Do Health Literacy
Disparities Explain
Racial Disparities in
Family Centered Care for
Youths with Special
Health Care Needs?



Deena J. Chisolm, PhD, Millie Harris, PhD, Laura Chavez, PhD, Mary Ann Abrams, MD, Lee Sanders, MD



Background

- The Teen Literacy in Transition Study (TeenLit) explores the role of teen and parent health literacy in information seeking, disease self-management, and transition readiness in youth with special health care needs (YSHCN)
- One important healthcare characteristic being studied is family centered care (FCC).



Youth with Special Health Care Needs (YSHCN)

- Criteria (National Survey on Children with SHCN):
 - Prescription medications
 - Medical care, mental health services, or education services
 - Emotional, developmental, or behavioral problem
 - Limitation compared to other children of same age
 - Special therapy



Family Centered Care (FCC)

 FCC is an approach to the planning, delivery, and evaluation of health care that is grounded in partnerships among providers and patients and their families

FCC is associated with improved health outcomes for YSHCN



Racial Disparities in FCC

 Persistent racial disparities in FCC may exacerbate disparities in health outcomes

Objectives

 Examine racial differences in health literacy (HL) and teen-assessed FCC

 Test whether HL moderates the relationship between race and FCC.



Methods

- Study population: 384 YSHCN ages 12-18 enrolled in pediatric Medicaid ACO and their healthcare responsible parent/guardian
- HL assessed using Rapid Estimate of Adult Literacy in Medicine (REALM) (standard and teen versions)
- FCC measured using an index: time spent with patients, careful listening, cultural sensitivity, provision of specific information, and engaging the patient as a partner



Analyses

 Group differences in HL and in FCC by race was explored for parents and teens

 A moderation analysis using logistic regression also explored whether racial disparities in FCC differs by level of HL



Sample Characteristics

Table 1: Teen demographics by race						
	n (%)	AA%	NHW%			
Total	384	134 (34.9)	250 (65.1)			
Gender						
Female	197 (51.3)	79 (58.96)	118 (47.2)			



Differences Among HL and FCC by Race

Table 2: Chi-square differences among measured health literacy and FCC among AA and NHW teens with chronic illness and their parents

	Teens		Parents			
	AA (%)	NHW (%)	AA (%)	NHW (%)		
Measured health literacy						
REALM adequate	41.8**	56.4	71.3**	85.5		
FCC clinical communication (usually or always). During the past 12 months, how often						
1.Did providers spend enough time with you?	41.0**	60.8	62.0**	77.2		
2.Did providers listen carefully to you?	76.1	80.0	84.5	85.9		
3.Did you get information from providers?	59.7	68.8	77.5	79.2		
4. Were providers sensitive to your family's values?	58.2	67.6	81.4	82.3		
5.Did providers help you feel like a partner?	62.7	68.8	82.2	84.3		
FCC composite measure	20.9**	35.2	49.6 ⁺	59.2		

⁺ p<0.10, *p<0.05, **p<0.01

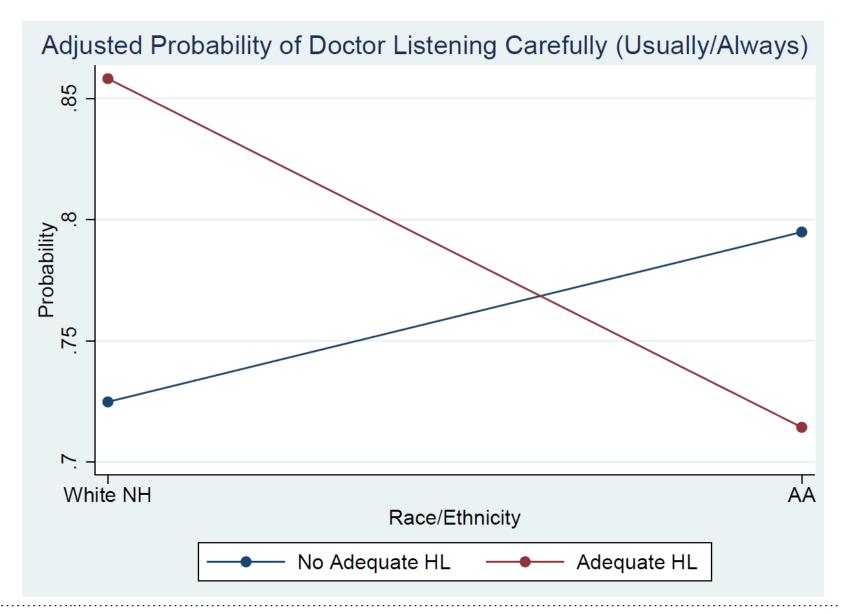


Moderation Analysis

Table 3: Health literacy moderators of racial disparities in perceptions of FCC among teens							
How often did providers spent enough time	Coeff.	SE	Z	p-value			
with you?							
Intercept	0.166	0.19	0.861	0.389			
Adequate HL	0.496	0.26	1.894	0.058			
AA race	-0.423	0.30	-1.418	0.156			
Adequate HL x AA race	-0.749 ⁺	0.44	-1.688	0.091			
How often did providers listen carefully to you?							
Intercept	0.968**	0.21	4.515	0.000			
Adequate HL	0.832**	0.32	2.576	0.010			
AA race	0.386	0.35	1.094	0.247			
Adequate HL x AA race	-1.270*	0.52	-2.442	0.015*			
How often did providers help you feel like a							
partner in your care?							
Intercept	0.428*	0.20	2.186	0.029			
Adequate HL	0.680*	0.28	2.459	0.014			
AA race	0.151	0.31	0.493	0.622			
Adequate HL x AA race	-0.824 ⁺	0.45	-1.811	0.070			

⁺ p<0.10, *p<0.05, **p<0.01







Discussion

 African American teens have disproportionally low experiences of FCC, a key component of the medical home and a predictor of health outcomes.

 Reducing disparities in FCC, which has the potential to reduce disparities in outcomes, will requires multifaceted approaches, policies, and programs that consider culture, HL, and communication needs.



References

- Committee on Hospital Care and Institute for Patient and Family Centered Care. Patient- and family-centered care and the pediatrician's role. Pediatrics. 2012 Feb;129(2):394-404
- 2. Davis TC, Long SW, Jackson RH, et al. Rapid estimate of adult literacy in medicine: a shortened screening instrument. *Family Medicine*. 1993;25(6):391-395.
- Davis TC, Wolf MS, Arnold CL, et al. Development and validation of the Rapid Estimate of Adolescent Literacy in Medicine (REALM-Teen): a tool to screen adolescents for below-grade reading in health care settings. *Pediatrics*. 2006;118(6):e1707-1714.
- 4. US Department of Health and Human Services HRaSAMaCHB. The National Survey of Children with Special Health Care Needs Chartbook 2005-2006. Rockville, MD2008.



Acknowledgements

 Research supported by NIH/NIMHHD #1R01MD007160-01A1

 Additional support for data collection provided by CTSA Grant #UL1TR001070



Thank You!

