

Challenges to physician–patient communication about medication use: a window into the skeptical patient’s world

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Abstract: Patients frequently do not take medicines as prescribed and often do not communicate with their physicians about their medication-taking behavior. The movement for “patient-centered” care has led to relabeling of this problem from “noncompliance” to “nonadherence” and later to a rhetoric of “concordance” and “shared decision making” in which physicians and patients are viewed as partners who ideally come to agreement about appropriate treatment. We conducted a qualitative content analysis of online comments to a *New York Times* article on low rates of medication adherence. The online discussion provides data about how a highly selected, educated sample of patients thinks about medication use and the doctor–patient relationship. Our analysis revealed patient empowerment and self-reliance, considerable mistrust of medications and medical practice, and frequent noncommunication about medication adherence issues. We discuss how these observations can potentially be understood with reference to Habermas’s theory of communicative action, and conclude that physicians can benefit from better understanding the negative ways in which some patients perceive physicians’ prescribing practices.

Keywords: patient–provider communication, trust, medical decision making, dissent and disputes, culture of medicine, health literacy

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Introduction

Between 30% and 60% of patients with chronic illnesses are not adherent to medical therapy, which can be both dangerous and costly, leading to hospitalization, adverse effects, and disease progression.¹ Whereas nonadherence is often thought of as failure to take medications consistently, a 2010 study of e-prescriptions reported that 22% were never even filled once,² with primary nonadherence rates of 28.4% for hypertension medications, 28.2% for hyperlipidemia medications, and 31.4% for diabetes medications. To make matters worse, physicians and patients often do not communicate about medication nonadherence.³ Known reasons for this nonadherence include concerns about adverse effects; worries about dependence, tolerance, and addiction; the potential harm from taking medicines on a long-term basis; and the possibility of medicines masking other symptoms.⁴ Medicines may present problems pertaining to disclosure and stigma. Some patients modify their regimens to minimize their intake of medicines, while some use nonpharmacologic treatments to either supplant or supplement their medicines. Patients often do not discuss these changes with their doctors.^{5,6}

The literature suggests diverse reasons for this lack of discussion. Patients keeping silent about their doubts could be demonstrating deference to doctors,⁷ or, alternatively, patients may fear provoking anger in the provider by admitting nonadherence.⁸ Questioning the provider risks creating tension.^{7,9} One study found that patients were

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much less likely to take medication if beliefs and concerns that conflicted with their physicians' beliefs were not addressed.¹⁰

Meanwhile, patient participation in the medical encounter is widely thought to have measureable benefits to patients.^{11–13} While until the mid-twentieth century a model of “benevolent paternalism,”^{14,15} where the patient's role was to trust and to follow “doctor's orders,” prevailed, a “patient-centered” care movement has more recently taken hold. Lipkin et al¹⁶ defined “patient centered” in 1984 as treating the patient “as a unique person with his [sic] own story to tell (p. 277)”. As part of this normative shift, the term “noncompliance”, which was seen as presuming a duty of obedience, was replaced by “nonadherence.”

An increased interest in “shared decision making”¹⁷ and “concordance”¹⁸ models since the late 1990s represents an effort to redefine the clinical relationship. The new models center on physicians and patients reaching agreement – via discussion that includes and respects the beliefs and wishes of the patient – about whether, when, and how medicines are to be taken.¹⁹ Cushing and Metcalfe²⁰ emphasize the importance of two-way communication in achieving concordance: “The challenge here is for the professional to delve beneath the surface of . . . deference to ensure that important issues which might affect adherence are not being ignored.” In the concordance model, the patient knows his or her views are respected and any subsequent difficulties the patient has with treatment can be discussed. This prevents the patient from being in the uncomfortable position of either telling the doctor that he or she has not followed their advice or, alternatively, of lying. However, Cushing and Metcalfe²⁰ conclude that changes in the patient provider dynamic have tended to be superficial and have failed to create real partnership.

