

Current Projects

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www.patientcentereddesign.org

Research Fund

The Institute for Patient-Centered Design, Inc. seeks to partner with academic research projects that inform the patient-centered design process. Full or partial sponsors of research projects will be acknowledged in the Institute's published research report.

Patient Toolkits

As a courtesy to patients who participate in research studies and surveys, we offer complimentary tools. Kits may include promotional items, such as pens, notebooks or journals for recording patient history/experience, bags for packing personal items for a hospital stay, water bottles, etc. If your organization is interested in providing helpful items that may be offered to patients, or a monetary donation to purchase such items, please visit <http://www.patientcentereddesign.org/sponsorship.html>



Patient-Centered Design Online™

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Patients Suffering in Pain

Potential solutions in designing specialty clinics

By T.S. Thompson, AIA

Last month, the Institute for Patient-Centered Design lost a supporter and strong patient advocate Wendy Smith-Oglesby. Wendy fought a lifelong battle with sickle cell disease; and she died before reaching the age of 40. This issue of *Patient-Centered Design Online™* is dedicated to Wendy, in an effort to raise awareness of the condition that she and thousands of other patients have faced.

In a recent letter to the Institute, Wendy wrote, *"I am hospitalized on average once every two months for a period of one to two weeks. I have a chronic disease called Sickle Cell Anemia. This disease is extremely debilitating and complications are unpredictable. I have developed a tolerance for hospitals that keeps me sane. When I go into the hospital, I expect nothing.... I wonder what could be done to make my stay better. First, I would like to see a patient advocate...make daily visits...to see how the patient's stay is going.... I would also like to see a physical therapy department that would allow patients to receive alternative holistic care that would complement the physician's plan of treatment."*

[Sickle cell disease](#) is a chronic illness that affects an estimated 70,000 to 100,000 Americans (National Heart, Lung and Blood Institute, 2009). It is an "inherited blood disorder that affects red blood cells." Sickle cell patients "have red blood cells that contain mostly hemoglobin S, an abnormal type of hemoglobin. Sometimes these red blood cells become sickle-shaped (crescent shaped) and have difficulty passing through small blood vessels (Sickle Cell Disease Association of America, Inc., 2010)." This compromised flow of blood cells may cause numerous complications, such as organ damage

and painful episodes. While there is no widely-accessible cure for the disease, research is evolving towards methods for treating it. Recently, patients with severe complications have successfully undergone bone marrow transplants as a potential cure for the disease; however, this is not a feasible option for most patients.

A sickle cell pain crisis is the result of clumping of sickle-shaped blood cells that decreases the amount of oxygen to the body's extremities and organs. These episodes can be agonizing and often require medical intervention. The length of a crisis varies from a few days to weeks. Treatment for serious pain crises generally occurs in a hospital. Pain management, administering of IV fluids, oxygen, and blood transfusions are sometimes necessary.

The onset of a pain crisis may occur with no warning. Often, patients seek immediate treatment in the emergency department of their local hospitals. Due to the overcrowding that occurs, many of these patients are forced to endure with extensive wait times in emergency room lobbies while suffering with excruciating pain. What are potential solutions to this delivery of care, which often is inhumane to patients experiencing intense pain?

Although the treatment of an acute pain crisis typically occurs in an inpatient healthcare facility, an alternate model of care is available. With the introduction of day clinics or 23-hour facilities, sickle cell patients suffering from pain crises are able to bypass the emergency department for immediate treatment in a sickle cell clinic. Patients are monitored by medical staff while receiving pain management and other forms of

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intervention to treat their episodes. These clinics are cost efficient by reducing the number of patients admitted to inpatient care and the average length of stay for patients who are admitted (Dumaplin, 2006). Patient care is also managed more effectively due to the comprehensive wellness and routine care options available in these specialty clinics. This model of care also creates a more patient-friendly environment by allowing patients immediate treatment with minimal (if any) waiting required upon arrival.

Hospitals and their facility design teams may wish to consider this model of care as an initial approach to treatment and a potential alternative to inpatient care for sickle cell patient populations. This approach would also allow some relief to the crowding experienced in many emergency departments that see a high concentration of sickle cell patients. There is currently only one dedicated sickle cell clinic in the world that is available to patients seeking urgent care 24 hours a day. That facility is the [Sickle Cell Center](#) at Grady Memorial Hospital in Atlanta, Georgia. This center allows patients to receive up to 23 hours of treatment before being discharged or admitted to Grady's inpatient facility for continued care.

