

PERCEIVED EMERGENCY DEPARTMENT CARE AND DISEASE STATUS IN PEDIATRIC SICKLE CELL PATIENTS

by

Kristen Janay Alston

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Director of Thesis: Cecelia Valrie, Ph.D.

Major Department: Psychology

The present study described the overall emergency department (ED) experiences of children with SCD, and examined the relationship between characteristics of care (waiting time, communication/interaction with the health care provider, pain management, speed of care), patient characteristics, disease severity (SCD type) and parent reported satisfaction with care. Guardians of children with SCD (n=125; aged 0 to 17 years) completed a survey concerning their children's ED experiences in the past 6 months. This included information concerning ED wait times, quality of the communication/interaction with the ED doctor, pain management, and their perception concerning speed of care. Almost half (42%) of the guardians reported that their child had been to the ED in the past 6 months. Also, guardians tended to report moderate overall satisfaction with their child's ED care. Shorter ED wait times and higher ratings of speed of care were significant predictors of higher patient satisfaction among guardians of pediatric SCD patients. In conclusion further efforts are needed to develop strategies that will reduce wait time and increase the rate at which patients' needs are met in the ED and that will lead to the production of more effective care for this population. Reduction of wait times and increasing the speed of care may be aided by supplying ED providers with continued education concerning the urgency of SCD emergencies and systematic programming to decrease ED wait times, as well as

by educating guardians regarding the importance of going to the ED when serious symptoms first arise and about realistic expectations regarding ED wait times.

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PEDIATRIC SICKLE CELL PATIENTS

A Thesis

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Kristen Janay Alston

APPROVED BY:

DIRECTOR OF THESIS:

Cecelia Valrie, Ph.D.

COMMITTEE MEMBER:

Christy Walcott, Ph.D.

COMMITTEE MEMBER:

Beng Fuh, M.D.

CHAIR, DEPARTMENT OF PSYCHOLOGY:

Kathleen A. Row, Ph.D.

DEAN OF THE GRADUATE SCHOOL:

Paul J. Gemperline, Ph.D.

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CHAPTER 1: INTRODUCTION

Sickle cell disease (SCD) is an inherited blood disorder that affects one in every 500 African Americans born each year in the United States. Seventy to one hundred thousand Americans are currently managing SCD and one out of twelve African Americans is a carrier of the sickle cell trait (Centers for Disease Control and Prevention, 2010). In the US, SCD is most prevalent among people of African descent, but can also affect people of Mediterranean, Middle Eastern, Indian, and Latino descent (Swain, Mitchell, & Powers, 2006).

SCD refers to a group of hemoglobinopathies involving a genetic mutation of the hemoglobin beta gene. Hemoglobin is responsible for the transfer of oxygen from the lungs to other areas of the body. However, in individuals with SCD, an abnormal variant of hemoglobin is produced called hemoglobin S. When an individual inherits two abnormal hemoglobin genes and a high level of hemoglobin S is produced, this causes red blood cells to become sickle or crescent shaped. While normal red blood cells are doughnut-shaped and flexible, allowing them to easily pass through tiny blood vessels, sickle-shaped blood cells can stiffen and cluster making it difficult for them to pass through the body's blood vessels to reach limbs, tissues, and organs (Gustafson, Bonner, Hardy, & Thompson, Jr., 2006). These vaso-occlusions can lead to severe pain, as well as tissue and organ damage. More specifically, damage to the kidneys, heart, and liver is plausible. When blood flow to the brain is restricted, cerebrovascular accidents can occur (Gustafson et al., 2006). Other symptoms include infection, anemic episodes, deterioration of vision, growth defects, and cardiovascular complications (Lutz, Barakat, Smith-Whitley, & Ohene-Frempong, 2004). These complications may result in early mortality or severe permanent damage. Individuals with hemoglobin SS (HbSS) often exhibit more complications associated

with the disease than individuals with other common types of SCD such as hemoglobin SC (HbSC) or hemoglobin SB (beta) thalassemia.

Notably, medical advances have made it possible for individuals with SCD to survive well into adulthood. The median life expectancy for individuals with HbSS is 42 and 48 years of age for men and women respectively, as compared to a median life expectancy of 14.3 years in 1973 (Platt et al., 1994). This increase in life expectancy has been linked to the early identification of SCD through neonatal screening, the advent of hydroxyurea in 1995-1996, penicillin therapy, and several vaccines to protect against infections (Centers for Disease Control and Prevention, 2010). However, this increase in life expectancy has also been accompanied by an increased use of the health care system. Vaso-occlusive episodes (VOE) account for the majority of health care utilization among the SCD population (Aisiku et al., 2007; Brousseau, Mukonje, Brandow, Nimmer, & Panepinto, 2009). Approximately, 79-91% of emergency room visits and 59-68% of hospitalizations are due to complications related to VOE (Jacob & Mueller, 2008). Furthermore, 19,000 pediatric hospitalizations in the U.S. are due to VOE, and result in 75,000 days spent in U.S hospitals annually and 14.4 million dollars spent on emergency department (ED) use (Aisiku et al., 2007; Brousseau et al., 2009).

With advances in medical treatment and increases in life expectancy, individuals with SCD are spending a significant amount of time within the health care system. Thus, the examination of satisfaction with the healthcare system among this population is greatly warranted. The purpose of the current study is to examine patient satisfaction among children and adolescents with SCD and factors related to patient satisfaction in this population. The following sections summarize the current literature pertaining to the general concept of patient satisfaction with healthcare, related factors, and patient satisfaction in the pediatric population.

