Stephen Nelson, M.D.

Stephen Nelson, M.D., attended medical school and completed his pediatric residency at Eastern Virginia Medical School in Norfolk, Virginia. His pediatric hematology/oncology fellowship was completed at Duke University Medical Center in Durham, North Carolina. Dr. Nelson joined the hematology/oncology program at Children's of Minnesota in 1993. He is the director of the Sickle Cell Clinic. His interests include working to decrease racial health care disparities.
Race, Racism and Health Inequity: What can we do about it?

MAPS 2018 Conference
“Reigniting Our Passion for Safe Care”

October 25, 2018

Stephen C. Nelson, MD
Director, Hemoglobinopathy Program

Nothing to Disclose
Race Matters: Perceptions of Race and Racism in a Sickle Cell Center

Stephen C. Nelson, MD* and Heather W. Hackman, MD

Background: Health care disparities based on race have been reported in the management of many diseases. Our goal was to identify perceptions of race and racism among both staff and patients/families with particular attention to provider attitudes as a potential contributor to racial healthcare disparities. Procedure. A confidential survey addressing issues of race and health care was given to all patients with sickle cell disease and their families upon arrival to clinic. The survey was made available online to all staff in the hematology/oncology program. Free text comments were obtained. Results. We received completed surveys from 112 patients/families. Surveys were completed by 135 of 156 staff members (85% return rate). The majority (92.6%) of patients/families identified as black, while 94.1% of staff identified as white (P < 0.001). More patients/families felt that race affects the quality of health care for sickle cell patients (60% vs. 33.6%, P = 0.003). More staff perceived unequal treatment of patients, especially in the inpatient setting (20.9% vs. 10.9%, P = 0.03). Conclusions. Provider attitudes contribute to continued racial health care disparities. We propose training health care providers on issues of race and racism. Training should provide critical thinking tools for improving medical providers’ comfort and skills in caring for patients who are of a different race than their own. Pediatric Blood Cancer 2013;60:451–454. © 2012 Wiley Periodicals, Inc.

Keywords: health care disparity; race; sickle cell disease
It is less useful to continue to characterize an insidious problem if these efforts do not result in the design and implementation of interventions that lead to meaningful change.

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Figure 1: Life expectancy, by race and sex, United States, 1999–2013

SOURCE: CDC/NCHS, National Vital Statistics System: Mortality
Why?

- Genetics
- SES, insurance, access, education

- Racism, Unconscious bias, Stereotypes
Why?

• Genetics
Human Genome Project

- 1990s
- > 60 families’ genes analyzed
- NO people of African descent
- Howard University belatedly invited

- Race has no genetic basis
- Human subspecies do not exist
- Most variation is within, not between “races”
- www.understandingrace.org

Why?

- SES, insurance, access, education
• “racial disparities”
• 2003- present
• 9455 citations!!
• 550 per year
• Over 10 articles per week

Racial/Ethnic and Socioeconomic Disparities in Survival Among Children With Acute Lymphoblastic Leukemia in California, 1988–2011: A Population-Based Observational Study

Renata Abraham, md, ms, 1,2,5,6 Daphne Y. Lichtenstein, md, s, er, 7 Karl C. Robbie, md, 3 Neyra M. Marins, md, 4 Ruth H. Keogh, md, 5 Rafael Marcon-Gregora, md, ss, no, 6, 7 Sally L. Glauser, md, 8, 7 and Theresa H.M. Keghan, md, ss, no, 6, 7

Fig 1. Overall survival by race/ethnicity among children (0–19 years old) diagnosed with acute lymphoblastic leukemia in California, 1988–2011.
NHDR Results

- Race is an independent factor

How are we doing in Minnesota?
### Twin Cities Mortality-Wilder Study

- Race is an independent factor
Children with long bone fracture
• ED 1-yr period
• N=880 with pain scores
• Time from injury to arrival in ED
  - White 8.3 hours
  - Black 10.7 hours \( p=0.014 \)
  - Biracial 11.9 hours \( p=0.004 \)
  - Native American 18.4 hours \( p=0.025 \)

76,931 ED encounters
• Mar 2, 2009- Mar 31, 2010
• Wait Times
  - White 32 minutes
  - Black 37 minutes
  - Native American 41 minutes
  - Hispanic 39 minutes \( P<0.001 \)
**Pediatric Emergency Care** • Volume 28, Number 11, November 2012

- 76,931 ED encounters
- Mar 2, 2009 - Mar 31, 2010

**Odds Ratio of LWCET**
- Black 2.04
- Native American 3.59
- Hispanic 2.15
- Biracial 2.77

$P < 0.001$

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**Pediatric Emergency Care** Volume 29, Number 4, April 2013

- Children with long bone fracture
- ED 1-yr period
- N=878

**Opioid-containing prescription**
- White 67.4%
- Black 47.1% RR 0.59
- Hispanic 47.9% RR 0.61
- Native American 58.3% RR 0.93
- Biracial 40.3% RR 0.45
NACHRI October 2011

- Chart review long bone fractures
- Jan 1 2008-Dec 31 2010
- 2206 patients
  - 1386 M  820F
- Bone
  - Radius/ulna 1116
  - Humerus 566
  - Ankle 189
  - Tib/fib 173
  - Femur 162

