Stigmatizing Language in Healthcare Documentation

…AND CHANGES YOU CAN MAKE TODAY

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Mandy Huber, APRN, CNM, IBCLC

- No disclosures
- My presentation does not represent the work or views of any of my employers

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Recognition

- Others in community doing this work including many w/ lived experience. Please support their work
- My lens - professional experience as midwife, nurse, IBCLC
- On my own learning journey – have own biases & make errors
- Please share your feedback! (positive, negative, constructive)

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Healthcare helps people

Healthcare helps some people more than others

Healthcare hurts some people

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WORDS HURT*

* Himmelstein (2022), Cox (2022), Goddu (2018), Park (2021), Puhl (2013), Sun(2022)

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Today's Aims

- Explore stigmatizing language
  - How appears in documentation
  - Who gets harmed
  - Negative effects
- Reflection and interactive exercises
- Directly apply to your documentation and practice

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AWHONN POSITION STATEMENT

AWHONN

Racism and Bias in Maternity Care Settings

An official position statement from the Association of Women's Health, Obstetric and Neonatal Nurses

AWHONN 1800 M Street, NW, Suite 740 South, Washington, DC 20036, (800) 673-8499

Approved by the AWHONN Board of Directors June 1, 2021.

Position

The Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN) maintains that maternity care providers should be aware of the effect of possible implicit bias and racism on their language and actions. We commit to reflective practice, self-development, and life-long learning and to identify and mitigate the causes and outcomes of structural racism.

Background

Profound racial and ethnic disparities in maternal health outcomes and health care quality continue to be major public health issues in the United States, and non-Hispanic Black women are most profoundly affected (Petersen et al., 2019). In a 2003 consensus study report, the Institute of Medicine concluded that racial and ethnic disparities in health care were associated with worse health outcomes, occurred independently of factors such as insurance status. (McLemore et al., 2018). Moreover, maternity care providers of all backgrounds, races, and ethnicity need to know how racially biased attitudes and beliefs, whether explicit or implicit, affect their actions, behaviors, and decisions (Scott et al., 2019).

Differential management and treatment for women of all races and ethnicities must be examined within the context of racial attitudes. Eliminating the inequities related to poor maternal health outcomes can be advanced if one understands the experiences of Black women in the United States from chattel slavery to the present (Noonan et al., 2016; Owens & Fett, 2019). Nurses must seek to change the structures, institutions, attitudes, beliefs, and practices that have legally or otherwise perpetuated racism, discrimination, mistreatment, and lack of treatment of Black women in the U.S. healthcare system (Owens & Fett, 2019; Prather et al., 2018).

Role of the Nurse

The nurse provides crucial care during reproductive

AWHONN (2021)

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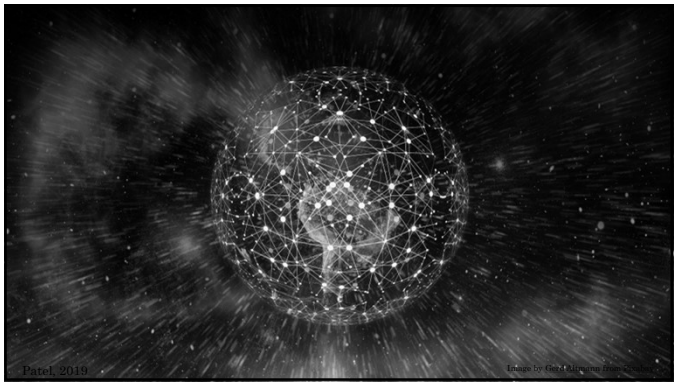

Patel, 2019

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Types of stigmatizing language

- Negative descriptors / "difficult patient"
- Jargon with negative connotations
- Judgement, blame, **disapproval**
- Labeling person as disease
- Cast doubt / question **credibility**
- Center on provider's authority, goals, perspective
- **Stereotyping** by race or class

Goddu 2018, Sun 2022, Park 201, Cox 2022

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Negative descriptors
- Difficult, challenging, resistant, insisted, demanded, refused, complains
- "She is belligerent with staff and resists staying on the fetal monitor"
- "They complain that headaches keeps them from looking for work"

Medical jargon/phrases with negative connotations

(Human organs do not have personality or independent will!)
- Incompetent cervix, hostile uterus, irritable bowel, ovarian insufficiency

Judgment or blame
- "Patient has failed her diabetic diet (or utox, etc)"
- "She cannot tolerate the oxygen mask"
- "Due to poor maternal effort a vacuum was used" "Bad pusher"
- "She had insufficient prenatal care"

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Labeling person as disease/condition
- "He is a poorly controlled obese diabetic"
- "The train wreck in Room 5"

Cast doubt / question credibility
- Claim, deny, supposedly, "using unnecessary quotes"
- "She claims she was "good with her diet" this week, and acts surprised that she gained weight".

