Patient Perceptions of an Adult Sickle Cell Program

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Abstract

The purpose of this study was to begin understanding how Sickle Cell Disease (SCD) patients adapted to the changes implemented by Yale-New Haven Hospital (YNHH) regarding the Adults Living with Sickle Cell Disease (ALSCD) Program. A telephone survey of forty-nine individuals participating in the ALSCD program was conducted. The survey was designed to evaluate individual patient care within the afflicted community, in order to, assess the degree of equanimity among patients involved during the transformation of the program. The format of the survey was designed to encourage patient input as well as subjectively evaluate the opinion and attitude evoked within the patients concerning the changes. Yale-New Haven Hospital began the re-organization of this program in 2012, in an effort to address the problems identified by hospital staff concerning the treatment of Adults Living with Sickle Cell patients.

Introduction

Sickle Cell Anemia (SCA) is a blood disease that occurs most commonly in persons of African or Middle Eastern ancestry that is characterized by anemia and the unpredictable onset of often-severe pain. SCA is an autosomal recessive genetic disorder that is caused by a single point mutation in the beta globin gene. The mutation causes the hemoglobin in red blood cells (RBC) to crystalize and form rigid rod-like polymers especially when in deoxygenated states. This causes the RBCs to assume an oblong sickle shape. This renders the cells non-deformable and subject to aggregation and fragmentation especially during passage through the small blood vessels. Aggregation causes diminished blood flow that leads to hypoxia (oxygen starvation) that can cause severe pain. Fragmentation leads to shortened RBC survival and anemia. Other globin gene mutations may be combined with the sickle mutation to cause related conditions that are referred to as sickle cell disease(s) (SCD). In adults pain in SCD may transition from episodes of acute pain to chronic (daily) pain punctuated by acute pain. The standard medical treatment for sickle cell pain is opioid pain medications. Most persons with SCD are treated with opioids at some time in their lives, and many end up taking opioids on a daily basis. Opioids are somewhat effective in the relief of pain, but are potentially addictive. Chronic pain treated with potentially addictive medicine places persons with SCD at risk for becoming dependent and/or abusing opioids and accommodating to a lifestyle of living in the hospital to receive opioids.

Identification of problems and implementation of solutions

In 2011 Yale-New Haven Hospital (YNHH) recognized problems in its approach to the care of adults living with SCD (ALSCD). Some ALSCD were spending several hours at a time in the emergency department, during sickle cell crises, waiting for pain treatment. These patients often were in conflict with doctors and nurses regarding pain treatment and especially the use of opioids. These conflicts were exacerbated by different attitudes and approaches among the many doctors and nurses concerning the appropriate management of pain with opioids. In 2012 YNHH re-organized its services for adults living with sickle cell disease (ALSCD) according to the concept that for most ALSCD pain is a chronic problem best managed on an outpatient basis with frequent clinic visits for the monitoring of pain and use of opioids. This approach would also facilitate delivery of other treatments of potential benefit that typically would not initiate in the hospital.

Important in inpatient care included:

1. A consistent approach to pain management directed by an expert in SCD and administered

by a small, highly, coordinated team of doctors and nurses.

2. Transitioning patients from the administration of relatively high doses of opioids by intravenous push by a nurse to "patient controlled analgesia" that involves relatively low doses of opioids administered automatically by a machine with a patient controlled interface and automatic features to prevent opioid overdose.
3. A focus upon rapid control of acute pain followed by transition to a pain management program that could be administered on an outpatient basis to facilitate early discharge.
4. Insistence upon regular clinic attendance as a prerequisite for ongoing opioid treatment.

Participants

Forty-nine patients where selected and asked to participate in the survey. 61% of those telephoned agreed to conduct the survey. 39% were not surveyed for the following reasons: 56% of those patients where unreachable with the given contact info, 21% where wrong or disconnected numbers, 16% stated they were not currently being seen at Yale New Haven Hospital, most common reason was because patient had moved, and the remaining 5% stated other reasons for not wanting to take survey. The gender distribution of those who completed surveys was 73% female and 27% male.

Data Collection

In order to ensure the integrity of the study, a third party individual, not previously associated with the program, conducted the survey and all patient information was kept confidential. From July-December of 2014, telephone interviews were conducted of Adult Sickle Cell Patients. The patient population interviewed consisted of individuals who where being treated at YNHH before, during, and after the restructuring of the ALSCD program in 2012. The survey consisted of twelve questions and obtained data on several key topics including: quality of patient care both in the Sickle Cell Unit and Emergency Department, amount of time spent in the hospital, how patients perceived the changes to the program, and an assessment of patient's overall welfare. The intent of the survey was to obtain quantifiable data on the described topics and also encourage open feedback from patients. Calls where made primarily between the hours of 5-8pm in the East Pavilion 6-7 Sickle Cell Unit and no recording device was used. Information received from patients was recorded as accurately as possible to ensure patients views where properly portrayed. Patient that participated in the survey where numbered in the order with which they where surveyed.

Results

For the purposes of this publication we will focus on three of the twelve questions. These questions gauge: the overall satisfaction of care at YNNH, the fairness in which the changes took place, and the patients' general welfare (*better/worse*) with respect to before and after the program changes occurred.

(1) "*Would you recommend Yale New Haven Hospital and its clinics to family members or friends with sickle cell disease?"* 52% of patients responded with *definitely yes*, 36% responded with *probably yes*, 12% said *probably no*, and 0% answered with *definitely no (figure 2)*. According to the data collected, the majority of ALSCD patients were satisfied with the care received in the YNNH Sickle Cell Unit. To better understand the patients perspective, they where then asked to describe reasons for recommending YNNH to others suffering from sickle cell disease. Patients felt that the transition to a consistent specialized staff of doctors and nurses trained to deal with sickle cell pain crises largely attributed to their overall satisfaction with YNNH clinics.

