



PALLIATIVE CARE CASE OF THE MONTH

“A 34-year-old drug addict with metastatic cancer” Exposing Harmful Language in Medical Documentation of Substance Use and Recommendations for Improvement”

by
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Introduction: Harmful language persists in medical charts, particularly in documentation of patients’ social histories and health-related behaviors. Despite global efforts to educate medical practitioners on patient-centered communication, less attention has been paid toward cultivating humanistic, sensitive documentation practices within the medical chart. This topic is particularly relevant to palliative care providers, who are uniquely attuned to patient-centered communication and often champion patient advocacy within their institutions. This case displays several examples of pejorative and judgmental language that may cause harm to patients. What’s more, reviewing this case offers an opportunity for us not only to avoid these pitfalls, but also to cultivate documentation practices that are actively patient-centered and de-stigmatizing.

Case: The patient is a 34-year-old man with a history of metastatic renal cell carcinoma of unclear subtype with metastases to the retroperitoneum and multiple lymph nodes, multiple substance use disorders, and depression. He follows with oncology and receives immunotherapy for his cancer. He also follows with providers in palliative care and addiction medicine, and has received Suboxone for opioid use disorder as well as multimodal therapies for cancer-related pain and symptoms. He has experienced several psychosocial barriers to care including substance use, limited social support, and limited financial income. During the course of his cancer treatment, he has not arrived at many outpatient appointments, and he has had frequent assessments in the emergency department. Upon review of his chart, there are numerous instances of harmful language written by providers, particularly within documentation of the patient’s substance use history and social history more broadly.

The following words, phrases, and documentation patterns were identified in the patient’s chart:

Harmful patient identifiers	<i>Drug user Drug abuser Heroin addict</i>
Pejorative terms	<i>Abuse (opioid abuse, methamphetamine abuse, drug abuse, etc.) IVDA Illicit drugs Recreational drugs Clean Relapse Sober up</i>
Judgmental quotes	<i>Attempted to go to "rehab", however states that they would not admit him with his port. He says he is "tired" of using.</i>

Taking a closer look at the patient’s chart: Words like *user*, *abuser*, and *addict* are harmful, not only because they are overtly stigmatizing, but also because they define the person in terms of their medical condition or behavior. When reading these identifiers, it becomes difficult to separate the person from their drug use. The pejorative terms that are listed in this patient’s chart assign blame and judgment. These terms might feel hurtful to a patient to read, and they could invite premature judgment from providers during subsequent encounters. What’s more, terms like *illicit drugs* and *abuse* are not particularly informative, insofar as they do not clearly describe the person’s behavior or shed light on whether the person has a substance use disorder. Moreover, several studies have shown that the term *abuse* has higher associations with negative judgments, stigma, and punitive responses than the term *substance use disorder* or *misuse*. A randomized study from 2010 assessed clinicians’ impressions of comparable vignettes of individuals with “substance use disorder” vs. “substance abuse,” and the participants in the “substance abuse” arm were more likely to characterize the individual as being personally culpable and deserving of punitive action.¹ It is now therefore recommended to use the terms *substance use disorder* (if the patient meets criteria) or *substance misuse*. Similarly, the term *relapse* can evoke negative judgments and represent personal failure on the part of the individual. *Recurrence* or *Return to use* are more supportive alternatives, as these terms tend to be less stigmatizing, and they represent the growing perspective that recurrence may be part of a normal, even successful recovery.² Lastly, the use of quotation marks can be read as casting doubt or skepticism. Writing the patient *says he is “tired” of using* could be read as discrediting, as though the provider does not believe the patient’s report. While the provider may have intended to represent the patient’s own words through the use of quotation marks, avoiding quotation marks here would have likely achieved the same goal without any tone of suspicion.

Open notes: In accordance with the 21st Century Cures Act of 2016, patients are intended rapid, free and complete access to their medical record including clinical notes and personal health information. Several studies have described apprehensions among healthcare providers about patients having access to their medical records; providers report devoting increased time and effort crafting documentation that is easily understood by patients and, sometimes, censoring or misrepresenting medication information for fear of troubling patients.^{3,4} However, open access to patient charts has demonstrated widespread benefits—in particular, improving patient-doctor communication, promoting patient education, and heightening patient engagement with medical care.^{5,6}

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How Patients Experience Harmful Language: Several articles have explored patient experiences reading harmful language in their medical charts. In their article, “Words Matter: What Do Patients Find Judgmental or Offensive in Outpatient Notes” Fernández et al summarized how language practices in the medical chart cause harm through misrepresentation, labeling, and disrespect.⁷ Misrepresentation happens when providers include inaccuracies or information simply not discussed with the patient during the encounter. Second, patients experience stigma or discrimination when they are or feel labeled by descriptors, identifiers, or pejorative terms written in their charts. Lastly, patients may feel disrespected not only by particular words and phrases, but also by language that is generally dismissive or undervalues their experience.