The interest in shared-decision models comes at a time of major change in society's access to information about prescription medications. The Internet has given patients access to information that was once available only to health care professionals.²¹ Muir Gray suggests this access may lead to stronger doctor–patient relationships. However, access to health information also increases awareness of clinical uncertainty and differences of opinion about treatment, which can result in a decline in deference toward and trust of the medical profession.²²

To better understand how physicians and patients are constructing the concept of concordance as they discuss adherence to prescription medications, we examined data from an online discussion that focused on these issues. We hypothesized that the postings of a self-selected group of

New York Times readers about medication adherence and physician–patient communication about medication adherence would provide unique insights into concordance about prescription medications.

Methods

We conducted a qualitative content analysis of online comments responding to an article published in the *New York Times* in 2010: “When patients don't fill their prescriptions,” by Dr Pauline W Chen.²³ The article reviewed a recently published paper by Fischer et al² that used e-prescribing data to quantify rates of primary nonadherence (ie, not filling a prescription in the first place). Chen²³ described Fischer et al's² findings, as well as those of other papers reporting similar findings, and speculated about patients' reluctance to admit nonadherence: “Bringing the topic up in the exam room feels more like a confession or inquisition than a rational discussion. Few of us want to talk about medication nonadherence, much less admit to it.”²³

As with all columns in the “Doctor and Patient” section of the *New York Times* online, a public comment section was available at the time Chen's²³ article appeared. The article was published on May 20, 2010, and comments were submitted from this date until October 27, 2010, with most posts occurring within days of the original publication. Our analysis is based on a complete retrieval of all comments made to the article as of October 27, 2010. By October 27, 2010, there were 130 comments posted by 117 unique users. Because of our interest in patient views, we excluded from analysis 21 comments from people who identified themselves as health care providers – including physicians, nurses, and pharmacists – in the body of their comments or in their signatures. The analysis was limited to comments in which people discussed their own beliefs, attitudes, and behaviors, rather than attributing attitudes and beliefs to others. Other than moderating comments to ensure they are on-topic, noncommercial, legal, and not abusive, the *New York Times* encourages a full range of opinion.²⁴

Anyone could comment: a subscription to the *New York Times* was not required. We cannot know anything about the demographic or socioeconomic characteristics of individual commenters, except for whatever internal evidence there may be in their contributions. *New York Times* readers are, on average, better educated and more affluent than the general public. According to survey data posted on the newspaper's Website, 88% of daily *New York Times* readers have a college degree, and readers have a median household income of \$168,400.²⁵ We received an opinion from the

Brown University Institutional Review Board that use of these publicly available data does not constitute human subjects research.

Use of online data for research purposes is increasing. A recent study found that Web forum discussions provided excellent insights into day-to-day concerns of people going through an experience, and that they are valuable for exploring sensitive subjects. In comparison with in-person interviews, online comments were less concerned with “presentation of a moral front characterizing an acceptable ‘self’.”²⁶

Four members of the research team reviewed the data independently, in its entirety, and agreed on a general approach including the criteria for inclusion and broad categories of interest. Categories emerged from the data inductively. One member of the team (TB) then developed specific codes using ATLAS.ti® software (v 6; Scientific Software Development GmbH, Berlin) to classify themes encountered in the data. Members of the research team then discussed these themes. At this stage we recognized that the framework of concordance/discordance was highly salient in the data and we allowed it to guide our interpretation. Two team members (TB and MBL) then worked iteratively to refine the interpretation and presentation, followed by final discussion and agreement among all of the authors.

Qualitative content analysis examines language intensely for the purpose of classifying large amounts of text into an efficient number of categories that represent similar meanings.²⁷ We applied what Hsieh and Shannon²⁸ call “conventional content analysis,” a method used to describe and summarize a data set. The comments often referenced and sometimes responded to previous posts, and aside from a few threads where people posted “me too!” – style comments, we found new contributions were additive. Therefore, we exercised caution in assessing the weight of any theme or opinion by the number of times it was mentioned.

