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HEMATOLOGY: BRIEF REPORT

Building the foundation of health-related knowledge via near-peer education for children with sickle cell disease

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Abstract

Health education for children with chronic illnesses (i.e., sickle cell disease [SCD]) has focused on educating adult caregivers with minimal consideration to educating the pediatric patients. We introduce a pediatric-focused educational paradigm, health-related knowledge (HRK), teaching pediatric patients developmentally appropriate general health literacy, and disease-specific knowledge. Using science, technology, engineering, and mathematics (STEM) education concepts, pediatric-specific HRK interactive activities address educational gaps: (a) general STEM education; and (b) general health and disease-specific knowledge to improve clinical outcomes. Total 144 pediatric SCD patients completed HRK activities, revealing overwhelmingly positive feedback (87%). Seventy-five percent of participants in 6th grade and above demonstrated thorough understanding of the STEM/HRK topics taught.

KEYWORDS
disease-specific knowledge, education, health literacy, pediatrics, sickle cell disease

1 | INTRODUCTION

Patient health literacy (HL) education, which enhances the understanding of basic health information and navigating medical services, and disease-specific knowledge (DSK) education, which focuses on teaching chronically ill patients aspects of their specific disease and management/treatment plan, can improve clinical outcomes.[1,2] However, HL and DSK programs are primarily for adult patients and caregivers, with minimal consideration to educating the pediatric patients themselves.[3,4] Here, we introduce a pediatric-focused educational paradigm, health-related knowledge (HRK), which teaches pediatric patients HL and DSK that is developmentally appropriate

Abbreviations: DSK, disease-specific knowledge; HL, health literacy; HRK, health-related knowledge; STEM, science, technology, engineering, and mathematics.

for children and adolescents with chronic illnesses. Importantly, HRK also integrates aspects of traditional school-aged science, technology, engineering, and mathematics (STEM) education, an important feature as one-fifth of US children suffer from chronic medical illnesses, representing an underserved and educationally disadvantaged population.[5–8] While this educational paradigm is relevant for all pediatric patients, here we focus on pediatric sickle cell disease (SCD). Children with SCD often experience academic difficulties or learning disabilities because of their disease pathophysiology, adverse treatment effects, and frequent school absences.[9,10] However, because children with SCD often spend significant amounts of time in clinical settings, they represent a “captive audience” where medical visits could become opportunities for learning. Accordingly, we leveraged adult HL and SCD DSK topics (i.e., general health information, SCD genotype/pathophysiology, medication scheduling, etc.) to create HRK, comprising new pediatric health educational content (i.e., components of blood, organ physiology, sickle red cell pathophysiology, etc.) using hands-on interactive activities, as displayed in Figure 1A. Accordingly, HRK closes two educational gaps for children with SCD and other chronic illnesses: (a) STEM education integrated with (b) health knowledge with an overarching goal to improve clinical outcomes.

While the literature includes successful patient education programs organized and led by medical students[11] (i.e., health fairs,[12] supervised interprofessional student teams who provide patient care and education,[13] and student-designed/student-run clinics providing primary care services[14]), our program uniquely involves biomedical engineering (BME) undergraduate students, referred to as “undergraduate teachers (UTs).” The UTs function as the primary educators, leveraging their backgrounds in biology, engineering, and design to create the STEM-based foundational model for HRK programs (Figure 1B). The UTs participate in this program under the auspices of an undergraduate design course. All activities align with state (Department of Education) and national (Common Core State Standard Initiative and Next Generation Science Standards) learning objectives,[15,16] and UTs receive extensive hospital volunteer training. Collaborating with hospital school educators, the UTs teach the HRK activities in a manner that (a) utilizes the SCD patient’s own medical experience as motivation for learning, (b) comprises hands-on interactive activities to teach concepts adaptable to each patient’s cognitive level, and (c) provides UTs with quality meaningful patient interactions and clinical experiences.

