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Sickle Cell in a Poor Community in Haiti: Attention, Emotion, and Sleep

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SICKLE CELL IN A POOR COMMUNITY IN HAITI:

ATTENTION, EMOTION, AND SLEEP

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ABSTRACT

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Hemoglobin disorders or inherited blood diseases affect about 5% of the world population. One main category of these disorders is sickle-cell disease (SCD). SCD can cause many physical complications, such as kidney problems, leg ulcers, and chronic pain. Less frequently discussed symptoms include complications like attention problems and emotion regulation. The study looked at a small sample of pediatric and adult patients (*N*=22) with SCD at a primary care clinic in a very poor community in Haiti, researching sleep and emotion regulation, given their shared neurobiological systems. As these symptoms can influence attention, the relationships among attention, emotion, and sleep were examined. A Haitian population was chosen because of the high rates of SCD in Haiti, the need to conduct international studies in SCD, and the long-standing collaboration between the Antioch Multicultural Center for Research and Practice and the Haitian primary care clinic, Partners in Development. The study provides a preliminary set of data from a select Haitian population for the measures used: (a) demographics questionnaire; (b) the Berlin Questionnaire (Netzer, Stoohs, Netzer, Clark, & Strohl, 1999); (c) the Cognitive Emotion Regulation Questionnaire (Garnefski, Kraaij, & Spinhoven, 2002), and (d) the Conners Continuous Auditory Test of Attention (Conners, 2015). Findings presented are generally descriptive. Sleep problems (specifically snoring/nighttime breathing problems)

and emotionality were significantly positively related to a moderate degree. Emotionality and sleep problems were not significantly related to attention; however, both were significantly positively related to attention to a moderate degree when the sample size was doubled with simulated data. Age was not correlated with sleep problems, emotionality, or attention. Participants were divided into two groups based on the presence or absence of documented attention problems. Results revealed that individuals with a history of documented attention problems had fewer sleep, emotionality, and attention problems on standardized tests but the differences were not significant. A single case assessment profile analysis was performed with three participants because the small sample size did not allow testing of potential group differences and because of the preliminary nature of the study. The findings, limitations of the study, and future directions of research are discussed. This dissertation is available in open access at AURA, http://aura.antioch.edu/ and Ohio Link ETD Center, https://etd.ohiolink.edu/edu

Keywords: sickle cell, poor people in Haiti, attention, emotion regulation, sleep, single case assessment profile analysis

Dedication

My dissertation research is dedicated to sickle cell patients in the poor communities of Haiti, specifically Blanchard, Damien, and Canaan. Sickle cell disease is an extremely difficult condition to deal with throughout an individual's life, even with all of the Western knowledge, technology, and medicine at one's disposal. The optimism and resilience with which the individuals from these poor Haitian communities dealt with their disease are an inspiration to me. A dedication is also offered to Partners in Development, Inc., Ipswich, MA, www.pidonline.org, which has been working tirelessly in Haiti for almost 30 years, touching countless lives.

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Sickle Cell in a Poor Community in Haiti: Sleep, Emotion, and Attention

Hemoglobin disorders, or inherited blood diseases, affect about 5% of the world population (Weatherall, 2010). Putting this into a global perspective, that is about the combined total population of the United States, 327 million, and South Korea, 51 million (Central Intelligence Agency, 2017). Thus, a large global population has hemoglobin disorders. These disorders fall into two main categories: (a) Thalassaemias and (b) Sickle Cell Disease (World Health Organization, 2011). The disorder of interest to the present study is Sickle Cell Disease (SCD). Hemoglobin, a protein that carries oxygen, is affected in the red blood cells (RBCs) of those who have SCD. This results in a change in shape of the RBCs, which can lead to shortened red blood cell survival or anemia. Anemia is a condition where the number of RBCs or their ability to carry oxygen is insufficient to meet the body's needs (World Health Organization, 2018). Diagnostic screening is done through a blood test. Newborn and prenatal screenings are available. There is no treatment for SCD but symptoms can be managed with medication and by maintaining a healthy lifestyle. The population of those with SCD is not evenly distributed throughout the world.

SCD affects approximately 15% of individuals living in northern Haiti, a percentage much higher than that of individuals with SCD in the United States (Hassell, 2010; Randolph, 2010). This difference persisted even when looking at only the prevalence of SCD in African Americans (0.2%), a population in the United States where SCD is highest. Sickle cell disease is caused by the sickle hemoglobin (HbS), a variant of the beta-globin gene (Ashley-Koch, Yang, & Olney, 2000). Because this gene is autosomal recessive, two copies of HbS or one copy of HbS plus another variant of the beta-globin (such as Hb C) are needed for the disease expression. HbSS is considered to be the most severe form of the disease. When a person inherits only one

abnormal allele (one HbS) but does not experience the full disease, they have sickle cell trait. The prevalence of African Americans with sickle cell trait is about 7.7% (Centers for Disease Control and Prevention, 2016). The combined rates of sickle cell trait and SCD in African Americans is still only roughly half of the prevalence of those in Haiti who have full SCD. Though SCD is present in many countries, there are pockets of the world where the prevalence rates are much higher but the resources to deal with the associated disease complications are low.

Pathophysiology of SCD

The sickling of the RBC comes from a mutation in the hemoglobin where valine is substituted for glutamic acid. This happens in the beta-globin chain at the sixth position (Ilesanmi, 2010). HbS is made of two normal α-globin and two abnormal β-globin chains. Normal chains carry oxygen but HbS begin to form semi-solid aggregate structures once oxygen is delivered to the tissues. The aggregates distort RBCs and decrease the cells' flexibility. Permanent RBC damage develops from repeated deoxygenation cycles (Ilesanmi, 2010). RBC injury results in extra- and intravascular hemolysis, endothelial dysfunction, vasculopathy, and occlusion of small and large vessels, producing tissue ischemia/reperfusion injury and inflammation (Kato, Steinberg, & Gladwin, 2017).

Individuals with SCD are at an increased vulnerability for infarcts and strokes (DeBaun et al., 2012b). Strokes may be overt, where there are clear symptoms like motor difficulties and speech changes. They can also be "silent," where there are no obvious symptoms and differences can only be detected through neuroimaging. Approximately 17% of children under the age of 14 and 23% of individuals under 18 have silent strokes, but they are often undetected in patients (The Internet Stroke Center, 2019). The following risk factors for individuals with SCD have been associated with cerebral ischemic events: (a) low oxygen content; (b) presence of cerebral

vasculopathy; (c) acute infection associated with fever; (d) cardiovascular risk factors common to the general population (i.e., diabetes mellitus, hypertension); (e) prior cerebral infarct happening in the previous two to three years; and (f) rapid increases in hemoglobin levels (i.e., blood transfusion therapy; DeBaun & Kirkham, 2016).

In a study that looked at the brain imaging for children with SCD ages 6 to 14, general brain changes that were found included RBC "sludging," distal field insufficiency, and occlusion of large and small vessels (Moser et al., 1996). Localized lesions were seen in the deep white matter and in distal field regions. For HbSS patients, local deep white matter lesions were most often seen in the frontal, parietal, and temporal lobes. Extensive lesions affected both deep white matter and the cortex of the frontal and parietal lobes. Brain atrophy was also prevalent.

Overt strokes are often located in the cortex and deep white matter, while silent strokes typically occur in the deep white matter of the frontal and parietal lobes (DeBaun et al., 2012a). Both overt and silent strokes are associated with significant neurobehavioral effects; however, research also indicates profound neurocognitive dysfunction can be seen even in the absence of abnormalities on neuroimaging (Wang et al., 2016). This indicates that the aforementioned risk factors for strokes (low oxygen content, presence of cerebral vasculopathy, etc.) could play a role in neurocognitive and neurobehavioral changes, even in the absence of observable brain changes. However, this warrants more research. As such, though SCD is a disorder of the blood, SCD can also be conceptualized as a disorder of the brain, or cerebrovascular system, because the brain is supplied by blood and can be greatly affected by problems with blood flow.

Common Symptoms

One of the most recognized complications of SCD is what is known as a "sickle cell crisis" or a vaso-occlusive crisis (National Heart, Lung, and Blood Institute, 2014). Because of

the abnormal shape of the RBC, these cells can become stuck and can block the blood flow to various parts of the body. As RBCs are tasked with delivering oxygen, these blockages can become very serious and can result in significant amounts of pain (Indiana Hemophilia & Thrombosis Center, Inc., 2012; Jensen, 2009). Individuals with SCD also report experiencing chronic pain separate from the episodic crises.

Individuals with SCD can have a host of other physical difficulties, which can be problematic themselves but can also lead to additional symptoms. Those with SCD can have leg ulcers, delayed growth and puberty, joint complications, kidney problems, increased risk of infarct or stroke, retinal damage, complicated pregnancies, and many other physical difficulties (National Heart, Lung, and Blood Institute, 2014). Many of these problems can likely be traced back to unmet oxygen demands. Additionally, chronic infection and compensatory lymphoid tissue hyperplasia can lead to symptoms such as excessive tonsillar and adenoidal growth, which can subsequently lead to problems such as disordered nighttime breathing (Rogers, Lewin, Winnie, & Geiger-Brown, 2010). It is important to note that there are effects of some of these physiological complications on the psychological and neuropsychological functioning of individuals with SCD. Anxiety, depression, and problems with emotion regulation are often seen in individuals with SCD (Anie, 2005). Additionally, many individuals with SCD have lower scores on measures of intellectual ability, processing speed, memory, and attention than controls (Crawford & Jonassaint, 2016; Vichinsky et al., 2010).

Daly, Kral, and Tarazi (2011) stated, “Sickle cell disease is among the most complex medical conditions of childhood, and neuropsychological evaluation offers an important means of assessing the many factors that are involved in the medical care of these children” (p. 919). Furthermore, SCD is chronic, and the idea of cumulative deficits impacting adults with SCD is

currently being researched (Crawford & Jonassaint, 2016). This is supported by MRI findings that show that the average number of brain lesions per patient with SCD increases with age, suggesting progressive brain injury (Moser et al., 1996).

Purpose of the Study

The purpose of the present study was to add to the knowledge of how SCD affects emotional regulation, sleep, and attention in a unique, underserved population, and to investigate the relationships between these areas of functioning. As stated previously, SCD is widespread in Haiti. The study was carried out in a primary care clinic that serves a poor community Haiti, as this population provided an important opportunity to examine the multidimensional effects of this disease.

The relationships amongst emotion regulation, sleep, and attention have not been sufficiently investigated in the context of SCD, but these domains share overlapping and interacting neurobiological underpinnings and can have significant effects on one another in daily life. Investigating these relationships could potentially lead to better integrated care by directing attention and treatment to somatic, psychological, and cognitive symptoms that may be associated with SCD. Integrated care can potentially be better care for patients as the actual perceived experience of the individual does not fall under separate medical, psychological, and neuropsychological umbrellas.

Measures were not used diagnostically in the study. Comparative levels of relative severity in the areas of interest (emotion regulation, sleep, and attention) and their relationships were studied, specifically how disordered sleep and poor emotion regulation could influence attention. There were no data for Haitians on these tests as local resources for obtaining psychological measures are scarce. Beyond the specific scope of the research topic, obtaining

data from a sample of poor Haitian individuals could be a preliminary collection of local data for the study's instruments.

Sleep

Sleep is the part of the body's rest cycle that is triggered by a group of hormones where the brain becomes less connected to the outside environment (Rechtschaffen, 1998). According to the American Psychological Association (2018), some common problems of sleep are sleep apnea (a condition where the individual temporarily stops breathing while asleep), insomnia (the inability to fall asleep normally or to stay asleep through most of the night), and daytime sleepiness (the inability to stay sufficiently aroused in the daytime, tending to nap, or feel the need to nap). Individuals with obstructive sleep apnea (OSA) have metabolite changes in the brain, impaired water diffusion, and gray matter loss, all resulting in changes of neural structures. Magnetic resonance spectroscopy reveals that those with OSA have decreased hippocampal membrane turnover (O'Donoghue et al., 2012). Inflammation and atrophy lead to structural changes in those with OSA (Macey, 2012). Once again, with reduced blood flow or less efficient transport of oxygen through red blood cells for those with SCD, atrophy is not an unlikely occurrence.

Disordered sleep and SCD. SCD can cause intense pain, which may result in reduced sleep. Research indicates that children who experience chronic pain have less efficient sleep, more night waking, and shorter overall sleep duration (Lewandowski, Ward, & Palermo, 2011). Individuals with SCD have increased risk of disordered breathing. For example, children with SCD have a greatly increased risk of having obstructive sleep apnea and disordered breathing during sleep (60–80% incidence rate). This is a striking percentage when compared to children without sickle cell disease where the incidence rates are about 2–3% (Mascarenhas, Loureiro,

Ferreira, & Dias, 2015). Adenotonsillar hypertrophy is attributed to being the main risk factor for OSA in children with SCD (Rogers et al., 2010). OSA does not go away when the child matures. High rates of sleep disordered breathing are also found in the adult sickle cell population (Sharma et al., 2015).

Individuals with SCD also experience more nocturnal desaturation (nighttime blood oxygen level drops; Rosen et al., 2014). This was demonstrated using oximetry metrics (measuring oxygen saturation) with a sample of children with SCD, ages 4 to 18. Greater desaturation time was associated with higher obstructive apnea hypopnea index scores (higher rates of shallow breathing due to obstructive apnea). Sleep saturation and basal hemoglobin are significantly related, which means that the more severe the SCD case, the more nocturnal desaturation (Ferreira, Morais, Ferrão, & Trindade, 2009). Additionally, hypoxemia, or low levels of oxygen in the blood, may increase risk of RBC sickling (Rogers et al., 2010).

Effects of poor sleep on everyday functioning. Slow wave sleep and REM (rapid eye movement) have been correlated with cognitive processing (Ferri, Novelli, & Bruni, 2012). Impaired sleep negatively affects cognitive functioning, most notably working memory, decision-making, long-term memory, and vigilance (Alhola & Polo-Kantola, 2007). Another cognitive consequence of disordered sleep is impaired attention. For individuals who were subject to sleep deprivation, there is an increase in both errors of omission and errors of commission in attention tests (Durmer & Dinges, 2005). It is also proposed that these sleep stages can have an important role in brain maturation, specifically regarding synaptic downscaling, which is the ability to maintain homeostasis by reducing the firing rate of neurons (Ferri et al., 2012). This information suggests that there are both short and long-term cognitive effects of poor or interrupted sleep.

Disordered sleep can also cause cardiovascular problems (Rosen et al., 2014). Untreated OSA can lead to higher rates of systemic hypertension, pulmonary hypertension, heart failure, cardiac arrhythmias, cardiovascular disease, and stroke (Golbin, Somers, & Caples, 2008). Children with even mild sleep apnea have been shown to have higher rates of behavioral dysfunction (Bourke et al., 2011). This can have negative consequences in the child's academic life was well as in their interpersonal life.

Emotion Regulation

Emotion regulation is the ability to manage and respond to emotional experiences in an effective way (Rolston & Lloyd-Richardson, 2016). Different situations call for different appropriate responses. When an individual is able to regulate their emotions in a healthy way, they tailor their response to the situation. Individuals with an ability to adequately regulate their emotions use internal and external coping strategies that allow them to interact with their stressful environment in a way that gets their needs met.

