



# The words we use matter

Stigma, language, and the implications for quality healthcare delivery



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C.R. was a 21-year-old woman with a history of sickle cell anemia. The medical record told her story as:

C.R. is a 21-year-old homeless woman and frequent flyer to the emergency department. She averages two emergency department visits per month for sickle cell pain crises. She reports 10/10 pain, or greater than 10/10 pain regularly during her visits. She has a prescription for opiate medication. Patient is believed to be diverting pain medications. Has been non-compliant with pain management contracts previously made and ratified with emergency department providers.

C.R. was eventually referred to a community outreach program designed to reduce visits to the emergency department among high utilizing populations. After spending time with C.R. and learning her story, the community health workers described her history as:

C.R. is a 21-year-old woman with a history of sickle cell anemia. C.R. previously lived with her grandparents. Her grandfather has an opiate use disorder. Though given scripts for opiate medication, C.R. is not filling them in order to prevent members of her family from using the medication. After an altercation with her grandfather, she moved out of the apartment they shared. C.R. is currently experiencing homelessness and living in her vehicle. C.R.'s pain from sickle cell anemia is poorly controlled at present. C.R. did not finish high school and has difficulty reading and writing; she could not read many of the words written on her pain contract that she had signed with providers.

The differences in these narratives seem slight, but their implications for C.R.'s care were not. In C.R.'s interactions with health care staff at the emergency department, she was labeled as deviant, with words like "frequent flyer," "non-compliant," and accusations of "diverting" pain medication serving to code her care. These terms, commonly used among members of the health community, prevented C.R.'s true story from being fully understood. This language signified deviance, non-adherence, and a violation of social norms inherent in the clinician-patient relationship. Being labeled as deviant in the medical record changed the care C.R. received. The words used to describe C.R., and all patients, matter as they have profound implications for how patients may access care, and how care is delivered by the healthcare system and individual caregivers.

By better understanding the sociological principles of deviance, stigma, and their relationship to care provided in healthcare settings, the medical community can better optimize language to provide the best possible care for all people.

### Sociology 101

Sociology, as a discipline, is becoming more widely recognized as an important aspect of pre-medical education.<sup>1</sup> However, beyond preparation for entry into medical school, its applications into undergraduate and graduate medical coursework differ.<sup>2</sup> As a framework for understanding social relationships, sociology is key to providing students and practitioners with the skills to negotiate patient, colleague, team, cultural, and systems-based interactions. It is also a field that serves to better illuminate ways in which certain patients are advantaged, or disadvantaged, by medical language.

Deviance may be understood as behaviors or acts that violate social norms. This can occur formally, as in the case of breaking the law, or informally, as in the disruption of social rules and mores. Deviance is a relevant term defined by the culture in which it occurs. Deviance in one context may not be deemed so in another. Location, age, social status, and society all contribute to whether something is coded as deviant. It is a question of the social relationships between people with different intersecting identities that forms the basis of deviant coding.

That social relationship is key, because where there is deviance, there is stigma. *The American Psychological*

## The words we use matter

*Association Dictionary of Psychology* defines stigma as, “The negative social attitude attached to a characteristic of an individual that may be regarded as a mental, physical, or social deficiency.”<sup>3</sup>

In his seminal work, “Stigma: notes on the management of spoiled identity,” sociologist Erving Goffman describes stigma as the “...situation of the individual who is disqualified from full social acceptance...[stigma is] an attribute that is deeply discrediting.”<sup>4</sup> Goffman posits that stigma is actually about the interaction between two groups; stigmatized and stigmatizer. In this understanding, stigma is a dichotomous social relationship. There is nothing inherently stigmatizable, rather, stigma comes from the reaction that the stigmatizer has to an attribute of the stigmatized.

When medical caregivers decide a patient is deviant, they introduce stigma and bias into their care. Mary Catherine Beach’s work on stigma in the medical record found that most instances of physician bias are implicitly communicated, rather than explicitly stated. In a webinar from the Center for Health Care Strategies, she outlines the negative themes her team identified as mechanisms by which physicians stigmatize patients.<sup>5</sup> Characterizing patients as “difficult or unpleasant,” stereotyping, communicating disapproval, and undermining the patient’s credibility by using words such as “insists,” “claims,” or “denies,” serve to invalidate the patient’s experience and introduce unnecessary bias into the medical record.