2 | METHODS

A total of 144 pediatric SCD patients were recruited to assess the learning objectives of three HRK activities: Blood Jar, Bone Model, and Eye Model, as shown in Figure 2A, D, and G, respectfully. Our teaching methodology begins with the UTs (10 UTs participated in this study) asking the pediatric SCD patients what they know about a SCD-related topic, enabling the UTs to tailor the conversations to match the patients’ cognitive levels while creating a dynamic learning experience. We have included procedural details of patient screening and the UT/patient interaction in the Supporting Material. During the Blood Jar activity (Figure 2A), the SCD patient learns basic biology of blood components via visual representations, verbal word associations, and kinesthetic learning techniques.[17] Direct visualization of adding water to represent hydration (important in SCD self-management) further reinforces dynamic HRK learning.

Our program assessment researched the following questions: (a) do the SCD patients enjoy the HRK activities with the UTs, (b) are we providing educational value to the SCD patients, and (c) are the SCD patients learning the educational objectives of the activities? This was accomplished at the end of each session with post-activity short open-response answer questionnaires conducted by the hospital school educators asking the SCD patients: (a) Did you enjoy the experience?; (b) Would you like to work with the UTs again?; and (c) activity-specific questions that evaluated each patient’s mastery of the activities’ learning objectives and nominally ranked demonstrated understanding (see Supporting Material: Activity assessment and questions, including the grading rubric and raw data). The research was approved by our institutes’ IRB and all human participants gave written informed consent.

3 | RESULTS AND DISCUSSION

Of the 144 participating pediatric SCD patients, 98 completed one activity, 43 completed two activities, and three completed all three activities. The responses were classified by grade range (kindergarten [K] to 2nd, 3rd to 5th, 6th to 8th, and High School [HS]). SCD patients in upper grade ranges exhibited higher HRK scores (Figure 2B,E,H), whereas younger children exhibited lower scores, demonstrating that younger children have less HRK (Figure 2C,F: solid bars, and Figure 2H). The K to 5th SCD patients scored “Clearly” and “Basically.” Further investigation revealed difficulty recalling scientific vocabulary. For example, it may have been the first time hearing the words “platelet” or “plasma.” To that end, we edited the assessment questions for K to 5th SCD patients, converting to a matching game with visual representations.[18] This matching game style mirrors those used for typical kinesthetic learners, is appropriate for any cognitive level, and was implemented during the 2019–2020 school year for the Blood Jar and Bone Model activities (Figure 2C,F: dashed bars).

Figures 2D and 2G show the structural layers and function of the Bone and Eye Models, respectively, and importantly, both organ systems are affected in SCD. The educational assessment scores (Figure 2E,F,H) followed a similar pattern, with highest HRK scores in the upper grade ranges and lower scores for K to 5th, reinforcing value of the matching game assessment questions.

As a near-peer age group to the SCD patients, relationship building with the UTs occurs naturally. Survey results substantiate the pediatric SCD patients enjoyed completing the hands-on activities and interacting with the UTs (Figure 2I). As one SCD patient stated, “it is something new, fun, and different at the hospital.” The innate near-peer-to-peer relationship building is consistent with child development theory in

