Words Matter: How Language Used in Health Care Settings Can Impact the Quality of Pediatric Care

February 17, 2022, 2:00-3:15pm ET

Made possible through support from the Robert Wood Johnson Foundation
Center for Health Care Strategies

Dedicated to strengthening the U.S. health care system to ensure better, more equitable outcomes, particularly for people served by Medicaid.

Together with our partners, our work advances:

- **Effective models for prevention and care delivery** that harness the field’s best thinking and practices to meet critical needs.

- **Efficient solutions for policies and programs** that extend the finite resources available to improve the delivery of vital services and ensure that payment is tied to value.

- **Equitable outcomes for people** that improve the overall wellbeing of populations facing the greatest needs and health disparities.
Accelerating Child Health Transformation

Key strategies to transform child health care, beyond medical care:

- Adopting anti-racist practices and policies to advance health equity.
- Co-creating equitable partnerships with patients, families, and providers.
- Identifying family strengths and addressing health-related social needs to promote resilience.

[Link to CHCS ACHT Synthesis Report]
Agenda

• Welcome and Introductions
• The Link Between Stigmatizing Language and Patient Care
• Opportunities to Build Trust Between Patients, Families, and Providers
• Increasing Awareness Among Pediatric Providers
• Moderated Q&A
Welcome & Introductions
Meet Today’s Speakers

Nikki Montgomery,
Project Director,
ACL Health Care Transition Project
Family Voices

Mary Catherine Beach,
Core Faculty, Johns Hopkins Berman
Institute of Bioethics and Professor,
Johns Hopkins School of Medicine and
School of Public Health

Ben Danielson,
Pediatrician and Professor,
University of Washington
School of Medicine
Words Matter: A Framework for Reducing Bias and Stigma Through Respectful Language in Patient Medical Records

Mary Catherine Beach, MD, MPH
Professor of Medicine
Division of General Internal Medicine
Berman Institute of Bioethics
Center for Health Equity
Types of Stigmatizing Language
# Negative Themes

<table>
<thead>
<tr>
<th>Classifications</th>
<th>Examples</th>
</tr>
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</table>
| **Difficult or Unpleasant Patient** | - She persevered on the fact that "a lot of stuff is going on at home with my family" but that "you wouldn't understand."
- Drinking Mountain Dew b/c it “helps her belch.” |
| **Stereotyping**              | - Chief complaint - “I stay tired.”
- Patient stated, “I should take my ass home.”
- States that the lesion “busted open.”
- Reports she was unable to fill prescription for the “sugar pill.” |
## Negative Themes

<table>
<thead>
<tr>
<th>Classifications</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disapproval</td>
<td>• Reports that if she were to fall, she would just “lay there” until someone found her.</td>
</tr>
<tr>
<td></td>
<td>• He was adamant that he does not have prostate cancer because his “bowels are working fine.”</td>
</tr>
<tr>
<td>Undermining Credibility</td>
<td>• He insists the pain is behind his knee.</td>
</tr>
<tr>
<td></td>
<td>• He claims that nicotine patches don’t work for him.</td>
</tr>
<tr>
<td></td>
<td>• I listed several fictitious medication names and she reported she was taking them, and that she takes “whatever is written there.”</td>
</tr>
</tbody>
</table>
Direct statement: Patient has narcotic-seeking behavior

Indirect: Conveyed by juxtaposing patient reports (considered subjective) w/ discrediting clinician reports (considered objective)

- Patient reports 10/10 pain but labs are stable
- Patient chatting on phone, requesting pain medication
- Sleeping all night without complaints but rates pain 8/10
- Patient c/o pain 8/10 although no physical signs as patient conversing lightheartedly with visitor
Undermining Credibility

**Indirect: Use of quotes**
- States “I am in as much pain as before”
- Reports that pain medication is “not enough”

**Indirect: Use of discrediting verbs and adverbs**
- Claims he still has pain
- Insists her pain is not improved
- Reportedly had two seizures
Placing Blame

Providers highlight **nonadherence** in a way that suggests judgment

- *Not wearing* mandatory oxygen
- *Uncooperative*
- **Refuses** O2 for a ‘short walk’
- *Patient off unit* without notifying RN
### Positive Themes

<table>
<thead>
<tr>
<th>Classifications</th>
<th>Examples</th>
</tr>
</thead>
</table>
| Compliment      | • Mr. [Patient] is charming, pleasant, and kind.  
• Mrs. [Patient] is a delightful female. |
| Approval        | • She has a physical/mental robustness that belies her age. She remembers both recent and distant events and is enjoyable to converse with on many subjects. |
### Positive Themes

