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MIXED-METHODS ANALYSIS OF PICA IN PEDIATRIC SICKLE CELL DISEASE

by

NIKITA P. RODRIGUES

Under the Direction of Lindsey Cohen, PhD

ABSTRACT

Pica is the developmentally inappropriate consumption of non-nutritive items for at least one month. Pica can lead to many adverse outcomes, but the exact pathophysiology of pica is unknown or variable across populations. Several studies have evidenced that there is a high prevalence of pica among youth with sickle cell disease (SCD). The overall aim of this study was to examine correlates of pica in pediatric SCD from a biopsychosocial framework. Qualitative ($n = 21$) and quantitative methods ($n = 58$ children with SCD and pica) were used to describe a sample of children with SCD and pica. Additionally, exploratory comparisons were conducted between children with SCD and pica and children with SCD without pica ($n = 55$) to examine relationships between hypothesized contributing variables and pica. Results supported the relationship between several psychosocial variables and pica and highlighted areas and methods for future research in this area. Additionally, clinically implications informed by this study are discussed.

INDEX WORDS: Pediatric, Pica, Sickle Cell Disease, Mixed-Methods

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NIKITA P. RODRIGUES

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

1   INTRODUCTION

Pica is the developmentally inappropriate consumption of non-nutritive items for at least one month (American Psychiatric Association, 2013). Pica can lead to many adverse outcomes that are well documented, but the exact pathophysiology of pica is unknown or variable across populations. Studies have evidenced that there is a high prevalence of pica among youth with sickle cell disease (SCD); 34-66% of pediatric patients with SCD have comorbid symptoms of pica (e.g., Hackworth & Williams, 2003; Lemanek et al., 2002). SCD is a group of inherited blood disorders, which are characterized by vaso-occlusive pain, fatigue, organ damage, and immunodeficiency. SCD can have multiple effects on quality of life for children including frequent school absences, reduction in daily activity, increased psychopathology, and reduced opportunities for social recreation (e.g., Anie, 2005; Edwards et al., 2005; Fuggle, Shand, Gill, & Davies, 1996). Although studies have detailed the relationships between many psychosocial factors and SCD symptomology, little work has been done examining the correlates of pica in SCD. When examining nutritionally-based therapies for SCD, Khan et al. (2016) noted that despite the fact that many children with SCD are affected by pica, pica has not gained the focus of health care providers. Related, despite the well-documented prevalence rates, clinical psychologists working with pediatric patients with SCD are left without evidenced-based treatment for this condition. Additionally, without theoretical understanding of the etiology of pica in SCD, it can be difficult to guide treatment decisions. Currently, the lack of knowledge regarding the correlates of pica contributes to clinically missing the condition, inaccurate diagnoses, and a lack of evidence-based treatments once pica is determined to exist. The overall aims of this study are to apply a biopsychosocial framework to better understand the correlates and possible etiological factors of pica in pediatric SCD.

1.1   Overview of Pica

Pica is the developmentally, culturally, and socially inappropriate and persistent consumption of non-nutritive items (e.g., paper, dirt) for at least one month. If it co-occurs with another mental (e.g., intellectual disability) or medical condition (e.g., pregnancy), the behavior must be in excess of what might be expected (American Psychiatric Association, 2013). Pica can lead to intoxication and can cause impairment in both mental and physical development (Blinder & Salama, 2008). Ingestion of non-food substances can result in serious health complications, including intestinal obstruction (Anderson, Akmal, & Kittur, 1991; Chiu, Ciaccio, & West, 2005); development of gastric bezoars, which are solid masses of indigestible material that accumulate in the digestive tract (Sprinkle & Hingsbergen, 1995; Stein-Wexler et al., 2006); lead poisoning (Issaivanan, Ahmed, Shekher, Esernio-Jenssen, & Manwani, 2009; Jones, 2009); dental injury (Barker, 2005); and electrolyte imbalance (Appel & Bleyer, 1999). Various substances have been reported to be craved and consumed including ice, clay or soil, grass, leaves, starch, plaster, paint chips, string, paper, cigarettes, buttons, and insects (Sayetta, 1986). The most common forms of pica are geophagia (soil), pagophagia (ice), and trichophagia (hair) (Gupta, Rajput, Maduabuchi, & Kumar, 2007).

In the general population, pica is most common in young children (Chatoor & Ammaniti, 2007), but it has also been reported in pregnant women (Corbett, Ryan, & Weinrich, 2003; Simpson, Mull, Longley, & East, 2000), individuals with intellectual and developmental disabilities (Danford & Huber, 1982, Matson & Bamburg, 1999; Williams, Kirkpatrick-Sanchez, Enzinna, Dunn, & Borden-Karasack, 2009), and individuals in lower socioeconomic groups (Rose, Porcerelli, & Neale, 2000). Across the world, 25-33% of all pica cases occur in childhood, 20% in pregnant women, and 10-15% in individuals with intellectual and

developmental disabilities (Barker, 2005). An increased incidence of pica in children with SCD has also been noted (Ahmed, Gaboli, & Attalla, 2015).

1.2   Overview of SCD

SCD is a group of genetic disorders characterized by the presence of abnormal hemoglobin S. This abnormal hemoglobin has a propensity to polymerize, or sickle, in some conditions and can lead to anemia, decreased oxygen delivery, and tissue hypoxia due to vaso-occlusion (Rogers & Lance, 2017). There are multiple genotypes of SCD; the majority of patients with SCD in the United States fall into four genotypes: Hemoglobin (Hb) SS (sickle cell anemia; ≈60% of patients), HbSC (≈30% of patients), and HbSβ° and HBSβ$^+$ (≈10% of patients) (Hassell, 2010). Patients with HbSS and HbSβ° thalassemia genotypes generally present with more severe symptoms and patients with HbSC and HbSβ$^+$ thalassemia generally present with more mild symptomology (Dampier, Ely, Brodecki, & O'Neal, 2002; Gill et al. 1995; Platt et al., 1991). However, all patients with SCD are at risk oflinic progressive organ damage, stroke, and silent cerebral infarcts (Kwiatkowski et al., 2009; Powars, Chan, Hiti, Ramicone, & Johnson, 2005; Quinn, Rogers, McCavit, & Buchanan, 2007). A recent United States birth cohort disease prevalence study revealed that approximately 119,000 individuals in the United States live with SCD and roughly 70-99% of these individuals are African American (Hassell, 2010). It is estimated that approximately 5,000 of these individuals living with SCD reside in the state of Georgia (Hassell, 2010).

Improvements in screening and treatment over the past 50 years have resulted in improved survival rates for individuals with SCD, with the average life expectancy increasing from 20 years in 1990 to approximately 38-48 years in 2005 (Lanzkron, Carroll, & Haywood, 2013; Platt et al., 1994). Previous studies of children with SCD have predominately applied a

biopsychosocial perspective on children's functional disability and psychosocial adjustment to pain (Schlenz, Schatz, & Roberts, 2016). These biopsychosocial perspectives have laid important groundwork in illustrating how psychosocial factors influence adjustment in children with SCD. However, one important and common comorbid psychological disorder, pica, has largely been ignored in pediatric SCD.

1.3   Pica in SCD

Research indicates a high prevalence of pica among youth with SCD (Hackworth et al., 2003; Lemanek et al., 1996). Based on one medical chart review, about 34% of 295 children with SCD were found to have pica, with a higher prevalence (36%) among youth with greater disease severity (i.e., HbSS) (Ivascu et al., 2001). Lemanek et al. (2002) assessed 139 youth with SCD and noted that 51.8% of children demonstrated clinically significant levels of dysfunctional eating patterns that included pica. Additionally, for children with sickle cell anemia and lead poisoning, 76% reported a positive history of pica (Issaivanan et al., 2009). A recent examination of pica in a Belgian cohort of children with SCD reported 56.4% exhibited symptoms of pica (Aloni et al., 2015). Ahmed et al. (2015) reported that 66.2% of Sudanese children with sickle cell anemia reported pica. In our setting, a pediatric healthcare system in Atlanta, Georgia, a recent study suggests that roughly 21-34% of patients with SCD, seen by psychological services, met criteria for pica (Reed-Knight, Thompson, Bigham, Sil, Griffin, & Johnson, 2015).

The exact pathophysiology of pica is unknown, though different contributing factors have been hypothesized and supported. A recent clinical review of pica across presentations conducted by Rose et al. (2000) noted that although pica has been evidenced since antiquity, there is no clear explanation for the cause of pica behavior. Their review of the literature suggested that the cause of pica is likely related to many factors that are complicated by the question of whether pica is a cause or effect of metabolic or behavioral states (Rose et al., 2000).

Several case studies examining pica have found benefits in conceptualizing symptoms from a biopsychosocial perspective (Hackworth & Williams, 2003; O'Callaghan & Gold, 2012; Stein-Wexler et al., 2006). Using a biopsychosocial framework, this study will cross-sectionally examine multiple variables that have suggested relationships with pica behavior in SCD (Figure 1).
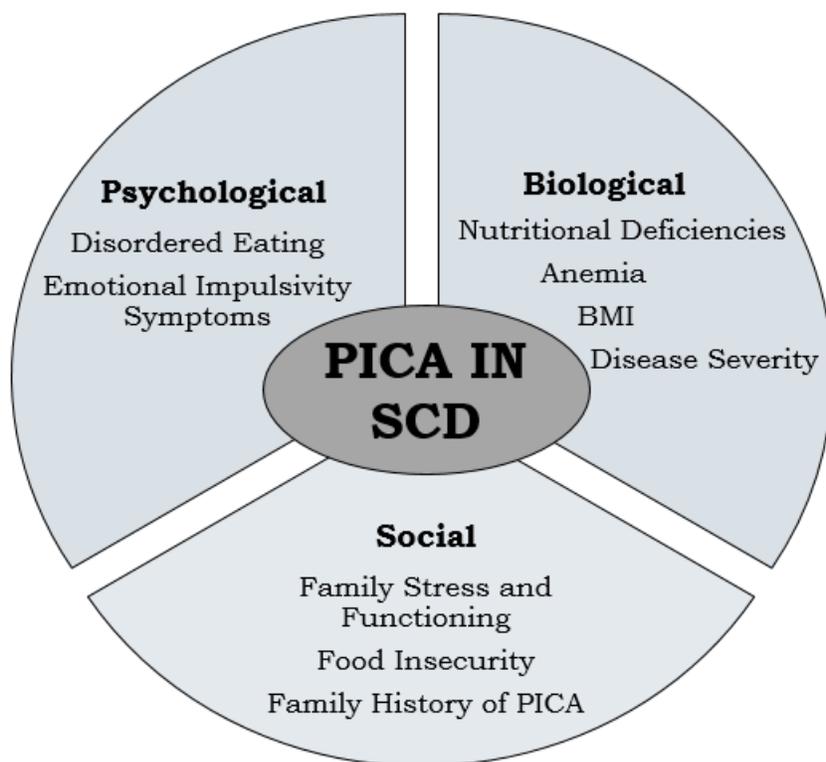
Figure 1 Biopsychosocial Model applied to Pica in SCD

1.4 Potential Correlates of Pica in SCD: Biological Variables

Sayetta (1986) ascertained that the strongest empirical evidence available on pica covariates supports nutritional deficiencies, specifically noting iron and zinc deficiencies as contributing factors to abnormal cravings. The author highlighted that for these patients, the item chosen in pica is often a poor source of the needed nutrient (e.g., clay or dirt) and ingestion of the substance may actually worsen the need and craving for further pica ingestion. However, for

these cases, appropriate mineral replacement therapy (e.g., iron supplementation) can quickly decrease pica behavior (Crosby, 1976). In studies of women who are pregnant, atypical levels of serum ferritin, iron deficiency, lower hemoglobin levels, and lower mean corpuscular volume were found at delivery in those pregnant mothers who engaged in pica (Lopez, Langini, & Pita de Portela, 2007; Rainville, 1998). This is consistent with the hypothesis that micronutrient deficiencies, particularly in iron, zinc, and calcium, are correlated with pica behavior during pregnancy (Young, 2010). Additionally, pediatric patients exhibiting pica have evidenced decreased iron and zinc absorption compared with control subjects (Arcasoy, Cavdar, & Babacan, 1978).

Pica has been found to be associated with iron deficiency anemia (Barker, 2005; Coltman, 1969; Karnath, 2004; Kathula, 2008; Kettaneh et al., 2005; Kushner, Gleason, & Shanta Retelny, 2004). When associated with iron deficiency, most researchers believe that pica is an effect rather than a cause (Kettaneh et al., 2005; Kushner et al., 2004), but further longitudinal study is necessary. However, supporting the idea that pica is the effect in this relationship, MacDonald and Marshall (1964) demonstrated decrease in pica in children with iron deficiency anemia with adequate hemoglobin maintenance through iron therapy. Other studies have similarly found a resolution for pica through iron level-maintenance in a variety of populations including SCD (Vinchinsky et al., 1981), iron deficiency anemia (Arbiter & Black, 1991, Bay et al., 2013; Singhi, Ravishanker, Singhi, & Nath, 2003), and celiac disease (Santos & Werdin, 1996). However, most studies in this area, both looking at correlates of pica and examining resolution of pica by iron supplement, are reports of case studies.

A recent meta-analysis found pica in a variety of patient populations to be associated with increased risk of anemia and low plasma zinc levels (Miao, Young, & Golden, 2015). Zinc

deficiency in SCD has been shown to be due to hyperzincuria from a decreased renal tubular reabsorption of zinc due to renal damage from repeated sickling (Yuzbasiyan-Gurkan, Brewer, Vander, Guenther, & Prasad, 1989). Serum zinc was significantly lower in children with pica and sickle cell anemia than those who did not report pica symptoms (Ahmed et al., 2015). Karayaclin and Lanzkowdky (1976) reported pica resolution following zinc supplementation. Sharma et al. (2014) found a rapid improvement in pica after children were prescribed supplementary zinc and iron and initiated an increased zinc and iron diet.

Although the evidence supporting the relationship between micronutrient deficiencies and pica is relatively strong, the strength of the association between pica and micronutrient deficiencies has been inconsistent. In a recent review of 28 cross-sectional general population studies of the association between pica and iron deficiency and/or anemia, pica was associated with iron deficiency or increased risk for anemia in only 19 studies (Young et al., 2010). Data from the few available intervention studies are also inconclusive. Some case series have noted that iron and zinc supplementation were associated with cessation of pica behaviors (Bhalla, Khanna, Srivastava, Sur, & Bhalla, 1983; Chen et al., 1985; Coltman, 1969; Lofts, Schroeder, & Maier, 1990), but these studies lacked controls and rigorous blinding. The two controlled double-blind studies of the effect of iron supplementation on geophagy (i.e., eating chalk or clay) found no effect (Gutelius, Millican, Layman, Cohen, & Dublin, 1962; Nchito, Geissler, Mubila, Friis, & Olsen, 2004). Additionally, although some studies have evidenced relations of micronutrient deficiencies to pica in SCD (Ahmed et al., 2015; Ivascu et al., 2001), others have found no differences in SCD groups with and without pica (Aloni et al., 2014).

