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# Examining Caregiver Coping and Clinic Attendance in Pediatric Sickle Cell Disease

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## Abstract

Sickle Cell Disease (SCD), the most common genetic disorder in the U.S., primarily affects youth of African or Latino backgrounds. Regular clinic attendance promotes positive health outcomes in pediatric SCD. Caregivers of youth with SCD endorse high levels of stress that may disrupt clinic attendance. Improved caregiver coping may help address barriers to clinic attendance in SCD families. The current study aimed to 1) describe the coping styles of caregivers of children with SCD, 2) assess clinic attendance rates in a pediatric SCD clinic, and 3) examine the relationship between caregiver coping and clinic attendance in pediatric SCD. Sixty-three caregivers and youth ($M_{age} = 13.2$, 60.3% male) completed the Responses to Stress Questionnaire- Sickle Cell Disease (RSQ-SC). The RSQ-SC assesses primary control engagement (PCE), secondary control engagement (SCE), and disengagement coping. The researchers tabulated percent of pediatric hematology appointments attended, canceled by patient/provider/due to hospitalization, and no-showed over the past year via medical chart review. Caregivers utilized more PCE and SCE coping responses compared to disengagement coping ($F(1.837, 113.924) = 86.071$, $p < .001$). The majority of appointments were attended (61%). A multiple regression revealed that higher PCE caregiver coping predicted lower rates of clinic non-attendance (percent of appointments canceled by patients and no-showed) [$F\ (3, 59) = 1.467$, $p = 0.050$, $R_2\,\Delta = .069$]. Therefore, caregiver coping may be an effective target for interventions focused on improving adherence to pediatric hematology appointments.

*Keywords:* sickle cell disease, caregiver coping, clinic attendance, pediatric psychology

## Introduction

Sickle Cell Disease (SCD) is a group of inherited disorders in which genetic mutations cause an abnormality in hemoglobin resulting in “sickled” red blood cells (CDC, 2017). These sickled red blood cells create blockages in blood flow that cause acute medical complications and chronic organ damage. SCD is the most common genetic disorder in the United States. SCD primarily affects youth of African or Latino ethnic backgrounds (CDC, 2017).

There are four main SCD genotypes (i.e., HbSS, HbS$\beta^0$, HbSC, HbS$\beta^+$). The severity and nature of SCD complications depends on the patient’s SCD genotype and disease management. Common complications associated with SCD include chronic and acute pain, anemia, infection, and stroke. The treatment regimen for SCD includes multiple different medical treatments. People living with SCD must attend regular healthcare appointments for routine vaccinations, Transcranial Doppler (TCD) testing for detection of stroke, blood transfusions, and the management of other disease-related factors. The only cure for SCD is bone marrow/stem cell transplant (CDC, 2017).

These symptoms and treatments can be overwhelming for families (Reader et al., 2017). Caregivers of children with SCD assume a large burden, as they must manage complicated treatment regimens and symptoms (Oliver-Carpenter et al., 2011). One determinant of disease management is caregiver coping. Parenting stress and health-related quality of life are interrelated in pediatric SCD (Barakat et al., 2007). Active coping (e.g., problem solving) promotes disease self-management and reduces health care utilization (Gil et al., 1991) while passive coping (e.g., denial) is associated with higher levels of healthcare utilization for children with SCD (Schlenz et al., 2014). Previous research demonstrates that caregivers of children with SCD use more engagement coping strategies (e.g., problem solving) compared to disengagement coping strategies (e.g., denial) (Barakat et al., 2007; Brown et al., 1993).

In addition, clinic attendance is a costly problem for many chronic illness populations (Dunbar-Jacob & Mortimer-Stephens, 2000). This is a specific concern for pediatric SCD as clinic attendance rates for this population are between 46-77% (Modi et al., 2012; Thornburg et al., 2010). Barriers to proper clinic attendance in pediatric SCD include forgetfulness, negative patient-provider relationships (e.g., concern that healthcare providers do not understand SCD) and unsatisfactory healthcare experiences (e.g., lack of attention from healthcare providers during clinic appointments) (Crosby et al., 2009). Clinic attendance is important to examine in SCD since it has predicted effective disease management in other populations (Markowitz et al., 2014; Park et al., 2007).

Previous literature has demonstrated spirituality, social support, and literacy as protective factors for clinic attendance. Meanwhile, risk factors for clinic non-attendance in SCD include financial insecurity, cognitive impairment, and depression (Cronin et al., 2018). Effective caregiver coping has the potential to address some of these protective and risk factors and improve clinic attendance in pediatric SCD patients. Although clinic attendance is an important aspect of SCD management (CDC, 2017), there is limited research regarding the distinct relationship between caregiver coping and clinic attendance in this population. Therefore, the current study aims to explore this relationship and the potential for caregiver coping to serve as an effective target in interventions aimed at improving clinic attendance in pediatric SCD patients.

