PERCEPTIONS OF ADULTS WITH SICKLE CELL DISEASE REGARDING TREATMENTS AMID VASO-OCCLUSIVE CRISIS

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Abstract

Patients with sickle cell disease experience painful crises that require them to seek treatment by health-care professionals. Data sets were collected through various research studies concerning sickle cell patients and their experience with health care professionals. Sickle cell patients are often treated with narcotic analgesics to manage their pain symptoms. Findings include that pain is the most common symptom among sickle cell patients, and patients view their themselves as difficult. The results of this research did not prove that sickle cell patients experience negative treatment from healthcare providers when seeking treatment. It is recommended that sickle cell disease based organizations should establish support groups to help sickle cell patients cope with their disease experience.

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Introduction

1.1. Background

Sickle cell disease (SCD) is a genetic blood disorder that primarily affects African Americans.[1] "Sickle cell disease limits the function of protein that carries oxygen in the hemoglobin. Hemoglobin is the protein in the red blood cells that carries oxygen to various organs in the body."[2] "Individuals with normal red blood cells have round, elastic and flexible cells that and can live up to 120 days."[3] However, individuals with sickle cell disease have blood cells that are sticky and shaped like crescent moons, that only live between 9 and 20 days.[4] As a result, patients with sickle cell disease may experience complications such as: frequent episodes of pain, anemia, fatigue and repeated infections.[5]

Originally, it is reported that, sickle cell trait developed as a mutation in geographical areas such as Africa, Mediterranean countries and parts of Asia with a high concentration of malaria.[6] "Researchers have traced the sickle cell mutation back 7,300 years to one child in Western Africa.[7] The sickle cell mutation occurred because children were at risk of severe falciparum malaria, and dying as an infant." Thus, the sickle cell mutation would allow children to live longer and to have children of their own.

Scientifically speaking, sickle cell disease occurs when an individual receives both trait of Hemoglobin S (HbS) or another abnormal variant of hemoglobin such as hemoglobin C, D, E or β- thalassemia.[8] "SCD is present at birth, but most infants don't show any signs until they are more than 4 months old."[9] Some individuals do not find themselves diagnosed with the disease until later in life.[10]

Historically, the discovery of the disease is over a century old. "In 1910, Dr. James Herrick a physician in Chicago, described the first recorded case of sickle cell anemia, in a Negro student from Grenada in the West Indies."[11] During the same year, Benjamin Earl, a medical student at the University of Virginia wrote about a second patient, Ellen Anthony, identified to have

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[1] "Sickle cell disease - Genetics Home Reference," U.S. National Library of Medicine,, accessed January 22, 2018, https://ghr.nlm.nih.gov/condition/sickle-cell-disease.

[2] Barakat schwarts radicliff

[3] Mayo Clinic, "Sickle Cell Anemia," Mayo Clinic, March 08, 2018, , accessed August 01, 2018, https://www.mayoclinic.org/diseases-conditions/sickle-cell-anemia/symptoms-causes/syc-20355876.

[4] Mayoclinic, sickle cell disease

[5] Mayo clinic

[6] D Desai H. Dhanani, "Sickle Cell Disease: History and Orgin," Journal of Hemotology 1, no. 2 (2003): 1.

[7] Daniel Shriner, whole genome sequence based haplotypes

[8] Maxine A. Adegbola et al., "Voices of Adults Living with Sickle Cell Disease Pain," National Black Nursing Association 23, no. 2 (December 2016): 17

[9] Walter A. Schroeder, Edwin Munger, and Darleen R. Powars, "Sickle Cell Anaemia, Genetic Variations, and the Slave Trade to the United States," Journal of African History 31 (1990): 164.

[10] Schroeder et al, 165

[11] Todd Savitt, "Tracking Down the First Recorded Sickle Cell Patient in Western Medicine," Journal of the National Medical Association 102, no. 11 (November 2010): 987.

abnormal sickle shaped cells.[12] During this century, sickle cell disease was shown to be more prevalent in African Americans.[13] This caused various scientists, chemists and geneticists to conduct further research on sickle cell anemia.[14] By November 25, 1949, Linus Pauling, Harvey A. Itano, S.J Singer and Ibert C Wells verified that sickle cell anemia was a molecular disease.[15] A molecular disease is a "disease in which there is an abnormality in, or a deficiency of, a particular molecule, such as hemoglobin in sickle cell anemia."[16]

Today, 100,000 people in the U.S. have sickle cell disease.[17] However, sickle cell disease is essentially an invisible disease. Unless a patient is experiencing pain from sickle cell disease, they appear healthy and fine. Nonetheless, due to the low prevalence of this disorder, clinicians have encountered marked difficulty when treating sickle cell patients.[18] Not many health-care professionals are interested in treating sickle cell patients, there are more hematological diseases with more afflicted patients. As a result of the low prevalence of sickle cell disease, there is not much attention paid to sickle cell disease patients; thus, treatment remains substandard. In fact, studies demonstrate that, "Many people with sickle cell disease live with chronic pain, especially in their bones. However, sudden pain that can occur anywhere in the body is the most common symptom of sickle cell disease."[19] Medical professionals refer to this pain as a vascular-occlusive crisis or "sickle cell crisis."[20]

1.1.1. Pain and Bias

Providing sickle cell patients with adequate care for pain is another consistent problem in the healthcare system.[21] This is primarily due to health related stigmas associated with sickle cell disease, such as race and socioeconomic status of patients with SCD.[22] Many people with sickle cell disease are black and live in urban areas, therefore healthcare providers associate race with pain tolerance.[23] Because of these stigmas, sickle cell patients are often criticized for being drug addicts. However, there is no evidence that suggests sickle cell patients are more likely to become addicted than anyone else.[24] In this thesis, I argue that, when treating sickle cell patients,

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[12]

[13] Wailoo, 57

[14] Wailoo, 57

[15] Shroeder et al, 168

[16] Dictionary.com

[17] Center of Disease Control and Prevention, "Sickle Cell Disease." Center of Disease Control and Prevention, August 31, 2017 accessed August 31, 2017, https://www.cdc.gov/ncbddd/sicklecell/data.html

[18] Carlton Haywood, "Disrespectful Care in the Treatment of Sickle Cell Disease Requires more than Ethics Consultation," The American Journal of Bioethics 13, no. 4 (April 01, 2014), doi:10:1080/14265161.2013.768847.

[19] "NIH Medline Plus," Sickle Cell Disease: Symptoms, Diagnosis, Treatment, and Recent Developments, last modified Winter 2011, accessed August 30, 2017, https://medlineplus.gov/magazine/issues/winter11/articles/winter11pg18.html

[20] Carolyn Rouse, *Uncertain Suffering: Racial Healthcare Disparities and Sickle Cell Disease* (Berkley and Las Angeles, CA: University of California Press, 2009), 84

[21] Nadine Matthie et al., "Perceptions of young adults with sickle cell disease concerning their disease experience," Journal of Advanced Nursing 72, no. 6 (2015): , doi:10.1111/jan.12760.