Other biological variables hypothesized to be related to pica include markers of disease severity including: hemoglobin S level (HbS), hematocrit level, and reticulocyte count. A meta-

analysis across samples (e.g., adults, children, individuals who were pregnant) found that pica was a marker for micronutrient deficiencies, noting significant associations with lower hemoglobin concentration, lower hematocrit concentration, and lower plasma zinc concentration (Miao, Young, & Golden, 2015). Hemoglobin is the most important component of red blood cells as it aids in the uptake of oxygen and release of carbon dioxide. When there is a higher level of HbS, the red blood cell will lose oxygen and appear sickle or crescent in shape. These sickle-shaped cells will then stick to the walls and have difficulty squeezing through the capillaries. Several studies reporting hemoglobin count found that hemoglobin S was significantly lower in children with pica and sickle cell anemia than those who did not report pica symptoms (Ahmed et al., 2015; Aloni et al., 2014; Castiglia, 1993; Geissler et al., 1998; Ivascu et al., 2001).

Another marker of disease severity found to be associated with pica is hematocrit level. The hematocrit is the proportion, by volume, of blood that consists of red blood cells and is expressed as a percentage (e.g., a hematocrit of 35% means that there are 35 milliliters of red blood cells in 100 milliliters of blood). The average range for hematocrit in healthy children ranges from 36-40%. Abnormal hemoglobin, as found in sickle cell anemia, is related to low hematocrit levels, and some studies have found that hematocrit levels were significantly lower in children with pica and sickle cell anemia that those without pica (Ivascu et al., 2001).

Additionally, studies have found that reticulocyte count was significantly higher in children with pica and sickle cell anemia than those who did not report pica symptoms (Ahmed et al., 2015; Aloni et al., 2014). Reticulocytes are newly produced, relatively immature red blood cells. The reticulocyte count rises when red blood cells are destroyed prematurely, which is common in sickle cell anemia. These relationships suggest that pica could be linked to severity

of chronic hemolysis as lower hemoglobin, lower hematocrit level, and higher reticulocyte count are markers of more severe SCD symptomology. However, the association remains unknown, and the direction of the relationship is often debated (i.e., does pica cause anemia or does anemia cause pica) (Ahmed et al., 2015). Additionally, other markers of disease severity (e.g., days in hospital, number of hospitalizations) have not been shown to be related to pica, thus the relationship between pica and disease severity is still unclear.

Finally, height and weight might be related to pica. Specifically, weight has been found to be lower among children with SCD and pica compared to those with SCD and no pica (Ahmed et al., 2015; Ivascu et al., 2001). Children with SCD and pica might be shorter than those without pica (Ahmed et al., 2015). However, similarly to other markers of disease severity, the direction of relationship between pica and physical development is unclear at this time as the dietary consequences of engaging in pica may also impact physical development.

1.5   Potential Correlates of Pica in SCD: Psychological Variables

Other theories of pica suggest possible relations with psychological problems including disordered eating, and obsessive-compulsive symptomology (Ukaonu, Hill, & Christensen, 2003). Supporting this position, some studies have evidenced the effectiveness of behavioral strategies in the treatment of pica (Hackworth, 1998; Finney, Russo, & Cataldo, 1982)

There is some evidence that pica is part of the obsessive-compulsive disorder (OCD) spectrum. A few studies have found an association between pica and OCD in healthy adults and commented on the compulsive nature of this behavior (Gundogar et al., 2003, Luiselli, 1996; Stein, Bouwer, & Van Heerden, 1996). In fact, it has been suggested that pica be reclassified in the Diagnostic and Statistical Manual of Mental Disorders (DSM) as an OCD-related disorder (Lacey, 1990; Upadhyaya & Sharma, 2012). One study of pica outlining five case studies

depicted patients who describe their pica behaviors as ritualistic behaviors they feel compelled to carry out, and that eating the desired substance leads to relief of tension or anxiety (Stein et al., 1996). Additionally, Stein et al. (1996) argued that pica may be reminiscent of an impulse control disorder, and that while all patients exhibited symptoms of impulsivity, only some of their patients had a compulsive nature to their engagement in pica. Some studies have found a reduction with SSRI treatment (Bhatia & Gupta, 2009; Gundogar et al., 2003); however, traditional behavioral treatment of OCD (psychotherapy) did not show the same effects on pica-related OCD as with other OCD presentations (Stein et al., 1996). It has also been suggested that pica is an outcome of both the impulsive nature of OCD and difficulties with emotion regulation (Bhatia & Gupta, 2009). When looking at emotion-based impulsivity, researchers often make a distinction between positive urgency, or the tendency to engage in impulsive behaviors in response to positive emotion, and negative urgency, the tendency to engage in impulsive behaviors in effort to mediate negative emotion (Cyders & Smith, 2008). The relationship between emotional impulsivity and pica has not been examined in children with SCD.

Within the psychological domain, Lemanek et al. (2002) were the first to explore the idea that pica is simply a symptom of larger patterns of dysfunctional eating. They suggested that patients with pica might be engaging in this practice as a way of mediating stress or other negative emotion. Like other dysfunctional eating patterns, such as over-eating and stress-induced eating of nutritive items, pica may lower stress by causing a release of dopamine and endogenous opioid peptides (Morley, Levine, & Rowland, 1983; Rowland & Antelman, 1976). Lemanek et al. (2002) found that caregivers of children with no symptoms of pica reported fewer dysfunctional eating patterns compared to caregivers of children with severe pica symptoms.

However, it should be noted, that their sample of children with severe pica symptoms was small ($n = 7$).

1.6 Potential Correlates of Pica in SCD: Social Variables

Other theories of pica in the general population have suggested an association with increased family stress or decreased family functioning (Edwards et al., 1994; Sayetta, 1986). Multiple studies have found that high family stress is common in families of patients with sickle cell anemia (e.g., Anie, 2005). Singhi, Singhi, and Adwani (1981) found that children with pica and iron deficiency anemia had significantly greater family stress than those without pica. They applied theories from the literature on general disordered eating behavior (i.e., anorexia, bulimia) and suggested that pica might be a response to stress that functions via various mechanisms (Singhi et al., 1981). Specifically, one mechanism through which stress may impact eating behavior is cortisol. Heightened cortisol has been shown to be a symptom of stress recovery, and is also known to stimulate appetite (Takeda et al., 2004). Additionally, studies have found that many people respond to chronic stressful situations by seeking out and consuming energy and nutrient dense foods (Oliver, Wardle, & Gibson, 2000; Schiffman, Graham, Sattely-Miller, & Peterson-Dancy et al., 2000). Other researchers have suggested that children develop pica in stressful environments through the use of oral activities to self-soothe when parental comfort is not adequate (Millican, Lourie, & Lawyman, 1956; Pueschel, Cullen, Howard & Cullinane, 1977). It is possible that children in heightened stress environments, with little control over food availability and familial comfort, may resort to pica as a way to manage their stress.

Pica has also been found to be more common in families with low socioeconomic status (SES) (Sayetta, 1986). This may be due to confounding features like high nutritional demands, less supervision of eating behaviors, and culturally ingrained preferences. Additionally, given the confounding nature of family history of pica and low SES, it is possible that pica may have a

genetic or inherited component (Ahmed et al., 2015). Along with the identified relationship

between pica and low SES, some researchers have suggested that pica may be a product of

inadequate food supply and food insecurity (Hackworth & Williams, 2003). Lower

socioeconomic status has been associated with pica during pregnancy (Lacey, 1990; Rose,

Porcerelli, & Neale, 2000; Simpson et al., 2000). However, no study to date has directly

examined this relationship for children with SCD.

Studies of pica in the general population have suggested that approximately 44% of

children with pica have a family history positive for pica (Gupta & Gupta, 2005; Robinson,

Tolan, & Golding, 1990). Ahmed et al. (2015) found that a family history of pica was present in

63.3% of pediatric SCD patients with pica. This suggests that there may be a learned or cultural

component to the initiation of pica behaviors, as well as a possible genetic or inherited risk.

Additionally, studies have found geographic trends of pica, specifically noting that there are

higher rates of pica in the southern United States (Rose et al., 2000). Familial and cultural pica

remains a common practice in communities all over the world, with reports of clay eating

common in pregnancy in India (Nag, 1994) and in fertility rituals in East Africa (Abrahams &

Parsons, 1996). Cultural pica is less commonly reported in the United States, but one study

documented the ingestion of kaolin (i.e., "white dirt," "chalk," or "white clay") in central

Georgia, specifically common in groups of African American women and men (Grigsby et al.,

1999). Grigsby et al. (1999) discovered through mixed-methods analysis that there was a

heightened population of African American women in Georgia that had been introduced to pica

of kaolin by family members or friends, either as children or during pregnancy. Given the current

sample, children with SCD residing in Georgia, examining potential familial history of pica and

pica as a learned behavior may be important in understanding the heightened rates of pica in this sample.

1.7   Study Summary

In summary, several studies have evidenced that there is a high prevalence of pica among youth with SCD. There is a small body of work examining the correlates of pica in the general population, but the correlates of pica in SCD are particularly poorly understood. Relationships between multiple biological, psychological, and social factors with pica in SCD have been posited, but there are sparse data other than case studies to support these hypotheses. The overall aim of this study is to examine pica in pediatric SCD within a biopsychosocial framework to better understand the correlates of this disorder in SCD. In addition, this study will highlight possible etiological factors for pica in SCD. Mixed-methods research combines strengths from both qualitative and quantitative approaches to obtain a richer understanding of human experience, and this methodology has been identified as specifically valuable to understanding the complex phenomena that occur within the health services field (Zhang & Creswell, 2013). This study will employ convergent, parallel mixed-methodology by collecting both quantitative and qualitative data concurrently and prioritizing both methods equally (Creswell & Plano-Clark, 2011). Analyses of both quantitative and qualitative results will initially remain independent and subsequently be mixed upon overall interpretation (Figure 2). This choice of mixed-method methodology was selected as both the quantitative and qualitative arms of this study will be utilized to obtain different, but complementary data on the same topic (Morse, 1991). Through utilizing both methodologies, I aim to bring together the strengths of both quantitative (e.g., trends, generalizations) and qualitative methods (e.g., details, emergence of novel experiences) to best examine the phenomena of pica in pediatric SCD (Patton, 1990).
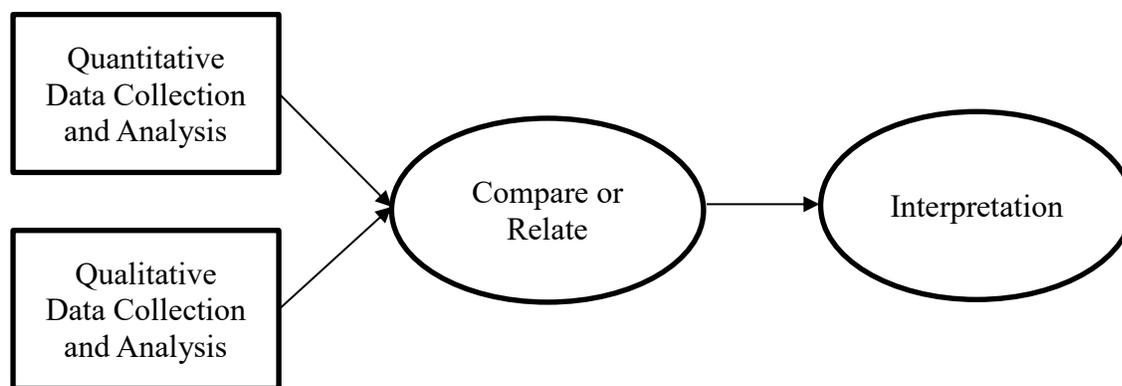
Figure 2 Convergent, Parallel Mixed-Method Design

1.8   Study Aims

Thus, this study used a convergent, parallel mixed methodology design to accomplish four primary aims:

1) Descriptive analyses of pica behaviors in children with SCD will provide the context of qualitative and quantitative assessment.

2) Qualitative interviews with pediatric patients and their parents will provide a rich understanding of this disorder and will allow for inductive generation of potentially novel contributing factors to pica in SCD.

3) Youth with SCD and pica will be compared to youth with SCD but no pica on quantitative measures in order to determine differences in proposed study variables.

4) Quantitative and qualitative data will be integrated and interpreted in conjunction to draw conclusions about pica and pediatric SCD in regards to the proposed biopsychosocial model and potential mechanisms and targets for intervention will be discussed.

Quantitatively, when examining biological variables, it is expected that children with pica will show greater levels of anemia, lower BMI percentage and higher disease severity, as measured by number of ER visits. When examining psychological variables, it is expected that

children with pica will have higher reports of dysfunctional eating patterns and emotional

impulsivity symptoms than children with no pica. When looking at social variables, I expect that

children with pica will have lower family satisfaction and greater food insecurity than children

with no pica symptoms. As is consistent with qualitative approaches, no hypotheses are made for

qualitative data (Creswell & Clark, 2011).

2   Method

2.1   Participants

For the quantitative portion of the study, participants included 113 children and

adolescents between the ages of 3 and 17 diagnosed with SCD and one of their parents ($n = 113$

parents). The wide age range in this study was included in order to assess variability in pica

presentation across childhood. Patients under the age of 3 were excluded as mouthing and

swallowing of non-food items is developmentally appropriate at that age. This age group (i.e., 3-

17) is similar to previous studies of pica and SCD (e.g., Ivascu et al., 2001, Lemanek et al, 2002).

Due to the conflation of pica incidence in children with developmental delays, exclusion criteria

included individuals with severe developmental delays (per medical chart review). A legal

guardian able to fluently read and write in English had to be present to provide consent on behalf

of the minor child. Of the larger sample, 58 children had SCD and comorbid pica, and 55 control

participants had SCD and no current symptoms of pica ($n =22$, history of pica but no current

symptoms; $n=33$, no history of pica). Pica (ICD-10-CM code F98.3) was defined according to

the DSM diagnosis and included patients who report eating nonnutritive, nonfood substances

over a period of at least 1 month for at least the last 6 months (American Psychological

Association, 2013). Patients in the pica group were generally identified by previous diagnosis by

medical providers through chart review. A few participants ($n = 7$) were identified as having pica

for first time upon enrolling as a control participant in the study and then endorsing pica behaviors.