Problems with the limbic system, which is in charge of emotion regulation and includes structures such as the amygdala, hippocampus, cingulate gyrus, and hypothalamus, could also likely explain issues in the behavioral problems seen in those with SCD (Lemanek, Buckloh, Woods, & Butler, 1995). Functional MRI reveals that when frightening images are shown, blood flow is increased to the left and right amygdala, the brain's fear center, and decreased in the prefrontal cortex, a region known to regulate emotion responses (Ahmad, Bookheimer, & Mazziotta, 2000). This is important because the amygdala is able to regulate emotion responses by modulating the encoding and storage of the emotion memories that the hippocampus creates. As suggested previously, having abnormally shaped blood cells inefficiently transporting oxygen to the brain could lead to abnormal functioning of important systems, such as the limbic system.

Poor emotion regulation and SCD. Children who have SCD are at an elevated risk of developing internalizing problems (Hijmans et al., 2009), which may include anxiety, withdrawal, depression, and obsessions. Hijmans et al. pose that this is consistent with literature on children who have chronic diseases. Oftentimes, feelings of hopelessness and low self-esteem are seen in individuals with SCD (Anie, 2005). Additionally, subgroups of children who have SCD are at a higher risk of developing severe externalizing problems, such as acting out and aggression (Hijmans et al., 2009). Children with SCD have been seen to have more emotional problems than what would be expected from the general population and this continues as the children approach adulthood. When compared to the general British population and to individuals with Haemochromatosis, those with SCD had performed generally worse on quality-of-life measures (i.e., general health, vitality, social functioning, physical functioning, etc.; Anie, 2005). Individuals with SCD also had significantly more role limitations due to emotional problems.

Effects of poor emotion regulation on everyday functioning. Physical symptoms like severe pain and fatigue may indirectly affect the ability of individuals with SCD to participate in a typical way in interpersonal relationships. But direct effects of the disease on emotion regulation may also result in social impairments and interpersonal stress. In a study of college students, emotion regulation ability was related to reciprocal friendship nominations, peer nominations of both prosocial tendencies and interpersonal sensitivity, and proportion of positive versus negative peer nominations (Lopes, Salovey, Coté, & Beers, 2005). This remained significant even after verbal intelligence, fluid intelligence, and the Big Five personality traits were controlled. Similarly, in a study that looked at younger children ages three to six, popularity was inversely related to anger caused by rejection from others (Fabes & Eisenberg, 1992). The

study also found that for both girls and boys, revenge and venting were also seen to be less common in those who were more socially competent.

Individuals with SCD are at a greater risk for emotional dysregulation, which could lead to increased social rejection (Anie, 2005). When looking at this problem using the ecological systems model, emotion dysregulation has the most profound implications at the microsystemic level (Bronfenbrenner, 1977). Individuals affected could be peers, family members, and neighbors. However, because SCD is an inherited disease that affects a significant proportion of citizens of Haiti, effects of emotion dysregulation on interpersonal relationships may be further exacerbated by the fact that multiple family/community members can be affected by SCD and related symptoms. Effects can extend into the mesosystemic and exosystemic levels as well.

Attention

The American Psychological Association (2018) defines attention as an awareness of perceptual stimuli. Attention is the ability to be able to perceive and take information through the five senses. Poor attention is when the stimuli are there but are not taken in by the individual. An individual may have a low baseline for attention, such as in attention-deficit/hyperactivity disorder (ADHD), or an individual may be distracted due to stress or fatigue, lowering their attentional ability only temporarily.

There are three different networks that represent different attentional processes: the alerting network, the orienting network, and the executive network (Posner & Peterson, 1990). The role of norepinephrine (NE) has been shown to be key to the alerting network. Areas of the brain associated with the source of NE (locus coeruleus) and the NE pathway (frontal cortex and parietal areas relating to the dorsal visual pathway) are involved in processing of alerting attention (Posner & Peterson, 2012). There has been mixed evidence on the laterality of alerting

signals. Ivry and Robertson (1997) reported that the left hemisphere is often involved in higher temporal (phasic) input while the right hemisphere is often involved in slower (tonic) effects.

The orienting network refers to the ability to prioritize incoming sensory stimuli (Posner & Peterson, 1990). The temporoparietal junction and the ventral frontal cortex play a role in switching attention from a predicted stimulus to a different target location (Corbetta & Shulman, 2002). Cholinergic systems that arise in the basal forebrain and continue to the superior parietal lobe can be seen to influence the ability for individuals to orient attention (Voytko et al., 1994).

The executive network is the concept of a target, or stimulus, capturing awareness (Posner & Peterson, 1990). This network has been demonstrated to be dependent on two different types of top-down control networks: the fronto-parietal and the cingulo-opercular networks (Dosenbach et al., 2007). The fronto-parietal network initiates and adjusts control. On a task of attention, this allows an individual to modulate responses to different stimuli. The fronto-parietal network is made up of the dorsolateral prefrontal cortex, inferior parietal lobe, dorsofrontal cortex, intraparietal sulcus, precuneus and middle cingulate cortex. The cingulo-opercular maintains stable control. It is made up of the anterior prefrontal cortex, anterior insula/frontal operculum, dorsal anterior cingulate cortex/medial superior frontal cortex, and thalamus.

Attention deficits and SCD. Individuals with SCD had higher rates of attention difficulties than their non-diseased siblings and many approached significance on attention deficit scales (Bonner et al., 1999). As stated previously, individuals with SCD are at increased risk of having cerebral infarcts or strokes, both of which may result in difficulties with attention, depending on what part of the brain is affected (National Heart, Lung, and Blood Institute, 2014). Berkelhammer et al.'s (2007) meta-analysis concluded that for children who have SCD,

there is a dose-dependent relationship between cerebral insult and attention problems. Individuals with SCD with no history of infarcts or strokes generally have more attentional problems overall when compared to healthy controls but it appears as if this is not widespread over all the attentional networks. In a meta-analysis looking at cognitive functioning for children with SCD and no history of strokes, attention and executive functioning were two general domains outside of IQ that was most notably affected by the presence of the disease (Schatz, Finke, Kellett, & Kramer, 2002). Craft, Schatz, Glauser, Lee, and DeBaun (1994) found that children with SCD with no history of infarct were no more impaired on an orienting attention task than their sibling controls. A study by Noll et al. (2000) found that children with SCD who had no history of overt strokes performed worse on the Kagan Matching Familiar Figures Test (MFFT), an attentional test measuring the executive network, than healthy controls.

Other factors that may contribute to or be related to attention impairments found in those with SCD include the other two highlighted symptoms, disordered sleep and problems with emotion regulation. As stated previously, sleep deprivation is seen to be linked to errors of omission and commission on attention tasks (Durmer & Dinges, 2005). Additionally, individuals who experience sleep disordered breathing, excessive daytime sleepiness, and periodic limb movement in sleep have been found to exhibit attention-deficit/hyperactivity disorder (ADHD) symptoms (Yoon, Jain, & Shapiro, 2012). In terms of emotion regulation, Talmi, Anderson, Riggs, Caplan, and Moscovitch (2008) demonstrated that individuals who were presented with emotional pictures paid more attention to those than to neutral photos. These aforementioned studies were not conducted on individuals with SCD but suggest potential relationships among the symptoms that individuals with SCD experience.

Effects of poor attention on everyday functioning. In school-age children, symptoms of inattention are seen to predict both school performance and special education needs, even after IQ and executive functioning abilities are controlled (Diamantopoulou, Rydell, Thorell & Bohlin, 2007). In a group of students aged eight to fourteen, students with attention problems performed significantly worse in reading, writing, and mathematic skills than a control group of students without attentional problems (Barry, Lyman, & Klinger, 2002). Compared to their control group of same aged peers, there was also a larger difference between actual and predicted achievement for students with attention problems.

These findings are especially concerning for students in Haiti. The majority of schools in Haiti are privately owned (Library for All, 2015). As such, tuition is a requirement. Parents also have to pay for books and school uniforms (World Bank, 2015). It is a financial hardship to get children to school for these reasons. Though the World Bank and Caribbean Development Bank instituted a tuition waiver program, not all schools qualify and not all of the expenses are covered (World Bank, 2015). Families spend large portions of their money so their children can attend school and can have better lives (World Bank, 2015). Students with significant attention problems may not be able to succeed in school, even if very intelligent, which could result in significant financial strain for families without a high income.

In adults, problems with attention have been seen to significantly reduce both quantity and quality in job performance. The World Health Organization created a multinational study looking at how ADHD affects performance in a work setting. Those who had ADHD had an average of 21.7 days of decreased work quantity and 13.6 days of decreased work quality (de Graaf et al., 2008).

Attentional problems are also seen to negatively affect social functioning. Low peer acceptance has been demonstrated to be a risk for school dropout, which would have a strong impact on these children's future job prospects (Parker & Ashler, 1987). Though the study was looking at individuals with diagnosed ADHD, many individuals with SCD approach significance on attention deficit scales (Bonner et al., 1999).

Information on Haiti

Haiti is a country in the Caribbean, located on an island, bordering the Dominican Republic. The population of Haiti is over 11 million (World Population Review, 2018). Creole and French are the official languages in Haiti, though French is usually the language taught in schools and Creole is generally the spoken language. Approximately 96% of the population is either Catholic or Protestant, though voodoo is also widely practiced (Embassy of the Republic of Haiti in Washington, DC, 2017). There is a large wealth disparity in Haiti, with the richest 1% of the population in possession of half of the country's wealth (World Population, 2018). Fifty nine percent of the population lives below the national poverty line of US$2.41 per day and 24% are living below the national extreme poverty line of US $1.23 per day (World Bank, 2018). Though considered to be the poorest nation in the Western hemisphere (World Bank, 2018), Haiti has a rich culture. Music and dance are deeply imbedded in the lives of Haitians. Emotions are expressed, stories are told, and community is formed around the beat of the drum (MacFarland, 2018).

However, Haiti has had many hardships. Individuals in Haiti have been through many significant disasters recently that have devastated an already poverty-ridden country (The Associated Press, 2010). For example, in the past ten years, there have been multiple devastating hurricanes, extensive flooding, a cholera outbreak, mudslides, and multiple earthquakes (Kang,

2016). The earthquake of 2010 spurred service providers, both internally and from abroad, to provide counseling and assistance to Haitians (Nicolas, Jean-Jacques, & Wheatley, 2012). In addition to natural disasters and disease, many Haitians have been subjected to violence by criminal gangs, a corrupt police force, and significant political rivalries (Lacey, 2007). These acts also brought providers to Haitian shores (Farmer, 2004).

Though the aforementioned natural and human-made disasters have brought an influx of providers to Haiti, scholarly research on psychological functioning in Haiti has been sparse (Farmer, 2004; Nicolas et al., 2012). This is a trend that is changing, as evidenced by the new Caribbean Journal of Psychology that was just recently been established (and is awaiting its first publication); however, more work needs to be done.

Trauma is something that is likely playing a role in many Haitians' lives, which can affect all areas of functioning in medical, psychological, and neuropsychological realms. The present study recruited a sample of individuals who were from the same area, which while not eliminating the presence of trauma, might have allowed for a similar degree of exposure to various traumatic events within the sample. However, it is important to note that there are individual differences in reactions to traumatic events, as was demonstrated in a study of resilience and vulnerability in Haitian children (Roysircar, Colvin, Afolayan, Thompson, & Robertson, 2017).

Research in Haiti and Cultural Considerations

It is important to note that most of the studies referenced in this chapter have been conducted in the United States. This reflects the general trends in psychology (Arnett, 2008). Americans dominate the psychological field and an "overwhelming" proportion of their participants are American (Sue, 1999, p. 1072). However, Americans only make up about 5% of

the world population (Arnett, 2008). Though many individuals and organizations in the United States have the means to carry out studies in ways that have high internal validity, their findings cannot often be generalized to international populations (Arnett, 2008). Sue (1999) posits that the scientific field has selectively enforced internal validity over external validity. Segall, Lonner, and Berry (1998) stated, "As national societies become increasingly diverse and international contacts become common, psychologists can no longer assume an acultural or unicultural stance" (p. 1101).

What is found in an American sample will not necessarily also be found in a sample from another country that has different opportunities and access to resources. For example, Lopes, Salovey, Coté, and Beers (2005) looked at the relationship between emotion regulation and positive versus negative peer nomination in a sample of college students. In the United States, 40.5% of young adults ages 18 to 24 years old were enrolled in a college or university (National Center for Education Statistics, 2017), whereas in Haiti, only 40% will make it through the sixth grade with that percentage steadily decreasing as the grade level increases (UNICEF, 2008). Though some studies may look at similar constructs, the populations that have been studied with regard to these constructs are often very different (e.g., education level) and their resources to deal with problems are also diverse.

Just as Americans may have more resources with regard to education, Haitians may have internal resources that Americans do not. When comparing religiosity in Americans and Haitians, only 76.6% of Americans identified as believing in some sort of organized religion compared to 99% of Haitians (World Atlas, 2017a; World Atlas, 2017b). Religiosity has been linked to high emotional well-being and implicit self-regulation (Koole, McCullough, Kuhl, & Roelofsma, 2010). For this reason, studies conducted on the emotion regulation of individuals

with SCD in the United States might provide different results than studies conducted on the emotion regulation of individuals with SCD in Haiti.

Nonetheless, these studies provide a theoretical foundation for research in divergent populations. If SCD negatively impacts sleep in affected Americans and this has an impact on their education and subsequent vocational attainments, it is equally important to know these relationships when making general predictions of functioning for individuals with SCD in Haiti. Similarly, if the baseline of emotion regulation for Haitians with SCD were higher than the baseline of emotion regulation for Americans with SCD, emotion regulation skills of Haitians with SCD will likely still be reduced relative to their peers without SCD. Though the baseline and scale may be different, seeing general trends from a population in another country could still have benefit. There is simply a need to increase international studies so that more direct comparisons can be made. As stated previously, that was one goal of the present study.

Summary and Study Aims

SCD is an inherited blood disease that affects about 15% of individuals living in northern Haiti. Individuals with SCD are at increased risk for disordered sleep, difficulty with emotion regulation, and attentional problems, and all these symptoms may be related to the pathophysiology of the disease. Disordered sleep and emotion regulation can influence attention. Difficulties in these areas can negatively affect everyday functioning, interpersonal relationships, and school/work. There has been little focus on understanding the presence of and interactions between various physiological, psychological, and neuropsychological complications that may be caused by the same underlying pathophysiology in SCD. The present study attempted to fill that gap. The study also aimed to expand the research on SCD to an international population with

a higher prevalence of SCD by providing preliminary findings for Haitians living in poverty on the designated measures.

The study sought to highlight several lesser discussed symptoms of SCD and describe their relationships. On the basis of this rationale, the research questions for the study are as follows:

1. Is there a relationship between disordered sleep and emotion regulation problems in Haitians with SCD living in poverty?
2. Is there a relationship between disordered sleep and attention problems in Haitians with SCD living in poverty?
3. Is there a relationship between emotion regulation and attention problems in Haitians with SCD living in poverty?

The study has significance on several levels. First, there has been no research that has looked at the impact of disordered sleep and emotion regulation on attention in SCD. Individuals have an integrated everyday experience of symptoms related to their body and mind. The study was intended to start a holistic conceptualization of a disease that has been traditionally regarded from a primarily "medical" perspective. Second, most of the research on SCD has taken place in the United States. Of note, the comparative rates of SCD are much higher in populations outside of the United States, like Haiti. It was important to gather data from a population that would benefit meaningfully from the information that the data might provide given the degree to which the country of Haiti is affected by SCD. Third, the study provides preliminary descriptive information for measures that have not been used in Haiti, and specifically with Haitians with SCD living in poverty. This could be helpful for future researchers who may use these measures with this population.

