

Discrimination in healthcare with chronic pain and sickle cell management



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“ Sickle cell disease is a complex genetic disorder that compromises multiple genotypes” (Conran, N., Franco-Penteado, CF., et al, 2009). Sickle cell disease affects 70 % of people of African American descent. Sickle cell consists of, repeated cycles of red blood cells sickling which leads to hemolysis and anemia. Along with Multicellular adhesions which involve red and white blood cells and platelets which causes Sickle, of the vessel walls. These cells then cause vaso occlusion that leads to chronic vascular damage, which often begins in early childhood. All of which over time due to genetics causes chronic pain in the individual and can become fatal.

Discrimination in healthcare patients with chronic pain related to sickle cell disease and Pain Management during exacerbations is a topic of much discussion. Throughout the U. S. and internationally. The individuals with sickle cell disease are discriminated against during exacerbations and frequent emergency room visits. These patients when they have episodes of exacerbation can be in severe pain and need hospitalization to gain pain control. This is a topic of interest to me because I can have a child with sickle cell. My son that experiences these exacerbations frequently and has had them over the past 30 years. I have dealt with discrimination toward my own child for treatment of sickle cell disease pain. Related to his chronic pain episodes and exacerbation. I have also worked in many settings with patients that suffer from sickle cell disease, many of these patients describe the pain as a neurologic pain in the joints and muscles like fibromyalgia pain, with a deep burning sensation and continued aching. When presented with episodes of exacerbation and chronic pain frequent emergent acute ER visits are necessary.

However, there have been several studies related to discrimination in emergency rooms for patients with chronic pain related to sickle cell. In this paper, I intend to enlighten the reader on the biases and the discriminatory facts of how Sickle Cell patients are treated during acute and chronic episodes of pain management in healthcare settings. Along with how sickle cell affects the family as a unit.

Keywords: Sickle cell (SCD), exasperations, Sickler, pain, acute, Emergency rooms (ER)

In describing this current health issue existing in the United States, I will begin with a study that was done among the Emergency Room Physicians which used the term Sickler in association with negative attitudes toward people with sickle cell disease (Glasberg, J., Tanabe, P., et al., 2013). In the study, medical practitioners would refer to adults and children with a diagnosis of sickle cell disease as Sickler's. There was a survey conducted in 2011 in which a hypothesis was tested to find out if providers had negative attitudes towards people with sickle cell disease, an acute Sickle Cell Pain. Several members that analyzed the data believed that the results of the Physicians involved we're not treating these patients as people. Moreover, the physicians we're providing them with low-quality care. Some felt that the term " Sickler" was used out of ignorance and without malice. Like CF (cystic fibrosis patients). Which had no association with the pain management of sickle cell disease patients? However, after the survey which contains 33 items was developed. There was found to be a statistically significant relationship between physician with negative attitudes towards individuals with sickle cell disease that use the term Sickler was found that providers <https://assignbuster.com/discrimination-in-healthcare-with-chronic-pain-and-sickle-cell-management/>

and less positive attitudes about these individuals. Adherence to evidence-based guidelines for acute care in the emergency departments. More than 9% of the participants indicated that they were “willing to re-dose opioids within 30 minutes for inadequate analgesia” (Glasberg, J, Tanabe, P, et al, 2013). For those that use the term Sickler for the Sickle Cell patients were 12% less likely to do redosing of opioids at a rate of . 88 % with a 95% confidence interval, which indicates that amongst the Physicians who frequently use the term Sickler over 70% of them were within this guideline that provided low quality pain management and care. To the patient with sickle cell exacerbation “These findings shed light on the common physician behavior that might be problematic during the widespread patient perspective that the term is despairing for this population of people” (Glasberg, J, Tanabe, P, et al, 2013).

Another Source of research on individuals with sickle cell disease which have experience discrimination and miss out on needed pain treatment. Was an article that was in the Science Daily, that presented information that because of discrimination of the race and health condition for sickle cell patients people Trust their Health Care Professionals less. Therefore, they don't follow the physicians' plan of care. All this can be related to mistrust of the provider's plan of care. “Often sickle cell patients do not follow the doctor's orders related to trust issues” according to, John Hopkins School of Medicine by Springer.