Results

One hundred and thirty unique comments were included in the analysis. Responses overwhelmingly addressed reasons for the high rates of nonadherence mentioned in the article. Rather than seeing nonadherence as a failure, most commenters defended or explained nonadherence as a reasonable or justifiable decision, often one the commenters had themselves made. We identified several themes: (1) mistrust and criticism of health care institutions; (2) patients shifting their strategies; and (3) patients not wanting to discuss adherence with their physicians.

Mistrust and criticism of health care institutions

Many commenters ($n = 33$) expressed distrust of the pharmaceutical industry, prescription medications, and the culture of medication prescription. Commenters noted the well-publicized instances in which approved pharmaceuticals had been found to be ineffective, dangerous, or overpromoted, such as thalidomide causing birth defects, recent studies calling into question the widespread prescribing of statins to people at low risk for coronary heart disease, and the initial enthusiasm for selective serotonin reuptake inhibitors followed by increasing evidence that they are of limited value for most depression sufferers.²⁹ Or, as one commenter put it, “a waste of time an[d] money for the overwhelming majority.” Commenters specifically noted distrust of the US Food and Drug Administration (FDA) drug approval system: “Fast-tracked through the FDA with sorely limited and cherry-picked trials? No thanks.” In light of this distrust, doctors’ enthusiasm for new drugs can appear misplaced: “That doctors have become shills for pills they often do not fully understand is surely part of the reason why caveat emptor sneaks into the medicine world.”

Many commenters ($n = 24$) criticized pharmaceutically oriented medical practice. Doctors were described as overeager to write prescriptions, writing “too many” prescriptions “at whim,” “without listening,” “for no reason,” as if “throwing the pills at a problem is the automatic answer.” Doctors were characterized as “out of control” in their prescribing; “[I]t’s a risk to even mention a ‘symptom’ because most people know they’ll just get another drug!” One commenter concluded that her doctor was using a prescription as a cheaper alternative to surgery and as a strategy “just to get rid of patients or in the hopes that patients will stop asking questions and leave.” (We base gender assignment on the signatures commenters used.) Doctors were characterized as being excessively influenced by pharmaceutical marketing; as one respondent put it, “Pharma Reps ... pump up the volume with hype.” Several commenters believed prescribing is in the financial interest of physicians. One referred to the doctor’s “commission” on filled prescriptions. Another wrote, “Always keep in mind that in the doctor’s world, his children’s tuition payments come first ... then the mortgage payment, assuming he has paid off his student loans, then the payments on his Mercedes.”

A few comments ($n = 9$) bemoaned the focus on medication instead of lifestyle alternatives: “I am surrounded by diabetics who eat the most dreadful diets imaginable and barely move their bodies” and “I’m stunned that they really believe the pills give cover for their woeful habits.”

For lifestyle diseases, one commenter was perplexed that someone would choose pills over lifestyle changes:

What I can't and don't understand is why on earth would someone prefer taking a pill – or pills, and usually expensive ones with very unpleasant side effects – to making truly enjoyable and simple lifestyle changes? Why? Is this the American way now?

Other commenters wrote that medication prescription has become commodified and that patients are under pressure to be good consumers. The first commenter, who signed her name “Noncompliant Nancy,” wrote, “Can’t be a good American and not be on pills of some sort, which I suppose is a natural consequence of good old Living Better Through Chemistry.” Whether taking medicine was characterized as a lazy alternative to lifestyle changes or as a complicit embrace of a commodified health care system, adherence was often stigmatized. Posts contained suggestions like “Throw out the pills.” But there was also dissent: 14 commenters wrote in defense of or in praise of medications. For example, “Medications have a place in our lives and have helped many people. Not all medications are bad,” or “Look, I don’t like taking 2 pills a day for high BP [blood pressure] but it works.” One commenter characterized comments stigmatizing pharmaceuticals contemptuously: “Sometimes the attitude of these high-and-mighty-Michael Pollan-spouting-no-carbon-footprint-I-only-feed-my-kid-lentils-don’t-watch-television-or-drive-a-car posters really get to me.”