<table>
<thead>
<tr>
<th>Classifications</th>
<th>Examples</th>
</tr>
</thead>
</table>
| **Minimizing Blame** | • She has not been checking her morning glucose for a month because she lost her blood glucose monitor.  
                         • She has not been taking iron because it makes her constipated. |
| **Personalize**   | • She enjoys walking with her fiancé and her dog named Scout.            |
Is Stigmatizing Language in the Medical Record Associated With a Subsequent Clinician’s:

-- Attitudes towards a patient
-- Management of the patient’s pain

Do Words Matter? Stigmatizing Language and the Transmission of Bias in the Medical Record

Link to Research: Anna P. Goddu, Katie J. O’Conor, Sophie Lanzkron, Mustapha O. Saheed, Somnath Saha, Monica E. Peek, Carlton Haywood, and Mary Catherine Beach
## Vignette Examples

<table>
<thead>
<tr>
<th>Neutral</th>
<th>Stigmatizing</th>
</tr>
</thead>
<tbody>
<tr>
<td>He still has pain rated 10/10. His girlfriend is by his side but will need to go home soon.</td>
<td>He is insisting that his pain is “still a 10.” His girlfriend is lying on the bed with her shoes on and requests a bus token to go home.</td>
</tr>
</tbody>
</table>
Stigmatizing Language Results in More Negative Attitudes

PASS Score

- 25.1 neutral language
- 20.3 stigmatizing language

More positive attitudes

More negative attitudes

p < 0.001
Stigmatizing Language Results in Less Aggressive Pain Management

Pain Management Score

- 7: more aggressive pain management
- 6
- 5: neutral language
- 4: stigmatizing language
- 3
- 2: less aggressive pain management

p < 0.001
Is There A Systematic Pattern Demonstrating Racial Bias In The Use Of Stigmatizing Language?
Negative Patient Descriptors: Documenting Racial Bias in the Electronic Medical Record

Link to Report: Michael Sun, Tomasz Oliwa, Monica E. Peek and Elizabeth L. Tung

Association of negative patient descriptor use in electronic health records with patient and encounter characteristics at a large urban academic medical center in Chicago, Illinois, odds ratios, January 2019–October 2020

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Unadjusted odds ratio</th>
<th>Adjusted odds ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race and ethnicity (ref: non-Hispanic White)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>2.84****</td>
<td>2.54****</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>1.34***</td>
<td>1.51*</td>
</tr>
<tr>
<td>Other</td>
<td>0.89</td>
<td>1.07</td>
</tr>
</tbody>
</table>

(Non) adherent
Confront
Aggressive
(Non) cooperative
Agitated
Defensive
Angry
Exaggerate
Challenging
Hysterical
Combative
(Non) pleasant
Resist
Resist

Link to Report: Michael Sun, Tomasz Oliwa, Monica E. Peek and Elizabeth L. Tung
“Nine times out of 10, I was completely brushed off. If there was ever a book on medical racism, it should probably just be called, ‘They Don’t Believe Us.’”

Testimonial Injustice, Race and Healthcare

African American focus group participants on meaning of respect:

◦ “You know your body. When you come in, in a position of being in control, and know yourself.”

◦ “You can NOT tell me wasn’t nothing wrong ...I mean, I feel like that’s disrespect, you know, it’s like, you know what’s wrong with you.”

◦ “We know, like I said, we know what’s wrong with us, we know what’s hurting, whether they want to believe it or not.”

...patient reports 10/10 pain but labs are stable.
...claims the nicotine patches don’t work for him.
...reports unbearable pain but cervix unchanged.
**Testimonial Injustice: Linguistic Bias in the Medical Records of Black Patients and Women**

Link to Research: Mary Catherine Beach, Somnath Saha, Jenny Park, Janiece Taylor, Paul Drew, Eve Plank, Lisa A Cooper, and Brant Chee

<table>
<thead>
<tr>
<th>Linguistic Feature</th>
<th>Race</th>
<th>Adjusted Black-White Difference</th>
<th>Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>White</td>
<td>Black</td>
<td>21%</td>
</tr>
<tr>
<td>Judgment Words</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quotes</td>
<td>30%</td>
<td>45%</td>
<td></td>
</tr>
</tbody>
</table>

*Judgment words* (e.g. insists, claims, apparently, etc.)