Chapter 2: Method

The study is correlational in nature. Participants were recruited due to a preexisting diagnosed condition but there was no comparison group. The variables that were looked at were performance in the domains of sleep, emotion regulation, and attention. Sleep and emotion regulation were considered variables that might be correlated with attention. Thus, the study looked at the relationship between and among several variables that may be connected neuropsychologically.

Multiple Single Case Analyses Rationale

According to Yin (2009), case study research is defined as an empirical enquiry that investigates a contemporary phenomenon in depth and within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident" (Yin, 2009, p. 14). The present study was exploratory because according to my knowledge, no one has to date used the measures of the study to look at sleep, emotion regulation, and attention in SCD patients in Haiti. SCD is a life-long disease so a "before and after" within-case analysis would not be appropriate. Additionally, the course of SCD varies and though major vascular and neurological events could be tracked, the nature of SCD includes also subtle events that could not be tracked in a poor Haitian population that has low healthcare access. Single case analyses are traditionally thought of as being qualitative and inductive, and Willis (2004) describes single case analyses as "transparadigmatic" and as being qualitative that does not require the experimental pre-post intervention method of analysis.

The advantage of using a single case assessment profile analysis allows for the opportunity of a more holistic account of an individual in question. This design fits well with the current study with a small patient sample in a primary care clinic on the outskirts of

Port-au-Prince, Haiti. Multiple single cases allow for more descriptive information and interpretation and provides a jumping off point for future studies. Additionally, the limited number of individuals available for the study made a larger, more robust quantitative study with a medium effect size not possible. A disadvantage of using multiple single case analyses is that this design is less methodologically rigorous and also leads to lower generalizability. Thus, a cautionary note is provided about the data analyses and ensuing results.

Participants

There were 22 participants ($N = 22$) ranging in age from 10 to 58 years ($M = 24.50$, $SD = 11.65$). Seven identified as men/boys and fifteen identified as women/girls. The participants had a varied amount of school education, with one individual having zero years of formal schooling and some ($n = 3$) having thirteen years ($M = 7.24$, $SD = 4.14$). None of the participants reported being told by a doctor that they had a transient ischemic attack (TIA) or stroke. Seven participants (31.8%) reported having been told that they had concentration problems. Reported stress levels ranged from one to ten ($M = 6.05$, $SD = 3.26$), with 1 representing no stress and 10 representing overwhelming stress. All individuals had SCD but as all information was obtained through the participants themselves, rather than through medical records, participant genotype is unknown.

The nature of the population served at a free primary care clinic in Haiti defined the participants of the study. All individuals were of Haitian origin, African Caribbean, and/or biracial. Participants were from a very low SES background. All individuals and their families were unemployed or underemployed.

Setting

The host site was Partners in Development (PID), located in Blanchard, on the outskirts of Port-au-Prince, Haiti, whose main office is located in Ipswich, Massachusetts. This small clinic sees approximately 26,000 patients per year, providing services ranging from emergency child delivery services to screenings for diabetes, cardiac concerns, HIV/AIDS, and SCD, to vitamin and nutrition therapy, PID also has a housing program, business loan program, and child sponsorship program to provide more comprehensive support for individuals in the community. Patients come from most of the impoverished areas of Haiti, some arriving on foot and others spending three hours on public transportation (i.e., the "tap-tap" bus) from remote village areas to take advantage of the services provided. The Antioch Multicultural Center for Research and Practice has partnered with PID since 2010 for disaster mental health services, assessment research, and evaluation of its Clinical Psychology students' mental health work at PID.

Measures

The battery consisted of a demographic questionnaire and four standardized measures.

Demographics Questionnaire. The assessment protocol started out with a brief demographic questionnaire. The questions asked about age, gender, education, and medical history (documented stroke, transient ischemic attack, or diagnosis of an attentional disorder). Participants were then asked to rate their stress level on a scale of one to 10 (one being "no stress" and 10 being "a great amount of stress.)" Stress was defined as the state of feeling overwhelmed by emotions and life events. See Appendix F for the demographic questionnaire.

Cognitive Emotion Regulation Questionnaire (Garnefski, Kraaij, & Spinhoven, 2002). The Cognitive Emotion Regulation Questionnaire (CERQ) was used as a measure of emotion regulation. The CERQ instructions asked participants to think of a negative event that

had happened and to answer 18 questions about how they were able to regulate their emotions following the event. The CERQ breaks down the responses into nine cognitive coping strategy subcategories: self-blame, acceptance, rumination, positive refocusing, refocus on planning, positive reappraisal, putting into perspective, catastrophizing, and other-blame (Garnefski & Kraaij, 2007). Each of the nine subcategories has a maximum score of 10. Elevated scores for self-blame, rumination, catastrophizing, and other-blame are associated with poor emotion regulation. Elevated scores for acceptance, positive refocusing, refocus on planning, positive reappraisal, and putting into perspective are associated with positive emotional regulation.

Each of these subcategories are next elaborated, as described in the CERQ manual (Garnefski, Kraaij, & Spinhoven, 2002). Self-blame refers to thoughts of blaming oneself for the event that has happened. Acceptance is described as resigning oneself to what has been experienced. Rumination is characterized by constantly thinking about how the person feels following the negative event. Positive refocusing refers to choosing to think about more positive matters than the event that has transpired. Refocus on planning is deciding what steps are needed to deal with the event. Positive reappraisal is the act of taking the event as a way to achieve self-growth. Putting into perspective is described by putting an appropriate amount of emphasis on the seriousness of the event compared to other events that have occurred. Catastrophizing is focusing on the terror of the experience. Other-blame can be described by thoughts of blaming other people for what a person has experienced.

Each of the nine subscales consists of two statements to which participants rate how often they experienced that thought. Statements includes sentences such as, “I tell myself that there are worse things in life” (Putting into Perspective) and “I feel that I am the one responsible for what has happened” (Self-Blame). Responses to how often these thoughts have been experienced are

answered on a five-point Likert scale. One means "(almost) never" while five means "(almost) always." The reliabilities of CERQ subscales ranged from $\alpha = .75$ to $\alpha = .86$. The CERQ norms come from west and southeast Netherlands (Garnefski et al., 2002). Normative data were collected from early adolescent, late adolescent, adult, geriatric, and psychiatric populations from 1998-2000. Education levels ranged from primary school to university level. Because the norms come from a very different population, raw scores were instead used in the present study with a small community-based clinical sample.

The test asks for responses to general negative external and internal stimuli that can be present in most settings. The researchers from the Antioch Multicultural Center and the director of PID deemed the questions broad enough so that they were not considered to be place or culture-specific. Examples of two items are: "I keep thinking about how terrible it is what I have experienced" and "I think I have to accept the situation." As such, this test was deemed culturally appropriate to use with the target Haitian population.

Berlin Questionnaire (Netzer, Stoohs, Netzer, Clark, & Strohl, 1999). The Berlin Questionnaire was used as a measure of disordered sleep, as it has been shown to help detect "low risk" or "high risk" of sleep apnea in adults (El-Sayed, 2012). This questionnaire consists of 10 questions about sleep habits and everyday functioning. An example question is, "Do you snore?" Answers include: yes, no, and don't know. The Berlin Questionnaire has three "categories." Category 1 consists of five questions that are focused on snoring and interrupted breathing in sleep. Category 2 consists of four questions that are focused on daytime sleepiness. Category 3 has a single question that asks about high blood pressure. The questionnaire has been used to detect risk factors for sleep apnea (Adenigbagbe, Vaknansky, Kupfer, Yoon, & Tessler, 2007).

Test-retest reliability for the Berlin Questionnaire ranges from r = .74-.98. Internal consistency was α = 0.68-.98 (American Thoracic Society, 2017). The interrater agreement and Cohen K coefficient of test-retest were 96.3% and r = .92, respectively (Chung et al., 2008). The Berlin Questionnaire was developed as a measure of disordered sleep in Berlin, Germany. Norms were established for this measure in Cleveland, Ohio using targeted populations that were known for differing socio-economic backgrounds. All patients were seeing board-certified physicians in internal medicine through a hospital-owned network in Cleveland (Netzer, Stoohs, Netzer, Clark, & Strohl, 1999). The Berlin Questionnaire has been translated and used in other languages, such as Arabic, Chinese, Dutch, French, Greek, Korean, Malay, Persian, Portuguese, Serbian, Thai, and Turkish (American Thoracic Society, 2017; Bouloukaki et al., 2013).

That being said, a few of the questions might not have been relevant to the Haitian population being tested. For example, one question asks if the individual has "nodded off or fallen asleep while driving a vehicle." The majority of individuals served at the PID clinic do not drive vehicles. They walk long distances or take the "tap-tap" bus. However, the researchers of the Antioch Multicultural Center decided to leave these few items on the questionnaire as they could be eliminated if there were a large number of missing responses for items specific to the U.S. American culture.

Conners Continuous Auditory Test of Attention (Conners, 2015). The Conners Continuous Auditory Test of Attention (CATA) is a test of sustained attention (Conners, 2015). In this test, participants are played a series of high and low-pitched tones. They are asked to press a key when they hear a low tone followed by a high tone but not to press the key when they hear a high tone only. This attentional task was chosen over other continuous performance tests for the Haitian sample to eliminate potential difficulties that might arise due to several

alphabetical differences between English and Créole. The stimuli are auditory as opposed to visual, which reduced the possibility that sickle cell-related visual problems could affect performance on the attentional measure. Additionally, this computer-based program of the Conners does not require the internet, which can be unreliable in certain parts of Haiti, like Blanchard.

The CATA yields T-scores of pronounced difficulty (differentiating stimuli), omission errors (missed stimuli), commission errors (incorrect response to stimuli), perseverative commissions (incorrectly responding before the target), hit rate (response speed), and standard deviation of the hit rate (consistency in response speed). The CATA is divided into blocks, where there are sections when the stimuli are presented more or less frequently (so individuals remain attentive and are not able to predict when the next stimulus will occur). The CATA also provides the T-score for the hit rate following a block change.

Because the literature on attention in patients with no history of stroke demonstrated that the executive network is impacted by the disease (Noll et al., 2000), but a study measuring the orienting network did not indicate impairments (Craft et al., 1994), the current study's attention variable needed to be one that measured the executive network. The current study uses d-prime (detectability), the variable that discriminates targets from non-targets, as a measure of attention for the analyses. This was chosen as a measure of attention as it is not as dependent on reaction time as some of the other variables. It was chosen over omission and commission scores, as d-prime incorporates both of these scores. Laterality was not an area of interest to the present study, so measures looking at laterality were not used as a measure of attention. For the purpose of clarity, this variable is referred to as the "detectability index" in the current study.

The CATA has good test-retest reliability of $r = .64$ (Pearson, 2017). To test how well the CATA improved diagnostic efficacy of the Conners 3-P and Conners CPT3 (both tests made by the same author, Conners), logistic regressions were conducted. When the CATA, Conners 3-P, and Conners CPT3 were all used together to make one composite score, the overall correct classification rate was 93.8%, overall sensitivity was 94.7%, and the specificity was 92.7%. When the CATA was used on its own, the values were 9.9%, 8.7%, and 10.9% higher for classification, sensitivity, and specificity, respectively, when compared to the Conners 3-P alone and the Conners CPT3 alone. The CATA was normed on a United States sample. For individuals ages 8-17, 55.1% of the participants were White, 21.8% were Hispanic, 14.3% were Black, and 8.8% were classified as "Other." For those 18+, 67.5% were White, 14.2% were Hispanic, 11.6% were Black, and 7.2% were Other.

This test uses auditory (tone) stimuli coming from the right side, left side, and both at once, so headphones were used in the present study so that this differentiation could be accomplished. As there are no soundproof rooms at the PID clinic and most of the testing took place in a shared one-room schoolhouse, headphones were necessary to cancel out outside noise. Up to three practice tests were administered if the participant requested more practice or if they scored low enough on the practice that the test prompted another trial. Unless there were extenuating circumstances or an obvious miscommunication, the CATA was discontinued after three failed practice tests.

Procedure

The application to do the study underwent a full review by Antioch University New England's Institutional Review Board because it was an international study and intended to utilize vulnerable patients as well (See Appendix A for the IRB application.) Gale Hull, director

of PID, wrote a letter of permission so that data collection could occur at the clinic (See Appendix B). The study received IRB approval.

According to the director at PID, Gail Hull, the estimated number of individuals that PID served, who were formerly diagnosed at the clinic with SCD and could be recruited to participate in the study in May 2017 was about 18-25. Due to the specific tests chosen, no one under the age of 8 was allowed to participate. All measures were completed by the actual participants, not parents or guardians. There was no maximum age limit. Participants needed to live close enough to PID so that they were able to get to the clinic for testing; all testing took place at the clinic. Because many participants had little to no education, illiteracy was not an exclusion criterion. For research participants, the medical staff identified patients who had a formal diagnosis of SCD and received primary health care from the PID medical clinic in Blanchard, Haiti. These individuals were given appointment times while the research team was in Haiti; however, individuals with SCD who happened to be visiting the clinic while the research team was there were encouraged to participate when the research team had open slots.

Each participant completed a battery of questionnaires and standardized tests yielding scores on disordered sleep, emotion regulation, and attention that lasted approximately an hour. Questionnaires were administered in Créole by translators of PID. Previously, the measures were sent to the main office of PID in Massachusetts where the director, Gale Hull, chose bilingual staff to translate the measures from English to Créole. These Créole translations were back-translated into English to ensure that the measures approximated the original measures in English.

When the research team arrived in Haiti, each researcher was assigned a Haitian translator employed by the Antioch Multicultural Center. The testing battery was reviewed with

the research team and translators before the testing was started. One English-speaking research team member and one bilingual Haitian translator were present at all times during the testing session with each participant to ensure that the test-taker fully understood each measure's administration instructions and test items. The administration was standardized for each participant.

Participants were first introduced to the researchers and their translators to establish rapport and to explain the process of testing. All adult participants read and signed an Informed Consent Form (See Appendix C) before taking part in the study. Illiterate participants were read the Informed Consent Form by a translator, after which the participant signed their name or placed a mark. A Parental Permission Form (See Appendix D) was used for participants under the age of 18. Underaged participants then read or were read aloud a Child Assent Form (See Appendix E), which they then signed. In each of the above-mentioned forms, participants were assured that their names and other identifying information would not be included in any written report. They also were assured that their diagnosis of SCD would not be discussed with any outsiders and that their answers would be kept under lock and key.

The study participants filled out a demographic questionnaire or answered orally if they could not read and the translator wrote down their answers. Then the participants were asked a series of questions about their general health and stress levels. The first part of the battery was the CERQ, which required the participant to have a degree of insight into their behavioral patterns. The Berlin Questionnaire was then administered. The Berlin Questionnaire relied fully on self-report for all participants, regardless of age, so some of the questions relied on the assumption that participants had been told of the presence of snoring. The CATA was the last test that the participants completed. At the end of the test administration, participants were given

a short debriefing explanation about the purpose of the study. They were informed that the PID would be notified about the results of the study, so that providers would have a better understanding of SCD and could potentially use the results to inform their SCD treatment services.