[22] Coretta M. Jenerette and Cheryl Brewer, "Health-Related Stigma in Young Adults with Sickle Cell Disease," Journal of the National Medical Association 102, no. 11 (November 2010): dio:10.1016/s0027-9684(14)30732-x

[23]

[24] Beryl Lieff Benderly, "Fighting the Misconceptions About Sickle Cell Disease in the ER, NPR, January, 24, 2014, accessed October, 25, 2017, http://www.npr.org/sections/health-shots/2013/01/24/170181517/fighting-misconceptions-about-sickle-cell-disease-in-the-er

healthcare professional use the term "addict" irresponsibly. When treating sickle cell patients, healthcare professionals should consider SCD patients to be "drug dependent", but not "drug seeking, because their pain symptoms are treated with narcotics."

Healthcare provider bias has been referred to as implicit bias, ie; the unconscious awareness that can lead to a negative evaluation of a person on the basis of irrelevant characteristics such as race or gender.[25] Healthcare provider bias can therefore present a serious challenge in managing sickle cell patients for pain. Healthcare provider bias can significantly affect sickle cell patient perception of how the perception of how medical officials believe about their disease.

To avoid generalization or implicit bias, we should recognize that when the blood sickles it become trapped in vessels, causing pain in joints or other part of the body. Although sickle cell patients are affected by pain; pain is simultaneously a biological, psychological and emotional experience.[26] The perception of pain is misunderstood in sickle cell patients because every patient's experience with the disease and problematic symptoms are diverse.[27] Pain is thus not simply biological phenomena, it has psychological and emotional components. Patients each have their specific needs when it comes to managing pain. During the first encounter with pain, the patient should take their prescribed opioid medication, and if, after several hours, the pain is overbearing, the patient should seek treatment at the Emergency Room. "The extent of treatment of painful SCD crisis depends on the healthcare provider, who assesses the SCD patients presentation and ultimately decides whether the individual's report of pain is credible and deserving of treatment."[28] As a result of possible provider bias and incredulity surrounding patients' pain, patients may receive improper dosage of medicine, thus, culminating in a longer duration of pain.

1.1.2 Purpose of Research

Patients with sickle cell disease have described their pain as unbearable, excruciating "like a hammer beating and beating, it is a "pain I wouldn't wish on my worst enemies.[29] Patients with SCD are likely undertreated for pain because their pain is likely unmeasured by the pain scale, and therefore clinicians do not believe patients' subjective pain assessment.[30] Nonetheless, a patient race may also affect how sickle cell patients are treated. In addition, healthcare providers require more knowledge about sickle cell disease in order to improve quality of care in cell patients.[31] Progress in managing sickle cell disease will remain questionable if healthcare professionals continue to hold significant biases towards sickle cell patients.[32]

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[25] Chloë Fitzgerald and Samia Hurst, "Implicit bias in healthcare professionals: a systematic review," BMC Medical Ethics 18, no. 1 (2017): , doi:10.1186/s12910-017-0179-8.
[26] Apa psychology of pain
[27] Alawi Habara and Martin H. Steinberg, "Minireview: Genetic Basis of Heterogeneity and Severity in Sickle Cell Disease," Experimental Biology and Medicine 241, no. 7 (2016): , doi:10.1177/1535370216636726
[28] Jenerette and Cheryl Brewer, 1053
[29] Smith, 23
[30] Smith, 23
[31] Jenerette, 1053
[32] Smith, 63

Carlton Haywood Jr., PhD, a core faculty member at the John Hopkins Berman Institute of Bioethics and Coretta Jenerette PhD, professor of Nursing at University of North Carolina, are prominent scholars who conduct research centered on the experience of sickle cell patients and their relationship with healthcare providers. The reviewed SCD literature illustrates that sickle cell patients are at undertreated due to the misconceptions of the disease.

With this clinical and historical context in mind, this study will examine the patient perception of sickle cell disease and their relationship with healthcare providers through a bioethical lens. Even though sickle cell disease has been in the scientific literature for over 100 years, patients continue to be unsatisfied with treatment. Other genetic disorders such as Cystic-Fibrosis and Tay-Sachs are shown to have more support by the medical community.[33] For example, Gold and Kaiser reported that Cystic Fibrosis, which affects 30,000 Americans receives 7-11 times more funding per patient than sickle cell disease from the National Health Institute.[34]

My research question is based on the perception of sickle cell patients and their lived experience with treatment. Pain is the most common symptom associated with sickle cell disease. Often, when a sickle cell patients experience pain, they seek care in the emergency department and must sometimes wait long hours. Because there is a lack of knowledge about sickle cell disease, healthcare providers encounter difficulty when treating patients, my research questions therefore focus on how patients perceive treatment.

1.2 Research Questions:

Primary Research Question

- How do sickle cell patients experience treatment from their healthcare providers during a vaso-occlusive pain crisis?

Secondary Research Question

- Do sickle cell patients experience specific challenges regarding pain management treatment, and if so what are these challenges?

[33] Savitt, 932

[34] Jenny Gold and Kaiser Health News, "Sickle Cell Patients Fight Uphill Battle for Research Funds - and Compassion," STAT, March 23, 2018, para 37, accessed June 07, 2018, https://www.statnews.com/2017/12/26/sickle-cell-research-treatment/.

1.3. LITERATRUE REVIEW

1.2. Background of literature Review

The review of literature includes research about sickle cell patients and their relationships with healthcare providers, pain management treatment and emergency wait time. The goal for this literature review is to highlight the experience of sickle cell patients as they receive treatment for vaso-occlusive crises. This literature review highlights the different methods previous scholars have used in order to determine how patients perceive the care they receive.

1.2.2 Methodology of Literature Review

For this literature review, my research is limited to peer reviewed articles. I used Google Scholar, the Overlook Library at Overlook Medical Center, and Drew University + Library Scholar Search. My search term included, "sickle cell disease" + "patient experience,"+ "vascular occlusive crisis" "healthcare provider" My inclusion criteria were articles that primarily discussed sickle cell patients experience, treatment for pain, as opposed to my exclusion criteria of articles about healthcare providers treating sickle cell patients.

1.2.3 Study Designs of the Review of the Literature

Of the ten studies examined in this literature review, five studies, Carlton Haywood et al. (2010), Haywood et al. (2014a), Haywood et al. (2014b) Coretta Jenerette et al. (2014) and Jerlym Porter (2012) utilized mixed methods studies while Ballas et al. (2005) David Brousseau et al. (2010), and Paula Tanabe et al. (2007) employed quantitative studies. Lastly, the remaining two studies Maxine Adegbola et al. (2012), Nadine Matthie et al. (2016) carried out their research using a qualitative study designs.

