UMass Chan Medical School
Tan Chingfen Graduate School of Nursing

*Individuals With Sickle Cell Disease Using SBAR as a Communication Tool: Secondary Data Analysis*

A Dissertation Presented

By

Deborah M. Jean-Baptiste

Approved as to style and content by:

_________________________________________
Maureen Wassef

_________________________________________
Susan Sullivan-Bolyai

_________________________________________
Coretta Jenerette

April 20, 2022
Date

Joan Vitello PhD, RN, NEA-BC, FAHA, FAAN
Dean & Professor
UMass Chan Medical School
Tan Chingfen Graduate School of Nursing
Table of Contents

Abstract ............................................................................................................................. 3

Dissertation Proposal ......................................................................................................... 4

Summary of Changes from Proposal ................................................................................. 34

Dissertation Defense Slideshow Presentation .................................................................. 35

Dissemination Plan ............................................................................................................. 50
Abstract

Purpose: The purpose of this study was to determine the usefulness of SBAR-cued web-based communication skills training and address study participants' perceptions of the training.

Specific Aims:
1. Evaluate the usefulness and accuracy of participants to answer prompts of SBAR-cued communication responses.
2. Describe individuals' perspectives of the acceptability of using SBAR patient-HCP communication simulation to better prepare for ED visits during a SCC.

Framework: This study was guided by The Theory of Self-Care Management for Sickle Cell Disease (SCMSCD).

Design: A secondary analysis was conducted using a qualitative descriptive approach. Inter-rater reliability (IRR) of qualitative data was used to evaluate the usefulness and accuracy of participants to answer prompts of SBAR-cued communication responses. Content analysis was also utilized to describe individuals' perspectives of the acceptability of using SBAR patient-HCP communication simulation to better prepare for ED visits during a SCC.

Results: IRR between raters ranged from 64%-94% with predominant themes of (1) Patient-Provider Communication and Interaction, (2) Patients want to be Heard and Believed, (3) Accuracy of the ED Experience and Incorporating the Uniqueness of each Patient and (4) Overall Usefulness of the Video Trainer emerging.

Conclusions: This secondary analysis supported how SBAR can be effectively used to assist patients in a SCC to communicate with their HCP. Participants' responses indicated the training module facilitated communication between patients and HCPs.
Introduction

Sickle cell disease (SCD) presently affects approximately 100,000 Americans (Centers for Disease Control and Prevention [CDC], 2020). African Americans have the highest prevalence of SCD. One in every 500 African Americans is born with SCD, and one in every 12 African Americans is born with the sickle cell trait (CDC, 2020). SCD typically presents as chronic pain that can be exacerbated by acute episodes known as sickle cell (SC) crisis, to which pain management is the cornerstone of care (Sedrak & Kondamudi, 2020). However, patients who present in the emergency department (ED) during a crisis frequently report delays in care (Matthie & Jenerette, 2015). This delay in care often stems from a lack of clear communication regarding healthcare needs between the patient and the healthcare provider (HCP; Rhee et al., 2019). During a SC crisis, it is imperative that patients communicate their symptoms and needs clearly to their HCP to avoid any delay in receiving appropriate treatment.

Many patients with SCD report dissatisfaction with the quality of care they receive (Haywood et al., 2014). Communication with their HCP has been identified as an essential element of quality care among patients who have SCD (Haywood et al., 2014). The literature suggests that poor communication between this patient population and HCPs may be due to a variety of factors. These may include the provider’s lack of knowledge about the disease progression, and the lack of objective assessment findings, including the subjective aspects of pain perception. An additional factor may revolve around possible stereotypical perceptions within the healthcare system. One common bias about this patient population includes pain management-seeking behavior (commonly referred to as drug-seeking behavior), which also serves as a barrier to effective communication (Sinha et al., 2019). It is important that
patients with SCD articulate their healthcare needs to the provider, especially in acute scenarios. This is essential in avoiding a delay in care. It also potentially impacts healthcare outcomes. A gap in the current literature exists in the communication between this population of patients and their caregivers, especially in acute or emergent situations.

The Self-Care Management for Sickle Cell Disease (SCMSCD) Theory (Jenerette & Murdaugh, 2008) can provide guidance regarding the use of effective communication with the ultimate outcome of maximizing patient health and well-being. One of the most crucial stages in this theory is understanding what makes a population vulnerable and how self-care practices influence outcomes. In this model, it is proposed that a relationship may exist between clear communication with HCPs and self-care practices. Further, these self-care practices will increase the likelihood of improving overall health outcomes. Clear communication between patients and HCPs could be essential in empowering these individuals and therefore promoting their self-care practices. According to the SCMSCD, communication is a self-care management resource. Self-care management resources provide a link between the factors that promote negative outcomes and the factors that promote positive outcomes (Jenerette & Murdaugh, 2008).

Use of the SBAR (Situation, Background, Assessment, Recommendation) communication tool has been investigated in an attempt to streamline communication between patients and their providers. SBAR is typically used by HCPs to communicate relevant patient information or updates in status with other HCPs and members of the healthcare team. It is widely used and accepted in healthcare and has been shown to be effective in relaying important information in an organized easy-to-understand format (Institute for Healthcare Improvement [IHI], 2019). An unpublished pilot study conducted by
Dr. Jenerette investigated the utility of the SBAR format for SCD patients to optimize communication with their HCPs (Jenerette, 2017). That team evaluated a web-based learning and coaching program using SBAR. No known published studies to date have attempted to apply the SBAR communication format to the patient-provider scenario. The purpose of this current study is to analyze the data from that pilot study to determine the usefulness of SBAR-cued communication responses and to address study participants’ perceived perspectives on using SBAR as a tool to improve communication with a HCP during a SC crisis. The specific aims are the following:

Aim 1: Evaluate the usefulness and accuracy of participants to answer prompts of SBAR-cued communication responses.

