



HealthBEAT: Health Beliefs & Attitudes of Teens and Young Adults with Sickle Cell Disease

Lori E. Crosby, Psy.D.
Psychological Consultant
Cincinnati Comprehensive Sickle Cell Center

*Study Supported by NIH Grant # 1U54HL070871
Cincinnati Comprehensive Sickle Cell Center*

Collaborators

- **Cincinnati Comprehensive Sickle Cell Center**
 - **Julia Bloom, BS**
 - **Monica Mitchell, PhD**
 - **Patricia Pearl**
 - **Patrick Kelly, MD**
 - **Clinton Joiner, MD, PhD**
 - **Transition Team**
- **University of Cincinnati Adult Sickle Cell Program**
 - **Annette Lavendar, MSN, FNP**

Background

- **Teens/Young adults with chronic illnesses, such as Sickle Cell Disease, often exhibit poor adherence with medical recommendations.**
- **It is possible that these patients' health beliefs and attitudes affect their adherence and coping.**

Purpose of the Study

To better understand the health beliefs and attitudes of teens/young adults with Sickle Cell Disease (SCD) as a means of informing and improving clinical service delivery

Design

- **Quantitative**
 - **Health Beliefs and Attitudes (General) / Health Attribution Test (Achterberg & Lawlis, 1977;1990)**
- **Qualitative/Survey**

Health Attribution Test

- Consists of 21 items
- Rate level of agreement on a 6 point likert scale
- Adapted to 4 point likert scale
- Scale scores - low, average, or high range on 3 scales (internal, powerful others, chance)
- Profile codes based on how participants score (e.g. **h**igh, **a**verage, **l**ow) across the 3 scales

Health Attribution Test (Achterberg & Lawlis, 1977)

Sample Items

- I can usually keep myself healthy by paying close attention to what I eat.
- If I were extremely sick, I might go to a faith healer.
- Most diseases or accidents can happen to anybody at any time.
- Thinking positive thoughts can help me get well and stay well.
- I will still get sick or hurt if that is what is supposed to happen even if I set my mind to stay healthy.
- Everyone should be responsible for his/her own health and not push responsibility off on a doctor.

Design

- **Quantitative**
- **Qualitative/Survey**
 - **Health Beliefs and Attitudes (Specific to Sickle Cell)**
 - **Barriers/Facilitators to Clinic Appointments**
 - **Decision Making about Attending Appointments**
 - **Perceived Role of the Clinic**
 - **How are we doing?**

Qualitative Survey

- Developed items specific to barriers, facilitators, SCD, and clinic services based on focus group data.
- Teens/young adults were asked to rate their level of agreement or disagreement with 35 items on a 4 point likert scale (strongly disagree, disagree, agree, strongly agree) and respond to 11 open-ended questions.

Health Beliefs and Attitudes – SC

Sample Items

- I do not think my Sickle Cell is a serious illness.
- If I take my pain medication/hydroxyurea the way the doctor says I should, it helps me keep feeling well.
- I think that I will have more pain as I get older.
- The side effects of my hydroxyurea are so bad that I do not want to take it at all.
- The side effects of my pain medications are so bad that I do not want to take them.
- I want to take every dose of my medicine the way the doctor says I should.
- If I attend clinic for routine visits, it helps me keep feeling well.

Open-Ended Survey

Sample Questions

- At what age do you feel you will become responsible for managing your own health? Why?
- What is the most important/valuable lesson that you have learned at a regular clinic visit?
- How would you prefer to get information about sickle cell? Please rank these with 1 being your first choice and 4 being your last choice:
 - talking one-on-one
 - written handouts
 - by mail
 - group discussion

Methods

- Eligible teens/young adults received a phone call from a research assistant explaining the study and arranging a time to administer the survey
- Teens/Young adults could also complete the survey during clinic visits