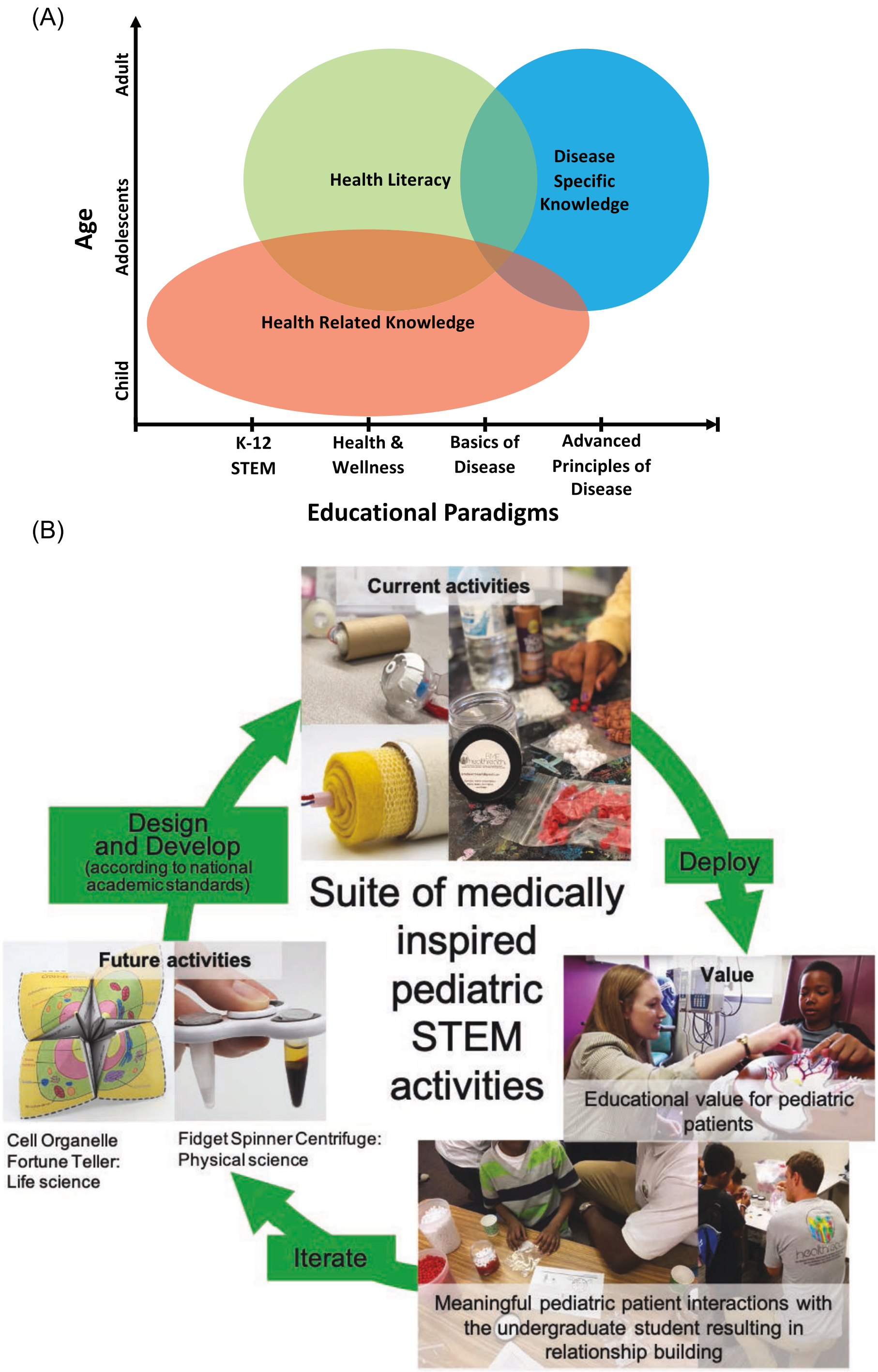

FIGURE 1 (A) Health education, specifically health literacy (HL) (understanding basic health information and navigating medical services) and disease-specific knowledge (DSK) (understanding treatments and compliance) are primarily created for adult patients and adult caregivers of pediatric patients, with minimal consideration to educating the pediatric patients themselves. Here, we show the intersection of educational paradigms between HL, DSK, and our new paradigm—health-related knowledge (HRK) created specifically for pediatric patients. HRK teaches pediatric patients HL and DSK topics using developmentally appropriate hands-on interactive activities. (B) Illustration of the program with images showing the current activities created by the undergraduate teachers (UTs). The UTs participate in an out-of-class design thinking course that allows the UTs to iteratively design and develop hands-on interactive science, technology, engineering, and mathematics (STEM) activities emphasizing that medicine is interdisciplinary and involves biology, physics, chemistry, and math. The UTs deploy and teach the activities as pictured by various interactions between UTs and patients. The UTs are able to create meaningful, longitudinal relationships with the pediatric patients, as well as providing educational value. These relationships are ideal for pre-medical UTs and inform their career choices within the medical field. Followed by iteration with continued STEM and HRK activity creation. Patient image Copyright 2014 by Georgia Institute of Technology. All rights reserved. Used/adapted with permission