In the case where a participant was illiterate, the questionnaires were read aloud to them in Créole by a trained Haitian translator. The researchers and Haitian translators remained with the participants throughout the process and would check in with the participants to see if they had any questions.

Altogether, completion of all tests was expected to take about an hour. Because of time restrictions and scheduling conflicts, the assessment occurred over two days for two participants. Testing was done at the PID medical clinic's one-room schoolhouse, which maximized privacy and minimized outside noise. Even so, the compound serves about one hundred people a day, so the noise did carry over into the schoolhouse. However, the participants appeared to be focused on the assessment tasks.

Two to three administrations were conducted simultaneously in corners of the room, where tables, benches, and plastic chairs were arranged. Patients sat on wooden benches. The CATA was downloaded onto a laptop so it could be easily passed around to the different participants. There was no stationary computer in the schoolhouse. The laptop and testing materials were placed on one of the wooden tables. Up to three participants were tested individually during the same testing session by the translators and researchers. Start times were staggered because the CATA could only be used on one computer at once.

Translators. The translators have been working for PID for an extended period of time and know the population well. As such, they were able to help in translating not only

linguistically but also culturally (as literal word-for-word translations often do not capture what is felt or said due to colloquialisms and lived experiences). During the session, the researchers had the translator doing the verbal translation from English to Créole for the participants and from Créole to English for the researchers. The researchers made their own behavioral notes. They also checked in with the translators about the translators' behavioral observations because the participants may have been showing subtle or even obvious mannerisms that American researchers would not naturally pick up on. After each test and at the end of the day, the researchers checked in with their translators to see if there were any obvious miscommunications noted so as to try to reduce these for future participants.

Confidentiality. Confidentiality of participants was of utmost priority throughout the data collection process. Data was downloaded to the primary researcher's password protected personal computer. Data collected in other password protected personal computers were deleted after they were transferred to the primary researcher's computer. Additionally, analyses of data were password protected. Hard copies of data were kept in a locked file cabinet in the primary researcher's home and in the office of the dissertation chair who was the director of the Antioch Multicultural Center for Research and Practice.

Research Hypotheses

The following hypotheses were made based on the previously stated research questions:

Hypothesis 1: There will be a positive relationship between disordered sleep and emotion regulation problems.

Hypothesis 2: There will be a positive relationship between disordered sleep and attention problems.

Hypothesis 3: There will be a positive relationship between emotion regulation difficulties and attention problems.

The word "problems," as in "attention problems" is used in the study to describe poorer functioning in various domains. However, the study used only individuals with SCD and were not comparing individuals to normative populations. Patients were compared among themselves and not to healthy controls or individuals with another disease. As such, the term "problems" should not be conceptualized in any sort of diagnostic sense and should not be compared to the general population.

Data Analyses

The objective measures used for the study have been normed on U.S. populations that are very different from the sample of the current study in culture, class, language, and health status. The tests were only linguistically adapted, accompanied with some basic, short oral cultural explanations when these were deemed necessary by the translators. Therefore, the present preliminary study's analyses were interpreted with significant caution. The tests were viewed in descriptive rather than diagnostic terms. Cutoff scores were not used. For the analyses, sample descriptive statistics were used for each measure (mean, standard deviation, variance, distribution skew). Because the different measures provided several subscale scores (for example, the CERQ has nine subscales, as described previously), and the sample was small, a total score was obtained so that the three full scales could feasibly be analyzed. The participants were compared to themselves (i.e., intrapersonal comparison or within case analysis) in the different areas of functioning. Each participant had three raw scores from which further analysis could take place.

Analyses consisted of correlations and ANOVAs. A series of cross-sectional Pearson correlations were used to evaluate the relationships between different domains of functioning. There were eight of these correlations in all. The correlation data have been illustrated/graphed with a bivariate scatter plot between each of the variable pairs. Correlations were also conducted to look at the relationship between age and the three measures. ANOVAs were done to see if there was a difference in sleep, emotionality, and attention in those who had documented attention problems and those who did not.

Conclusion

The study presents assessment data collected from a few individuals with SCD in a primary care clinic in a very poor part of Blanchard, Haiti. The symptoms assessed were attention, emotion regulation, and sleep. The test battery included a demographic questionnaire, the Berlin Questionnaire, the Cognitive Emotion Regulation Questionnaire, and the Conners Continuous Auditory Test of Attention. The purpose of the study was to add to the research knowledge about a particular Haitian population. It is hoped that the study has provided an overall understanding of impoverished patients with SCD in Haiti and its interacting symptoms that likely affect these patients' quality of life and everyday functioning.

Chapter 3: Results

This chapter provides both sample and group analyses. Additionally, it provides assessment results for the participants in the study using descriptive single case profile presentations. Data on the internal consistency reliabilities of measures are presented first. Following the reliability information, correlational matrices are presented with a scatter plot for each of the relationships between variables. Because of the limited number of participants, another correlational matrix is presented with simulated data to determine effect size for future studies. Because the patients ranged in age from 10 to 44 years, correlational analyses were run to see if age affected sleep, emotionality, and attention. The 16 participants who finished all measures were `placed in two groups based on the presence or absence of documented attention problems. Three one-way Analyses of Variance (ANOVAs) looking at group membership and its relationship with measured variables are tentatively presented. Following descriptive information on these two groups, specific data of three individuals are provided as case illustrations.

Internal Consistency Reliabilities of Measures

CERQ. The CERQ, consisting of 18 items and 9 subscales, had a Cronbach's alpha of α=.664. If subscale 1, Self-Blame, were to be removed because of a low item-total correlation, the α would increase to .682. See Table 1 for the CERQ's item-to-total scale statistics.

Table 1
Item-Total Statistics for the CERQ

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item -Total Correlation	Cronbach's Alpha if Item Deleted
CERQ1	46.16	78.585	.068	.682
CERQ2	45.63	71.912	.249	.655
CERQ3	44.21	55.509	.715	.539
CERQ4	45.32	62.006	.460	.607
CERQ5	44.16	71.696	.265	.652
CERQ6	45.11	71.322	.207	.667
CERQ7	45.05	69.608	.219	.667
CERQ8	44.16	57.251	.664	.555
CERQ9	47.37	72.912	.203	.665

Note. Number of items = 9. α=.664. CERQ1 = Self-Blame; CERQ2 = Acceptance; CERQ3 = Rumination; CERQ4 = Positive Refocusing; CERQ5 = Refocus on Planning; CERQ 6 = Positive Reappraisal; CERQ7 = Putting into Perspective; CERQ 8 = Catastrophizing; CERQ 9 = Other -Blame

Berlin Questionnaire. The Berlin Questionnaire, consisting of 10 items, had a Cronbach's alpha of α=.438. The snoring/nighttime breathing problems subscale consisted of five items, with a Cronbach's alpha of α=.556. The tiredness/effect on daily functioning subscale consisted of four items, with a Cronbach's alpha of α=.504. Because the study was not looking at high blood pressure specifically, question 10 was included in the analyses of the Berlin Questionnaire total but separate analyses with question 10 (Category 3) were not conducted. See Tables 2, 3, and 4 for the Berlin Questionnaire's total and subscale item-to total scale statistics.

Table 2
Item-Total Statistics for the Berlin Questionnaire

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item -Total Correlation	Cronbach's Alpha if Item Deleted
B1	21.3000	22.958	.066	.441
B2	21.3500	20.976	.377	.372
B3	21.0500	16.155	.400	.295
B4	20.2500	22.513	.247	.411
B5	18.9500	20.682	.050	.477
B6	19.5500	18.471	.177	.419
B7	19.5000	19.316	.109	.456
B8	21.9000	23.463	.184	.430
B9	21.7000	19.800	.384	.350
B10	21.4500	23.103	.058	.442

Note. Number of items = 10. α=.438. B1 = Presence of snoring; B2 = Snoring Volume; B3 = Frequency of Snoring; B4 = Impact of Snoring; B5 = Lapses of Nighttime Breathing; B6 = Fatigue during the day; B7 = Fatigue upon Waking; B8 = Tiredness while Driving; B9 = Frequency of Tiredness while Driving; B10 = Presence of High Blood Pressure

Table 3
Item-Total Statistics for the Berlin Questionnaire Subscale: Snoring/Nighttime Breathing Problems

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item -Total Correlation	Cronbach's Alpha if Item Deleted
B1	8.9000	9.568	.433	.466
B2	8.9500	9.313	.547	.430
B3	8.6500	6.029	.454	.409
B4	9.3500	12.766	-1.81	.648
B5	6.5500	6.261	.417	.443

Note. Number of items = 5. α=.556. B1 = Presence of snoring; B2 = Snoring Volume; B3 = Frequency of Snoring; B4 = Impact of Snoring; B5 = Lapses of Nighttime Breathing

Table 4
Item-Total Statistics for the Berlin Questionnaire Subscale: Tiredness/Effect on Daily Functioning Subscale

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item -Total Correlation	Cronbach's Alpha if Item Deleted
B6	6.0000	5.143	.387	.343
B7	5.9091	4.658	.436	.279
B8	8.4545	10.355	.256	.528
B9	8.2727	8.494	.286	.454

Note. Number of items = 4. α=.504. B6 = Fatigue during the day; B7 = Fatigue upon Waking; B8 = Tiredness while Driving; B9 = Frequency of Tiredness while Driving

Table 5
Sample and Scale Statistics for Measures

	Ber1	Ber2	Ber3	CQ1	CQ2	CQ3	CQ4	CQ5	CQ6	CQ7	CQ8	CQ9
Sample Statistics												
# of Cases	22	22	22	21	21	19	21	21	21	21	21	21
# of Items	5	4	1	2	2	2	2	2	2	2	2	2
Mean	.86	1.27	.27	4.81	5.62	6.68	5.14	4.1	5.14	4.95	6.76	3.62
Scale Statistics												
z-score	.06	.53	-1.16	-0.27	0.24	0.7	-0.03	-0.64	-0.03	-0.11	0.78	0.64
Standard Error of Mean	.201	.188	.097	.306	.375	.484	.489	.377	.439	.475	.436	.381
Standard Deviation	.94	.88	.46	1.40	1.72	2.11	2.24	1.73	1.98	2.18	2.0	1.75
Minimum Score	0	0	0	0	0	0	0	0	0	0	0	0
Maximum Score	6	3	1	10	10	10	10	10	10	10	10	10
Skew	.670	-.140	1.097	-.109	-.715	-.605	-.05	.929	.123	-.221	-.553	.59
Kurtosis	-.671	-.915	-.887	.761	1.113	-.273	-1.622	2.017	-1.043	-1.562	.226	-1.15

Correlational Analyses

The correlation matrix of Table 5 shows the Pearson *r* relationships among the measures of the study: Cognitive Emotion Regulation Questionnaire (total), Berlin Questionnaire (total, category 1, and category 2), and the Continuous Auditory Test of Attention detectability index.

There were two relationships that were statistically significant. The Cognitive Emotion Regulation Questionnaire and the Berlin Questionnaire total had a significant moderate positive correlation ($r = .567$, $p = .009$), meaning that those who reported emotionality also reported more sleep problems to a moderate degree. The Cognitive Emotion Regulation Questionnaire total and the Berlin Questionnaire category 1 had a medium positive significant correlation *(*$r = .510$, $p = .022$), indicating that those who reported higher emotionality also reported more snoring/nighttime breathing problems to a moderate degree. The Berlin Questionnaire category 2 and the Cognitive Emotion Regulation Questionnaire total had a medium positive correlation ($r = .412$, $p = .071$), but missed significance narrowly; those who reported daytime sleepiness also reported higher levels of emotionality.

Table 6

Correlation Matrix of Cognitive Emotion Regulation Questionnaire, Berlin Questionnaire, Continuous Auditory Test of Attention

Variables	CERQTOT	BRLNTOT	BRLNCAT1	BRLNCAT2	CT1
CERQTOT	---	.567**	.510*	.412	.377
BRLNTOT			----	----	.380
BRLNCAT1			.	.344	.459
BRLN2					.033
CT1					

Note. N = 17-21. *p < .05. **p < .01 CERTOT = Cognitive Emotion Regulation Questionnaire total; BRLNTOT = Berlin Questionnaire total; BRLNCAT1 = Berlin Questionnaire Category 1; BRLNCAT2 = Berlin Questionnaire Category 2; CT1 = Continuous Auditory Test of Attention detectability index

Scatter Plots for Measures

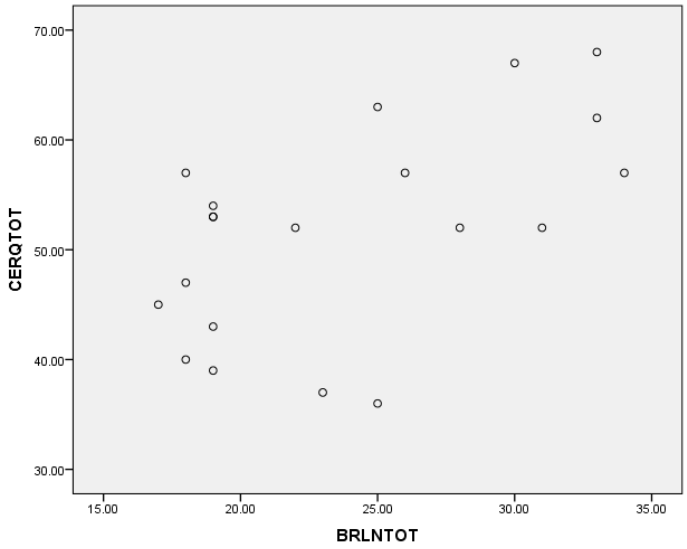

Figure 1. Relationship between scores on the Berlin Questionnaire Total and the Cognitive Emotion Regulation Questionnaire Total. Pearson's r = .567, p = .009.

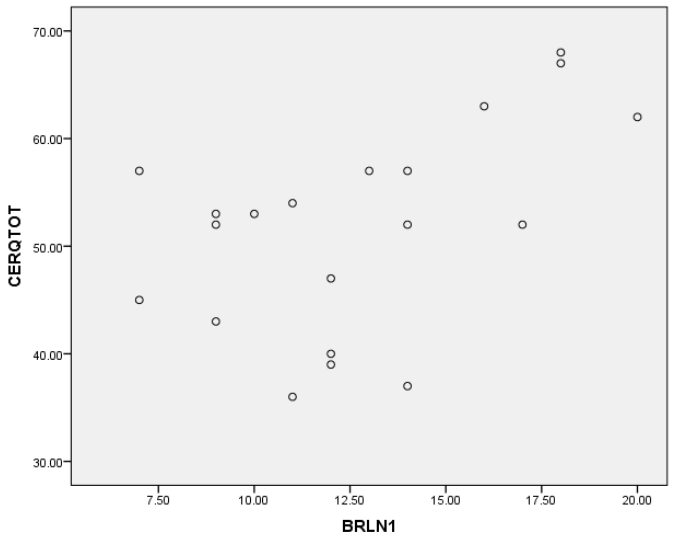

Figure 2. Relationship between scores on the Berlin Questionnaire Category 1 and the Cognitive Emotion Regulation Questionnaire Total. Pearson's $r = .510$, $p = .022$.