Inspired by this model of care, Institute for Patient-Centered Design is launching a campaign to raise awareness and generate support for the development of more 24-hour clinics in areas with high volumes of sickle cell patients. This initiative seeks to create design guidelines that address the needs of the sickle cell patients in a 23-hour clinic prototype. **For more information on this initiative, or to pledge your support, please visit www.patientcenterreddesign.org/sponsorship.**

References:

1. Dumaplin, C.A. (March 2006). "Avoiding Admission for Afebrile Pediatric Sickle Cell Pain: Pain Management Methods." *Journal of Pediatric Health Care* (Vol. 20, No.2, p. 115-122).
2. National Heart, Lung & Blood Institute. (2009). "Sickle Cell Anemia: Who Is At Risk?" Bethesda, MD: US Department of Health and Human Services, National Institutes of Health. (Online), March 15, 2010. http://www.nhlbi.nih.gov/health/dci/Diseases/Sca/SCA_WhoIsAtRisk.html
3. Sickle Cell Disease Association of America, Inc. (2010). "What is Sickle Cell Disease?" (Online), August 30, 2010. http://www.sicklecelldisease.org/about_scd/index.phtml



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Patient Letters

Each month, we feature a letter from a patient addressing a specific need or inquiry identified during his or her hospital stay. Patients are encouraged to write letters to communicate their concerns to the designers and operators of healthcare facilities. To submit a letter, visit www.patientcenterreddesign.org/perspectives.



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Understanding the *Patient* in Patient-Centered Design™
Continuing Education Series

"Patient-Centered Design" is a principle that should be in the forefront of any health facility project. Often, designers find themselves working with limited information about patients. This series will offer new lessons regularly that explain the commonly overlooked details of seeking medical treatment and how these factors may be influenced by the built environment. Written *by* designers and *for* designers, the lessons include valuable input from interviews with patients and clinicians. For more information on the series, please visit http://www.patientcenterdesign.org/education_series/all_courses.html

Please feel free to contact the editor with your questions, comments, or concerns at editor@patientcenterdesign.org

Calendar of Events

September 27-29, 2010

Better Care, Better Health: Delivering on Quality for All Americans AHRO's 2010 Annual Conference

Bethesda, Maryland

<http://www.ahrq.gov/about/annlconf10.htm>

October 5-8, 2010

2010 Planetree Annual Conference

Denver, Colorado

<http://www.planetree.org/>

October 19, 2010

Quarterly Meeting of AIA AAH of Georgia
Atlanta, Georgia

<http://www.linkedin.com/groups?mostPopular=&qid=3078062>

November 1-4, 2010

Hospitals and Communities Moving Forward with Patient- and Family-Centered Care Intensive Training Seminar

Pinehurst, North Carolina

<http://www.ipfcc.org/events/seminars.html>

November 13-1, 2010

Healthcare Design 2010

Las Vegas, Nevada

www.hcd10.com

May 26-29, 2011

Child Life Council (CLC) Annual Conference
Chicago, Illinois

<http://www.childlife.org/Annual%20Conference/SavetheDateFutureAnnualConferences.cfm>

As a courtesy to site users, we have listed information about upcoming events and links to related websites for more details. This does not constitute a relationship between the Institute for Patient-Centered Design and any of the websites or events listed. Nor does this represent an endorsement or guarantee of any kind. While we strive to keep such information updated, we make no legal or otherwise binding commitment to do so. We do not guarantee any of the information on the websites listed. Nor do we guarantee the events themselves.

The views and opinions expressed in this newsletter do not necessarily reflect the views of the Institute for Patient-Centered Design, Inc. We respect the rights of patients, family members and professionals to express their opinions and welcome comments on the topics published in this newsletter. We reserve the right to publish comments and letters at our discretion.

Letter from a Patient

Dear Institute for Patient-Centered Design,
From 2004-2006, I was a 24/7 caregiver for my daughter's cancer treatment, and I now sit on a family advisory board to her former children's hospital oncology division. One of the things I learned was the disparity between higher childhood cancer survival rates and lower adult survival rates for similar cancers (leukemias/lymphomas). Of course there are many factors involved, but I cannot help but wonder whether the physical environment of oncology facilities plays a role. The life-affirming decor, playrooms, family-friendly design flow, and even bicycles allowed on the treatment floor make most pediatric cancer facilities in the US much more "healing" environments than adult facilities. They understand a child's work is to play, regardless of being attached to an IV pole. Couldn't a similar emphasis on play be incorporated into adult facilities?
Erin Waterman

Dear Erin,

Thank you for your letter. Although we are not prepared to address the clinical reasons for the variance in survival rates between adult and pediatric cancer patients, we believe that you have made an interesting observation in noting the differences in treatment accommodations for the two groups. Pediatric health facility design incorporates components of play and learning as natural elements of the healing environment. In fact, these facilities often include a dedicated "[Child Life](#)" department to address the needs of their pediatric population, such as emotional, social, and family-related issues (to name a few).

While adult facilities are not as interactive, the patients do have similar concerns that should be addressed. This month's article entitled, "Patients Suffering in Pain" features excerpts of a letter from a patient who wished to explore a more "holistic" approach to patient care. In our patient interviews and research on the subject, we have discovered that adult patients are interested in services that address their physical and mental wellness while receiving treatment for a health condition. These services may include physical fitness facilities, with professionals available to develop modified exercise programs to complement patients' care plans. They may also include nutrition centers and therapy gardens, as well as professionals to address physical and psychological therapy needs. We hope that your letter will inspire healthcare design researchers and developers to consider these needs.