Two articles by Haywood et al. (2014a) and Haywood et al. (2014b) conducted their studies using data from the Improving Patient Outcomes with Respect and Trust (IMPORT) study. Both studies indicated that the IMPORT study was, "a federally funded observational cohort study of SCD patients experiences with healthcare provider taking place at two academic medical centers in Washington district of Columbia area DC.[35] However, Haywood et al. (2014a) measured patients adherence to physician recommendations over a prior two-year period;[36] while, Haywood et al (2014b) measured patients experience of discrimination from healthcare providers over the previous twelve months,[37]

Brousseau et al. (2010) and Ballas et al. (2005) measured hospital readmission in sickle cell patients using discharge summaries.[38] The two studies that employed a descriptive study

[35] Carlton Haywood et al., "Perceived Discrimination, Patient Trust, and Adherence to Medical Recommendations Among Persons with Sickle Cell Disease," Journal of General Internal Medicine 29, no. 12 (2014): 1568; Carlton Haywood et al.,"Perceived discrimination in health care is associated with a greater burden of pain in sickle cell disease." *Journal of pain and symptom management* 48, no. 5 (2014):,935-936

[36] Haywood et al., 1658

[37] Haywood et al., 936

[38] David C. Brousseau et al., "Acute Care Utilization and Rehospitalizations for Sickle Cell Disease," Jama 303, no. 13 (2010):1289; Samir K. Ballas and Margaret Lusardi, "Hospital Readmission for Adult Acute Sickle Cell Painful Episodes: Frequency, Etiology, and Prognostic Significance," American Journal of Hematology 79, no. 1 (2005): 18

design, Adegbola et al (2012) and Matthie et al (2016) measured patients and their disease experience using semi-structured interviews. Adegbola et al. (2012) interviewed patients based on their experience living with pain;[39] while Matthie et al. (2016) performed life review interviews on past experiences.[40] These differences are significant because their research involves sickle cell patients and how their disease relates to seeking quality care from healthcare providers. In addition, the different methods show similar conclusions about the perception of sickle cell patients.

1.3.3. Sampling, Data Collection of the literature review

1.3.3.1. Sampling

In terms of pathology, hemoglobin SS (HbSS) appeared to be the most common hemoglobinapthy in all ten of the studies. Jenerette et al. (2014) and Ballas et al. (2013) carried out their research only using patients diagnosed with HbSS. However, eight studies in this literature review included sickle cell disease patients in with the following hemoglobinapathies: HbSS, HbSC, HbSS, Beta-Thalassemia or HbSS/a-thalassemia. Identifying different genotypes is important because healthcare professionals may judge a patient according to the patient's hemoglobin disorder and *not* according to their level of pain. HbSS is considered to be the most severe form of sickle cell disease as opposed to HbSC, HbSS Beta-Thalassemia or HbSS/a-thalassemia. Therefore, healthcare providers may not consider a patient with a milder form of sickle cell disease to be in as serious amount of pain as a patient with HbSS.

Porter et al. (2012), Haywood et al. (2010) had smaller samples of less than two hundred presented in one state. Brousseau et al. (2010), had the largest sample of 21, 112 patients and was the only study reviewed that examined various age groups: 1 to 9 years, 18-30 years, 31 to 45 years, 46 to 64 years, and 65 years and older.[41]

As part of the IMPORT study, Haywood et al (2014a) and Haywood et al (2014b) had similar samples of (n=291) and (n=273) and performed their study at an academic medical center.[42] I found treating sickle cell patients at an academic hospital to be important because it provides insight on patients who experience treatment from health-care professionals who are still in training and learning how to physically treat sickle cell patients.

Three studies Ballas et al. (2005) Jenerette et al. (2014) and Matthie et al. (2016) carried out their studies at sickle cell centers.[43] Jenerette et al. (2014) had a sample size of sixty-nine, while Matthie et al. (2016) had a sample size of twenty-nine. Ballas et al. (2005) had the largest

[39] Adegbola et al., 18

[40] Nadine Matthie et al., "Perceptions of Young Adults with Sickle Cell Disease concerning Their Disease Experience," Journal of Advanced Nursing 72, no. 6 (2015):,1444

[41] Brousseau et al., 1289

[42] Haywood et al: 1659; Haywood et al., 93

[43] Ballas et al., 19; Coretta M. Jenerette, Cheryl A. Brewer, and Kenneth I. Ataga, "Care Seeking for Pain in Young Adults with Sickle Cell Disease," Pain Management Nursing 15, no. 1 (2014):. 327; Matthie et al.,1445

sample of one-hundred and eighty-two patients.[44] Adegbola et al. (2012) performed their study at a national sickle cell support center[45]. The articles that used a qualitative method tended to be more detailed in providing more insight into patients' perceptions and interactions with healthcare providers.

1.3.3.2 Data Collection

Four studies collected data during a clinical visit. Jenerete et al. (2014) interviewed patients during one scheduled visit; while Matthie et al. (2016) conducted two session interviews from August 2010 to September 2012.[46] Haywood et al. (2014a) and Haywood et al. (2014b) recruited patients from the waiting rooms at a sickle cell clinic, informants participated in a completed comprehensive questionnaire administered by audio-computer assisted self-interviews.[47] Two studies, Porter et al. (2012) and Tanabe et al. (2007) collected data through a medical record review. Porter et al. (2014) interviewed patients between 7 and 14 days following their visit.[48] Tanabe et al. (2007) abstracted data through a structured medical review including the following variables: analgesic agent and dose, route, and time of administration of initial analgesic.[49] Ballas et al. (2005) collected data using a comprehensive database of patient discharge summaries.[50]

1.3.3.3. Demographics of literature review

Haywood et al. (2014b) is the only article that specifically reported on race and educational characteristics with a population of 97% African American patients and less than 64.9% of patients had a high school education.[51] Three studies; Adegbola et al. (2012), Ballas et al. (2005) Matthie et al. (2016), reported that all participants were African American.[52] Porter et al. (2012) had a sample of 98% African Americans, two informants in this sample were Hispanic while Tanabe et al. (2007) had a sample of 97% of African Americans with one participant who was Hispanic and the other participant was White.[53]

Three studies reported on the patients' educational levels. Haywood et al. (2010) reported that 36.8% of informants had a high school education.[54] Haywood et al. (2014b) reported that less than 64.9% of informants had a high school education, while Jenerette et al. (2015) noted that average education was a little more than high school (13.2) years.[55]

There were more females than males in eight of the studies. Tanabe et al. (2007) is the only article that reported 52% of participants as male.[56] Brousseua et al. (2010) did not report on any demographic characteristics.