Enrollment rates were not fully tracked for this study. Based on tracking completed for approximately 60% of recruitment days, approximately 90% of approached families enrolled in the study. Families who did not have a history of pica were more likely to deny participation in the study.

Initially, the study had been designed with the control group consisting only of participants with no current or prior pica. However, ANOVAs and planned contrasts on study variables indicated that the 22 participants who had a past but no current pica were significantly different from the pica group but not the control (no current or prior pica; Table 1). Thus, the two groups of participants with no current pica were combined for subsequent analyses.

Table 1 Group Differences: Control, Pica Past, Pica Present

	Control *(M, SD)*	Pica Past Only *(M, SD)*	Pica Present *(M, SD)*
Anemia	1.85 (1.7)[a]	2.05 (1.8)[a]	2.06 (1.55)[a]
BMI Percentage	57.41 (32.22)[a]	50.11 (29.02)[a]	52.99 (31.22)[a]
ER Visits	1.97 (1.86)[a]	2.32 (1.76)[a]	2.80 (2.71)[a]
Impulsivity	4.50 (6.55)[a]	4.42 (6.05)[a]	11.07 (10.23)[b]
Dysfunctional Eating	8.68 (6.99)[a]	9.41 (5.57)[a]	11.77 (5.78)[a]
Family Satisfaction	42.42 (6.79)[a]	44.32 (4.64)[a]	37.88 (8.44)[b]
Food Insecurity	1.39 (1.15)[a]	1.32 (0.78)[a]	2.16 (1.87)[a]

Note. Means with different superscripts were significantly different ($p < .05$).

Few studies have examined the variables proposed in this study in relationship with pica or non-pica in SCD, but for those variables that have been studied (i.e., hemoglobin level, dysfunctional eating) there has been a range of effect sizes (i.e., .25-.83; Ivascu et al., 2001; Lemanek et al., 2002). Based on these effect sizes, it was determined using G*Power (Faul, Erdfelder, Lang, & Buchner, 2007), that a sample of 26 in each group would be needed to determine a large effect, 64 in each group for a medium effect, and 253 in each group for a small

effect. Thus, we were adequately powered to identify medium to large but not small effects.

Descriptive statistics of the groups are included in Table 2.

Table 2 Group Demographics

	Pica Group (*n*=58)	Control Group (*n*=55)
	n (% of sample)	*n* (% of sample)
Gender		
Male	31 (53.4%)	27 (49.1%)
Female	27 (46.6%)	28 (50.9%)
Race		
Black or African American	56 (96.6%)	52 (94.5%)
Multiracial	2 (3.4%)	3 (5.5%)
Type of SCD		
SS	40 (69.0%)	42 (76.4%)
SC	10 (17.2%)	13 (23.6%)
S-B Thal +	4 (6.9%)	
S-B Thal 0	2 (3.4%)	
Other	2 (3.4%)	
	M (SD)	*M (SD)*
Age	10.16 (4.02)	9.86 (3.87)
Family Income	$39,795.92 (29,667)	$46,489.36(30,161)

For the qualitative interviews, as we were interested in families' experiences with pica and the strategies they have used to try to stop pica behavior, we included families both with children who currently engage in pica and families whose children have done so in the past. For the qualitative portion of the study, a smaller sample of the 81 participants with SCD and pica and their parent completed the qualitative interview (*n*=21 families). Parents from each family participated in the brief, semi-structured interviews (*n*=21 parents). For families who had children over the age of eight (*n*=14 children), their children also completed an interview. A total of 35 interviews were completed. Participants opted into the qualitative interviews, and they were conducted until theoretical saturation (Glaser & Strauss, 1967) and appropriate representation across developmental spectrum (see Figure 3). Seven of the families had children between the ages of 3-7, nine families had children between the ages of 8-12, and five families

had children between the ages of 13-17. This methodology was in line with previous studies

utilizing this methodology which have enrolled qualitative samples ranging from 15-30 people

(Creswell, 2007).
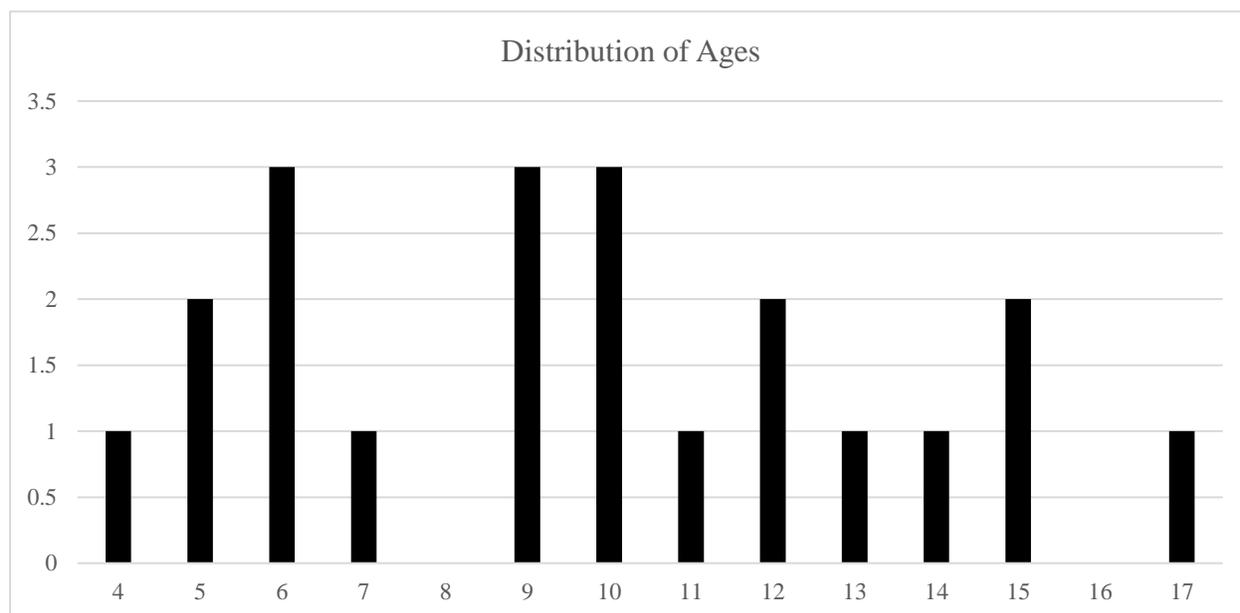
Figure 3 Ages of Children in Qualitative Interviews across Age

2.1.1   Quantitative Procedures

Recruitment procedures. In collaboration with the Children's Healthcare of Atlanta

(CHOA), participants were recruited from the Egleston and Hughes Spalding children's hospital

sickle cell clinics and inpatient floors. Children presenting for clinic visits and children on

inpatient floors were approached for enrollment in the study. An IRB approved cover letter was

distributed, which provided the goals of the study, a brief description of the questionnaires,

issues of confidentiality, risks and benefits of participation, and the right to withdraw. If the

family wished to participate, they were provided with the questionnaire battery. On the last page

of the questionnaire battery, families in the pica group had the opportunity to check a box if they

were interested in participating in a 20-minute qualitative phone interview for an additional $10

compensation. Biological variables were to be collected as part of standard care (i.e., nutrient

levels, blood variables). These variables were then extracted from the medical record. Given the reading level of the survey and the range in study participant age, only children over 8 in either condition completed a self-report measure of their pica habits. Otherwise, all questionnaires were parent-report measures and no other child-report data was collected.

2.1.2   Qualitative Procedures

For families that indicated willingness to participate in a phone qualitative interview, they were contacted via a family-provided phone number to schedule a 20-minute interview at their convenience. Of the 60 current pica-group families and the 21 past pica-group families, 50 families agreed to participate in the qualitative interview. All families were called a minimum of three times and given an opportunity to schedule. Six families scheduled phone interviews but did not answer the phone at the agreed-upon time and could not be reached in subsequent attempts. One family declined in participating once called, and 22 families were never successfully reached after three attempts. Children over the age of eight also completed a 20-minute interview. A verbal consent was read that highlighted confidentiality and benefits of honest participation. Additionally, participants were informed that interviews were audiotaped for later transcription, but in an attempt to alleviate reactivity, the audiotape was only acknowledged at the beginning of the interview.

2.1.3   Quantitative Measures

Demographics (Appendix A). Demographic data was collected using a demographic measure to assess patient age, gender, ethnicity, race, education level, income, sickle-cell genotype, and insurance type.

Information about Pica (Appendix B and C). A questionnaire developed for this study was used to determine what nonfood items children in the study were consuming; the

questionnaire also asked for details regarding how much, how often, since when, and where these items were being consumed. Parents of children of all ages completed a parent-report version. Children above 8 completed a self-report version as well. Cornstarch was included as a powder in this questionnaire, and ice was also a listed as a pica item. Although these are technically foods, they were included in the questionnaire as clinical psychologists working with our study sample have noted reports of non-typical eating of these items. For ice, families had to report that their children were eating more than ½ a cup of ice at a time, several days a week. For cornstarch, families had to report that this item was being eaten on its own, not as an ingredient mixed with other food items.

2.1.3.1   Biological Variables

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Nutritional Deficiencies. All patients presenting to clinic or inpatient floors provide a blood sample as part of their routine medical care. Results of their blood sample are entered into their medical record once analyzed. Anemia was defined as done in most studies, with the difference between patient's hemoglobin values and the WHO definitions for anemia by age group being calculated (Miao, Young, & Golden, 2015). Higher differences indicated higher levels of anemia. This study had initially intended to also extract and examine zinc levels for participating children. However, only 8 children in the pica group had completed a zinc blood test in the past 5 years. Thus, zinc levels were not analyzed for this study.

Height and Weight. Given the wide age range included in this sample, BMI percentages were extracted from patient medical records to best characterize the sample. BMI percentages express a child's BMI relative to children in the US of the same sex and age.

Disease Severity. The number of emergency department visits over the course of one year prior to study enrollment was extracted from patient medical records as a measure of disease severity.

2.1.3.2 Psychological Variables

Emotional Impulsivity Symptoms (Appendix D). To measure child tendencies to engage in impulsive behaviors based on mood-state (either positive or negative moods), parents completed the negative and positive urgency subscales of the UPPS Impulsive Behavior scale – Parent Report Version (Lynam, Smith, Whiteside, & Cyders, 2006). The scale uses a 1 (agree strongly) to 4 (disagree strongly) response format. The UPPS has demonstrated excellent internal consistency and convergent validity (Whiteside & Lynam, 2001) and this was replicated in our study, $\alpha = .94$. Additionally, studies have shown that the subscales make unique contributions to different disorders, thus suggesting that the scale represents important aspects of impulsivity (Whiteside, Lynam, Miller, & Reynolds, 2005). Scores were reversed so that a higher score indicates more impulsivity.

Dysfunctional Eating (Appendix E). Replicating methods by Lemanek et al. (2002), the Children's Eating Behavior Inventory (CEBI) was utilized to assess dysfunctional eating patterns. The CEBI has shown acceptable internal consistency ($\alpha > .70$) and construct validity in clinical and nonclinical samples of children (Archer, Rosenbaum, & Streiner, 1991). In our study, internal consistency was found to be slightly low, $\alpha = .69$. Each of the 15-items is rated on a 4-point scale. In this study, a sum of ratings of all items will be utilized to characterize disordered eating patterns. Scores were reversed so that a higher score indicates more disordered eating.

2.1.3.3 Social Variables.

Family Stress (Appendix F). The family satisfaction subscale of the Family Adaptability and Cohesion Evaluation Scale (FACES, Olson, 1991) was used in this study to assess satisfaction with family functioning. In an effort to reduce participant burden, the subscale was chosen as it is a 10-item measure that assesses many facets of family functioning, including ability to cope with stress, resolve conflicts, and positive relationships between family members. The complete FACES measure has shown acceptable reliability and validity (Perosa & Perosa, 1990). This specific subscale has shown adequate internal consistency in previous studies ($\alpha =$ .91; Kazak et al., 1997), and reliability was demonstrated in this study, $\alpha = .95$. A higher score indicates greater family satisfaction.

Food Insecurity (Appendix G). The 6-item short form of the Food Security Survey Module was used to assess food insecurity. This questionnaire was developed by researchers at the National Center for Health Statistics and has demonstrated effectiveness (Blumberg, Bialostosky, Hamilton, & Briefel, 1999). It has been shown to identify food-insecure households with reasonably high specificity and sensitivity. Food security was coded from 0-12, with a higher score indicating greater food insecurity.

Family History of PICA (Appendix B). Family history of pica was collected on the parent pica questionnaire.

2.1.4 Qualitative Measures

A semi-structured interview was developed to include open-ended questions to allow patients to generate data content with both parents and children over the age of eight (Appendix H & I). The interview covered topics of which items are consumed, how often they are consumed, when the child started eating the items, insight into why the behavior began, whether

any attempts to stop have been made, details about the context around periods of eating, what happens when desired items are not available, and thoughts and feelings about engagement in pica behavior.

2.2 Data Analysis Plan

2.2.1 Quantitative Data Analysis Plan

The Information about Pica interview was used to characterize pica behaviors for the pica group. Types and number of items consumed were calculated. Descriptive statistics, including means, standard deviations, and ranges were calculated to characterize the sample on study variables (i.e., anemia, number of ER visits, BMI percentage, dysfunctional eating, impulsivity, family satisfaction, food insecurity; Table 3). Normality tests revealed that anemia, BMI percentage, and number of ER visits were normally distributed, but all other variables showed varying levels of skew and kurtosis. Thus, it was decided to examine group differences through use of dummy coding and regression analyses as this allows for skew in outcome variable. Linear regression was used for analysis of anemia, BMI percentage, and number of ER visits as these were continuous variables with a wide range of outcomes. Ordinal regression analyses were used for the four psychosocial variables (i.e., dysfunctional eating, impulsivity, family satisfaction, and food insecurity) as these were all rated on Likert scales with a range of 3-5 possible answers.

