Using Design Thinking to Enhance the Transition to Adult Care in Pediatric Sickle Cell Disease

Lori E. Crosby, PsyD
Associate Professor
Behavioral Medicine & Clinical Psychology

NHLBI Grant#: 1K07HL108720
Overview

• Background on transition in pediatric sickle cell disease

• Describe a qualitative research study conducted with the Livewell Collaborative

• Describe 3 patient-oriented tools currently being refined and tested

• Benefits of using design thinking in research studies
  – Livewell Collaborative
  – CCTST Design Thinking Awards
Sickle Cell Disease (SCD)

- Sickle Cell Disease is a genetic blood disorder that primarily affects individuals of African and Mediterranean descent.

- In the U.S., approximately 1 in 500 African Americans and 1 in 1000 Hispanics/Latinos are born with the disease (NHLBI).
Hemoglobin S

- People with Sickle Cell Disease have an abnormal Hemoglobin Gene

- Instead of adult Hemoglobin A gene, they have Hemoglobin S genes

- Hemoglobin S genes make Red Blood Cells “sickle”
“Sickled” red blood cells clog vessels and the blood flow to organs, resulting in pain and other features of Sickle Cell Disease.
Management of SCD

- SCD requires a substantial amount of self-management
- Treatment regimens may include daily medications (Penicillin, Ex-Jade, Hydroxyurea), monthly transfusions, immunizations (Flu, Prevnar, etc.) and regular screenings (eye exam, dental, brain MRI, etc.)
Late adolescence is a vulnerable time period when the potential for complications increases, treatment adherence typically decreases, and mortality rates increase\(^1\).

Studies have reported mortality rates as high as 20% within 10 years of transitioning to the adult healthcare system\(^2\).

\(^1\) Hassel, 2010
\(^2\) Aduloju, 2008; Ballas & Dampier, 2004
Identified Barriers to Transition

**Patient**
- Attachment to providers
- Fear that adult providers might not understand their needs
- Reluctance to assume responsibility (being treated like an adult)
- Concerns about payment for the cost of care

**Parent**
- Attachment to providers
- Reluctant to transfer responsibility
- Fear of minimized role in adult care
- Concerned about impact of transition on child’s health

**Provider**
- Not knowing when patient is “ready”
- Difficulty finding adult providers
- Concerns about patient’s future
- Concerns about adult care setting
Larger Study Aims

- To design, refine, and pilot patient and provider tools to enhance patient self-management and the transition to adult care.

- To understand the impact of these tools on health and psychosocial outcomes:
  - 1) patient perceptions of patient-provider communication,
  - 2) patient perceptions of transition outcomes (readiness to transition), and
  - 3) health outcomes (disease self-efficacy, quality of life, disease severity, health utilization)
PROJECT SCOPE

Explore patient-provider tools to improve the transition from Pediatric to Adult Care for sickle cell disease patients.
1 RESEARCH: UNDERSTAND
EFFECTS OF SICKLE CELL DISEASE ON THE BODY

Sickle cell disease is when red blood cells form an abnormal sickle or crescent shape. These sickled cells deliver less oxygen and break into pieces, getting stuck in blood vessels, blocking oxygen flow.

The three most common types: SC, S beta, and SS, which is the most severe.

- **ACUTE CHEST SYNDROME**
  Causes shortness of breath, chest pain, fever, low oxygen levels, and fatigue.

- **GALLSTONES**
  Red blood cells die faster in SCD patients causing a bilirubin buildup; the makings of gallstones.

- **BONE PAIN**
  Pain in the spine, pelvis, and/or long bones due to tissue death from sickle cell blockages.

- **SILENT STROKES**
  Causes cognitive delays dealing with memory, responsibility traits, and rate of maturation.

- **HEART PROBLEMS**
  Trapping of red blood cells that should be in the body causing the spleen to grow and deteriorate.

- **SPLENIC CRISSES**
  Sores on the legs’ surface causing mild to severe pain.

- **LEG ULCERS**
  Sickle cells block small blood vessels in hands and feet causing pain, swelling, and fever.

©Lori E. Crosby, PsyD; Cincinnati Children’s Hospital Medical Center & Live Well Collaborative
PAIN MANAGEMENT OF SICKLE CELL DISEASE PATIENTS

TWO TYPES OF PAIN

ACUTE PAIN
Unpredictably abrupt pain onset without any other explanations that last hours to days with varying intensity from mild to severe.

CHRONIC PAIN
Debilitating pain, both physically and psychologically, that lasts 3—6 months or more and no longer serves as a warning function.

MEDICATIONS & TREATMENTS

NSAIDS: Or non-steroidal anti-inflammatory drugs such as ibuprofen.

Mild Opioid/Morphine: Side effects include sedation, nausea, vomiting, and respiratory depression.