This is followed by a review of literature on patient satisfaction in the SCD population, which discusses specific SCD factors related to patient satisfaction and patient satisfaction in the SCD population as compared to other chronic disease populations.

Patient Satisfaction

Patient satisfaction is a complex construct that has received an increasing amount of attention in the literature in recent years. This growing interest is largely due to the fact that patient satisfaction has become a critical factor in evaluating health care services and health policies. However, patient satisfaction research has suffered due to poor conceptualization of the construct. In fact, a clear, concise definition of the construct has yet to be developed, although most concur that patient satisfaction is a subjective construct seen from the patient's perspective. Linder-Pelz (1982, pp. 578) defines patient satisfaction as "positive evaluations of distinct dimensions of the health care," while Ware's theory holds that patient satisfaction is the result of subjective responses to the care received which are mediated by personal expectations (Gill & White, 2009; Ware, Snyder, Wright, & Davies, 1983). Also, a review of the literature conducted by Sitzia and Wood (1997) indicated that a major function of patient satisfaction research is to allow the patient to evaluate his or her perception of the health care quality received, while enabling the research community to develop a better understanding of the care process.

Patient satisfaction with the healthcare system has been used as a predictor of health-related behaviors and clinical outcomes (Pascoe, 1983). According to Pascoe (1983), higher levels of patient satisfaction have been related to increased levels of health care use, while lower levels of satisfaction have been associated with termination of services and decreased willingness to return to the service provider. Furthermore, research has indicated a positive relationship between patient satisfaction and compliance, such that individuals who report higher levels of

satisfaction are more likely to report a willingness to follow instructions provided by the healthcare provider, attend scheduled appointments, and comply with medication regimens (Pascoe, 1983). When individuals partake in poor health behaviors, this can be detrimental to their overall health status and clinical outcomes, and based on the above information, this can be related to satisfaction with healthcare.

Factors Related to Patient Satisfaction

In the adult literature, a number of factors have been shown to be related to patient satisfaction. For example, patient characteristics, such as age and ethnic status, have been identified as factors related to patient satisfaction. Research has shown a positive relationship between age and patient satisfaction, such that as age increases, so does expressed patient satisfaction (Rahmqvist, 2001). Research has also shown that White patients express higher levels of satisfaction than do Non-White patients; however, this must be interpreted carefully as race is a complex construct that interacts with numerous variables (Sitzia & Wood, 1997). In contrast, research on the relationship between gender and patient satisfaction has been more inconsistent with some research indicating that men are more satisfied and with other research suggesting that women express higher levels of satisfaction (Hall & Dornan, 1990).

Research has also linked patient satisfaction to characteristics of care (e.g., waiting time, patient-provider communication) in the adult population. For example, longer waiting times have been associated with lower levels of satisfaction (Booth, et al., 1992). This association may be because lengthy waiting times increase patient frustration and thus, decrease a patients' sense of control (Thompson, Yarnold, Williams, & Adams, 1996). A study by Spaite et al. (2002) demonstrated an overall increase in patient satisfaction when a rapid process redesign in a university-based ED decreased the median waiting room interval from 31 minutes to four

minutes over a six month period. Another characteristic of care, patient-provider communication, has been studied in relation to patient satisfaction. A study by Gross, Zyzanski, Borawski, Cebul, & Stange. (1998) indicated that longer visits and the provider spending time communicating about topics other than the health of the patient increased patient satisfaction. In addition, literature suggests a positive relationship between the physician's positive affect, friendliness, social conversation, and patient satisfaction (Williams, Weinman, & Dale, 1998).

Health status has also been examined as a factor related to patient satisfaction in the adult population. The majority of these studies have indicated that healthier individuals tend to be more satisfied than those with poorer health (Rahmqvist and Bara, 2010; Rahmqvist, 2001). In a study by Zapka et al., (1995), participants were asked to rate their general health as "poor", "fair", "good", "very good", or "excellent". Patient satisfaction was measured using Patient Reports on Systems Performance (PROSPER), which is a set of indicators of performance quality of the healthcare system (Hargraves et al., 1993). Participants were also asked to report whether they had a chronic illness. Results indicated a significant relationship between health status and patient satisfaction. A greater percentage of individuals with poor health indicated their care was not excellent as compared to individuals with good health. The individuals with poor health were also more likely to report that the care received could have been better. Interestingly, this study also indicated that individuals with a chronic illness were more satisfied with care; however, very little explanation is offered to explain this result. In addition, the study did not examine the relation between health ratings and reports of satisfaction with care for just the chronically ill sub-population. Notably, the majority of the studies examining health status as related to patient satisfaction have used subjective measures to examine the concept of health

status. Therefore, we are less informed of the relationship between objective measures of health status and patient satisfaction.

