

# A Health Literate Approach to Create a Virtual Sickle Cell Trait Education Program

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Health Literacy Annual Research Conference 2020  
October 20, 2020



**We have no disclosures.**

# Background

- ~2,000 infants born annually with Sickle Cell Disease (SCD)
  - Autosomal recessive chronic blood disorder
  - Complications: pain, stroke, early mortality
  - Primarily affecting minorities
- ~3 million people in US have Sickle Cell Trait (SCT)
  - Typically asymptomatic
  - At risk for having children with SCD
    - Must be knowledgeable about their own SCT status; SCD; & partner's SCT status
  - Commonly unaware they have it<sup>1</sup>
  - Reliably detected through universal newborn screening (NBS)
- NBS SCT Education programs
  - Vary by state
  - Not rigorously evaluated for effectiveness



<sup>1</sup>Treadwell MJ, McClough L, Vichinsky E. J Natl Med Assoc 2006.

## Pre-COVID – Ohio:

# Individual In-person SCT Education for Parents of Young Children with SCT

- Purpose:
  - Understand SCT & SCD basics
  - Encourage parents to be tested since they are also at risk of having SCT
  - Use results to make informed reproductive decisions
  - Inform their children who have SCT of their status when older
- Trained Educator
  - Verbal & visual materials, but no formal curriculum
- ~800 infants with SCT born annually in Central Ohio
  - ~60% have  $\geq 1$  parent attend the in-person education
- Previous knowledge assessment among participating parents<sup>2</sup>:
  - 52% w/ low health literacy (HL)
  - 90% w/ high SCT knowledge immediately post-session
  - Lower baseline & gains in knowledge among parents with limited HL
  - Long-term knowledge retention uncertain
  - Despite reporting intention to obtain SCT testing, none did

<sup>2</sup> Creary S, et al. *Mol Genet Genomic Med.* 2017.

# COVID – Ohio:

## Change to Telephone-only SCT Education

- March 2020
  - Prompted by social distancing and funding changes
  - Does not include any visual materials
- **Opportunity** to apply findings from a HL-focused review & evaluation of the in-person education to establish a HL-informed individually- and virtually-delivered SCT education program — SCTaware
  - Accessible
  - Engaging
  - Adherent to HL principles & best practices
  - Promote sustained SCT knowledge retention
  - Actionable

# Methods: Review & Evaluation Participants

- Recruitment:
  - Biologic parent(s) of children <3yo w/ SCT identified by NBS attending Summer 2019 in-person SCT education
    - English proficiency
  - Enrollment goal:  $\geq 3$  w/ low HL &  $\geq 3$  w/ low SCT knowledge
- Videotaped in-person sessions
- Verbally-administered measures:
  - Newest Vital Sign (NVS)
    - <4 = limited HL
  - SCT Knowledge Assessment (SCTKA)
    - <75% correct = low SCT knowledge
  - Education Effectiveness Survey
  - SCT Testing Needs Assessment

Measure	Before	After
Demographics	x	
Newest Vital Sign	x	
SCT Knowledge Assessment	x	x
Education Effectiveness Survey		x
SCT Testing Needs Assessment		x

# Methods: Videotaped Session Review & Print Materials Assessment

- Multidisciplinary evaluator SCT Team:
  - 2 pediatric hematologists; 2 HL experts; primary care pediatrician; adult learning theory expert; genetic counselor; 2 parent stakeholders (children w/ SCT & SCD); SCT educator
  - Four 2-hour small group review meetings
    - Content
    - Order
    - Teaching methods
    - Effective components
    - Opportunities for improvement
    - Length
- Print Materials Assessment:
  - 3 trained evaluators independently scored in-person session materials, then met to finalize scores
    - PEMAT A/V: understandability & actionability
    - CDC-CCI—modified: clarity

