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Does Attendance at a Sickle Cell Educational Conference Improve Clinician Knowledge and Attitude towards Patients with Sickle Cell Disease?

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Abstract

Background—Sickle cell disease (SCD) is a genetic disease associated with both chronic pain and acute painful events referred to as vaso-occlusive crisis. Individuals suffer from a multitude of medical complications in addition to pain. Patients are often stigmatized as “drug-seeking” and receive inadequate pain management.

Aim—The purpose of this study was to compare clinicians’ SCD knowledge and attitudes towards patients with SCD, before attending a two-day conference on SCD (T1), to immediately post-conference (T2), and 2 months post-conference (T3).

Design—A prospective, descriptive survey design was used.

Setting/Participants—We administered surveys to assess SCD knowledge and clinicians’ attitudes towards patients with SCD at three time points: T1(N=59), T2 (N=38), and T3 (N=30). SCD knowledge was measured using a 20 item survey, and clinicians’ attitudes towards patients with SCD were measured with the General Perceptions about Sickle Cell Patients Scale which included items on four independent sub-scales: positive attitudes, negative attitudes, concern raising behaviors, and red-flag behaviors were administered. We compared changes in knowledge and attitudes scores between T1-T2 and T1-T3.

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Results and Conclusions—Overall, knowledge scores were significantly improved ($p<0.001$), as well as significantly increased between T1-T2 ($p<0.0001$), and T1-T3 ($p = 0.01$). Negative attitudes trended lower over the three time points ($p=0.07$), but a significant decrease in the negative attitudes score was only noted between T1-T3 ($Z=-2.16.17$, $p=0.03$). **We conclude** attendance at an educational SCD conference was an effective means to improve knowledge and decrease negative attitudes among clinicians. These differences were maintained at 2 months post-conference.

Keywords

Sickle cell; pain; knowledge; attitudes; healthcare providers

Background

Sickle cell disease (SCD) is an inherited condition resulting in a defective hemoglobin and is the most common genetic disorder in the United States (Creary, Williamson, & Kulkarni, 2007; Pack-Mabien & Haynes, 2009). The resulting classically shaped “sickled” red blood cells cause hemolysis, vaso-occlusion, and inflammation affecting every body system. However, the most prominent features of SCD are anemia and pain- acute and chronic. In fact, the hallmark of SCD is pain episodes or crises that can affect any area of the body where blood flows. Ballas, Gupta, and Adams-Graves (2012) agree with an earlier SCD pain description by Diggs (1956) noting sickle cell pain as typically being sudden onset in the low back, or one or more joints or extremities. It can be confined to one area or it can migrate and the pain is often continuous and throbbing. Pain episodes last an average of 9–11 days and treatment typically includes intravenous fluids and opioids (Ballas, 2007). These crises are the primary reason for care-seeking in individuals with SCD (Lattimer et al., 2010).

Unfortunately, there are no objective measures of a sickle cell pain crisis. Therefore, patients with SCD are dependent on clinicians to believe their reports of pain as credible in order to receive appropriate and timely treatment. Nurses are often the first providers to interact with patients with SCD in emergency departments (ED) and in the inpatient setting (Jenerette, Pierre-Louis, Matthie, & Girardeau, 2015), but receive very little education about SCD in their curriculum.

Because many individuals with SCD seek treatment for pain in the ED, much of the literature regarding the treatment of individuals with SCD has been focused in that area. Some providers refer to patients with SCD as “sicklers” – a term perceived as offensive to many in the sickle cell community. In an exploration of the importance of the term “sickler” and its association with attitudes and practices of ED physicians, Glassberg and colleagues (2013) found a statistically significant relationship was observed between physician negative attitudes toward individuals with SCD and the use of the term “sickler” (Glassberg et al., 2013). It is important to resolve these negative attitudes because they may influence the provision of care. Individuals with SCD reported the main reasons they delay seeking care for pain via the ED is because of the way they have been treated in the past (Jenerette, Brewer, & Ataga, 2014). For example, individuals with SCD who seek care for pain in the

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ED often experience a wait time of 25% longer than other patients (Haywood, Tanabe, Naik, Beach, & Lanzkron, 2013). An educational conference including both providers from the ED and individuals living with SCD could help to clarify perceptions associated with inappropriate labels.