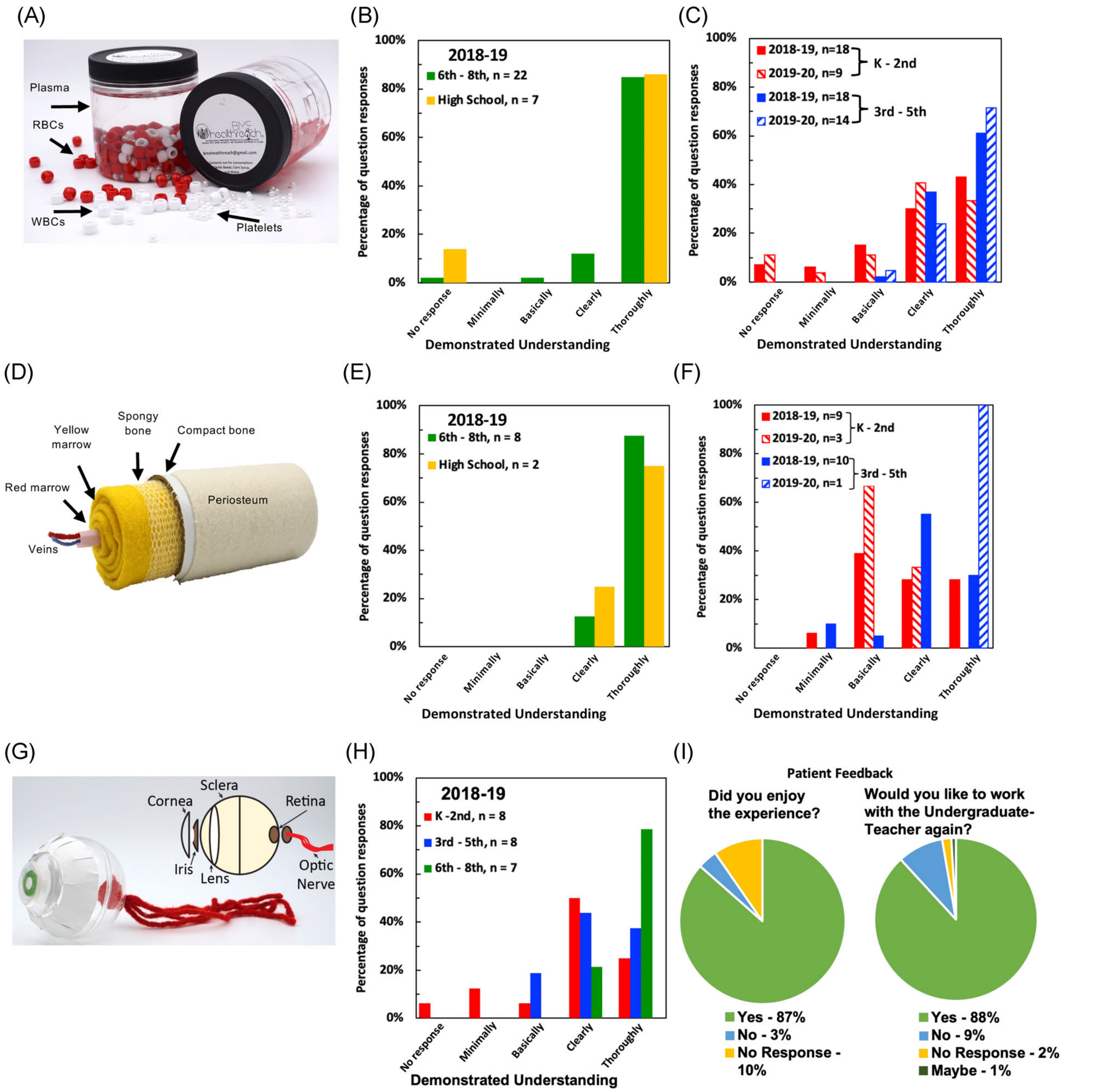

FIGURE 2 The undergraduate teachers (UTs) lead sickle cell disease (SCD) patients through hands-on interactive science, technology, engineering, and mathematics (STEM) activities, with a focus on improving health-related knowledge (HRK). Activity assessment responses (n = 144 pediatric SCD patients) were rated based on demonstrated understanding: "Thoroughly" (highest score), answers everything correctly, "Clearly," answers the assessment question correctly but is unable to apply the scientific vocabulary correctly, "Basically," understands how the activity works, can recreate the activity, but is unable to answer the assessment questions, "Minimally," and "No Response." The assessment results are divided into grade-in-school categories—K (kindergarten) to 2nd grade, 3rd to 5th grades, 6th to 8th grades, and high school. (A) Blood Jar activity, which entails learning about the four main components of blood and the effects of hydration in SCD by integrating the inclusion of water to the activity. Assessment question results for 65 pediatric SCD patients revealed that (B) 75% of 6th grade and above scored "Thoroughly." (C) In light of the assessment, for K to 5th graders, the question style was changed to that of a "matching game" for the 2019–2020 school year (dashed bars), in which 23 pediatric SCD patients participated. Accordingly, 3rd to 5th graders scored more consistently with this new assessment style, and improvement with K to 2nd graders resulted in higher scores in the "Clearly" category. (D) With the Bone Model activity, which includes learning about the basic structural components of bone and their functions, assessment with 29 pediatric SCD patients revealed that (E) 88% of grades 6th to 8th and 75% of high school SCD patients scored in the "Thoroughly" category, and (F) lower scores for the K to 5th grade, with 28% of K to 2nd, 30% of 3rd to 5th scoring "Thoroughly" during the 2018–2019 school year (solid bars) and improvement in 2019–2020 (dashed bars) using "matching game style" assessment. (G) With the Eye Model activity, which involves teaching the basic components of the eye and their functions, assessment with 23 SCD patients revealed that (H) from K to 8th grade, 79% of 6th to 8th grade SCD patients scored in the "Thoroughly" category, with only 25% of K to 2nd and 38% of 3rd to 5th scoring in that category. (I) Pediatric SCD patient feedback from the interactions with the UTs revealed that over 87% of the patients enjoyed the experience and would like to work with the UTs again (www.bmehealthreach.gatech.edu)

which maintaining peer-to-peer relationships is necessary for healthy cognitive development.[19–21]

As the activities are rooted in Department of Education standards for math and science, in which life science is introduced and taught in 5th and 7th grades, respectively, 10–14-year-old patients are our target audience. However, during preliminary activity design iterations, we found any SCD pediatric patient (regardless of age or school grade) was receptive of the activities. Therefore, all pediatric patients can benefit from the HRK activities and the personal interaction with UTs.