Abstract and case-specific defenses of medications notwithstanding, disenchantment extended to the entire system: “[I]t’s my conviction that we have a broken system of health care,” “Thanks, health care bill, for nothing,” and “The way we handle health care in the US is beyond stupid, wasteful, dangerous and designed more for increased corporate profits than a reasonable quality of health care for all of those who want it.” Two posts bemoaned the fragmentation of the US system, one concluded that “too much is scattered across too many for any reasonable person to ensure that the right things get done for the right reasons most of the time.” Additionally, several posts complained of doctors not taking enough time with their patients. One warned against “doctor-bots, blithely following ‘protocols.’”

The insurance industry was often singled out for criticism. Insurers were said to make unethical deals with drug companies, fixing which drugs to put on formularies, such as one commenter who reported being forced to take Risperdal® instead of Abilify®. The commenter demanded, “I want to know how the insurance company can ‘prescribe’

your medication! It is not even on the FDA site as being comparable!” Insurance companies were said to contribute to the adherence problem through high co-pays, insistence on generics when there is no generic, having to make multiple requests to get even “maintenance” drugs covered, rapidly increasing premiums, refusing payment for some medications and regulating certain medicines as “top tier”. One commenter concluded, “All that counts is the money saved.” Twelve posts cited cost as a barrier to adherence for them personally. Twenty more assumed cost was a barrier in the abstract.

Patients shifting their strategies

Commenters expressed the belief that the onus is on them to compensate for these health care problems:

Dr Welby is obsolete. No time, must hurry, get a test, leave, get out. So then we see what scraps we can find ... on the internet ... then, decide ... Patients want to at least be their own consultant.

Commenters described researching each new prescription on the Internet and catching contraindicated medicines; “Doctors shouldn’t be quite so astonished or dismayed that their patients take their medicinal edicts with the grain of salt once they’ve had a bad experience.” One patient, who complained that her various doctors do not adequately interview her or consult with one another, wrote, “If I didn’t keep a medical notebook and if I wasn’t educated, I wonder if there would be any kind of congruency in my care.”

The posts demonstrated that commenters believed they had high health literacy. One concluded that doctors must be “too busy to do meaningful research on efficacy, drug reaction, etc.” Commenters had access to a great deal of information and to the latest research, and they indicated that they used it to calculate their own risks. For example, one commenter refused an immunosuppressant for ulcerative colitis because, by her calculation, her risk for colon cancer is only “1% higher ... than the rest of the population.” (The authors do not assess the accuracy of her reasoning.)

Commenters used assertive language, emphasizing their own empowerment, such as “I REFUSE”, “I said ‘no’ ... and am glad”, “I have decided”, “I’ve switched doctors”, “I had enough and went off the medication”, and “I am the one in charge.” In response to the phrase used in the article, one commenter wrote, “The term ‘noncompliant’ is telling. A treatment plan is not an order given by an all-powerful doctor to a submissive, grateful patient.” Another commenter agreed: “we need to stop calling it ‘noncompliance.’ I’m not your charge. I can choose to do whatever I want.” Some commenters advocated

changing doctors: “If you go to a doctor who seems to always prescribe you medication, which you don’t want to take, then you should find another doctor, one who shares your views or is at least sympathetic to them,” and “If you do not like the recommendation of your doctor, talk to him/her regarding alternatives. If they have none, consider another doctor.”

Some of these patients had already taken on the role of primary decision maker. Reacting to the surprise about nonadherence expressed in the article, one commenter wrote, “Noncompliance with a doctor’s advice, regarding taking medications, seems like it ought to be an expected outcome, not surprising.” Automatically following doctor’s orders was presented as outdated:

There was a time – let’s see, was it when Eisenhower was President? – that a doctor gave you a prescription and you had it filled. Then came the proliferation of specialists and myriads of drugs, some miraculous, some monstrous.

