Listening to TikTok — Patient Voices, Bias, and the Medical Record

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Videos of people reacting to the language in their medical records are common on the popular social media app TikTok. In one video, a person laughs in front of a screenshot of the phrase "High risk homosexual behavior," with the caption, "WHY DID MY DOCTOR PUT THIS ON MYCHART" and several crying emojis (@findingricky; July 25, 2023; links to videos are available from author). Over an expletive-filled audio track, a person in another video puts a hand over their mouth below the text "me reading MyChart results." The screen behind them focuses on the phrase "habitual aborter" (@diary0fabratt; February 22, 2023). Content creators, who often use humor to critique the language of medical charts, sometimes acknowledge the conventions of clinical terminology, yet they remain frustrated: @diary0fabratt writes in a comment, "Yes I know [habitual aborter is] the medical term [for recurrent miscarriage]. However it is heartbreaking to read."

Apps such as TikTok provide patients with a platform to share experiences of medical care that have left them feeling disrespected or judged. Such videos can highlight common and often preventable failures in clinical communication. In an era of easily accessible electronic medical records, they illuminate the disconnect between the norms of clinical language and the experiences of patient audiences, thereby offering lessons for making care more patient-centered.

One common theme in such videos is discomfort with descriptions of the patient's appearance. One creator posted a video of themself scrolling through their chart laid over an audio track about a "fat ass, giant, morbidly obese squirrel" (@meganelizabeth922; January 16, 2024). Others joke about euphemisms, as in the case of a person whose record referred to them as "generously proportioned" (@renwalshhh; May 31, 2024). Even when descriptions of appearance don't contain negative language, patients may find them strange or irrelevant; one video features a person dancing to the lyrics, "I'm thin, I'm blonde" and flipping their hair in front of a chart reading, "Patient is a pleasant white female in NAD [no acute distress]. She is wearing a UF [University of Florida] sweatshirt and black leggings. She has long blonde hair" (@michellemmt; December 6, 2022).

These videos sometimes receive hundreds or thousands of comments, many containing similar anecdotes. Such comments highlight that experiences with stigmatizing medical language are widespread. In some of the thousands of comments on a video captioned "Why do they always have to word things so harsh?" (@shepherdplayspiano; March 19, 2024), commenters noted that they had found in their records diagnoses that hadn't been communicated to them ("I found out I have borderline personality disorder on mine. Like shouldn't we be treating that???"), suggestions that they had been dishonest about their habits ("My doctor wrote 'patient CLAIMS to eat healthy and exercise' EXCUSE ME"), and evidence that they hadn't been heard ("Me: I'm in pain and exhausted. My chart: Patient is well and has no complaints.").

A growing body of research explores similar criticisms of the language used in medical records. One large survey found that 1 in 10 patients reading notes felt judged or offended by the content. One respondent wrote, "I wasn't offended. It was actually betrayal." Themes in survey responses echoed those in TikTok videos: frustration over discovering undiscussed diagnoses; objections to labels or descriptors such as "obese," "well-groomed," "anxious," or "delightful"; and interpretations of phrases such as "patient claims" as signaling distrust.[1]

Studies have also found patterns of bias in medical records. In the same survey, feelings of judgment or offense were reported more frequently by female respondents than by male respondents and more frequently by people who reported having fair or poor health or being unable to work or who described their race as "other" than by other respondents.[1] A study of charts of people with substance use disorder, chronic pain, or diabetes found more stigmatizing language in the charts of non-Hispanic Black patients than in those of non-Hispanic White patients with the same conditions; increased severity of diabetes was also correlated with more stigmatizing language.[2]

In a study of more than 40,000 notes, negative descriptors — including terms such as "nonadherent," "aggressive," and "noncompliant" — were identified in the charts of 8.2% of patients;

Black patients were more than twice as likely as White patients to have such language in their charts.[3] Another study found that use of quotations, words implying judgment (e.g., "claims" or "insists"), and evidentials (i.e., reports of patient symptoms as hearsay) was more common in the charts of Black patients than in those of White patients and that use of quotations was more common in the charts of female patients than in those of male patients. Researchers described use of this type of language as a form of injustice, one that involves discounting the patient's self-knowledge.[4] Such language can affect medical care: in one study, medical trainees who had read a note containing stigmatizing and racialized language held more negative views of a hypothetical patient with sickle cell disease and recommended less aggressive pain management than their peers who had read a more neutral version of the note.[5]

One response to criticisms of chart language is that clinicians are simply relying on medical conventions, and commonly used language is being misinterpreted by patients. Indeed, many patient videos have received comments from clinicians noting that the language included in the person's chart is medically necessary and neutral. But we believe the attitudes that determine the norms of clinical language deserve scrutiny. In one survey, a respondent acknowledged that wording found in the chart was "simply the language that doctors are taught to use." But the respondent went on to reflect on the underlying logic: "Patient reports are considered 'subjective' and therefore cast as slightly unreliable."[1] Clinicians should think critically about the politics of clinical language rather than dismissing it as neutral.

What would taking seriously the critiques made on TikTok entail? Researchers have recommended changes to clinical language that can reduce stigma, such as documenting body-mass index rather than referring to a patient as "obese" or describing patients' rationale for declining medical care rather than simply documenting that they "refused" treatment.[1] The themes that appear in these videos provide additional guidance. Clinicians could document appearance only when it is clinically relevant and without using euphemisms. They could reflect on and find alternatives to language implying disbelief, particularly when working with patients from marginalized communities. Rather than burying stigmatized diagnoses in documentation, they could discuss them with patients. The *International Classification of Diseases*, 11th Revision (ICD-11), code for "habitual aborter" (GA33) is also linked to the more neutral "recurrent pregnancy loss," which suggests that clinicians or coders can sometimes choose less stigmatizing language without affecting reimbursement. And although bureaucratic factors may at times require that stigmatizing language be used, clinicians can communicate openly, respectfully explaining to patients the language that will appear in their records and why. Such practices could build trust, whereas unexplained use of stigmatizing language may damage it.

Adopting some of these changes, such as opting for less stigmatizing terms when multiple choices are available, takes little time. But impossibly tight schedules, bureaucratic systems, and rigid computer interfaces are beyond the control of individual practitioners. Ideally, use of less stigmatizing language would be facilitated by means of updated diagnostic codes and documentation interfaces; education for medical trainees that addresses potential biases, proper formatting in patient charts, and clinical jargon; and increased time for patient education and documentation — enough, even, to explore collaborative charting with patients. We believe medical professionals should continue to advocate for such reforms. In the meantime, however, these videos can remind clinicians that patients are a primary audience for documentation and encourage reflection. In the context of a system of medical documentation in which patients have little power to shape their own narratives, clinicians should respect the channels they have chosen to use to share their stories and listen to the messages they convey.

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