Patient satisfaction in the pediatric population has not been examined to the same extent as in the adult population. However, the available literature examining patient satisfaction in the pediatric population is mostly congruent with the adult literature on patient satisfaction (Magaret, Clark, Warden, Magnusson, & Hedges, 2002). For example, higher satisfaction ratings for pediatric patients have been related to characteristics of care, such as the quality of the interactions and communication with the provider, information provided, and perceived waiting times, all of which are common factors examined in the adult satisfaction literature. In examining patient satisfaction of 5 to 17 year old pediatric patients in the ED, results from Magaret et al.'s (2002) study indicated that patient satisfaction was significantly correlated with perceived quality of patient-doctor interactions, perceived adequacy of information given, the resolution of the child's pain, shorter waiting room times, and shorter time spent in the examination room prior to being seen by a doctor. A limitation of this study, like others which have examined satisfaction of pediatric patients, is the lack of attention to the relationship between the characteristics of the pediatric patient, such as age and gender, and patient satisfaction. It is possible that pediatric patient satisfaction may be influenced by certain child characteristics, but the knowledge regarding this relationship is scarce, as few studies have aimed to specifically examine this relationship. Notably, one study by Brousseau et al. (2009) found no significant association between age of the pediatric patient and the proportion of parents who were dissatisfied. However, further research needs to be conducted in order to investigate the possible influence of pediatric patient characteristics upon parent reported satisfaction.

Patient Satisfaction in the SCD Population

While an abundance of research has examined patient satisfaction and related factors, very little research has examined patient satisfaction in the SCD population. The majority of studies examining patient satisfaction in the SCD population have done so by comparing patients with SCD to other chronic disease populations and general pediatric populations. For example, a study conducted by Kam, Panepinto, Brandow, and Brousseau (2008) indicated that a larger percentage of parents of children with SCD were likely to report low satisfaction with medical care as compared to parents of children with cancer and parents of general pediatric patients, 29.4 %, 5.6%, and 6.8% respectively. This is consistent with the majority of literature, which suggests that individuals with SCD feel they receive inadequate care (Dorsey, Phillips, & Williams, 2001). Notably, because the majority of studies examining satisfaction in the SCD population have been comparison studies, very little is known about factors within the SCD population that are related to patient satisfaction.

Among the SCD population, painful episodes are the leading cause of morbidity and account for the majority of ED visits. However, research has shown that individuals with SCD experience significant delays in analgesic administration for the management of pain and vaso-occlusive events (Tanebe et al., 2007). In fact, children with SCD may be one of the most undertreated populations (Stinson & Naser, 2003). Research suggests health care providers' inadequate knowledge regarding SCD, including misconceptions related to opiate dependence and addiction, and conflicting perceptions between patients, families, and health care professionals contribute to the inadequate management of pain among this population (Stinson & Naser, 2003). Therefore, studies examining patient satisfaction among the SCD population have focused largely on pain and the management of pain in the health care system. Findings from

these studies suggest that dissatisfaction with pain management is related to significant delays in analgesic intervention and inadequate pain control (Brousseau, et al., 2009). For example, Melzer-Lange, Walsh-Kelly, Lea, Hillery, and Scott (2004) found that decreased intervals between morphine treatment in the ED were associated with higher pediatric patient satisfaction. In assessing dissatisfaction with hospital care, Brousseau et al. (2009) found that a higher percentage of parents of children with SCD reported dissatisfaction with pain control as compared to parents of children with asthma and those on the general pediatric service, 11.8%, 4.0%, and 6.4% respectively.

Among children with SCD, parents have also expressed decreased partnership with the health care provider. A study by Brousseau and colleagues (2009) indicated that a significantly higher proportion of parents of children with SCD believed that their child was treated differently as a result of race/ethnicity as compared to parents of children with other medical conditions. Furthermore, a significantly higher proportion of parents of children with SCD expressed that they would have liked to be more involved in the medical decision-making process concerning their child. These findings are important as previous work has indicated that the patient-provider partnership is related to patient satisfaction, with problems in the partnership domain being related to higher levels of dissatisfaction (Sitzia & Wood, 1997; Brousseau, 2009).

In addition to the abundance of research that has sought to compare individuals with SCD to other medical groups, comparison studies have also examined satisfaction differences according to medical setting. Aisiku, et al. (2007) sought to examine differences between the quality of care received by adults with SCD who receive their care in a specialized center versus those who receive care in nonspecialized centers. Notably, these authors found that those individuals who receive treatment from specialized centers had higher overall mean satisfaction

scores. Differences in structure and resources may account for these findings. These findings are also important as EDs represent nonspecialized care centers, because attending providers are often unfamiliar with SCD, have had limited exposure to the disease, and have little training in chronic pain management (Aisiku et al., 2007). Therefore, an understanding of the factors that influence satisfaction with ED care among this population is vital.

