

**The Bucksbaum Institute for Clinical Excellence
2012 Pilot Grant Program Final Report**

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**University Of Chicago Adult Sickle Cell Care Team –
“Patient-centered Self Management Tools”**

Introduction/Background

Sickle Cell Disease is a genetic disease that results in chronic and debilitating pain from recurrent vascular insults. Neurocognitive deficits are very common in patients afflicted with this disease, often rendering them unable to adhere to specific treatment plans, and causing great difficulty in communicating with healthcare providers about their particular disease complications. The presence of pain, a quite subjective symptom, as the hallmark of this disease creates a particularly unique dilemma in terms of the most appropriate course of treatment; there is a fine balance between treating pain adequately, and contributing to the potentially deleterious physical and psychosocial consequences of prescribing opiate therapy. For these reasons, the Adult Sickle Cell Care Team created a project to develop self-management tools, including a comprehensive and portable medical record and a pain action plan for clinic patients.

Methods

Clinic patients were invited by phone and during clinic sessions to participate in a focus group to give input on rough drafts of a “Sickle Cell Care Card” and a “Sickle Cell Pain Action Plan.” On September 11th, 2012, twenty-four (24) sickle cell clinic patients participated in an approximately 2 hour focus group on self-management tools for sickle cell disease. During this focus group, team members and medical students administered formal questionnaires to the group; some of these questionnaires allowed the patients to rate features of these tools based on a Likert scale, while others asked open-ended questions to stimulate discussion for patient input.

These responses were then consolidated and reviewed by the sickle cell team to incorporate patient recommendations into a subsequent revised version of a sickle cell care card.

The new patient-oriented “Sickle Cell Care Card” was then distributed to patients in a rollout that began on February 27th, 2013, and will continue for the next 6 weeks, with cards being dispensed to patients during their clinic visits. We will plan to mail cards to patients who will not be seen in clinic by mid-April 2013.

Results

The focus group and subsequent integration of the input by patients has been considered as successful, as deemed by nearly reaching the participation goal at 24 patients (the goal was to have 25-30 patients participate with the group.)

Discussion

The Adult Sickle Cell Care Team Project, “Patient-Centered Self-Management Tools”, has been an interesting venture for the team. Receiving feedback from patients via a focus group has proven beneficial for the team as providers, in terms of relating to the patient experience better. In addition, this focus group allowed for patients to build improved relationships and thus support systems with their peers who also suffer from sickle cell disease. Perhaps the most revealing information that has been gleaned from this focus group is the fact that one particular tool, the “sickle cell pain action plan”, which was postulated by the team to be a useful potential tool, is not thought to be useful by the actual patients. This information, along with the positive feedback that was received from patients about the “sickle cell care card”, has resulted in the team re-focusing all of its energy into optimizing this care card. By soliciting information from patients, it appears that this card will become a standard tool for improving the care of University of Chicago adult sickle cell patients. In this same vein, this project, with its inclusion of patient input, embodies the spirit of the Bucksbaum Foundation, and improving the patient-doctor relationship.