Table 3 Study Variable Descriptive Data

Variable	Total Sample	Pica Group	Control Group	Total Sample	Pica Group	Control Group	Total Sample	Pica Group	Control Group
	M (SD)			*Median*			*Range (minimum-maximum)*		
Anemia	1.99 (1.63)	2.06 (1.55)	1.93 (1.73)	2.20	2.30	2.10	-1.90-6.30	-.90-5.30	-1.90-6.30
BMI Percentage	53.73 (30.94)	52.99 (31.22)	54.49 (30.92)	54.95	53.70	55.79	0.01-99.36	0.01-99.36	0.57-97.90
ER Visits	2.46 (2.33)	2.80 (2.71)	2.11 (1.81)	2.00	2.0	2.0	0-13	0-13	0-7
Impulsivity	7.83 (9.11)	11.07 (10.23)	4.47 (6.30)	4.00	7.00	2.0	0-36	0-36	0-27
Dysfunctional Eating	10.43 (6.24)	11.77(5.78)	8.95 (6.45)	9.64	11.79	8.0	1-31	2-27	1-31
Family Satisfaction	40.42 (7.82)	37.88 (8.44)	43.21 (6.02)	41.00	38.00	44.5	20-50	20-50	28-50
Food Insecurity	1.77 (1.56)	2.16 (1.87)	1.36 (1.00)	1.00	1.00	1.0	1-8	1-8	1-7

In order to evaluate whether the study variables differed on any demographic variables, appropriate correlation and mean difference analyses were conducted. Specifically, correlation analyses were used to assess the associations between age and family income and study variables (Table 4), and mean difference tests were employed to examine differences in gender (Table 5) and type of SCD (Table 6) and study variables. Family income was significantly negatively correlated with food insecurity, but given this expected relation and the confounding features of these variables, it was not used as a control variable for food insecurity analysis. As expected given overall prevalence rates (Chapple & Johnson, 2007), males were reported to have significantly higher symptoms of impulsivity than females. Gender was entered as a covariate in analysis of group differences in impulsivity. Also as expected given relationship between sickle type and disease severity (Dampier et al., 2002), children with HbSC showed significantly less anemia than children with HbSS. Type of SCD was be entered as a covariate in analysis of group differences in Anemia. Correlations were run to understand relationships between study variables (Table 7). Higher anemia was significantly correlated with lower BMI percentage. Higher reports of dysfunctional eating symptoms was correlated with higher general impulsivity and higher food insecurity.

Table 4 Intercorrelations among Age, Family Income, and Study Variables

Variable	Age	Family Income
Anemia	.13	-.16
BMI Percentage	-.01	.01
ER Visits	.14	.04
Impulsivity	.12	-.11
Dysfunctional Eating	.12	-.03
Family Satisfaction	.04	.03
Food Insecurity	.19	-.33**

Note. ** $p < .01$.

Table 5 Gender Mean Differences among Study Variables

	Male	Female
Variable	*M (SD)*	*M (SD)*
Anemia	2.08 (1.73)	1.89 (1.53)
BMI Percentage	53.82 (30.29)	53.53 (31.91)
ER Visits	2.70 (2.44)	2.21 (2.20)
Impulsivity	9.65 (10.35)	6.02 (7.34)*
Dysfunctional Eating	10.80 (6.45)	10.05 (6.06)
Family Satisfaction	40.11 (8.90)	40.75 (6.61)
Food Insecurity	1.95 (1.82)	1.59 (1.22)

Note. *$p < .05$.

Table 6 Type of SCD Mean Differences among Study Variables

	SS	SC	S-B Thal +	S-B Thal 0	Other
Variable	*M(SD)*	*M(SD)*	*M(SD)*	*M(SD)*	*M(SD)*
Hemoglobin	2.55 (1.42)	0.17 (1.04)	1.08 (.94)	2.20 (.85)	1.20 (00)*
BMI Percentage	51.53 (30.57)	60.44 (32.86)	54.72 (23.59)	42.95 (39.44)	97.46 (00)
ER Visits	2.35 (2.19)	2.57 (2.69)	2.00 (1.63)	4.50 (3.53)	7.00 (0.00)
Impulsivity	7.52 (9.42)	8.83 (8.74)	10.67 (10.50)	3.00 (4.24)	9.50 (3.54)
Dysfunctional Eating	10.02 (5.37)	12.34 (8.92)	10.32 (6.00)	8.00 (5.66)	10.00 (11.31)
Family Satisfaction	40.28 (8.11)	42.09 (5.74)	35.75 (10.72)	38.00 (16.97)	39.00 (2.83)
Food Insecurity	0.84 (1.74)	0.57 (0.87)	0.25 (0.50)	0.00 (0.00)	2.00 (1.41)

Note. *p $< .01$

Table 7 Intercorrelations among Study Variables

	1	2	3	4	5	6
1. Anemia	-					
2. BMI Percentage	-.34*	-				
3. ER Visits	.01	.02	-			
4. Impulsivity	-.02	-.06	.08	-		
5. Dysfunctional Eating	-.04	.14	-.25	.28*	-	
6. Family Satisfaction	-.22	.05	.14	-.19	-.11	-
7. Food Insecurity	-.14	.06	-.15	-.01	.31*	.12

Note. *p $< .05$

2.1.5   Qualitative Data Analysis Plan

Transcriptions were analyzed using framework analysis. This type of analysis allows for the identification of commonalities and differences in qualitative data, and then for a focus on relationships between different parts of the data to draw descriptive or explanatory conclusions clustered around themes (Gale, Heath, Cameron, Rashid, & Redwood, 2013). The framework method is most commonly used for thematic analysis of semi-structured interview transcripts and produces structured outputs of summarized data (Pope, Ziebland, & Mays, 2000). The procedure for framework analysis requires several stages including (1) transcription, (2) familiarization with the interview, (3) coding, (4) developing a working analytical framework, (5) applying the analytical framework, (6) charting data into the framework matrix, and (7) interpreting the data (Gale et al., 2013). To counter the inherently subjective nature of qualitative analysis, two data analysts independently coded the transcripts. Coding was done without consideration of biopsychosocial model and one coder was blinded to theoretically derived model and to quantitative study hypotheses. After the second coder coded 25% of the data, both coders met to discuss any areas of confusion in the codes and definitions. At that point satisfactory agreement had already been reached (κ = .86), but discrepant codes were discussed and the thematic framework and code conceptualizations were modified to reflect the second coder's impressions and to ensure a better fit with the data (Appendix J). An additional 25% of the data was double-coded at which point reliability was assessed again (κ = .92), indicating satisfactory agreement (κ > .60; Stemler, 2001). Once reliability was established, the first coder continued to index the remaining 50% of the data. Miles, Huberman, and Saldana (2014) identified guidelines to help maintain objectivity when interpreting findings. They emphasized that logical connections could be drawn between themes when patterns appear in multiple cases that are found in expected

places and counterexamples can be explained. Analysis of the data was aided by the computer software package Atlas.ti.

  The developed coding scheme resulted in 5 major themes with 4-5 subcodes per theme. Major themes included child/parent reactions, patterns of behavior, why engages in pica, family history of pica, and strategies to stop pica (see subcodes; Appendix J). In general, child/parent code reactions encompassed parents worry about the impact of this behavior on their child, feeling more concerned because their child has SCD, and empathizing with their child about the behavior but still wanting them to stop. Several parents also described not reacting strongly due to the belief that pica was just a phase the child would grow out of, and the last subcode included codes when parents or children described feeling shame about their pica behavior.

  When asked about identified patterns of pica behavior, parents and children reported that children were often sneaky about the behavior and thus parents did not know exactly what precipitated the behavior. Parents and children also noted that the behavior is more likely to occur when the child sees the desired item, and that children often become frustrated when they are denied access to the item. Finally, many children and parents just reported a general lack of awareness of antecedents or consequences of pica engagement. When asked why parents think their children engage in pica or asking children to report themselves, four subthemes arose. These included wondering if pica had something to do with sickle cell or anemia, describing it just as an urge or craving, denying that it was related to general hunger, and similarly to questions of pattern, many families denied insight into explaining this behavior. Family history was coded anytime parents or children mentioned other family members that engaged in pica behaviors. And finally, parents and children identified four strategies that they have used to help curb or stop pica behaviors. These included use of substitution foods (i.e., real food items that

have a similar texture to the desired nonfood item), trying to keep busy or distracted when having an urge or craving, parents trying to remove access to the item, and parents either talking to their children about how pica is bad or unhealthy or children trying to think about that in effort to stop the behavior.

2.1.6   Integration Plan

Results are presented here in an integrative framework. First, the pica sample is characterized by quantitative measure and qualitative themes. Qualitatively, once a coding scheme was finalized, codes were mapped onto the proposed biopsychosocial model (Table 8). Codes that fit within the model are presented in line with quantitative analyses of constructs. Codes that did not fit within the proposed model are outlined within the model dimension with which they are proposed to fit and the model was updated to reflect integration of novel qualitative themes. Quantitative results are presented in line with qualitative findings. Seven group comparisons were made using regression analyses, as proposed. Two additional quantitative analyses were included, with questions prompted by qualitative results. Specifically, qualitative analysis indicated that parents and children may have different knowledge of pica behaviors. Thus, parent and child reports of pica behavior were compared on the Information about Pica questionnaire. Additionally, parents and children in the qualitative interviews reported high rates of family history of pica, however when looking at quantitative data, few families indicated a family history. Thus, consistency between paper and qualitative results was examined for families who participated in the qualitative interviews.

Table 8 Coding Scheme Mapped onto Biopsychosocial Model

Reporting Pica Behaviors
Sub code of Child/Parent Reactions: s(he)'s just a baby/kid, (s)he'll grow out of it

Sub code of Patterns of Behavior: the child does it sneakily; parents don't know the extent of the behavior
Biological Correlates
Sub code of Child/Parent Reactions: worry about child getting sick/choking
Sub code of Child/Parent Reactions: pica is more concerning due to the child already having SCD
Sub code of Why: deficiency, something about sickle cell or anemia
Psychological Correlates
Sub code of Why: urge/craving
Sub code of Pattern of Behavior: when (s)he sees it, (s)he wants it
Sub code of Pattern of Behavior: when denied access, child is frustrated
Sub code of Why: no idea; lack of awareness
Sub code of Child/Parent Reactions: child or parent feels shame about pica
Social Correlates
Sub code of Why: different from hunger
Sub code of Child/Parent Reactions: empathic but wants them to stop
Family history of pica

3   Results

3.1   Pica Sample Characterization

The Information about Pica questionnaire was examined to characterize the pica sample in regards to types of items eaten. Fifty-eight parents completed this questionnaire and 43 children over the age of 8 completed the child version of the questionnaire. All items on the questionnaire were endorsed by at least one participant and 13 other items were written in (i.e., mattress, plastic, cardboard, washing powder, deodorant, shoe boxes, soap, pencils, metal, batteries, carpet, Velcro, gift wrap tissue). Paper, fabric and ice were the most commonly reported items by both parents and children. Additional details regarding item endorsement are provided in Table 9. The number of different items eaten over the child's lifetime ranged from 1-18 different items (Figure 4). The average child in this sample ate 4 different items (past and present) and was currently eating 2-3 different items.

Table 9 Pica Items Endorsed by Parents and Children

	Parent past or present endorsement (*n*=58)	Child past or present endorsement (*n*=42)
Paper (paper, tissue)	41	30
Fabric (Cloth, String)	19	13
Dirt	8	6
Clay	3	3
Chalk	8	5
Drywall	10	6
Paint	5	3
Hair	7	4
Powder (Baby Powder, Cornstarch)	9	10
Rocks	6	4
Foam	8	8
Sponge	10	6
Cotton	5	4
Ice	32	18
Lotion	0	1
Other*	18	6

*Note. Other included items: mattress, plastic, cardboard, washing powder, deodorant, shoe boxes, soap, pencils, metal, batteries, carpet, Velcro, gift wrap tissue.
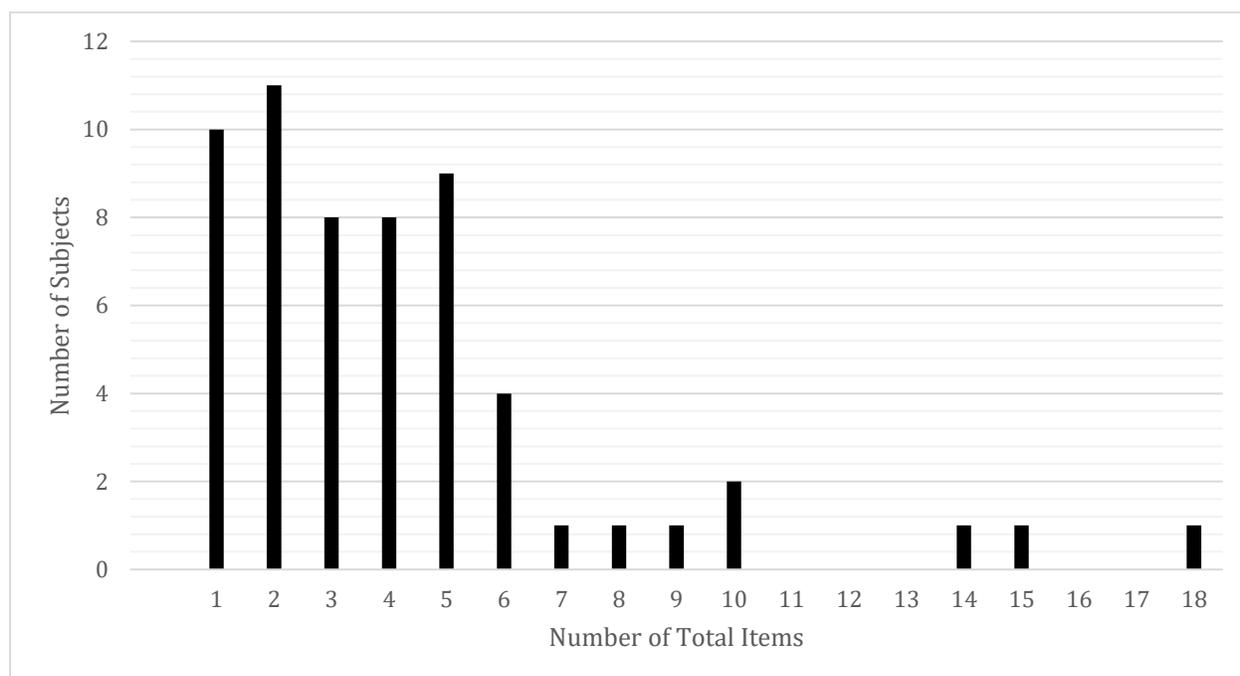

Figure 4 Number of Different Items Consumed in Lifetime

In line with the finding that paper, fabric, and ice were the most frequently endorsed items, families in the qualitative study talked about these pica behaviors being the most

challenging to address, as these items are the most easily accessible. For example one parent noted that her child's tissue and ice consumption have continued, despite outgrowing or successfully managing previously eaten items of crayons and sheet rock.