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[44] Ballas et al.18
[45] Adegbola et al., 20
[46] Matthie et al. 4
[47] Haywood et al., 1668; Haywood et al. 936
[48] Porter et al. 450
[49] Tanabe et al. 420
[50] Ballas et al., 18
[51] Haywood et al., 937
[52] Adegbola et al., 19; Ballas et al., 18; Matthie et al., 1443
[53] Porter et al., 251; Tanabe et al. 451
[54] Haywood et al. 545
[55] Haywood et al., 1660Jenerette et al. 326
[56] Tanabe et al., 421

1.3.3.3. Data Analysis of literature Review:

Ballas et al. (2005) Tanabe et al, Porter et al Jenerette et al. (2014) entered data into a database.[57] However, Tanabe et al (2007) and Porter et al. (2012) used a Mann-Whitney U and Kruskal-Wallis tested to calculate pain management. Haywood et al. (2014a), Haywood et al (2014b) and Haywood et al. (2009) used a t-test and chi-square test to examine their study variables. Adegbola et al. (2012) and Matthie et al. (2016) Jenerette et al. (2015) instead used a thematic analysis to analyze and assess their data.

1.3.3.4 Results in the literature review

Two studies Brousseau et al. (2010) and Ballas et al. (2005) identified readmission in sickle cell patients to be common in adult patients due to recurrence of new acute episodes of pain.[58] Ballas et al. (2005) reported the admission was higher in males than female.[59] Brousseau et al. (2010) found patients who had private paying insurance showed to have lower rates of readmission.[60]

Four studies Adegbola et al. (2012) Haywood et al. (2009), Jenerette et al. (2015) and Matthie et al. (2014) reported that patients had negative experiences with healthcare providers due to mistrust.[61] Adegbola et al., (2012) reported when patients are in acute crisis, they find it difficult to communicate with their emergency department healthcare providers who were not their usual healthcare provider.[62] Adegbola et al. (2012) illustrates what Jenerette et al. (2015) also found, 55.7% of patients delayed seeking care because of how they have been treated by healthcare providers in the past.[63] Matthie et al. (2014) also concluded that patients experience with pain control from healthcare providers who specialized in sickle cell disease was sometimes not satisfactory and cause patients to delay seeking care.[64] Furthermore, Haywood et al. (2009) identified that patients who experienced less hospital utilization had lower education, were older in age and had lower house hold income.[65] This suggests that younger patients are perhaps more educated and more assertive in their expectations of what the appropriate standard of care should in fact be, whereas less educated patients seem to question the system less.

As part of the IMPORT study Haywood et al. (2014a) reported that patients are less likely to take advice from healthcare providers because they experience discrimination.[66] In addition to the IMPORT study, Haywood et al. (2014b) stated that disease-based discrimination appears to be more relevant than race-based discrimination, when patients are treated for sickle cell pain. "Age, greater emergency room utilization, having difficulty persuading providers about pain, were

[57] Ballas et al.21 Tanabe et al. 421;Jenerette et al.328; Porter et al. 451

[58]Ballas et al. 22; Brousseau et al., 1291

[59] Ballas et al 18

[60] Brousseau et al.

[61] Adegbola et al. 20;Haywood et al.,545; Jenerette et al.327; Matthie et al.1448

[62] Adegbola et al., 20

[63] Jenerette et al., 327

[64] Matthie et al., 1149

[65] Haywood et al.,545.

[66] Haywood et al. 937-938

independently associated with greater disease-base discrimination."[67] Despite sickle cell being common amongst African-Americans, no other study in the literature review discussed race in their results. In addition, Porter et al. (2012) is the only study that reported positive experience. Patients reported being treated with respect and trust when receiving treatment in the emergency department.[68] Conversely, Tanabe et al. (2007) reported that patients with sickle cell disease waited longer to be treated for pain in the emergency department.[69]

1.3.3.6 Interpretation of results in literature review

Similar analytical trends can be identified in the three studies that used qualitative analysis, Adegbola et al., (2012), Matthie et al.,(2016) Jenerette et al. (2014) report that patients are more inclined to manage their pain at home, because of past experience of being labeled drug seekers.[70] This thematic analysis provided more insight into the experience of patients' lives within the healthcare community and society. The studies that used a quantitative and qualitative measure provided a more detailed perception of patient's experience and treatment with healthcare providers.

The other studies, Tanabe et al., (2007) Broussuear et al., (2010) and Ballas et al.(2005) did not identify any common themes because the studies do not report how patients experience treatment. However, it provided reasons as to why patients need to receive care. Although these studies provided insight about sickle cell patients, they did not report on the experience of the patient which is why, Tanabe et al. (2007), Broussuear et al. (2010), and Ballas et al.(2005) could have been excluded from the literature review.

1.2.6.Conclusion and Recommendation of Literature Review

The eight studies in this literature review each conclude that further research needs to be conducted in order to improve quality of care for sickle cell patients. Tanabe et al. (2007) reported that their study on initial analgesics management for patients with acute episodes of pain was the first study in which they were aware.[71] Brousseau et al. (2010) reported their findings could be used to improve quality of care and reduce mortality in sickle cell disease patients. These authors conclude that studies in quality of care in sickle cell patients can improve patient outcome.[72]

Studies that focused on relationship and health-care providers recommend that communication between healthcare providers and sickle cell patients also need more attention. Haywood et al. (2014) declared interventions aimed at improving the interpersonal skills of medical providers and sickle cell patients is an important factor to consider.[73] Future research in this area could examine the transactional process of the actual interaction between healthcare providers and ED patients. [74]

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[67] Haywood et al, 1661
[68] Porter et al., 452
[69] Tanabe et al., 423
[70] Adegbola et al.21;Jenerette et al.,331; Matthie et al., 1450;
[71] Tanabe et al., 423
[72] Brousseau et al., 1294
[73] Haywood et al., 1660
[74] Porter et al., 454

Matthie et al. (2016) and Adegbola et al. (2012) further recommended that sickle cell patients require more support from their sickle cell community and health-care community. Matthie et al. (2016) recommended that pediatrics providers prepare adolescent sickle cell patients to transition to adult care.[75] Adegbola et al. (2012) reported that healthcare providers need more training since patients reported that the pain scale does not accurately measure their pain.[76]

Conclusion of Literature Review.

There is a limited amount of research available regarding the relationship between patient and healthcare provider and the experience of treatment. This literature review identifies that patients are not treated with empathy by healthcare providers. Nonetheless, patients delay seeking care because of past mistreatment by healthcare providers. These findings from the literature review will guide my research by not only helping to determine what methods have been established concerning patients experience by revealing how patients perceive mistreatment from healthcare providers.

2.0 Theoretical Framework.

The theoretical lens used to examine this thesis highlights he physician-patient relationship and four principles of bioethics adapted from Edmund D. Pellegrino. However, I will associate the four principles of ethics to be imperative to every healthcare provider treating sickle cell patients.

