Blood Soup and Learning through Play: Development of an Educational Curriculum for a Sickle Cell Summer Camp

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INDIANA HEMOPHILIA & THROMBOSIS CENTER, INC.

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Disclosures

- **None**

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Objectives

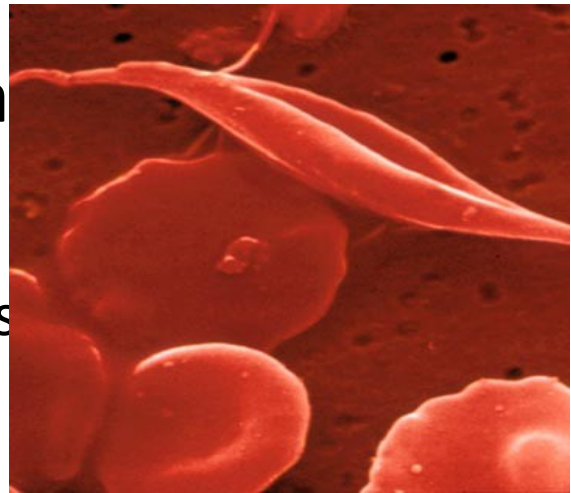
- Identify 4 key components of an education program for children with sickle cell disease in a traditional summer camp environment.

- Describe the value of non-pharmacolgoical coping techniques and impact of age appropriate education in relation to pain and anxiety in children with Sickle Cell Disease.

- Outline the future of Camp Silver Moon education and assessment for learning during camp

Sickle Cell Disease Ups and Downs

- Affects 1/500 African American births
- Average lifespan of HbSS patient: 40-50 years
- Hallmark of the disease is painful crisis
  - Unpredictable
  - Triggered by temperature changes, dehydration, stress, fever
- Negatively impacts quality of life of pa
  their caregivers
  - Loss of school time and missing social events
- No universal cure available



Why Coping is so Important

- **Seven Domains of Stressors**
  - SCD-related medical complications
  - Treatment and side effects
  - Disruption in daily routine
  - Emotional reaction
  - Communication issues
  - Social challenges
  - Concerns about the future

Hillenbrand, A., Barakat, L., et al., Journal of Pediatric Hematology and Oncology . 2015 January; (1):25-34.

Importance of Camp

- Improved social support and attitude toward illness
- Children have less loneliness and higher feelings of normalcy and sense of belonging
- Increased understanding of diagnosis and management
- Improved physical symptoms
- Higher self esteem and quality of life

- **DiDomizion, P.G., Gillard, A., Journal of Pediatric Nursing;40 (2018): 37-46.**

Why Residential Camp?

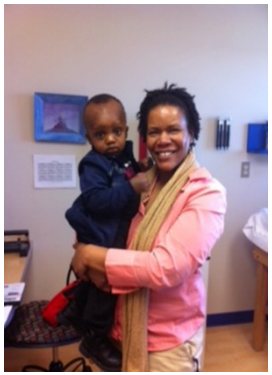
"Camp is a novel setting away from home that was carefully scheduled and provided opportunities for healthcare reinforcement."

- **Many studies show that the positive outcomes gained at camp have lasting effects**
  - Months
  - Years

- Gillard, A., Allsop, J. Children and Youth Services Review. (2016.): (65) pp. 112-119.

IHTC's Sickle Cell Program

- **SickleSafe – newborn screen**
  - 0-3 years
  - initiated in 2009



SAFE

SCORE

PATH
PEDIATRIC TO ADULT TRANSITION FOR HEMOGLOBINOPATHIES

- **SCORE – care**

Camp Silver Moon – year 1

- **Established 2017**
  - Children ages 7-12 and siblings
  - 18 campers, 10 female, 8 male