Another mechanism Beach describes is the act of placing blame on patients for non-adherence to recommended medical treatments.<sup>5</sup> Beach’s work has found that use of this language changes patient care.

Stigmatizing language viewed by other clinicians in the medical record leads to statistically significant less favorable views of patients, and changes the clinician’s practice. Physicians provide less pain medication to patients whom they viewed less favorably.<sup>5</sup> Research by Cox and Fritz substantiates the notion that such language disempowers, belittles, and infantilizes patients, further stripping them of their humanity in medical settings.<sup>6</sup> As one patient explained, “being described as ‘non-compliant’ is awful and does not reflect the fact that everyone is doing their best.”<sup>7</sup>

### Homelessness and poverty

Homelessness and poverty are among the most common foci in which stigmatizing language is used in medicine. In their 2019 study, Purkey and MacKenzie spoke with people experiencing homelessness and those who

were unstably housed. They concluded that, “The experiences [in healthcare settings] of stigma among [people with lived experience] were overwhelming. In some cases, the stigma was so painful that it superseded any health complaints, previous trauma, or other concerns a patient might have.”<sup>8</sup>

Patients experiencing homelessness associate clinician bias with substandard care, especially when it comes to situations where the patient is experiencing mental illness, addiction, and chronic pain. In one patient’s words, “They find out you’re on the street or living at [a shelter] and immediately they decide you’re a drug addict....The doctor told me last time, ‘Don’t bother coming back....’”<sup>9</sup>

Patients are defined in medical settings—often as early as the one-liner that begins their history by the social attributes they lack. Referencing patients as “homeless,” or “the homeless,” ascribes a “dehumanizing collective noun,” to the human reality of an experience.<sup>10</sup> Medical students are taught illness scripts in medical textbooks that tie deviant behaviors such as tobacco, alcohol, and drug use, criminality, and instability in finding and keeping employment with individuals experiencing homelessness. With the label “homeless,” comes assumptions and perceptions about the patient’s motivations for seeking care, their substance use history, and the rationale behind their housing status.

Stigma is prevalent, observable, and felt. It is also codified in the labels ascribed to individuals without a consistent place to rest their heads, often poisoning the quality of their health care.

### Race, women’s health, and psychiatric disability

It’s not just in narratives about poverty or homelessness that clinicians must consider their language use. Race has often, and historically, been used in medical settings and education as a proxy for genetics and biology, with racial essentialism a mechanism to perpetuate harmful ideas about patients. Similarly, the impositions and injustices of racism are often overlooked as contributors to health outcomes.<sup>11</sup> Black patients are 2.5 times more likely, and Hispanic or Latino-identifying patients 1.5 times more likely, to have descriptors such as “aggressive,” “agitated,” “combative,” and “exaggerate” used to describe them in documentation, when compared to white patients.<sup>12</sup>

Women’s health and reproductive medicine is similarly fraught. Pregnant patients in labor may “earn” themselves a diagnosis of gestational hypertension, or contend with an “incompetent” cervix during pregnancy. It is

commonplace to say that a patient “failed” IVF treatment or “failed to progress” in labor.<sup>13</sup> As Moore and Cattapan note, “Jargon that describes women’s bodies as inherently and necessarily reproductive perpetuates the blame, stigma, and sense of failure associated with infertility, and works to disempower women.”<sup>13</sup>

Such descriptors about women place the onus of physical pathology on the patient. This becomes particularly destructive when the behavior coded as “deviant” by the clinician is the behavior of the body in functions that societally and culturally, people with uteruses are expected to be able to do. In this case, it is not that the uterus or pelvis is “inadequate,” for the function the clinician assumes it should perform, rather these words tell the patient that they too have failed.