Aim 2: Describe individuals’ perspectives of the acceptability of using SBAR patient-HCP communication simulation to better prepare for ED visits during a SC crisis.

**Background and Significance**

**Sickle Cell Disease**

SCD is a chronic congenital blood disorder characterized by periodic episodes of acute pain (Pulte et al., 2016). It is caused by mutations in the gene encoding the hemoglobin subunit β. This mutation causes blood cells to form into a sickle shape rather than the usual round cell. This sickling makes vascular circulation difficult, which results in pain (Ware et al., 2017). SCD is one of the most common genetic diseases in the United States. Approximately one in 500 African Americans is affected, with about one in 12 African Americans carrying the autosomal recessive mutation (Sedrak, & Kondamudi, 2020).

SCD affects almost every body system. Acute pain is the hallmark of this disease secondary to vaso-occlusion, which causes decreased oxygen to body systems. This can lead
to blood clots, infections, anemia, and organ failure. Chronic manifestations include long-
term damage to organ systems, which results in organ dysfunction over the patient’s lifespan
(Ware et al., 2017). This is the main cause of morbidity and mortality in this disease.

According to Xu et al. (2020), psychological stress can cause vaso-occlusive crisis
(VOC) in patients with SCD. Although the mechanism is not completely understood, Xu et
al. discuss the connection of stress and intestinal permeability that facilitates the expansion
of aged neutrophils and vaso-occlusion. During a VOC, or acute pain crisis, patients
experience severe pain episodes along with ischemia, tenderness, fever, hand-foot syndrome,
priapism, and chest pain (Verghese et al. (2019).

Presently, clinical trials are being conducted of revolutionary gene therapy that
include bone marrow transplant, stem cell transplants, and genotype modification (Salinas et
al., 2020). Other treatment modalities include medications and blood transfusions. Bone
marrow from a matched sibling donor is transplanted and begins to produce healthy blood
cells, which prevents VOC and facilitates healthy organ function. Stem cell transplants use
autologous cells that have undergone genetic manipulation to prevent sickling. Biologic
medications have also shown promise in reducing VOC (Salinas et al., 2020). Hydroxyurea is
used often in the treatment of SCD. Studies have shown the use of hydroxyurea decreases
episodes of acute crisis, reducing the need for hospitalization and blood transfusions by
aiding the body in producing fewer sickle-shaped blood cells (Rigano et al., 2018). Blood
transfusions are used to increase the number of healthy round blood cells in circulation
(Kapoor et al., 2018). More common treatment modalities are predicated on preventing
complications. Opioid analgesics are used for pain. Several patient self-care modalities, such
as heat, rest, hydration, decreasing stress, and balanced diet, can assist in treatment management as well as preventing an acute crisis (Matthie & Jenerette, 2015).

Patients who are experiencing a sickle cell crisis often present to the ED when their symptoms are no longer manageable at home (Pulte et al., 2016). The pain in SCD patients is described as ongoing on most days over the past 6 months with one of the following: pain sensitivity with palpation or movement, decreased range of motion or weakness in the painful region, or evidence of chronic disease complications associated with pain (Kingsley, 2020). Patients who present to the ED often receive delayed care, and lengthy hospitalizations. A perceived disconnect exists between observed pain behavior and the subjective pain report in the HCP’s assessment of these patients (Kingsley, 2020). This is likely due to biases and stigma associated with this population (Jenerette & Brewer, 2010). A study conducted by Evensen et al. (2016) revealed that 83% of participants with SCD reported past negative experiences in the ED when they sought care, which led to their decision to delay care.

**Bias and Stigma**

The literature suggests racial biases play a significant role in the care this population receives (Wakefield et al., 2017). One systematic review conducted by Bulgin et al. (2018) illustrated that stigma against patients with SCD interfered with their psychological and physiological well-being, had negative social impacts, and impaired interactions between patients and the HCP. That review also revealed that stigma was influenced by several factors including disease status, opioid use, racism, and sociodemographics, which further served to promote negative consequences such as decreased patient well-being, poor disease care and management (Bulgin et al., 2018).
Patients with SCD overwhelmingly report biases and stigma when seeking care for their illness. They report stress, sadness, and anger associated with their interactions with HCPs secondary to racial bias (Wakefield et al., 2017). These patients may also be perceived as pain-medicine-seeking by HCPs who have negative biased attitudes surrounding pain and pain management leading to improper assessments and management of these patients. As a result, patients with SCD report discrimination by HCPs such as poor treatment and feeling like their concerns are not prioritized (Jenerette et al., 2015). Therefore, by providing individuals with SCD more efficient and effective communication skills, they may be better able to self-advocate and feel less victimized.

**Communication**

Poor communication in the healthcare setting has been linked to poor outcomes, leading to misdiagnosis, errors, and increased patient mortality (Müller et al., 2018). According to Müller et al., lack of communication was cited by the Joint Commission as a major cause of adverse events in the hospital setting in more than 60% of the records they reviewed. The causes of these poor communication strategies are likely multifactorial. Kostoff et al. (2016) describe poor communication as the product of complex healthcare systems, interdisciplinary teams that use varying communication methods, organizational and disciplinary hierarchies that stifle communication, and frequent changes within the system to accommodate changes in the research. In addition to poor communication issues between HCPs, failure to communicate between patients and HCPs may also be a source of these adverse events.

