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Evaluation of a Sickle Cell Disease Educational Website for Emergency Providers

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Sickle cell disease (SCD) is a complex multisystem debilitating disease that affects 90,000 to 100,000 Americans (Centers for Disease Control and Prevention, 2011; Hassell, 2010), and is more prevalent among African Americans and Hispanic Americans in the United States (Hassell, 2010; National Heart Lung and Blood Institute, 2010). SCD causes shortened life spans; the average person with SCD dies before the age of 50. In 2005, the median age of death was 38 years and 42 years for males and females, respectively (Lanzkron, Carroll, & Haywood, 2013). Persons with SCD suffer from major complications such as stroke, pulmonary hypertension, obstructive lung disease, chronic kidney disease, sepsis, and vaso-occlusive crisis (VOC) (National Heart Lung and Blood Institute, 2010), and are frequently hospitalized (Brousseau, Owens, Mosso, Panepinto, & Steiner, 2010; Jiang, Barrett, & Sheng, 2006; Shankar, Arbogast, Mitchel, Cooper, Wang, & Griffin, 2005). Pain, typically caused by VOC, is the most common reason for emergency department (ED) visits and hospitalizations (Yusuf, Atrash, Grosse, Parker, & Grant, 2010). VOC leads to tissue hypoxia and ischemia and is associated with acute intolerable painful episodes, where the pain may radiate throughout the body or intensify in areas such as the chest, hips, abdomen and joints (National Heart Lung and Blood Institute, 2010). Despite the complexity of SCD, most health care providers (HCPs) (nurses, physicians, respiratory therapists and social workers) receive little formal education about providing care for individuals with SCD.

It is essential that HCPs, especially those in the ED, are comfortable caring for individuals with SCD. However, many HCP's often lack adequate knowledge and have a poor understanding of the complexity of SCD (Booker, Blethyn, Wright, & Greenfield, 2006; Tanabe et al., 2013). In addition, many HCP's have misperceptions about patients with SCD

and believe the prevalence of opioid addiction among patients with SCD to be high (Brown, Weisberg, Balf-Soran, & Sledge, 2015; Pack-Mabien, Labbe, Herbert, & Haynes, 2001; Wright & Adeosun, 2009), despite lack of data to support this misconception. Negative provider attitudes have been associated with inadequate pain management for patients with SCD (Brown, Weisberg, Balf-Soran, & Sledge, 2015; Haywood et al., 2009). Nurses have been found to have greater levels of negative attitudes and express greater levels of frustration in caring for patients with SCD compared with physicians (Freiermuth et al., 2014). It is, therefore, important to develop resources to improve HCP knowledge, reduce negative attitudes, and ultimately improve care for persons with SCD in the ED.

To address this barrier, an open-access, educational website, “*Emergency Department Sickle Cell Disease: Crisis Management and Beyond*” (<http://sickleemergency.duke.edu>), was created. The website is a collaboration between Duke University School of Nursing, Wake Forest Baptist Medical Center, Johns Hopkins Medicine, and Icahn School of Medicine at Mount Sinai. The goal of the website is to provide education about SCD to ED providers who are not SCD experts, but who provide care for patients with SCD. The website offers many educational resources including short educational modules, lectures from SCD conferences, videos, treatment algorithms (i.e., VOC management, fever, stroke), and case management resources. It also contains a quality improvement framework which is useful to emergency departments [the Emergency Department Sickle Cell Assessment of Needs and Strengths (ED-SCANS) and Family Centered Pediatric ED-SCANS, FC-Peds-ED-SCANS)]. Specific SCD educational modules available on the website include acute chest syndrome, Sickle Cell Disease epidemiology/genetics/ pathophysiology, use of the incentive spirometer, and sickle cell pain. Each educational module includes learning objectives, two pre- and post-test study questions, and approximately ten slides of relevant content. One of the modules (incentive spirometer) includes a short demonstration video.