# Results: Parents Receiving In-person SCT Education, Summer 2019

<b>Descriptive Characteristics (n=7)</b>	
<b>Characteristic</b>	<b># (%)</b>
<b>Female</b>	6 (86%)
<b>Age</b>	
18-24 years	2 (29%)
25-39 years	5 (71%)
<b>Race</b>	
Black	4 (57%)
White	2 (29%)
More than one	1 (14%)
<b>Household Annual Income</b>	
< \$10,000	2 (29%)
\$10,000-\$20,000	1 (14%)
\$20,001-\$35,000	2 (29%)
\$35,001-\$50,000	1 (14%)
\$50,001-\$75,000	1 (14%)
> \$75,000	0
<b>Highest Education Level</b>	
Some high school	2 (29%)
High school graduate	3 (43%)
Some college	1 (14%)
College graduate	1 (14%)
<b>Primary Language in Home</b>	
English	6 (85%)
Other	1 (14%)

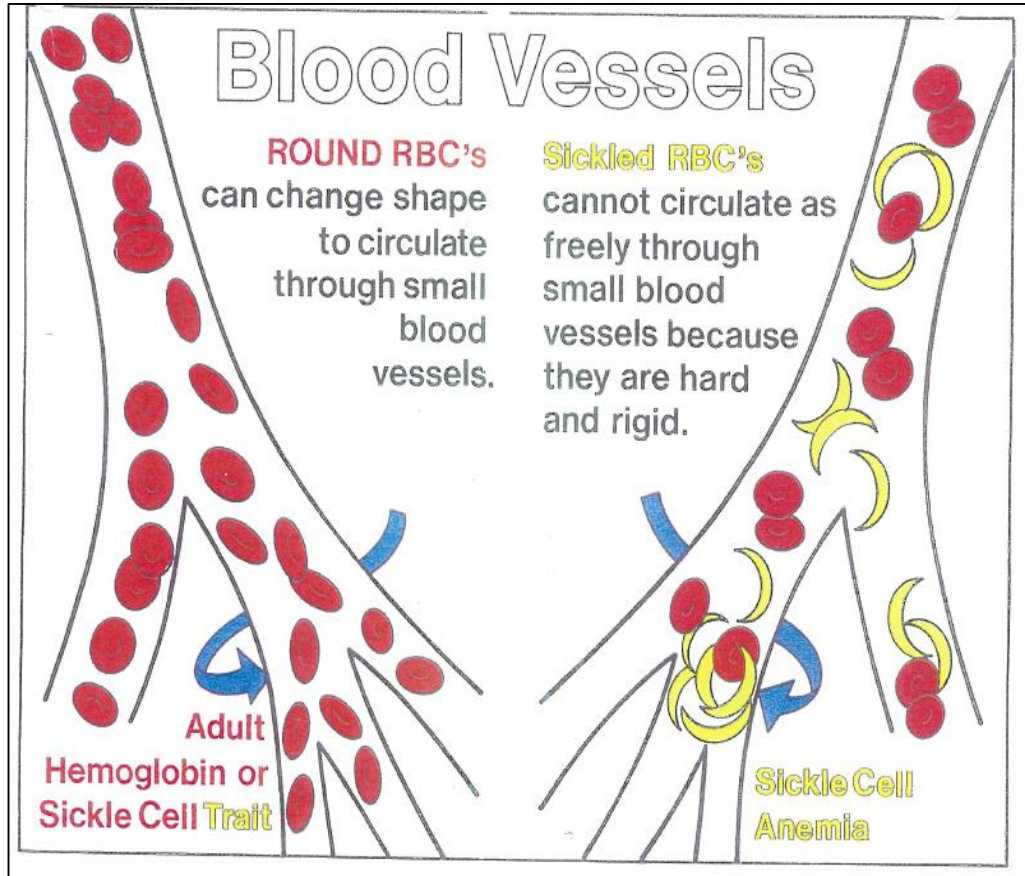
<b>Health Literacy &amp; SCT Knowledge (n=7)</b>	
<b>Parent Survey Responses</b>	<b># (%)</b>
<b>Health Literacy (NVS)</b>	
Limited health literacy (<4)	3 (43%)
Adequate health literacy	4 (57%)
<b>Baseline SCT Knowledge (SCTKA)</b>	
Low (<75% correct)	4 (57%)
High (≥75% correct)	3 (43%)