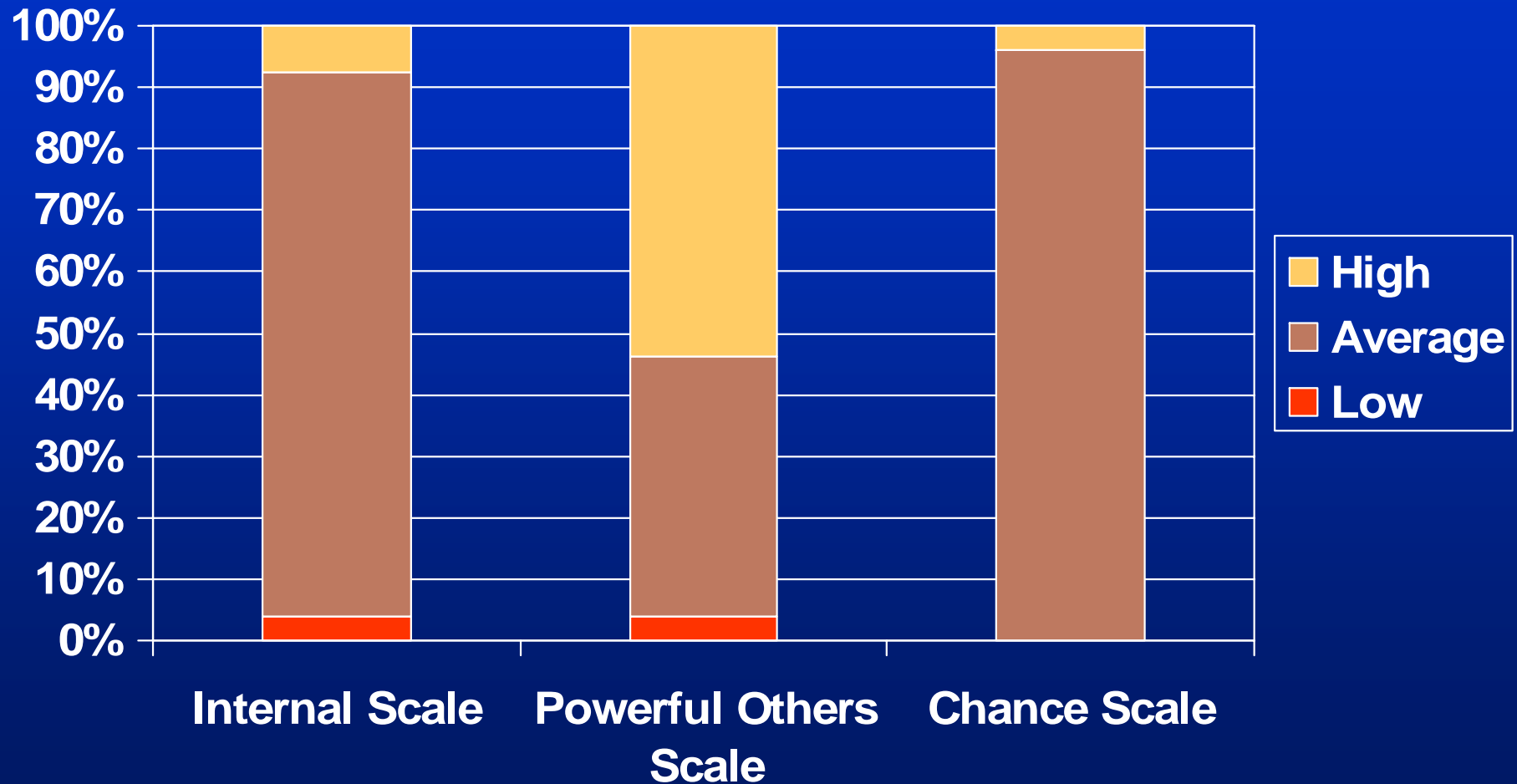
Target Population

- **85** teens and young adults ages 13-23
teens/young adult patients of the Sickle Cell
Transition Clinic at CCHMC or the Adult
Sickle Cell Program at University Hospital
- Cross-section of teens/young adult patients
representative of the clinics