In contrast, effective communication between patients and HCPs has shown to lead to positive outcomes. A systematic review conducted by Howick et al. (2018) found positive
HCP-patient communication can benefit patients, especially those with pain. According to Howick et al., a link exists between self-efficacy and patient-provider communication. As a large portion of SCD care is predicated on self-care, this could suggest that effective communication between the HCP and their SCD patients can facilitate increased patient outcomes (Chan et al., 2015).

Patients with SCD describe difficulty communicating with their HCP, even when factors like race, socioeconomic status, health status, age, and education were controlled for (Jenerette et al., 2015). These patients are less likely to feel respected and heard (Haywood, 2014). This leads to patients who are less likely to receive chronic disease management care and more likely to visit emergency services secondary to lack of chronic disease management care (Sinha et al., 2019).

African American patients are at higher risk for poor outcomes. Valente et al. (2020) found that African American patients had higher rates of hospital readmissions than their white counterparts even though they had the same follow-up care via a primary care provider (PCP). Valente et al. found that the transition period between the acute care phase and the chronic disease management phase was critical in aiding to reduce readmissions. According to Sullivan (2020, p. 18), “Trust is often regarded as the central feature of the physician-patient relationship.” Patients stated they did not trust the PCP or HCP to effectively understand the barriers they face and attributed this to racial bias (Rhee et al., 2019).

According to Arnett et al. (2016), medical mistrust is a source of care disparity. This medical mistrust accounts for higher rates of ED utilization, lower rates of preventative care, and less health maintenance behaviors (Arnett et al., 2016). This mistrust stems from the troubled history of race relations in this country and has bled into the physician-patient relationship,
thereby impeding the care physicians can provide and the care patients can receive. This is seen as an institutional rather than an individual problem, thus contributing to its persistence (Evans et al., 2020). The HCP did not feel as though African American patients wanted to effectively partner with them in their care (Valente et al., 2020). Valente et al. further found that adequate engagement on both sides was paramount in facilitating effective communication.

Communication styles and techniques greatly impact patient outcomes. When psychosocial needs are met, care is more effective. When care is tailored to patient needs, long-term goals are more likely to be met (Jager et al., 2017). Effective communication has the potential to minimize errors and hesitancy for these patients to seek care, thereby reducing poor outcomes (Haywood et al., 2014).

In order to aid in effective communication, an organized, easy-to-understand approach delivers important information, decreases errors, and is vital to patient care. SBAR offers this approach and is widely used among HCPs. SBAR allows for the transfer of vital information in a logical and systematic manner. Furthermore, because of its simplicity and universal understanding, it eliminates confusion between the sender and receiver of information. The use of SBAR increases patient safety (Müller et al., 2018). Implementing SBAR as a communication strategy with pharmacy students in order to improve patient safety is discussed by Franko et al. (2020). Effective communication techniques can be taught, and the literature suggests that when a focus on communication exists in training programs, nursing students report more comfort and open acknowledgment of areas that need improvement (Foronda et al., 2016).
**SBAR**

SBAR is a communication tool that is traditionally used between HCPs to communicate patient status (Institute for Healthcare Improvement, 2019). The acronym SBAR stands for Situation, Background, Assessment, and Recommendation. This tool offers a standardized technique that promotes safe and effective communication that occurs in a timely fashion. SBAR, table 1, is an evidence-based tool that allows for clear and effective communication regarding the patient’s condition (Jurns, 2018). The SBAR tool has been shown to be effective with patient handoffs and transmitting pertinent information (Shahid et al., 2020). The cause of communication barriers is multifactorial. One factor is the complexity of the information. The literature suggests that, even among HCPs, there is a lack of understanding of the components of SBAR especially if the tool is not consistently used in that setting. This implies training increases compliance and improves understanding of the tool (Shahid, & Thomas, 2018).

SBAR was created by clinical staff at Kaiser Permanente in Colorado in the late 1990s (Institute for Healthcare Improvement, 2019). It offers a framework that provides critical information in an easy-to-remember and understandable way, allowing for HCPs to focus on an area that needs immediate action and communicate with other HCPs (Institute for Healthcare Improvement, 2019). The original use was to focus on HCP-HCP communication. SBAR has been used in a limited capacity with HCP-patient communication. The literature does suggest, anecdotally, that SBAR can be taught to patients with SCD as a tool to aid in communication especially in emergency situations (Denham, 2008). Jenerette and Brewer (2011) further suggest that SBAR should be further adopted by HCPs to educate patients with chronic disease. A gap needs to be filled in the research that examines best practices.
regarding how patients with SCD effectively communicate with their HCPs. Most of the research seems to be predicated on the communication styles of only the providers. Investigation is warranted in the feasibility of providing the patient with similar tools to better communicate their healthcare needs.

**Theoretical Framework**

The framework (Figure 1) that will guide this study is the Theory of Self-Care Management for Sickle Cell Disease (SCMSCD) developed by Jenerette and Murdaugh in 2008. This theoretical framework will serve as a guide to understanding the role that self-care and communication play in management of SCD. This theory was adapted from the middle-range theory Self-Care Management of Vulnerable Populations (Dorsey & Murdaugh, 2003). The SCMSCD describes how vulnerability factors such as socioeconomic and health needs factors negatively affect outcomes (Jenerette & Murdaugh, 2008). Conversely, health outcomes are positively impacted by self-care management resources. Included in self-care management practices are communication skills. SCMSCD supported the hypothesis that self-care management influences the relationship between vulnerability and health outcomes (Jenerette, & Murdaugh, 2008).