Centers on provider's power, authority, goals, even coersion
- Leaving AMA (Against Medical Advise)
- "I" statements by healthcare provider
- "I made a plan but she refused treatment"
- "I delivered Room 4 and next I will consent the new triage."

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Who is harmed by stigmatizing documentation?

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Students

Our future care providers

Image by Yerson Retamal from Pixabay

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"I learned it by watching you!"

PSA from Partnership for a Drug-Free America, 1987

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CrossMark

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

Anna P. Goddu, MSc[1], Katie J. O'Conor, BA[1], Sophie Lanzkron, MD, MHS[2], Mustapha O. Saheed, MD[3], Somnath Saha, MD, MPH[4,5], Monica E. Peek, MD, MPH, MSc[6], Carlton Haywood, Jr., PhD, MA[2], and Mary Catherine Beach, MD, MPH[1]

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BACKGROUND: Clinician bias contributes to healthcare disparities, and the language used to describe a patient may reflect that bias. Although medical records are an integral method of communicating about patients, no studies have evaluated patient records as a means of transmitting bias from one clinician to another.
OBJECTIVE: To assess whether stigmatizing language written in a patient medical record is associated with a subsequent physician-in-training's attitudes towards the patient and clinical decision-making.
DESIGN: Randomized vignette study of two chart notes employing stigmatizing versus neutral language to describe the same hypothetical patient, a 28-year-old man with sickle cell disease.
PARTICIPANTS: A total of 413 physicians-in-training: medical students and residents in internal and emergency medicine programs at an urban academic medical center (54% response rate).

KEY WORDS: bias; stigma; language; disparities; medical record; communication; clinical decision-making.

J Gen Intern Med 33(5):685–91
DOI: 10.1007/s11606-017-4289-2

INTRODUCTION

It is well documented that patients are not treated equally in our healthcare system: some receive poorer quality of healthcare than others based on their racial/ethnic identity,[1–4] independent of social class. Others, such as older adults[5,6] and individuals with low health literacy,[7,8] obesity,[9,10] and substance use disorders[11] may also be viewed negatively by health professionals in a way that adversely impacts their healthcare quality. Implicit bias among clinicians is one factor

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Reading stigmatizing language is bad for learners

- Negatively effects perceptions of patients *and* plan of care
- Perpetuates the cycle of bias, stigma, & harm (from professors/clinicians to learners)
- Relation of negative perception : years of practice
  - Goddu:
    - Residents > Med Students
    - **Bias** ***increased*** with each year of training
  - Himmelstein:
    - *Decreased* with each postgrad year
    - Study included APPs but did not specifically report their negative perception

Goddu et al 2018, Himmelstein 2022, Cox 2022

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Harm to patients

- Receive worse or harmful care from providers
  - less aggressive treatment (pain relief, sickle cell disease)
  - more likely to receive punitive approach than therapeutic (SUD, DM)

- Patients = Dissatisfied, disengaged, disempowered, depart from care
  - 10% in general feel judged or offended by documentation language
  - 19% labeled "fat" or "obese" avoid future appointments
  - 21% labeled "fat" or "obese" find a new care provider

Goddu 2018, Fernández 2021, Puhl 2013, Cox 2022

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Missed Opportunities

If we are consumed with negative/ judgmental approach & language when do we do the therapeutic nursing work:

… listen and learn?

… identify barriers?

… understand the patient's goals?

… empathize?

… explore options and resources?

... share information?

… partner in care?

… be present?

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Which patients?

