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## Use of Social Support during Communication about Sickle Cell Carrier Status

Lisa Bradford<sup>1</sup>, Sara J. Roedl, Stephanie A. Christopher, and Michael H. Farrell

<sup>1</sup>Center for Patient Care and Outcomes Research, Medical College of Wisconsin, Milwaukee, WI, USA

### Abstract

**Objective**—To examine the use of social support behaviors by primary care providers during delivery of positive newborn screening results for Sickle Cell Anemia carrier status.

**Methods**—Transcripts from 125 primary care providers who conveyed Sickle Cell Anemia carrier status to standardized parents were content analyzed using categories derived from Cutrona and Suhr's social support taxonomy. Frequencies and cross-tabulation matrices were calculated to study providers' social support utilization.

**Results**—Results showed most primary care providers (80%) incorporate social support behaviors into delivery of Sickle Cell Anemia carrier results and most frequently employed social network (61.6%) and informational support (38.4%) behaviors. Providers used tangible aid (8%), esteem (1.6%), and emotional support (9.6%) behaviors less frequently.

**Conclusion**—Cutrona and Suhr's taxonomy may be a useful tool for assessing supportive communication during the delivery of Sickle Cell Anemia carrier status and could be incorporated into population scale assessments of communication quality assurance.

**Practice Implications**—Primary care providers may need training in how to adapt supportive behaviors to parents' needs during communication of Sickle Cell Anemia carrier status. They also may benefit from specific training about how to use esteem and emotional support.

### Keywords

Communication; Social Support; Newborn Screening Results; Sickle Cell Anemia; Patient-Provider Communication

## 1. Introduction

Newborn screening (NBS) is a population-scale public health program that tests newborns for 50 genetic and metabolic diseases [1–2]. The benefit of this testing is early detection of serious developmental conditions so treatment of symptoms can begin soon after birth [3]. NBS is required in many countries and each of the United States [4]. Each NBS program selects which conditions to screen for [4]. Screening typically occurs 24–48 hours after

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Corresponding author at: Lisa Bradford, Medical College of Wisconsin, Center for Patient Care and Outcomes Research, 8701 Watertown Plank Road, Milwaukee, WI 53226 USA, Phone: (414) 456-7542, Fax: (414) 456-6689, lbradford@mcw.edu.

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birth. Blood is drawn from the infant's heel and sent to a central laboratory for testing. Results are sent to the infant's health care providers.

Sickle Cell Anemia (SCA) is a heritable disease affecting the quality and quantity of hemoglobin, an essential part of the blood. SCA is included in many NBS panels. Heterozygous carriers, or people who have only one mutation for an autosomal recessive disease, are inadvertently identified during NBS. A person with carrier status does not and will not ever have the disease, but may pass the mutation on to his or her offspring. SCA carrier status is most prevalent among individuals whose ancestors came from Africa, Central or South America, India, Mediterranean countries, Caribbean islands, and Saudi Arabia [5].

Although SCA carrier status is rarely associated with negative health effects, helping parents understand the implications of carrier status may be challenging for primary care providers (PCPs), who typically are responsible for informing parents about carrier results. Previous studies addressing communication about NBS carrier status show that false positive and carrier results may be confusing for parents and may lead to undue anxiety and stress about the infant's health [6–8], confusion about the difference between disease and carrier status [6, 9–11], unrealistic limits on their child's physical activities [7], difficult parent-child bonding, parental/sibling "survival" guilt, disease stigma, nonessential dietary interventions [7], and vulnerable child syndrome [9].

The ability of PCPs to deliver NBS results has been criticized [12, 13]. Many PCPs have only a limited understanding of genetics and no evidence-based guidelines exist for what information to share [14] and how to communicate results to parents [15]. Even PCPs who understand genetics and have excellent communication skills might find it difficult to help parents achieve an appropriate balance between concern about their infants' health and assurance that their child is healthy. Due to the challenging nature of this task, the PCP's therapeutic communication skills may be critical for minimizing psychosocial risks. Parents need to feel welcome to seek clarification and support from their PCP after receiving NBS results. For example, communicating social support may help PCPs create and maintain a caring relationship characterized by continued dialogue and the opportunity to evaluate parents' understanding and adjustment.

Social support facilitates therapeutic communication in healthcare. Social support includes behaviors that persuade others that they are cared for and valued, and enhances coping skills by helping people believe they can proactively manage health challenges [16]. There are a variety of multi-dimensional definitions of social support. Cutrona and Suhr identified five major support categories that reflect the convergence of previous social support research [17]. These are classified into two main categories: action-facilitating support (tangible aid and informational support) and nurturing support (esteem support, emotional support, and social network support) [16]. Action-facilitating support includes actions performed to assist another person in managing daily challenges such as running an errand or searching for informational resources. Nurturing support involves conveying messages that acknowledge emotions, provide companionship, and help to build self esteem. The functions of social support can be explained in terms of buffer theory.