When patients think of themselves as their own primary caregiver, doctors’ roles become advisory rather than paternalistic:

Adults have agency and can decide for themselves whether the advice they’ve received makes sense and is fit for them ... In other fields, people use consultants all the time whose advice they blatantly ignore, when the advice doesn’t fit with their worldview

Some comments revealed a patient who took responsibility for communicating this relational preference to physicians:

I’m well educated and assertive and will demand that doctors listen to all my concerns and explain all possible side effects of a medication or treatment before we reach an agreement together on whether or not to use that treatment or medication.

Another writes, “Physicians seem to have a much lower threshold for finding drugs worthwhile than I do. That’s OK as long as we understand each other.” However, others revealed that they didn’t share their decision making with their doctors.

When my doctor prescribes antibiotics without doing a culture, I don’t fill the prescription ... not filling the prescription is easier than arguing.

Commenters expressed a great deal of confidence in their own research, and in their own assessments about whether to follow their physician’s advice about medication taking.

When patients’ certainty directly conflicts with what is traditionally the doctor’s domain (applying medical protocol,

assessing risk, providing expertise), it may be difficult to communicate a difference of opinion without undermining the status of the doctor. The collapse of status difference between doctors and patients became explicit in a heated exchange that erupted over the use of the phrase “busy doctors.” The phrase was condemned as an excuse “as if that explains or forgives a multitude of shortcomings in the delivery of care.” One post celebrated the pushback against the phrase that seems to summarize “the pervasive physician-as-ultra-special-case mindset.” Another post added, “Of course physicians are busy. Anybody who does serious work is busy and also has spent gobs of money on education and equipment.” In this comment forum, the status of physicians was readily challenged: “Hey – who isn’t busy? I’m really, really busy today because it took me 3 hours to spend 15 minutes with my doctor – and at a time of her choosing.”

Patients not wanting to discuss adherence with their physicians

Three commenters admitted to not talking with their doctors about their nonadherence, but they did not describe their reasons for their silence. A fourth named cost as part of the barrier to disclosure: “Did I want to tell my doctor I couldn’t afford it – especially when I didn’t believe I truly needed it?”

Several commenters suggested strategies for doctors to improve communication. These included asking about cost, asking about compliance, and anticipating and troubleshooting problems ahead of time. Strategies for improving the patient side of communication also abounded, mainly encouraging patient assertiveness: “Ask questions, seek alternatives, be realistic, but don’t ignore your health.” Patients were encouraged to inform themselves, ask about alternatives, and share concerns about side effects. They were reminded, “you need to make sure you and your doctor are on the same page.” Several posts provided testimonials of successful communication: “in my experience, doctors are more than willing to work with you to alter a prescription to come up with a more affordable option.” Posts about not disclosing nonadherence or disagreements assumed “people do not feel comfortable challenging their doctors or asking questions.” One scolded, “Honestly, the behavior ... reminds me of when I was a kid and I’d lie to the dentist about how often I brushed my teeth.”

Discussion

Two main themes emerged from our analysis. The first was criticism and distrust of various elements of the health care system including pharmaceutical companies, the FDA, the drug development process, pharmaceutically oriented

medical practice, physicians' financial incentives and motivations, insurance company practices and affordability of medications. The second was a shift in the patient role toward self-reliance and self-protection.

One way to think about this shift in patient roles is via Habermas's theory of "communicative action," as Stevenson and Scambler³⁰ did in their discussion of the concept of "concordance." Habermas³¹ makes a useful distinction between strategic and communicative action. Communicative action is oriented toward "reaching understanding," and, ideally, is free of coercion. In strategic action, speakers are less interested in mutual understanding and more focused on achieving individual goals. Strategic action succeeds to the extent that the actors achieve their individual goals, whereas communicative action succeeds insofar as the actors freely agree that their goal (or goals) is reasonable and merits cooperative behavior. Communicative action is thus an inherently consensual form of social coordination that describes the core ideal of concordance.