This theory has been used in the literature to support the use of self-care and its influence on health outcomes in this population. Crosby et al. (2020) noted that low efficacy was associated with poor outcomes and high efficacy was associated with improved outcomes in adolescents with SCD. A study conducted by Curtis et al. (2019), which discussed the usefulness of a medication administration app for children with SCD, used this theory to form participant questions regarding their perceptions about their SCD and its management. Within the SCMSCD Theory, communication is identified as a self-care
management resource. Furthermore, it is proposed that self-care management resources are positively associated with health outcomes. Based on this theoretical premise, providing the patients with tools to promote communication with their HCPs will positively impact their health outcomes.

**Description of Parent Study**

The parent study was a cross-sectional descriptive study with the purpose of educating patients with SCD to express their healthcare needs during a SC crisis. Dr. Coretta Jenerette, the principal investigator (PI), conducted a pilot study to evaluate a web-based learning and coaching program using SBAR. The aims for the parent study included the following:

- Train patients with skills to improve patient-provider communication so that patient needs will be met.
- Pilot and evaluate the web-based learning and coaching program with at least 50 participants.

The parent study was guided by the SCMSCD Theory (Jenerette & Murdaugh, 2008). Its setting was the University of North Carolina (UNC) School of Medicine-Comprehensive Sickle Cell Program Clinics. Approval for the parent study was obtained from the Institutional Review Board (IRB) of the UNC at Chapel Hill. The participants were recruited using a convenience sample. The clinic roster included 400 patients, and the patients were chosen during a clinic day. Patients who fit the criteria were selected by clinic staff and were approached by the study team members for recruitment. Inclusion criteria included (a) diagnosis of sickle cell disease, (b) 18 years of age or older, and (c) able to read, write, and
understand English. All patients who met the inclusion criteria were included. A total of 31 participants were recruited.

Eligible adult patients were recruited by a member of the study team during a clinic appointment. Informed consent was explained. Participants were advised that their involvement was voluntary, they could withdraw at any time, and participation would not influence their care. Informed verbal consent was obtained prior to participation. A $25 gift card was provided as compensation for participation. The participants’ names were collected, and they were also assigned a study number to protect confidentiality. The study number was kept with audiotape and transcription data. The PI maintained the list of participant names and demographics separately and securely.

The data were collected by the study team using a Qualtrics online survey to obtain demographics and then the Project Sickle Cell SBAR website for the intervention and post-intervention survey. This website was created by the research team for the purpose of the parent study. The participants completed the study activities before or after their clinic appointment in a private area. The web-based activity recorded an audio response from the participants’ responses to communication questions that simulated a SC crisis event.

The study included web-based training, video vignettes, and coaching to teach the participants how to use SBAR as a communication tool during a SC crisis. The participants were given information and educated about the use of each component of SBAR. They were shown a video of an interaction with and without the use of SBAR. After the video training, they were able to practice their skills. They were asked to imagine they presented to the ED during a crisis. The HCP in the scripted video discussed with the participant an aspect of their care, followed by HCP-patient communication, using each component of SBAR to
stimulate the conversation. Table 2 describes the HCP communication and a prompt to aid the participant in responding to the interaction using the appropriate SBAR component. Table 3 describes the qualitative question posed after the virtual training activity.

Table 2 outlines what information the participant was given to prompt their response to each component of SBAR. The data set consists of the transcribed recordings of their responses to each part of SBAR and the scenario provided. Five pieces of qualitative data for each participant were contained with the transcript. Included were the questions to each component of SBAR as well as the response to the post-intervention survey.

**Methodology of Current Study**

This secondary analysis of qualitative data will utilize a qualitative descriptive approach. According to Beck (2019, pp. 35) secondary data analysis is defined as the use of existing data to ask a new question or a question that differs from the primary study. To address the specific aims of this study, interrater reliability (IRR) of qualitative data and content analysis will be utilized.

**Aim 1:** Evaluate usefulness and accuracy of participants to answer prompts of SBAR-cued communication responses.

This study aim will be addressed through the use of IRR of qualitative data. According to Sandelowski et al. (2009), quantizing of data facilitates the understanding of patterns and verification of interpretations. IRR measures the level of agreement between two to three, (2–3), raters to determine the agreement and accuracy of items used (McHugh, 2012). IRR also measures the level of consistency between raters (Gisev et al., 2012). Using a scoring system, raters will analyze the data and assign a numeric score. Using statistical analysis software, the researcher will determine the IRR and therefore the level of agreement.
between raters indicating the usefulness of the SBAR communication. The parent study PI (Dr. Jenerette), the doctoral student/researcher of this study, and the committee chair of this dissertation will be known as the raters.

Using a numerical system to assess the first aim using IRR will determine if the participants of the parent study correctly used SBAR in each scenario. This method has been used in the literature to provide numerical data to qualitative data and facilitate IRR. Wassef et al. (2015) created a scoring system based on a theoretical framework to assess affective learning based on reflective journals of nursing students. This allowed for multiple researchers to analyze the data and assign scores, which were then compared. McDonald et al. (2019) discuss IRR as establishing agreement between two researchers in qualitative data. Using a scoring method in this study will allow for the same level of analysis of the data. This will provide an understanding of whether learning occurred.

In IRR of qualitative data, a theoretically supported coding system is developed to guide the raters in their analysis of each response (Tables 4 and 5).

**Aim 2:** Describe individuals’ perspectives of the acceptability of using SBAR patient-HCP communication simulation to better prepare for ED visits during a SC crisis.

Using a qualitative content analysis of the data, themes will be analyzed and guided through the lens of the study’s theoretical framework and specific aims.

IRB approval will be obtained through the University of Massachusetts Medical School (UMMS) prior to the transfer of data.