Buffer theory posits that social support provides emotional protection from or helps people cope with stressful events [18]. Receiving support from others can buffer the effect of misfortunes [19] and stressful events [20]. Ideally, interactions between PCPs and patients or family members should include social support both in response to and in anticipation of feelings of concern, distress, or grief. Previous research suggests that social support from providers may help patients cope with illness [21, 22]. In the case of communicating the

results of SCA carrier status, use of social support by PCPs may reduce parental distress. Social support may help minimize negative emotions that could prevent parents from fully comprehending the benign nature of carrier status. Social support behaviors may also increase parents' ability to believe the PCP is an active partner in addressing the infant's health needs.

Societal changes in perspectives about the patient-provider relationship have focused more attention on the need for providers to engage in therapeutic communication [23]. As a result, some PCPs may work to convey social support during challenging conversations. However, since past research suggests that physicians spend only about 2% of their conversation time with patients engaging in supportive communication [24], their use of supportive behaviors may be limited.

This study had two aims. The first aim was to determine whether PCPs used social support behaviors during communication of the SCA carrier results to parents, and if so, what types of social support they used. The second aim was to determine whether PCPs' communication of social support varied by their gender, race/ethnicity, or experience level.

## 2. Methods

### 2.1. Study Design

The Wisconsin Project on Improvement of Communication Process and Outcomes after Newborn Screening is a statewide project that invites physicians to demonstrate with a with a standardized parent how they plan to discuss SCA carrier results with an actual parent in their practice [25]. The evaluation of the PCPs' performances in the rehearsals establishes a baseline level of skill and indicates areas of their communication that should be targeted for improvement in designing a quality assurance intervention. This paper describes a content analysis of the transcribed conversations between standardized parents and PCPs about NBS results for infants with SCA carrier status.

### 2.2. Study Participants and Data Collection

Study participants were 125 PCPs contacted during the larger study when a patient of theirs was found to have SCA carrier status, and who volunteered to rehearse delivery of SCA carrier status news over the telephone to a standardized parent. Rehearsals that simulate patient encounters were used in the Wisconsin Project study to avoid the potential logistical, privacy, and consent issues related to recording actual patient encounters that would create tremendous challenges for routine use. Further, knowledge that the simulations will be evaluated for quality might motivate physicians to put forth their best effort, thus providing a ceiling for their expected performance with actual parents.

Researchers at the Wisconsin Project received NBS results from Wisconsin's NBS laboratory and faxed each infant's PCP the results and an introduction to the project. Then they called the PCPs to verify the patient-provider relationship, to confirm receipt of the fax, to provide additional information about the project, and to invite them to rehearse with a standardized patient. As of March 1, 2011, when data analysis began, 128 PCPs recorded a rehearsal for communicating SCA carrier results. Three rehearsals were excluded due to recorder failure. The remaining 125 rehearsals form the dataset for this analysis. Demographic information for these participants is shown in Table 1. The larger project also included rehearsals for Cystic Fibrosis carrier status which will be reported later. All of the materials and procedures were approved by the researchers' institutional IRB prior to beginning data collection.

### 2.3. Data Analysis

In the first phase of the data analysis, data from the transcribed rehearsals were analyzed using qualitative content analysis. Content analysis is employed to make valid inferences from communication texts about the message sender(s), the message, or the message audience [26]. Frequently, to increase validity, data are coded using categories previously created and validated by other researchers [27]. This study utilized five coding categories based on Cutrona and Suhr's social support taxonomy (Figure 1). The 23 specific behavioral subcategories that form the full version of Cutrona and Suhr's Social Support Behavior Code were not used because of the unique features of the study context (delivering NBS screening results to parents). The unit of analysis was the entire transcript and each category was coded as present or absent for the transcript. Hence, each unit of analysis could have multiple codes if more than one type of social support occurred.

The coding dictionary included category names, definitions, and behavioral examples for all five of the categories. Three communication researchers were trained with the coding dictionary, and instructed to note whether social support was communicated by the PCP using behaviors outside the existing categories. Transcripts were divided evenly between researchers for coding. Cutrona and Suhr's categories were found to be exhaustive and mutually inclusive for these data, because coders did not find any additional methods of communicating social support.