"But this is just something that she knows is everywhere and she knows she can kind of get to it wherever." [Parent HS1, child age 6]

Although the Information about Pica questionnaire provided data about the number of items consumed, it appeared evident during the qualitative interviews that families were not entirely forthcoming on study quantitative measures or clinic visit surveys regarding pica behavior. Families often endorsed items in the qualitative interviews that they had denied or omitted from the questionnaire. When queried about this inconsistency in the qualitative interviews, families typically responded that they had forgotten about some of the pica behaviors when completing the surveys or that they had not realized that some items were considered non-food items until discussing the topic in more depth during interviews. For example, one parent had only endorsed chewing on clothes on the quantitative measure, but five minutes into the interview she remembered her child used to persistently eat the stuffing in her bed mattress. When asked if she ever spoke to the medical team about it, she responded,

"No, the first time was the last time they even asked me about pica and it was for this study. Even when I was filling it I was thinking no, no, no, my daughter doesn't do this. But then, while you were talking I remembered the soap eating and the mattress eating... She used to take out the foam from the bed mattress and she would take it out and eat and eat and eat. She still does the bed foam every now and then." [Parent EG21, child age 5]

Many parents noted that they thought the pica behavior was simply a childhood phase that would remit over time and thus not worthy of sharing with the medical team. Others

explained that they did not report pica behaviors to the medical team because they did not realize it could be related to sickle cell or because they did not consider it to be of relevance to their child's healthcare. For example, one parent said,

"I didn't know it had something to do with sickle cell. When we told the pediatrician they just said it could be a phase that kids just grow out of and they gave me a pamphlet. That's what they told us so we didn't think anything about it." [Parent EG14, child age 9]

Another parent noted that they did not bring it up to the medical team until things became more severe stating,

"I thought it was maybe just a little phase. I thought it was just normal- like little kids eat toilet paper- I thought it was just a phase he would go through. It started getting serious when I found metal and other stuff in his body." [Parent HS19, child age 9]

Additionally, a few children noted that their parents did not tell the healthcare team about pica behaviors even when they alerted their parents about the behavior. For example, one teenager stated during the qualitative interview,

"When we go to clinic, it's like they first give you that paper that they give the nurses and it has that question like, 'Do you see them eat things like paper or not?' And I was like "Well sometimes I do eat paper," and she was like, "WHAT?! No you don't!" And I was like, "Yeah sometimes I do and I just don't think about it, it just happens." And she just says "no you don't" and marks no." [Child EG25, age 17]

There are many reasons why parents might not be able to accurately report pica behaviors quantitatively, but one consistent qualitative theme was that children often engage in pica in secret and thus parents are not fully aware of the extent of the behavior. When one parent was asked if they had noticed any patterns to their child's pica eating, she stated,

"Well he does it when no one is looking- when he thinks we're not paying attention. So the Kleenex box, he'll eat it whenever he thinks [we're not paying attention], and then he'll hide it. Like he'll eat a portion of the box and then hide it behind the couch or something. So I can't say, even now I don't know exactly when he does it because it's something he tries to hide."
[Parent HS21, child age 12]

Children in the qualitative study noted hiding their pica behavior from their parents due to fears of punishment,

"I don't really talk to them about it. My dad gets pretty mad when I do it [eat plastic]. I think he thinks it's going to mess up my teeth so he's pretty scary. My mom slaps my hand and tells my father and then I get in trouble. So I just don't do it when they're around. So I might see something and put it in my pocket for when they're not around." [Child EG16, age 15]

Additionally, children described fighting urges to eat their desired items when parents were around, but then determined ways to access the substances later. For example, one child reported,

"If I couldn't get it [dirt] right away I would just be thinking and plotting of how I could get back to my grandmother's house to get some more. My grandmother would try and stop me and watch me closely so I couldn't go out there, but I would just be thinking about it and plotting so that when she had to go to the bathroom or take a phone call I would run out there and eat some and pack some up in my pocket for later." [Child HS11, age 14]

Given this theme in qualitative data of parents' lack of awareness of the extent of pica behaviors, we decided to examine the discrepancy between parent and child report of pica behaviors on the Information about Pica questionnaire. Of the 42 families who had both a parent and his/her child complete the quantitative measure (i.e., families with children over the age of 8

who engage in pica), 40 of them (i.e, 95% of the sample) had discrepancies in a) the number and type of items that were reported or b) in whether they classified the eating of specific items as past or current. Follow up analyses revealed that 21 families had parent reporting more pica behavior than children reported, 16 families had children reporting more pica behavior than parents reported, 3 families had agreement between parents and child in number of items consumed but disagreed about which items were eaten, and 2 families had agreement on both indices (Figure 5).
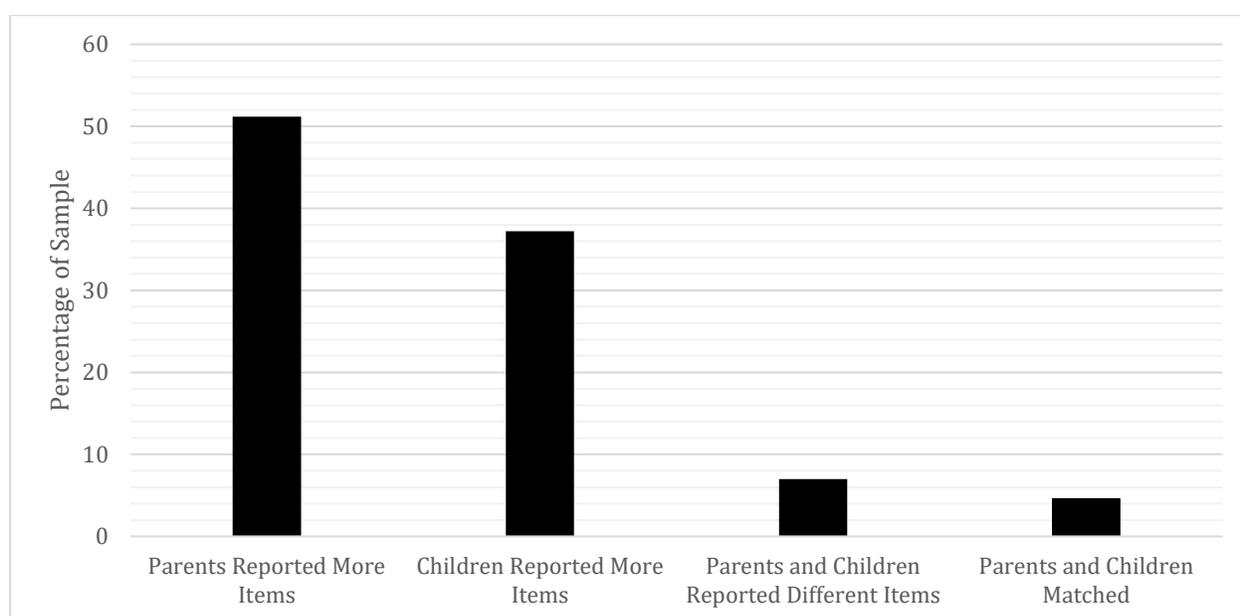
Figure 5 Differences between Parent and Child Quantitative Report of Pica Behaviors

3.2 Biological Correlates

During qualitative interviews, most families did not report noticing a connection between pica behaviors and sickle cell symptoms. As mentioned above, most parents denied having any knowledge regarding the potential connection between sickle cell and pica,

"I took her to her primary care. I never took her to the sickle cell team for that. And they gave me a pamphlet on pica and I researched it but I didn't see anything about sickle cell. I

wasn't really sure if there was a correlation between sickle cell patients and pica." [Parent

EG50, child age 7].

When parents did mention a potential biological explanation for pica, it was often when

they were discussing their own histories with pica. For example one parent who has sickle cell

herself stated,

"Yeah I eat ice. I love ice. I crave it, I really crave it. It's been going on for a while, but

it's not like I need it. It's more that when I want it I really want it. And I have sickle cell too and

it feels like it's when I'm getting more anemic, like my iron's low." [Parent HS32, child age 10]

One parent when discussing family history pica noted that her child with SCD had more

difficulty stopping pica behavior than her children without SCD, which made her wonder if there

was some connection,

"No I only started it [corn starch] in pregnancy and then after. And I have 4 kids without

sickle cell and one kid with it and they all ate it [corn starch]. When they were little till about 4-5

years old when I stopped buying it. But then my daughter with sickle cell started eating baby

powder. Like the other kids just stopped, but I guess she was looking for something similar and

ate the baby powder and we didn't know until we found the entire bottle empty in her room. So

maybe it was the sickle cell?" [Parent EG13, child age 11]

Finally, qualitatively, even if parents did not notice a specific connection between

nutrient and blood variables and pica, they often recognized that there appeared to be something

innate in their children that was driving them towards the behavior:

"*As to what I've learned pertaining to my son, he only wants it when it's available. It's*

just like when you're pregnant, it's like 'umm I want that but I know I really shouldn't be eating

it, but it's not me it's just my hormones". So I think that's what it is for him. I've tried to talk to

him about it but I don't think he's comprehending it." [Parent EG2, child age 6]

Quantitatively, we hypothesized that children with pica would show more signs of anemia, lower BMI percentages, and greater disease severity as measured by number of ER visits.

When controlling for type of SCD, pica group was not a significant predictor of anemia. The results of the regression indicated that the two predictors explained 19% of the variance, $R^2 = .19$, $F (2,108) = 12.51$, $p < .001$. It was found that SCD type significantly predicted anemia, $\beta = -.44$, $p < .001$, but pica group did not, $\beta = .11$, $p = .21$. Pica group was also not a significant predictor of BMI percentage. The results of the regression indicated that pica group explained 0.1% of the variance, $R^2 = .001$, $F (1,110) = .065$, $p = .80$. It was found that pica group was not a significant predictor of disease severity. The results of the regression indicated that pica group explain 2.2% of the variance, $R^2 = .022$, $F (1,108) = 2.46$, $p = .12$.

Although these hypotheses were not supported quantitatively, the fact remained that children's sickle cell status impacts the family's response to pica behaviors. A theme raised qualitatively noted that parents' concern about pica behavior was elevated due to child's SCD diagnosis. For example, one parent said,

"It's a huge problem because I don't want her to get sick or anything more than her

sickle cell- with sickle cell I have to worry about her anyway so it's a big problem." [Parent HS20, child age 9]

Additionally, parents noted using their child's SCD diagnosis as rationale for why they were attempting to intervene on pica behavior,

"I would say 'okay you have sickle cell. If you eat this stuff it's going to be worse on your body than it would be on mine. Like I can't eat sponges either, but you really can't eat sponges." [Parent HS3, child age 13]

3.3   Psychological Correlates

When looking at psychological correlates, it quickly became apparent that both parents and children described the impetus for pica behaviors to be an urge or a craving. For one parent, who recognized some connection with iron, she believed that craving was the overriding factor.

"It's not that it's always low iron all the time. It's just that they crave it. Like he really craves it and it doesn't really matter about iron. Like it's his thing- it's just what he does so you know you can't really take it away from him, you just have to kind of roll with it." [Parent HS5]

Others noted that these impulses and cravings are hard to deny and that children often become frustrated when they cannot satisfy their impulses. For example, one parent said,

"It's kinda hard to stop them from doing something they crave because it's like he craves it. Because it's like, well when he was small he'd try to eat the baby powder and he'd throw a tantrum if I stopped him. And now he gets really upset you know if you don't let him stick his fingers in the bowl of flour. Like you're taking away something a child likes, like his favorite stuff animal or toy, that's just like how he likes flour." [Parent HS32, child age 10]

One child described feeling as though the more they gave into the pica impulses the stronger their cravings would be,

"Well as I was continuously eating it [dirt and clay], I would crave it more. I ate it very very often, non-stop. It would be daily." [Child HS5, age 12]

Both parents and children expressed feelings that sometimes the behavior seems out of the child's control. For example one child said,

"You know what pica is? It's when you eat something so good and you can't stop eating it. That's basically what it is, but it's stuff you're not supposed to eat." [Child HS3, age 13]

Given the perceived lack of control, one parent reported that she feels guilty when she punishes pica behavior.

"But I don't want her to feel punished for having pica. At this point I feel like it's more of an impulse thing rather than her consciously doing it wrong." [Parent HS1, child age 6]

Additionally, many families noted a general lack of awareness of patterns around this behavior, many noting that they believe the child is even unaware of the antecedents or triggers of the behavior. Although no families ever mentioned general disordered eating patterns outside of the pica behavior, one child described the lack of mindful eating with pica nonfoods, saying,

"I don't really notice it. It'll be like if it's next to me or like if there's a muffin, I'll eat the whole muffin. Like the muffin and the paper. Or if it's a lollipop, I'll eat the lollipop and the stick. Or with cards, if it's just there, then that's just yeah, I'll eat it." [Child EG25, age 17]

Quantitatively, when examining group differences in dysfunctional eating symptoms, the results of an ordinal regression analysis indicated that the odds that a child with SCD and pica was reported to have more dysfunctional eating patterns was 4.12 (95% CI, 1.43-5.57) times that of a child with SCD and no pica, a statistically significant effect Wald $\chi^2(1) = 8.886$, p = .003. Additionally, the results of an ordinal regression analysis when controlling for gender indicated that the odds that a child with SCD and pica were reported to engage in more impulsive behavior was 4.12 (95% CI, 2.05-8.28) times that of a child with SCD and no pica, a statistically significant effect Wald $\chi^2(1) = 15.77$, $p < .001$.

One novel theme that was noted in the qualitative interviews was that several children reported feeling shame about pica, which may contribute to the hiding and persistence of the behaviors. For example when asked how he feels about having pica, one child said,

"I'm not proud of myself but I feel like everybody has their flaws and this one is one of mine." [Child HS21, age 12]

Another child, when asked how they feel after eating the items, noted,

"After I eat it, physically I don't really feel anything. Mentally though, mentally I feel remorse or something. I'm sorry that I ate it." [Child EG8, age 10]

Parents also noted feeling shame about their child's behavior. For example, one mother described the reaction she perceived from the medical team when her child had to have a scope done to examine what items he had consumed,

"I didn't like it. He had strings coming out and then tubes down his throat. And then they're looking at you like you're crazy because he's eating this stuff and I'm thinking I've got two other kids that I've got to watch and I don't know. It was hard at the time." [Parents HS19, child age 9]

3.4 Social Correlates

Although families in the qualitative interviews did not speak directly about general family functioning difficulties, many parents noted the frustration and stress associated with dealing with pica behaviors. For example, one mother noted being both understanding of the behavior and being annoyed by it, stating,

"I'm actually in between because some days I think he's gotten over it and then I get home and I'm like what did you do now? I thought you'd gotten over this, but there are holes in all your socks. 'Baby, don't you understand that I can't keep buying you this stuff'? And he just says

'Mommy I don't know why.' That's his answer to everything is he doesn't know why. So I feel

bad for him and I'm kind of over it and I'm trying to get him help. But it's also kind of annoying

that I have to keep replacing these things. But I also don't want him to be without cause he seems

out of control with it." [Parent HS47, child age 5]

Another parent described the varying emotions she has had about her child's pica as her

child has grown older.