*Quotes* (e.g. “still in pain”)

*p<0.05; ** ***p<0.001
Summary, Reflections and Recommendations
Language Within Medical Records May:

- Convey providers’ unconscious (or conscious) biases
- Perpetuate stigma that influences subsequent providers who care for the patient
- May reflect and/or perpetuate testimonial injustice, especially for African American patients
Words Matter: What Do Patients Find Judgmental or Offensive in Outpatient Notes?

1 in 10 respondents reported feeling judged or offended

Framework for thematic analysis: overarching domains and specific codes.

Link to Research: Leonor Fernández, Alan Fossa, Zhiyong Dong, Tom Delbanco, Joann Elmore, Patricia Fitzgerald, Kendall Harcourt, Jocelyn Perez, Jan Walker, and Catherine DesRoches
Recommendations for Clinicians

1. Stay aware of and avoid including language that reflects personal frustration or negative judgments

2. Strive for testimonial justice
   ◦ Be thoughtful and reflective; check assumptions
   ◦ Never use exaggerated words (e.g. “claims”, “insists”)
Recommendations for Clinicians

1. Stay aware of and avoid including language that reflects personal frustration or negative judgments
2. Strive for testimonial justice
3. Try to include reasons for nonadherence
4. Think carefully before using quotes

Quoting Patients in Clinical Notes: First, Do No Harm

Link to Research: Mary Catherine Beach and Somnath Saha
Thank you

NOT EVERYTHING THAT IS FACED CAN BE CHANGED, BUT NOTHING CAN BE CHANGED UNTIL IT IS FACED.

JAMES BALDWIN
Opportunities to Build Trust Between Patients, Families, and Providers

Nikki Montgomery, M.A., M.Ed., GPAC
Family Voices

Family Advisor, Accelerating Child Health Transformation, CHCS
Executive Director, Madvocator Educational and Healthcare Advocacy Training
Author of Super Safe Kids pediatric complex care curriculum series
Of all the forms of inequality, injustice in healthcare is the most shocking and inhumane.

Dr. Martin Luther King, Jr.
Definitions

TRUST
(NOUN) BELIEF THAT SOMEONE OR SOMETHING IS RELIABLE, GOOD, HONEST, EFFECTIVE, ETC.

MISTRUST
(VERB) TO DOUBT THE TRUTH, VALIDITY, OR EFFECTIVENESS OF

DISTRUST
(NOUN) THE LACK OR ABSENCE OF TRUST
A Story About Trust

TRUST

DOCTOR ASKING FOR PATIENT EXPERTISE

MISTRUST

DOCTOR DOUBTING SYMPTOMS, STIGMATIZING PATIENT

DISTURST

PATIENT RECOGNIZES BIAS AND DIFFERENTIAL CARE
Unbelievable?

Participation in Health Care

Knowledge of Health Care

Education and Socioeconomic Status

Communication Skills
The Direction of Trust

- Trust conversations focus on increasing trust among Black patients
- How can health care providers (un)learn to (mis)trust Black patients?

“Tell me who I have to be to get some reciprocity.”

Lauryn Hill
“The Performance”

**ADAPTATIONS**
- Speech and posture
- Eye contact and attention
- Charisma
- Preparation
- Credentialing

**INTENDED OUTCOMES**
- Humanizing
- Capable
- Credible
- Needs met
What Black Patients Know

- Personal experiences of anti-Black bias in society
- History of poor treatment and outcomes in health care
- Institutions with a legacy of poor treatment of Black patients
- Vulnerability to bias and not being seen as credible in health care settings

“I can’t believe what you say because I see what you do.”

Ike & Tina Turner
Changing the Default Setting

EXAMINE THE IMPULSE TO DISBELIEVE PATIENTS.

- What layers of privilege make a patient more believable to you?
- What kinds of patients do *you* have trouble believing?
- How do your doubts affect the patient’s experience?
- How do your doubts influence the care you provide?
Building (Your) Trust

SET THE STAGE
- Understand patients’ layers of privilege
- Communicate clearly and ensure common understanding

DEMONSTRATE TRUST
- Ask patients what they think about health concerns
- Assure patients that you will listen to their concerns
- Prompt two-way discussions and relationships
Increasing Awareness Among Pediatric Providers

Ben Danielson, MD
Pediatrician and Professor,
University of Washington School of Medicine
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