



Navigating Health Literacy in Pediatric Sickle Cell Disease

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**Texas Children's
Hospital®**

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**

Raphael JL, Kavanagh KL, Wang CJ, Mueller Bu, Zuckerman B. Translating scientific advances to improved outcomes for children with sickle cell disease: a timely opportunity. *Pediatric Blood Cancer*. 2011;56(7):1005-8.

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 \geq 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**

Shook M. A Pilot Study of the Health Literacy of Adolescents and Young Adults with Sickle Cell Disease. Abstract # 266546. *American Public Health Association Meeting*. October 2012.

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**

Freeman HP. A model patient navigation program. *Oncol Issues* 2004;19:44-6.

Dohan D, Schrag D. Using navigators to improve care of underserved patients: current practices and approaches. *Cancer* .2005;104:848-55.

Evidence Base for Patient Navigation

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

Wells KJ, Battaglia TA, Dudley DJ, et al. Patient navigation: state of the art or is it science? *Cancer* 2008;113:1999-2010.

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

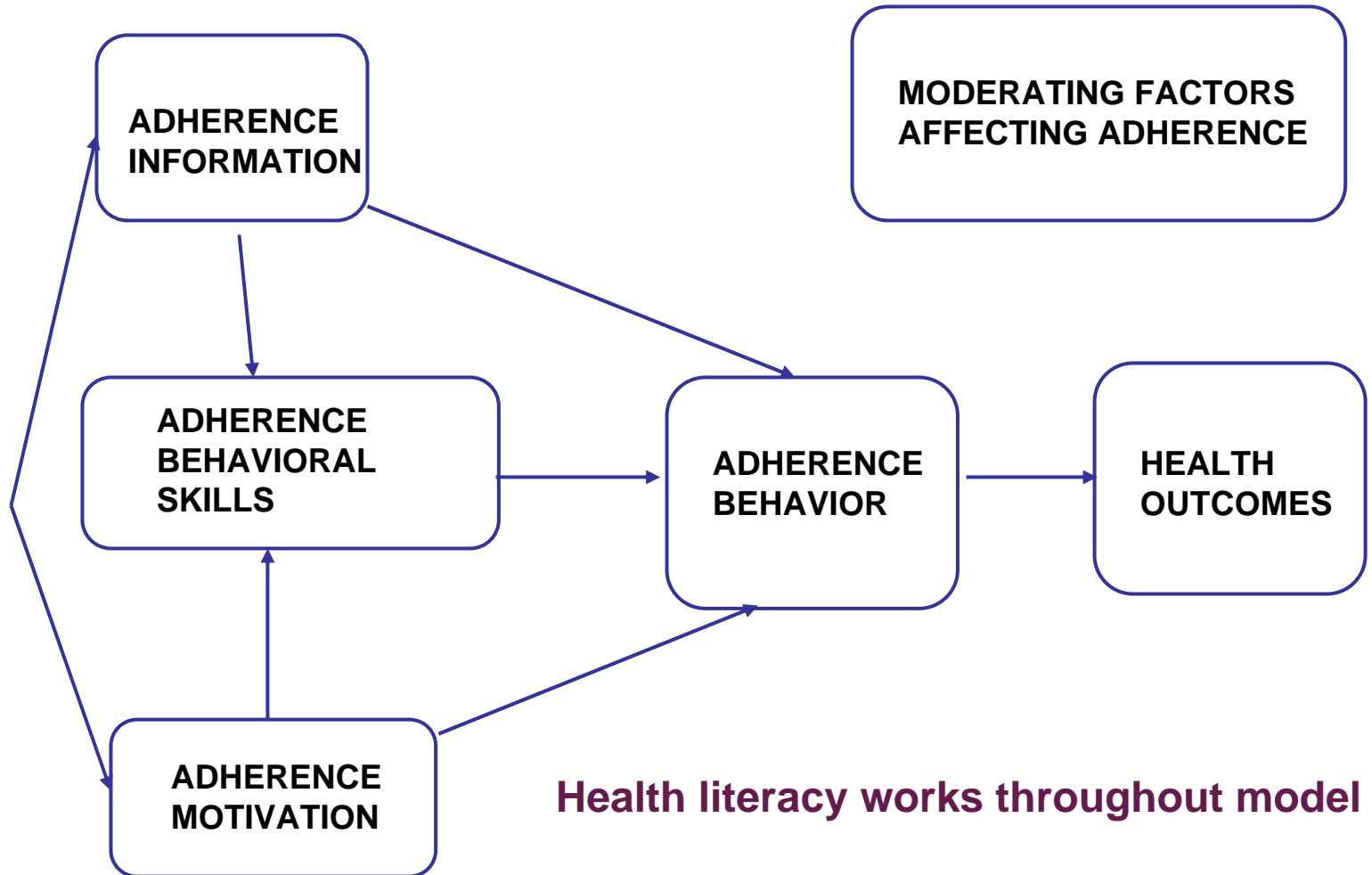
IMB Model

- **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**

Fisher JD, Fisher WA, Amico KR, et al. An information-motivation-behavioral skills model of adherence to antiretroviral therapy. *Health Psychol* 2006;25(4):462-473.

Kelly S, Melnyk BM, Belyea M. Predicting physical activity and fruit and vegetable intake in adolescents: a test of the information, motivation, behavioral skills model. *Res Nurs Health* 2012;35(2):146-163.

Information-Motivation- Behavioral Skills (IMB) Model



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**

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