Lack of knowledge of the pathophysiology, and management of both the medical and psychosocial complications may contribute to limited self-care management skills by patients and the development of negative health care provider attitudes towards patients with SCD. Negative attitudes towards persons with SCD and the perception that persons with SCD are addicted to opioids are prevalent among healthcare providers (Jenerette et al., 2015; Shapiro, Benjamin, Payne, & Heidrich, 1997) and can result in health-related stigmatization (Jenerette & Brewer, 2010). However, Haywood and colleagues (2011) demonstrated a decrease in negative attitudes immediately after viewing a video of SCD patients describing negative experiences with healthcare providers (Haywood et al., 2011). Also aimed at improving provider attitudes, our conference brought healthcare providers and individuals with SCD together in the same venue. Education and training offer an opportunity to improve the knowledge of SCD (Tanabe, et al. 2011) and may improve attitudes towards persons with SCD.

People with SCD receive care in emergency departments, intensive care units, medical units, pediatrics, surgery, orthopedics, and obstetrics. It is important for health care providers, specifically nurses, who typically receive little education about SCD, to be familiar with the complexity of caring for individuals and families with SCD. It is also important for patients and their families to understand their disease and practice appropriate self-management. Increased knowledge by healthcare providers and individuals and family members may contribute to improved hospital quality of care, morbidity, morality, and quality of life. Including both nurses and patients/families in the same educational venue provides a unique opportunity to interact and learn about the patient and family experience.

An educational sickle cell conference was provided to healthcare providers, mainly nurses, and families about the complexity of SCD. While taking advantage of the opportunity to gather healthcare providers and individuals and families living with SCD in one venue, the purpose of this study was to evaluate clinicians' SCD knowledge and attitudes towards patients with SCD before attending the two-day conference on SCD, immediately afterwards, and 2 months post-conference.

Methods

Design

Using a prospective, descriptive survey design to address the project aims, data were collected from August 2014-November 2014. Surveys measuring conference attendee knowledge of SCD and the *General Perceptions about Sickle Cell Patients Scale* (Haywood et al., 2011) were administered at three time points: T1) pre-conference attendance, T2) at the end of conference and T3) 2 months after the conference. Permission to conduct the study was approved as an exempt project by the Institutional Review Board at Duke University- the site of the conference. A waiver of written and verbal consent was granted,

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and individuals were informed participation was voluntary, and all survey responses were anonymous.

The Conference: Participants and Data Collection

A two day conference “Improving Healthcare for Individuals and Families Living with Sickle Cell Disease” was developed from experience with previous conferences and educational needs of healthcare providers (HCPs) who care for individuals with SCD. Individuals and families living with SCD also attended the conference, but were not asked to complete knowledge and attitudes surveys. Day one focused on care of adults living with SCD while day two focused on care of children and families living with SCD. Both days addressed assessment and treatment of pain and other common medical and psychosocial complications associated with SCD. The conference was marketed to healthcare providers from the local and surrounding areas near two large medical centers, both with comprehensive adult and pediatric sickle cell programs, in the southeast. Healthcare provider attendees were primarily nurses, nurse practitioners, pharmacists, social workers, and healthcare educators. All healthcare providers who attended the conference were eligible for survey participation.