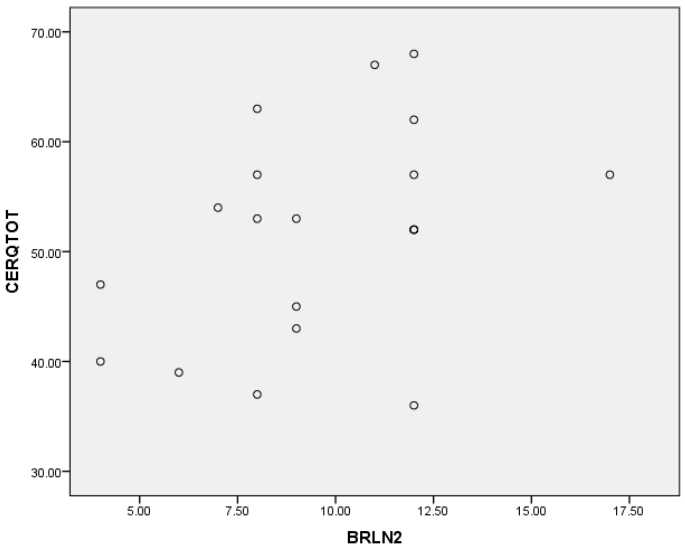

Figure 3. Relationship between scores on the Berlin Questionnaire Category 2 and the Cognitive Emotion Regulation Questionnaire Total. Pearson's $r = .412$, $p = .071$.

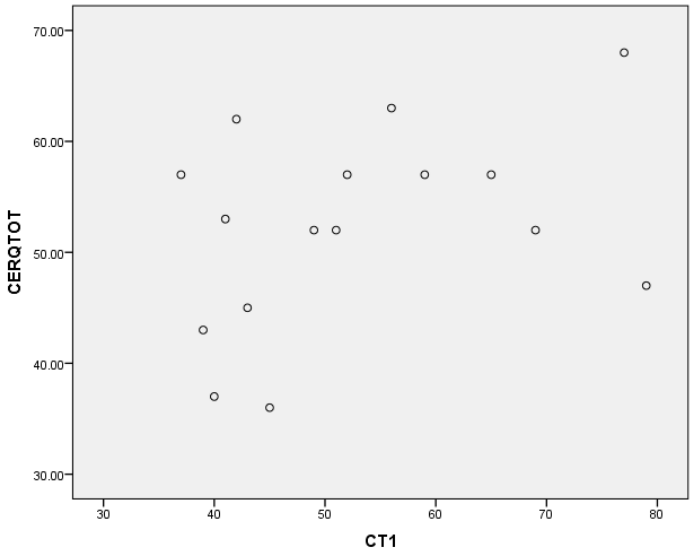

Figure 4. Relationship between scores on the Continuous Auditory Test of Attention detectability index and the Cognitive Emotion Regulation Questionnaire Total. Pearson's $r = .377$, $p = .150$.

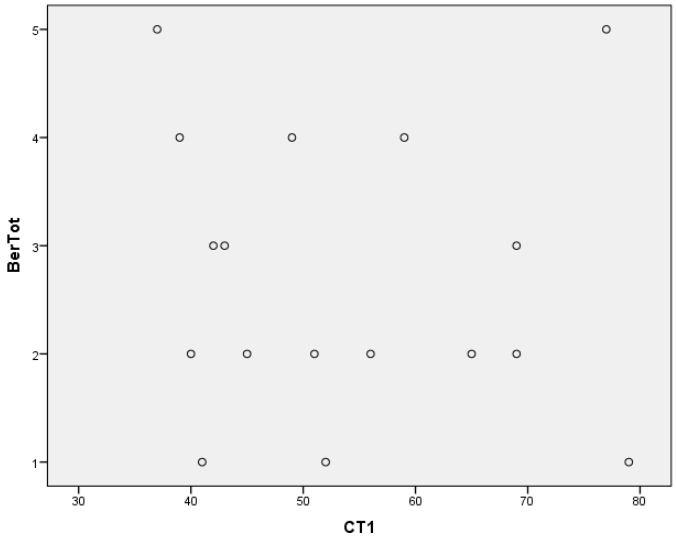

Figure 5. Relationship between scores on the Continuous Auditory Test of Attention detectability index and the Berlin Questionnaire Total. Pearson's $r = .380$, $p = .162$.

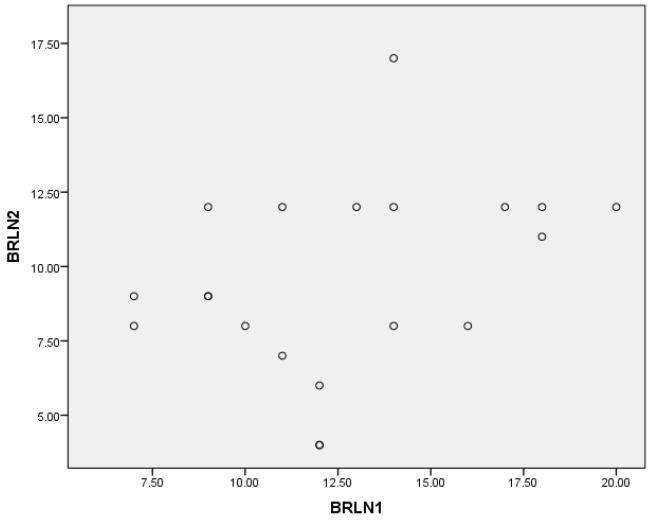

Figure 6. Relationship between scores on the Berlin Questionnaire Category 1 and the Berlin Questionnaire Category 2. Pearson's $r = .344$, $p = .138$

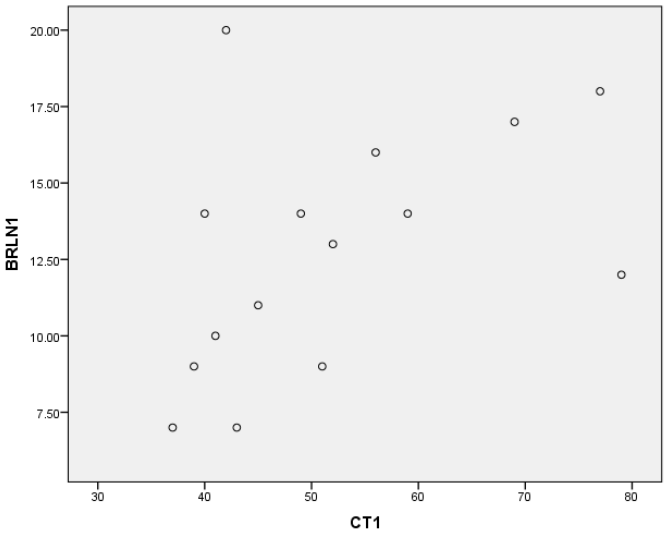

Figure 7. Relationship between scores on the Continuous Auditory Test of Attention detectability index and the Berlin Questionnaire Category 1. Pearson's $r = .459$, $p = .085$.

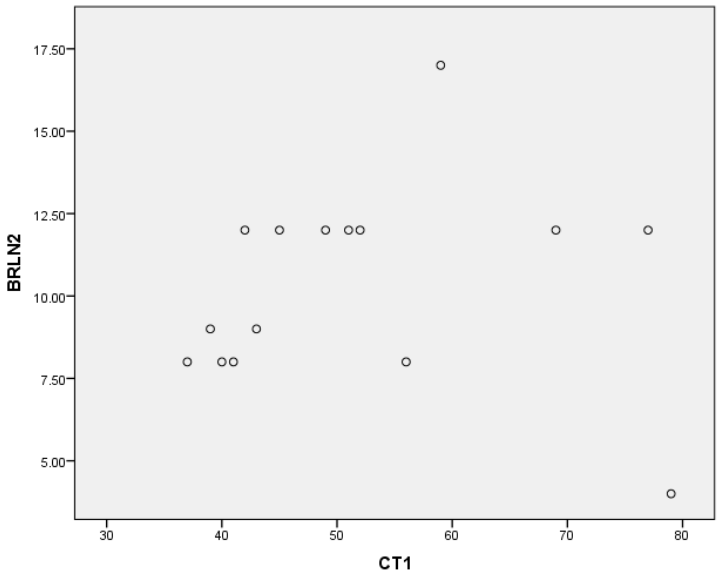

Figure 8. Relationship between scores on the Continuous Auditory Test of Attention detectability index and the Berlin Questionnaire Category 2. Pearson's $r = .033$, $p = .906$.

A correlation of .567 indicates a moderate degree of positive relationship between the Berlin Questionnaire Total and the Cognitive Emotion Regulation Questionnaire Total. A correlation of .510 indicates a moderate degree of positive relationship between the Berlin Questionnaire Category 1 and the Cognitive Emotion Regulation Questionnaire Total. A correlation of .412 indicates a modest degree of positive relationship between the Berlin Questionnaire Category 2 and the Cognitive Emotion Regulation Questionnaire Total. A correlation of .377 indicates a modest degree of positive relationship between the Continuous Auditory Test of Attention detectability index and the Cognitive Emotion Regulation Questionnaire Total. A correlation of .380 indicates a modest degree of positive relationship between the Continuous Auditory Test of Attention detectability index and the Berlin Questionnaire Total. A correlation of .344 indicates a modest degree of positive relationship between the Berlin Questionnaire Category 1 and the Berlin Questionnaire Category 2. A correlation of .459 indicates a moderate degree of positive relationship between the Continuous

Auditory Test of Attention detectability index and the Berlin Questionnaire Category 1. A correlation of .033 indicates there is no relationship between the Continuous Auditory Test of Attention detectability index and the Berlin Questionnaire Category 2. Closer inspection of the items in the Berlin Questionnaire Category 2 revealed that two of the questions under this category (prevalence falling asleep while driving and frequency) may not have been culturally applicable to the specific population as most did not drive. Patients were instructed to say "no/never" to these questions but this may have distorted the results as these patients might have otherwise said "yes/almost every day" to another more relevant question about significant daytime sleepiness.

Simulated Data

Simulated studies use computer-generated data to examine questions of interest. The most common purposes for simulated studies have been to determine sampling distributions for test statistics, comparing parameter estimators, evaluating an algorithm, or determining sample size and effect (Beaujean, 2018). Simulated data are also used to collect large data sets for structural equation modeling or to conduct neuroscience/neuropsychological research because of the low availability of brains that have been subjected to surgeries or for brain studies of hidden and complex functioning processes. In such situations, there is often very limited data to test clinical hypotheses that are generalizable beyond a single case. A simulated study must be based on a conceptual model that includes the major variables that are thought to affect outcomes (Beaujean, 2018). The use of simulated data seemed reasonable to test the study's correlational hypotheses because of the limitations of the study's small sample.

The correlation matrix of Table 6 shows the relationship among the measures of the study: Cognitive Emotion Regulation Questionnaire (total), Berlin Questionnaire (total, category

1, and category 2), and the Continuous Auditory Test of Attention detectability index if the total number of participants were doubled (N=44). For this simulated sample, seven of the eight relationships were statistically significant. The Cognitive Emotion Regulation Questionnaire and the Berlin Questionnaire total had a significant moderate positive correlation (r = .567, p <.001), suggesting that those who reported higher emotionality also reported more sleep problems to a moderate degree. The Cognitive Emotion Regulation Questionnaire total and the Berlin Questionnaire category 1 had a moderate positive correlation *(*r =.510, p = .001), indicating that those who reported more emotionality also reported more snoring/nighttime breathing problems to a moderate degree. The Cognitive Emotion Regulation Questionnaire total and the Berlin Questionnaire category 2 had a moderate positive correlation (r =.412, p =.008), meaning that those who reported higher levels of emotionality also reported more daytime sleepiness to a moderate degree. The Cognitive Emotion Regulation Questionnaire total and the Continuous Auditory Test of Attention detectability index had a modest positive correlation (r =.377, p <.05), indicating that those who reported more emotionality also tended to show attention problems to a modest degree. The Berlin Questionnaire total and the Continuous Auditory Test of Attention detectability index had a modest positive correlation (r = .380, p <.05), indicating that those who reported sleep problems also demonstrated attention problems to a modest degree. The Berlin Questionnaire category 1 and the Continuous Auditory Test of Attention detectability index had a moderate positive correlation (r =.459, p <.05), indicating that those who reported more snoring/nighttime breathing problems also had attention problems to a moderate degree. The Berlin Questionnaire category 1 and category 2 had a modest positive correlation (r =.344, p <.05), such that those who had nighttime breathing problems tended to have more daytime sleepiness. Overall, the simulated data demonstrated that many of the correlations would be

significant at the $p < .01$ and $p < .05$ levels, meaning that should the study be replicated, future researchers should have approximately 44 participants. However, the significant correlations were moderate to modest at best.

Table 7

Simulated Data Correlation Matrix of Cognitive Emotion Regulation Questionnaire, Berlin Questionnaire, Continuous Auditory Test of Attention

Variables	CERQ TOT	BRLN TOT	BRLN CAT1	BRLN CAT2	CT1
CERQTOT	---	.567**	.510**	.412**	.377*
BRLNTOT			----	----	.380*
BRLNCAT1			.	.344*	.459*
BRLNCAT2					.033
CT1					

Note. $N = 44$. *p < .05. CERTOT = Cognitive Emotion Regulation Questionnaire total; BRLNTOT = Berlin Questionnaire total; BRLNCAT1 = Berlin Questionnaire Category 1; BRLNCAT2 = Berlin Questionnaire Category 2; CT1 = Continuous Auditory Test of Attention detectability index

Correlations and Scatter Plots for Age

Age and the Berlin Questionnaire Total had a nonsignificant modest negative correlation ($r = -.262$, $p = .265$), meaning that those who were older reported fewer sleeping problems to a modest degree. Age and the CERQ Total had a nonsignificant modest negative correlation ($r = -.302$, $p = .184$), meaning that those who were older reported less emotionality to a modest degree. Age and performance on the CATA detectability index were not correlated ($r = -.061$, $p = .815$), suggesting that age was not related to attention.

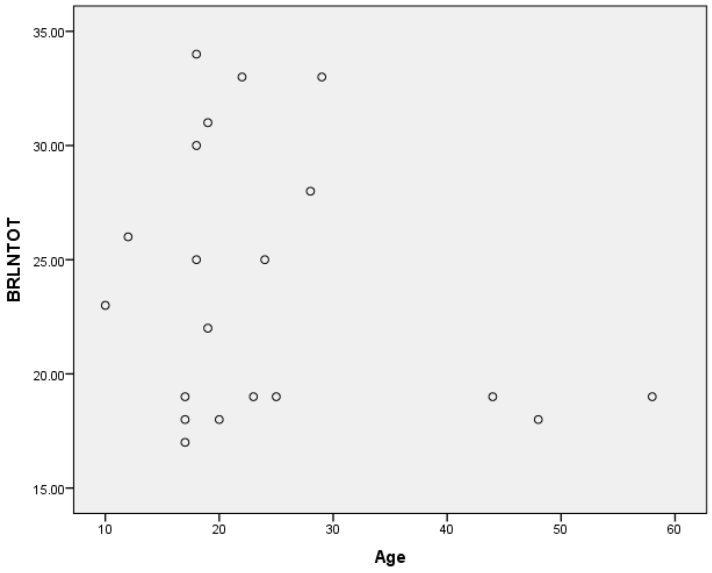

Figure 9. Relationship between age and scores on the Berlin Questionnaire Total. Pearson's r = .-.262, p = .265.