## Aims and Hypotheses

The study's first aim is to describe the voluntary coping styles utilized by caregivers of children with sickle cell disease. The authors hypothesized that caregivers would endorse more engagement coping responses compared to disengagement coping responses. The second aim is to assess clinic attendance rates in the UF Health Pediatric Sickle Cell Disease specialty clinic. The researchers hypothesized that there would be a greater frequency of appointments attended and that the rates of no-showed and canceled (by patient, provider, or due to hospitalization) appointments would be similar. The third aim is to examine the relationship between caregiver coping styles and clinic attendance rates in a pediatric sickle cell disease population. The researchers hypothesized that increased caregiver engagement coping would be associated with a lower percentage of non-attended appointments (appointments canceled by patients and no-showed).

## Method

### Participants

Participants (*N* = 63) included youth diagnosed with SCD and their caregivers. These dyads were recruited as part of a larger study from the UF Health Pediatric Hematology/Oncology Clinic. Youth participants included 38 males (60%) and 25 females (40%). The majority of youth were diagnosed with one of the two more severe types of SCD (HbSS: 62%, $HbS\beta^0$: 6%). Most youth identified as African American (97%). Caregivers ranged from 24-63 years old (*M* = 39.3, *SD* = 8.7). Most caregivers were female (90%) and mothers (84%); however, fathers (8%) and other caregivers (8%) participated. The majority of caregivers identified as African American (95%). The majority of families had an annual income of $34,999 or less (68%), and almost half of families (46%) were living below the poverty line (U.S., 2014).

### Measures

Caregivers completed the following questionnaires using paper and pen.

**demographic information and medical history.** Caregivers provided the following information: relationship to the participating child, gender, age, total number of people living in their home, employment status, race, total income, highest level of education attained, and their child’s gender and race.

**caregiver coping.** The Responses to Stress Questionnaire- Sickle Cell Disease version (RSQ-SC) assessed caregiver coping strategies. The RSQ-SC measures involuntary (i.e., automatic) and voluntary (i.e., coping) responses to SCD-related stress (Connor-Smith et al., 2000). For the purposes of this study, the authors only reported voluntary responses since these are within the caregiver’s control, and therefore, modifiable by intervention. The RSQ-SC distinguishes voluntary coping responses as primary control engagement (PCE), secondary control engagement (SCE), and disengagement coping (Connor-Smith et al., 2000). PCE coping includes emotional regulation/expression and problem solving. SCE coping includes cognitive restructuring, positive thinking, and acceptance. Disengagement coping includes denial, distraction, avoidance, and wishful thinking (Connor-Smith et al., 2000). Caregivers reported their endorsement of specific coping responses (e.g., “When I’m around other people, I act like my child’s sickle cell disease does not exist”) to SCD-related stress. Higher scores indicated higher use of specific coping responses.

The RSQ-SC has strong psychometric properties and is a valid measure for studying coping in pediatric SCD (Prussien et al., 2017; Compas et al., 2012). The RSQ uses proportion scoring in which each sub-scale coping score is divided by the total RSQ score. The coping literature utilizes proportion scores to control for individual differences in the base rate of item endorsement and response bias (Osowiecki & Compas, 1999; Vitaliano, et al., 1990).

**clinic attendance.** Study staff collected clinic attendance rates for each child from UF Health’s electronic medical record system (Epic). All pediatric hematology appointments within the past year from the participant’s study date were included in one of five groups: appointments attended, canceled by the patient, canceled by a provider, canceled due to patient hospitalization, or no-showed.

A medical provider in the UF Health Pediatric Hematology/Oncology Clinic and a UF Health Information Technology specialist provided consultation in establishing a categorization scheme for clinic attendance collection. The researchers devised an appointment categorization scheme based off the “Description” label for each appointment in Epic. Study staff followed standard procedures and reached consensus for each disputed appointment. Several youth participants received routine blood transfusions which consist of two separate appointments occurring 2-3 days apart. Study staff were advised to only count one appointment per transfusion treatment.