Participant Demographics – Age, Gender, Hemoglobin Type

- **N = 26 teens and young adults (to date)**
- **Ages 13 – 22 (mean age: 16.8 years old; s.d = 2.47)**
 - **19 (73%) were in the 13-18 age range**
 - **7 (27%) were in the 19-23 age range**
- **Gender**
 - **69% female**
 - **31% male**
- **Type of SC Disease**
 - **11 (42%) Hgb SS**
 - **10 (38%) Hgb SC**
 - **4 (16%) Hgb S β +Thal**
 - **1 (4%) Didn't Know**

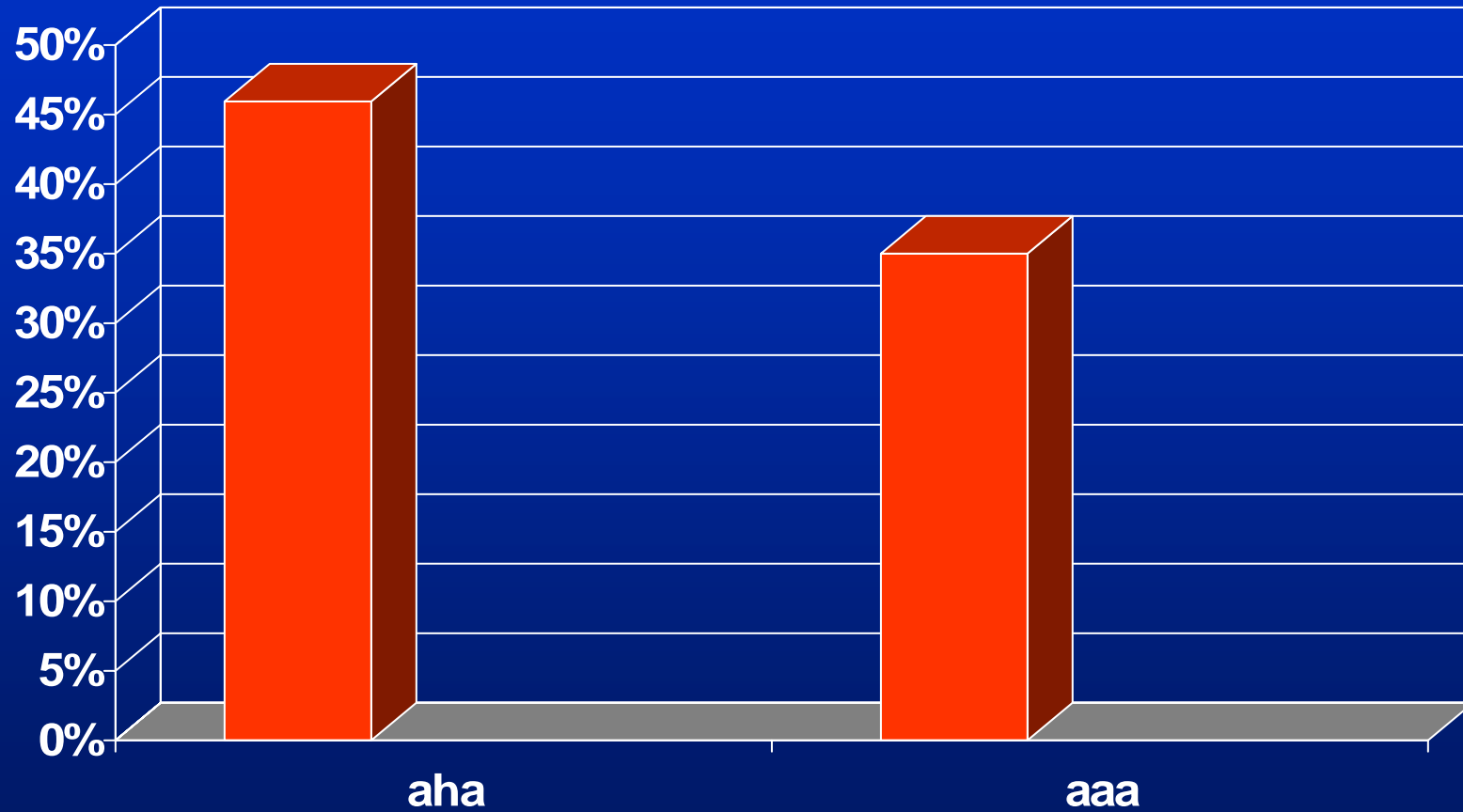
Health Attribution Test Scale Score Results