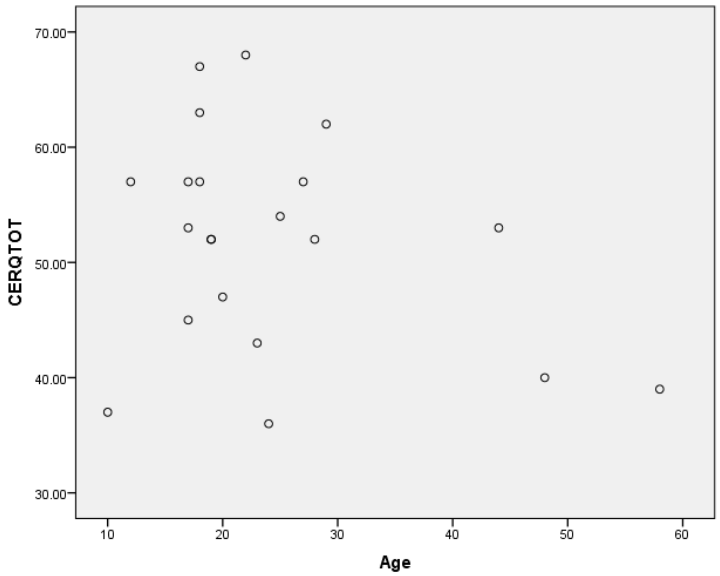

Figure 10. Relationship between age and scores on the CERQ Total. Pearson's r = -.302, p =.184.

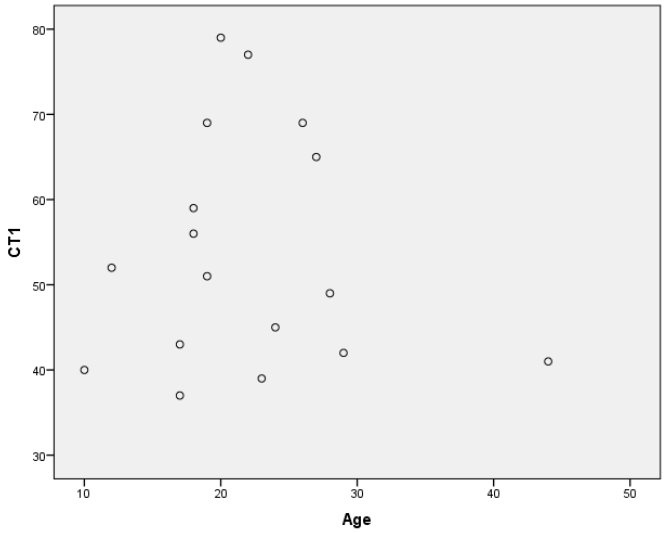

Figure 11. Relationship between age and performance on the CATA detectability index. Pearson's r = -.061, p =.815.

Group Results

Because six participants did not or were unable to finish the whole battery, the following analyses included those who completed every task (N =16). All 16 participants were separated into two groups called the Documented Attention Problems group and the No Documented Attention Problems group. Three profiles are reported after performing three ANOVAs.

Documented Attention Problems Group. This group consisted of five individuals ranging in age from 10 to 28 years with the average age being 20 years. These individuals had completed approximately 7.6 years of education. The average stress level was 4.6 out of 10 (1 being minimal and 10 being extreme stress). All five of these individuals reported being told by a physician that they had concentration problems.

No Documented Attention Problems Group. This group consisted of 11 individuals ranging in age from 17 to 44 with the average age being 22.45. These individuals had completed approximately 7.55 years of education. The average stress level was 8.27 out of 10 (1 being

minimal and 10 being extreme stress). None of these individuals had ever been told by a physician that they had attention problems.

ANOVAS. A one-way between-subjects ANOVA was conducted on disordered sleep for the two groups. An alpha level of $p < .05$ was used. The Documented Attention Problems group members had an average score on the Berlin Questionnaire of $M = 24.00$ ($SD = 3.92$) and the No Documented Attention Problems group members had an average score on the Berlin Questionnaire of $M = 25.00$ ($SD = 6.72$). Differences of group membership on sleep problems were not significant, ($F(1,13) = .077$, $p = .786$) $\eta^2 = .006$. A one-way between-subjects ANOVA was conducted on emotionality for the two groups. An alpha level of $p < .05$ was used. The Documented Attention Problems group members had an average score on the CERQ of $M = 49.2$ ($SD = 8.9$) and the No Documented Attention Problems group members had an average score on the CERQ of $M = 53.82$ ($SD = 9.06$). Differences of group membership on emotionality approached significance, ($F(1,14) = .902$, $p = .358$) $\eta^2 = .064$. A one-way between-subjects ANOVA was conducted on attention for the two groups. An alpha level of $p < .05$ was used. The Documented Attention Problems group members had an average score on the CATA detectability index of $M = 49$ ($SD = 10.56$) and the No Documented Attention Problems group members had an average score on the CATA detectability index of $M = 54.45$ ($SD = 14.9$). Differences of group membership on attention were not significant, ($F(1,14) = .537$, $p = .476$) $\eta^2 = .038$.

Individual Assessment Profiles

Individual assessment profiles are provided for three individuals: one from the Documented Attention Problems group and two from the No Documented Attention Problems group, as this group is twice as large.

Patient 6 (Documented Attention Problems Group). Patient 6 was a 27-year-old female. She went through 12 years of schooling. She reported very low amounts of stress in her life (1 on a scale of 1-10). She had never had a stroke or TIA. Patient 6 reported having had a physician tell her that she had concentration problems and on the CATA, she had difficulty discriminating on a sustained attention task. Though she denied snoring while sleeping, she felt fatigued upon waking 3-4 days a week. During the day, she reported feeling "not up to par" almost every day. When she was asked to think about how she coped with distressing events, Patient 6 reported low self-blame and other-blame, high rumination and very high catastrophizing. She reported low positive reappraisal and putting into perspective, moderate positive refocusing and refocus on planning, and very high acceptance.

Patient 6 interpretation. Though Patient 6 did not spend a lot of time thinking about where to place the blame, she thought a lot about the consequences when bad things occurred. She thought about the worst but also accepted that negative things happen. Perhaps because she did not place a lot blame on herself or others, acceptance was her way to gain control and make sense of things. Even though she thought a lot about negative things, this kind of almost radical acceptance may be a reason why her reported stress level is so low. However, Patient 6 also reported feeling "not up to par" several days of the week. She could have been somaticizing; she had difficulty discriminating between feeling stress physically versus psychologically. Alternatively, she might have had more demands at home or interpersonally that could lead to low overall energy in the day but adequate ability to psychologically deal with stressors.

Participant 6 does not fit in with the general trend of sleep problems and attention problems for the study. Snoring/nighttime breathing problems and high blood pressure were associated with more detectability-based attention problems, while daytime fatigue was not.

Participant 6 reported daytime fatigue but no snoring/nighttime breathing problems and had a lower overall score on the Berlin Questionnaire. She did not know if she had had high blood pressure. Participant 6 performed poorly on the CATA, which was not in line with the study trend of sleep and attention. However, she reported higher overall emotionality, higher than many individuals in her Documented Attention problems group, which was seen in the study to be associated with more detectability-based attention problems.

Patient 8 (No Documented Attention Problems Group). Patient 8 was a 44-year-old female. She completed three years of education. She reported moderate amounts of stress in her life (5 on a scale of 1-10). She had never had a stroke or TIA. Patient 8 stated that she had never had a physician tell her that she had concentration problems and on the CATA, she had the lowest difficulty discriminating on a sustained attention task. Patient 8 denied snoring but did report that she had been told that she stops breathing in her sleep about 1-2 times a month. When she would initially wake up, she felt fatigued 1-2 times a month, but during her normal waking hours, she felt tired 3-4 times a week. She denied having high blood pressure. On the CERQ, Patient 8 reported low self-blame and other-blame, and moderate rumination and catastrophizing. She reported low acceptance and positive reappraisal, moderate refocus on planning, and high positive refocusing and putting into perspective.

Patient 8 interpretation. Like Patient 6, Patient 8 did not spend a lot of time thinking about how she or others are to blame. However, Patient 8's acceptance was low. She preferred to reframe the situation by thinking about next steps and how good can come from the situation rather than simply accepting it for what it is. As the oldest of the three select participants, she had more life experience to practice balancing the good and bad parts of life. This could be a reason why her reported stress levels fell in the moderate range. She may also have had higher ability to

focus on the task at hand and compartmentalize, which would account for Patient 8 doing the best on a detectability-based attention task.

Patient 8 had low symptoms of sleep problems, moderate emotionality, and minimal attention problems. This is consistent with relationships found among symptoms in the sample data. However, she reported fewer symptoms overall than many individuals in the No Documented Attention Problems Group.

Patient 19 (No Documented Attention Problems Group). Patient 19 was an 18-year-old female. She has completed 12 years of schooling. She reported high amounts of stress in her life (9 on a scale of 1-10). She had never had a stroke or TIA. Patient 19 stated that she had never had a physician tell her that she had concentration problems, but on the CATA, she had moderate difficulty discriminating on a sustained attention task. Patient 19 denied snoring. When she would initially wake up, she felt tired almost every day. However, after that initial time, she indicated that she rarely felt fatigued in the day. She denied having high blood pressure. On the CERQ, Patient 19 reported low other-blame, moderate self-blame, and very high rumination and catastrophizing. She reported low acceptance, moderate positive refocusing and positive reappraisal, high putting into perspective, and very high refocus on planning.

Patient 19 interpretation. Like Patient 6 and 8, Patient 19 did not place a lot of blame on others. Patient 19 placed slightly more blame on herself. She spent a lot of time thinking about what bad has happened and what bad may still happen. At the same time, she was able to put things into perspective and was able to think of tangible next steps. However, her reported stress level was at a 9. This method of coping via flexibility and resilience has been documented extensively in research on Haitians following the 2010 earthquake (Rahill et al., 2016; Roysircar, Geisinger, & Thompson, 2019). Though she may have thought about next steps and how to turn

bad situations around, she may have also been internalizing some of her stress, leading to poor sleep and some difficulties on attention tasks.

Patient 19 had more difficulty on a task of detectability-based attention than Patient 8 but less difficulty than Patient 6. Though she denied snoring, her total score on the Berlin Questionnaire was more than those of both Patient 8 and Patient 6. The study found that there was a moderate positive correlation between higher scores on the Berlin Questionnaire and more trouble on a detectability-based attention task. Patient 19's elevated total on the Berlin Questionnaire fell in line with this as she also had moderate attention difficulties. She also reported higher overall emotionality, which positively correlates with attention difficulties.

Comparison of emotionality for individual case results. Figure 13 shows the emotionality on each subscale side-by-side for the three participants. Self-blame, other-blame, and positive reappraisal were rated low to moderate by all three participants. Positive refocusing was endorsed slightly more by each participant but the difference among their reports was fairly small.

The subscales that revealed the most differences for the three individuals were rumination, catastrophizing, refocus on planning, and acceptance. In all of these, Patient 8 (from the No Documented Attention Problems group) endorsed only low to moderate emotionality. Though low rumination and catastrophizing would theoretically be associated with high acceptance, Patient 8's low endorsement of all of those subscales could indicate a degree of dissociation. Dissociation in this instance is defined by Somer (2006 as "the experience of having a mind in which there can be at least two independent streams of consciousness flowing concurrently, allowing some thoughts, feelings, sensations, and behaviors to occur simultaneously or outside awareness" (p. 213) and should not be thought of as a necessarily

psychopathological, but rather a "normative idiom of disavowing" in a non-Western culture (p. 214). For example, low rumination/catastrophizing and low acceptance, could be more akin to nonpathologic indigenous dissociation that involves depersonalization (Somer, 2006). Patient 8 does not dwell as much on the negative things that have happened, but she also doesn't spend a lot of time trying to make peace with the negative things as well. She could be more accustomed to things remaining in a state of flux. As she is older, she has likely encountered more traumatic events, be those of intergenerational trauma, natural disasters, unstable political states, or personal traumatic events. It may have been adaptive for her to adopt a more dissociative/depersonalized tendency as things around her are constantly fluctuating. Looking at this concept in another way, perhaps the low acceptance is simply an adaptive strategy. Rahill (2016) described Haitian community members creating artwork following the 2010 earthquake with the rubble under which the remains of family/friends lay. Instead of being forced to "accept" or not accept circumstances, perhaps individuals met harsh realities and rerouted their energies into other avenues: for example, rubble turned into art. Though positive refocusing wasn't extremely elevated in Patient 8, it was slightly higher for her compared to Patient 6 and 19. Perhaps reporting lower or mid-line scores for each item is reflective of a cohort difference. Even though mental health and psychology, as conceptualized by Western culture, is still in the very early stages of being talked about at all in Haiti, there could be differences in what is deemed "private" between age cohorts. For example, Patient 19 may have been less likely to endorse 'I continually think how horrible the situation has been" as this may be thought of as a private affair and not something to be shared with strangers, much less foreigners.

Differences between Patient 6 and Patient 19 on the subscales of rumination, catastrophizing, refocus on planning, and acceptance showed a split. Though they both endorsed

higher rumination and catastrophizing, there were large differences in their reports of refocusing on planning and acceptance. Patient 6 reported moderate refocus on planning and very high acceptance while Patient 19 reported very high refocus on planning and low acceptance. Though they both thought a lot about the negatives that happened and could still happen, Patient 6 was spurred to think about what to do next, while Patient 19 simply accepted that bad things happen. Depending on the situation, both opposing responses could be adaptive or maladaptive in different situations. Also, importantly, individual differences as well as similarities were indicated across the three cases.

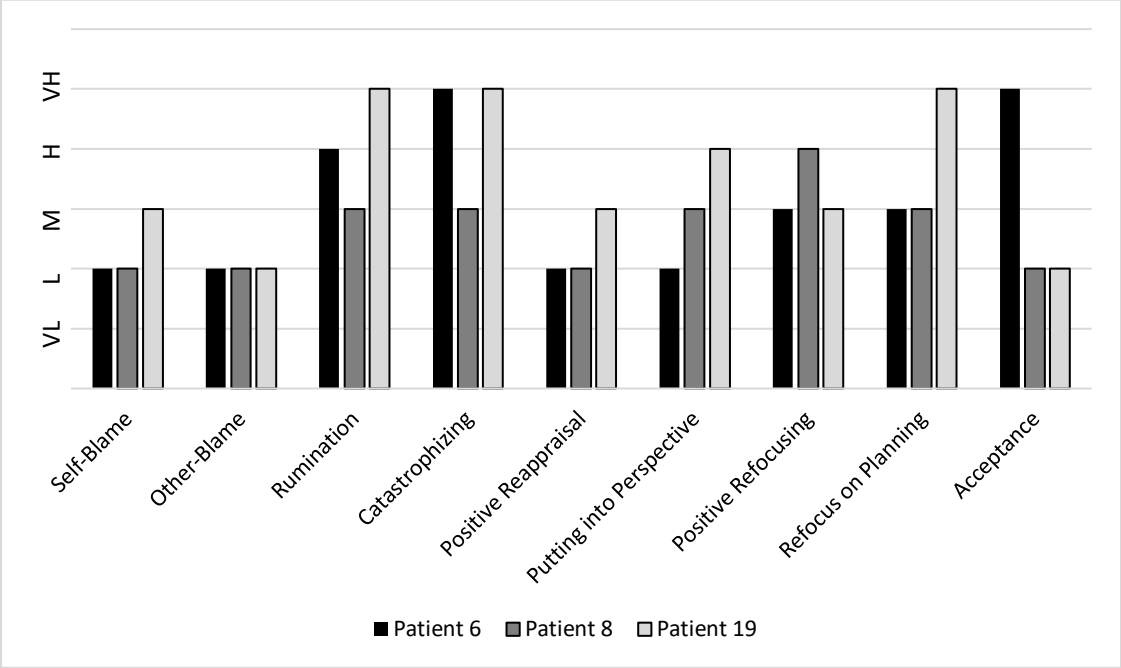

Figure 12. Emotionality on each subscale for three participants. VL=Very Low; L=Low; M=Moderate; H=High; VH=Very High.

