. Eligible and interested participants were interviewed in a private room in the clinic.

Interview Protocol

Patient voice and perspective were needed to inform effective, comprehensive strategies for the reduction of transfusion-related complications. Therefore, we utilized qualitative methods (interviews) as a means of data collection. Qualitative methods capture participants' direct words (voice) and allow researchers to more comprehensively explore perspectives that can sometimes be missed when using quantitative measures such as surveys. Therefore, a team of physicians, academic researchers, and patient advocates developed the study protocol and interview guide aimed at gathering individuals with SCD perspectives of the transfusion experience. Examples of interview questions included, "I would like to begin by asking you to briefly share a transfusion experience," "What are the good and/or bad things about receiving a blood transfusion?," and "How would you feel about your personal blood and transfusion information being stored on a phone app, wallet card, or electronic registry so that you and doctors treating you could get access to this information anywhere?"

Patients who expressed interest in participating in the study were interviewed for 20 to 30 minutes by the research team on the same day of their medical appointment. Interviews were audio recorded with patients' written informed consent. All study procedures were approved by the Institutional Review Boards.

The interview consisted of 3 parts: open-ended questions about patient knowledge and experience; patient review of a brief, lay-language summary of the National Institutes of Health's National Heart Lung and Blood Institute practice recommendations for transfusion in SCD; and a general health literacy assessment using The Newest Vital Sign instrument (9). This aspect of the study is outside the scope of the current article.

Reflexivity

Within the context of the current study, the members of the research team involved in conducting face-to-face interviews with study participants needed to consider the ways in which their interactions with participants might be influenced by their own professional backgrounds, experiences, and prior assumptions. The interviewers (Ashley Singleton and Robert Gibson) are academic researchers with nonclinical backgrounds. R.H.L. is a university professor and was the lead data analyst. R.H.L. has personal experience with SCD. An important question to be addressed concerned the impact the interviewer's professional background could have on participants' willingness to freely discuss their experiences and the bias this could have created. Additionally, in acknowledgment of R.H.L.'s biases related to personal experience with the topic, interview notes and transcripts were also read and analyzed by a team of researchers and compared with evidence-based literature to substantiate and verify themes and conclusions that emerged from the data. The team analyzed data through an iterative process to reduce bias.

Data Analysis

Interview audio recordings were deidentified and professionally transcribed prior to analysis. The analysis approach was adapted from the Sort and Sift, Think and Shift method: data inventory, written reflection, reflective diagrams, categorization, bridging, and data presentation (10). Initially

Table 1. Emergent Themes.

Domain Name	Corresponding Themes	Exemplary Quote
Patient knowledge of transfusion and potential complications	Basic knowledge	I know I need it [transfusion] because I have low blood
	Varying comprehension and utilization of complex health information	The more blood transfusions you have, the harder it is for you to keep getting them and get matches. You develop antibodies and things like that."
Patient attitudes and preferences about ways to store and share their transfusion history	Advantages/drawbacks for any method of storage	A card, you can lose it. So, that's the only thing . . . the app, even if you lose your phone, you download it and that information . . . it's still there.
	Generational differences in preference	The app is more for the younger generation [because] they just app, app, app all day.
	Privacy concerns	I could see [having a registry], as long as my name is not associated with it.
Patient perspectives on the transfusion experience.	Unpleasant, but helpful	The first word to come to mind would be aggravating. The good thing is, I felt better afterwards.

researchers created neutral domain names that corresponded with each interview question. For example, the interview question, "What information have you been given about transfusions?" corresponded to the domain name "patient knowledge of transfusions." Next, a summary template was developed that included each domain name. Team members used this template to code one common transcript to test the template which allowed the team to determine if the domain names were intuitive, if any domains were missing or mislabeled, ease of use, length of time required for completion, and variation in reviewer style (type of quotes, length, etc). After consistency was established, transcripts were divided among the team for summary using the final template. Analyses occurred from June 2017 to August 2017. When all summaries were complete, they were transferred to a matrix so that researchers could determine similarities, differences, and common themes.

Results

Participants

Twenty-two interviews were conducted with eligible participants. All participants were African American and were 18 years or older. Interviews lasted an average of 20 to 30 minutes. While all participants had at least one transfusion, their lifetime transfusion experiences ranged from rare or occasional to chronic.

The emergent themes can be found in Table 1. The results are further summarized for each of the 3 domains explored: knowledge about transfusions and potential complications; attitudes about transfusion history storage and sharing; and perspectives of the transfusion experience.

Knowledge About Transfusions and Potential Complications

Participants had general physiology, blood product, and blood transfusion knowledge. However, important aspects of these topics were lacking. Participants varied in comprehension and utilization of complex health information.