The incidence and the prevalence of the issue and problem among populations of African Americans with sickle cell disease have been ongoing and repeated patterns of care over Geographic areas. Rural and urban areas <https://assignbuster.com/discrimination-in-healthcare-with-chronic-pain-and-sickle-cell-management/>

and the utilization of services of people in Alabama with sickle cell disease. Another article that I reviewed was a study Article on the differences of access and utilization of services among people in Alabama. This study examined the relationship between socioeconomic factors and geographic distribution of sickle cell disease in Alabama between 1999 and 2001 of individuals which lived in urban and rural areas. Services for sickle cell disease for those living in rural and urban areas reported higher limited services for rural clients than Urban clients. This is related more to access to implications and available programs rather than health care neglect at the community level. The primary focus of the study was to answer the research question of: “What is the relationship between urban-rural disparities for individuals with sickle cell disease in Alabama, and also the difference in social economic Community distress health status, including physical functioning, medical problems and access to utilization of the Human and Health Services” (Telfair. J, Haque, A. et al, 1974)? Realizing the burden of the blacks in Alabama, live below the poverty level, have decreased available resources and episodic interventions with providers. Often the providers are not familiar with the patient. Have little health history information. Also, most of the individuals with sickle cell disease. In Alabama 88% are children under the age of 18 which are served by these Physicians. Many of the African American citizens living in rural counties and do not have regular access to clinicians, multidisciplinary teams, or regular providers. There are seven community-based Centers funded by the state of Alabama of the sickle cell disease Association of Alabama Incorporated. These community-based

centers provide several types of services for children and adults. Although these services are available to the black's access to insurance and finances are limited. Therefore, with many of these services that are included, sickle cell disease screening, education, counseling, and social support, along with psychosocial Management Services they are not being accessed.

However, with more of an attempt to have working relationships with these groups of minorities, and to better serve them increased exacerbation of sickle-cell episodes cause utilization of acute emergency room service in this geographical location. Although there is a wide disparity of socioeconomic conditions. The findings that the income in the urban areas considered midrange is 21, 600 compared to the rural area's income of 19, 001. This showed that the education level in urban areas reflected the educational background for rural areas. These statistics reveal a disparity in socioeconomic conditions between the two, " highlighting that SCD clients are worse off for health care services than their counterparts" (Tefar. J, Estienne. M, et al, 2003). For the healthcare disparities in the state of Alabama includes the number of individuals with sickle cell disease which is not only a family problem but a population problem. This population with low educational backgrounds poverty level incomes and the use decreased access to healthcare all play a role in the disparities for these people. Often starting employment at an early age to help supplement family income causes distress for not only the population but the families of the area in comparison to the social economic status among blacks with sickle cell disease. Also, with a Lower understanding of preventive medicine and

measures to reduce exacerbation encounter with the health care system of clients with a sickle cell in this population areas.

The descriptive study of 1999-2007 published by the Elsevier Inc. On behalf of the American journal of preventive medicine, presented emergency departments visits made by patients with SCD. This study displayed the number of encounters related to visits to the emergency departments that occurred each year from 1999-2007. " An estimated 197, 333 visits happened each year of patients with SCD" (Yusuf, H. Atash, H. et al, 2010)

The primary symptoms of the visits included, but were not limited to chest pain, unspecified pain, breathing problems, SOB, fever, infection, and many other reasons all were SCD patients. The most common symptom was a pain. Although in conclusion, substantial numbers of individuals with sickle cell disease utilize the ER rather than the clinic for Primary care. Patients with SCD make 2 to 6 times more visits to ER yearly. Mainly for pain management, an onset of infection and chest pain. These patients were labeled in the study as black or African American. Also, it was found that SCD patients utilize the use of ER as a major mode of health care. Therefore, one can see where providers would feel that the need for pain analgesics was being abused.

The CDC states: " Sickle cell-related death among Black or African-American children younger than 4 years of age fell by 42% from 1999 through 2002. This drop coincided with the introduction in 2000 of a vaccine that protects against invasive pneumococcal disease. The mortality rate for 1999-2002 decreased by 68% (95% confidence interval [CI]= 58% to 75%) at age 0 to 3 years, by 39% (95% CI= 16% to 56%) For the most recent period studied, a <https://assignbuster.com/discrimination-in-healthcare-with-chronic-pain-and-sickle-cell-management/>

significant (42%) reduction in mortality at age 0 to 3 years was seen between 1995-1998 and 1999-2002, with essentially no reduction in SCD mortality at older ages” (Yanni E, Grosse SD, et al., 2008). This data is supported by many sources and studies of geographic location.