Hydroxyurea: Makes red blood cells less likely to bend into abnormal shapes.

Exjade: Removes excess iron in the body; for people who receive transfusions.

Coumadin: Blood thinner that decreases the clotting ability of blood.

Transfusions: Raises the oxygen carrying capacity of blood and decrease sickle red blood cells in the bloodstream.

MANAGEMENT STRATEGIES

These strategies are patient specific and mainly have to do with how each patient handles their pain, medication adherence, and how pain affects their daily life.
UNDERSTANDING THE TRANSITION PROCESS

1. DISCUSSION OF TRANSITION WITH PATIENT
2. TEAM PICKS PATIENT TO BE TRANSITIONED
3. SCHEDULES APPOINTMENT FOR TAYA CLINIC
4. PATIENT GOES TO TAYA CLINIC APPOINTMENT
5. MEETS PCP AND/OR ADULT HEMATOLOGIST
6. INFORMATION FAXED TO PCP AND/OR ADULT HEMATOLOGIST
7. APPOINTMENT WITH PCP AND/OR ADULT HEMATOLOGIST
8. ADULT HEMATOLOGIST INFORMS PEDIATRICIAN PATIENT SHOWED UP
9. PATIENT TRACKED FOR 1 YEAR
10. SUCCESSFUL PATIENT TRANSITION

MEASURABLE OUTCOMES
- Patient showed up to adult appointment
- Attends more than one adult visit
- Disease state the same
- Smart aims/vocational education plans in place
- Self management
- Experience of care

© Lori E. Crosby, PsyD; Cincinnati Children’s Hospital Medical Center & Live Well Collaborative
2 RESEARCH: INTERVIEWS
INTERVIEWING AT PHOTO VOICE

APPOINTMENT SHADOWING AT THE CHILDREN'S CLINIC

APPOINTMENT SHADOWING AT THE ADULT CLINIC

INTERACTIONS OBSERVED: PATIENT & PARENT
PATIENT & PROVIDERS
PATIENT & CARE MANAGER
PATIENT & NURSE PRACTICER
PATIENT & SCHOOL INTERVENTIONIST

©Lori E. Crosby, PsyD; Cincinnati Children's Hospital Medical Center & Live Well Collaborative
3 RESEARCH: SYNTHESIS
EACH SICKLE CELL PATIENT IS DIFFERENT.
THE WAY SICKLE CELL AFFECTS THEIR BODY.

- **ACUTE CHEST SYNDROME**: Causes shortness of breath, chest pain, fever, low oxygen levels, and fatigue.
- **GALLSTONES**: Red blood cells die faster, causing a bilirubin buildup—the makeup of gallstones.
- **SILENT STROKES**: Causes cognitive delays dealing with memory, responsibility traits, and rate of maturation.
- **RAPID HEART RATE**: Can have an enlarged heart and high blood pressure.
- **SPLENIC CRISES**: Trapping of red blood cells causing the spleen to expand and deteriorate.
- **BONE PAIN**: Pain in the spine, pelvis, and/or long bones due to tissue death from sickle cell blockages.
- **LEG ULCERS**: Sores on legs causing mild to severe pain.
- **HAND-FOOT SYNDROME**: Blockage of small blood vessels causing pain, swelling, and fever.
THE PAIN THEY EXPERIENCE.
THEIR SUPPORT SYSTEM.
PATIENT PROFILES

ROBBIE
AGE: 21 / TRANSITIONING

© Lori E. Crosby, PsyD; Cincinnati Children’s Hospital Medical Center & Live Well Collaborative
LELEITA
AGE 22 / TRANSITIONED

i transition.

"I didn't feel prepared... but I wouldn't say I felt embarrassed."

LELEITA
SCD EFFECTS ON THE BODY

DIAGNOSIS
Antoine was diagnosed with the SS form of sickle cell disease.

ACUTE CHEST SYNDROME
"Your chest will start to get tightened and it will stay like that and every time you move or walk it hurts and you will want to lay down and not move at all."

BONE PAIN
Hurts for him to pick up his kids. Wants to own a ranch house so he can move around easily when he's older.

ANTOINE

FUTURE

<table>
<thead>
<tr>
<th></th>
<th>become a nurse at CCH</th>
</tr>
</thead>
<tbody>
<tr>
<td>SELF MANAGEMENT</td>
<td>low</td>
</tr>
<tr>
<td>PAIN RATING</td>
<td>1-3</td>
</tr>
<tr>
<td>TRANSITIONING</td>
<td>negative</td>
</tr>
<tr>
<td>SUPPORT</td>
<td>low</td>
</tr>
</tbody>
</table>

DAILY LIFE
AGE: 20 FATHER OF TWO
Antoine is the father of two girls who take up most of his time during the day with park trips. He keeps a journal of things he never wants to forget (Alzheimer’s runs in his family and he is worried he will have it, too). His family recently got a new puppy that his girls adore.