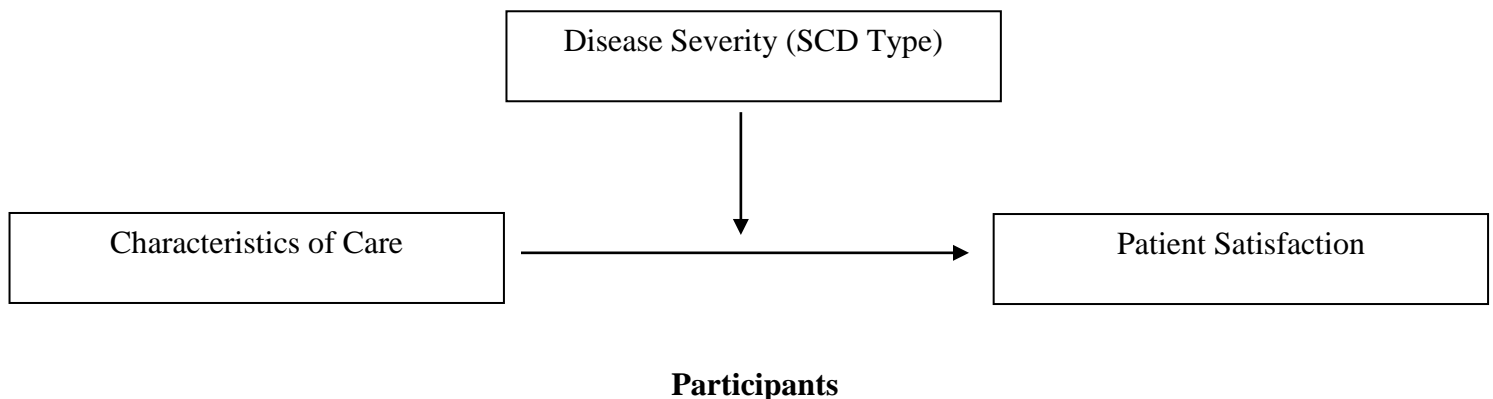
CHAPTER 2: METHODS

While an abundance of literature has examined the general concept of patient satisfaction, very little research has examined patient satisfaction among pediatric populations, and specifically the pediatric SCD population. Research has indicated that guardians of children with SCD report lower levels of satisfaction as compared to other populations. However, beyond exploring the influence of pain as a contributing factor to overall satisfaction with care, very little is known about what other factors are related to satisfaction. It is unclear whether or not factors proposed to influence satisfaction in the general population are related to patient satisfaction in the SCD population. Therefore, the primary purpose of the present study is to examine the relationship between characteristics of care (waiting time, communication/interaction with the health care provider, pain management, speed of care), patient characteristics, disease severity (SCD type) and patient satisfaction in the SCD population. It is hypothesized that characteristics of care will be significantly related to overall patient satisfaction. Specifically, waiting time will be negatively related to overall patient satisfaction, while higher ratings regarding communication/interaction with the health care provider, pain management, and speed of care will be related to higher ratings of patient satisfaction. It is also hypothesized that objective measures of disease severity will be significantly related to patient satisfaction with individuals with more severe SCD types reporting lower overall satisfaction. Lastly, based upon the small amount of research that exists related to pediatric patient characteristics and satisfaction, it is hypothesized that pediatric patient characteristics will not be significantly related to patient satisfaction.

A secondary purpose of the present study is to examine the possible influence of disease severity, as indicated by SCD type, upon the relationship between patient satisfaction and

characteristics of care. In the adult satisfaction literature, poorer perceived health status has been associated with lower levels of satisfaction. However, little is known about whether the relationship between individual characteristics of care and patient satisfaction changes as a function of disease severity, namely SCD type. Therefore, it is also hypothesized that disease severity (SCD type) will moderate the relationship between characteristics of care and patient satisfaction, such that the relationship between characteristics of care and patient satisfaction will be weakened for individuals with more severe forms of SCD (See Figure 1).

Figure 1. The Moderator Relationship.



A total of 125 children and adolescents (mean age = 7 years, SD = 5.49 range = 0-17 years) and their guardians participated in the study. The sample consisted of 64 males and 61 females. Of the sample, 74 children and adolescents (59%) HbSS, 44 HbSC (35%), and seven (6%) had sickle cell beta thalassemia. Of the guardians who completed surveys, about 83% were mothers and about 7% were fathers. The remaining guardians consisted of grandparents and other family members.

Procedure

All participants were recruited from the ECU Pediatric SCD Clinic. Possible participants were approached during their routine comprehensive SCD visits, informed of the nature and details of the study, and those individuals who agreed to participate in the study were given consent and/or assent forms to sign. Upon completion of the consent and assent forms, the parent or guardian who accompanied the child was provided a survey to complete, which assessed basic demographic information and past experiences and perceptions of ED care. Then, the medical charts of participating children and adolescents were reviewed to extract information related to disease status (type of SCD).

Measures

The evaluation survey (see Appendix 1) assessed four types of information vital to the project: demographic information, use of the ED, characteristics of care, and patient satisfaction with ED care.

Demographic Information

Demographic information collected consisted of the child's date of birth, the date of the evaluation, and the guardian's relationship to the child or adolescent.

Use of the ED

To assess ED utilization, participants were asked an open-ended question: "In the past 6 months, how many times did your child go to the emergency room?" Participants were also be asked: "If you do not remember the exact number of times, what is your best guess about the number of times your child went to the emergency room?" Participants were provided with three response choices: none in the past six months, once or twice (1 or 2 times) in the past six months, or three or more times in the past six months. In order to obtain as much information as possible,

these two questions were collapsed into one score. Specifically, responses to the first question were collapsed into one of the three provided categories in the latter question.

Characteristics of care

Patient experience consisted of four subareas: 1) Waiting time; 2) Communication with the healthcare provider; 3) Pain management; and 4) Speed of care. In order to assess ED waiting times, participants were asked: “In the past 6 months, when you took your child to the emergency room, how long did you have to wait to receive service on average?” They were also asked: “If you are not sure about the average number of hours, what is your best guess about how long you usually had to wait in the emergency room?” Responses were categorized as less than one hour, 1-2 hours, 3-5 hours, 6-8 hours, or greater than 8 hours. The two questions were also collapsed into one score. Specifically, responses to the first question were collapsed into one of the three provided categories in the latter question.