We administered validated instruments (surveys) to measure changes in healthcare provider attendee attitudes towards patients with SCD and knowledge of SCD, between pre-conference attendance, immediately post conference and 2 months after the conference. Upon registration, a link to an anonymous *Qualtrics*© (Qualtrics, Provo, UT) online survey was emailed to healthcare provider registrants. Attendees who did not complete the surveys prior to the conference day were given an opportunity to complete the survey on-site, immediately prior to the start of the conference. At the end of each conference day, each provider attendee was asked to complete a paper survey (attitudes and knowledge surveys) on site. Participants completed the survey at the end of the conference (T2), only one time, even if they attended both days of the conference. SCD content to address the knowledge questions were included in presentations on both days. Two months after the conference, healthcare provider attendees were emailed a link and asked to complete the surveys the third and final time to assess knowledge and attitudes. Attendees received two email reminders to complete the final survey. Unique identifiers were not collected. Thus, a repeated measurement analysis could not be conducted.

Instruments

The survey included three sections, demographic, attitudes, and knowledge questions. Demographic questions were collected for each time point, for each survey respondent, and included race, ethnicity, type of professional training, years of experience, and number of different patients treated with vaso-occlusive crisis in their career. The *General Perceptions about Sickle Cell Patients Scale* (Haywood et al., 2011) was used to assess providers change in attitudes pre-post conference attendance. This survey was previously validated with a sample of 276 nurses and house staff working at a large, urban, academic medical center with reported Cronbach’s alpha for each of the following sub-scales derived from a principal components analysis, followed by principal axis factoring: Negative Attitudes (6 items, 0.89), Positive Attitudes (4 items, 0.85), Concern Raising Behaviors (3 items, 0.82), and Red

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Flag Behaviors (3 items, 0.76). The scale has a total of 17 items. For example, a score of 90 on the positive attitudes sub-scale reflects highly positive attitudes, and a score of 90 on the negative attitudes sub-scale reflects highly negative attitudes. Each sub-scale is scored separately, using a linear transformation, for a possible total score between 0–100, for each sub-scale. For each sub-scale, a higher score reflects a higher attitude. Only surveys with complete data were analyzed.

A 20-item, previously validated *Knowledge of Sickle Cell Disease* questionnaire was used to assess provider changes in knowledge of SCD (Tanabe et al., 2011). The questionnaire includes nine items assessing knowledge of pain assessment and treatment, or, knowledge of definitions of terms commonly misunderstood (i.e. addiction and tolerance). The original version of the survey was administered to 55 emergency department providers who attended a one day workshop on SCD. The mean (SD) pre-post conference scores showed significant improvement; pre-score: 13 (2), post-score: = 16 (2); mean difference (95% CI) 2.96 (2.36, 3.57). Scores ranged between 0–20. Unanswered knowledge questions were treated as missing data. Each answer was coded as correct or incorrect, and a total percent correct was calculated only for surveys with complete data for all 20 questions. This decision was made because we were unsure if unanswered questions were skipped by accident, or the participant did not know the answer.

Data Analysis

Descriptive statistics were used to report demographic data. Changes in attitudes and knowledge surveys were measured as a time cohort, rather than paired individual data due to subject anonymity. Paper data surveys received during the conference were manually entered into the *Qualtrics*© database. All other data were entered by each subject using the direct link to the database. Data were analyzed using SAS 9.3. Kruskal-Wallis test, a non-parametric option to a one-way ANOVA, was used to compare knowledge and attitude scores over three time points due to the small sample size. A Wilcoxon Two-Sample test was used to conduct *a priori* pairwise comparisons so as to compare knowledge and attitudes scores between T1-T2, and T1-T3. A total score was calculated for each of the attitudes sub-scales and knowledge test percent correct comparisons for each sub-scale were analyzed separately.

Results

On day one (T1) the following number of individuals/discipline attended the conference: nurses (37), nurse practitioners (10), “others” including educators and social workers (28), students (8), individuals living with SCD (15), family/community members (35), and children (2). On day two, the following individuals attended the conference: nurses (19), nurse practitioners (5), “others” including educators and social workers (14), students (10), individuals living with SCD (14), family/community members (30), and children (25). Table 1 reports demographic characteristics of the respondents who completed the knowledge and attitudes surveys at each time point. The majority of respondents were nurses.