**Data Management**

De-identified data will be transferred using the secure data transfer service at UMMS through a program called MoveIT. This allows for entities not affiliated with UMMS
to securely share data. An account will be created for both the sender and receiver of this data. The data will then be transferred within 10 days. Data will be stored on the UMMS secure and encrypted server. This is managed by UMMS and is backed up daily. The dataset will be returned the PI of the parent study upon conclusion of the study.

**Data Analysis**

The first part of the analysis will use IRR of qualitative data to evaluate the usefulness and accuracy of participants to answer prompts of SBAR-cued communication responses using a formula outlined by Miles and Huberman (McAlister et al., 2017; see Figure 2).

**Figure 2**

*Formula Used by Miles and Huberman to Determine Interrater Reliability (IRR) Among Two or Three Raters*

\[
\text{reliability} = \frac{\text{number of agreements}}{\text{number of agreements} + \text{disagreements}}
\]

(McAlister et al., 2017)

This approach was outlined by McAlister et al. (2017) to determine IRR using three raters. This calculation is a method to measure consistency, or IRR, between raters. Raters will be Deborah M. Jean-Baptiste (the researcher/doctoral student), Dr. Coretta Jenerette (PI of the parent study), and Dr. Maureen Wassef (Committee Chair of this dissertation). Descriptive statistics will be performed on the available demographic data of the participants.

The raters will use an exemplar and best practices for using the SBAR tool to determine whether the parent-study participant answered the component of SBAR correctly by assigning a score to each response. The raters will use the participants’ answers to SBAR
prompts to determine if the component of SBAR had been answered. These best practice exemplars were determined from the literature regarding the use of SBAR as well as the prompts provided to the participants (Table 5).

A pilot study will first be conducted on three participant transcripts selected at random and scored by the three raters to establish reliability and ensure consistent procedures between raters, answer questions, and address any potential problems (McAlister et al., 2017). This initial scoring will allow each rater to compare their scoring using the best practice exemplar and ensure that instructions are understood. This data will not be included in the final analysis.

Based on the results of this process, any changes to the procedure or clarification to the coding system will be conducted and documented. This will be followed by all three raters scoring the remaining 28 participant transcripts. In order to score the data, each component of SBAR will be evaluated for each participant on a scale based on how the component of SBAR was answered. Zero (0) would indicate the participant did not respond using SBAR. One (1) indicates they addressed the component of SBAR correctly. This will also provide a composite score for each participant. This composite score will be determined by adding up the score they receive for each component of SBAR. This composite score would be between 0–4. IRR will be determined for this composite score as well. According to Miles and Huberman, an IRR of 80% agreement between raters on 95% of the scores is sufficient agreement among multiple coders (McAlister et al., 2017).

Qualitative content analysis (Hsieh & Shannon, 2005) will be used to analyze the open-ended qualitative data.
1. The researcher will begin by reading the entire transcript several times to immerse herself in the data.

2. Codes will be derived by identifying words that capture important concepts.

3. The researcher will read through the text, taking note of first impressions and initial analysis. As the researcher continues reading, labels will emerge for codes that encompass complex thoughts.

4. These codes will then be categorized based on whether and how they are related.

5. These categories will be further coded into meaningful groups. These groups will be used to cluster similar codes.

6. If appropriate, based on the coding, categories may be grouped into subcategories based on their relationships with one another.

7. These categories will be defined.

8. The researcher will use exemplars from the data to support the categories and subcategories.

These codes will initially be guided by Jenerette’s SCMSCD Theory. The final result will be a rich summary of the perspectives of the participants.

**Reflexivity**

According to Palaganas et al. (2017), reflexivity addresses the changes and challenges that the researcher may experience during the research process based on their own beliefs and experiences. The researcher has the potential for bias as she is a primary care provider and treats this population in another facility. The researcher also recognizes her personal connection with sickle cell as she has family members who have suffered with this illness. To deal with the potential bias, the researcher will write a self-reflexive journal of notations,
feelings, potential biases, and other observations, which she will review during the entire data analysis process.

**Trustworthiness**

This proposal will use the standards of trustworthiness described by Lincoln and Guba (1985) to establish validity and reliability. Lincoln and Guba describe four standards of trustworthiness, which include credibility, transferability, dependability, and conformability. When conducting this analysis, these standards will be applied in order to ensure the rigor of the study:

Credibility (similar to internal validity, truth of data) ensures the readers’ perspective aligns with the participants’ views; meaning the interpretations are viewed in a similar way (Lincoln & Guba, 1985). Due to this being a secondary analysis, member checks will not be possible. However, peer debriefing with a colleague researcher who is not involved in the study will be done in order to discover any potential coding biases. Dr. Susan Sullivan-Bolyai will perform debriefing.

Transferability refers to whether the analysis might be applicable to others. A rich description of the findings will be presented to establish that others reading the results can determine if the findings are transferable to their area of clinical interest. This description includes the sample size and demographics, setting, and data collection process.

Dependability, similar to reliability, ensures the process used to analyze the data is sound and whether the process is clearly documented (Lincoln & Guba, 1985). The researcher will provide detailed information and meticulously follow/record the procedure/data management keeping an audit trail to ensure this study has the ability to be replicated and generalized, at least in this population.
Confirmability is demonstrated when dependability, credibility, and transferability are achieved (Lincoln & Guba, 1985). The “audit trail” during this study will serve to support confirmability.

**Conclusion**

This study has the potential to inform future studies regarding the communication styles of patients with SCD, especially when they are most at risk, during a SC crisis. It allows researchers as well as clinicians to understand how to use communication to improve outcomes in this patient population.
References


Centers for Disease Control and Prevention (CDC). (2020). *Sickle cell disease (SCD)*. Data and statistics on sickle cell disease. CDC.