The other scales were based on the Consumer Assessment of Healthcare Providers and Systems (CAHPS) program surveys, which are funded and administered by the U.S. Agency for Healthcare Research and Quality. Research has indicated acceptable psychometric properties for the CAHPS program surveys (Hays, et al., 1999; Hargrove, Hays, & Cleary, 2003). Four point Likert scale items were used with “1” indicating “never”, “2” indicating “sometimes”, “3” indicating “usually”, and “4” indicating “always”. To ascertain participants’ perceptions in regard to communication/interaction with the healthcare provider, participants were asked: 1) “How often did the doctors treat you with courtesy and respect?” 2) “How often did the doctors listen carefully to you?” 3) How often did the doctors explain things to you in a way that you could understand?” 4) “How often did the doctors spend enough time with you?” To assess pain management, participants were asked: “How often was your child’s pain well-controlled?” and

“How often did the hospital staff do everything they could to help with your child’s pain?” Speed of care was assessed by asking participants “When your child needed care right away, how often did your child get care as soon as you thought he or she needed it?” Scores for each sub area was calculated by averaging the responses of all questions in that sub area.

Patient satisfaction

A global satisfaction rating was obtained by asking participants to rate their emergency room visit in the past 6 months on a scale from 0 to 10, with 0 indicating “worst” and 10 indicating “best”. Previous studies have assessed overall satisfaction using a similar item and have yielded acceptable psychometric properties (Brousseau et al., 2009; Co, Ferris, Marino, Homer, & Perrin, 2003). Brousseau et al., (2009) used a single item to assess overall parent reported dissatisfaction with hospital care for 639 children, ages 2-18, who had SCD, asthma, or were general pediatric patients. This measure of satisfaction was found to be highly correlated with partnership with the healthcare provider. Similarly, a study by Co et al. (2003) included a single overall rating of care item to assess parents’ perceptions of their child’s inpatient quality of care and found this item to be correlated with information provided to the parent and problems in the partnership domain.

Data Analysis

Regression analyses were performed to investigate four hypotheses. First, it was hypothesized that characteristics of care would be significantly related to overall patient satisfaction with waiting time being inversely related to patient satisfaction, and higher ratings regarding communication/interaction with the health care provider, pain management, and speed of care being related to higher ratings of patient satisfaction. Second, it was hypothesized that objective measures of disease severity would be significantly related to patient satisfaction with

individuals with more severe SCD subtypes reporting lower overall satisfaction. Third, it was hypothesized that pediatric patient characteristics (age, gender) would not be significantly related to overall patient satisfaction. Fourth, it was hypothesized that disease severity (SCD type) would moderate the relationship between characteristics of care and patient satisfaction, such that the relationship between characteristics of care and patient satisfaction would be weakened for individuals with more severe SCD types.

First, descriptive statistics related to the demographic variables, characteristics of care, ED use, disease severity, and overall satisfaction were calculated. Then, in order to narrow the variable pool for further analysis Pearson correlations and point biserial correlations were conducted to determine which variables were significantly related to overall patient satisfaction. To examine hypotheses one, two, and three, a simultaneous multiple regression model was calculated predicting overall patient satisfaction using characteristics of care, SCD type, and patient characteristics (age & gender). To test the fourth hypothesis (e.g., whether SCD type moderates the relationship between individual characteristics of care and overall patient satisfaction), the interactions between SCD type and each of the characteristics of care variables (e.g., waiting time, communication/interaction with the health care provider, pain management, and speed of care) were included in the previously described simultaneous regression model predicting overall patient satisfaction.

CHAPTER 3: RESULTS

Emergency Department Use

Of the 125 participants, 52 (42%) had visited the ED in the past six months. Of the 52 children and adolescents who visited the ED, 50% were males and 50% were females. About 81% of the guardians of the subsample who visited the ED reported that their child went to the ED once or twice in the past six months and 19% reported that their child went to ED three or more times in the past six months. The average age of the participants who visited the ED in the past six months was 6.6 years (SD = 5.8 years, range 0 to 17 years). Thirty-five of the 52 participants who visited the ED had HbSS subtype (67%), while the remaining 17 participants who visited the ED had HbSC or sickle cell beta thalassemia (33%).

Emergency Department Experiences

Table 1 summarizes the descriptive statistics for the subsample of participants who visited the ED in the past 6 months. For the subsample of participants who visited the ED, the average rating of overall satisfaction with ED care was 6 on a 10 point scale (SD = 2.7, range: 0-10), which indicates moderate satisfaction. In addition, the guardians reported that on average they usually experienced good quality communication with their child's doctor (mean = 3.34, range = 2-4), that their child's pain was usually well controlled in the ED (mean = 3.54, range = 2-4), and that their child usually received care in a timely manner in the ED (mean = 3.12, range = 1-4). Of those who visited the ED, 45.1% of the guardians reported ED wait times of less than one hour, 35.29% reported waiting times between 1-2 hours, and 19.61% reported waiting times between 3-5 hours.