SELF MANAGEMENT
HIGH SELF MANAGEMENT
Antoine has taken control of his disease through mind/body interventions, keeping up on his medication, and never missing a doctor’s appointment.

TRANSITIONING ATTITUDES
REFUSES, WANTS TO BE THE EXCEPTION
Antoine does not want to transition. He says he will be the exception to the age rule. He jokes that if he transitions he’ll never go to his adult hematologist or the UC ER and die.

FAMILY
HIS MOTIVATION
Antoine’s family is his main motivation. They are the drive for his high self management because he wants to create a future for his kids and he wants to be in it as long as he can.

CARE PROVIDER INTERACTION
CLOSE WITH NURSES AT CCH
Antoine is close with the nursing staff at CCH, as well as his care manager. They joke with each other and discuss his transition. He doesn’t really like his adult hematologist because she only sees him once in a while, and does not really listen to what he is saying.

ENVISIONING THE FUTURE
OWN A RANCH HOME, BECOME A NURSE AT CCH
Antoine wants to own a ranch house in Kentucky with a huge yard for a dog and his daughters to run around in. He wants to own a ranch because he knows it will become more difficult for him to move around as he ages because of his sickle cell. He is attending Cincinnati State for nursing and plans to work at CCH helping other kids with sickle cell disease.
PAIN MANAGEMENT

PAIN RATING
Antoine suffers from both ACUTE PAIN and CHRONIC PAIN. Says his pain has been less than a 10 on a scale of 1 to 10 for years.

MANAGEMENT STRATEGIES
MIND BODY INTERVENTIONS
Saw a special on the Discovery Channel on how pain is an emotion. He goes to his room and listens to rap music, focusing on the beats of the music instead of the throbbing of the pain. He does this so he doesn’t have to go to the ER.

HEALTHY HABITS
Drinks lots of water.

MEDICATIONS & TREATMENTS
EXJADE: Hates taking his Exjade. Didn’t know he could mix it with juice, though he could only mix it with water.

TRANSFUSIONS: Every 3 to 4 weeks receives transfusions. Usually gets his labs and transfusions in the company of his wife and kids.

SUPPORT SYSTEM

SUPPORTERS
Perception of involvement for supporters of Antoine’s treatment and management of sickle cell disease.

HIGH
Family
Nurse Practitioner
Care Manager
Social Worker

LEVEL OF SUPPORT

LOW
0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24

AGE (in years)

Pediatric Hematologist

Adult Hematologist

School Interventionist

Psychologist

Vocational Educator

Care Manager

Primary Care Provider PCP

Nurse Practitioner

Transition in Personnel

©Lori E. Crosby, PsyD; Cincinnati Children’s Hospital Medical Center & Live Well Collaborative
4 IDENTIFYING OPPORTUNITY AREAS
HOW CAN WE...
IMPROVE PATIENTS’ SELF MANAGEMENT SKILLS?
HOW CAN WE...
CHANGE THE NEGATIVE
PERCEPTION OF THE ADULT
CLINIC?
HOW CAN WE...
HELP PATIENTS CONNECT SELF MANAGEMENT SKILLS TO THE FUTURE THEY ENVISION FOR THEMSELVES?
HOW CAN WE...
HELP PATIENTS UNDERSTAND
HEALTH INSURANCE?
HOW CAN WE...
MAKE USE OF PATIENTS' 
DESIRE TO SOCIALIZE WITH 
OTHER PATIENTS?
HOW CAN WE...
HELP PARENTS HAVE A
POSITIVE ROLE IN THE
TRANSITION PROCESS?
HOW CAN WE... HELP PATIENTS THAT PERCEIVE TRANSITION AS A DRAMATIC EVENT?
5 IDEATE
HOW CAN WE...
IMPROVE PATIENT’S SELF MANAGEMENT SKILLS?
HOW CAN WE... HELP PARENTS HAVE A POSITIVE ROLE IN THE TRANSITION PROCESS?
HOW CAN WE...
USE PATIENT MOTIVATIONS
TO HELP OTHERS,
TO MOTIVATE THE
TRANSITION PROCESS?
② PROCESS IDEATION

TASK UNIFICATION:

DIVISION:
Patient tracked for one year.

Team picks patient to be transitioned

Tour of Adult Clinic

Patient meets PCP and/or Adult Hematologist

Information transferred to Adult Clinic

Patient goes to first appointment at Adult Clinic

Adult Clinic notifies Ped. that patient showed up

Patient tracked for one year.
WHAT ARE THE BENEFITS?