“ Healthy People 2020 defines health equity as the “ attainment of the highest level of health for all people” (HEALTHY PEOPLE 2020). In patients with sickle cell disease they are the minority group which frequently have decreased resources to health care as related to insurance ignorance and cognitive inability to understand. Often then these individuals need help they seek one-time resources. The goal of the healthy people 2020 is to have adequate housing that increases the probability the individuals no matter of race or ethnicity will have the ability to exercise and eat healthy access health care and broaden the continuum across the board. Better childhood education and clean water in the environment. All this will provide a means for better health equality and less health disparity in general. As a goal for individuals with SCD, there needs to be more accessible generalized ensuring cultural competence among health care providers and improving health literacy among patients.

Health care disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status, gender, cognitive, racial identity; geographic location; or other characteristics linked to discrimination or exclusion. All of this causes discrimination toward specific groups of people. This current health problem of discrimination of SCD patients and pain management is of importance to the nurse because the nurse has the <https://assignbuster.com/discrimination-in-healthcare-with-chronic-pain-and-sickle-cell-management/>

first encounter with these individuals. Usually the client is in an acute phase of the pain and is not rationale. Very upset and eager to feel better, Rude and non-compliant. The patient needs to feel better and the nurse is attempting to access the patient needs. According to: J Natl Black Nurses Assoc. (2012).

“ Pain related to SCD is especially challenging because it is unpredictable and reflects qualities that are both nociceptive and neuropathic. K., 2011; Wilkie et al., 2010). “ SCD pain can be acute (also called crisis), chronic (with unknown etiology or known etiology, and necrosis), or both acute and chronic at the same time”. Acute pain combined with chronic pain is also called mixed pain SCD pain is all encompassing and negatively impacts the patient’s quality of life”(Ballas, k., 2011). Therefore, the nurses, often are apprehensive about their pain management needs with the SCD patient. Although most nurses are an escape for their shortcomings. Most nurses are compassionate and willing to access and meet the needs of the patient. However, the nurse is also limited to only the orders the providers give. These nurses often are apprehensive about their pain management needs. That apprehension about the validity of pain often continues during inpatient admission.

Opioid analgesics have a significant role in pain management of SCD disease. In the case of SCD, Solomon,(2010), found that opioid administration often was not in compliance with recommendations. Nurses are responsible for communicating ongoing patient needs to other members of the healthcare team. “ Nurses have a significant role to improve the pain

management experience of individuals with SCD, patient advocate and educator” (McCaffery & Pasero, 1999).

Ethical principles and concepts involved in SCD as a family health issue are ethical choices, both minor and major, every day in the health care for persons living multicultural society. In the patients with SCD, we can we find moral action and confusion or conflict about what ought to be done to aid them in their moral dignity related to their disease. Across many different health care resources SCD is thought to be an unmanaged genetic cultural disease. Due to the many variables that exist in the clinical cases of SCD. There are several ethical principles that seem to be applicable in this situation. The principles include Autonomy which is the patient should be respected and allowed to make decisions on an about his/her care. Patient also, has the right to accept or decline intervention of care according to Ballas, (2001). The health care team has an obligation to provide the patient with advocacy. All patients Have the right to ethical justice to be treated fairly and with equality. There is a difference in equality and equitability. Equality is equal for each person and equability is steady or even for all uniformity. For patients with acute exacerbation of SCD often their ethical needs are not met. The thought of the health care professionals is that one that they SCD patients are drug seekers and addicts. These patients are the most misunderstood group of individuals.

An article was done on Opioid drug epidemic and SCD: guilt by association: in the article it describes how the CDC related death and overdose of opioids to patients with SCD. in 2008 14, 795 persons died of opioid related to self-medicating the pain of SCD only ten were reported. However, this has been <https://assignbuster.com/discrimination-in-healthcare-with-chronic-pain-and-sickle-cell-management/>

increasing and the trend has not changed since 1999. Moreover in 2013, ninety five patients died due to drug overdose with sickle cell disease (Ruta, J I.& Ballas S. K. , 2016). Pain relievers are often prescribed for SCD pain and are abused this is a known factor. However, how does one decide when the pain relievers are not being used properly. Since this review the American association of medicine and other government agencies have brainstormed ways to better tracking narcotics provide patient with opioid needed for pain management. The institution of pain clinics has grown in the U. S. and this has cut down on the frequent prescribing of opioids for pain management. “ The current national opioid phobia may, unwittingly deny patients who really need them, especially those who experience recurrent episodes of acute pain such as patients with sickle cell disease” (Ballas, S. K. , 2016).