Table 1. Descriptives for Subsample who Visited the ED

	Mean	SD	Range	Possible Range
Age	6.6	5.8	0-17	0-17
Patient/Provider Communication	3.34	0.62	2-4	1-4
Pain Management	3.54	0.61	2-4	1-4
Speed of Care	3.12	0.9	1-4	1-4
Satisfaction	6	2.75	0-10	0-10

Factors Related to Overall Patient Satisfaction

Prior to correlation and regression analyses, SCD type was recoded and dichotomized (0=HbSS subtype; 1=HbSC or Sickle cell beta Thalassemia) as individuals with HbSS may often exhibit more SCD related complications than individuals with HbSC or sickle cell beta thalassemia. Wait time was also recoded and dichotomized (0=less than 1 hr; 1 = 1 hr or more) as almost fifty percent of those who visited the ED reported wait times of less than one hour. In addition, only 3 of the 5 wait time categories were indicated by participants (45.1% < 1 hour; 35.29% 1-2 hour; 19.61% 3-5 hours). Pearson product correlations and point biserial correlations were conducted to determine which variables of interest were related to overall ED satisfaction (Table 2 and Table 3). Analyses indicated that satisfaction was significantly related to wait times ($r = -.48, p < .01$) and speed of care ($r = .41, p < .01$), such that shorter waiting times and higher rating for speed care were related to higher ratings of satisfaction. Other characteristics of care, age, gender, and SCD type were not significantly correlated with overall satisfaction. Correlations indicated that several characteristics of care were significantly inter-correlated with the strength of the correlations ranging from 0.57 to 0.68.

Table 2. Pearson Correlations Between Variables of Interest

	1	2	3	4	5
1. Age	—				
2. Patient/Provider Communication	-0.04	—			
3. Pain Management	0.11	0.57**	—		
4. Speed of Care	0.06	0.61**	0.68**	—	
5. Satisfaction	-0.06	0.24	0.26	0.41**	—

^aSCD type was recoded (0=HbSS subtype; 1=HbSC or Sickle cell Beta Thalassemia)

^bWait Time was recoded (0=less than 1 hr; 1 = 1 hr or more)

* $p < .05$; ** $p < .01$;

Table 3. Point Biserial Correlations Between Variables of Interest

	Gender	SCD Type	Wait Time
Satisfaction	-0.04	-0.10	-0.48**

^aSCD type was recoded (0=HbSS subtype; 1=HbSC or Sickle cell beta Thalassemia)

^bWait Time was recoded (0=less than 1 hr; 1 = 1 hr or more)

* $p < .05$; ** $p < .01$;

A simultaneous multiple regression was conducted to examine the unique contribution of the two factors found to be significantly related to overall satisfaction, SCD Type and gender (Table 4). In order to reduce the likelihood of over fitting the model due to the small subsample of those who visited the ED, only those characteristics of care that were found to be significantly correlated with overall satisfaction were included in the regression model. The overall model accounted for 25% of the variance ($F = 4.80, p < .01$). Both ED waiting time and speed of care were significant predictors of lower satisfaction. Specifically, longer wait times were significant

predictors of lower satisfaction ($\beta = -.40, p < .01$), accounting for 15% of the variance in satisfaction, while higher ratings of speed of care were predictive of higher satisfaction ($\beta = 0.29, p < .05$), accounting for 8% of the variance in satisfaction.

Table 4. Simultaneous Regression Model Predicting Patient Satisfaction

	t	β	Partial R²	F	Total Adjusted R²
				4.80**	.25**
SCD Type^a	-0.32	-0.04	0.00		
Gender	-0.61	-0.08	0.01		
Wait time^b	2.98**	-0.4**	.15**		
Speed of Care	2.15*	0.29*	.08*		

^aSCD type was recoded (0=HbSS subtype; 1=HbSC or Sickle cell beta Thalassemia)

^bWait Time was recoded (0=less than 1 hr; 1 = 1 hr or more)

* $p < .05$; ** $p < .01$

SCD Type as a Moderator of the Characteristics of Care-Satisfaction Relationship

To investigate whether SCD type moderated the characteristics of care-satisfaction relationship, each of the characteristics of care and the interaction between SCD type and each characteristic of care was entered into the model predicting overall patient satisfaction. The overall model was significant ($F = 2.16, p < .05$) accounting for 18% of the variance. Although the interactions between SCD type and characteristics of care were not predictive of patient satisfaction, the small sample size of the subsample that visited the ED may have impacted the ability to find significant effects.

CHAPTER 4: DISCUSSION

Overall, parents of children with SCD reported good satisfaction in each of the domains of care and moderate overall satisfaction with their ED visit. ED wait time and speed of care were found to be the most important predictors of overall parent reported satisfaction with ED care. Findings indicating that wait time is a unique predictor of patient satisfaction is consistent with other studies that have found wait time to be significantly related to parent reported satisfaction in the SCD population (Magaret et al., 2002). This may be because wait time may impact the parents' sense of control over the ED experience. Specifically, when wait time is shorter, patients may feel a greater sense of control as their needs are met in a timely matter. In contrast, lengthy wait times may lead to increased levels of frustration and a lowered sense of patient control (Thompson et al., 1996).

The significant association between wait time and overall patient satisfaction has implications for the ED. Specifically, instituting improvements at multiple levels in the ED to lower wait time may be the key to providing more effective health care for pediatric SCD patients in the ED and improving patient satisfaction. As previously mentioned, a study conducted by Spaite et al. (2002) demonstrated that a multifaceted approach focusing on improving staff to patient ratios, shortening the triage and registration process, and using electronic means to make lab processes more efficient significantly decreased the median waiting room time from 31 minutes to four minutes. Notably, it is possible that the influence of wait time on patient satisfaction was influenced by participants' expectations of wait time, as previous research has related higher levels of patient satisfaction with perceived wait times that were shorter than expected by the patient (Thompson et al., 1996). This suggests that patients' expectations when they arrive in the ED is an important factor when considering different

approaches to improving ED care. Providing parent education concerning possible wait times may impact patient satisfaction as incongruencies regarding expectations of wait time vs. actual wait times can be eliminated if parents are better prepared for what to expect.

