Sickle cell pain management meets technology: Everybody wins

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Summary Sickle cell disease is a chronic disease characterized by frequent exacerbations of its symptomatology. Intense pain is a hallmark of a sickle cell crisis, yet unfortunately, inadequate pain management in this population is well documented. Frequent visits to the Emergency Department (ED) by those in crisis expose them to several barriers that inhibit effective care, particularly pain management. Suspicion of drug seeking behaviour based on ethnicity or race, requests for specific drugs and doses, administration of large doses of opioid without relief, and a general lack of knowledge regarding pain management among healthcare professionals are some of these barriers. Using information technology, an effort was undertaken to simultaneously address many of the barriers to pain management for sickle cell crisis patients in the emergency department, and enhance the quality of pain management they receive.

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The pain of a sickle cell crisis is one of the most intense pains reported. Painful crises are often unpredictable and can have a profoundly negative effect on a person’s quality of life [1]. Despite the fact, it is well documented in the literature that sickle cell patients often are stigmatized when they seek medical attention in emergency departments [2]. McCaffery and Pasero indicate that patients can be stigmatized for being 'frequent flyers' to Emergency Departments (ED), by obtaining opioids from more than one provider, requiring higher doses of opioids than other patients, for taking opioids long term, and being a 'clock watcher' [3]. Although each of these stigmatizations can indeed be an indicator of somebody seeking opioids for reasons other than pain control, they are also the signs of a person who has not benefited from adequate pain control. Those seeking help for a painful sickle cell crisis also must face other barriers that are well beyond their control. The vast majority of sickle cell patients are of African descent, and that alone often carries its own cultural and racial barriers to prompt and proper treatment during a painful crisis [4]. In a qualitative study from Maxwell and Streetly, patients reported being neglected, stigmatized, and experiencing mistrust from healthcare providers [5].
The ED itself has been studied regarding its assessment and treatment of pain in general and the results have shown that patients’ pain is poorly controlled and some even have worse pain scores leaving the ED as compared to their arrival [6—10].

Given the realities of the above issues, it was thought that the care of patients suffering from a painful sickle cell crisis could be enhanced using published guidelines and information technology. A combination of informatics and The American Pain Society publication “Guideline for the Management of Acute and Chronic Pain in Sickle Cell Disease” were to be implemented in order to enhance the pain management of sickle cell patients that arrive at any of our EDs. Using Per-Se Technologies patient 1/Ulticare H.I.S. System, a criteria engine was built on our live database. A historical search of sickle cell patients making ED visits in the last 3 years was completed. Sickle cell patients making subsequent visits to one of our ED’s would activate an interrupt message on the computer screen identifying them as a sickle cell patient. All new sickle cell patients would have the interrupt message added to their patient file, and this would occur once their name or identification number is entered into the computer system. Once the patient was treated and discharged from the ED (either home or to an inpatient unit), the ED physicians would then dictate a note outlining the care the patient received in the ED, particularly the analgesics used, dosage, route, and effect. This letter would then become part of the patient’s electronic file, and would be readily accessible on subsequent visits. Consideration was given to a copy of the letter being given to the patient for reference at other hospitals (during vacations for example), but this was a point of much debate, that remained unresolved. The acute pain service would be consulted as needed. An e-mail message would be automatically sent to the computer of the sickle cell clinic nurse upon admission, identifying the patient name, location, and date of admission. Patients making frequent visits to the ED would be given the opportunity to be followed up in the Sickle Cell Clinic.

The ED staff would be educated on the guidelines published by the American Pain Society on Sickle Cell Disease. An evaluation process was to occur at 6 months intervals initially, and then annually. Feedback prior to implementation from ED physicians, and the Sickle Cell Clinic Staff was unanimously positive and supportive.

The expected positive outcomes include, but are not limited to: identification of sickle cell patients via computer prompt and patient letter will allow for patient specific attention in the ED, and possibly alleviate concerns of drug seeking. Information from the last visit will provide guidance regarding appropriate starting doses of opioids individualised for each patient. Better sharing of information can enhance the overall quality of patient care. Prompt attention to sickle cell crisis can lead to decreased length of admission and enhanced patient satisfaction.

Some of the potential problems include: the lack of identification of new sickle cell patients to the ED, Reluctance of healthcare professionals to use historical data, particularly if the recommended opioid dose is extremely high. Drug seeking behaviour cannot be ruled out by this initiative, and because there is no specific laboratory or radiological test for painful sickle cell crisis, the staff must still believe the patients’ subjective reports of pain.

Staff feedback on the initiative expressed concerns regarding confidentiality issues, and a process was being worked on that would establish a consent form of this plan for patients.

This program is designed as an assistive tool only. A thorough health history and appropriate physical exam must still occur, preferably in an environment of compassion rather than suspicion. Evidence has shown that three or more painful crises in a year is associated with increased morbidity and mortality [11]. Evidence has also shown that prompt, appropriate treatment of painful sickle cell crisis by specifically trained staff can reduce admission rates, length of stay, and treatment time in the ED [12]. Although this program cannot prevent a painful episode, it can potentially create a more comfortable environment for the patient. If those in sickle cell crisis feel comfortable in their initial interaction with the healthcare team, they might seek treatment earlier in the crisis, leading to a less severe crisis.

This initiative has the potential to enhance the care of sickle cell patients in the ED. Technology alone cannot improve care, but if used effectively, it can be a useful tool in guiding patient care, and potentially improving patient satisfaction and outcomes.

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