# Results: Videotaped In-person Education Review Observations

- Parent Experience:
  - Appeared comfortable
  - Engagement/participation low
  - Asked few questions
  - Encountered occasional distractions (e.g., young child)
- Education Delivery & Content:
  - Caring tone & pace; established rapport
  - Information provided in consistent order from session to session
  - Consistent non-directive genetic counseling
  - No response to body language suggesting parent confusion
  - Closed questions without teach-back
  - Limited explanation of visual print materials
  - Omission of need-to-know concepts
  - Jargon & undefined technical terms
  - Interchanged similar medical terms (e.g., sickle cell trait & sickle cell disease)
  - Purpose of some content not clearly evident
- Median length of in-person sessions - 10:47 (range 7:53-21:59)

# Results: In-person Print Materials Assessment



Average Scores of All In-person Education Visual Materials (n=18)	
Tool*	Score (range)
<b>PEMAT-A/V</b> Understandability Actionability	<b>2.83 (0-4)</b> <b>0.06 (0-1)</b>
<b>CDC-CCI—Modified</b> Clarity	<b>2 (0-4)</b>

\* PEMAT-A/V = Patient Education Materials Assessment Tool for Audiovisual Materials  
 CDC-CCI—Modified = Modified CDC Clear Communication Index

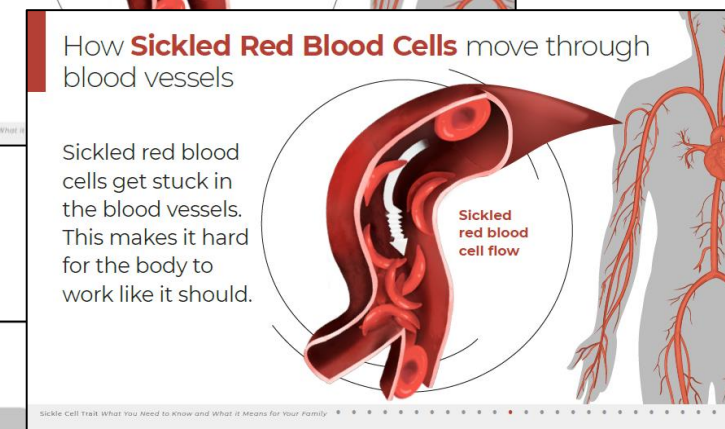
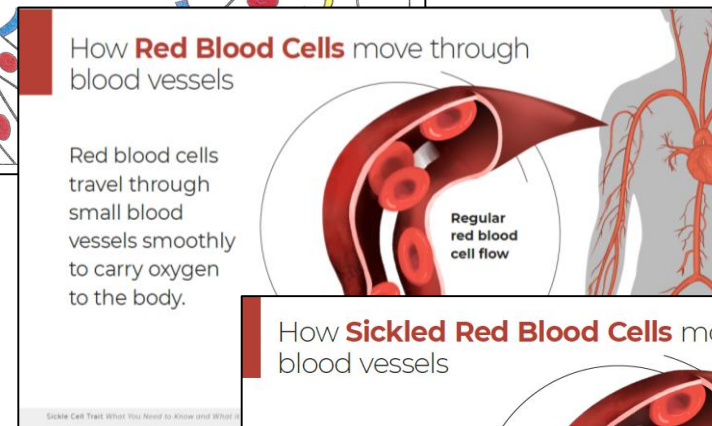
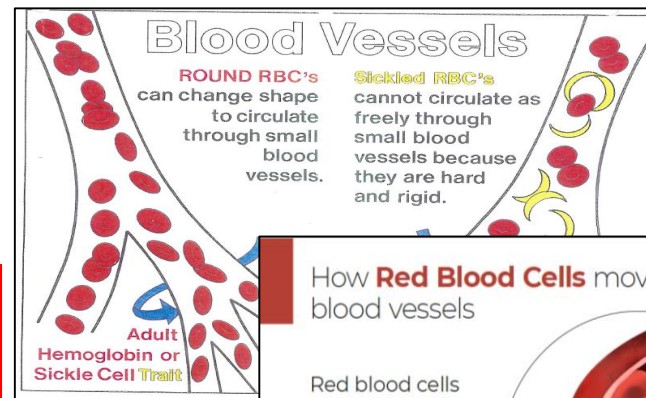
# Creation of Virtual SCTaware Education Program