According to Pellegrino, the four basic principles of medical ethics are:

- "Autonomy is the personal rule of the self that is free from both controlling interference of others and from personal limitations that prevent meaningful choice. Therefore, health-care providers should respect the right of the patients."[77]
- "Beneficence is the action that is done for the benefit of others. Physicians should not cause harm to the patient."[78]
- "Non-Maleficence requires an intention to avoid needless harm or injury that can arise through acts of commissions or omission. Physicians should not neglect their patient for it can cause harm to the patient."[79]
- "Justice is the form of fairness of treatment"[80]

Autonomy, beneficence, maleficence and justice are principles that physicians must adhere to in order to provide a proper ethical treatment patient experience. Physicians are responsible for prescribing drugs and treating patients to the best of their knowledge. The healthcare provider's behavior can influence how sickle cell patients experience care. Pellegrino argues that, "The four principles should not be abandoned. Rather, they need to be redefined and grounded in the reality of doctor-patient relationship."[81]

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[75] Matthie et al., 1449
[76] Adegbola. et al., 1451.
[77] Pellegrino, 27
[78] Pellegrino, 28
[79] Pellegrino, 27
[80] Pellegrino, 15
[81] Pellegrino, 187

II. The Research Methodology

The methodology utilized for this research allowed me to analyze the experience of sickle cell patients receiving treatment from healthcare providers. I have conducted a comparative analysis to understand the experience of being a sickle cell patient.

3.1 Study Design

The study design used for this research is a mixed method research design that examine pre-existing quantitative or qualitative data.

3 Data Collection of the Data Sets

The subjects of my data sets includes male and female patients with any variant form of sickle cell disease. The sample of this study include data sets from various studies on sickle cell disease. The literature review in this thesis allowed me to choose data sets based on past research that has been conducted on sickle cell disease.

Lattimere et al. (2010) conducted a cohort study with adult sickle cell patients, when patients were admitted into the hospital for a pain crisis, they conducted brief interviews to assess their hospital experience. Bediako et al. (2016) developed a stigma scale then administered a 31-item of the MoSCS to a convenience sample of adults who sought care for pain at a clinical academic hospital. Maxwell et al. (1999) used a focus group discussion and semi structured interview to collect their data. Yusef et al. (2015) collected data from the National Hospital Ambulatory Surveys (NHAMCS) from 1999 to 2007. "The survey collects patients visits-related information from the national probability sample of the emergency department and outpatient visit to short-stay hospital."[82]

I chose these data sets because they explore the perception of sickle cell patients who are experiencing pain and receiving treatment from healthcare providers. I also chose these data sets because they have similar themes regrading patients experience in the emergency department, and experience with pain management. The themes I searched for regarding sickle cell disease and treatment included stigmatization and communication. The inclusion criteria of the data sets include data that highlights the sickle cell patients experience. The exclusion of these data sets include data that identifies the perception of healthcare provider treating sickle cell patients, and sickle cell caregivers.

Data collection consisted of employing data sets that examined the quality of care in sickle cell patients. These data sets include research conducted in Emergency Rooms with health-care providers that are not their primary healthcare physicians or primary hematologists.

I obtained my data sets by searching in the articles from my literature review, and also employing a general search in the Google search engine to find data that relates to my subject. I then went to Drew University Scholar search engine and Google Scholar to search for the studies that were mentioned in some of the references from the literature review. I tried to collect data sets that were more focused on the adult patient experience rather than the perceptions of children and healthcare providers. However, some data did not yield details about age.

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[82] Yusef et al, 2

3.5 Data Analysis

I used a closed content thematic analysis to analyze the data sets. Data sets used in this thesis were quantitative and qualitative. Datasets from multiple sources were analyzed to determine the experience of sickle cell patients being treated by healthcare providers. I placed data with similar themes together. Every data set was coded with a number.

3.6 Bias.

"Cultural bias is the phenomenon that involves of interpreting and judging phenomena by standards inherent to one's own culture."[83] A large percentage of the sickle cell population is significantly affected by African American population. Therefore, I chose data sets that included information on African American patients affected by sickle cell disease. From a phenomenological standpoint, I have experienced living with sickle cell disease which has framed my own interest in this study.

[83] dictionary

IV. Results

4.1 Background

The following tables identify the perception of sickle cell patients and their experience with pain and seeking treatment from healthcare providers. Four tables were used to represent information on sickle cell patients and their common symptoms, personal feeling about their disease, and relationship with healthcare providers and pain management. A detailed description was provided for each table to explain how it answers the research question or how the data benefits the study.

4.2.1 Reasons to see why hospital visits by sickle cell patients, 1999-2007

Table 1. identifies the common reason sickle cell patients seek care in the Emergency Department. Yusef et al. (2010) carried out a descriptive study on Emergency Department visits made by sickle cell patients. Data came from the National Hospital Ambulatory Care Surveys (NHACS) from 1999 to 2007. This survey was conducted by the CDC, National Center for Health Statistics. "At each hospital, trained staff collected information on patients' visits occurring during a randomly assigned 4 week reporting period."[84]Visits were calculated using an ICD-9-CM codes, and nationally weighed estimates were calculated. Analysis was conducted using an SAS, version 9.2. The estimated average annual number of emergency visits made by sickle cell patients was derived by dividing the weighted total of these visits by 9, the number of years of survey data's used.[85]Reasons for visits include: chest pain, other pain or unspecified pain, fever infection, shortness of breath, anemia and other. 11.1% of patients reported chest pain, 67.1% reported other pain or unspecified pain, 5.5% reported fever and infection, 4.8 reported shortness of breath, 49.8 reported anemia and 14.% reported other.

This table does not show any information on the patient's perceptions of treatment from healthcare providers; however, according to the data pain, is highest rate among reason for hospital visits.

[84] Yusef 2
[85] Yusef 3

Table 1. Reasons for hospital visits by sickle cell patients, 1999-2007

Patient-cited reasons for the visit by patients with SCD, 1999–2007 (% [SE] unless otherwise indicated)

Reason for visit	All visits	Visits by patients aged 0–19 years	Visits by patients aged ≥20 years	*p*-value*
Chest pain	11.1 (1.7)	**8.7 (2.7)**	12.0 (2.2)	0.357
Other pain or unspecified pain	67.2 (3.1)	62.1 (6.1)	69.1 (3.3)	0.276
Fever/infection	5.5 (1.4)	**16.4 (4.6)**	**1.4 (0.6)**	<0.001
Shortness of breath/breathing problem/cough	4.8 (1.0)	**8.1 (2.7)**	**3.5 (0.9)**	0.052
Anemia[a]	49.8 (2.8)	37.7 (5.1)	54.3 (3.1)	0.004
Other	14.0 (2.0)	27.9 (6.2)	8.8 (1.7)	0.001

Note: Estimates in boldface have a relative SE (RSE; SE/point estimate) of >30% and/or are based on <30 observations; estimates with an RSE of >30% do not meet standards of reliability or precision.

[a] Category includes sickle cell anemia.

* *p*-value for Rao–Scott chi-square test for % with characteristic among patients aged 0–19 years and those aged ≥20 years.