Table 1

*Explanation of Use of the SBAR Tool*

<table>
<thead>
<tr>
<th>Questions</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>S—Situation</strong></td>
<td>What is happening? What is the current situation regarding the patient status?</td>
</tr>
<tr>
<td><strong>B—Background</strong></td>
<td>What is the background of the patient or situation? What are the details of the acute problem?</td>
</tr>
<tr>
<td><strong>A—Assessment</strong></td>
<td>What is the problem?</td>
</tr>
<tr>
<td><strong>R—Recommendation</strong></td>
<td>What is the next step?</td>
</tr>
</tbody>
</table>

SBAR: Müller et al. (2018)
<table>
<thead>
<tr>
<th>SBAR Component</th>
<th>HCP Interaction/statement</th>
<th>Prompt regarding how patient would respond using SBAR component</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Situation:</strong></td>
<td>What brought you in today?</td>
<td>You will describe the interaction in a few words. Include that you have SCD and your pain score on a scale from 0–10. Remember, you didn’t wait until your pain was 9 or 10 before you sought care. Remember to include the location of the pain.</td>
</tr>
<tr>
<td>Pretend you are a patient with SCD, seeking care in the ED. You have a pain crisis. The doctor came in to assess you.</td>
<td>“Most sicklers come in with pain at 9 or 10. I need to examine and decide what to do next.”</td>
<td>You will describe the background in a few words. Remember to include anything about the normal course of your pain crisis and what you tried before coming to the ED.</td>
</tr>
<tr>
<td><strong>Background:</strong></td>
<td>“Your vitals look good. You say you already tried pain pills?”</td>
<td>You will describe the assessment in a few words. Explain what you think is going on. Include what you think is going on and anything about the normal course of your pain crisis.</td>
</tr>
<tr>
<td>Pretend you are a patient with sickle cell, seeking care in the ED. You have a pain crisis. The doctor came in to assess you.</td>
<td>“We try to see the sickest patient first and you don’t look that bad. I noticed you were listening to music when I came in.” “You look pretty good, and when I came in you were listening to music.”</td>
<td>Include your recommendation for what should happen next. Explain in a few words why you were listening to music (or what ever you might do as distraction) Add your goals for discharge and your desire to go home if possible.</td>
</tr>
<tr>
<td><strong>Assessment:</strong></td>
<td>“We try to see the sickest patient first and you don’t look that bad. I noticed you were listening to music when I came in.” “You look pretty good, and when I came in you were listening to music.”</td>
<td>Include your recommendation for what should happen next. Explain in a few words why you were listening to music (or what ever you might do as distraction) Add your goals for discharge and your desire to go home if possible.</td>
</tr>
<tr>
<td>Pretend you are a patient with sickle cell, seeking care in the ED. You have a pain crisis. The doctor came in to assess you.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Table 2**

*Participant Prompts*
## Table 3

*Qualitative Posttraining Question*

<table>
<thead>
<tr>
<th>Qualitative survey question</th>
<th>Tell us anything you would like to share about this communication skills website using video and the trainer</th>
</tr>
</thead>
</table>
Table 4

*IRR Sheet*

<table>
<thead>
<tr>
<th>SBAR participant #1</th>
<th>Debora Jean-Baptiste Rating</th>
<th>Coretta JeneretteRating</th>
<th>Maureen Wassef Rating</th>
<th>IR R</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>S (0–1)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>B (0–1)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>A (0–1)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>R (0–1)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Composite (0–4)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 5

*Exemplars for IRR*

<table>
<thead>
<tr>
<th>Component</th>
<th>Exemplar, or identify best practice criteria from literature</th>
</tr>
</thead>
</table>
| S         | Participant identifies specific problem, symptoms or situation that brought them into the ED.  
**Exemplar:** Disclosed diagnosis of sickle cell, pain score, and location of pain |
| B         | Participant identifies the relevant details or history.  
**Exemplar:** Described the normal course of crisis and interventions attempted before coming to the ED. |
| A         | Participant discusses their impression of what is happening.  
**Exemplar:** Explained what they believe is happening. |
| R         | Participant discusses what their current needs are and why/how this would address the current problem.  
**Exemplar:** Discuss past pain-relieving interventions, goals for discharge, and expectations for care. |
Figure 1

*The Theory of Self-Care Management for Sickle Cell Disease (SCMSCD)*

(Jenerette & Murdaugh, 2008)
Summary of Changes from Proposal

No changes were made to the original study proposal.
Introduction

- Sickle Cell Disease (SCD) is a hemoglobinopathy and the most common genetic disease in the United States, affecting 1 in 500 African Americans.
- Blood cells form a sickle shape rather than a round cell causing them to stick to one another in the vascular space.
- The hallmark of this disease is acute/chronic pain and pain management is the cornerstone of care during a sickle cell crisis (SCC).
- Many patients report dissatisfaction with their care specifically in the area of pain management.
- Patients with SCD also report delays in treatment and symptom management that stem from poor communication with the healthcare provider (HCP).
Background and Significance

- Literature suggests stigma and racial biases may also play a role in the care this population receives
  - Patients with SCD report stress, sadness, and anger associated with the interactions with their HCP
  - Patients often perceived as med seeking by HCP who have negative attitudes or lack of knowledge surrounding disease process