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Office of Equity
UNIVERSITY OF COLORADO
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Matrix of Oppression*

Social Identity Categories	Privileged Social Groups	Border Social Groups	Targeted Social Groups	Biases with Power/ "Ism's"
Race	White/Caucasian	Biracial/Multiracial	Asian, Black, Latinx, Native/Indigenous	Racism
Sex	Assigned Male at birth	Intersex	Assigned Female at birth	Sexism
Gender	Gender Conforming (Cisgender), Identify as Male or Female	Gender Ambiguous, Gender Queer, Agender	Transgender, Gender Queer, Intersex, Gender Ambiguous, Agender	Transphobia/Trans* Oppression
Sexual Orientation	Heterosexual	Bisexual, Queer, Lesbian, Gay, Questioning, Aces (Asexual/Aromantic), Polyamorous	Lesbian, Gay, Queer, Questioning, Aces (Asexual/Aromantic), Polyamorous	Heterosexism, Homophobia
Social Status/Class	Wealthy, Upper Class	Middle Class	Working Class, Poor	Classism
Ability/Disability	Temporarily Able-Bodied	People with Temporary Disabilities, and/or "Invisible" Disability	People with Disabilities (*often physically identifiable*)	Ableism
Religion	Protestant, Christian	Roman Catholic (Historically), Spiritual	Jewish, Muslim, Hindu, Atheist	Religious Oppression/Intolerance
Age/Generational	Adults (*Ages 35-55*)	Young Adults (*Ages 25-35*)	Elders (*55+*) and Adolescents/Children (*25 and under*)	Ageism/Adultism

NOTE*: You cannot enter a room as ONE identity or as one part of yourself. All your identities work together simultaneously. Your world experience is based on the interplay of your identities within multiple dimesions of societal oppression i.e. ***intersectionality***.
For more information, review the *Intersectionality Self-Guided Learning* section on our website.

* Patricia Hill Collins "Black Feminist Thought" (1990) –created of concepts of matrix of domination and intersectionality of -isms

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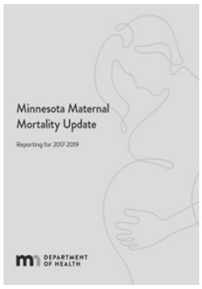

MN snapshot of inequities in birthing people: % population vs pregnancy-associated deaths

Black: 13% pop vs 26% deaths

American Indian: 1.7% pop vs 12% deaths

North West Region: 3.2% pop vs 10.7% deaths

South Central Region: 4.8% pop vs 9.3% deaths

Minnesota Department of Health, January 2024

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HEALTH EQUITY

By Michael Sun, Tomasz Oliwa, Monica E. Peek, and Elizabeth L. Tung

Negative Patient Descriptors: Documenting Racial Bias In The Electronic Health Record

DOI: 10.1377/hlthaff.2021.01423
HEALTH AFFAIRS 41,
NO. 2 (2022): 203–211

ABSTRACT **Little is known about how racism and bias may be communicated in the medical record. This study used machine learning to analyze electronic health records (EHRs) from an urban academic medical center and to investigate whether providers' use of negative patient descriptors varied by patient race or ethnicity. We analyzed a sample of 40,113 history and physical notes (January 2019–October 2020) from 18,459 patients for sentences containing a negative descriptor (for example, resistant or noncompliant) of the patient or the patient's behavior. We used mixed effects logistic regression to determine the odds of finding at least one negative descriptor as a function of the patient's race or ethnicity, controlling for sociodemographic and health**

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Tomasz Oliwa, University of Chicago.

Monica E. Peek, University of Chicago.

Elizabeth L. Tung, University of Chicago.

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Sun et al. 2022, a Must Read!

- Large sample in urban academic medical center
  - 18,459 patients
  - 40,113 H&P notes
- Inpatient, outpatient, emergency department
- January 1, 2019 – October 1, 2020 *
  * chosen for Covid period – pre and post pandemic comparison
- Excluded patients with dementia diagnoses

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Negative descriptors search

- (non-)Adherent
- Aggressive
- Agitated
- Angry
- Challenging
- Combative
- (non-)Compliant
- Confront
- (non-)Cooperative
- Defensive
- Exaggerate
- Hysterical
- (un-)Pleasant
- Refuse
- Resist

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Who, where, when

Negative descriptors used disproportionately for:

- Race: Black > White (2.54 times adjusted odds ratio)
- Medicaid/Medicare > private insurance (2.66 / 2.08 AOR)
- Not married > married (2.12 AOR)
- Higher Charlson Comorbidity Index (risk of death within 1 year) (1.11 AOR)
- Inpatient > outpatient
- Notes written before 3/1/2020 (pre-pandemic)

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JAMA Network | Open

Original Investigation | Health Policy

Examination of Stigmatizing Language in the Electronic Health Record

Gracie Himmelstein, MD; David Bates, MD, MS; Li Zhou, MD, PhD

Abstract

IMPORTANCE Stigmatizing language in the electronic health record (EHR) may alter treatment plans, transmit biases between clinicians, and alienate patients. However, neither the frequency of stigmatizing language in hospital notes, nor whether clinicians disproportionately use it in describing patients in particular demographic subgroups are known.