Intercoder reliability was calculated using Cohen's kappa [28]. This was established based on each coder independently coding 20% of the sample. Intercoder reliability was 0.86, which is above the 0.75 kappa level used to indicate excellent coder agreement levels [29].

In the second phase of the data analysis, frequencies were tabulated to describe PCPs' patterns of social support use. Cross tabulation matrices were constructed to explore variations in the use of social support categories by PCPs' demographic characteristics (gender, race/ethnicity, or experience level). These relationships were tested for significance with Pearson's Chi-square statistic using SPSS 18.0.

## 3. Results

### 3.1. PCP's Overall Use of Social Support Behaviors

Our data suggest that PCPs used each of Cutrona and Suhr's five categories of social support behaviors (See Table 2). These categories were both inclusive of these data and mutually exclusive. Coders failed to identify any support behaviors that did not fit within these categories. Further, the frequencies reveal that the majority of PCPs ( $n = 100$ , 80%) employed behaviors from at least one of the five social support categories. Table 2 reports the frequency of PCPs that used each social support category when they delivered SCA carrier status results to the standardized parent.

### 3.2. Social Network Support

Our data show that social network support was used most frequently by the PCPs, occurring in 61.6% of the rehearsals. Use of social network support can be seen in the following example:

“...and I certainly can answer any other questions. If you don't have any today and you think of some later, just let me know.”

This PCP communicates that the phone conversation is only an initial contact, and that that parent is welcome to call to ask questions as they come up. This shows the parent that the PCP is interested in assisting the parent as he or she learns about SCA carrier status. In the

example below, the PCP communicates social network support by expressing a willingness to participate with the parents as an active partner in the infants' medical future.

"I think this is something that we're going to want to talk about again as he gets older, um, but that should not cause him any problems in the immediate future."

### 3.3. Informational Support

Informational support behaviors were the second most frequently used type of social support and were used in 38.4 % of the rehearsals. Informational support most often took the form of an offer to provide a pamphlet prepared by the state or other nonprofit organization. Below are two examples in which PCPs offer informational support:

"...then use this handout that we've provided here from the state that'll give you more information about what sickle cell trait is and means."

"I have some information that I can give you...to learn a little bit more about it..."

In the first example the PCP offers a specific handout to supplement the information already presented. In the second, the PCP makes a general offer to provide additional information beyond what the parent has received.

### 3.4. Emotional Support

Emotional support was used by only 9.6% of the PCPs. In the example below, the PCP demonstrated emotional support by anticipating the parent's potential worries after the conversation.

"If you talk with anybody...and they make you worried or anything like that and you think of anything else that you need to talk with me about, you can please give me a call but otherwise we can talk at your next visit."

Here the PCP both acknowledges the parent's possible future emotions and communicates understanding by offering to provide additional support in the form of opportunities for continuing their relationship beyond this interaction (social network support) by being available to address concerns. This PCP achieves one type of social support while also offering a second type of support at the same time.

### 3.5. Tangible Aid Support

Tangible aid support behaviors were used relatively infrequently 8% (n = 10). The following quote demonstrated the use of tangible aid when the PCP offers to support to the parent by setting up the appointment with the geneticist.

"...what we'll do on our end is we'll make some follow-up appointments for you to get you and your husband to be able to sort of sit down with the geneticist and kind of review this and talk about this in more detail as well."

### 3.6. Esteem Support

Esteem support was rarely found in this study, occurring in just two (1.6 %) rehearsals. In both of these rehearsals the PCPs made generic comments to the parents about how well they were taking care of their infants.

"I'm glad you brought him in for the—her in for the checkup and she's feeding well, eating well. It looks like you're doing a great job."

"...the most important thing for right now is just to keep doing what you're doing... [baby] is very healthy..."

### 3.7. Mixing Social Support Types and Timing

Some PCPs (24.8%) employed multiple types of social support in their rehearsals, as the following quote demonstrates:

“You know what? I can get you some information and explain it ‘cause I know sometimes when I say things over the phone, um, you’ve kinda shut down, you don’t hear too much after that...that you just think oh, there’s something wrong. It really isn’t anything that’s gonna be a problem today or tomorrow, but, um, let me send you some information. You can read about it, and then we can set that up... and we’ll talk about it the next time you come in and we can have that repeated if need be.”

This PCP communicated social network support by inviting further discussion of SCA carrier status at the next appointment. Additionally, the PCP recognized that the parent’s initial reaction to the results could be a barrier to understanding them. To address this barrier, the PCP communicated informational support by offering to send more information about SCA carrier status as a follow up to the phone call.