A formal evaluation was conducted to assess the accuracy and relevance of the website content, and the effectiveness of the education modules in improving knowledge among HCPs. This paper reports: 1) the approach taken to conduct a formal website evaluation; 2) the results of the evaluation; 3) the modifications made to the website based on the evaluation; and 4) future directions.

Methods

Study Design

Electronic survey assessments were used to conduct the evaluation of the website and educational modules. All participant responses were anonymous; the project was deemed exempt by the Duke Institutional Review Board.

Sample

A convenient sample of ED providers (physicians and nurses), accelerated bachelor of science in nursing (ABSN) students in their second semester of study, SCD experts, and website experts were identified by the website collaborators. Leaders from five ED's across the United States were invited to solicit survey participation from ED nurses and physicians

in their departments. ED providers are end users of the website and their input was solicited to obtain their assessment of the usefulness of the website and educational modules, and to assess their change in knowledge scores after viewing the educational modules. Two national SCD experts were solicited to evaluate the website and educational modules for content accuracy. Two experts on website development at Duke University were invited to evaluate the website using formalized criteria published by Health on the Net (HON; <https://www.healthonnet.org/HONcode/Pro/Visitor/visitor.html>). Finally, ABSN students were invited to participate by viewing the educational modules and completing the pre-and post-test assessments. Evaluation of their SCD knowledge change was assessed by comparing their pre- and posttest scores.

Educational Modules and Website Evaluation Process

Table 1 provides an overview of the educational modules and website evaluation plan. A formative evaluation of the educational modules and the website as a whole was conducted. The evaluation consisted of: 1) *individual module knowledge assessment* pre- and post-review of website; 2) *content validity* assessment of the four individual modules; 3) *overall website* content assessment and 4) *overall website* assessment, using HON established core principles. HON is a non-government organization that aims to provide an assurance of quality health information on health websites. HON established eight core principles (Table 1) to formally evaluate and certify health websites. Finally, ED providers and ABSN students recorded the actual time it took to complete each educational module from start to finish.

To ensure anonymity to study participants, the Duke Office of Clinical Research (DOCR) served as an honest broker and conducted the survey process, de-identified the data, and prevented duplicate survey submission. At no time did the study team have access to participants' names or emails. A separate survey was developed for each category of participants (ABSN, ED providers, SCD experts, and website experts) using REDCap™, a secure web-based application for developing and managing online surveys. DOCR received email addresses from interested participants and sent an email with the link to the appropriate survey based on participant category. In addition, ED providers and ABSN students were required to complete pre- and post-knowledge surveys. They initially received an email with the knowledge pretest and the link to the website. One hour later, they received an email with the posttest. Email addresses of participants were destroyed after completion of the project.

Data analysis

Data was exported from REDCap™ into SAS 9.3 for analysis. Descriptive statistics were computed to summarize the sample characteristics and responses on survey items. Knowledge total scores for the assessment administered before and after the knowledge module were calculated as the total number of correct answers on an eight-item knowledge test. Thus, the knowledge score had a possible range of 0 to 8. A paired t-test was conducted to compare the mean difference in knowledge total scores for the ABSN students. The difference score represented the post minus pretest knowledge test score. Due to the small sample size, significance testing was not conducted for ED providers. The item on relevance

of each educational module which was initially scored on a scale of 1–4 (1 being not relevant to 4 being highly relevant) was collapsed into “not relevant” (responses of 1 or 2) and “relevant” (responses of 3 or 4).

Results

Demographic characteristics of participants [27 ABSN students, nine ED providers (five nurses and four physicians)], two sickle cell experts, and two website experts] are presented in Table 2. We did not collect demographic information on the website experts. While we had 30 ABSN student participants, only 27 provided complete knowledge data during the pre-assessment, 20 completed the post-assessment and of those 19 provided knowledge data at both the pre and post time points. Similarly, while nine ED providers participated, only seven provided knowledge data during the pre-assessment and six provided knowledge data at both the pre and post time points.