The way ethical practices could be implemented into the nurse role to promote advocacy for these patients. This would be a knowledge of their needs on behalf of the family and the individual. Encouraging the family and the patient to “ speak their own voice” (Kaakinen 2018, p 18). The nurse will consult the family and provide education on family centered care like support and self-care management of chronic disease (SCD). The nurse as an advocate can aid the family in problem solving and facilitate guidance to resources to cope with long term literacy.

A nurse can collaborate care for the patient and the family by providing information to the Interdisciplinary team. “ Connecting the family to organizations that work with their chronic health issues. Sickle cell disease is a chronic, complex syndrome that requires a multidisciplinary approach for patients to receive the best care possible” (Mandell, E., 2000 p. 1) Many of <https://assignbuster.com/discrimination-in-healthcare-with-chronic-pain-and-sickle-cell-management/>

these patients have frequent, encounters with healthcare system and often it's impossible, to coordinate their care. By using a holistic approach to patient care, nurses, and other team members can help to collaborate patient/family care coordination. Collaborating with other disciplines honoring and respecting their way of life and experiences.

Assisting family and patient to problem solve, presenting the family with measures to decrease emergency room visits, Allowing the family and patient to build on their experiences, knowledge of the disease, also, incorporating healthy lifestyle changes such as diet and exercise will allow the sickle cell patient and family to have better health outcomes. This is how the family nurse can collaborate the care of this family unit and provide better health outcomes.

Preventive care is a part the educating patients and their families to recognize the signs and symptoms of acute or life-threatening complications of sickle cell disease. When the nurse helps to design a plan of collaboration of care. The nurse needs to involve all sources of support for the patient because it takes several to provide and develop a plan of care for the patient.

The nurse can reduce health disparities and social justice for the patients with using the 2015 ANA revised eight set of standards of the professional nurse. These include the following Planning, assessment, implementation, outcome identification, coordination of care, health teaching and promotion of care, ethics and culturally congruent practice. “ By implementing these Standard nurses will RAISE the bar... and make important contributions

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toward reducing racial and ethnic disparities in both health outcomes and healthcare services” (Marion. L, 2015, P 19). Nurses increasingly serve as role models for clinicians, providers, and consumers. According to; Marion, (2013) “ Cultural congruence is part of nurses competencies because of this nurse will RAISE the bar and make important contributions toward reducing racial and ethnic disparities in both health outcomes and healthcare services”. Often, Segregation and/or social isolation, language barriers or cultural health behaviors, environmental factors socioeconomic status, and access to care and health insurance, are all problem the nurse will come upon. These are known causes of direct and indirect discrimination by the healthcare systems. To decrease these effects on the patient population the nurse must be knowledgeable on the need to provide the patients with the access to these resources to implement the plan of care. Studies have shown that the health care disparities and social justice would be a benefit for blacks and Hispanics if they were able to access a regular source of care and their insurance was that as compatible to whites. This too would decrease health care disparities. There has been changes in the system of health promotion policies over the past few years. According to; (Kaakinen, J. et al, 2018) “ However, much more education is needed for the health care professionals and changes to social policies to avoid growing disparities”.

In conclusion sickle cell disease is a genetic blood disorder. And the red, white blood cells and platelets are affected the disease causes the patient severe pain and episodes of exacerbations which cause them frequent visits to emergency departments. These people often seek analgesic pain medications for relief. The disease affects an African American group of

people with poor insurance and finances. Often the individuals are discriminated against related to their decreased preventive care and reduced education on ways to manage their care. The physicians provide low quality care to these patients. There have been proven studies to this effect. In working as a nurse in different settings clinics, hospitals and homecare these individuals deserve the same degree of compassionate care as the patient with an acute ER visit for any other reason. The families of these patients are not always knowledgeable about the facts of the patient disease and need guidance to receive the best possible outcomes for their family as a unit. The nurse as an advocate, educator and facilitator can help the family to collaborate with the interdisciplinary teams to produce a plan of care to assist the family to have resources available to utilize when episodic events occur. This will give the patient and his /her family a plan of care to implement interventions and Reduce the need for emergent care. This paper was directed toward the health care disparities the cultural bias that SCD patients endure with exacerbations of their disease. Poor insurance. minimal care, stereotypes, trust issues, decreased finances, low level education about the disease and more.

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