### 3.8. Variation in Social Support Use by PCP Characteristics

The analysis revealed slight gender differences in whether social support was offered; but, this difference was not statistically significant ( $p = .411$ ). One type of support offered did vary slightly by gender for one category ( $p = .05$ ). Male PCPs ( $n = 28$ , 22.4%) were slightly more likely to communicate informational support than female PCPs ( $n = 20$ , 16%).

No significant relationship between ethnic background and the use of social support strategies could be identified ( $p = .205$ ). The sample was relatively homogeneous (See Table 1). Experience level did not seem to significantly influence communication of social support ( $p = .176$ ). PCPs at each experience level were equally likely to offer social support behaviors when they presented SCA carrier results. Eighty percent of beginners ( $n = 20$ ), 80% of experienced level ( $n = 24$ ) and 79.7% of expert level ( $n = 55$ ) PCPs employed social support behaviors in their communication with standardized parents.

## 4. Discussion and Conclusion

### 4.1. Discussion

The aim of this study was to determine whether PCPs employed social support behaviors during the communication of SCA carrier results to parents. In contrast to an earlier study that suggested PCPs spend little time providing social support [23], these data from PCP rehearsals with standardized parents indicate that most PCPs include at least one type of social support in their communication about SCA carrier results. These PCPs employed social support from each of the five categories in Cutrona and Suhr’s taxonomy [17]. Past research has shown that patients highly value informational and emotional support [30], but the PCPs in our study tended to employ social network support and informational support more frequently than tangible aid, emotional, and esteem support. It is important to note that research suggests patients confronted with the genetic testing process may have a greater desire for informational support than other patients [30].

Communicating SCA carrier results to parents is an important communication quality assurance issue and a complex challenge for PCPs. Finding that the majority of the PCPs in this study communicated some type of social support is encouraging since follow-up conversations with parents may be necessary to verify parents’ understanding of SCA carrier status [13, 25]. These PCPs may use social network support most frequently because they may have been specifically trained to talk about future appointments with patients [23].



Informational support may have been more common because most PCPs have readily accessible materials about SCA carrier results so it requires little effort to provide them to parents. For example, brochures and other informational resources are made available by NBS laboratories and a variety of non-profit organizations—PCPs simply have to remember to offer them to parents. Interestingly, past research has shown that patients prefer high quality information and may seek highly technical information [30], but the standard brochures PCPs distribute include very little technical information.

The rarity of PCP's utilization of emotional support is consistent with previous research showing that physicians have difficulty identifying patients' emotions [31], and also with recognizing requests for emotional support from patients' verbal cues [32]. Further, one study shows they only respond to patient's emotional cues about 21% of the time [33]. The socialization of medical students in traditional models of medical education may be teaching students to ignore, detach, and distance themselves from emotions [34].

In previous research, relationship quality has been identified as a factor that influences perceptions of support [35]. Emotions may be especially challenging for PCPs to identify if no previous relationship exists, as may be the case with parents of a newborn. Similar emotional or continuity challenges also may be responsible for the rarity of esteem support, although it is also possible that many PCPs may not have been trained to provide esteem support or they may not be aware of its value in supporting parents. Parents of newborns may be very concerned about whether they are properly caring for their infants or worried that they may have been responsible for an illness [23]. Reassurance from the PCP may be especially important for building a successful parent-provider relationship.

No differences in PCPs use of social support were apparent for gender, ethnic/racial background or years of experience. Future studies with a more heterogeneous sample may help identify variations in the use of social support by subgroups of PCPs. There may be many other factors responsible for the variability in the use of social support behaviors, such as differences in the PCPs' training, resources, or perceived priorities that should be the focus of further research.

Some study findings could be artifacts of the data collection method. Infrequent use of tangible aid may be an artifact of the study design. PCPs may not have thought to perform helpful tasks for standardized parents like they would have for "real" parents. However, PCPs working with real parents may underestimate the supportive power that offering to assist with simple tasks, such as setting up an appointment for further testing, provides parents. Further, during the PCP rehearsals, the standardized parents were instructed to portray a neutral emotional state so PCPs had fewer emotional cues to attend to than in conversations with "real" patients. However, given the previously referenced findings on studies from actual patient interactions that suggest physicians tend to miss patient's emotional cues and infrequently respond to them [31–33], PCPs may have been only slightly more motivated to respond to "real" parent emotions than those of the standardized parent.

Another limitation of the standardized patient method is that it may have inhibited the inclusion of practical or logistical support (e.g., tangible aid support behaviors), although it should be noted that there was no apparent inhibition about informational support—the other action-facilitating behavior. Finally, PCPs may have been affected by a Hawthorne-like effect and attempted to provide an above average presentation of SCA carrier status results because they knew that their efforts were going to be scrutinized for quality. Hence, these results may over-estimate the amount of support they would show during their actual communication of SCA carrier results with parents.