OBJECTIVE To examine the prevalence of stigmatizing language in hospital admission notes and the patient and clinician characteristics associated with the use of such language.

DESIGN, SETTING, AND PARTICIPANTS This cross-sectional study of admission notes used natural language processing on 48 651 admission notes written about 29 783 unique patients by 1932 clinicians at a large, urban academic medical center between January to December 2018. The admission notes included 8738 notes about 4309 patients with diabetes written by 1204 clinicians; 6197 notes about 3058 patients with substance use disorder by 1132 clinicians; and 5176 notes about 2331 patients with chronic pain by 1056 clinicians. Statistical analyses were performed between May and September 2021.

Key Points

Question How frequently does stigmatizing language appear in the admission notes of patients who are hospitalized, and does the frequency vary by patients' medical conditions and race or ethnicity?

Findings In this cross-sectional study of 48 651 admission notes, 2.5% of all notes included stigmatizing language. Across all medical conditions studied, stigmatizing language appeared more frequently in notes written about non-Hispanic Black patients.

Meaning These findings suggest that improved conscientiousness and

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Himmelstein, 2022 – A Must Read

- Large sample of *inpatient* urban academic medical center
  - 29,783 patients
  - 48,651 admission notes
- January – December 2018 (pre-pandemic)
- Searched for 60 descriptors
- Isolated patients with diagnoses most likely to include negative descriptors:
  - Diabetes
  - Substance use disorder (SUD)
  - Chronic pain

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Most common negative descriptors

- Fail
- Control
- Abuse
- Adherent
- Compliant
- Refuse

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Who, where, when

2.5 % of *all admission notes*

Negative descriptors used disproportionately for patients with:
- Diabetes 6.9%
- SUD 3.4%
- (chronic pain 0.7%)

- Race identifier: Black > White
  (0.67 AOR total / 2.16 SUD, 2.11 DM, 1.0 chronic pain)
- Increased with severity of diabetes

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Scenario 1. Identify stigmatizing language

Miss XYZ is a 24-year-old G7 P2143 who complains of breakthrough bleeding with her Mirena IUD, inserted 1 month ago. Unfortunately, she has failed other birth control methods including oral pills (noncompliance with daily pills), Depo Provera (she no-show'ed for return injections and claims "the shot made me get all fat"), and the ring (let partner take it out for sex, then neglected to re-insert). She has already had 4 elective abortions and does not want more children. She won't get a tubal ligation, even though she was informed that was her best choice.

She demands Mirena IUD removal today and refuses other methods. I made a plan for her to try at least 2 more months, and warned her about the risk of unwanted pregnancy. I again informed her she should consider another LARC method (Nexplanon or copper IUD) or sign tubal papers today.

Patient persisted in refusing above options. IUD removed against my advice without complication.

I sent her to the pharmacy for prenatal vitamins given high risk sexual behavior and risk of unwanted pregnancy. I instructed her to return to clinic for pregnancy visit with first signs of pregnancy.

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She demands Mirena IUD removal today and refuses other methods. I made a plan for her to try 3 more months, and I warned her about the risk of unwanted pregnancy. I again informed her she should consider another LARC method (Nexplanon or copper IUD) or sign tubal papers today.

Patient persisted in refusing above options. IUD removed against my advice without complication. I sent her to the pharmacy for prenatal vitamins given high risk sexual behavior and risk of unwanted pregnancy. I instructed her to return to clinic for pregnancy visit with first signs of pregnancy.

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What about *positive* descriptors?

"Patient is a delightful 18 year old; she has been a joy to care for and after our visit she was empowered to make positive choices."

- Compliments
- Approval
- (Provider) Self-disclosure (of own experience or of personal positive feelings re: patient)
- Minimizing patient blame or responsibility
- Personalization
- *Highlight patient authority for own decisions* (instead of shared decision-making)

Park et al 2022

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JAMA Network | Open

Original Investigation | Ethics

Physician Use of Stigmatizing Language in Patient Medical Records

Jenny Park; Somnath Saha, MD, MPH; Brant Chee, PhD; Janiece Taylor, RN, PhD; Mary Catherine Beach, MD, MPH

Abstract

IMPORTANCE Negative attitudes toward patients can adversely impact health care quality and contribute to health disparities. Stigmatizing language written in a patient's medical record can perpetuate negative attitudes and influence decision-making of clinicians subsequently caring for that patient.