The researchers calculated clinic attendance variables by dividing scores for appointments attended, canceled by the patient, canceled by the provider, canceled due to patient hospitalization, or no-showed by the total number of appointments. The following equation serves as an example.

$$Appointments\ Attended\ (\%) = \frac{\#\ of\ appointments\ attended}{\#\ of\ total\ appointments}$$

An additional percent non-attendance variable was created using the following formula:

$$Non - Attendance\ (\%) = \frac{\#\ of\ appointments\ canceled\ by\ patients + \#\ of\ appointments\ no{-}showed}{\#\ of\ appointments\ attended + \#\ of\ appointments\ canceled\ by\ patients + \#\ of\ appointments\ no{-}showed}$$

Appointments canceled by providers and appointments canceled due to patient hospitalization were not included in the denominator of this formula because patients did not have the opportunity to attend these appointments. Therefore, the percent non-attendance variable captures the percent of appointments that were missed by patients out of the total number of appointments that patients could attend.

### Statistical Analyses

The authors conducted all statistical analyses using The Statistical Package for Social Sciences (SPSS) Version 25.0. Descriptive statistics characterized caregiver coping and clinic attendance. Additionally, a repeated measures ANOVA compared the frequencies of coping styles endorsed by caregivers.

A Pearson correlation test examined the relationship between potential covariates (child age, child gender, SCD genotype, family income, and caregiver education) and percent non-attendance. These potential covariates were determined based off previous literature in pediatric clinic attendance (Paterson et al., 2010; Cronin, et al., 2018; Shaffer et al., 2016; Schlenz et al., 2016).

A multiple linear regression tested whether the three types of voluntary caregiver coping (PCE, SCE, and disengagement) (IV's) predicted percent non-attendance (DV).

## Results

### Descriptive Findings

**aim 1: caregiver coping.** Proportion scores from the RSQ-SC indicated that the most common voluntary coping style was SCE coping (*M* = 0.28, *SD* = 0.05). PCE coping (*M* = 0.21, *SD* = 0.05) and disengagement coping (*M* = 0.13, *SD* = 0.03) were the second and third most common voluntary coping styles, respectively.

A repeated measures ANOVA using raw scores and a Greenhouse-Geisser correction demonstrated a significant difference within the three voluntary coping scores (*F*(1.837, 113.924) = 86.071, *p* < .001). Post hoc comparisons using the Bonferroni correction revealed that caregivers in this sample utilized significantly more PCE coping responses (*M* = 2.75, *SD* = 0.66) compared to disengagement coping responses (*M* = 1.75, *SD* = 0.54). Caregivers also used significantly more SCE coping responses (*M* = 2.78, *SD* = 0.66) compared to disengagement coping responses (*M* = 1.75, *SD* = 0.54); however, there was not a significant difference between caregiver use of PCE (*M* = 2.75, *SD* = 0.66) and SCE coping responses (*M* = 2.78, *SD* = 0.66).

**aim 2: clinic attendance rates.** The majority of pediatric hematology appointments in this sample were attended (*M* = 0.61, *SD* = 0.24). Non-attended appointments included appointments canceled by the patient (*M* = 0.16, *SD* = 0.15), no-showed (*M* = 0.12, *SD* = 0.15), canceled by a clinic provider (*M* = 0.09, *SD* = 0.13), or canceled due to patient hospitalization (*M* = 0.02, *SD* = 0.06).

### Hypothesis Testing

**aim 3: relationship between caregiver coping and clinic attendance.** A Pearson correlation test between potential covariates and percent non-attendance revealed no significant relationships.

**Table 3-1.** Correlations between Covariates and Percent Non-attendance

| | % Non-attendance | Caregiver Education | Child Age | Child Gender | SCD Genotype | Family Income |
|---|---|---|---|---|---|---|
| Caregiver Education | -0.18 | 1 | | | | |
| Child Age | 0.00 | | 1 | | | |
| Child Gender | 0.04 | | | 1 | | |
| SCD Genotype | -0.11 | | | | 1 | |
| Family Income | -0.14 | | | | | 1 |
| % Non-attendance | 1 | -0.18 | 0.00 | 0.04 | -0.11 | -0.14 |

*Note.* PCE= primary control engagement, SCE= secondary control engagement,
SCD genotype: dichotomous variable; more severe (HbSS or HbSβ0) and less severe (HbSc or HbSβ+)
Family income (annual): 0 = less than \$5,000; 1 = \$5,000-11,999; 2 = \$12,000-15,999; 3 = \$16,000-24,999; 4 = \$25,000-34,999; 5 = \$35,000-49,999; 6 = \$50,000-74,999; 7 = \$75,000-99,999; 8 = \$100,000 +

A multiple linear regression analyzed the impact of caregiver coping (PCE, SCE, and disengagement coping) on percent non-attendance. All general linear model assumptions were met, and there was no multicollinearity between the three coping scores. The results indicated that a higher frequency of PCE caregiver coping predicted lower percent non-attendance [$F$ (3,59) = 1.467, $p$ = 0.050, $R_2 \Delta = 0.069$]. The effect size of the regression model was small-to-medium ($F^2 = 0.07$).