"*I reacted as any normal parent would… panic, because they were talking about doing*

surgery to get the items out of her stomach. So at age three you don't want to see your child go

through anything like that. Now when I catch her, I'm just stressed out. I get mad, you know. I

talk to her, but to no avail. But I definitely understand now more than before about her control

issues with pica." [Parent EG8, child age 10].

Although questions were not specific to pica behaviors, quantitatively, the results of an

ordinal regression analysis indicated that the odds that a child with SCD and pica was reported to

come from a home with lower family satisfaction was 3.25 (95% CI, 1.65-6.38) times that of a

child with SCD and no pica, a statistically significant effect Wald $\chi^2(1) = 11.60$, $p = .001$.

When asked about the relationship between pica and hunger, all parents denied noticing a

relationship between the two. For example, one parent stated,

"*She doesn't do it when she's hungry. They don't do it intentionally or because they want*

to eat something- it's not about when they are hungry it's more about when they see it. If they

don't see it then they don't do it." [Parent EG21, child age 5].

Children also often denied that they engaged in the behavior due to hunger. One child

explained the difference by noting,

"It was different than hunger. Because when I'm hungry I'll want just anything, but with this sometimes I just want that and nothing else." [Child EG13, age 11]

Even when stating that they engaged in the behavior because of hunger, children often noted it was not because they did not have other real food options. For example, one child described engaging in pica by saying,

"I would go to the pantry to find a snack but then I would find myself looking at the cardboard boxes and I'd think 'hmm I don't want to eat that so I should probably eat this thing.'" [Child HS21, age 12].

Despite the denials of a relationship to hunger qualitatively, quantitatively, the results of an ordinal regression analysis indicated that the odds that a child with SCD and pica was reported to come from a home with more food insecurity was 3.19 (95% CI, 1.35-7.54) times that of a child with SCD and no pica, a statistically significant effect Wald $\chi^2(1) = 6.97$, $p = .008$.

Throughout the qualitative interviews, family history of pica was a consistent theme. Parents and children often noted difficulty with stopping pica behaviors because other members of the family were engaging in pica. For example, one mother noted that her son often eats dirt with his aunt, who watches him after school.

"*He actually has an aunt who eats dirt a lot too. So it's like a thing, a bonding thing, between the two of them that they do together."* [Parent EG2, child age 6]

One child described trying to stop eating nonfood items, but found it difficult when others around her were still engaging in it,

"Yes it was hard because other people were eating it, like my cousins and sisters, and I'd just have to try and walk away." [Child EG13, child age 11]

A few parents remembered seeing family members engage in these behaviors growing up and did not think about them as odd or different until they were asked about pica in sickle cell clinic. For example, one mother stated,

"My mother, her grandmother, said she had pica when she was pregnant with all of us. And her preference was the white dirt they sell at stores. My mom was craving stuff and I have a sister that eats ice and I have a couple of nieces that eat stuff and her dad eats ice. And before I knew any better I just thought it was something my family did and I just didn't know that there was a name for it." [Parent HS1, child age 6]

When speaking of family history of pica, many families noted that white dirt specifically was often eaten by the older generations in their families,

"My grandmother was eating white dirt- like that clay. Yeah when I was pregnant I used to eat that. It wasn't that she [my grandmother] suggested it or anything it was just that I knew she was eating it and I wanted to eat it too. It didn't have a taste or anything so I don't know why I liked it. There was actually a lady in my neighborhood who sold it from her house but they also have it at the farmers market. I didn't really like that kind- the store bought kind, I liked the one from that lady. And I know she was selling it to be eaten because she was an older lady as well and I think it's a common habit in older people like that and maybe they pass it down to their grandchildren or something." [Parent EG26, child age 10]

This parent's son also talked about eating white dirt, noting that it was something he would do with his mother,

"My mom used to eat chalk and white dirt. I tried it too- it was good. I would only eat small pieces of it because my mom wouldn't give me the big pieces. I liked how it taste. I would

eat it when my mom had it, but she stopped like last year when I was going back to school. If

mom had it again, I would definitely want it." [Child EG26, child age 10].

Similar to the discrepancies between children and their parents in their reports of pica items, there were disagreements in the qualitative and quantitative report of family history of pica. On quantitative measures, only 13 of the 58 families in the pica sample endorsed a family history of pica. However, when looking at the families who participated in the qualitative interviews, of the 21 families who participated in the qualitative study, on paper only 5 endorsed a family history of pica. When interviewed, 16 parents (76% of the sample) of this group endorsed a family history of pica.

4   Discussion

The current study was the first to investigate a range of biological, psychological, and social variables related to pica in pediatric SCD using a mixed method design. Several studies have evidenced the high prevalence of pica among youth with SCD, but there is a scarcity of research examining the correlates of pica in SCD. Thus, the heightened prevalence remains poorly understood and the development of evidence-based treatment has been limited. Relationships between multiple biological, psychological, and social factors with pica in SCD have been posited, but there are sparse data other than case studies to support these hypotheses. The current study aimed to examine pica in pediatric SCD within a biopsychosocial framework. Quantitative measures were utilized to explore correlates posited in the literature to allow for some generalizations to be made to the broader pediatric SCD population. Qualitative methods were utilized to allow for an inductive study of pica in SCD given the lack of theoretical foundation available in the literature.

4.1   Pica sample characterization

When characterizing the pica sample in this study, similar to previous studies, gender was equally distributed (e.g., Aloni et al., 2015, Ivascu et al., 2001). We did find that most children in the group had SCD-SS type, however, that was also true for the control group. One previous study found pica to be more prevalent in the SS-subtype than other types (Ivascu et al., 2001); however, that study used retrospective medical chart review, thus, SCD type was representative of the entire patient sample. Given that we were recruiting from clinic waiting rooms, we may have a sample that is slightly biased to include more patients with SS-type, as these patients typically have higher disease severity and thus have more regular clinic visits. Similar to other studies, paper and fabric were the most common items consumed (Ivascu et al., 2001). Although previous studies have not consistently detailed the number of items children were eating, Ahmed at al. (2015) reported that 68% of their sample was only eating one item. We found that only 31% of our sample was currently eating only one item and only 17% of our sample had a history of only eating one item.

Qualitatively, two themes arose when attempting to characterize the sample. One was that parents often did not report pica behaviors to the medical team when their child was young because they believed the behavior to be either developmentally appropriate or a passing phase. Given that parents often did not know about the heightened prevalence of pica in SCD, many reported first going to their primary care providers for information about pica. Two clinical implications can be informed from this finding. One is that families should be educated early about pica at SCD clinic. Families described noticing pica behaviors as early as 9-12 months with descriptions that appeared beyond expectations for that age. Being informed to look for these behaviors early could help families normalize the behavior, react with less shame and punishment, and work on removing items before the behaviors become habits. Second, primary

care providers may benefit from awareness campaigns about the heightened prevalence of pica in SCD so that when their patients with SCD present with this behavior, they know to either refer them to their SCD care team, or to not work from the assumption that the child will outgrow the behavior. Although similarly to other studies, all families in our sample were asked about pica behaviors as part of routine clinical care, it is possible that our families with young children were not as forthcoming in endorsing this item. We did find that our pica sample was slightly older than those reported in previous studies (i.e., our median and mean age was around 10.5 years old, whereas other studies have reported mean and median age around 7.5-8.5 years old). However, all families over the age of 3 presenting to clinic were approached for enrollment and all families had the opportunity to fill out the pica questionnaire. It is also possible that we are identifying younger patients with pica, and that our site is doing a better job at assessing pica for older children. Specifically, previous studies have used only written questionnaires to ask about pica behaviors. In our clinic, parents are given a written question on a psychosocial screener when they present to clinic and then a nurse asks about pica when both the child and parent are present in the exam room. This multi-method assessment of pica may result in more accurate assessment of pica in older patients.

Both parents and children in the qualitative study often noted that parents are not always aware of the extent of the behavior. As parents reportedly use punishment, or reasoning, or removal of nonfood items as a consequence when they find their child engaging in the behavior, children were reported to often begin sneaking the behavior or doing it when their parents were not around. This finding was supported by analysis of parent-child discrepancies in reports of which and how many items were reported on the pica questionnaire developed for this study. These findings have important implications for how pica is assessed during clinic visits. Follow-

up analyses of discrepancies revealed that there was roughly equal distribution of parents and children who reported more current pica behaviors, thus, there are likely individual family differences as to why parents or children might be more forthcoming in reports. Parents and children should both be asked about pica behaviors, and ideally, these questions should be asked individually. Children may be scared to admit pica behaviors due to fear of consequences from their parents, but accurate reports are important for appropriate clinical care. Although we did have fairly robust reports of pica behaviors by questionnaire by both parents and children, often times during qualitative interviews families would either remember items they had not previously endorsed or would name other items as the interviews progressed and comfort and rapport increased. Thus, while regular questionnaire child and parent assessments can be beneficial, good individual clinical interviews of behaviors may also be warranted for follow-up.

4.2   Biological Correlates

Qualitatively, families rarely identified a relationship between pica and sickle cell-related factors (i.e., nutrient deficiencies, disease severity). This is not surprising as awareness of biological drivers of behavior is often not as intuitive as recognizing psychological or social factors. It has been suggested that quantitative measures are best for examining biological aspects of behavior and that qualitative approaches are optimal for social and cultural qualities of behavior (Wilms et al., 1990). Although there were few comments about nutrient or disease-specific variables that might contribute to pica behavior in their children, parents did identify iron-deficiency or anemia as a potential cause of their own pica behavior. Overall, the data are in line with the child development literature that suggests parents are more likely to attribute their children's behavior to environmental rather than hereditary influences (Miller, 1988).

Quantitatively, we did not replicate findings from previous studies identifying hemoglobin differences in children with SCD and pica and children with SCD without pica (e.g., Ahmed et al., 2015; Aloni et al., 2015, Ivascu et al., 2001). The average hemoglobin level in both our pica and control samples was similar to what other studies (e.g., Aloni et al., 2015) have documented for their control groups (i.e., mean hemoglobin ~ 9.5). Of note, similar to other studies with averages at that level, the majority of the total sample (~87%) met criteria for anemia by WHO standards (WHO, 2001). It is possible that anemia still drives pica behaviors but that other variables in our model are maintenance or disinhibiting factors that children in the control group do not have. Alternatively, it is possible that children in our pica group did show higher levels of anemia when they began engaging in pica behaviors, but then despite improvements in their anemia, the pica behavior continued. This of course, is a limitation of cross-sectional study design, and a longitudinal study including analysis of anemia levels at time of pica behavior initiation could help clarify the nature of this relationship over time.

Similar to other retrospective studies, we were not able to assess for iron and zinc deficiencies as collection of these variables is not presently part of standard care for children with SCD and pica. Given the limited support of this relation in the literature, future studies should consider collection of these variables. When examining height and weight, we did not find differences in BMI between the pica group and control patients. Our sample was generally healthy, with most patients falling in the normal weight category (i.e., 69% of pica patients, and 74.5% of controls). However, it was noted that the percentages of patients who fell in the overweight and obese categories was higher than the general population (i.e., 22.4% and 21.8% per group respectively; Hales, Carroll, Fryar & Ogden, 2017). This was surprising given that children with SCD have historically been reported to be underweight (Platt, Rosenstock, &

Espleland, 1984). However, recent studies have suggested that mimicking weight status in the general pediatric population, the average BMI percentile for children with SCD has been rising over the past two decades (Chawla et al., 2012). The relationship between BMI and pica remains unclear.

Finally, when looking at markers of disease severity, we did not find group differences in number of ER visits between pica and control patients. This has only been examined in one other study and they also did not find a relation (Ivascu, et al., 2001). At this time, we do not have reason to believe that pica has relation to general SCD severity.

4.3   Psychological Correlates

When examining qualitative themes, describing pica as an urge or as craving was the most consistent theme across interviews. This is a novel finding in the pica and SCD literature. However, descriptions of urges and craving have been described in varying non-SCD pica case studies (e.g., Stein et al., 1996). This qualitative theme may support the idea that when pica presents in SCD, it may be better compared to other compulsive behavior disorders and treatment decisions may reflect this similarity. Specifically, when examining meta-cognitions in Tourette's disorder, tic disorders, and body-focused repetitive behavior disorders, identification of a sensory or premonitory urge has been noted as a prominent feature (O'Connor, St.Pierre-Delorme, Leclerc, Lavoie, & Blais, 2014). Although families often lacked awareness regarding the triggers or antecedents of these "urges," they often noted that once the urge was present, it was very difficult to control.

Consistent with this finding, our data demonstrated higher ratings of general behavioral impulsivity in the pica group than in the control group. To our knowledge, this construct has not been studied quantitatively in children with pica and SCD, so further study and replication is

warranted. Of note, although this finding was statistically significant and demonstrated a moderate effect size, in general, parents' reports of impulsivity were relatively low. Data were heavily skewed, with 27% of the sample strongly disagreeing that their children showed signs of impulsivity and 45% of the sample not agreeing with any of the statements (i.e., strongly disagreeing or disagreeing with all statements) regarding impulsivity. One reason why we may have had lower ratings of impulsivity reported in our sample than in normative samples is that samples previously studied with this measure have not been well-represented by African-American populations, thus, we do not know if there may be cultural differences in reports or perceptions of impulsive behavior in children. Other studies examining perceptions of ADHD-related symptoms among parents of African American children and parents of white children have found that there are important differences, and that parents of white children are often more likely to endorse ADHD behaviors (Hillemeier et al., 2007). Additionally, it may be possible that our quantitative data collection was impacted by demand characteristics, specifically as due to questionnaire and consent script design, families would likely be aware if they were being recruited as a pica patient or control. Future studies may benefit from measuring a wider variety of behavioral traits to mask specific hypotheses.

Qualitatively, our semi-structured interview did not query specifically about dysfunctional eating patterns outside of pica behaviors. However, a general lack of awareness and lack of mindful eating did arise as a qualitative theme. This is in line with other compulsive behavior disorders; developing awareness of the behaviors is a first line of treatment (e.g., Grant, Stein, Woods, & Keuthen, 2012). Quantitatively, and consistent with findings by Lemanek et al. (2002), children in the pica group were reported to have higher rates of dysfunctional eating patterns than those in the control group. By examining specific items, it appeared that families in

the pica group were more likely to endorse that their children ask for food that they should not have, take food between meals without asking, and ask for food between meals. Although we did not find differences in biological variables of disease severity, it is possible that children with pica are showing signs of higher calorie demands due to disease severity or in general just experiencing higher degrees of hunger.