OBJECTIVE To identify and describe physician language in patient health records that may reflect, or engender in others, negative and positive attitudes toward the patient.

DESIGN, SETTING, AND PARTICIPANTS This qualitative study analyzed randomly selected encounter notes from electronic medical records in the ambulatory internal medicine setting at an urban academic medical center. The 600 encounter notes were written by 138 physicians in 2017. Data were analyzed in 2019.

MAIN OUTCOMES AND MEASURES Common linguistic characteristics reflecting an overall positive or negative attitude toward the patient.

Key Points

Question What types of stigmatizing language are written by physicians about patients in their medical records?

Findings This qualitative study of 600 encounter notes from 138 physicians found 6 ways that physicians express positive feelings toward patients in medical records, including compliments, approval, and personalization. This study also found 5 ways that physicians express negative feelings toward patients, including disapproval, discrediting, and stereotyping.

Meaning These findings suggest that physicians should increase their

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Effect of positive descriptors

- Potential for positivity bias / influence other clinicians
- Patient may perceive some clinicians like them better or give better treatment (compared to neutral notes)
- Centers on the perspective & goals of the clinician
- Gives credit to clinician ("I like to empower patients")
- Paternalistic

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Limitations: Where are the Nurses in the literature?

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DOI: 10.1111/nin.12557

ORIGINAL ARTICLE

Nursing *Inquiry* WILEY

A qualitative analysis of stigmatizing language in birth admission clinical notes

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Abstract

The presence of stigmatizing language in the electronic health record (EHR) has been used to measure implicit biases that underlie health inequities. The purpose of this study was to identify the presence of stigmatizing language in the clinical notes of pregnant people during the birth admission. We conducted a qualitative analysis on $N = 1117$ birth admission EHR notes from two urban hospitals in 2017. We identified stigmatizing language categories, such as Disapproval (39.3%), Questioning patient credibility (37.7%), Difficult patient (21.3%), Stereotyping (1.6%), and Unilateral decisions (1.6%) in 61 notes (5.4%). We also defined a new stigmatizing language category indicating Power/privilege. This was present in 37 notes (3.3%) and

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Unique features:

Most common type of stigma:

- Disapproval 39.3%
- Question credibility 37.7%
- Difficult patient 21.3%
- Stereotyping 1.6%
- Unilateral decisions 1.6%

ID'd new category:

Power/Privilege bias (+) vs other –isms

Author / type of note:

- OB triage note: 16%
- OB admission note: 14.5%
- Initial Nutrition assess 14.0%
- Misc. Nursing Note: 13.9%
- Anesthesia resident note 13.8%
- OB PP note: 13.7%
- SW initial assess 13.7%

Barcelona et al 2023

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What & how SHOULD we document?

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Ctrl H*

is for Word Docs,

not Behaviors

*Find and Replace

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Remember the *intention*

of your practice.

How can you center documentation on that?

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General Guidelines

- If you wouldn't want the Patient to read it, don't write it
- Be transparent / Share the screen while typing
- Avoid "complain" and "chief complaint" if possible (hard w/ EHR templates)
- Person-first language (not disease focused)
- Objective, descriptive, and neutral language
- Write *what & how* you discussed
- Keep it clinically relevant

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General Guidelines, continued

- Motivational interviewing – assess patient goals & readiness
- Use trauma informed approach
- **Ask the patient!**
  - –What is your preferred name?
  - –How would you (like me to) describe this?
  - –I want to be sure I understand, does this describe what you told me?
  - –Is it OK to put this in your health record? (IPV or hx trauma)

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1st change practice. Then change language.

Instead of:	Try…
Insufficient prenatal care	Explore barriers to attending clinic appointments including (transportation, childcare, withdrawal sx, etc). Document "Significant barriers to attending clinic including xyz."
Pushing LARC / tubal ligation (esp cases when pregnancy incompatable w/ maternal health)	Ask about desired family size, family values. Empathize. Refer as needed to SW, discuss ways to grow family, etc. Describe "Grief re: X condition makes pregnancy life threatening. Desires large family. Referred to Maternal mental health. Considering contraceptive options, wants to discuss with family. RTC in 1w. Referred to SW to discuss foster/adoption."
Pt **refuses** post-term induction	Express your worry for pt & fetus. Learn & address concerns. Describe conversation: "Discussed at length risks of X. Recommended Y. She declined Y, fearful of side effects of Y. Discussed precautions, present to L&D at any time for IOL. RTC in 2d for antenatal surveillance"
"Diabetic geriatric multipara"	Name the person, not the condition: (Name) is a G6P5005 at 38 weeks with diet-controlled gestational diabetes