HAT Profile Results

- **14/26 (53.8%) Scored in the High Range on the “Powerful Others” Scale**
- **Persons who score high on this scale often believe that doctors, nurses, medical professionals, a higher power (i.e. “powerful others”):**
 - **Are responsible for their health**
 - **Blame “powerful others” for their health**
 - **Rely on “powerful others” for help**

HAT Profile Codes



HAT Predominant Profile Codes

- 12/26 (46%) obtained an **aha profile** (average on internal scale, high on powerful others, average on chance scale). Persons with this profile may be at risk for psychological dependence on “powerful others.”
- 9/26 (35%) obtained an **aaa profile** (average on all scales) profile. Persons with this profile often have a balanced set of health beliefs.

Survey Results

SCD-specific

- **35% did not agree that their SC Disease was a serious illness**
- **92% agreed that knowing and understanding about how SC affects the body would prolong life**
- **77% agreed that attending regular clinic visits would help prolong life**
- **Preferred method for receiving SC education was talking one-on-one followed by group discussions, handouts, then mail.**

Survey Results

■ Barriers/Facilitators

- 39% agreed that they do not want to go to the clinic if they do feel well
- 31% agreed that they have to be at the hospital for so much when they are sick that they don't want to go to the clinic when they feel well
- 73% reported that they used a calendar/planner to remember clinic appointments
- 85% agreed that their parents keep track of their appointments for them
- 100% agreed that clinic staff takes medical concerns seriously

Survey Results

■ Decision Making

- 39% agreed that they go to clinic based on the way they feel that day
- 65% agreed that they decide on their own if they will attend clinic appointments

Survey Results

■ Role of Clinic

- Introduce patients to adult doctors and tell patients what to expect
- Provider reminders about appointments

Survey Results

■ Satisfaction Survey

- 89% did not agree that clinic staff treats them too young
- 77% did not agree that the clinic waits were too long
- 100% agreed that clinic staff explains information about my illness in terms they can understand

Conclusions

- Many adolescents may blame professionals for their health but also rely on them for treatment.
- This paradox may lead to distrust of medical team and an externalization of control and responsibility.

Clinical Implications

- Measures like the HAT allow for identification of patients who may be at risk for difficulties with adherence and avoidant behavior
- These patients may need assistance with striking a balance between relying on “powerful others” and being proactive in self-care. They may also need support to help build confidence that their actions can have an impact.
- An assessment of patients health beliefs may aid in developing more effective, developmentally and culturally appropriate, individualized treatment plans for teens and young adults with SCD

Research Implications

- **The mix of qualitative and quantitative assessment methods provided patients with a voice but also allowed for a more objective assessment of health beliefs.**
- **This methodology may be developmentally-well suited for teens and young adults who may not feel valued or heard by the medical system and/or larger society.**

Future Directions

- **Go the Distance**
 - **Increase our “N”**
 - **Summer Event**
- **Add a coping measure (CSQ)**
- **Pilot an adherence measure**
- **Further Analyses**
 - **e.g. the relationship between scores on the “powerful others” scale scores/profile codes and pain frequency, coping, adherence**