Overall, there was a significant improvement in knowledge scores (Kruskal Wallis x^2 = 21.23, $p<0.0001$). Table 2 provides descriptive statistics for the knowledge total scores at

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each time point. There was a significant increase in overall knowledge score between T1-T2 (Z= 4.31, p<0.001), and between T1-T3 (Z= 2.4, p = 0.0125). However, there were seven questions where the T3 knowledge score was less than the baseline score (T1) suggesting not all of the information was retained over time. Table 3 reports percent correct per question and time point.

Table 4 reports differences in attitude sub-scales between T1-T2 and T1-T3. Negative attitudes trended lower across the three time points (Kruskal Wallis x^2 = 5.16, p=0.07), but a significant decrease in the total negative attitudes score was only noted between T1-T3 (Z= −2.16.17, p=0.03). No significant changes in attitude sub-scales over T1-T2 or T1-T3 were found for the other three sub-scales, positive attitudes (chi-square = 1.85, p =0.39), concern raising behaviors (chi-square = 2.10, p=0.35), and red flag behaviors (chi-square = 0.05, p=0.97).

Discussion

Our goal was to convene a sickle cell conference over two days for individuals and families living with sickle cell, healthcare providers, and community members to improve healthcare providers' SCD knowledge and attitudes towards patients with SCD. Based on attendance, we were able to bring together a diverse group of attendees that would conclude that they all learned from each other. We know healthcare providers and patients often do not interact with each other outside of the sick role within a healthcare facility. The conference provided an opportunity for these interactions to take place. Speakers, most often healthcare providers, would often be engaged with questions from individuals living with SCD, and panels of individuals living with SCD provided unique insight into their lives

SCD is a rare disease, affecting approximately 100,000 individuals in the US. For this reason and perhaps others, healthcare providers often do not receive sufficient education about SCD and its complexity. Therefore, our goal was to improve the SCD knowledge of healthcare providers who care for individuals with SCD. Overall, based on the percentage of correct knowledge questions, we were able to significantly improve knowledge from pre to immediately post conference and from pre to 2 months post conference.

Based on the percent of correctly answered knowledge questions there are some important areas of information that still need to be conveyed to healthcare providers who care for individuals with SCD. For example, the healthcare providers did not improve in their understanding of strokes in children with SCD (question 2). In fact, after the conference, fewer healthcare providers knew the following statement is false: Acute hemorrhagic stroke is more common in children than adults. Interestingly, there were a few statements wherein 2 months post-conference, the knowledge obtained was not maintained. This was the same case for statement 16: Addiction is a state of adaptation in which exposure to a drug induces changes that result in a diminution of one or more of the drug's effects over time. This statement is false. Healthcare providers improved immediately post-conference with a score of 82%, but 2 months post-conference the scores decreased to near the pre-conference percentage at 52%. Although the overall goal was achieved, it would have been ideal if knowledge of each statement post-conference was correct by at least 80%. Similarly, in a

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previous workshop aimed at determining the difference in pre-test and post-test sickle cell knowledge scores among ED providers, Tanabe and colleagues (2011) found participants scored lower on items related to pathophysiologic complications, addiction, or ED utilization. We can use these knowledge test results to identify areas where content should be enhanced and perhaps areas where boosters would be useful. Knowledge is important, but attitude may be even more important in the provision of care to individuals with SCD.

Our goal was to improve healthcare providers' attitudes towards individuals living with SCD. Our strategies to achieve this included both the content provided during the conference and the structure which included interactions between individuals living with SCD and healthcare providers, including a panel of individuals living with SCD on both days of the conference. After each panel member spoke, HCPs were invited to participate in an open question and answer session with the panel. The tool we used to measure these attitudes has four subscales. Although it would have been ideal to improve attitudes in each area, the conference did result in a significant reduction in negative attitudes from pre-conference to post-conference. Positive attitudes towards individuals with SCD trended higher over time, but not significantly. Concern raising behaviors decreased from pre-conference to immediately post conference, but then trended back up 2 months post-conference. Red flag behaviors went up from pre-conference to immediately post-conference, but decreased from pre-conference to post-conference. These trends were informative, but not significant. It is not surprising that we did not see a change in red flag behavior attitudes. One of the items on this sub-scale is related to a patient manipulating a patient controlled analgesia pump. Red flag behaviors are typically thought to be very concerning to health care providers and thus are less amenable to change.