One novel theme that arose during the analyses of qualitative data was a sense of shame around pica behaviors. This sentiment was often discussed along with the theme of sneaking or hiding pica behavior. Parents commented that they sought strategies to address the pica behaviors without using punishment or shame, in part to decrease the hiding behavior. It is possible that shame contributes to hiding or discreet pica, which in turn leads to fewer opportunities for intervention. In this sense, shame could serve as a maintenance or mediating factor between pica initiation and persistence of the behavior. In a review of studies of body-focused repetitive behaviors, shame was identified as a strong contributor to secrecy, withdrawal, and avoidance; the authors argued that shame may act as a treatment barrier (Weingarden & Renshaw, 2015).

4.4 Social Correlates

Family functioning difficulties were not discussed directly in qualitative interviews; however, families noted that pica causes stress for their family and requires varying means of parent behavioral management. When examining the quantitative data, there were statistically significant differences between groups and a moderate effect size indicating that families in the pica group reported significantly less family satisfaction than those in the control group. In terms of clinical significance, at the item level for family satisfaction, parent reports in the pica group were more likely to fall in the "generally to very satisfied range" and parent reports in the control

group were more likely to fall in the "very to extremely satisfied range." Although there were some parents who endorsed some dissatisfaction on specific items, in general, parents in both groups reported satisfaction with family functioning. Additionally, given the cross-sectional nature of the study, understanding the directionality in the relationship between pica behaviors and family stress and functioning is limited, though families did not make this connection qualitatively.

For the majority of study findings, we found good convergence between qualitative and quantitative results. The only exception was hunger and food insecurity. Families in the qualitative interviews often denied a relationship between hunger and pica behaviors and even if they attributed initiation of pica to hunger, they denied that eating non-food items was related to necessity. Although quantitative measures did not directly assess the relationship between food availability at home and pica behaviors, we did find that children in the pica group came from homes with greater food insecurity, though the effect was small. The relationship between low SES and pica has been demonstrated in other populations (e.g., Simpson et al., 2000), but this study was the first to look specifically at food insecurity for children with pica and SCD. Clinically, this may be an important factor to assess when treating children with pica as it may serve as a maintaining factor and limit treatment options. Families who had successfully stopped pica behaviors often talked about using other foods as substitutes when having the urge or craving. This treatment option might be more challenging in families with food insecurity.

When examining family history of pica, only 22% of the pica study sample endorsed a family history of pica behaviors on questionnaires. This was much lower than what has been previously reported in the literature (44-64%; Ahmed, 2015; Gupta & Gupta, 2005). However, through qualitative analysis, we found that the families who participated in our interviews

frequently endorsed a family history of pica. Again, it is possible that families did not remember their own pica behaviors or that of family members until having a more in-depth conversation about pica. Additionally, it is also possible that quantitative questioning of this topic may not be the best approach given potential shame around this behavior. Other studies may not have faced this barrier as the two previous studies that have reported on family history have come from other countries (i.e., Sudan, India) where the behavior may be more culturally practiced and less stigmatized (Ahmed, 2015; Gupta & Gupta, 2005). Children acknowledged that family engagement in pica often contributed to their pica behaviors and made it more challenging to stop. Thus, when treating pica in pediatric SCD, a supportive, verbal assessment of family history of pica may lead to more accurate reporting and inform treatment decisions. It is important to note that we included family history within the social domain of our model as we were conceptualizing family pica practices as a contextual factor that may impact child behavior. Family history could also be considered within the biological domain as it is possible that there is a genetic marker for pica engagement predisposition. As pica rates in sickle cell disease are higher than the general population, pica may be genetically linked along with SCD traits.

Finally, when discussing family history of pica behaviors, we found similar results to Grigsby et al.'s (1999) mixed-methods analysis of kaolin consumption in central Georgia. Specifically, families described cultural practices of eating kaolin (i.e., white dirt, chalk, or white clay) that were often introduced in childhood or pregnancy and available from local stores or neighbors (Grigsby et al., 1999). Although the consumption of kaolin is likely not limited to Georgia, there may be heightened frequency of ingesting this specific item in children with SCD and pica who are raised in Georgia.

4.5   Study Limitations and Future Directions

The current study adds to the literature assessing correlates of pica in SCD and provides important theoretical foundation for the assessment of pica in SCD and potential avenues of treatment. However, this study is not without limitations. In regards to the study sample, subjects were recruited from the waiting rooms of two hospitals in Atlanta, GA. For this reason, families who are less stressed, arrive earlier to appointments, and regularly attend scheduled clinic appointments may have been more likely to enroll in the study. We also did not screen or exclude children being treated via chronic transfusion. As children on transfusion are generally sicker and require more frequent clinic visits, some of their study variables may have been disproportionately different (e.g., anemia, BMI percentile, number of ER visits, family satisfaction). Future studies may consider excluding children being treated via transfusion, especially if blood nutrient variables are to be collected and studied. Additionally, we found significant skew in most study variables, which could be evidence of biased reporting or of poor measure choice for this specific minority population. Thus, the distribution of some study variables might influence the results and limit the generalizability to other populations.

In terms of study design, the present study was a cross-sectional study, which is associated with limitations. Specifically, causality cannot be inferred from the study results. Thus, we can only make inferences about causal or maintaining factors of pica in SCD. For example, it is possible that in line with previous theories, heightened family stress leads to more disordered eating patterns including pica. However, it is also possible that the stress of coping with pica behaviors leads to more family conflict and dissatisfaction. In addition, we made the decision to include children with a history of pica in our control group. This was based on mean difference analysis of study variables and to increase our power to detect group differences. Although we believe this decision was statistically sound, it is worth noting that we did not have a "pure"

control group with no history of pica behaviors. Additionally, our basis of classifying participants as having past or current pica was based on self-report. This comes with obvious limitations and our questionnaire was not designed with a definition of what classifies as "past". For this reason, our past-pica group could have great variability in pica history depending on how they chose to define past. It is possible that some participants in our control group engaged in pica one month ago, while others haven't done so for several years. Further research may benefit from keeping children with a past history of pica in separate group and looking for unique qualities that may have facilitated their ability to disengage from pica behaviors.

Although all participation was voluntary and thus sample bias is an issue, the participants in the qualitative portion might have been even more biased given that they agreed to discuss pica in more detail. For example, they might have less shame about pica. Additionally, though conducting the interviews over the phone appeared to facilitate a perception of anonymity for participants, it also allowed for some of lack of control over participants' environment when they were answering questions. Parents and children were asked to complete the interview in a separate room from each other, but this might not have always been the case.

4.6   Conclusion

The current study explored factors that relate to pica in pediatric SCD. Overall, the mixed methods results presented an expanded view of correlates of pica in SCD. Qualitative results suggested that children with pica and SCD appear to be driven by impulsivity, have a general lack of awareness of eating patterns, and feel shame about pica. Additionally, pica appears to contribute to parent-child conflict and stress and children with pica often report having family members who also engage in pica. Specific culturally-based practice of kaolin-eating was also described by families participating in the qualitative interviews. Quantitative findings provided

some support for these findings, indicating that children with pica and SCD showed more symptoms of general impulsivity and disordered eating than those without pica. Additionally, parents of children with pica and SCD were more likely to report higher levels of family stress and food insecurity. The initial biopsychosocial model of pica in SCD was updated to reflect these findings (Figure 6). This study did not discover relationships between biological variables and pica group membership, but this might be partially due to study limitations (e.g., no zinc blood testing). Thus, further study is warranted into biological correlates of pica in SCD. Despite our study results, given the support in the literature (e.g., Ahmed et al., 2005; Aloni et al., 2014, Ivascu et al., 2001), nutritional deficits, anemia, and BMI were retained in the model. As disease severity has limited support in the existing literature and was not supported in this study, it was removed from the model. In general, this study highlighted the importance of psychosocial variables in the maintenance of pica behaviors. Although causality cannot be assumed, attention to these variables when assessing risk for pica, or addressing ongoing pica is likely warranted. Additionally, this study highlighted the limitations of quantitative assessments when examining stigmatized or "secret" behaviors. Lastly, discrepancies between parent and child reports and quantitative and qualitative disclosures indicated the need for multi-informant and multi-method assessment in future studies and in clinical assessment of pica in SCD. In conclusion, these findings expand our understanding of the complex nature of pica in pediatric SCD. In clinical and research domains, our data highlight a range of factors to consider in terms of the etiology as well as the maintenance of the eating of non-food items in pediatric SCD.
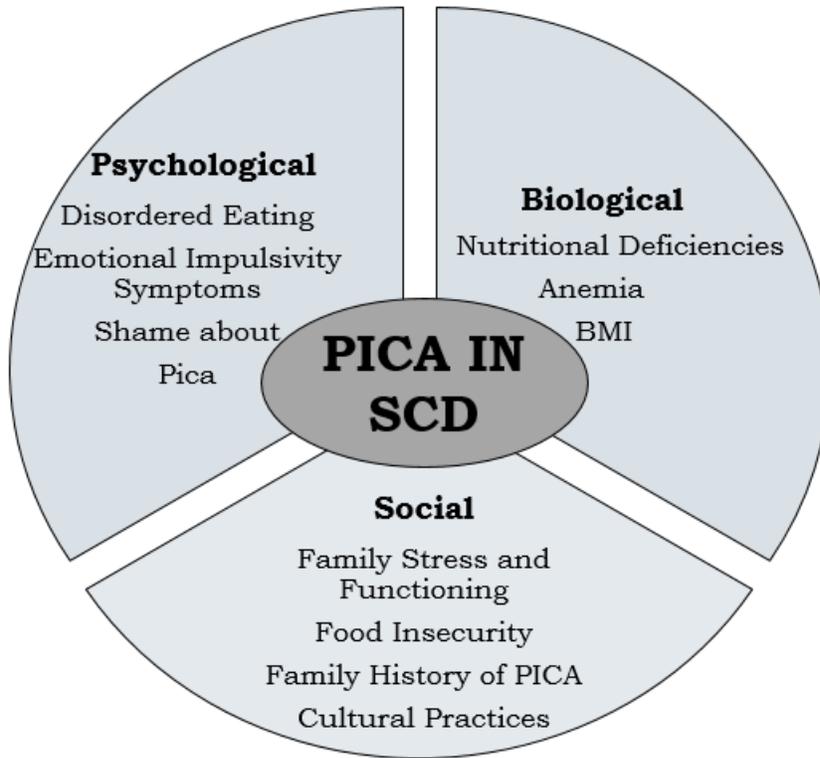
Figure 6 Updated Biopsychosocial Model of Pica in Pediatric SCD

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6   APPENDICES

6.1   APPENDIX A: Background Information

Please tell us a about yourself by the checking the correct response or filling in the blank.
Questions about you:
1.   Relation to Child: _____ Biological Mother _____ Biological Father _____ Non-biological Mother _____ Non-Biological Father _____ Other Guardian: _____
2.   Child's Sex: ___Male   ___Female
3.   Child's Age: ____ yrs. ____ mos.

4.   Please select your child's ethnicity:

   ___Hispanic or Latino (A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race)

   ___Not Hispanic or Latino

5.   Please select your child's race

   ___American Indian or Alaska Native   A person whose family is originally from any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.

   ___Asian   A person whose family is originally from the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.

   ___Black or African American   A person whose family is originally from any of the black racial groups of Africa.

   If so, please check one:
   ____ From the Caribbean Islands
   ____ From South America
   ____ From Southern Africa
   ____ From Northern Africa
   ____ Other, please list: _____
   ____ Don't know

___Native Hawaiian or Other Pacific   A person whose family is originally from any of the original peoples of Hawaii, Guam,

       Islander   Samoa, or other Pacific Islands.

___White   A person whose family is originally from any of the original peoples of Europe, the Middle East, or North Africa.

___ More than one race. Please list: _____

6. What type of SCD does your child have?

___SS   ___SC   ___S-B Thal + ___S-B Thal 0 ___Don't Know   ___Other:_____

7. What grade is your child in at school? _____

8. Please circle your approximate total family income per year:

     a. Up to $10,000   f. $50,001 – 60,000

     b. $10,001 – 20,000   g. $60,001 – 70,000

     c. $20,001 – 30,000   h. $70,001 – 80,000

     d. $30,001 – 40,000   i. $80,001 – 90,000

     e. $40,001 – 50,000   j. $90,000 and above

                     k. Don't know

6.2   APPENDIX B: Parent PICA questionnaire

1) Has your child ever eaten any of the following nonfood things?

		How much in one sitting?	How often?	When did they start eating this thing?	Where do they eat these things? (eg. school, home)
☐ Paper	☐ Past ☐ Current				
☐ String	☐ Past ☐ Current				
☐ Dirt	☐ Past ☐ Current				
☐ Clay	☐ Past ☐ Current				
☐ Chalk	☐ Past ☐ Current				
☐ Dry Wall	☐ Past ☐ Current				
☐ Paint	☐ Past ☐ Current				
☐ Hair	☐ Past ☐ Current				
☐ Tissue	☐ Past ☐ Current				
☐ Baby Powder	☐ Past ☐ Current				
☐ Rocks	☐ Past				

	☐ Current				
☐ Foam	☐ Past				
	☐ Current				
☐ Sponge	☐ Past				
	☐ Current				
☐ Cloth	☐ Past				
	☐ Current				
☐ Cotton	☐ Past				
	☐ Current				
☐ Ice	☐ Past				
	☐ Current				
☐ Cornstarch	☐ Past				
	☐ Current				
☐ Lotion	☐ Past				
	☐ Current				
☐ Other: _____	☐ Past				
	☐ Current				
☐ Other: _____	☐ Past				
	☐ Current				
☐ Other: _____	☐ Past				
	☐ Current				
☐ Other: _____	☐ Past				
	☐ Current				

2. Does anyone else in the family or living in the same home as your child eat nonfood things? If so, who and what do they eat? -

_____

_____

_____

6.3   APPENDIX C: Child/Adolescent PICA Questionnaire

1.   Have you ever eaten any of the following nonfood things?

		How much in one sitting?	How often?	When did you start eating this thing?	Where do you eat these things? (eg. school, home)
☐ Paper	☐ Past ☐ Current				
☐ String	☐ Past ☐ Current				
☐ Dirt	☐ Past ☐ Current				
☐ Clay	☐ Past ☐ Current				
☐ Chalk	☐ Past ☐ Current				
☐ Dry Wall	☐ Past ☐ Current				
☐ Paint	☐ Past ☐ Current				
☐ Hair	☐ Past ☐ Current				
☐ Tissue	☐ Past ☐ Current				
☐ Baby Powder	☐ Past ☐ Current				
☐ Rocks	☐ Past ☐ Current				
☐ Foam	☐ Past				

	☐ Current				
☐ Sponge	☐ Past ☐ Current				
☐ Cloth	☐ Past ☐ Current				
☐ Cotton	☐ Past ☐ Current				
☐ Ice	☐ Past ☐ Current				
☐ Cornstarch	☐ Past ☐ Current				
☐ Lotion	☐ Past ☐ Current				
☐ Other: _____	☐ Past ☐ Current				
☐ Other: _____	☐ Past ☐ Current				
☐ Other: _____	☐ Past ☐ Current				
☐ Other: _____	☐ Past ☐ Current				
☐ Other: _____	☐ Past ☐ Current				

2) Who else knows that you eat these things?