Knowledge total scores were statistically improved after viewing the educational modules for ABSN students ($t=9.55$, $df = 18$ $p < .0001$). The ED providers mean score also improved but differences were not analyzed for statistical significance because of the small sample size (Table 3). Scores for all items improved except for one test item which asked how to evaluate if a patient is correctly using the incentive spirometer.

Overall, SCD experts and ED providers agreed that the *content of the modules* was clear and easy to understand, accurate, comprehensive, relevant, and met module objectives. Related to the pre and post test questions, respondents reported that the questions were clear and addressed the module objectives. Table 4 provides the content evaluation by SCD experts and ED providers for each individual educational module. The average time spent by ED providers on each module ranged from a mean of 7.5 (SD=2.7) minutes to 12.5 (SD=10.4) minutes.

Open-ended survey questions asked SCD experts and ED providers to evaluate the overall website and make additional comments about the individual educational modules. Participants commented that the following were *strengths of the website*: clear, easy to navigate and use, visually appealing, short modules, good quality and important information, and the inclusion of videos. Recommendations for *improvement to the website* included to embed videos within the educational modules and include references to other resources. SCD experts and ED providers also commented that the following were *strengths of the individual educational modules*: provided focused information in one location, the content was important for busy ED providers, modules were short and concise, and the modules contained objectives. They particularly thought that the pre-test questions in each educational module were important to highlight the key points. When asked how *individual educational modules could be improved*, participants recommended using a standardized template for all modules and simplifying some of the slides. They also recommended adding educational modules on VOC management, opioid abuse, fever, management of high ED utilizers, biliary disease, avascular necrosis, and management of stroke.

Two website experts provided an evaluation of the website based on the HON code guidelines (<http://www.hon.ch/HONcode/Webmasters/Guidelines/guidelines.html>), and indicated that the website met some but not all HON code guidelines. Results are presented in Table 5.

Discussion

Although the website evaluation process was complex, the information gained from this project was incredibly valuable and provided direction for enhancing and expanding the educational modules. The comments of the SCD experts also provided information for future efforts to add relevant educational content, ultimately improving the clinical care of patients with SCD.

The education modules contained on the “*Emergency Department Sickle Cell Disease: Crisis Management and Beyond*” website were successful in improving the ED physicians’, nurses’ and ABSN student’s knowledge of SCD. The website is especially useful for HCPs who work in the emergency department and who have frequent contact with patients with SCD presenting in times of crisis or adverse events. The evidence-based resources are readily available through the website and the educational modules are concise, user-friendly, and focused on specific and relevant SCD topics, making them particularly useful for busy HCP’s like ED nurses, physicians and inter-professional healthcare team members who need to access information in short timeframes. The educational modules could be considered for annual continuing education requirements or as adjunct learning resources by quality improvement committees, safety committees and clinical educators. Because of the generalizability of the knowledge obtained in these modules, there is great potential and benefit for these to also be used in the primary care settings where providers might not be comfortable providing care for patients with SCD. The educational modules and resources on the website provide quick primers for enhancing care of patients with SCD and are a convenient resource for guidelines and tools that could improve care for patients with SCD.

The educational modules and resources might also be valuable resources for educators of pre-licensed healthcare students. This free, open-access website provides education modules and vital clinical information. The learning objectives and concise modules could be easily incorporated into the curriculums of Nursing, Medicine, Advance-practice nursing, Physician Assistant, Medical Social work and Respiratory Therapy training programs. The pre-and post-test design enhances student learning and could be considered as part of course requirements or an adjunct to didactic or clinical coursework for students in Pediatric, Adult, ED, acute or critical care clinical rotations. The modules could also be offered as a “thread” throughout HCP education programs, enhancing knowledge and retention on SCD topics through repetition as students progress through training and prepare for clinical practice. After academic preparation, the modules and resources would remain available and pertinent to those HCPs practicing in settings which provide care for patients with SCD.