PATIENT CAN BE TRACKED BEFORE THE TRANSITION TO HELP PERSONALIZE THE PROCESS TO THEIR INDIVIDUAL NEEDS.
6 CONCEPTS
DEFINE A TRANSITION PROCESS USING DEVELOPMENTAL MILESTONES.
MILESTONE CARDS
Milestone:

Go to their appointment on their own.

Missions:
1. Schedule appointment.
2. Plan transportation.
3. Talk to provider on their own.

Health Navigation Module:
Scheduling Appointments
DEFINE A TRANSITION PROCESS THAT CAN BE PERSONALIZED TO EACH PATIENT'S INDIVIDUAL NEEDS.
PROVIDING A STRUCTURE TO DEFINE A PERSONALIZED TRANSITION PROCESS:

COGNITIVE ABILITY

MOTIVATIONS

HEALTH CONDITION
Parent Education Toolkit

Provide a toolkit that helps communicate clear expectations for how parents should be involved in patient’s care.

Help them understand their role before transitioning and how to gradually “hand-off” responsibility to the patient.

Role Play

Present the patients with pre-planned scenarios and have them act out what to do. Have them watch videotapes of their appointments to help point out things they are doing well and things they can improve.

Going to their appointment on their own.

Missions:
1. Schedule appointment.
2. Plan transportation.
3. Talk to provider on their own.

Health Navigation Module: Scheduling Appointments
2 PROVIDER INTERFACE
PROVIDES A SHARED UNDERSTANDING OF THE TRANSITION PROCESS ACROSS MULTIPLE STAKEHOLDERS.

VISUALIZES PROGRESS & ROLE OF POWER-UPS

“UNITED FRONT”
Patient

**Schedule an appointment.**

**Steps:**
1. Find the doctor's contact number and your health insurance information.
2. Make sure to have your schedule and a pen and paper.
3. Write down the appointment information.

**Health Navigation Module: Scheduling Appointments**

**Tools:** Calendar

---

**Plan transportation to your appointment.**

**Steps:**
1. Find the address of your clinic.
2. Look up the bus route, or call Medicaid if necessary.
3. Write down the address and your doctor's contact information.

---

**Talk to your doctor on your own.**

**Steps:**
1. Write down a list of questions, what medications you are taking, problems you're having.
2. Make sure to ask if you don't understand something.
3. Ask the doctor to write down any instructions they give you.

**Health Navigation Module: Communication**

---

**EXJADE MEDICATION**

Reduces the iron in your blood if you are receiving blood transfusions.

It is dissolved in water or juice.
DEFINING A PROCESS

COMMUNICATE IT ACROSS TEAM MEMBERS

GIVE THE PATIENT A VOICE
NEXT STEPS
My Patient Profile

Tell us about your experience.
How has your body been impacted by Sickle Cell? What kind of pain have you experienced since your last visit?

Tell us about your management skills.
How do you manage your pain? Tell us about the strategies you have come up with on your own, and see what other patients are doing.

Talk to your doctor.
Print out your profile or save it on your phone, and use it at your next visit to tell your practitioners how you have been doing.

Type your name here: [Input Field]  Go!
My Patient Profile

Tell us about your experience.
How has your body been impacted by Sickle Cell? What kind of pain have you experienced since your last visit?

Tell us about your management skills.
How do you manage your pain? Tell us about the strategies you have come up with on your own, and see what other patients are doing.

Talk to your doctor and your nurses.
Print out your profile or save it on your phone, and use it at your next visit to tell your practitioners how you’ve been doing.

Type your name here: [ ] Go!
<table>
<thead>
<tr>
<th>Age</th>
<th>Health Management</th>
<th>Educational</th>
<th>Disease Management</th>
<th>Social</th>
</tr>
</thead>
<tbody>
<tr>
<td>14</td>
<td>Use Pain Action Plan</td>
<td>Obtain Referral for SIP</td>
<td>Know Your Pain Triggers and Treatments</td>
<td>Roleplay How to Tell a Close Friend About your SCD</td>
</tr>
<tr>
<td>15</td>
<td>Get Your Flu Shot</td>
<td>Use School Intervention Coordinator (SIC) services</td>
<td>Know What Hydroxyurea Is</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Get Your Immunizations</td>
<td>Obtain Medical Paperwork for School</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
You have a new Mission!

Flu shot
You have a new **Mission**!

**Flu Shot**

- Mark your calendar for October. This is when flu shots are usually available.
- Get it through your medical provider, drug store, college, or the health department.
- Write down when you had your flu shot. Make sure your medical team has this information.
ON-LINE INTERVENTION
Welcome.

Transitioning from teenager to adult is just like how you learn to drive.

1. First of all, you had to watch your parents driving while sitting next to them.

2. Then, you started to study traffic regulations for the knowledge test. You got your TEMPORARY DRIVER LICENSE.
YOU ARE THE DESIGNERS.