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## CLINICAL COMMENTARY

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### The Embarrassing Patient History – “Do you have to write this down?”

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David Gunn, MD

A 25-year-old Asian American male with no medical history presented for evaluation of cough. Upon entering the room, he explains he does not actually have a cough, but wants to discuss something else. “Is that ok?”

The patient explains that two days ago, after consuming a large quantity of alcohol with his friends, he wandered off along the street, and started talking with a woman standing in front of a convenience store. After a brief exchange, they went behind the corner into an alley and had intimacy. The patient after discovering the woman was a transgendered male, asked for and attempted to receive insertive anal penetration from the presumed sex-worker. There was no penetration or ejaculation, and the encounter lasted for a brief period of time. The patient had no symptoms, other than still being hungover, tired and rather embarrassed by his behavior. He had consumed approximately 160 grams of ethanol, or 10-12 standard drinks, and had no previous episodes of impaired judgement or impulsive behavior while drinking. He has no history of a mood disorder nor any other medical conditions.

“What about post-exposure prophylaxis for HIV? I was reading that it’s still not too late for that. Oh, also I’m still on my mom’s insurance, and really want to keep this private. Can you not write any of this down? Will she be able to see what we talk about?”

It used to be that the patient and physician relationship was ultimately very private – records were the physician’s and were usually sparse and kept under lock and key in the physician’s office. Patients were generally not privy to what was recorded and often times they were, frankly, illegible. In an integrated health system with electronic records, consultants, billers, administrators and others could have access to the patient’s record now and in the future. There is also risk of data breaches or other lapses of security. To tell “your doctor” something in the strictest of confidence, only to have it inadvertently disclosed to another person – whether or not part of a health system – can seriously damage the doctor-patient relationship. No longer does what happens in the exam room stay between the patient and physician – there are chaperones, “Care Everywhere” records, emergency department records and automatic pharmacy importations to be reconciled. I have had patients with genuine surprise tell me “Where did you get that information?” and “How did you know that?!” Even after explaining how these information sharing systems work, I can see the patients begin to choose their words more carefully.

Ultimately, our duty is to the patient – to respect the patient’s privacy while protecting their health. At the same time, a physician cannot ethically write down a false history in a chart – if for no other reason than lying is fundamentally wrong, and at the very least because it can mislead other doctors in the future. Nevertheless, what can a physician do in a situation like the one described above to honor both the patient’s request for privacy and the physicians obligation to accurately record the patient history? Moreover, what compromises can be safely made to ensure that both obligations are met dutifully?

I would argue it is not necessary to include such details as the transgender identity of the sex worker – a high-risk encounter is high risk no matter what the gender. In this way, some details that were particularly embarrassing to the patient can be safely omitted while not affecting the quality of care the patient receives. Clearly, the alcohol use must be recorded if only to the point that it shows his judgment was impaired and that he denied having had previous episodes of similar behavior. As for the diagnosis code? I would argue for “Screening for STD” Z11.3 as a benign diagnosis, rather than the more descriptive “High risk sexual behavior” Z72.51 or the “At risk for HIV due to homosexual contact” Z91.89.

The issue of transparency in record keeping is a double edged sword in this respect – some things are meant to be private, yet there is a push for greater transparency from patients to access their complete medical record on demand. Part of this is undoubtedly curiosity – “what is he writing down about ME?” – but there are also genuinely interested patients who forget what is said, or who want to return to their medical record, laboratory results and diagnoses to understand their symptoms, health and illness.

Physicians have mixed feelings on the issue. According to a panel interview of residents and faculty, there were concerns about the potential harm to the doctor-patient relationship, as well as the increased time needed to adjust or correct the medical record to the patient’s satisfaction—especially on details that were not deemed medically necessary, i.e. “I grew up in Houston, not Dallas”, or “my brother died when he was 62, not 65”,<sup>1</sup> etc. While at the same time, they acknowledged that it could show the patient just how much thought went into their medical care, akin to bedside rounding. However, they also noted that some patients would likely be upset by copy-pasting of previous notes. There was concern about misreading the written word, especially on sensitive topics such as weight, substance abuse, sexual history and the habit of noting potential, though remote, diagnoses to consider—i.e. cancer or Par-

kinson's or Alzheimer's. And to this end, notes could suffer by becoming more vague, or even confusing to the patient if these "black cloud" diagnoses were ultimately not proven to be the case.<sup>1</sup>

Another study of patients' experiences accessing notes,<sup>2</sup> cited refreshing memory, improving their understanding of the health information and confirmation of their understanding. They reported improved trust and quality. Patients reported feeling more empowered for self-care and greater sense of control. In fact, patients who not only accessed the open notes, but who did so more frequently (defined at least 8 viewings over 2 years) reported less confusion, fewer safety and privacy concerns and increased trust. Female patients reported better understanding and appreciation of their doctor's work and skills. Patients with anxiety, depression, substance abuse, psychosis or other mental illness more frequently experienced improved communication, care coordination and increased ability to self-manage when compared to patients without these diagnoses. There were comments about customizing notes and changing or adjusting details or comments on notes, and they did want the opportunity to give the doctor comments or feedback. Surprisingly, some patients also commented about withholding information from the doctor to avoid other people seeing it.<sup>2</sup> In another study,<sup>3</sup> patients who reviewed previous notes sometimes inquired about postponing their upcoming check-up "because after reviewing your last note I'm quite sure nothing has changed."

In a review of reactions to open notes,<sup>4</sup> 1-8% of patients reported confusion, worry or offense to the notes' content, 26-36% reported concerns over privacy of the notes' content, 60-78% of patients reported increased medication adherence. However, doctors reported longer visits (0-5%) and more time addressing patients' questions outside of visits (0-8%). Three to thirty-six percent of doctors reported changing documentation content after the patients' review.

Despite the studies that were quite successful in enrolling patients to use open notes, the literature review reports patients' reaction to open notes is very much population specific – some patient demographics and subpopulations will certainly use this technology more or less than others. To this end, a study<sup>5</sup> attempted to merely enroll patients in an "open access medical record" of the ~15,000 patients in the practice, only 450 registered to use the service, and only 153 actually accessed their record at least twice over a 12 month period. If these figures are any reflection of the state of medical record use in the UCLA system, there may not be much access happening at all. However, as the adage goes, it is 10% of the people who use 90% of the resources.

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