Source: Yusef et al., "Emergency Department Visits Made by Patients with Sickle Cell Disease."[86]

[86] Yusef et al. 11

4.3.1 How Sickle Cell Patients View their Disease

Table 2. identifies the level of stigma in sickle cell patients. Bediako et al. (2016) developed the measure of stigma scale (MoSCS) in a focus group on sickle cell disease patients and then a preliminary evaluation phase. Bediako et al. (2016) administered a 31 item version of the MoSCS a convenience sample of adults who sought care for sickle cell disease at a clinic with an academic hospital in Cincinnati, OH. All questionnaires were self-administered in the waiting are or in a consultation room of the clinic. This table compares the PCA of the MoSCS between the development sample of 70 and the present sample of 262. The 11 item questionnaire loaded measured social exclusion, internalized stigma, disclosure and expected discrimination.

The mean scores for social exclusion produced a score of 1.41 of a scale from 1-6. The three similar problems that were listed together were "People have physically backed away from me because I have sickle cell disease," "as a rule telling others I have SCD has been a mistake," "People seem to be afraid of me because I have sickle cell disease." These problems were grouped together because they address the perception of sickle cell patients and their social experience around people. If sickle cell patients feel a burdened to humanity this may impact the perception of sickle cell patients receiving treatment from healthcare providers.

Internalized stigma had a mean score of 1.53, the three categories included the following responses, "I feel guilty because I have sickle cell SCD," "in many areas of my life, having SCD makes me feel like I'm a bad person," "I feel, I am not as good as others because I have SCD." These categories represent how internalized stigma relates to the disclosure concerns. The three phrases that were grouped together included:

Disclosure concern has a mean score of 3.04."In many areas of my life no one knows I have sickle cell disease, I am very careful who I tell I have sickle cell disease, telling someone I have sickle cell disease is risky." These phrases were grouped together because they report how sickle cell patients are hesitant to discuss their disease with people.

Expected discrimination had a mean score of 1.62., the categories include people lose jobs when employers learn they have sickle cell disease, "I worry about people discriminating against me because I have sickle cell disease." These categories were grouped together because they report how sickle cell patients feel discriminated in their daily lives.

This data does not show any correlation with sickle cell patients involving treatment from healthcare providers, nor does it show their experience with pain. However, the data in this graph details how sickle cell patients perceive their disease to the general public. The numbers from this data suggest that sickle cell patients may be hypersensitive about their disease and generally view themselves as a burden. Because sickle cell patients view themselves as difficult, this may impact how the perceive being treated for pain when seeking treatment from healthcare providers.

Table 2: Comparisons of factor that measure sickle cell stigma

Table 1

Comparison of factor loadings of *MoSCS* items.[a]

	Social Exclusion		Internalized Stigma		Disclosure Concerns		Expected Discrimination	
	A	B	A	B	A	B	A	B
Cronbach's α (subscale)	.89	.80	.84	.78	.74	.79	.76	.79
People have physically backed away from me because I have SCD	.75	.68						
As a rule, telling others that I have SCD has been a mistake	.69	.59						
People seem to be afraid of me because I have SCD	.67	.75						
I feel guilty because I have SCD			.85	.77				
Having SCD makes me feel that I am a bad person			.81	.69				
I feel I am not as good as others because I have SCD			.79	.63				
In many areas of my life, no one knows that I have SCD					.76	.74		
I am very careful who I tell that I have SCD					.70	.80		
Telling someone I have SCD is risky					.53	.44		
People lose jobs when employers learn they have SCD							.84	.71
I worry about people discriminating against me because I have SCD							.79	.75

MoSCS: Measure of Sickle Cell Stigma; SCD: sickle cell disease.

[a]Column A: developmental study ($N = 70$); column B: present study ($N = 262$).

Source: Bediako et al. "The Measure of Sickle Cell Stigma: Initial finding from the Improving Patient Outcomes through Respect and Trust study"[87]

[87] Bediako et al., 16

4.3.1. Problematic Hospital Experience by Sickle Cell Patients

Table 3 identifies the problematic hospital experience by sickle cell patients from September 2006 to June 2007, Lattimer et al.(2010) conducted a cohort study of adults with sickle cell disease at an urban academic medical center in mid-Atlantic region. Informants participated in a brief interview when they were admitted for a pain crisis. Patients hospital experience were measured using a validated instrument, the Picker Patient Experience Questionnaire (PPE-15). A sample binomial test was used to compare the percentage of sickle cell patients to estimates from he published sample of 44,4493 U.S adults. A secondary analysis using the Kruskal-Wallis tests to determine which patient characteristics were associated with having greater number of problems. a binomial regression model was used to examine the correlation number of reported problems after adjusting the age and sex of the patient.

86% of patients reported that they were insufficiently involved in decisions about medical care. 64% of patients reported that hospital gave conflicting information. 61% of patients reported that they could not discuss their concerns with a medical staff. 58% reported that doctors answers was not clear. 56% percent reported that nurses answers to question was not clear. 53% reported that doctors did not always discuss patients fears and anxieties. 52% of patients reported that nurses did not always discuss fears and anxiety. 50% reported that they were not treated with respect and dignity and the staff did not do enough to control their pain. 37.2% of patients reported that family was not given enough information to help with recovery. 36% of patients reported that doctors sometimes talked as if they were not present. Sickle cell patients reported more problems than the national sample.

Table 3. report on patient's experience with communication g with healthcare providers and their involvement in making decisions about their care. The information from this table answers my research question about how patients perceive treatment from healthcare providers during a pain crisis.

Table 3. Problematic hospital experience by Sickle Cell Patients.

PATIENT-REPORTED PROBLEMS IN EXPERIENCE OF HOSPITAL QUALITY, SCD PATIENTS VS. U.S. POPULATIONS SAMPLE

	% US population sample reporting problem N=44,493	% SCD patients reporting problem N=45	p-value[a]
Doctors' answers to questions were not clear	23.9	57.8	.001★
Nurses' answers to questions were not clear	28.7	55.6	.001★
Doctors did not always discuss patients fears/anxieties	15.9	53.3	.001★
Nurses did not always discuss patients ears/anxieties	12.5	52.3	.001★
Doctors sometimes talked as if patients weren't there	23.6	35.6	.077
Not easy to find someone to discuss patients' concerns	36.9	61.4	.001★
Had insufficient involvement in decisions about care and treatment	32.4	86.4	.001★
Were not always being treated with respect and dignity	33.5	50.0	.025★
Staff gave conflicting information	17.9	64.4	.001★
Staff did not do enough to control pain	17.3	50.0	.001★
Family didn't get the opportunity to talk to a doctor	27.6	36.4	.236
Family was not given enough information to help with recovery	25.5	37.2	.082

[a] One-sample binomial tests to compare SCD patients with US population.

★ Indicates statistically significant difference from nationally reported percentages.