Modifications made to the website based on the evaluation

As a result of the project evaluation, several modifications were made to *Emergency Department Sickle Cell Disease: Crisis Management and Beyond* website. Specifically, we

added a “Contact Us” tab which sends an email directly to the project and website Lead. We also re-organized the website quick-link “Tabs” to include: Home, Educational Resources, Pain/Case Management, Treatment Algorithms, ED-SCANS, References and About Us. The educational content was re-structured under the Educational Resources Tab to make it easier for users to distinguish the location of the topic-specific educational modules and SCD-relevant expert lectures from previously held SCD conference offerings. As recommended by the participants, we added the link to the National Heart, Lung, and Blood Institute (NHLBI) recent recommendations for the management of SCD to the Home page of the website (<http://www.nhlbi.nih.gov/health-pro/guidelines/sickle-cell-disease-guidelines>). In regards to the individual educational modules, we re-formatted the slides of all of the modules to provide consistency, and updated and enhanced the references for each module. To enhance the modules, a video that existed previously on the website (CRISIS: Experiences of People with Sickle Cell Disease Seeking Health Care for Pain) was embedded into the relevant education module (Sickle Cell Pain). Also, new videos were filmed and added to two of the existing modules which were without interactive visual content prior to the project.

In response to the participant suggestions for additional modules, we developed four new SCD educational modules: Pain Management, Fever, Stroke, and the High User Patient. These modules are consistent with the previous modules in their format, learning objectives and pre- and post-test questions. The new modules were enhanced with five-minute video clips which were developed and filmed to demonstrate the assessment and management of patients with SCD presenting with different complaints in the ED or acute care setting. Based on the evaluation responses, the website now includes a total of eight education modules, each with a short video clip.

Future directions

The *Emergency Department Sickle Cell Disease: Crisis Management and Beyond* website will continue to improve and serve as a valuable resource to HCPs who care for patients suffering from SCD. The site, especially valuable to ED clinical teams, will be disseminated via announcements at professional conferences and publications, email messaging, social media and by the content experts affiliated with the website. The site will be routinely updated with relevant conference proceedings, evidence based practice tools and emerging SCD research. Future plans include evaluation of the site by primary care providers who encounter patients with SCD, but are not SCD experts. The educational modules remain available to clinicians and educators as a resource and learning tool for continuing education of practicing HCPs and healthcare learners. The value of these modules is that they provide important knowledge about SCD, require little effort and preparation on the part of the educator/trainer and are user-friendly and readily available. Future educational modules will be considered based on user recommendations and requests.

Limitations

Limitations of the project include a convenience sample and a small sample size of healthcare providers and students. Although we obtained surveys from only nine ED

providers, we believe that the input they provided was substantive in providing future direction for the website. We chose not to collect demographic data for the website experts.

Conclusions

The Emergency Department Sickle Cell Disease: Crisis Management and Beyond website is a valuable resource for HCPs and health care students, especially those who serve (or plan to serve) in Emergency Departments, where many patients with SCD present for initial care and management. The website is a useful tool in providing education and evidence-based resources which are relevant to the care, management, and support of patients with SCD.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Website and Individual Educational Module Evaluation Plan

Type of evaluation	Description	Evaluation period	Participants (n)
Individual module knowledge assessment	2 questions per module (total=8 questions) Participants completed pretest, viewed modules, and then completed posttest.	Pre and post module review	ABSN students (pretest: n=27) (posttest: n=20) ED providers (pretest: n=7) (posttest: n=6)
Content validity assessment	Each of four modules assessed for: 1 Clarity (yes/no) 2 Accuracy (yes/no) 3 Comprehensiveness (yes/no) 4 Meet stated objectives (yes/no) 5 Relevance to ED providers (1–4, 1= not relevant, 4 = highly relevant) 6 Pre-test/post-test questions clear (yes/no) 7 Pre-test/post-test questions assessed the module objectives (yes/no)	One time after module review	SCD experts (n=2) ED providers (n=9)
Overall website content assessment	5 open-ended items on: 1 Strengths of the website 2 Opportunities for improvement 3 Strengths of the individual modules 4 Opportunities for improvement of the individual modules 5 Recommendations for additional modules relevant to ED providers	One time after website review	SCD Experts (n=2)
Overall website assessment	8 items based on Health on the Net core principles: 1 Qualifications of website authors listed 2 Information on the website complement the healthcare provider/ patient relationship 3 Privacy and confidentiality of personal data respected 4 Source of data & information clear 5 Claims made relating to the benefits and performance of the website backed up 6 Availability of email address to submit questions 7 Advertising clearly distinguished from editorial content 8 Funding sources identified	One time after website review	Website experts (n=2)