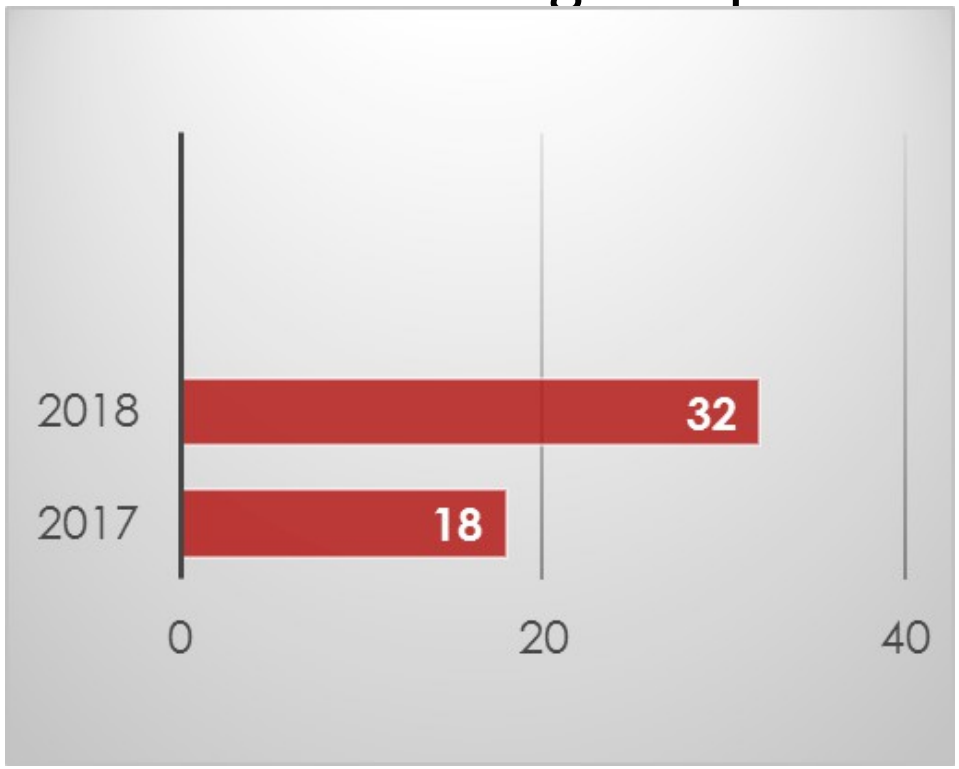
- DiDomizion, P.G., Gillard, A., Journal of Pediatric Nursing;40 (2018): 37-46.
- Koller, D., Journal of Clinical Nursing. (2016) 26, 2657-2668

Camp Silver Moon – year 2

- **Growth in 2018**
- Children ages 7-12 and siblings
- 32 campers - 21 female, 11 male

Camp Silver Moon – year 2

- **78% Growth in 1 year**
  - 13 returning campers



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Transition Begins NOW – Importance of Education about SCD and its Management

1. **Prepare for Transition**
   - Sickle Cell Disease Education
   - Management of SCD-specific issues
2. **Transition to Independence**
   - Navigation of health care system

Early Age Transition = better outcome for adherence to treatment

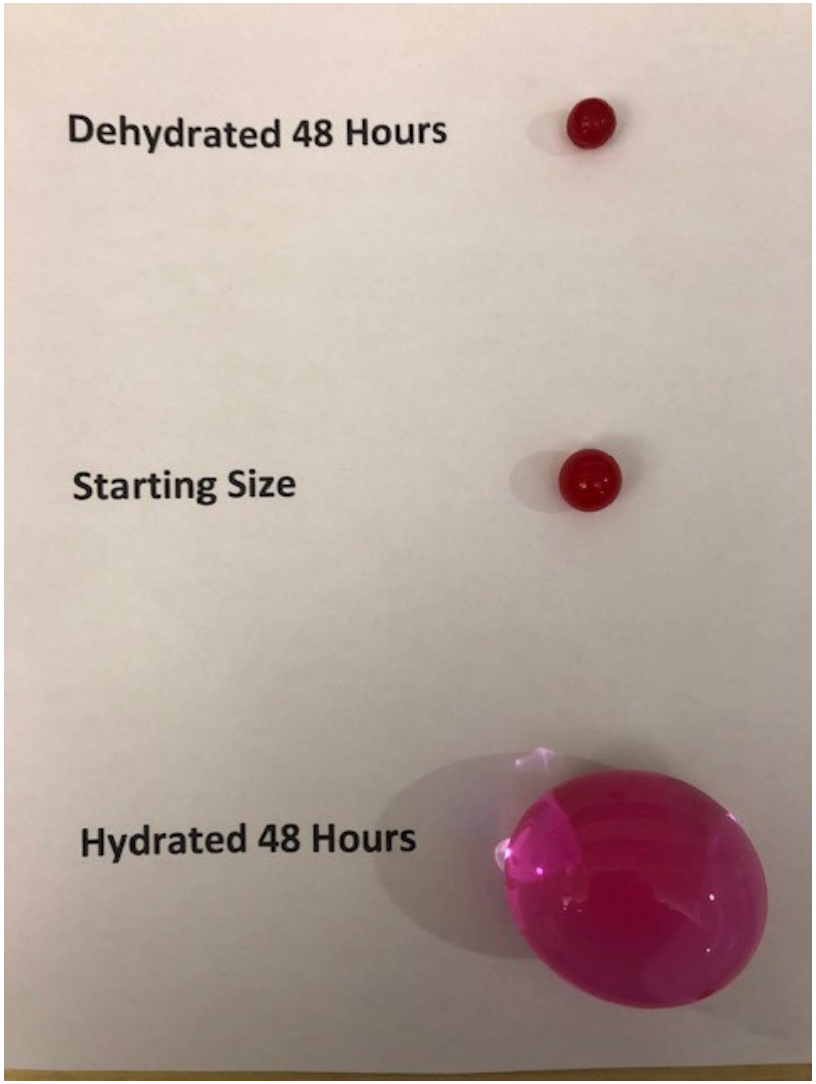
- *Andemariam, B., Owarish-Gross, J., et.al., Pediatric Blood Cancer 2014;61:697-701.*