Source: Lattimer et al. "Problematic Hospital Experiences among Adult Sickle Cell Disease Patients"[88]

[88] Lattimer et al., 1118

4.4.1 Patients Reporting hospital concerns-raising behavior

Table 4 identifies the number of patients reporting hospital concerns-raising behaviors in Baltimore and London. Elander et al. (2011) collected data through patient interviews at clinical centers. The interview focused on pain management. In London the sample included 51 adult patients with a mean age of 34 years old.

In Baltimore the sample included 95 adult patients. The table shows the percentage of what patients reported. In Baltimore, 66% of patients reported disputes with staff, 31% reported suspected/accused of analgesic misuse. 9% reported using analgesics part from those prescribed. 32% reported tampering with analgesic delivery system, 49% reported self-discharge from the hospital, 79% reported one concerned raising behavior.

In London 39% of patients reported disputes with staff, 20% reported being accused of analgesic misuse, 9% reported using analgesic from those prescribed, 4% reported being accused of tampering with analgesic delivery system, 14% reported discharging themselves form the hospital, 79% reported at least one concerns- raising behavior. The overall rates and those for three of the five concern-raising behaviors were significantly higher in London.

Since patients reported that they have disputes with staff, the data in this table answers how patients perceive the treatment involving healthcare providers and pain management. This data also identifies

Table 4. Percentage of patients reporting hospital concern-raising behavior

Numbers of patients (%) reporting in-hospital concern-raising behaviors (CRBs) in Baltimore and London.

Concern-raising behavior	Baltimore, USA ($n = 91$)[a]	London, UK ($n = 51$)	p
Disputes with staff	60 (66%)	20 (39%)	0.002[b]
Suspected/accused of analgesic misuse	28 (31%)	10 (20%)	0.149[b]
Using analgesics apart from those prescribed	8 (9%)	2 (4%)	0.277[b]
Tampering with analgesic delivery systems	29 (32%)	2 (4%)	<0.001[b]
Self-discharge from hospital	44 (49%)	7 (14%)	<0.001[b]
At least one concern-raising behavior	72 (79%)	30 (59%)	0.01[b]
Mean (SD) CRBs per patient	1.85 (1.39)	0.80 (0.80)	<0.0001[c]

[a] Sample size less than 95 because of missing values for outcomes of interest.

[b] Chi-square tests.

[c] Independent groups t-test.

Source: Elander et al. "Respect, trust and the management of sickle cell disease pain in hospitals."[89]

[89] Elander et al., 16

V. Discussion

5.1 Meaning of the Results

The results of this study do not provide enough insight on the perception of sickle cell patients receiving treatment from healthcare providers, therefore: my results are inconclusive. However, the findings in Table 1. Identify that pain is a common symptom associated with sickle cell disease. Patients are more likely to seek treatment for pain from health care provider rather than other problematic symptoms.

Table 2. identifies four factors that appear to measure social exclusion, internalized stigma, disclosure concerns and expected discrimination. Overall, participants reported low to moderate levels of stigma, with mean values on a scale ranging from 1 to 6) 2.02 (SD=1.14) for social exclusion, 1.94. These results represent the psychosocial experience of people with sickle cell disease, and its impact on health related outcomes. However, these numbers do not identify the perception of sickle cell patients receiving treatment from healthcare providers, but identifies how patients perceive their disease experience in the general public. From the results one can conclude that sickle cell patients are hypersensitive and perceived themselves as being difficult. Patients with sickle cell disease are primed to be treated different to healthcare providers.

Table 3. identifies how sickle cell patients perceive their treatment from healthcare providers while seeking treatment in the hospital. According to the data in Table 3, six items were found to be the highest problematic experience out of 11 item questionnaire. Although sickle cell patients reported more problems than the national sample this data does not support that patients perceive negative treatment from healthcare providers and have issues with pain management.

Table 4. reported on concerning behaviors sickle cell patients experience with healthcare providers. Disputes with staff occurred at a higher rate; while, suspected accused of analgesics misuse, using analgesics apart from those prescribed and tampering with analgesics delivery systems self-discharge from hospital reported to be low percentages. However, out of the six items on the questionnaire, disputes with staff had the highest rating concerning behaviors. This data does not support that sickle cell experience negative treatment, have difficulty with pain management and experience long wait time.

5.2 Connections Between Literature and Results:

The results in this research did not provide enough evidence to correlates with the results in the literature review. The results in this research do not prove that sickle cell patients have negative experience with health care providers during a pain crisis or that they wait longer to receive treatment. The results in this research are not consisted with previous research where Adegbola et al. (2012) Haywood et al. (2009), Jenerette et al. (2015) and Matthie et al. (2014) reported that patients had negative experiences with healthcare providers due to mistrust.[90] poor communication and delay care seeking due to negative experiences. In this study, the results did not report patients to be labeled "drug addicts," when seeking treatment for pain. Adegbola et al., (2012), Matthie et al.,(2016) Jenerette et al. (2014) previously report that patients are more inclined to manage their pain at home, because of past experience of being labeled drug seekers.[91] The

[90] Adegbola et al. 20;Haywood et al.,545; Jenerette et al.327; Matthie et al.1448

[91] Adegbola et al.21;Jenerette et al.,331; Matthie et al., 1450;

literature review does not relate to the result in this study.

Table 2 reported that patients have issues with personal and social relationships and often feel ashamed about their disease and telling other people about their disease. it may be interpreted that patients are hypersensitive about their disease and patients perceive themselves as difficult. Informants reported low to moderate level of stigma and discrimination from the public. One possible reason the results do not correlate with the previous research may be due to small sample, there were not enough data that examined the patient's perception for the results to be generalizable.

5.4 Understanding the Results via the Theoretical Framework

5.4.1 The Bioethical Framework

Autonomy

Pellegrino. 2008 asserts that, "Respect for autonomy seeks to balance the enormous power of expert knowledge which figures so prominently in private and public decisions in industrialized and technological oriented societies. Autonomy calls for protection of the moral and personal values of each individual and thus, of the integrity of the person."[92] Entwistle et al.2010 argues, "The principle of respect of autonomy is usually associated with allowing or enabling patients to make their own decisions about which healthcare interventions they will or will not receive."[93] Considering the negative attitudes sickle cell patients have for themselves, it is important for them to be involved in making decisions about the care they receive.

Beneficence and non-maleficence

"Beneficence and its corollary, non-maleficence, require acting to advance the patients interests, or at least not harming them." There is a lack of beneficence if the healthcare provider is not engaging in benefitting the patient. Gillon 2003. State "Beneficence and non-maleficence to other autonomous agents both require resect for the autonomy. Although there is some general norms of human needs, benefits and norms, people vary in their individual perceptions and evaluations of their own needs, benefits and harms.[94] In order to benefit the patient, the patient must be allowed to make their own decisions about treatment.