For example, participants with a basic understanding of blood transfusions often stated, "I know I need it [transfusion] because I have low blood." Participants further stated that the need for a transfusion occurred "when my blood count drops below a certain number." Participants with a deeper understanding of the concept could explain that, "it was [because] my hemoglobin was low." Participants did not express understanding of reasons for receiving a blood transfusion beyond having a low blood count.

Some expressed a basic awareness that getting too many transfusions could cause complications, leading to a need to limit transfusions to when they are truly necessary. One said, "The more blood transfusions you have, the harder it is for you to keep getting them and get matches. You develop antibodies and things like that."

Some patients misunderstood or were misinformed on important points, including the notion that a transfusion is necessary "for reducing pain" or because of "low blood." Participants also had some misconceptions about antibodies, with many indicating that they believed they were given "the wrong blood" or "bad blood" during a transfusion and that this was the cause of an unpleasant reaction, such as itching. Several participants expressed that their antibodies were caused by mistakes in the matching process. One participant said, "I thought everybody has the same antibodies." Another said, "That's one part of the reasons why I have antibodies is because at one point they slipped and gave me the wrong blood."

Participants expressed concerns about blood safety, stating that they were afraid of disease transmission, specifically HIV/AIDS and hepatitis. When asked about their knowledge and concerns regarding transfusions, the most commonly expressed concern was "Was it tested properly for HIV, hepatitis, anything?"

Participants had some understanding of iron overload and its relationship to having multiple transfusions. Participants

generally understood that iron overload was a state of having "too much iron" in the body.

They knew that too much iron was harmful to the body and that doctors would give them medicine to lower it when it was too high. One participant expressed this basic level of understanding by saying,

> Iron overload is when you have too much iron. That's what my mom said, that I have too much iron and then I have to take Vitamin D or Vitamin C, something to that effect. But if I have too much iron it hurts my liver or whatnot.

Another participant expressed this general sentiment by stating, "Your iron is too high . . . and they give you medicine, and it's supposed to bring your iron down." Participants did not demonstrate more than a cursory knowledge of iron overload and could offer no further information beyond these basic facts.

Attitudes About Transfusion History Storage and Sharing

Participants' preferences varied regarding how they would like their transfusion information stored. Each method suggested—wallet cards, smartphone applications, and registries—had advantages and drawbacks. No modality received overwhelming support from the participants who recognized the possibility of generational differences in their responses. One said,

> The cards might work for older patients. You know, older people keep stuff. I guess the app is more for the younger generation [because] they just app, app, app all day.

Participants also expressed concern about those who might lack access to, or not be frequent users of technology. "I don't think so [to the app] because I have a hard time checking my mail, let alone checking antibodies."

Most participants spoke favorably about a registry, noting its accessibility when patients present in different clinical settings or during a pain crisis:

> [I would rather have a registry] because it would be easier. A lot of times, if I'm in a real bad crisis and I'm in pain, it would be easier, more convenient, if they could just look it up.

At the same time, many expressed privacy concerns and offered suggestions about ways to maintain patient confidentiality. Privacy was a concern for each of the tracking methods. Participants noted that cards may be lost or stolen, smartphone apps can be hacked, and registries might be accessed by people other than a clinician in conjunction with treatment.

> A card, you can lose it. So, that's the only thing . . . the app, even if you lose your phone, you download it and that information . . . it's still there. If somebody takes your stuff, they have your information [if it's on a card].

Participants also expressed the need for privacy within the clinic setting.

> I could see [having a registry], as long as my name is not associated with it. So [the provider] could give me a registry number, M9250, and nobody really knows who that is, except who ever puts that information in . . . or something like that.

Perspectives on the Transfusion Experience

Participants generally described the transfusion experience as unpleasant.

> The first word to come to mind would be aggravating, and this is for a number of reasons. I mean, obviously, the reason that you're having to have one means you're not feeling good at all, so you know, just that alone makes the whole process just unpleasant. You're in excruciating pain and a lot of discomfort, so going through that—it's the process to feel better but going through it was just not fun.

A few of the participants expressed "annoyances" regarding the transfusion process such as "cold rooms" and "long waits" or "itching." Still, they overwhelmingly reported that transfusions yield positive results: "The good thing is, I felt better afterwards."

Participants expressed interest in receiving more information on the benefits and uses of transfusions. Some reported signing transfusion consent forms out of fear of negative consequences, or a sense of obligation to the doctor, as opposed to a sense of mutual patient–provider decision-making. One said,

> [The doctor] doesn't tell you in detail exactly how the process is going to help. It's just supposed to help the pain. They just tell you what's gonna happen. They don't really tell you the purpose and stuff like that.

Patients were able to offer few other suggestions for improving the transfusion experience because they were often in the midst of a pain crisis when they received them, and not fully aware of the process.