4 Key Components of Education at Camp Silver Moon

- **Physical**
  - Hydration
  - Heat vs Cold
- **Emotional**
  - Non-pharmacological coping techniques
- **Knowledge**
  - What does Sickle Cell mean?
- **Review**
  - What we have learned?

Education at Camp – Physical Component

- **Hydration**
  - Water bottles decorating
  - Dehydration experiment
- **Hot vs. Cold**
  - Rice Bags
    - .

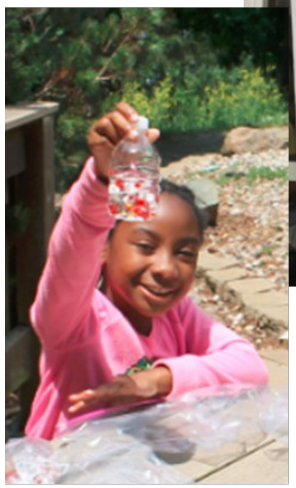


Education at Camp – Emotional Component

- **Non-pharmacological coping techniques**
  - Journaling
  - Stress Balls

Education at Camp – Knowledge Component

- **Making Blood Soup**
  - Red Blood Cell
  - White Blood Cell
  - Platelets
  - Plasma
- **Sickle Cell**
  - Triggers
    - Stress
    - Cold
    - Dehydration
  - Helpers
    - Water3



Education at Camp – Review Component

- **What have we learned?**
  - Review questions
  - 1.What color are the cells that carry oxygen around your body?
  - 2. Red blood cells contain _____ that carries oxygen in your blood.
  - 3. Hemoglobin helps carry ____ to all parts of the body
  - 4. Sickle Cell is a genetic disorder that affects the _____.
  - 5. A person with Sickle Cell disease should drink plenty of _____?
  - 6. Sickle Cells can block the

Assessment of Knowledge – year 1

- **What have we tried?**
  - Pre/Post Quiz
  - Focus on 3 main areas
    - Inheritance and blood
    - Complications
    - Health Maintenance
- **Results**
  - Limited

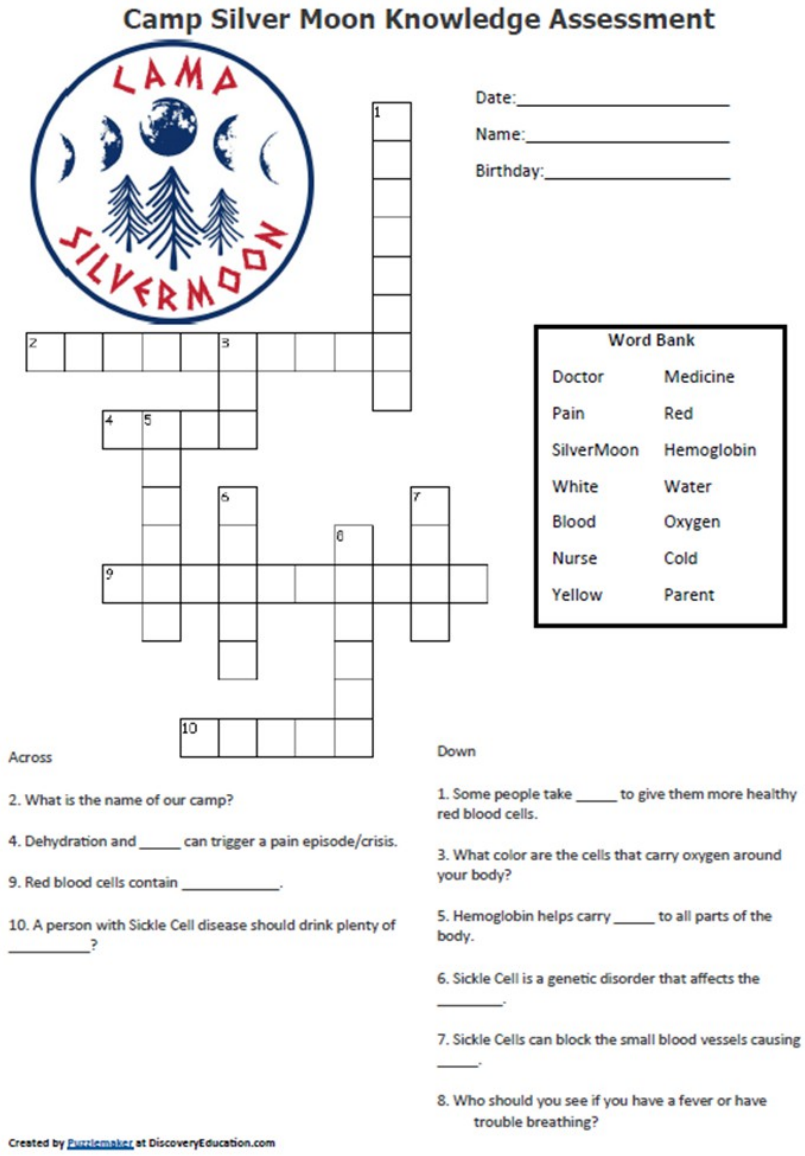
WHY?