Comparing our educational conference "intervention" to the video intervention of Haywood and colleagues (2011), who conducted a post-test only, we both had similar post-intervention negative attitude mean scores (34.9 vs. 32.3) (Haywood et al., 2011). We do not know if this significant decrease in negative attitudes will result in changes in practice that can improve outcomes for individuals with SCD.

Limitations

There are several limitations to the project. To address the threat of social desirability, the study team elected to keep all knowledge and attitudes questionnaires anonymous. It was therefore not possible to track within subjects responses. It is possible that respondents between time periods were different. However, our objective was to measure changes among attendees as a group, vs. individuals, over time. Finally, the sample size was small, especially at T3. Our sample of healthcare providers was too small to analyze the data by healthcare provider type although the majority was nurses. Future conference interventions should target larger groups of healthcare providers and perhaps consider assigning identification numbers at the time of registration that will be used to better track changes over time.

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Conclusions

Although other approaches have been used to identify and change healthcare providers' attitudes towards individuals with SCD (Freiermuth et al., 2014; Glassberg et al., 2013; Haywood et al., 2011; Haywood, Williams-Reade, Rushton, Beach, & Geller, 2015; O'Connor et al., 2014; Ratanawongsa et al., 2009), we report data from an education conference intervention that facilitated interaction among healthcare providers, individuals living with sickle cell disease, and family members as a part of enhancing sickle cell knowledge and healthcare provider attitudes. Because the intervention is successful in both improving healthcare provider knowledge and decreasing negative attitudes even with a small sample, we consider this educational conference approach as a feasible first step in closing the SCD knowledge gap of healthcare providers while also influencing their attitude toward individuals living with SCD. Future research should explore the relationship between healthcare provider attitudes, analgesic management practices, and patient reported pain relief.

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Table 1

Clinician Demographics of Survey Respondents

	Pre-conference (T1) n=59	**Immediately post-conference (T2) n=38**	**Two months post conference (T3) n=30**
Ethnicity (%)	Hispanic/Latino (4) Non-Hispanic Latino (96)	Hispanic/Latino (3) Non-Hispanic Latino (97)	Hispanic/Latino (3) Non-Hispanic Latino (97)
Race (%)	White (61) Black (34) Asian (3) Other (2)	White (59) Black (35) Asian (3) Other (3)	White (44) Black (50) Asian (3) Other (3)
Profession (%)	RN (58) NP (8) Student (10) Social worker (10) Other (14)	RN (74) NP (5) Student (5) Social worker (5) Other (11)	RN (48) NP (14) Student (4) Social worker (17) Educator (7) Other (10)
Number of years experience (mean SD)	16 (13)	19 (12)	17 (13)
Number of patients with SCD treated in career (%)	0 (18) 1–5 (21) 6–10 (18) >10 (43)	0 (14) 1–5 (28) 6–10 – (14) >10 (44)	0 (24) 1–5 (23) 6–10 (3) >10 - (50)

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Table 2

Comparison of Total Knowledge Scores between Time Periods

	Pre-conference (T1)	Immediately post-conference (T2)	Two months post conference (T3)
Total number of complete surveys	47	36	20
Median (IQR)	14; (12.0, 16.0)	18; (15.5, 19.0)	16; (14.5, 17.0)
Minimum score	9	9	11
Maximum score	19	20	18