_____

_____

_____

6.4   APPENDIX D: Behavior

1. My child has trouble controlling his/her impulses

   Agree Strongly | Agree Some | Disagree Some | Disagree Strongly

2. When my child is very happy, he/she can't seem to stop himself/herself from doing things that can have bad consequences

   Agree Strongly | Agree Some | Disagree Some | Disagree Strongly

3. My child has trouble resisting his/her cravings (for food, cigarettes, etc.).

   Agree Strongly | Agree Some | Disagree Some | Disagree Strongly

4. When my child is in a great mood, he/she tends to get into situations that could cause him/her problems

   Agree Strongly | Agree Some | Disagree Some | Disagree Strongly

5. My child often gets involved in things he/she later wishes he/she could get out of.

   Agree Strongly | Agree Some | Disagree Some | Disagree Strongly

6. When my child is very happy, he/she tends to do things that may cause problems in his/her life

   Agree Strongly | Agree Some | Disagree Some | Disagree Strongly

7. When my child feels bad, he/she will often do things he/she later regrets in order to make himself/herself feel better now

   Agree Strongly | Agree Some | Disagree Some | Disagree Strongly

8. My child tends to lose control when he/she is in a great mood.

   Agree Strongly | Agree Some | Disagree Some | Disagree Strongly

9. Sometimes, when my child feels bad, they can't seem to stop what they are doing even though it makes them feel worse.

   Agree Strongly | Agree Some | Disagree Some | Disagree Strongly

10. When my child is really ecstatic, he/she tends to get out of control.

    Agree Strongly | Agree Some | Disagree Some | Disagree Strongly

11. When my child is upset, he/she often acts without thinking.

    Agree Strongly | Agree Some | Disagree Some | Disagree Strongly

12. Others would say my child makes bad choices when he/she is extremely happy about something.

    Agree Strongly | Agree Some | Disagree Some | Disagree Strongly

13. When my child feels rejected, he/she will often say things they later regret

    Agree Strongly | Agree Some | Disagree Some | Disagree Strongly

14. Others are shocked or worried about things my child does when he/she is feeling very excited

    Agree Strongly | Agree Some | Disagree Some | Disagree Strongly

15. It is hard for my child to resist acting on his/her feelings

    Agree Strongly | Agree Some | Disagree Some | Disagree Strongly

16. When my child gets really happy about something, he/she tends to do things that can have bad consequences	Agree Strongly	Agree Some	Disagree Some	Disagree Strongly
17. My child often makes matters worse because (s)he acts without thinking when (s)he is upset	Agree Strongly	Agree Some	Disagree Some	Disagree Strongly
18. When overjoyed, I feel like my child can't stop him/herself from going overboard	Agree Strongly	Agree Some	Disagree Some	Disagree Strongly

6.5

6.6   APPENDIX E: Children's Eating Behavior

	Never	Seldom	Sometimes	Often	Always	Is this a problem for you?	
1. My child chews food as expected for his/her age	1	2	3	4	5	Yes	No
2. My child enjoys eating	1	2	3	4	5	Yes	No
3. My child asks for food which he/she shouldn't have	1	2	3	4	5	Yes	No
4. My child feeds his/her self as expected for his/her age	1	2	3	4	5	Yes	No
5. My child gags at mealtimes	1	2	3	4	5	Yes	No
6. I feel confident my child eats enough	1	2	3	4	5	Yes	No
7. My child vomits at mealtimes	1	2	3	4	5	Yes	No
8. My child takes food between meals without asking	1	2	3	4	5	Yes	No
9. My child chokes at mealtimes	1	2	3	4	5	Yes	No
10. My child makes food for him/her self when not allowed	1	2	3	4	5	Yes	No
11. I get upset when my child doesn't eat	1	2	3	4	5	Yes	No
12. At home my child eats food he/she shouldn't have	1	2	3	4	5	Yes	No
13. My child uses cutlery as expected for his/her age	1	2	3	4	5	Yes	No
14. At friends' home my child eats food he/she shouldn't eat	1	2	3	4	5	Yes	No
15. My child asks for food between meals	1	2	3	4	5	Yes	No
16. My child chews on, but doesn't swallow, things that are not food (e.g., pencil, eraser, rim of cup)	1	2	3	4	5	Yes	No
17. My child chews on and swallows things that are not food (e.g., dirt, foam, hair)	1	2	3	4	5	Yes	No
18. Other people have observed my child chewing on or eating nonfood items	1	2	3	4	5	Yes	No
19. Nonfood items have been found in my child's body wastes	1	2	3	4	5	Yes	No
20. My child has had problems with a blockage of the intestines or bowels because of eating nonfood items	1	2	3	4	5	Yes	No

6.7 APPENDIX F: Family Satisfaction

1	2	3	4	5	
Very Dissatisfied	Somewhat Dissatisfied	Generally Satisfied	Very Satisfied	Extremely Satisfied	

1. The degree of closeness between family members

    1 2 3 4 5

2. Your family's ability to cope with stress.

    1 2 3 4 5

3. You family's ability to be flexible.

    1 2 3 4 5

4. Your family's ability to share positive experiences

    1 2 3 4 5

5. The quality of communication between family members.

    1 2 3 4 5

6. Your family's ability to resolve conflicts.

    1 2 3 4 5

7. The amount of time you spend together as a family.

    1 2 3 4 5

8. The way problems are discussed

    1 2 3 4 5

9. The fairness of criticism in your family.

    1 2 3 4 5

10. Family members concern for each other

    1 2 3 4 5

6.8   APPENDIX G: Food

These questions are about the food eaten in your household in the last 12 months and whether you were able to afford the food you need.

1. The food that we bought for the house just didn't last, and we didn't have the money to get more
    a. Often true
    b. Sometimes true
    c. Never true
    d. Don't know

2. We couldn't afford to eat balanced meals
    a. Often true
    b. Sometimes true
    c. Never true
    d. Don't know

3. In the last 12 months, did you ever cut the size of your meals or skip meals because there wasn't enough money for food?
    a. Yes
    b. No
    c. Don't know

4. If yes, how often did this happen?
    a. Almost every month
    b. Some months but not every month
    c. Only 1 or 2 months
    d. Don't know

5. In the last 12 months, did you ever eat less than you felt you should because there wasn't enough money for food?
    a. Yes
    b. No
    c. Don't know

6. In the last 12 months, were you ever hungry but didn't eat because there wasn't enough money for food
    a. Yes
    b. No
    c. Don't know

6.9   APPENDIX H: Parent Qualitative Interview

"Hello, my name is _____ . I'm here today to talk to you a little bit about your child's pica."

"Do you know what pica is? And do you know why the medical team is interested in your child's pica behavior?"

(Validate/acknowledge response) *"Pica is the persistent eating of substances that have no nutritional value or nonfoods. It comes in a lot of forms and a lot of kids and adults engage in pica. There is actually a really high rate of pica in children and adults who have sickle cell."*

"Thank you for completing this survey. I'm hoping to ask you some additional questions today just to get a better understanding of your and your child's experience with pica. For some people it can be a hard thing to talk about, but I want you to know that this is a no-judgment space - which means that I'm just here to listen and that's it. We're hoping to get a better understanding of what pica is and why kids with sickle cell might be more likely to eat nonfood items. It is our hope that through better understanding of why so many of the children we work with engage in pica, we'll be better able to make sense of their experience and help them overcome pica as we know that it can eventually lead to poor medical outcomes. That being said, today is just the gathering information stage and we were hoping you might help by sharing your and your child's experience with pica. Would it be okay if I ask you some questions?"

(Verify survey response regarding non-food items consumed)
- *"I see that on this survey, your child used to eat or currently eats (this much) (item) (this often) and it started when he/she was (age). Is that right?"*
-

Questions regarding pica behavior
- *"Tell me about the first time you realized your child was eating nonfood substances."*
- *"Did you ever notice any patterns when your child was engaging in this behavior?"*
    - **PROMPT IF NEEDED**
        - **"Did you notice times when your child engaged in pica more than other times?"**
        - *"Were there certain places where she/he did this more?"*
        - *"Where did he/she get (item/s) from?"*
- *"Do you have any ideas as to why he/she engaged in eating nonfood items?"*

Questions regarding parent response to pica behavior:
- *"How did you react when you found out that your child had eaten nonfood items?"*

- *"Did your reaction change over time?"*
- *"Have you ever talked to other parents about your child's pica either to seek advice or support?"*
- *"Have you ever sought information about pica online or in books?"*
- *"Did you ever seek professional help with stopping your child's pica?"*
  - o **(IF YES)** *"Was it hard to find services? How did people react when you told them?"*
  - o **(IF NO) "***Why not?"*
- *"How do you feel about your child having pica?"*
- *"Were you concerned about your child eating non-food items?"*
- *"How big of a problem do you think it is that your child ate non-food items?"*
- *"Did you ever try to get your child to stop?"*
  - o **(IF YES)** *"What happened?" "How or what strategies did your child use to stop eating (item/s)?" Were there any strategies that didn't work?" Do you have any other ideas of what might be helpful to your child?*
  - o **(IF NO)** *"Do you have any ideas of what might be helpful to your child to stop eating nonfoods?"*

(**Verify survey response – Family History)**
- "*Does anyone else in the family or living at home with your child currently eat non-food items or have a history of eating non-food items?"*
  - o **(IF YES) "***Which family members (clarify if they are blood-related)? What did/do they eat?*

Summarize, thank for participation, and ask:
- ***"Is there anything else you'd like to share with us?"***

6.10 **APPENDIX I***: Child (Age 8-17) Qualitative Interview*

"Hello, my name is _____. I'm here today to talk to you a little bit about pica."

"Do you know what pica is?"

(**Validate/acknowledge response)** *"Pica is the repeated eating of things that are not food. It comes in a lot of forms and a lot of kids engage in pica, especially kids who have sickle cell."*

"Thank you for completing this survey. I'm hoping to ask you some more questions today just to get a better understanding of your experience with pica. For some kids it can be a hard thing to talk about, but I want you to know that this is a safe place where we will listen and try to better understand what pica is and why some kids might be more likely to eat nonfood items. We were hoping you might help by sharing your experience. Would it be okay if I ask you some questions now?"

(Verify survey response regarding non-food items consumed)
- *Tell me a little bit about your eating of nonfood things."*
- *"I see that on this survey, your child used to eat or currently eats (this much) (item) (this often) and it started when he/she was (age). Is that right?"*

Questions regarding pica behavior:
- *"Tell me about what's going on when you eat nonfoods."*
- *"Are there certain times or places when you eat nonfoods more?"*
- *"What are you normally doing before you eat nonfood items?"*
- *"What thoughts do you have before you begin eating nonfood things?"*
- *"Where do you get the items you eat?"*
- *"Does anyone help you get these nonfood items?"*
- *"Do you ever seek them out or do you only eat them when they happen to be in front of you?"*
- *"Have you ever wanted to eat a nonfood substance and you couldn't find it or get it?"*
  - **(IF YES)** *"How did that make you feel?"*
  - **(IF NO)** *"How do you think that would make you feel?"*
- *"Did you ever go somewhere where you knew you wouldn't be able to get (item)?"*
  - **(IF YES)** *"Did you ever do anything to solve this problem? Like packing some (item) in your bag?"*
  - **(IF NO)** *"Do you think you would do anything to solve this problem? Like packing some (item) in your bag?"*
- *"How do you feel after you have eaten nonfood items?"*
- *"How do you feel about eating non-food items?"*

- *"Why do you think you eat nonfood things?"*
  - **PROMPT IF NEEDED (If patient says I don't know, give specifics)**
    - *"Do you think you eat nonfood items when you're hungry? Bored? Tired?"*
- *How big of a problem do you think it is that you eat non-food items?*

Questions about stopping pica behavior
- *"Have you ever tried to stop eating (item/s)?"*
  - **(IF YES)** *"Why did you stop eating (past item/s)?" "What strategies did you use?" "Did some work better than others?" "Did you ever stop eating (past item) but then start eating it again?"*
  - **(IF NO)** *"Do you want to stop eating (current item/s)?" "How hard do you think it would be to stop?"*
- *"Do you want to stop eating (current item/s)?"*
- *"How hard do you think it would be to stop?"*

(Verify survey response)
- *On this survey, you said your (teacher, friend, parents, doctors) know you eat nonfood items – is there anyone else who knows?*
- *How do they know?*
- *"How do your parents react if/when they find out that you have eaten nonfood items?"*
- *Do you know anyone else who eats nonfood substances?*
  - **(IF YES)** *"Who? And what do they eat?"*

Summarize, thank for participation, and ask:
- *"What else would you like to share with us about eating nonfood items?"*

6.11 APPENDIX J: Coding Scheme

Child/Parent Reactions
Reaction: worry about child getting sick/choking
Reaction: (s)he's just a baby/kid, (s)he'll grow out of it
Reaction: pica is more concerning due to the child already having SCD
Reaction: empathic but want them to stop
Reaction: child or parent feels shame about pica
Pattern or times when they're more likely to do it
Pattern: the child does it sneakily; parents don't know the extent of the behavior
Pattern: when (s)he sees it, (s)he wants it
Pattern: when denied access, child is frustrated
Pattern: after engaging in pica, feel satisfaction
Why engages in pica
Why- deficiency, something about sickle cell or anemia
Why: urge/craving
Why: different from hunger
Why: no idea; lack of awareness
Family history of pica
Family history
Strategies to stop pica
Strategy- substitution foods
Strategy- keep busy/distraction
Strategy- try to remove access
Strategy- talk to child about how it's unhealthy; child thinks about how it's bad/unhealthy