- **Examples of questions from quiz**
  - Sickle Cell is a genetic disorder that affects the _____.
    a. Bones
    b. Blood
    c. Brain
    d. Skin
  - What are the signs and symptoms of sickle cell disease?
    a. Fatigue or tiredness
    b. Pain
    c. Jaundice (yellowing of the skin and eyes
    d. All of the above

Epstein, I., Stinson, J., & Stevens, B., *Journal of Pediatric Oncology Nursing (2005): 22(2), 89-103.*

Assessment of Knowledge – year 2

- **What have we tried?**
  - Pre/Post Quiz
  - Simplified
    - Written on 1st/2nd grade level
    - Answer Key Given
  - Cross Word format
- **Results**
  - Limited



Camp Silver Moon Knowledge Assessment

Date:_____

Name:_____

Birthday:_____

Word Bank	
Doctor	Medicine
Pain	Red
SilverMoon	Hemoglobin
White	Water
Blood	Oxygen
Nurse	Cold
Yellow	Parent

Across

2. What is the name of our camp?

4. Dehydration and _____ can trigger a pain episode/crisis.

9. Red blood cells contain _____.

10. A person with Sickle Cell disease should drink plenty of _____?

Down

1. Some people take _____ to give them more healthy red blood cells.

3. What color are the cells that carry oxygen around your body?

5. Hemoglobin helps carry _____ to all parts of the body.

6. Sickle Cell is a genetic disorder that affects the _____.

7. Sickle Cells can block the small blood vessels causing _____.

8. Who should you see if you have a fever or have trouble breathing?

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Assessment of Knowledge

- **Are we Assessing the Right Thing?**
  - "What is stressful or hard fro you about having SCD or treatment for SCD?"
  - "What is the hardest part of SCD or its treatment for you right now?"
  - "Is there anything about SCD or its treatment that might be hard for you in the future?"
  - "What do your parents do to help you deal with SCD or its treatment?"

"A thorough understanding of coping has important implications for clinical practice, assessment development and refinement, and interventions to promote positive psychosocial outcomes for children with SCD."

Assessment of Knowledge – year 3

- **Expected for 2019**
  - Electronic
  - Child Friendly Format
  - Focus on Psychosocial Impact of diagnosis and treatment
  - Audible
- **What we want**
  - User Friendly
  - Limited time involvement
  - Qualitative/Quantitative
  - Adapt educational needs based on results

Where Do We Go From Here?

- **Possible small group education sessions**
  - Pill Swallowing
  - Pain Management
  - Anxiety Management
  - Emotional Self-Regulation
- **Transition**
  - Teen Cabin 13-16 years
  - Counselor In Training Program 17– 18years
  - Should an Adult SC provider be at camp?

- **What we consider when choosing education at camp.**
  - Group or Individual
  - Is there time?
  - Is this appropriate for camp?
  - Does it fit in anywhere else?

Gillard, A., Space, S. (2014).. American Camp Association. http://acacamps.org/volunteers/care/carebriefings

Andemariam, B., Owarish-Gross, J., et.al.,. Pediatric Blood Cancer 2014;61:697-701.

Providing a residential camp experience for children with Sickle Cell and their siblings.

Teach, Advocate. Empower. Inspire.

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QUESTIONS?