Analysis of data from rehearsals as opposed to actual PCP-parent interactions is a study limitation. Delivering positive SCA carrier results to a real patient may be more stressful and may motivate more concern for the quality of the interaction than a rehearsal with a trained standardized parent. However, data for this study was collected from rehearsals with standardized parents based on ethical and logistical reasons. Respect for the privacy of parents receiving screening results and their initial emotional response to the information was paramount in deciding not to record actual result disclosures. Given that standardized patient encounters are a commonly used teaching method during medical education, it was expected that PCPs would recognize that the goal of a standardized parent rehearsal is to imagine an interaction with an actual parent and to rehearse as closely as possible behaviors that they would employ in “real” conversations with parents.

One limitation of employing quantitative methods to analyze how PCPs utilized social support is that the researchers are limited to focusing on precise, objective findings, as opposed to the more holistic perspective afforded by qualitative analysis [36]. In effect, quantitative methods necessarily reduce the richness of qualitative data. However, in this study, we chose to employ both qualitative and quantitative analytical techniques in an effort to understand the types of social support PCPs used and the prevalence with which different types of social support behaviors were used. The usage patterns identified in these analyses should not be generalized to the behavior of all PCPs.

## 4.2. Conclusion

This study found that many PCPs communicated social support when delivering SCA carrier results to standardized parents. Social network support and informational support were the most commonly communicated support types, perhaps because they require the least resources to employ. These social support messages may address parents’ needs for information and facilitate an ongoing relationship with PCPs. However, they may not completely fulfill parents’ needs and expectations for social support as they learn about their infant’s carrier status. Some parents may need and appreciate other forms of support (i.e., tangible aid, emotional, and/or esteem support). These results failed to show variation in PCPs communication of social support by their gender, racial/ethnic backgrounds, or years of experience.

These data support the use of Cutrona and Suhr’s taxonomy for assessing use of social support by PCPs in the context of delivering NBS carrier results. These categories could be incorporated in population scale assessments of communication quality assurance. Future research should investigate how PCP characteristics influence communicating social support.

## 4.3. Practice Implications

Conveying SCA carrier results to parents can be challenging because parents may not initially understand or believe that carrier status poses little threat to their infants’ health. PCPs may not be successful in providing parents with sufficient information and assurance about the infant’s health status when they initially deliver SCA carrier status results. The communication of social support may buffer negative psychosocial risks, introduce information resources, and motivate future interactions. However, these data suggest that PCPs may be too reliant on social network support and informational support in their delivery of SCA carrier results. While these types of social support may motivate future opportunities to help parents understand SCA carrier results and provide them with additional sources of information, they may not help address the emotional impact that the results have for parents. PCPs should understand how to communicate all five types of social support. They should be trained to assess parents’ emotional responses to SCA carrier



results and tailor their communication to include the social support responses that are most likely to assist individual parents. These data suggest that PCPs may need additional training in the use of esteem and emotional support.

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**Table 1**

## PCP Self-Reported Demographic Data

Characteristic	N	Percentages
Gender		
• Male	60	48.0
• Female	65	52.0
Racial/Ethnic Background		
• Non Hispanic White	99	79.2
• Non Hispanic Black	12	9.6
• Hispanic	1	0.8
• Asian/Pacific Islander	11	8.8
• Other/Mixed Ethnic	2	1.6
Provider Experience (Years Since Medical School Completion)		
• Beginner (1–6 years)	25	20.0
• Experienced (7–12 years)	30	24.0
• Expert (13+ years)	69	55.2
Type of Provider		
• Physician	118	94.4
• Nurse Practitioner	7	5.6

**Table 2**

Percentages of PCPs Who Employed Each of Cutrona &amp; Suhr's [16] Social Support Categories

Type	Definition	N	Percentages <sup>a</sup>
Action-Facilitating			
• Tangible Aid	Performing tasks or favors to assist the other person	10	8.0
• Informational Support	Giving or seeking information that will help increase the other person's ability to understand and make good decisions	48	38.4
Nurturing Support			
• Esteem Support	Providing encouragement to the other person that produces feelings of value and competence	2	1.6
• Emotional Support	Acknowledging and communicating an understanding of the emotions the other is feeling	12	9.6
• Social Support Network	Communicating companionship and maintaining an ongoing relationship that extends beyond the crisis.	77	61.6

<sup>a</sup>Percentages do not add up to 100% because participants may have used more than one social support behaviour.