Preassessment questions to differentiate between previous knowledge and knowledge gained were not included in this study, but will be included in future investigations. Long-term longitudinal knowledge retention assessments, with emphasis on the transition period from pediatric- to adult-centered care, will also be included. With the HRK framework established, additional SCD-related DSK education can be included (i.e., sickled shaped beads in the Blood Jar, vaso-occlusive episode education related to the Bone Model, and impact of SCD on the retinal blood vessels).

Furthermore, this program provides value for the UTs as approximately one-half anticipate applying to medical school. The valuable clinical experiences and in-depth personal interactions provided by our program are an important component (Supporting Material Statements) of their medical school applications,[22] and as patient privacy and in-depth credentialing requirements continue to rise, these meaningful patient interactions are becoming more difficult to attain.

Research shows that improving DSK and HL for SCD patients and their caregivers can result in long-term positive health outcomes.[2] Specifically, adolescents with lower literacy skills were more likely to use alcohol and tobacco than those with higher literacy.[23] This is especially important in SCD, where both tobacco and alcohol use could have significant implications in complicating the disease, as tobacco smoke could lead to lung complications and alcohol could lead to sickle red cell dehydration. Therefore, educating patients about blood and red cells, as well as body organ systems and how they interact with one another, can provide patients with insights about their bodies and disease they may otherwise not know. Our program has received overwhelming positive responses from the SCD patients; 87% enjoyed their time and were interested in additional visits from the UTs. This represents an innovative approach to teach HRK through the lens of STEM education by (a) engaging SCD patients, who are uniquely suited to learn important STEM concepts within the context of their own disease and improve their own HL; (b) providing learning to SCD patients during extended school absences; (c) allowing UTs to iteratively design, develop, and teach STEM activities; (d) provide UTs with meaningful patient interactions and social value that may impact career planning; and (e) addressing a need for quality innovative STEM education and HL programs. Additionally, we envision translating HRK to other childhood chronic conditions, improving STEM education and HL for all pediatric patients.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest relevant to this article.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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