**Title: The Spot Check Methodology**

**Research Project Proposal:Improving Patient Engagement and Experience: The Solution to Health Inequities for Individuals with Sickle Cell Disease**

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**Project Description: Background**

The causative mutation in SCD primarily arose on the African continent because of the protective effect of the carrier state against malaria, so most patients with SCD have a shared African ancestry. Although SCD is a global disorder affecting people of all races, in the United States, as a direct result of the transatlantic slave trade, nearly all patients with SCD are Black. This fact would be mere medical trivia if we did not live in such a highly racialized society.

 Unfortunately, the social construct of race in America requires the majority of patients with SCD not only to face the consequences of a serious health condition, but also to navigate a society in which the color of their skin is often an unfair disadvantage. In addition, the absolute need to eliminate the words “Drug Seekers”.

MYTH: Sickle Cell Patients have a higher degree of drug addiction than the general population. The data regarding opioid addiction in patients with sickle cell disease provides less evidence for addiction than popular opinion would suggest.

FACT: The data regarding opioid addiction in patients with sickle cell disease provides less evidence for addiction than popular opinion would suggest. Prevalence estimates for opioid addiction among patients with sickle cell disease range from 0.5% to 8% vs 3% to 16% in patients with other chronic pain syndromes, and in the general population • Behaviors often described in patients with sickle cell disease, such as requesting a specific dose of opioid or requesting that the opioid be administered intravenously, may be normative in patients who have experienced a history of under treatment of pain.

 Spot Check Methodology

The aim of the project is to:

·        Demonstrate that applying the Spot Check Methodology to patient and clinical staff will result in a non-judgmental unbiased patient engagement for patients with SCD and will improve communication, collaboration, and health outcomes.

·        Knowing who the individual patient is and not the perception of who the individual is will decrease ED visits, readmissions, compliance, health outcome and increase patient trust.

·        Delivery of innovative and sustainable solutions, inclusive of cultural competency for individuals with Sickle Cell Disease, as they are one of the most vulnerable populations.

·   Demonstrate the importance of patients’ voices and how they can provide insight for helping improve the patient experience such as in the ED, In-patient, and Ambulatory Care settings.

**Research Methodology**

·        Collaborate with a hospital with a significant Black Population in the application of the Spot Check Methodology

·         Obtain data on readmissions, HCAHPS scores, Leapfrog scores

·    Staff survey on the population served. Purpose is to determine the perception vs. reality of the population served.

· Application of the Spot Check Methodology to be given to      patients and physicians simultaneously

· To obtain a better understanding of individual patients with SCD,  patients will answer the following questions:

1.Who am I as an individual?

2. What are my fears?

3. What's important to me?

4. Where am I in the acceptance of my diagnosis?

**Purpose of the questions:** When an individual, family member or a mother who just gave birth to a beautiful son or daughter and is given an unexpected diagnosis that could be life threatening, there is no preparation for coping with a non-negotiable disease. There is confusion, fear and not having a coping mechanism. The questions are designed to help patients identify who they are, their fears, what is important and their acceptance of the diagnosis. Equally important is to share the information with their healthcare providers.

**Instructions for the clinical team in the ED, In-patient and Ambulatory care settings.**

Refer to the Spot Check methodology when having a conversation with patients and address the issues in the methodology. Speak to patients and families, Pacify Patient fears, and identify what is important to the individual as patients with SCD are generally not a part of this type of conversation doctors have with these particular patients.

 Address who is the individual comprehensively in the social history and not just in terms of the common language: no toxic substance, nondrinker, nonsmoker, drug seeker.

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| --- | --- |
| Speak to patient/family to understand who is the individual | Who is the individual Married/Single/Separated/ Divorced; Mother/Wife/Grandma/Widower; Father/Husband/Grandfather/Widower;Higher Ed/ High School Ed; Employment.Place of Birth; Family Origin; South/North; East/West Coasts; English-speaking, non-English, limited English, bi/multilingual.      Belief System |
| Pacify fear factors if  possible | What are the fear factors that keep the individual up at night?(i.e. Am I going to die?Will the treatment make me feel worse?Can I have a normal life?Is this my fault? Did God do this to me?) |
| Outline what is important to the individual | Family, Work, Character, Religion/Culture/Ethnicity, Finance, Health, Fun & Recreation, Privacy, Dignity & Respect, Choices |
| Take into consideration the time it takes an individual to accept the disease | Where is the individual in the acceptance of the disease? Are they in denial and how do we as health professionals put forth a plan to help the individual in the acceptance of the disease?                                     © 2019 Mauvareen BeverleyMD                                                                                                                                                                        |

**Study Design**

A retrospective analysis of the medical records for all patients seen in the emergency room from January 2019 to current will be reviewed. A cohort of patients will be identified and contacted with approval to be a part of the study.

**Expected Outcomes**

· Elimination of Conscious and unconscious bias towards patients with SCD

· Assess the sustainability of decreased ED visits, readmission kept appointments, and better health outcomes

· Assess improvement in  HCAHPS scores.

·  Increase patient and physician collaboration.

·       Increase Trust by patients of the hospital and clinical teams

·     Elimination of the word Drug Seeker

·     A more comprehensive Social History applied

 **Association of Racial Bias With Burnout Among Resident Physicians**[Liselotte Dyrbye, MD, MHPE1](https://jamanetwork.com/searchresults?author=Liselotte+Dyrbye&q=Liselotte+Dyrbye); [Jeph Herrin, PhD2](https://jamanetwork.com/searchresults?author=Jeph+Herrin&q=Jeph+Herrin); [Colin P. West, MD, PhD3](https://jamanetwork.com/searchresults?author=Colin+P.+West&q=Colin+P.+West); et al[Natalie M. Wittlin, MS4](https://jamanetwork.com/searchresults?author=Natalie+M.+Wittlin&q=Natalie+M.+Wittlin); [John F. Dovidio, PhD4](https://jamanetwork.com/searchresults?author=John+F.+Dovidio&q=John+F.+Dovidio); [Rachel Hardeman, PhD5](https://jamanetwork.com/searchresults?author=Rachel+Hardeman&q=Rachel+Hardeman); [Sara Emily Burke, PhD6](https://jamanetwork.com/searchresults?author=Sara+Emily+Burke&q=Sara+Emily+Burke); [Sean Phelan, PhD, MPH7](https://jamanetwork.com/searchresults?author=Sean+Phelan&q=Sean+Phelan); [Ivuoma Ngozi Onyeador, MA, PhD4](https://jamanetwork.com/searchresults?author=Ivuoma+Ngozi+Onyeador&q=Ivuoma+Ngozi+Onyeador); [Brooke Cunningham, MD, PhD8](https://jamanetwork.com/searchresults?author=Brooke+Cunningham&q=Brooke+Cunningham); [Michelle van Ryn, PhD, MPH9](https://jamanetwork.com/searchresults?author=Michelle+van+Ryn&q=Michelle+van+Ryn)

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When Actions Speak Louder Than Words — Racism and Sickle Cell Disease

 Alexandra Power-Hays, M.D., and Patrick T. McGann, M.D.Treatment of Sickle Cell Pain Fostering Trust and Justice William T. Zempsky, MD JAMA. 2009;302(22):2479-2480.