Mean time to getting pain med 50.3 min

- Black 64 minutes
- White 45 minutes

IV narcotics
- White 57.8%
- Black 48.4%  p <0.001

Conclusions
- Racial and cultural differences need study to identify:
  - Variable tolerance to pain
  - Hesitation to reporting pain based on culture or poor health care literacy
Long Bone Fracture-time to analgesia

- Jan 2016-Jan 2018
- n=1308
  - 398 Black kids
  - 910 White kids
- Average time to pain meds
  - Black kids    75.9 minutes
  - White kids   60.9 minutes
  \[ p=0.039 \]
Health Care and Medical Education

DOWNSTREAM

Biology
Behavior
Society
Structure

UPSTREAM
Barriers to Equity

- **System**
  - Whiteness/lack of diversity
  - Poor access
  - Social Determinants of Health
  - transition to adult care
  - research and support money
- **Racism**
- **Patients**
  - Poor health literacy
  - Fear and mistrust
  - Internalized racism
- **Community**
  - advocacy
  - public awareness
- **Providers**
  - Implicit bias/stereotyping
  - Power
Implicit Bias

- What is it?
- How do I know?
- Does this really affect care?
- How do I avoid it?
Implicit (Unconscious) biases

- Common (Normal)
- Rooted in stereotyping
  - cognitive process where we use social categories to acquire, process, and recall information about people
- Helps us organize complex information
- Heavy cognitive load
  - rely on stereotyping to process information
  - consciously reducing this is hard work
“The problem with stereotypes is not that they are untrue, but that they are incomplete. They make one story become the only story.”

-Chimamanda Ngozi Adichie
Nigerian American novelist

Implicit Bias

• What is it?
• How do I know?
• Does this really affect care?
• How do I avoid it?
Implicit Bias

- Human
- Implicit Association Test
  - [https://implicit.harvard.edu](https://implicit.harvard.edu)

Power/Bias

- Gender/Identity
- Race
- Language
- Religion
- Sexuality
- Education
- Income
- Obesity
- Smoking
- Ability/Disability
- Deaf/Hard of hearing
Implicit Bias

- What is it?
- How do I know?
- Does this really affect care?
- How do I avoid it?
The Role of Bias by Emergency Department Providers in Care for American Indian Children

Susan E. Puaumala, PhD.† Katherine M. Burgess, MPH,‡ Anupam B. Kharbanda, MD, MSc.§ Heather G. Zuck, MA, § Dorothy M. Castille, PhD,¶ Wyatt J. Pickner, BA, BS*, and Nathaniel R. Payne, MD##

FIGURE 1. Categorized responses to the Implicit Association Test (IAT) by type: adult, IAT with pictures of adults; child, IAT with pictures of children.

Medical Care • Volume 54, Number 6, June 2016

The Effects of Oncologist Implicit Racial Bias in Racially Discordant Oncology Interactions


A

Lower patient perception of oncologist patient-centeredness

Higher oncologist implicit bias

Less patient confidence in treatment

Indirect effect = −0.13; SE = 0.05; 95% CI, −0.24 to −0.06 (n = 78)
The Effects of Race and Racial Concordance on Patient-Physician Communication: A Systematic Review of the Literature

Megan Johnson Shen¹ • Emily B. Peterson² • Rosario Costas-Muníz³ •
Milida Hunter Hernandez⁴ • Sarah T. Jewell⁵ • Konstantina Matoukis⁶ •
Carma L. Ryland⁷

Received: 18 October 2016 / Revised: 2 February 2017 / Accepted: 6 February 2017 DOI 10.1087/040615-017-0350-4

• 40 studies between 1995-2016

• Effect of Black race and racial concordance on patient/physician communication
  - Communication quality
  - Information giving
  - Patient participation in decision-making
  - Satisfaction
  - Partnership building
  - Length of visit
  - Talk-time ratio

• Black patients experienced poorer communication compared to white patients

• Racial concordance = Better communication

“Crisis”

• http://www.youtube.com/watch?v=FuelQDBOxXI

• CRISIS: Experiences of people with sickle cell disease
Implicit Bias

- What is it?
- How do I know?
- Does this really affect care?
- How do I avoid it?
Provider Training

- Diversity Training
  - Awareness
  - Appreciation

- Cultural Competency Humility
  - Cross-cultural communication
  - Information gathering
  - Skills training

Provider Training

- Social Justice
  - Oppression
  - Power
  - Societal resources
  - Structural barriers
  - Race/racism/whiteness
  - Implicit bias
Tools

• Recognize
  − Critical race lens
  − Cognitive dissonance
  − Aversive racism
  − Catch yourself seeking alternate explanations
  − Discomfort

• Health Equity Timeout
  − Emotional regulation
  − Be in the moment
  − Lean in to the discomfort

“Of all forms of inequity, injustice in healthcare is the most shocking and inhumane.”

Martin Luther King, Jr.
National Convention of the Medical Committee for Human Rights
Chicago- 1966

“Not everything that is faced can be changed. But nothing can be changed until it is faced”

James Arthur Baldwin
novelist, essayist, playwright, poet

(August 2, 1924 – December 1, 1987)