Tips for Fetal and Infant Mortality Review Teams: Identifying Bias, Discrimination, and Racism in Medical and Social Service Record Review and Abstraction

Evidence of Differential Treatment

Abstraction of all records for services received by the childbearing family for Fetal and Infant Mortality Review (FIMR) is critical to building the story and revealing structural inequities. A FIMR abstractor may observe a variety of disparities or encounter indicators of bias, discrimination, and racism in materials reviewed as part of the case record. Bias, sometimes called implicit or unconscious bias, is defined as attitudes, behaviors, and actions that are prejudiced in favor of or against one person or group compared to another.[1] Discrimination is the unequal treatment of members of various groups based on race, gender, social class, sexual orientation, physical ability, religion, and other categories. One form of racism is defined as one group having the power to carry out systematic discrimination through the institutional policies and practices of the society and by shaping the cultural beliefs and values that support those racist policies and practices.[2]

Abstractors are encouraged to acknowledge and check their own biases before taking on the role of reviewing case records and compiling the FIMR case summary. Abstractors and other FIMR team members can access resources to help them to get insight into their own bias (we all have biases) through the Harvard University Project Implicit, or the Kirwan Institute for the Study of Race and Ethnicity. Exploring one's own attitudes and beliefs is a step toward assuring that case information will not be presented to the review team through a specific lens (popular narrative, racist and/or biased connotations, heteronormative, etc.).

A few examples of how bias, discrimination, and racism manifest in medical and social service records reviewed are explored below.

Stigmatizing language

Stigmatizing language in patient charts can be characterized by three linguistic features:[3]

- Casting doubt on the patient's pain

[1] https://diversity.nih.gov/sociocultural-factors/implicit-bias

[2] https://www.edi.nih.gov/blog/communities/understanding-racial-terms-and-differences

[3] 27. **O'Conor KJ, Lanzkron S, Haywood C Jr, Beach MC**. Implicit Bias and Stigmatizing Language in Medical Records of Patients with Sickle Cell Disease. Society of General Internal Medicine Annual Meeting. Hollywood, FL. 13 May 2016.

- Portraying the patient negatively, often with irrelevant or unnecessary indicators of lower socioeconomic status
- Implying patient responsibility with references to uncooperativeness

Examples of descriptors that portray a patient in a negative light may include terms like *refused care, non-compliant, non-adherent, uncooperative, aggressive, angry, challenging, combative, defensive, hysterical,* or *unpleasant.* Other signs of bias in medical records may be observed when providers express disbelief in patients. Examples include:

- Quotation marks around patient communication, such as a "reaction" to a medication
- Specific disbelief judgment words, such as "claims" or "insists"
- Evidentials, which is when the clinician describes a patient experience or symptom as hearsay

- **Dehumanizing language**
  Using terms like *alien* or *illegal* to describe people who are undocumented, or *drug addict* to describe a person with a substance use disorder.
- **Negative patient/provider/facility interaction**
  Evidence of provider not listening to or dismissing patient concerns; lack of provider to patient communication; provider not including patients/family in decision making process; not providing informed consent.
- **Excessive gatekeeping**
  A gatekeeper can be described as one who manages a patient's treatment. This means that the gatekeeper is in charge of authorizing the patient's referrals, hospitalizations, medications, and lab studies. Signs of bias and discrimination may be observed when patients are unable to reach a provider, leave messages, etc. Repeated ED visits in a short time frame or use of urgent care versus a primary care provider may also be signs of excessive gatekeeping.
- **Cultural incompetence**
  Failure to provide adequate translation services or lack of awareness or attempt to understand a patient's cultural preferences.
- **Lack of access to health care before, during, and after pregnancy** (structural bias)
- **Treatment/decisions/recommendations inconsistently applied or inconsistent with best practice**
  Signs of inconsistent application may include evidence of:
  - Over treatment
  - Undertreatment
  - Delay in treatment
  - Assumptions about patient's adherence to treatment

Team Deliberation

After review of de-identified case summaries of fetal and infant death, teams identify issues present in each case, and issues they determine were contributing factors in the death of the infant – not necessarily causative, but factors that played a strong role in determining the outcome. A simple grid may assist abstractors and review teams in identifying if specific factors related to bias, discrimination or racism impacted the pregnancy outcome.

Did any of these factors impact the pregnancy outcome or care and services received by the family?

	Yes	No	Unknown
Race/ethnicity			
Age			
Income			
Insurance status			
Citizenship/immigration status			
Disability			
Language			
Gender			
Sexual identity			
Weight			
Socioeconomic status			
Other (please specify)			

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. FIMR, with is inclusion of qualitative data, the voices of parents and families who have experienced the loss of an infant, and in-depth exploration and identification of factors that contribute to poor maternal and child health outcomes, are in a unique position to provide great insight into the problems families, especially communities of color, face in seeking and obtaining quality healthcare, as well as significant information about health inequity and disparities.

Resources

Health Equity Style Guide: Principles and Preferred Terms for Non-Stigmatizing, Bias-Free Language. Centers for Disease Control and Prevention: https://ehe.jhu.edu/DEI/Health_Equity_Style_Guide_CDC_Reducing_Stigma.pdf

How to improve Cultural Competence in Health Care: https://publichealth.tulane.edu/blog/cultural-competence-in-health-care/

Improving Cultural Competence to Reduce Health Disparities for Priority Populations: https://effectivehealthcare.ahrq.gov/products/cultural-competence/research-protocol

P. Goddu, A., O'Conor, K.J., Lanzkron, S. *et al.* **Do Words Matter? Stigmatizing Language and the Transmission of Bias in the Medical Record.** *J GEN INTERN MED* **33,** 685–691 (2018). https://doi.org/10.1007/s11606-017-4289-2

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