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Table 3

Percent Correct per Knowledge Question at Each Time Point

Question	Pre-Conference (T1) % Correct	Post-Conference (T2) % Correct	Two Months Conference (T3) % Correct
1. Which of the following pathophysiologic mechanisms are associated with SCD? Hemolysis Vaso-occlusion *Hemolysis and vaso-occlusion None of the above	77%	84%	79%
2. Which of the following complications is **not** common among children with SCD? *Avascular necrosis Acute splenic sequestration Dactylitis Acute chest syndrome	49%	71%	65%
3. Acute hemorrhagic stroke is more common in children than adults. True *False	56%	58%	46%
4. Iron overload is common in all adults with SCD. True *False	56%	66%	65%
5. Patients with a hemoglobin of < 5 g/dL should always be transfused. True *False	51%	74%	64%
6. Acute chest syndrome may be associated with which of the following presentations? Shortness of breath A new infiltrate on chest x-ray Hypoxemia *All of the above	81%	100%	82%
7. Many patients with SCD experience both acute and chronic pain. *True False	88%	100%	86%
8. Which of the following pain syndromes should	85%	95%	82%

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Question	Pre-Conference (T1) % Correct	Post-Conference (T2) % Correct	Two Months Conference (T3) % Correct
warrant further investigation for the cause? Abdominal pain Chest pain Headache *All of the above			
9. Which of the following painful conditions is frequently the initial manifestation of SCD in children? *Dactylitis Acute stroke Acute splenic sequestration Arm and leg pain	32%	79%	68%
10. All children with the genotype SS should be placed on penicillin until age 5. *True False	49%	71%	75%
11. Which of the following approaches to analgesic management is considered the gold standard? *Individualized plans Nurse initiated, standing orders Individual orders by the emergency department physician None of the above	78%	92%	75%
12. Leg ulcers are more common in women than men. True *False	47%	89%	68%
13. List the most common contraindication to NSAIDS for patients with SCD. Allergy Gastrointestinal ulcers History of acute chest syndrome *Renal failure or insufficiency	56%	87%	67%
14. Long and short acting opioids have a role in the management of SCD for patients with chronic pain. *True False	98%	97%	96%
15. Methadone may be indicated for which of the	76%	75%	65%

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Question	Pre-Conference (T1) % Correct	Post-Conference (T2) % Correct	Two Months Conference (T3) % Correct
following patients: A patient with a prolonged QT interval and chronic pain A patient who cannot be managed on extended release morphine sulfate A patient who cannot be managed on hydromorphone *B & C			
16. Addiction is a state of adaptation in which exposure to a drug induces changes that result in a diminution of one or more of the drug's effects over time. True *False	50%	82%	52%
17. Using opioids to treat insomnia, anxiety, or for some other purpose than treating pain defines Chemical coping *Substance misuse Addiction Pseudoaddiction	69%	87%	67%
18. Which of the following social issues may influence patients with SCD? Poor school attendance Lack of understanding of SCA by family members Difficulty finding a physician to treat SCA *All of the above	96%	97%	100%
19. Which of the following psychological issues are **not** common among patients with SCD? *Opioid addiction Anxiety Depression Neuro-cognitive deficits	41%	76%	65%
20. Which of the following genotypes is most common and associated with more complications? SC SB^0 *SS SB^+	78%	89%	100%

*Indicates correct answer.

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Table 4

Attitude Sub-Scale Scores per Time Point

	Pre-conference (T1)	Immediately post-conference (T2)	Two months post conference (T3)
Positive (n=responses) median (IQR)	54 75.0 (60.0, 85.0)	36 80.0 (62.5,90.0)	26 75.0 (70.0, 90.0)
Negative (n=responses) median (IQR)	54 33.3 (26.7, 43.3)	36 30.0 (23.3, 40.0)	24 26.7 (23.3, 36.7)
Concern Raising Behaviors (n=responses) median (IQR)	50 45.0 (35.0, 60.0)	37 35.0 (30.0, 60.0)	24 40.0 (32.5, 60.0)
Red Flag Behaviors (n=responses) median, (IQR)	46 66.7 (53.3, 80.0)	29 66.7 (53.3, 73.3)	20 63.3 (46.7, 73.3)