Communication

- Poor communication with the HCP
  - Linked to poor healthcare outcomes, misdiagnosis, errors and increased patient mortality
  - Potential for poor communication escalates when patient is in an acute sickle cell crisis (SCC)
- Effective communication
  - When patients can effectively communicate with HCP and express their needs, this can lead to improved health outcomes and effective pain management
• Standardized Communication tool used to communicate patient status between healthcare providers
• SBAR
  • Situation
  • Background
  • Assessment
  • Recommendation
• May be effective as tool to facilitate patient provider communication
• The use of SBAR for patients provides a clear, easy to understand template for use by patients.
• Improving communication potentially improves outcomes

---

**Explanation of Use of SBAR Tool**

<table>
<thead>
<tr>
<th>Questions</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>S</strong>—Situation</td>
<td>What is happening?  What is the current situation regarding the patient status?</td>
</tr>
<tr>
<td><strong>B</strong>—Background</td>
<td>What is the background of the patient or situation?  What are the details of the acute problem?</td>
</tr>
<tr>
<td><strong>A</strong>—Assessment</td>
<td>What is the problem?</td>
</tr>
<tr>
<td><strong>R</strong>—Recommendation</td>
<td>What is the next step?</td>
</tr>
</tbody>
</table>

First, the speaker discusses the situation. Identifies self and the patient. Describes the problem/situation.

The speaker describes the history such as the patient’s diagnosis or reason for admission, medical status, and relevant history.

Then specify information on vital signs, recent labs, and other information regarding patient status. Speaker may disclose their impression of the problem.

Current needs are expressed. Included are what is needed and why to address the current problem.

SBAR: Müller et al. (2018)
The purpose of this study was to determine the usefulness of SBAR-cued web-based communication skills training and address study participants' perceptions of the training using a secondary data analysis.

**Purpose of This Study**

Theory of Self-Care Management for Sickle Cell Disease

![Diagram of self-care management factors and outcomes](image)

- Vulnerability Factors
  - Complications
  - Lack of Sickle Cell Crisis Cue
  - Recognition/Response
  - Crises per Year
  - Overprotection

- Health Outcomes
  - Health-Related Quality of Life
  - Depressive Symptoms
  - Self-Esteem
  - Pain Management Experience
  - Health-Related Stigma

Self-Care Management Resources
- Assertive Communication Skills
- Coping Behaviors
- Self-Care Ability
- Self-Care Actions
- Self-Efficacy
- Social Support

Jenerette & Brewer (2010)
The primary purpose of the parent study was to educate patients with SCD to communicate their healthcare needs during a SCC guided by the SBAR standardized communication tool.

- Participants completed web-based training, video vignettes and coaching.
- Participants utilized components of SBAR as they responded to clinically based prompts.
- A convenience sample was recruited from a southeastern outpatient sickle cell program.

Aims of parent study:

- Train patients with skills to improve patient-provider communication so that patient needs will be met.
- Pilot and evaluate the web-based learning and coaching program with at least 50 participants.

Data consisted of the transcriptions of audio recording:

- Participant’s responses to the clinically based prompts using SBAR.
- Participant’s responding to open ended question regarding perceptions of training.

Participants reviewed web-based trainer and coaching regarding the use of SBAR.

- After training participants viewed video vignette’s of simulated ED SCC scenario.
  - Asked to imagine they were seeking care in the ED during a SCC.
  - Respond to simulated provider response for each component of SBAR.
- Responded to SBAR components via recordings.
- Post training they responded to open ended qualitative question regarding the use of the trainer.
Specific Aims for the Current Study

**Aim 1**
Evaluate the usefulness and accuracy of participants to answer prompts of SBAR cued communication responses.

**Aim 2**
Describe individuals’ perspectives of the acceptability of using SBAR patient-HCP communication simulation to better prepare for ED visits during a sickle cell crisis.

Methods
This secondary data analysis used a qualitative descriptive approach including inter-rater reliability (IRR) of qualitative data and content analysis to address the study aims.
**Methods**

**IRR of Qualitative Data**

Aim 1: Evaluate the usefulness and accuracy of participants to answer prompts of SBAR-cued communication responses.

- Used a coding system and IRR to determine if the participants of the parent study, after instructions, correctly used SBAR in each scenario.
- In IRR of qualitative data, a supported coding system based on the components of SBAR was developed to guide the three raters in analyzing each participant’s response.

---

**Methods**

**Qualitative Descriptive Approach**

**Content Analysis**

Aim 2: Describe individuals’ perspectives of the acceptability of using SBAR patient-HCP communication simulation to better prepare for ED visits during a SCC.

- Used a qualitative descriptive approach, employing content analysis of the data from the open-ended post training question, where the participants were asked to provide feedback.
- This analysis was guided through the lens of the study’s theoretical framework. The transferred data included the transcribed audio recordings of the participants from the parent study.
- IRB review: exempt status was obtained through the University of Massachusetts Medical School (UMMS) prior to the secure transfer of study data.
Data Analysis  
IRR Qualitative Data (Aim 1)

• Three raters used the clinical scenario, theoretically based coding system and SBAR table as a guide
• For each study participant, they rated their response for each component of SBAR (0-1)
• Pilot study completed
• Cohen’s Kappa was calculated using Edition 24 of SPSS Statistical analysis software

Data Analysis  
Qualitative Content Analysis (Aim 2)

• Qualitative descriptive analysis of themes guided by through the lens of the study’s theoretical framework
• Trustworthiness established using the standards described by Lincoln and Guba (1985)
• Open ended qualitative questions used analysis described by Hsieh & Shannon (2005)
• Codes were derived by identifying words that capture important concepts
• Taking note of impressions in the initial analysis
• Labels emerged that encompass complex thoughts
• Codes categorized based on how they are related
• Categories coded into groups and defined
• Exemplars from the data used support the categories.
Results