**Table 3-2.** Multiple Linear Regression Analysis of Caregiver Coping on Percent Appointments Attended

| Step | | $\beta$ | $b$ | $t$ | $p$ | 95% Confidence Interval | $R^2$ | $F^2$ | $n$ |
|---|---|---|---|---|---|---|---|---|---|
| 1 | Caregiver Coping | | | | .12 | | 0.07 | 0.07 | 63 |
| | PCE Coping | -0.28 | -1.38 | -2.00 | .05 | [-2.77, -0.00] | | | |
| | SCE Coping | 0.13 | 0.60 | 0.93 | .36 | [-0.70, 1.91] | | | |
| | Disengagement Coping | -0.08 | -0.68 | -0.53 | .60 | [-3.25, 1.89] | | | |

*Note.* PCE = primary control engagement, SCE = secondary control engagement

## Discussion

Caregiver coping rates in this sample compare to previous SCD research (Barakat et al., 2007). Overall, the results of the ANOVA supported the authors' hypothesis that SCD caregivers in this sample would utilize more engagement coping strategies compared to disengagement coping strategies. This is encouraging, as engagement coping can improve pain management and healthcare utilization in pediatric SCD (Schlenz et al., 2014).

The results supported the authors' second hypothesis that there would be a greater frequency of appointments attended and that the rates of no-showed and canceled appointments would be similar. Clinic attendance rates were comparable to those reported in previous SCD literature (Modi et al., 2012; Thornburg et al., 2010). However, clinic attendance rates in the current sample and those reported in previous pediatric SCD literature are lower than other pediatric illness populations (Modi et al., 2012; Thornburg et al., 2010). Clinic attendance rates are between 57-94% and 66-92% appointments attended in pediatric diabetes and pediatric asthma, respectively (Kipp et al., 2001; Cadario et al., 2009; Yoon et al., 2005; Welcom et al., 2015; Goldbart et al., 2009).

There is room for improvement in pediatric SCD clinic attendance. Research suggests that healthcare administrators and providers can make changes to improve clinic attendance. Provider should make their clinic spaces developmentally appropriate for a wide range of youth and improve communication among staff (Crosby et al., 2009). Providers should regularly solicit feedback from patients since patient satisfaction has been associated with improved clinic attendance (Freed et al., 1998; Smith & Yawn, 1994).

Research demonstrates the potential for alternative deliveries of care to improve clinic attendance rates in pediatric SCD. Many SCD families express a need for more flexible clinic appointment schedules (Crosby et al., 2009). Pediatric SCD healthcare administrators and providers should offer more diverse clinic appointment times (e.g., evenings and weekends). There is potential for technology (e.g., a web-based Disease Management Interview-SCD (WDMI), phone call/text message reminders) to improve clinic attendance in pediatric SCD (Modi et al., 2012; O’Brien & Lazebnik, 1998; Sawyer et al., 2002).

The results of the regression supported the authors’ third hypothesis that greater rates of engagement coping would be associated with a lower frequency of non-attended appointments. The results indicate that caregiver primary control engagement (PCE) coping responses (e.g., problem solving) may contribute to successful clinic attendance in pediatric SCD families (Prussien et al., 2018). To our knowledge, this is the first study to examine caregiver coping as an isolated predictor of clinic attendance in pediatric SCD. Further exploration of the psychosocial factors related to clinic attendance in pediatric SCD is necessary to inform interventions in this illness population. The results of the current study suggest that caregiver PCE coping may be an effective target for current and future interventions aimed at improving attendance to pediatric hematology appointments in pediatric SCD. Pediatric SCD providers should encourage caregivers to utilize PCE coping responses when facing barriers to clinic attendance.

There are several limitations to consider. Self-reporting measures for coping are common in pediatric health literature (Brown, et al., 2000; Compas et al., 2012); however, it is possible that caregivers had a positive response bias in completing the RSQ-SC. Clinic appointment rates varied greatly among participants due to individual appointment regimens; however, the categorization scheme did not account for these differences. In addition, there are many factors that impact a patient's ability to attend clinic appointments (e.g., transportation) which were not measured in this study.

## Conclusion

Future research should utilize a larger sample to investigate the impact of caregiver coping on clinic attendance in pediatric SCD populations. Future research should account for participants' unique clinic schedules since this may influence the impact of psychosocial factors on clinic attendance. Future studies should examine other factors potentially related to clinic attendance in pediatric SCD including patient-provider relationships, families' distance to clinics, medical insurance status, responsibility sharing among SCD families, and the use of technology.

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