The Influence of Health-Seeking Behavior on the Health Literacy of Adolescents with Sickle Cell Disease

Elizabeth Perry Caldwell, PhD, RN
Libby Rosonet, DNP, RN, CPHON

Baylor University
Speaker Disclosure Statement

**Elizabeth Perry Caldwell, PhD, RN and Libby Rosonet, DNP, RN, CPHON have no industry relationships to disclose.**
Learning Objectives

• At the end of this presentation, the learner will be able to:
  • define health-seeking behaviors of adolescents with SCD
  and
  • describe the influence of health-seeking behaviors on health literacy levels in adolescents with SCD.
• Between 94% and 98% of children with sickle cell disease (SCD) are living to age 18 years and beyond.
• Significant morbidity and mortality occurs after transfer from pediatric care to adult care
  • **Hypothesis:** Health literacy plays a role in this transition.
• **Health literacy**: “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”. (Ratzan & Parker, 2000)
Purpose

The purpose of this study was twofold:

a) to explore health-seeking behaviors of adolescents with SCD and

b) to determine if there are significant differences in health literacy levels of adolescents with SCD based upon health-seeking behaviors.
Methods

• Cross sectional, descriptive study

• Convenience sampling from large, tertiary care center in Dallas, TX

• **Sample:** 134 Black, non-Hispanic adolescents with SCD between 10-19 years of age

• **Inclusion Criteria:** Diagnosis of one of the four primary genotypes of SCD, English as primary language and age 10-19 years

• **Health Literacy:** Newest Vital Sign (NVS) health literacy instrument
Results

Sample

• 134 Black, non-Hispanic adolescents with SCD
  • 71 males (53.4%) and 62 females (46.6%)

• Mean age: 14.8 years (SD=2.2)

• Age range: 10.3-18.4 years

• Mean grade level: 8.5

• Mean NVS score: 2.7 (SD=1.6)
  • Possibility of “limited” health literacy
Results

Research Question 1: Health-seeking behavior

• When asked “Where do you go first for health information?” 110 participants responded.

• The two most common responses were the Internet (29.6%; n=40) and health care providers (27.4%; n=37)

• No participants chose “radio” or “magazines”
Results

Health Seeking Behavior

- Internet: 37%
- Healthcare Providers: 34%
- Friends/Family: 13%
- SCDAA: 8%
- Books: 3%
- Other: 3%
- TV: 1%
- No Answer: 1%
Results

Research Question 2: Health-seeking behavior and health literacy

- There was no difference in health literacy scores based on health-seeking behaviors

NVS Scores Based on Health-Seeking Behaviors

<table>
<thead>
<tr>
<th>Source</th>
<th>Mean (n)</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Internet</td>
<td>2.5 (40)</td>
<td>1.6</td>
</tr>
<tr>
<td>Healthcare Providers</td>
<td>2.9 (37)</td>
<td>1.3</td>
</tr>
<tr>
<td>Friends and Family</td>
<td>3.2 (14)</td>
<td>1.6</td>
</tr>
<tr>
<td>SCDAA</td>
<td>2.1 (9)</td>
<td>1.5</td>
</tr>
<tr>
<td>Books</td>
<td>3.3 (4)</td>
<td>2.4</td>
</tr>
<tr>
<td>Other</td>
<td>2.3 (3)</td>
<td>1.5</td>
</tr>
</tbody>
</table>
Discussion

• Different results than previous studies that show African-American adolescents go 1st to friends and family (Manganello, 2016)
  • Caregiver health literacy does NOT influence adolescent health literacy in adolescents with SCD (also different) (Caldwell, 2019).
  • Perhaps because chronic illness (previously only 12% had chronic illness) leads to more independence and trust with healthcare providers?
Discussion

• Web-based interventions?
• Healthcare providers’ responsibility?
• Role of family and peers?
Discussion

• **Future Research:**
  - National sample
  - Measure e-Health literacy
  - Further evaluation of technology (using smartphones or computers?)
  - Development of health and health literacy interventions in adolescents with SCD
Conclusions

• Adolescents with SCD prefer the Internet and healthcare providers as their 1st source of health information.
• There is no relationship between type of health-seeking behavior and health literacy of adolescents with SCD.
• Future research is indicated to provide more insight into both of these findings.
Acknowledgements

• Thank you to all of our brave patients and amazing staff at Children’s Health Dallas for your unwavering help with this project.

**This study was funded by grants from Baylor University, Sigma Theta Tau and the Rew Graduate Fellowship at the University of Texas at Austin.**