• All available data were used in the analysis
  1. 29 participants recruited in parent study
  2. 18 transcripts available for analysis
  3. 15 transcripts analyzed using IRR
  4. 10 transcripts analyzed using qualitative content analysis

Results

• Participants
  • Ranged from age 18-62 years old
  • Education level- varied

<table>
<thead>
<tr>
<th>Education level</th>
<th>Gender</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>8th through 11th grade</td>
<td>Female</td>
<td>68%</td>
</tr>
<tr>
<td>Completed High School or GED</td>
<td>Male</td>
<td>32%</td>
</tr>
<tr>
<td>After High School Training</td>
<td>3%</td>
<td></td>
</tr>
<tr>
<td>Some College</td>
<td>39%</td>
<td></td>
</tr>
<tr>
<td>College Graduate</td>
<td>23%</td>
<td></td>
</tr>
<tr>
<td>Post Graduate</td>
<td>3%</td>
<td></td>
</tr>
</tbody>
</table>
Results
Specific Aim 1: Evaluate usefulness and accuracy of participants to answer prompts of SBAR cued communication responses

- Percent agreement between raters ranged between 64% and 95%.
- Cohen’s Kappa= acceptable level of IRR is 0.6 indicating substantial agreement (acceptable level of agreement)

<table>
<thead>
<tr>
<th>Component of SBAR</th>
<th>IRR percent agreement among participant responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Situation</td>
<td>0.889</td>
</tr>
<tr>
<td>Background</td>
<td>0.949</td>
</tr>
<tr>
<td>Assessment</td>
<td>0.822</td>
</tr>
<tr>
<td>Recommendation</td>
<td>0.641</td>
</tr>
</tbody>
</table>

Results
Specific Aim 2: Describe individuals’ perspectives of the acceptability of using SBAR patient-HCP communication simulation to better prepare for ED visits during a sickle cell crisis.

Patient-Provider Communication and Interaction

Patients want to be Heard and Believed

Accuracy of the ED experience and Incorporating the Uniqueness of each Patient

Overall Usefulness of the Video Trainer

Themes
"The way the nurse and doctor talked to her is exactly how they talked to you as they think that you are lying about how you are feeling."

Participants shared patient-provider communication in the vignettes was an accurate reflection of the attitude and tone of their real experiences.

HCP providers make dismissive assumptions leading to delayed care.

Perception that HCP believed patients were lying.

"Just because one does not look like he is in pain does not mean he does not feel it."

The participants described wanting the providers to listen, understand and believe their perspectives.

Simply listening had the potential to improve the interaction and help the patient.
Accuracy of the ED Experience and Incorporating The Uniqueness of each Patient

"This thing hits all of us very different."

The participants varied on the accuracy of the trainer and how it illustrated their specific experience.

A. Trainer could not reflect accurate accounts of their individual experiences with healthcare providers due to the uniqueness of their patient experience.

B. Equate vignette to their own experiences and trainer represented a realistic view

Overall Usefulness of the Video Trainer

"I think SBAR is a great method for better and more thorough communication with health care providers."

Trainer was helpful in facilitating communication

Aid in garnering trust and allowing for more thorough communication

Felt they could apply modalities learned in the trainer to their own lives.
**Discussion**

Specific Aim 1: Evaluate the usefulness and accuracy of participants to answer prompts of SBAR cued communication responses

- In this study we found the trainer was useful and effective in teaching the use of SBAR.
- IRR and Cohen’s Kappa indicated substantial agreement across raters.
  - Demonstrating ability of the SBAR tool and trainer to facilitate communication between patients and HCP.
- IRR for “SBA” components significantly higher than IRR for “R” component
  - Limited past experience in facilitating their care
  - More development needed in trainer for the “R” component

**Discussion**

Specific Aim 2: Describe individuals’ perspectives of the acceptability of using SBAR patient-HCP communication simulation to better prepare for ED visits during a sickle cell crisis

- This study found the trainer and SBAR were acceptable tools that could facilitate communication.
- Participants could use the tools they learned and advocate for themselves and their healthcare by communicating their needs in a way that HCP could understand based on SBAR.
- Mixed results on ability for trainer to capture individuality of patient experience.
- Clinical implications include impact on patient provider communication.
  - Better and informed care for these patients, which leads to increased health outcomes.
Conclusion

• A web-based SBAR training model is an important first step in using the gold standard of communication among HCPs in a nuanced way to benefit a vulnerable patient population.
• This study has provided beginning evidence to support the use of SBAR as a modality to foster patient-HCP communication
  • Marginalized populations
  • Expand to other disease processes
• Limitations
  • Limited to responses provided by participants
  • Small N
• Next steps
  • Further study with larger pool of participants
  • Tailoring vignette’s for more generalizability

Acknowledgements and Thank you

• Through God, faith and prayer all things are possible
• Mom- Thank you for loving me, pushing me to better and instilling in me the importance and power of education.
• David- Thank you for your love and support.
• Dissertation Committee
  • Dr. Wassef
  • Dr. Jenerette
  • Dr. Sullivan Bolyai
• Dr. Crawford
• Dr. Morris
• Diane Quinn
• Tan Chingfen GSN Community
References

Centers for Disease Control and Prevention (CDC). (2020). Sickle cell disease (SCD). Data and statistics on sickle cell disease. CDC. https://doi.org/10.1016/j.pec.2014.05.013


Institute for Healthcare Improvement (2019). SBAR Tool: Situation-Background-Assessment-Recommendation. Cambridge, Massachusetts, USA.


Dissemination Plan

The primary description of this dissertation work was submitted as a manuscript on May 20, 2022 to the International Journal of Environmental Research for Public Health for review and consideration for publication.