Conclusion

Internal consistency reliabilities were presented followed by correlations among measures. Results revealed a statistically significant positive relationship between total sleep problems and emotionality. More specifically, higher emotionality was associated with more snoring/nighttime breathing problems to a moderate degree. Although not statistically significant, modest positive correlations emerged between attention problems and higher emotionality, and between attention problems and total sleep problems, particularly snoring/nighttime breathing problems. Simulated data was created by doubling the number of participants, as the sample size was small. With the simulated data, seven of the eight relationships were statistically significant: emotionality and total sleep problems, emotionality and snoring/nighttime breathing problems, emotionality and daytime sleepiness, emotionality and attention problems, total sleep problems and attention problems, snoring/nighttime breathing problems and attention problems, and nighttime breathing problems and daytime sleepiness. Age was not correlated with sleep problems, emotionality, or attention in the sample. A one-way between subjects ANOVA was conducted to look at differences in sleep, emotionality, and attention in the two groups of individuals (Documented Attention Problems, No Documented Attention Problems). Individuals with a history of documented attention problems actually performed better on a test of sustained attention, but this difference was not statistically significant. Sleep problems and emotionality were also lower in those who had documented attention problems, but these were not significant. Individual assessment profiles from each of the three groups of individuals were presented and interpreted in order to illustrate clinical considerations when working with this population. The chapter concluded with a comparison of emotionality for the individual case results.

Chapter 4: Discussion

This chapter begins with revisiting the three proposed hypotheses comparing the obtained data as well as the simulated data. Reasons why some results were non-significant are discussed. Group outcomes and their differences are discussed. Limitations of the study are addressed. The chapter ends with suggestions for future research. Individual assessment case analyses were interpreted in Chapter 3 Results, as allowed by qualitative, inferential methods.

Hypotheses

Hypothesis 1. Hypothesis 1 stated that there will be a positive relationship between disordered sleep and emotion regulation problems. This relationship was found to be significant in the study as well as with the simulated data. Disordered sleep and emotionality were moderately correlated, such that individuals with higher self-reported emotionality were more likely to report snoring/nighttime breathing. Snoring/sleep disordered breathing was significantly related to emotionality in the data collected but daytime sleepiness was not. In the simulated data, both snoring/disordered breathing and daytime sleepiness were significantly related to emotionality.

The study was not designed to look at causality; however, possible interpretations include the following: Daytime sleepiness may have been a result of snoring/disordered nighttime breathing and a predicting factor of emotionality, a research indicates that sleep quality can predict low positive affect (Bower, Bylsma, Morris, & Rottenberg, 2010). Partial sleep deprivation is linked to increased mood lability and higher depressed mood. Individuals could have had disrupted sleep due to disordered nighttime breathing, affecting both their energy levels during the day as well as their perception of their own energy levels. Daytime fatigue could result in individuals feeling less able to regulate their emotions in an appropriate way, and more likely to “catastrophize” and place blame on themselves and others.

Hypothesis 2. Hypothesis 2 stated that there would be a positive relationship between disordered sleep and attention problems. Though this relationship was not found to be significant in the study, the simulated data demonstrated a moderate, significant, positive correlation between disordered sleep and attention problems. In the simulated data, snoring/nighttime breathing problems were associated with attention problems. Daytime sleepiness was not associated with attention problems for either the sample data or the simulated data.

One reason why daytime sleepiness was not found to be significantly correlated with attention problems while snoring/nighttime breathing problems was significantly correlated could be the result of how these variables were measured. Out of the four questions for the daytime sleepiness category, two were about falling asleep/nodding off when driving a vehicle. Though a handful do, most of the individuals included in the study do not drive. The patients were instructed to say "no" and "never" to these questions as they were not applicable. However, this may have distorted the results as some of the patients who have significant daytime sleepiness may have otherwise selected "yes" and "almost every day." Alternatively, there may not actually be a relationship between snoring/nighttime breathing problems and attention. Maybe sleep disordered breathing is more related to hypoxemia at night, and therefore may have more effects on brain functions necessary for attention regulation.

Hypothesis 3. Hypothesis 3 stated that there would be a positive relationship between emotion regulation difficulties and attention problems. This relationship was not significant in the current study, but the simulated data demonstrated a medium, significant, positive correlation between emotionality and attention problems. Those who endorsed more emotionality performed more poorly on a detectability-based attention task.

As discussed in the literature review, the hippocampus and the amygdala work together within the limbic system to process emotions. The amygdala regulates emotion responses by modulating and encoding the storage of the emotion memories that the hippocampus has created. The amygdala sends a signal to the prefrontal cortex, which helps regulate the amygdala, depending on how frightening the situation is in reality. Though selecting items on the CATA does not accurately represent long-term information-gathering and emotion-encoding as it is a relatively short task, if someone is prone to having an overactive amygdala, this could lead to difficulties on this task. Individuals who were more prone to being highly emotional may have gone into the task with more anxiety and became easily distracted. Though having timed tests is stressful for many Americans, it is generally accepted to be a common practice for certain kinds of assessments. That is not the case in Haiti, so its novelty and expectations to respond quickly could have resulted in task-specific stress.

Group Outcomes

When the participants were separated by the presence or absence of documented attention problems, several trends were seen. Those who had documented attention problems were younger (and included the youngest member of the whole sample), while the second group was older (and included the oldest member of the sample). This could reflect a generational trend toward documenting and considering attention problems, which is becoming more commonplace. The average number of years of formal education was almost exactly the same (7.6 years and 7.55 years). Stress levels were approximately double for those who did not have documented attention problems.

The Documented Attention Problems group members reported generally fewer sleep problems, less emotionality, and better detectability on a standardized test of attention. In

essence, the Documented Attention Problems group performed better on all measures. However, these differences were not significant. It is possible that stress had some impact on the three highlighted symptoms, as those who did not have documented attention problems reported higher stress levels. However, this variable was not directly included in the analyses. Stress could lead to rumination, sleeplessness, and subsequent daytime sleepiness. The way that the stress level question was worded could indicate either state or trait anxiety as there was no timeline attached to the stress rating. Individuals who were prone to feeling more anxious may have been more aware of slight changes in observable sleep problems or emotionality, leading to a slightly higher endorsement of symptoms. It is possible that the more stressed individuals chose not to report attention problems on their own accord to a medical professional because they were worried about other things. Alternatively, they may have felt too stressed to visit a medical professional in the first place. Or it could be possible that symptoms were higher in the more stressed population, even though these differences were not significant.

The data showed that many of the individuals who did not have documented attention problems performed similarly to those who had attention problems documented by a medical professional on a measure of auditory attention. Research indicates that individuals with SCD have higher rates of attention problems when compared to the general population. The study did not compare the participants to a healthy sample, so it cannot add to that research. However, results did indicate that attentional problems in SCD may be underdiagnosed/underreported by medical professionals, at least in a poor Haitian sample.

Attention Problems and Supports

For children with attention problems in the United States, there are many supports that can be put into place, especially in schools, through Individualized Education Plans (IEPs), so

that the children are better able to be successful in school despite attention problems. In Haiti, these types of supports, such as separate rooms for certain tasks and providing printed teacher notes before class, would not be possible. However, recommendations such as providing seating at the front of the room and helping keep the student's desk clear of distractions could be implemented.

The impact of attention difficulties on individuals extends beyond school years. In a study looking at attention difficulties (vigilance, the alerting network) as a result of disrupted sleep, 20 to 25-year-olds were seen to be the most negatively affected (Alhola & Polo-Kantola, 2007). Decreased vigilance at work could lead to a termination of the worker. Job security is especially important to pay attention to when discussing Haiti, as unemployment rates in Haiti are over three times as high in Haiti compared to the United States (Trading Economics, 2017). This is particularly salient because there are fewer organizations and programs available to help individuals who are struggling financially in Haiti and losing employment could be disastrous for the affected family. Untreated sleep problems and significant emotionality could be warning signs for clinicians working with this population that attentional problems are present. Having this knowledge could lead to better treatment of attentional problems, such as medication.

Limitations of the Study

The study had several limitations. The study provided small group and intrapersonal descriptive data, also comparing test performance within participants of a sample of 22 participants in a primary care clinic in Haiti. Findings cannot be generalized to other SCD Haitian patients in other geographic parts of Haiti and of other social classes. Though certain steps were taken to ensure standardized testing procedures, the study was carried out at an active medical clinic, not a laboratory or assessment clinic. Some distractions were unavoidable and

could have affected performance on attentional tests. Objective testing is not common in Haiti as it is in the United States and was likely a new experience for participants. Such testing could lead to increased anxiety, decreased motivation, or increased excitement/eagerness. Though the communications among the researchers and the instructions for the test administration were translated linguistically and culturally, there was the possibility for miscommunications. As discussed previously, there were some problems with applicability for some of the questions in the daytime sleepiness category of the Berlin Questionnaire. This questionnaire was selected because it was deemed more culturally appropriate overall than other similar sleep questionnaires. However, there may have be an instrument that I was unaware of that could be even more culturally appropriate. Additionally, as sleep research is a blossoming field, there may have been another measure that has been developed since this project was approved in 2017. Furthermore, the Berlin Questionnaire, as well as the other measures used in the study, were not developed and normed on the population, limiting the ability to use comparison to a normative population in analyses. Because of the setting, a full medical history was not available. Genotypes were not known, which could have provided for more in-depth comparisons. One study found that there were approximately twice as many infants born to Haitian immigrants coming in Miami with haemoglobin S compared to hemoglobin C (Pegelow & Mack, 1989). If these findings were representative of all of Haiti, that would mean that the majority of the participants had HbSS in the present study. However, the results shown by Pegelow and Mack were not necessarily generalizable to the sample of the present study. Additionally, the neurologic history that was obtained was relatively brief and relied on self-report. Silent strokes are one of several unaccounted-for conditions that could have affected performance. Because of the limited time available for research in Haiti and the focus on looking at symptom profiles,

individuals did not undergo a formal testing of intelligence, which may have explained some of the differences between individuals. Although a comparison of the constellation of all SCD symptoms (outside of attention, emotion regulation, and sleep) and the severity of the symptoms was not something that was addressed, it is noted that the course of SCD is not exactly the same for each person and this variability within the sample may have affected the results.

Directions for Future Research

The current study looked at the relationships between sleep, emotionality, and attention in individuals with SCD. Because of the small sample, causality was not investigated even though research suggests that both disordered sleep and emotionality can impact attention. Further studies with larger samples or simulated data to estimate a larger sample could be used to look more at causality and predictability. Additionally, other variables such as stress and age could be added in as moderators or mediators of these relationships.

Though emotionality was broken down into different subscales for the individual assessment profiles, it was aggregated into an "emotionality" index for group and sample analyses. Being able to relate the different emotionality subscales to attention could provide more information on these relationships. For example, are individuals who are prone to rumination more likely to be distracted by outside stimuli? These more specific analyses were not done as each subscale on the CERQ consisted of only two items. Emotionality, as it was defined in the study, was made up of many varied components. Future research using measures more specific to different kinds of emotionality and emotional responses could be beneficial in looking at relationships.

Using neuropsychological tests to tease apart which networks are less efficient could lead to more insight on which parts of the brain are not working as well in the participants. This may

be particularly salient in this population, as neuroimaging is extremely difficult to do in Haiti. In the present study, attention was operationalized as the ability to discriminate between two auditory stimuli over a sustained period of time. The task required both sustained attention as well as executive control. Posner and Peterson (1990) outlined three different attentional network processes: the alerting network, the orienting network, and the executive network, each with dissociable neurologic correlates. All three processes were needed for the task used in the study. Each network has been linked to different parts of the brain. The literature reveals that with no history of infarct, there may be no effect of SCD on the orienting network, but the executive network does seem to be impacted by the presence of the disease. Using other parts of the CATA besides just the detectability index or adding in a task of executive functioning could confirm if this is true and could help isolate what is breaking down when participants have difficulty on these tasks. Reaction time was not incorporated as a separate variable in the study. Research indicates that severity of SCD has a negative effect on reaction time when individuals are presented with auditory stimuli (Hamon, Seri, & Sangare, 1990). Future research incorporating reaction time into the analyses could give more information on the severity of SCD for the participants. Additionally, using attentional tasks that are similar but rely on other modalities besides audition, such as the visual stimuli in the CPT or the Test of Variables of Attention (T.O.V.A.; The TOVA Company, 2019), could provide a more comprehensive view of how attention is affected in SCD.

The present study framed SCD as a cerebrovascular disease because the brain and associated processes are greatly affected by the complications brought on by the pathophysiology of the disease. A potential next step could be looking directly at how the various neuroanatomical circuits that are associated with the three highlighted symptoms are affected in

the SCD brain of poor individuals living in Haiti. Although access to advanced medical care and technology in this area of Haiti is currently limited, advances in these areas (e.g., availability of neuroimaging and long-term comprehensive medical records) would allow for more in-depth analysis that might reveal or further explain trends seen in the study. For example, this would allow further understanding of the impact of overt and silent strokes on neurobehavioral functioning in individuals with SCD relative to other disease processes like vasculopathy, chronic anemia, and inflammation, which are not observable on neuroimaging.

Conclusion

The study examined relationships between sleep, emotionality, and attention in SCD. A Haitian population was chosen because of the high rates of SCD in Haiti, the need to conduct international studies in SCD, and the long-standing collaboration between the Antioch Multicultural Center for Research and Practice and the Haitian primary care clinic, Partners in Development. Emotionality and sleep problems (specifically snoring/nighttime breathing problems) were moderately correlated, such that greater self-reported emotionality was associated with greater self-reported sleep problems. Emotionality and sleep problems were not seen to be significantly related to attention in the current sample; however, when the sample size was doubled (N=44) with simulated data, a positive correlation was observed. Age was not correlated with sleep problems, emotionality, or attention in the study. Participants were divided into two groups based on the presence or absence of documented attention problems. Results revealed no significant differences between groups on an objective measure of auditory attention. There was a trend for individuals with documented attention problems to report fewer sleep problems and emotionality, but this was not statistically significant. A single case assessment profile analysis was performed using three participants due to the small sample size, potential

between group differences, and the preliminary nature of the study. These profiles were discussed ideographically in Chapter 3 Results. The findings, limitations of the study, and future directions of research were discussed.

On the basis of the study's results, it appears that sleep and emotionality may have an effect on attention on poor patients with SCD in Haiti, although we were unable to evaluate a predictive or causal model considering contributions of these and other factors such as age, education, and stress on attention in this population. It is clear that subsets of these patients may be at risk for disordered sleep, emotion regulation problems, and/or attention problems and that these symptoms are interrelated. Therefore, structured and routine screening is recommended with targeted intervention when indicated to reduce functional morbidity for individuals with SCD.

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Appendix A: Letter of Permission from PID to Conduct Research

Partners In Development, Inc.