Table 2

Frequency Table for Survey Participants' Characteristics

	ED nurses	ED physicians	ABSN students	SCD experts	Website experts *
n	5 **	4 **	27 **	2	2
Gender					
<i>Female</i>	5	0	25	1	
<i>Male</i>	0	4	2	1	
Race					
<i>White</i>	5	4	21	2	
<i>African American</i>	0	0	4		
<i>Asian</i>	0	0	2		
Ethnicity					
<i>Non-Hispanic/ Latino</i>	5	4	24	2	
<i>Hispanic/Latino</i>	0	0	2	0	
Median years of experience (minimum, maximum)	23.5 (5,33)	12.5(2,20)	NA ***	26.5 (18, 35)	

* Demographic data was not collected for Website experts

** 27 ABSN students provided complete knowledge data during the pre-assessment, 20 completed the post-assessment and of those 19 provided knowledge data at both the pre and post time points. Also white nine ED providers participated, only seven provided knowledge data during the pre-assessment and six provided knowledge data at both the pre and post time points.

*** NA= Not applicable

Table 3

Knowledge Total Score: ABSN students and ED Providers

	N	Mean (SD)	Minimum	Median	Maximum
ABSN students*					
<i>Pre-test</i>	27	3.6 (1.2)	1	4	5
<i>Post-test</i>	20	6.7 (1.1)	3	7	8
<i>Mean difference**</i>	19	2.8 (1.3)	0	3	5
ED providers*					
<i>Pre-test</i>	7	4.0 (1.6)	1	4	6
<i>Post-test</i>	6	7.2 (0.4)	7	7	8
<i>Mean difference**</i>	6	3.2 (1.7)	1	3	6

Knowledge total scores were calculated as the total number of correct answers on the knowledge test with a possible range of 0–8.

* ABSN students provided complete knowledge data during the pre-assessment, 20 completed the post-assessment and of those 19 provided knowledge data at both the pre and post time points. Also while nine ED providers participated, only seven provided knowledge data during the pre-assessment and six provided knowledge data at both the pre and post time points

** the difference score was the post minus pre difference in number of correct on the test

Table 4

Content validity module evaluation by individual educational module

Modules	Frequency for yes (ED providers & SCD experts, N=8)					Pre/posttest questions assess objectives
	Clear	Accurate	Comprehensive	Meets objectives	Relevant	Pre/posttest questions clear
1. Epidemiology, genetics, patho-physiology	8	7	8	7	7	8
2. Acute chest syndrome	7	8	7	7	8	8
3. Incentive spirometry	7	8	8	8	6	7
4. Sickle cell pain	8	8	8	8	8	8

Frequency for yes answers by ED providers and SCD experts evaluating the content validity of each of the four education module.

Table 5

Website Experts' Evaluation

Health on the Net code principles	Yes
Are the qualifications of the website authors listed	1
Does the information on the website complement the health care provide/patient relationship vs. replace it?	2
Is the privacy and confidentiality of personal data submitted to the site by the visitor respected?	NA *
As appropriate, are the source and date of information on the website clear?	2
Are claims made related to the benefits and performance of the website backed up?	1
Is there an email address on the website that can be used for visitors to the site to submit questions?	0
Is advertising clearly distinguished from editorial content?	NA *
Are any funding sources for the website identified?	0

Frequency for yes answers by website experts (N=2) that the website meets each of the eight Health on the Net code principles.

* NA= not applicable