- Purpose: close knowledge gaps & lead to high actionable, sustained SCT knowledge
- 5 Primary SCT Knowledge Objectives
- Plain Language SCT Talking Points Guide
  - Content organized to ensure coverage of all key concepts
  - HL-informed strategies:
    - Plain Language
    - Chunk & check
    - Teach-back for key messages
    - Open-ended questions
    - Prompts to encourage parent questions
  - Use to train Educator, develop visual materials, & guide Educator through virtual session
- Visual materials developed by design team
  - Culturally-diverse
  - Accessible (device; color-blind; narrated version available after session)
  - Iterative review, testing, & revision in collaboration w/ evaluator SCT Team

# SCTaware Education Program Print Materials

Comparison of Scores of Selected In-person & Virtual Education Visual Materials		
Red Blood Cell Flow	In-person (n=1)	Virtual (n=2; mean)
<b>PEMAT-A/V*</b>		
Understandability	4/11 (36%)	8/8 (100%)
Actionability	0/3 (0%)	0/3 (0%)
<b>CDC-CCI—Modified*</b>		
Clarity	2/6 (33%)	3/5 (60%)
<b>In Your Own Words</b>	<b>In-person</b>	<b>Virtual (n=1)</b>
<b>PEMAT-A/V*</b>		
Understandability	N/A	7/8 (88%)
Actionability		3/3 (100%)
<b>CDC-CCI—Modified*</b>		
Clarity	N/A	5/5 (100%)

\* PEMAT-A/V = Patient Education Materials Assessment Tool for Audiovisual Materials  
 CDC-CCI—Modified = Modified CDC Clear Communication Index



# Creation of Virtual SCTaware Education Program

- Educator Training

- Existing 2-day Hemoglobinopathy Counselor Training Course
- Experiential HL training:
  - AMA video: *Health Literacy and Patient Safety: Help Patients Understand*
  - 1-on-1 discussion w/ HL content expert
  - *Always Use Teach-back!* Toolkit Interactive Learning Module  
<http://www.teachbacktraining.org/home>
- Genetic Counseling training & observation
- Role-play SCTaware education – observation & practice
- Ensure fidelity via observation of selected sessions & ongoing coaching

- SCTaware Education Assessment

- Number of knowledge objectives covered
- Adapted Teach-back Observation Tool
- Parent engagement

The image shows a screenshot of a form titled "Always Use Teach-back!" with the subtitle "Teach-back Observation Tool". The form includes fields for "Care Team Member:" and "Date:". Below these is a table for observation. The table has columns for "Yes", "No", "N/A", and "Comments". The rows of the table contain the following questions and criteria:

Observer:	Yes	No	N/A	Comments
Did the care team member... Use a caring tone of voice and attitude?				
Display comfortable body language, make eye contact, and sit down?				
Use plain language? Ask the patient to explain in their own words what they were told to do about: • Signs and symptoms they should call the doctor for? • Key medicines? • Critical self-care activities? • Follow-up appointments? Use non-shaming, open-ended questions? Avoid asking questions that can be answered with a yes/no				

# Next Steps

- October 2020 – Implement virtual SCTaware education
- Review & evaluate effectiveness among parents 6 months after receiving telephone-only education:
  - Assess parent knowledge
    - Close knowledge gaps?
    - Sustain knowledge gains?
  - Feasibility
  - Accessibility (device; transportation barriers)
  - Acceptability
  - Actionability
  - Generalizability

# Conclusion

- HL-informed review & evaluation of in-person SCT education used to create virtual SCTaware education program
  - Tools available, easy to use (PEMAT, CDC-CCI, on-line HL resources, parent feedback)
  - May serve as model for other health education topics & interventions, e.g., SCD, non-hematologic conditions
- Addressing HL an important component of interventions to reduce health disparities
  - Convey clear actionable communication that supports long-term retention
  - Assess & ensure understanding
- Imperative to incorporate HL-informed strategies into all educational programs, especially virtual formats
  - Use will likely remain high
  - Mitigate risk of being ineffective, especially for populations with learning barriers like low HL
  - Potential to improve access, flexibility, satisfaction, & outcomes

# Acknowledgements

- R03HL146877 from the National Heart, Lung, and Blood Institute
- The Ohio Department of Health