Discussion

The current study shows patients with SCD have general knowledge of physiology, blood products, and blood transfusions, including knowing the risk of complications. However, participants vary in comprehension of complex health information and level of misinformation. Most common misinformation included overestimating the risk of acquiring an infection from a transfusion, believing that the transfusion is "for reducing pain," or thinking that having antibodies is

from getting "bad blood." Participants also varied in preferences for how they would like their transfusion information stored. They saw both advantages and disadvantages to wallet cards, smartphone applications, and registries. Differences in preferences could, in part, be due to generational differences.

Participants described general discomfort during the transfusion experience; but most reported that the procedure helped make them feel better. The transfusion experience of many participants was in acute situations when their attention to transfusion-related processes was minimal given their overwhelming pain. When patients did remember the interactions they had with providers, they indicated playing little role in transfusion decision-making.

This parallels previous research findings that while patients might recall consenting to transfusion, they might not recall specific information with regard to its risks and benefits (11,12). Patients report being unable to take in information or make decisions when in crisis, which is the time many say they were offered information about transfusion or a role in transfusion decisions. Previous researchers have observed that patients suffering from other life-threatening medical conditions tend to trust their physicians' judgment regarding transfusion and rarely question providers about risks, benefits, and alternatives (11). As in other studies, current study participants expressed a desire to gain deeper understanding of the process of transfusion and wanted their physicians to address "individual, patient-specific fears/concerns" (11, p24).

Implications from this study align with current scientific evidence and protocols, calling for a patient-centered approach that involves transfusion education and shared decision-making (11,13,14). Elements of a traditional informed consent include "1) a description of the risks, benefits, and treatment alternatives (including nontreatment); 2) the opportunity to ask questions; and 3) the right to accept or refuse transfusion" (15, p9). Shared decision-making, however, is a broader concept that includes "1) recognizing and acknowledging that a decision is required; 2) knowing and understanding the best available evidence; and 3) incorporating the patient's values and preferences into the decision" (16, p1306).

In order to enable shared decision-making, it is important for patients to have a working knowledge of blood transfusion, free of common misconceptions. While key messages regarding safe transfusion need to be addressed, patients also desire detailed information about the process of transfusion (11). Preferably, this information should be shared during routine encounters or other nonemergency situations when a truly meaningful consent process occurs as there is no time constraint or anxiety with the impending procedure (15,17).

In order to reduce transfusion-related complications, patients must understand clinical practice recommendations for transfusion, including best practices for avoiding transfusion-related complications and the importance of advocating for themselves.

The patient blood management strategies (18) call for a multidisciplinary approach and patient-centered approach to address adult SCD patients' needs. The National Heart, Lung, and Blood Institute's 2014 expert panel report recommends that providers obtain an accurate transfusion history, including locations of prior transfusions and any previous adverse effects. This requires interviewing the patient and contacting blood banks that provided previous transfusions. This is a cumbersome manual process fraught with challenges, but it is critically necessary and relies heavily upon empowered and educated patients' ability to communicate their SCD-related history, as well as their blood transfusion-related history.

Limitations

Although interviews were continued until no substantially new information was heard, the sample size is small and may not encompass the full range of knowledge, attitudes, and experiences of SCD patients regarding therapeutic blood transfusion. This is especially true given that all participants were recruited at comprehensive SCD centers. It is possible that they may be more trusting or deferential toward their providers, whom they know are leading specialists in their condition. Patients living in areas without such specialists might have a greater urgency to educate themselves on their disease, have different attitudes about data storage, and may have had different experiences while receiving transfusions.

Acknowledgments

We would like to acknowledge each of the individuals with SCD who participated in these interviews. We are forever grateful. We would also like to acknowledge Dr Robert Gibson for his invaluable contribution to both the planning and implementation of this study.

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) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research was funded by the Centers for Disease Control and Prevention (CDC) through cooperative agreement 5NU58DD001138. However, its contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC or U.S. Department of Health and Human Services.

ORCID iD

Raymona H Lawrence, DrPH, MPH, MCHES https://orcid.org/0000-0001-6554-3354
Ashley Singleton, MPH https://orcid.org/0000-0002-3183-0993