Findings also indicated that speed of care was uniquely related to overall reports of parent satisfaction. Speed of care encompasses the rate at which patients receive the services that they need, and when factors such as time spent in the room waiting for the nurse or doctor creates a barrier to them receiving care in a timely fashion, satisfaction may become compromised. Magaret et al. (2002) found that among parents of children with SCD time spent in the examination room waiting to be seen by the doctor was significantly related to parent reported satisfaction. The unique association between speed of care and patient satisfaction may be in part due to the fact that speed of care was also significantly correlated with wait time. These two factors taken together suggests that parents have a sense of urgency when it comes to their child's health care and receiving care immediately is of vital concern.

Although hypothesized to be associated with patient satisfaction, pain management and patient-provider communication were not uniquely related to overall satisfaction ratings. These findings are inconsistent with previous research which has found these factors to be related to overall satisfaction (Brousseau et al., 2009; Magaret et al., 2002). However, the small sample of children and adolescents who have been to the ED may have influenced the ability to detect effects of these variables. Therefore, these analyses should be repeated with a larger sample size to see if these factors may in fact be related to overall satisfaction. Also, the lack of relationship between patient-provider communication and satisfaction may be due to the fact that our survey evaluated patient-provider communication by assessing factors related to how well the provider

engaged with the patient, while some previous studies have examined patient-provider communication on the basis of provider characteristics, such as affect (Williams et al., 1998), which may have be more salient to patient satisfaction.

Originally, SCD severity was hypothesized to be related to overall satisfaction, with individuals with more severe SCD types reporting lower satisfaction. However, this relationship was not supported by the findings. VOE are the most common reason for ED use in children and adolescents with SCD, accounting for 79-91% of ED visits (Jacob & Mueller, 2008). Thus, because we are dealing with a select group of individuals who evidence the most severe symptoms of SCD, particularly pain requiring them to go to the ED, it is possible that there may be a ceiling effect which minimizes the influence of SCD type upon overall satisfaction. Also, SCD type is just one indicator of disease severity and a gross one at that, which may explain why SCD severity was not found to moderate the relationship between characteristics of care and overall patient satisfaction. Notably, the experience of pain is a more refined indicator of disease severity. As previous research has indicated that the lack of adequate pain management is significantly related to patient satisfaction ratings, it would be interesting to look more carefully at this relationship to ascertain whether or not the pain experience moderates the relationship between characteristics of care and satisfaction in the ED as pain resolution is such an integral part of care.

Other patient characteristics (e.g., age) were also found not to have a significant influence on the level of overall satisfaction with ED care. This was expected as it is consistent with findings from Brousseau et al. (2009) which also found no significant relationship between the age of the pediatric patient and the proportion of parents who were dissatisfied. This indicates that parents' reports of satisfaction with care are not heavily influenced by their child's

characteristics. Previous studies have sought to examine parent characteristics in relation to parent reported satisfaction of their child's ED experiences. However, these studies did not find parent characteristics to be significantly related to reported satisfaction (Magaret et al., 2002).

Limitations and Future Directions

A limitation of the current study is its retrospective nature. It is possible that participants may have exhibited some biases when asked to recall ED experiences that occurred over the past six months. It may be more beneficial to have participants describe their ED experiences as soon as they occur in order to avoid recall bias. Another limitation includes the fact that the survey was self-report. For example, because our survey was self-report, we have no objective measures of wait time, only the parents' perceptions of wait time. Of note, previous research that has compared the effects of actual versus perceived wait times upon patient satisfaction found that perceived waiting time, rather than actual waiting time, was predictive of patient satisfaction (Thompson et al., 1996). In addition, the current study involved a cohort of SCD patients from the same region and there are likely regional differences in the ED experiences of children and adolescents with SCD. As mentioned previously, the small sample size for the subsample that visited the ED may have affected our ability to detect effects and generalize findings to a larger population.

Lastly, the design of the self-report measure may have influenced the findings. The measure, though based on a validated assessment, is not standardized. In addition, it does not include questions about the participants' reasons for visiting the ED. Having a better understanding of presenting concerns when visiting the ED will enable us to better ascertain whether or not patient satisfaction differs depending upon the presenting concern of the patient. In addition, the survey may be improved by including more items to better assess each of the

domains of care, allowing for a more comprehensive understanding of the overall ED experience. To our knowledge, there are currently no measures of patient satisfaction designed specifically to assess the ED experiences of the pediatric SCD population. Therefore, efforts should be made to develop a measure that will allow a better understanding of health care experiences among this population.

Conclusion

In conclusion, these findings indicate that ED wait time and speed of care are the most important predictors of overall satisfaction in the ED and reducing ED wait time and increasing the rate at which effective care is afforded may be important for improving ED satisfaction for pediatric patients with SCD and their families. Further efforts are needed to develop strategies that will reduce wait time and increase the rate at which patients' needs are met in the ED and that will lead to the production of more effective care for this population. Reduction of wait times and increasing the speed of care may be aided by supplying ED providers with continued education concerning the urgency of SCD emergencies and systematic programming to decrease ED wait times, as well as by educating guardians regarding the importance of going to the ED when serious symptoms first arise and about realistic expectations regarding ED wait times.