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Instead of:	Try…
"She **snuck out** of L&D, **claims** she 'checked on her car' and returned **reeking** of THC. She **denied** using drugs. **Refused** to leave UTOX".	The pt was absent from her room from 1600-1800. She reported that she went out to check on her car. Staff expressed concern re: absence, safety, medication timing. Verbally screened for substance use, screening negative. Recommended urine toxicology, she declined.
Noncompliance / non-adherance "**Failure** to adhere to GDM diet"	Inquire pt's goals, discuss your recommendations. Assess readiness for change. Express concern & empathy. Describe. Pt lives in shelter serving carb-heavy diet, little control over meals. or Pt lives in food desert, no transport to grocery store. Buys simple carbs avail at nearby gas station. Referred to SNAP, SW, CHW. Virtual visit in 1 week, review blood sugar, eval for insulin
Complains of / Chief complaint (esp when visit is not problem visit)	Pt **here for** preconception counseling. Pt **reports** ongoing vaginal discharge and malodor for past 2 weeks.
"She **denies** daily alcohol intake, and **claims** to drink 'only on Fridays!' "	She reports drinking alcohol once per week, 2 drinks per occasion. BAC today is 0.08. Discussed result…

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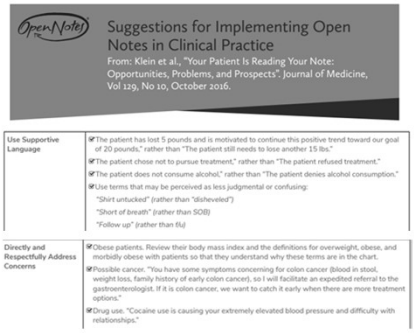

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Hard Ones: Complexities, questions, grey areas

- Billing & coding drives documentation

  (Who needs to dx obesity instead of BMI> 40

  re: antenatal surveillance reimbursement?)
- When to cite a patient's race?
- When to use a patient's quotes?
- AMA (Against Medical Advice) – signal for discord btn providers and patient
  - "Patient departed before completion of care"
  - "Patient-driven / self discharge. Pt did sign the AMA paperwork"

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Hard Ones: Complexities, questions, grey areas, cont.

- What to do with hx not relevant to this visit? (but informative)
- How to communicate relevant but private /difficult information to colleagues?
  - Shared sticky notes (Epic pink or blue)
  - Problem lists – in notes section below problem title
  - "Locked" / private documentation
  - Secure email – to limited group
  - Staff meeting

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"What about breastfeeding?"

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Meals are a family affair:

Everyone gets a seat at the table!

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Inclusive Feeding Language

RETIRE: "Breast or Bottle?" and "Breast is best"

USE descriptive language: What, How, Who?

WHAT is the child eating?

- Mother's milk, chest milk, human milk, parent's milk
- Expressed milk, EBM or ECM… "pumped milk"? (+/-)
  - Prob w/ "pumped milk" is that the PUMP gets the credit!
- Formula (and what kind if specialty)
- Human Donor Milk (pasteurized vs informal sharing)
- Not sure what it is or what to call it? ASK!

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Inclusive Feeding Language, continued

HOW is the child eating?

- At breast/chest
- Tools: bottle, finger-feed, cup, feeding-tube, SNS, nipple shield, etc.
- Not sure what terminology the family prefers? ASK!

WHO is doing the feeding? (when relevant)

- Patient's name & correct pronouns: always a winner!
- Name of patient's partner/ family member
- Not sure who they are or how they identify? ASK!

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Example 2.

Ms. ABC is a 38-year-old G4P2103 at 25w who presents 15 min late for visit b/c her bus was late. She has missed 10 weeks of PNC. She supposedly did not get a reminder call and "she's busy." She complains of heartburn, which her mother says is "because the baby has a lot of curly hair." She did not pick up her prescription as ordered but claims that milk works.

She persists in requests for note to stop working. Claims varicose veins make it hard to work. Only tried Jobst stockings 1x, could not tolerate so threw away. Calls nurse line frequently pressuring them to send her a work letter.

Today I will send her to lab for 3rd tri labs (risk for failing 28w appointment), re-schedule US (no show'ed last appt), and instructed her to attend next appt.

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Questions & Discussion

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Feedback?

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