Serving the poorest of the poor in developing countries since 1990

March 2, 2017

Members of the IRB Committee at Antioch University New England:

As the Director of Partners in Development (PID), Ipswich. MA, I have a long-standing relationship with Gargi Roysircar and have partnered with her on several of her trips to Blanchard, Haiti, where PID operates a primary care clinic that is licensed by the Haitian Department of Public Health. I have communicated with Gargi and her research assistant, Sarajane Rodgers, about their upcoming trip to Haiti. I am pleased to give them permission to obtain neuropsychological data from the sickle cell patients served by our clinic.

I have reviewed the Recruitment letter and informed Consent forms, and my staff will translate them into Creole. I will distribute these documents to the sickle cell patients at the clinic. In addition to informing patients about the research project, my clinic staff will translate into Creole both the initial directions for test-taking and the measures that will be used for assessment. Translators at the clinic will help with the test administration to sickle cell patients.

I would also like to address the issue of local and national laws and regulations for research with human participants. Partners in Development, Inc. (PID) has been working in Blanchard for over 23 years and our medical clinic has been operating for 17 years. We are well-acquainted with the political and regulatory climate of our local community and of Haiti. To our knowledge and in our experience, the Haitian government has no laws and/or regulations in place that address, regulate, or codify the policies and procedures for conducting research with human participants.

It is my understanding that the Disaster Shakti members have investigated the Haitian Public Health website (http://mspp.gouv.ht/newsite/) and were unable to locate any links or language that directly addressed regulations on research using human subjects. They have also contacted the Embassy of Haiti in Washington, DC, by telephone to inquire about such regulations. The embassy staff was not able to identify any legal requirements or regulations, nor could they direct them to agencies within the Ministère de la Santé Publique et de la Population (MSPP) that could address their inquiry into this matter.

Partners In Development, Inc.

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www.pidonline.org

Partners In Development, Inc.

Serving the poorest of the poor in developing countries since 1990

In my view, Dr. Roysircar's study will be conducted ethically, appropriately, and with sensitivity towards Haitians that PID serves in Blanchard and its neighboring areas.

I look forward to partnering again with the Antioch Multicultural Center and its director, Gargi Roysircar.

Thank you,

Gale Hull, Doctor of Letters

President, Partners In Development
55 Market St. Suite 201
Ipswich, MA 01938
www.pidonline.org

Appendix B: Informed Consent to be translated or read by a translator

Dear PID client:

We are counselors at the PID Blanchard clinic who work with families, adolescents, and children. We are interested understanding the symptoms of sickle cell anemia and how these symptoms together affect a person's functioning. This project has the approval and support of *Partners in Development* and Ms. Gale Hull, the PID Director.

Our research examines problems with attention, emotion, and sleep associated with sickle cell anemia. You have been selected by PID to participate in the research because you have the diagnosis of sickle cell anemia.

PID translators will give instructions for all tests. Each participant will complete a computer test and a paper-and-pencil test.

For the paper-and-pencil test, you can record your own answers or the translator will write your answers in a notebook. The tests will take no longer than 1 and 1/2 hours, and can be spread over multiple sessions if fatigue is an issue.

Your answers will remain confidential.
We will not use your name in any report. All test answers will be kept under lock and key. Other than the counselors who are giving you the tests, no one will know whose scores and answers these are. Your diagnosis of sickle cell anemia will not be discussed with any outsider.

You may choose not to take the tests. Even if you choose not to take the tests, PID services will continue to be available to you and your family. You may choose to stop completing the tests and withdraw at any time.

If you have any questions about the research, you may contact Gale Hull, the PID Director.

If you have any questions about the research procedures or your rights as a participant, contact Dr. Kevin Lyness, Chair of the Antioch University New England Human Research Committee or Dr. Melinda Treadwell, Provost of Antioch University New England.

_____ I, _____, am willing to take part in this study.
_____ I, _____, am not willing to take part in this study.

_____ _____
(Parent's Signature or Mark) Date

Informed Consent (in Creole)

Ou dwe dako ak tout infomasyon nan dokiman sa apre yo fin tradyi'l ak li'l pou ou

Che kliyan PID:

Nou se konseye nan Klinik PID nan Blanchard kap travay ak la fanmi, jèn, ak timoun. Nap travay pou nou ka konprann Anemi Falsifòm ansanm ak kisa li fe nan fonksyonman lavi nou. Projè sa jwenn sipò *Partners in Development* Ak Mme. Gale Hull, ki se direktris.

Rechech na fè la ap fouye konprann zafe manke somèy, paka konsantre ansanm ak gro emosyon Anemi Falsifòm bay moun. Nou chwazi'w pou patisipe nan rechech sa, paske nou remake ou gen Anemi Falsifòm lan nan san'w.

Tradiktè ak Entèprèt PID yo va esplikew kisa pou fe nan tes sa. Chak moun kap patisipe pral pase on test sou òdinatè ak on lòt tès alekri (sou papye).

Pou tès alekri a, ou ka bay younn nan tradikte PID yo anrejistre repons ou yo nan yon kanè nòt. Tès la pap dire plis ke 1è ak 30 minit, epi nou ka kanpe epi rekomanse valè fwa ou vle, si ou santiw fatige.

Repons on yo ap rete sekrè.

Nou pap ni site, ni itilize non ou nan rapò final lan. Tout rezilta tès ak egzamen ap sere anba kadna. Sèl konseye kap pase'w tès ak egzamen yo k'ap konn rezilta yo. Pyès lòt moun pap konnen. Rezilta analiz Anemi Falsifòm ou a pap pale ak okenn lòt moun.

Ou ka toujou refizi fè tès yo. Menmsi ou ta chwazi pa fè tès sa yo, PID ap toujou kontinue by oumenm ak fanmi'w menm sevis li yo. Ou gendwa sispann oubien rale kow nan tès sa yo nenpont lew vle.

Si ou ta gen kestion sou rechèch sa na fè la, ou met mande Gale Hull ki se direktris PID.

Si ou ta gen kestyon sou fason nap mennen rechèch sa ansanm ak tou dwa ou genyen antan ke moun kap patisipe ladann, ou met kontakte Dr. Kevin Lyness, Direktè Komite nan Antioch University New England Human Research oubien Dr. Melinda Treadwell, administratè nan Antioch University New England.

_____ Mwen, _____, mwen vle patisipe nan etid sa.

_____ Mwen, _____, mwen pa vle patisipe nan etid s.

_____ _____

(Siyati paran) Dat

Appendix C: Parental Permission to be translated or read by a translator

Child's Name:_____Age: ___

Dear Parent:

We are counselors at the PID Blanchard clinic who work with families, adolescents, and children. We are interested understanding the symptoms of sickle cell anemia and how these symptoms together affect a person's functioning. This project has the approval and support of *Partners in Development* and Ms. Gale Hull, the PID Director.

Our research examines problems with attention, emotion, and sleep associated with sickle cell anemia. Your child has been selected by PID to participate in the research because he/she has the diagnosis of sickle cell anemia.

PID translators will give instructions for all tests. Each participant will complete a computer test and a paper-and-pencil test.

For the paper-and-pencil test, your child can record their own answers or the translator will write your child's answers in a notebook. The tests will take no longer than 1 and 1/2 hours, and can be spread over multiple sessions if fatigue is an issue.

Your child's responses will remain confidential.
We will not use your child's name in any report. All test answers will be kept under lock and key. Other than the counselors who are giving your child the tests, no one will know whose scores and answers these are. Your child's diagnosis of sickle cell anemia will not be discussed with any outsider.

Your child may choose not to take the tests. Even if he/she chooses not to take the tests, PID services will continue to be available to you and your family. Your child may choose to stop completing the tests and withdraw at any time.

If you have any questions about the research, you may contact Gale Hull, the PID Director.

If you have any questions about the research procedures or your rights as a participant, contact Dr. Kevin Lyness, Chair of the Antioch University New England Human Research Committee or Dr. Melinda Treadwell, Provost of Antioch University New England.

_____ **I give my permission** to have my child,_____, included in the study.

_____ I **do not** give my permission to have my child,_____, included in the study.

_____ _____
(Parent's Signature or Mark) Date

Parental Permission (in Creole)

Permision Paran apre enteprèt fin tradyi li pou ou

Non timoun lan:_____Laj: ___

Chè Paran:

Nou se konseye nan Klinik PID nan Blanchard kap travay ak la fanmi, jèn, ak timoun. Nap travay pou nou ka konprann Anemi Falsifòm ansanm ak kisa li fe nan fonksyonman lavi nou. Projè sa jwenn sipò *Partners in Development* Ak Mme. Gale Hull, ki se direktris.

Rechech na fè la ap fouye konprann zafe manke somèy, paka konsantre ansanm ak gro emosyon Anemi Falsifòm bay moun. Nou chwazi pitit ou a pou li patisipe nan rechech sa paske nou remake li gen Anemi Falsifòm lan nan san li.

Tradiktè ak Entèprèt PID yo va esplikew kisa pou nou fe nan tes sa. Chak moun kap patisipe pral pase on tès sou òdinatè ak on lòt tès alekri (sou papye).

Pou tès alekri a, pitit ou a ka bay younn nan tradikte PID yo anrejistre repons li yo pou li nan yon kanè nòt. Tès la pap dire plis ke 1 è ak 30 minit, epi pitit ou a ka kanpe epi rekomanse valè fwa nou vle, si li santi'l fatige.

Repons pitit ou a ap rete sekrè.

Nou pap ni site, ni itilize non pitit ou a nan rapò final lan. Tout rezilta tès ak egzamen ap sere anba kadna. Sèl konseye kap pase pitit ou a tès ak egzamen yo k'ap konn rezilta yo. Pyès lòt moun pap konnen. Rezilta analiz Anemi Falsifòm pitit ou a pap pale ak okenn lòt moun.

Pitit ou a ka toujou refize pase tès yo. Menmsi li ta chwazi pa fè tès sa yo, PID ap toujou kontinue bay oumenm ak fanmi'w lan menm sevis li yo. Pitit ou a gendwa sispann oubien rale kò'l nan tès sa yo nenpont lè li ta vle.

Si ou ta gen kestion sou rechèch sa na fè la, ou met mande Gale Hull ki se direktris PID.

Si ou ta gen kestyon sou fason nap mennen rechèch sa ansanm ak tou dwa ou genyen antan ke moun kap patisipe ladann, ou met kontakte Dr. Kevin Lyness, Direktè Komite nan Antioch University New England Human Research oubien Dr. Melinda Treadwell, administratè nan Antioch University New England.

Mwen,_____, **Mwen bay pèmisyon'm** pou pitit mwen,_____, patisipe nan etid sa.

Mwen,________, **mwen pap bay** okenn pèmisyon'm pou pitit mwen,_____, patisipe nan etid sa.

_____ _____

(Siyati paran) Dat

Appendix D: Child Assent Form to be read/translated to the child

Child's Name_____

RESEARCH STUDY ON SICKLE CELL DISEASE SYMPTOMS

We are counselors at the Blanchard Clinic and we serve children and their families. We are interested understanding the symptoms of sickle cell anemia and how these symptoms together affect a person's functioning. We are asking you and other children at the Blanchard clinic to take part in our project to find out about your symptoms of this disease.

If you agree to do this, we will ask you to answer some questions about your sleep and emotions. You will also do a test with a pen and paper connecting letters and numbers. Then, we'll have you do a test on a computer that measures your attention. A PID translator will help us to talk with each other. This project will take place at Partners in Development (PID) for about an hour.

Other children will not know your answers to our questions. We will not show them your pen and paper test or your scores on the computer test.

Of course, you don't have to do this if you don't want to, even if your parents give their permission. If you do not want to do this or if your parents asked you not to do this, just tell us. It is OK with us if you don't want to tell us about your sleep and emotions or if you do not want to do either the pen and paper test or the computer test. No one will know that you did not take part in the project.

Do you have any questions? We will answer all of your questions. If you agree to do this, please sign this paper.

The study on sickle cell disease has been explained to me and my questions have been answered. I would like to take part in the project.

_____ _____

Child's Signature or mark Date

Child Assent Form (in Creole)

Akò Timoun lan apre Tradiktè ak Entèprèt PID yo fin li'l pou li.

Non Timoun lan_____

RECHECH AK ETID SOU KISA ANEMI FALSIFOM FE SOU MOUN

Nou se konseye nan Klinik PID nan Blanchard kap travay pou bay timoun ak fanmi yo sevis. Nou enterese konprann kisa Anemi Falsifòm fè sou nou epi kijan li aji sou fonksyonman lavi nou. Nap mennen ankèt sou oumenm ak lòt timoun nan klinik Blanchard lan pou nou ka konprann maladi sa ak sa li ka fe sou moun.

Si ou dakò pou nou fè sa, nou pral poze'w kek kestyon sou your somey ou ak sa ou resanti. Nou pral baw papye ak plim oswa kreyon tou pou ou trase ak konekte kek repons lèt ak chif sou li. Apresa, wap fè kèk egzamen son on odinatè kap mezire konsantrasyon ou. On tradiktè osinon on entèprèt pral pèmèt mwen avèw youn konprann lòt. Projè sa pral fèt nan klinik PID nan Blanchard; lap dire 1 nèd tan.

Okenn lòt timoun pap konn repons ou bay yo, epi nou pap montre pyès moun saw ekri nan papye yo, ni rezilta egzamen sou òdinatè yo.

Biensi ou gendwa pa fè yo si ou pa anvi, menmlè paran'w ta bannou pèmisyon pa yo pou'n travay avèw. Si ou pa ta vle fe'l oubien paran ou ta diw pa fè li, ou met di nou sa. Nou papgen problèm si ou pa vle pale nou de sa ou resanti, de somey ou, ni pase tès sou papye ak plim oubien kreyon, ni tès sou òdinatè. Pyès moun pap konnen ke ou pat patisipe nan projè sa.

Ou gen kestion? Nap kontan reponn ou. Si ou dakò, siyen oubien ekri non ou nan papye sa.

Yo bien esplikem a fem konprann Etid sa sou Anemi Falsifòm. Mwen bien konprann li epi yo reponn tout kestyon mwen yo. Mwen vle patisipe nan projè sa.

_____ _____

Mete siyati'w lan la Dat

Appendix E: Demographic Questionnaire

Age:

What is your age? _____

Gender:

What is your gender? _____

Education:

How many years of school have you had? _____

Medical history:

Have you ever been told that you had a mini-stroke by a doctor? _____

If yes: How many have you had? _____

Have you ever been told that you had a stroke by a doctor? _____

If yes: How many have you had? _____

Have you ever been told that you have problems with paying attention by a doctor? _____

Stress:

On a scale of 1 to 10, 1 being no stress and 10 being a great amount of stress, what would you rate your stress levels to be? Please circle one.

1 2 3 4 5 6 7 8 9 10

Demographic Questionnaire (in Creole)

Kestion sou Moun yo.

Laj:

Ki laj ou? _____

Seks:

Ou se Fi oubien Gason? _____

Edikasyon:

Nan konbien lanne lekol ou rive? _____

Eta sante:

Esk on doktè ko janm di'w ou te fè sa yo rele "mini strok" oubien atak? _____

Si repons lan se wi: Konbien ou te fè? _____

Eske on doktè janm di'w ou gen difikilte pou konsantre'w oubien kenbe atansyon ou? _____

Strèss:

Ant 1 a 10, kote 1 ta vle di pa gen strèss ditou epi 10 ta vle di anpil strèss, ki nivo stèss ou tap bay tèt ou? Tanpri fè on sèk sou chif ou chwazi a.

1 2 3 4 5 6 7 8 9 10