Justice

Justice is fairness in treatment. Pellegrino state, Societies and institutions must establish mechanisms, with only minimal recourse to law, for unilateral discontinuance of the relationship when either patient or physician feels personal integrity is being compromised."[95]

The four principle of ethics are important because it helps healthcare providers avoid two polar dangers, moral realism—any ethics will do—and moral imperialism—this is the one and only correct way of employing ethics." The findings for this research does not support the theoretical framework because the data does not show evidence of healthcare providers disrespecting and harming sickle cell patients. However, the findings support that pain and other

[92] Pellegrino 189
[93] Vikki A Wntise et al. supporting patient autonomy
[94] Gillion, 2008
[95] Pellegrino, 225

specified pain is common among sickle cell patients. Pain is an important concept to consider when healthcare providers are treating sickle cell patients, because pain is a subjective experience. Cole 2002 states:

> "Because pain is experienced in the mind and requires the interpersonal bodily sensations, there is a psychological overlay with most pain experiences…To understand fully the relationship between nociception and the psychological effect of acute and chronic pain, practitioner must have recognized emotional distress as a cause of pain (in addition to nociception) and understand the psychological mechanisms do intensify pain perception."[96]

Healthcare providers may not consider pain to be life threatening, and therefore sickle cell patients may perceive their disease experience as difficult. Previously, Adegbola et al. 2013, reported that numeric pain rating scales were not useful for treating SCD acute pain, did not report the magnitude of pain experienced and resulted in the prescription of insufficient medication.[97] Tanabe et al. 2007. confirmed that patients waited an average of 45 minutes longer before receiving their first analgesic when compared with patients assigned a higher triage priority, despite pain score being equal.[98] The findings in this research did not prove that sickle cell patients wait longer to receive pain medication and did not report issues with the pain scale. However, "the obligation to respect ones' autonomy is important when practicing medicine because, pain especially chronic pain, may be particularly frustrating for doctors and nurses"[99] Considering that sickle cell patients are hypersensitive, it is important for them to make their own decisions when seeking treatment for pain to promote their autonomy.

[96] Cole. 200w, 26
[97] Adegbol et al. 2013
[98] Tanabe et al 423
[99] Eric L. Diamond and Ken Grauer, "The Physician's Reactions to Patients with Chronic Pain," American Family Physician 34, no. 3 (1986): 18.

VI. Conclusion:

6.1 Introduction

"SCD patients experience many problems with the interpersonal quality of their care from healthcare providers, and these problems have an impact on the trust that SCD patients have in the medical profession."[100] The results in this study, did not prove that patients are mistreated by healthcare professionals. However, according to their disease experience, patients are hypersensitive and primed to view themselves as difficult.

Thomas et al. 2002, stated "the degree to which individuals experience positive feelings about their present, past and future situation are important aspects of the psychological domain in measures of quality of life.[101]Cole 2002, state, "No single therapeutic approach manages all types of pain for all types of patients under all clinical circumstances. The various options for treatment must be considered every time a physician attempts to control pain." It is important for the patient to be involved in shared decision making when seeking treatment for pain from healthcare providers.

5.3The Sickle Cell Treatment Act of 2003: The Law's Provisions and Opportunity for Advocacy Policy Brief

The Sickle cell Treatment Act (SCTA) provides an important opportunity to work with federal policies that will ultimately lead to improved care and health outcomes for those living with sickle cell disease (SCD)."[102] "The SCTA was the first major legislative initiative in more than 30 years focused on SCD."[103]

The provision of the sickle cell treatment act of 2003 include:

1. "Creating a new, optical Medicaid benefits that explicitly allows stares to increase reimbursement for SCD treatment including chronic blood transfusion and stroke prevention, in addition to adding generic counseling and testing as reimbursable services."[104]
2. "Making available Medicaid reimbursements (at 50 percent federal administrative

[100] Haywood et al. 1660
[101] Thomas et al 358
[102] The Sickle Cell Treatment Act 2003, issue brief, SCDAA, Community Catalyst, August 2012, , accessed July 4, 2018, https://www.communitycatalyst.org/doc-store/publications/SCTA-Paper-FINAL-1.pdf. P. 1

[103] The Sickle Cell Treatment Act 2003, issue brief, SCDAA, Community Catalyst, August 2012, , accessed July 4, 2018, https://www.communitycatalyst.org/doc-store/publications/SCTA-Paper-FINAL-1.pdf. 2

[104] The Sickle Cell Treatment Act 2003, issue brief, SCDAA, Community Catalyst, August 2012, , accessed July 4, 2018, https://www.communitycatalyst.org/doc-store/publications/SCTA-Paper-FINAL-1.pdf. 2

matching rate) for public education campaign activities specifically related to SCD."[105]

3. "Authorizing the Sickle Cell Disease Treatment Demonstration Program to improve access to service for those with SCD in addition to improving and expanding patient and provider education around SCD."[106]

This regulation was put into place to improve quality of care in sickle cell patients, and to spread awareness of sickle cell disease. This regulation addresses the issue to improve the quality of care in sickle cell patients.

6.2 Recommendations

Findings from this research suggest that researchers should indeed conduct more research on how sickle cell patients perceive and understand their disease and experience with pain. "It may also be useful to develop mentoring relationships between middle aged/older adults with sickle cell disease who are successfully aging and young adults as they transition to provide social support in addition to knowledge of living with sickle cell disease."[107] "Information gained from learning about an individual's pain experiences can support a specific, personalized approach from improving care and can minimize the risk for popular health outcomes."[108] Sickle cell disease based organizations should also hold support groups to help patients cope with their disease experience.

6.3 Limitations of the Study

Having only observed sickle cell patients, I can only discuss the patients' perceptions. Since all measures in this research were based on secondary data sets involving a small sample size it is still difficult to determine the perception of sickle cell patients and their healthcare experience. Furthermore, Table 3, and Table 4 are the only samples that answered the research questions about experience with healthcare providers and pain management? Table 1. And Table 2, did not meet my objectives. Table 1. Provided information of common symptoms sickle cell patients seek treatment for, and Table 2. identified how sickle cell patients feel about their disease and how it affects their social lives. However, the information provided from Table 1. and Table 2. offered ideas for further potential research centered on the social behaviors of sickle cell patients Further research should explore the perception of sickle cell patients and their disease experience with pain.

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[105] The Sickle Cell Treatment Act 2003, issue brief, SCDAA, Community Catalyst, August 2012, , accessed July 4, 2018, https://www.communitycatalyst.org/doc-store/publications/SCTA-Paper-FINAL-1.pdf. 2

[106] The Sickle Cell Treatment Act 2003, issue brief, SCDAA, Community Catalyst, August 2012, , accessed July 4, 2018, https://www.communitycatalyst.org/doc-store/publications/SCTA-Paper-FINAL-1.pdf.

[107] Matthie et al. 12

[108] Adegbola et al 11

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