References

1. Blum RW, Garell D, Hodgman CH, Jorissen TW, Okinow NA, Orr DP, et al. Transition from child-centered to adult health-

care systems for adolescents with chronic conditions. A position paper of the society for adolescent medicine. J Adolesc Health. 1993;14:570-576. https://www.sciencedirect.com/science/article/pii/1054139X9390143D?via%3Dihub
2. 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. doi:10.1002/ajh.21880.
3. Van Staa AL, Jedeloo S, Van Meeteren J, Latour JM. Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers. Child Care Health Dev. 2011;37:821-832. doi:10.1111/j.1365-2214.2011.01261.x.
4. Brousseau DC, Panepinto JA, Nimmer M, Raymond GH. The number of people with sickle-cell disease in the United States: national and state estimates. Am J Hematol. 2010;85:77-78. doi:10.1111/j.1365-2214.2011.01261.x.
5. Anie KA, Telfair J; Sickle Cell Disease Transition Study Working Group. Multi-site study of transition in adolescents with sickle cell disease in the United Kingdom and the United States. Int J Adolesc Med Health. 2005;17:169-178. doi:10.1515/IJAMH.2005.17.2.169.
6. Evidence-based management of sickle cell disease: expert panel report, 2014. National Heart, Lung, and Blood Institute. National Institutes of Health; 2020. https://www.nhlbi.nih.gov/health-topics/evidence-based-management-sickle-cell-disease
7. Chou S. Transfusion therapy for sickle cell disease: a balancing act. 2013. http://asheducationbook.hematologylibrary.org/content/2013/1/439.long
8. Snyder AB, Zhou M, Theodore R, Quarmyne MO, Eckman J, Lane PA. Improving an administrative case definition for longitudinal surveillance of sickle cell disease. Public Health Rep. 2019;134:274-281. doi:10.1177/0033354919839072.
9. Osborn CY, Weiss BD, Davis TC, Skripkauskas S, Rodrigue C, Bass PF, et al. Measuring adult literacy in health care: performance of the newest vital sign. Am J Health Beha. 2007;31:S36-S46. doi:10.5555/ajhb.2007.31.supp.S36
10. Maietta RC, Curry L, Shield RR, Wetle TT, eds. State of the art: integrating software with qualitative analysis. Improving Aging and Public Health Research: Qualitative and Mixed Methods. American Public Health Association and Gerontological Society of America; 2006.
11. Cheung D, Lieberman L, Lin Y, Callum J. Consent for blood transfusion: do patients understand the risks and benefits? Transfusion Med. 2014;24:269-273. doi:10.1111/tme.12141
12. Chan T, Eckert K, Venesoen P, Leslie K, Chin-Yee I. Consenting to blood: what do patients remember? Transfusion Medicine. 2005;15:461-466. doi:10.1111/j.1365-3148.2005.00622.x.
13. Davis R, Vincent C, Sud A, Noel S, Moss R, Asgheddi M, et al. Consent to transfusion: patients' and healthcare professionals' attitudes towards the provision of blood transfusion information. Transfusion Medicine. 2012;22:167-172. doi:10.1111/j.1365-3148.2012.01148.x.
14. American Association of Blood Banks (AABB). Guidelines for Patient Blood Management and Blood Utilization. AABB; 2011.
15. Friedman M, Arja W, Batra R, Daniel S, Hoehn D, Paniz AM, et al. Informed consent for blood transfusion: what do medicine residents tell? What do patients understand? Am J Clin Pathol. 2012;138:559-565. doi:10.1309/AJCP2TN5ODJLYGQR
16. Vetter TR, Adhami LF, Porterfield JR, Marques MB. Perceptions about blood transfusion: a survey of surgical patients and their anesthesiologists and surgeons. Sur Anesthesiol. 2014;58:321. doi:10.1097/01.sa.0000455302.21795.df
17. Schenker Y, Meisel A. Informed consent in clinical care: practical considerations in the effort to achieve ethical goals. JAMA. 2011;305:1130. doi:10.1001/jama.2011.333.
18. National Blood Authority—Australia. National Patient Blood Management Strategy. National Blood Authority. 2020. https://www.blood.gov.au/system/files/National-Patient-Blood-Management-Strategy-2017-2021-Final.pdf

Author Biographies

Raymona H Lawrence is an associate professor of Health Policy and Community Health in the Jiann Ping Hsu College of Public at Georgia Southern University. Her main research focus is community engagement in rural, minority populations-especially those with sickle cell disease. She is the Principal Investigator of a large, PCORI-funded, multi-site study, the director of research for the Sickle Cell Community Consortium and serves on several National Committees committed to the care and treatment of individuals with sickle cell disease.

Ashley Singleton is the program and research manager for the Injury Prevention Research Center at Emory University. She manages the daily operations of the center, supports the center's five task force workgroups and monitors the execution of multiple program deliverables. The work reported here was completed while she was a Research Associate II at GHPC.

Jane Branscomb is an assistant project director with the Georgia Health Policy Center, in the Andrew Young School of Policy Studies at Georgia State University. She provides training in systems thinking, policy engagement and adaptive leadership to support cross-sector collaborations seeking population health transformation and equity. She also directs programs that bring high-quality evidence to bear in policy and practice advances for sickle cell disease and thalassemia populations.