Navigating Health Literacy in Pediatric Sickle Cell Disease

Jean L. Raphael, M.D., M.P.H.
Assistant Professor of Pediatrics
Baylor College of Medicine

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Sickle Cell Disease

- Inherited autosomal recessive disease of the red blood cell (RBC)

- RBC are sickle shaped and unable to transport oxygen effectively

- Complications include anemia, pain episodes, infections, stroke, and end organ damage
Sickle Cell Disease

• 90,000 – 100,000 individuals in US

• Most prevalent among those of sub-Saharan Africa, Mediterranean, Saudi Arabian and Latin American descent.
Rationale for Assessing Health Literacy among Sickle Cell Population

- Chronic condition that predominantly affects underserved children
- Poor adherence to care
- Translational gap between scientific advances and health outcomes

Research to Date

Understanding Health Literacy within Sickle Cell Disease
Parental Factors Associated with Child Health Care Utilization

- **Site:** Texas Children’s Hospital

- **Objective:** Determine parental factors associated with pediatric utilization in cross sectional study

- **Population:** 150 caregivers of children with SCD

- **Administration of Test of Functional Health Literacy in Adults (TOFHLA)**
Parental Factors Associated with Child Health Care Utilization

• Mean score 34.8, range 26-36

• All parents met criteria for functional health literacy (score ≥ 23)

• Findings likely represent limitations of TOFHLA in pediatrics

• No associations between parental health literacy and health care use
Health Literacy of Young Adults with Sickle Cell Disease

- Site: Cincinnati Children’s Hospital
- Objective: Identify health literacy skills of adolescents and young adults with SCD
- Population: 37 adolescents with SCD, ages 14-22
- Administration of Rapid Estimate of Adolescent Literacy in Medicine (REALM-Teen) and demographic survey

Health Literacy of Young Adults with Sickle Cell Disease

- 48% scored 6-7th grade
- 20% scored 10th grade or above
- 8% scored less than third grade
Health Literacy of Young Adults with Sickle Cell Disease

- Confidence in understanding medical information
  12% always, 52% usually, 36% half the time

- Confidence in understanding directions on prescriptions
  62% always, 20% usually, 18% half the time
Patient Navigation

An Intervention to Improve Health Literacy
Patient Navigation

• Theoretical and conceptual roots in cancer care

• Barrier driven intervention to improve care for minority and underserved populations

• Patient navigators provide individualized assistance to patients


Evidence Base for Patient Navigation

- Timeliness of definitive diagnosis
- Timeliness to initiation of therapy
- Patient satisfaction
- Quality of Life

Policy Implications of Patient Navigation

- Innovative approach to health disparities
- Interactive intervention to address health literacy
- Potentially cost-effective strategy
Information-Motivation-Behavioral Skills (IMB) Model

A Conceptual Model for Patient Navigation
IMB Model

- Information, motivation, and behavioral skills are determinants of health-related behaviors

- Validated with a number of behaviors including medication adherence, high risk adolescent behavior, physical activity, and nutritional intake


Information-Motivation-Behavioral Skills (IMB) Model

Health literacy works throughout model

ADHERENCE INFORMATION

ADHERENCE BEHAVIORAL SKILLS

ADHERENCE MOTIVATION

MODERATING FACTORS AFFECTING ADHERENCE

ADHERENCE BEHAVIOR

HEALTH OUTCOMES
Designing a Patient Navigator Intervention

A Research Plan for Sickle Cell Disease
Specific Aim 1

- Assess in a longitudinal study the relationships between IMB measures, health literacy, and health resource utilization

- **Hypothesis:** Low scores on IMB measures and health literacy will be associated with increased emergency care visits and hospitalizations
Specific Aim 2

• Develop a 6-month parent navigator program for parents of school-age children with SCD informed by parent focus groups, an expert panel, and quantitative data from Specific Aim 1
Specific Aim 3

• Test the feasibility of a 6-month pilot parent navigator program on health outcomes including utilization, IMB measures, and health literacy

• *Hypothesis*- Parents who complete the navigator program will increase scores on IMB measures and health literacy
Conclusions

• Children with sickle cell disease represent a high-cost, resource intensive, and underserved group of children

• Research demonstrates that health literacy needs to be addressed

• Patient navigation represents a novel approach to health literacy among minority and underserved populations