Principles for Patient-Centered Documentation:

Person-First Language: it is critical to separate the condition or behavior from the individual instead of defining the person by their condition or behavior. For example, *drug user*, *addict*, and *alcoholic* suggest that the substance use is an inherent part of the person, where as *a person who uses drugs* and *a patient with alcohol use disorder* are examples of person-first alternatives.

Neutral, Non-Judgmental Description: It is nearly impossible to generate a comprehensive list of harmful terms and phrases that should be avoided in medical documentation. The National Institute of Drug Abuse (NIDA) has a very helpful list of recommendations for supportive terminology around substance use and addiction that is worth reviewing.⁸ Of course, it is striking that NIDA has the word *abuse* in its name. Interestingly, NIDA is in the process of proposing a formal name change to “National Institute on Drugs and Addiction” with these considerations in mind.

Perhaps more important than familiarizing oneself with a list of “do’s and don’ts” is cultivating an approach of neutral description and careful reflection. As a general rule, providers should record patient information in a way that is descriptive without judgement. How can we do this? Being as specific as possible without generalizing, paraphrasing, or editorializing patient information minimizes opportunity for bias and unfair value judgments. Consider the following statements: *the patient is addicted to illicit drugs* and *the patient injects heroin daily*. The second statement is more supportive and, in fact, more informative by virtue of being specific and fact-based. It is recommended that providers ask themselves frequently, *does what I have written assign blame?* and *Can I be more specific?* In some cases, a patient may self-identify with terms that may be considered pejorative—for example, a patient may identify as an addict or an alcoholic. In those cases, this self-identification may be documented (e.g. *Patient identifies as an alcoholic and is in recovery*). It is important, however, to explore with the patient

whether the patient’s use of specific terminology is affirming versus self-stigmatizing, as it is not uncommon for patients to internalize societal judgment through the use of these terms in a way that may be disempowering.

Avoiding Judgmental Quotations: an important principle of patient-centered documentation is avoiding quotation marks that may cast skepticism or discredit the patient’s experience. Compare the statement in our patient’s chart *he says he is “tired” of using* with the statement *he says he is tired of using*. Although perhaps unintended, the use of quotation marks around the word “tired” conveys a doubting and questioning attitude towards the patient—whereas their absence reads as neutral, even kinder towards the patient. Quotation marks are frequently utilized to highlight the patient’s voice, however there are other ways to convey the same effect (e.g. *the patient shares that they... or the patient emphasizes...*). We recommend providers ask themselves if their use of quotation marks is truly necessary to achieve a particular meaning, or whether it is gratuitous in which case it should be omitted.

EMR Considerations:

There are several features of the electronic medical record that invite and perpetuate harmful documentation practices. Data registered in standardized sections of the medical chart (for example, in the Social History and Medical History sections in Epic), although out of date and potentially inaccurate, may still autopopulate medical notes. Similarly, providers frequently copy forward prior notes, which may preserve harmful words and immortalize potentially disparaging portrayals of patients. It is critical that providers take care in reviewing prior notes and registered health data, both for accuracy and compassionate patient representation. Lastly, it’s worth noting that the systemic language instituted within the EHR may not be patient-centered and may reflect outdated terminology. For example, the standard urine drug screen utilized in Epic still includes an item “Drug of abuse comment” in each result.

Conclusion: Part of the practice of palliative care is a commitment to inclusive, sensitive, and compassionate patient-provider communication. It is important for providers to recognize that communication extends well beyond the interpersonal interaction, and that patient-friendly documentation is an important communication skill in and of itself. The words and phrases we choose in our documentation may cause harm, particularly for folks who are the most marginalized—by substance use or other psychosocial determinants of health. Using person first language, promoting nonjudgmental description, and avoiding unnecessary quotations are some of the ways we can make our medical documentation more patient-centered.

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It is also worth noting that language is a highly dynamic and social phenomenon, and that the words that are considered respectful and appropriate today may no longer serve us tomorrow. It is vital that we remain sensitive and open to evolving social norms and the language changes that come with them.

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