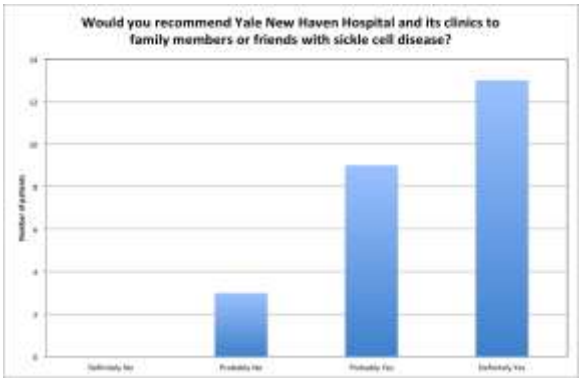

Figure 2: *Results describing patient views on YNNH Sickle cell clinic care*

(2) "Were the changes to the program done fairly?" Here the responses where more evenly distributed between the positive and negative choices with 40% of patients responding positively (20% *sort of fair* and 20% *very fair)* and 52% responding negatively (32% *sort of unfair* and 20% *very unfair)*. 8% where indifferent and perceived that the changes were done *neither fair nor unfair (Figure 3)*. Patients that disapproved received a follow-on question that asked why they felt the program changes were done unfairly. The majority of patients expressed that they should have been consulted about the changes before they took place and allowed to participate in deciding what changes would occur.

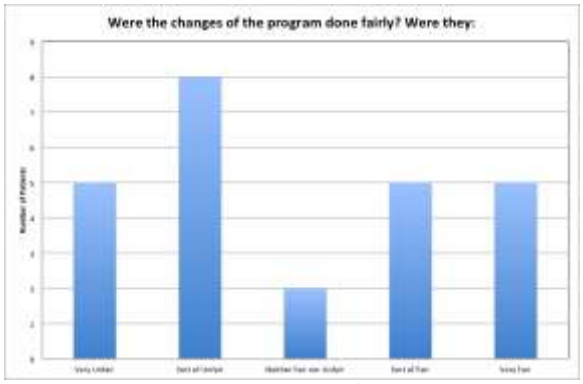

Figure 3*: Results analyzing patient satisfaction concerning methods of implementation*

(3) "Since the program has changed, are you worse off or better off?" This comparative question allowed us to assess the effectiveness at which the program changes where able to improve the quality of life for ALSCD patients and is arguable the most important aspect of the study. 64% of patients responded positively (40% were *much better off* and 25% were *a little better off*), 16% responded negatively (12% *much worse off* and 4% *a little worse off)*, and 12% of patients reported feeling *the same* with no change in their overall welfare (*figure 4*). Patients' reasoning for being *much worse off* or *a little worse off* was highly variant and no common themes were identified. However, patients that felt either *much better off* or *a little better off* commonly reported that having a consistent and well-trained staff attributed to their improved condition.

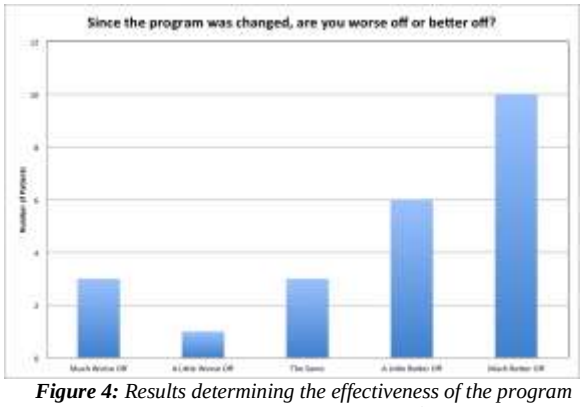

Figure 4: *Results determining the effectiveness of the program changes with regards to patient welfare*

Discussion

This study was designed to collect data on patient perceptions of the ALSCD program restructuring that occurred in 2012 at YNHH. The study also aimed to assess the effectiveness of the program changes regarding a patient's ability to control pain at home. Pain crises associated with Sickle Cell disease can often leave patients with a low quality of life. The ability to manage pain outside the hospital is a crucial component in allowing ALSCD the opportunity to engage in normal activities. Frequently scheduled clinic visits coupled with pain medication regiments, developed by YNHH ALSCD Staff, is proving to be an effective method of controlling pain crises.

Conclusions

The information collected from patients suggests that the ALSCD program changes were beneficial in helping manage pain crises. Patient perceptions of the Yale New Haven Hospital Sickle Cell disease clinic were generally positive. The E-P 6-7 doctors and nurses are regarded as knowledgeable and competent by sickle cell patients. However, ALSCD patients did express a desire to be more involved with decisions concerning their healthcare. Future program changes should be made more transparent and patient concerns should be identified and addressed before changes are implemented.

References

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Image 1: From right to left; Dr. John Roberts,

Biography

Robert Rousseau is a senior graduating in the spring of 2016 with a Bachelor of Science degree in Premedical Biology at the University of New Haven. Robert is a Veteran of Armed Forces and spent six years as an Army Infantryman, during which, he deployed three times to Iraq conducting military operations in support of Operation Iraqi Freedom (OIF) and Operation New Dawn (OND). Upon graduation, he wants to pursue a carrier as a Surgical Physician Assistant.