As this study indicates that parents of children with SCD report moderate satisfaction with ED care, future studies need to examine the influence of satisfaction on the overall health and health behaviors of individuals with SCD. Previous research suggests that patient satisfaction within the healthcare system may be a predictor of health related behaviors and clinical outcomes, linking higher ratings of satisfaction to better compliance and medication adherence (Pascoe, 1983). Therefore, future studies should seek to understand the influence of overall ratings of satisfaction upon health related behaviors among the pediatric SCD population.

More specifically, research examining overall satisfaction as a predictor of SCD self-care behaviors, overall health-related behaviors, and clinical outcomes in this population would be beneficial for further understanding a comprehensive model of care for the pediatric SCD population and for eventually developing interventions to improve health outcomes within the population. In addition, future studies should assess satisfaction among the SCD population in other health care settings such as primary care to ascertain how ratings of satisfaction may differ depending upon the provider. Expanding this literature to examine satisfaction in different health care settings will lead to interventions that may help improve overall health care among this population.

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Appendix A: Patient Satisfaction Survey

CareCard Program Evaluation Survey

Child Name _____ Date of Birth _____ Today's Date _____

Name of Person Completing Form _____ Relationship to child _____

1. In the past 6 months, how many times did your child go to the emergency room? _____
If your child did not go to the emergency room in the past six months, you may stop here.
2. If you do not remember the exact number of times, what is your best guess about the number of times your child went to the emergency room?
 - none in the past six months
 - once or twice (1 or 2 times) in the past six months
 - 3 or more times in the past six months
3. Were you the person who took your child to the emergency room each time?
 - Yes
 - No If no, how many times were you the person who took your child to the emergency room? _____ times

For the following questions, please circle your answer: Never, Sometimes, Usually, or Always.

In the past 6 months, when you took your child to the emergency room,

4. How often did the doctors treat you with courtesy and respect?	Never	Sometimes	Usually	Always
5. How often did the doctors listen carefully to you?	Never	Sometimes	Usually	Always
6. How often did the doctors explain things to you in a way that you could understand?	Never	Sometimes	Usually	Always
7. How often did the doctors spend enough time with you?	Never	Sometimes	Usually	Always
8. How often was your child's pain well-controlled?	Never	Sometimes	Usually	Always
9. How often did the hospital staff do everything they could to help with your child's pain?	Never	Sometimes	Usually	Always
10. When your child needed care right away, how often did your child get care as soon as you thought he or she needed it?	Never	Sometimes	Usually	Always

11. In the past 6 months, when you took your child to the emergency room, how long did you have to wait to receive service (on average)? _____ hours
12. If you are not sure about the average number of hours, what is your best guess about how long you usually had to wait in the emergency room?
 - < 1 hr
 - 1-2 hrs
 - 3-5 hrs
 - 6-8 hrs
 - > 8 hrs
13. Using any number from 0 to 10 (0 = worst, 10 = best), what number would you use to rate your emergency room visits in the past 6 months? *(please circle one number)*

0 1 2 3 4 5 6 7 8 9 10

Appendix B: IRB Approval Documentation



EAST CAROLINA UNIVERSITY

University & Medical Center Institutional Review Board Office
1L-09 Brody Medical Sciences Building • 600 Moye Boulevard • Greenville, NC 27834
Office 252-744-2914 • Fax 252-744-2284 • www.ecu.edu/irb

TO: Beng Fuh, MD, ECU, BSOM, Pediatric Hematology/Oncology, PCMH MA Suite 333
FROM: UMCIRB *KWB*
DATE: June 1, 2011
RE: Expedited Continuing Review of a Research Study
TITLE: "Improving Sickle Cell Patient Care using Care Cards"

UMCIRB #10-0181

The above referenced research study was initially reviewed and approved by expedited review on 04/15/2010. This research study has undergone a subsequent continuing review using expedited review on **05/31/2011**. This research study is eligible for expedited review because it is research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior), or research employing survey, interview, oral history, focus groups, program evaluation, human factors evaluation, or quality assurance methodologies. (NOTE: some research in this category may be exempt from the HHS regulations for the protection of human subjects 45 CFR 46.101(b)(2) and (b)(3). This listing refers only to research that is not exempt. The Chairperson (or designee) deemed this **unfunded** study **no more than minimal risk** requiring a continuing review in **12 months**. Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The investigator must adhere to all reporting requirements for this study.

The above referenced research study has been given approval for the period of **05/31/2011 to 05/30/2012**. The approval includes the following items:

- Continuing Review Form (date 04/16/2011)
- Informed consent – Parental Permission (UMCIRB receipt date 05/09/2011)
- Informed consent – Adult Sickle Cell (UMCIRB receipt date 05/09/2011)
- Child Assent – (UMCIRB receipt date 05/09/2011)

The Chairperson (or designee) does not have a conflict of interest on this study.

The UMCIRB applies 45 CFR 46, Subparts A-D, to all research reviewed by the UMCIRB regardless of the funding source. 21 CFR 50 and 21 CFR 56 are applied to all research studies under the Food and Drug Administration regulation. The UMCIRB follows applicable International Conference on Harmonisation Good Clinical Practice guidelines.