Patients with psychiatric disabilities fare no better. Words like “alcoholic,” and “addict,” are still common in medical discourse. Using case studies, researchers demonstrated that mental health and addiction specialists were highly influenced in their recommendations for a patient based on whether that patient was referenced in the material as a “substance abuser,” versus an individual with “substance use disorder,” when all other words were kept the same.<sup>14</sup> Clinicians were more likely to recommend jail or prison time when the patient was categorized as an “abuser” than a person with a “disorder.” Awareness of such bias in perception and language by the layperson may result in patients delaying or avoiding treatment for psychiatric concerns. Furthermore, research has shown that such bias can influence whether or not a patient with a psychiatric comorbidity receives speciality care.<sup>15</sup>

### **Positive signs for the future**

There is sufficient evidence to note that the current state of medical discourse requires additional interrogation and reform. In addition, there are evident efforts to remedy many of the language problems in medicine. The push for person-first and destigmatizing language is growing. The American Medical Association Center for Health Equity, in collaboration with the Association of American Medical Colleges, recently released a health equity guide to inclusive language. “Advancing Health Equity: A Guide to Language, Narrative, and Concepts,” is an instructive toolkit to guide learners and practitioners in updating their practice to be anti-racist, trauma-informed, and person-centered.<sup>16</sup>

Similarly, organizations such as the Centers for Disease Control and Prevention and the National Institutes of Health have resources that provide healthcare workers

support in the use of non-stigmatizing language.<sup>10,17</sup> These efforts represent a crucial advancement in a collective drive to reform the quality of medical communications.

These changes are not without challenges. So many of the words used in medical settings help provide context for clinicians, a shared means of communicating information quickly. To further complicate matters, a patient’s individual perception of offensive or inappropriate language may differ. A term that may offend one patient, may not be perceived as such by another.

In Tate’s analysis, “Your Father’s a Fighter; Your Daughter’s a Vegetable: A Critical Analysis of the Use of Metaphor in Clinical Practice,” the author examines the differences in appreciation for, and of, metaphors by patients, depending on their background and experiences. While descriptors like “fighter,” for patients negotiating critical illness, and “vegetable,” for others with terminal brain injury may be perceived as insensitive and counter-productive for some patients, Tate notes that verbiage describing war metaphors is helpful for some patients with a history of military service or combat.<sup>18</sup>

Similarly, critics may contend that consideration of language, and promotions for change to its use, is tantamount to watering down, or restricting the ability to communicate. In reference to changes to diagnostic labeling in psychiatric care, Black and Balon pose the question, “In the race to avoid making someone uncomfortable, are we losing our ability to communicate?”<sup>19</sup>

Communication in medicine does require precision, and while, it is correct to assert that, “changing the term doesn’t make the patients go away,” and “in another 20 to 30 years, these new terms may become stigmatizing and politically incorrect, too,” failing to change the way medicine uses language now, simply because it might again become outdated in the future, is a failure to meet the present moment.<sup>19</sup> Medicine, as a discipline, is continuously evolving. The words used to discuss our patients and their health conditions should too.

Ultimately, patient-centered care requires a patient-centered approach to language. The language health care professionals use to talk with, and about, patients should not come at the cost of understanding their narrative and endeavoring, in all ways possible, to destigmatize the language used to engage with them.

Terms such as “drug-seeking,” and “non-compliant,” acted as code among members of the health care team, preventing C.R. from gaining access to support she needed. C.R. became a “difficult patient,” one who was a “burden,” and “drain,” on the system. When this language

## The words we use matter

was stripped away, C.R. was able to exist as both a patient and a human being. Using the appropriate language to understand C.R.'s reality enabled her to access the necessary care.

Medical professionals must examine the language and words used to speak of, and about, patients to avoid codifying stigma into their practice. Endeavoring to destigmatize the way the medical community speaks about patients is not without its challenges. Doing so, however, promises to advance health equity and better the care provided to all.

*Author's note: The patient described in this narrative was one with whom the author developed familiarity in the course of community based work. Key elements of the patient's history, including any identifying information, have been changed to protect patient privacy. No text is taken directly or verbatim from the medical record, to which the author does not and did not have access at the time these events took place, but rather reflects main ideas and keywords summarized and included based on the author's intimate understanding of the case.*

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