Communicative action is characteristic of and generative of the "lifeworld," the universe of culturally grounded shared understandings in which people interact with and make mutual accommodations with their neighbors. For Habermas, the lifeworld is "colonized" by bureaucratic systems and interests, such as industries and markets, which practice "strategic" communication in pursuit of pre-established goals, resulting in systematic distortion of communication. For example, some might argue that drug companies are not as interested in reaching a shared understanding with potential customers as they are in persuading them to take pills. Habermas thus imports speech act theory into an analysis of institutional power relationships by recognizing the essential role of trust in the production of perlocutionary force and the interpretation of speech acts.

The physician, in representing the medical profession while engaging with individual patients as particular persons, is squeezed between powerful health care institutions ("The System") and patients' lifeworlds. The forum commenters in the current analysis frequently described physicians as (at least in some cases) untrustworthy because they appeared to be engaged in strategic action on behalf of drug companies and the health care institution, rather than being engaged in communicative action in pursuit of understanding and consensus with their patients. The well-publicized scandals about drug companies withholding unfavorable findings

from publication,³² paying for ghostwritten articles,³³ and the influence of drug manufacturers on physicians³⁴ make such distrust seem understandable.

Implicit in many of the posts is an important redefinition of the traditional physician–patient relationship. Some patients feel the onus is on them to double-check doctor recommendations, perform their own research, or decide how to make their care congruent with other demands of life including financial pressures. Others take this even further and appear to be using doctors as "consultants" whose advice they may ignore. Furthermore, it appears that these older models of how the physician and patient should interact are sometimes being replaced without explicit discussion and recognition that this is happening.

Habermas's conceptual framework may help us understand these role changes. Previous research has noted how the professional status of doctors is reinforced by patient deference and by avoiding open disagreement and conflict.^{35,36} This fits within the long-noted tendency of politeness to prevail in asymmetric power relationships.³⁷ Patients' criticism of the medical system may be difficult to bring up in polite exchange. Indeed, if there is a preoccupation with holding up a norm of politeness and deference while covertly mistrusting the system and the doctor, then communicative action is impossible. Only strategic action can get the parties through the visit comfortably.

Patients who challenge the status of their doctor in their own minds may be avoiding conflict on two levels: (1) withholding their medical concerns and (2) withholding their preferences for a different model of physician–patient relationship. Defending one's own research conclusions and expert status without being explicitly invited by the provider would upend the "physician expert" model. Complaining about being made to wait because one feels one's time is as valuable as a doctor's time challenges traditional norms in a different way. It is difficult to imagine how a patient who vehemently critiques commonplace medical assumptions and speaks of doctors as naïve participants in a broken system, as some of these comments suggest, would voice these views with the very practitioners about whom they seem to hold such low opinions. Doctors would not only have to solicit patient input but also prove that they can accept this level of patient criticism amicably.

Furthermore, Stevenson and Scambler³⁰ suggest the emphasis on patient-centered care may in itself create a barrier to open communication:

The movement towards mutuality and reciprocity ... means open strategic action has become less acceptable. It may have been replaced by concealed strategic action. Concealed strategic action incorporates not only conscious deception or manipulation but also unconscious deception or systematically distorted communications.

We know that discussing nonadherence can be a delicate matter. In research specific to human immunodeficiency virus care, physicians have been described as lecturing or scolding patients about adherence,³⁸ and some patients have reported concealing their nonadherent behavior at future visits or even, in some cases, discontinuing clinic attendance or stopping medication taking altogether as a result.^{38,39} Forcing the topic into the open is probably not sufficient to improve the quality of doctor–patient discussion of nonadherence.

Whereas the focus of this article is physician–patient communication about medication adherence, not about the outcomes or consequences of medication-taking decisions, we would be remiss not to comment on the medical risks for patients and the legal risks for physicians that dysfunctional communication can engender. The dismissive attitude that some commenters expressed about physicians' interest, expertise, and caring could easily lead to errors and injury if beneficial medications are forgone, harmful ones are taken, or dangerous combinations are used. It is hard enough to provide high-quality, safe pharmacologic care to patients, particularly those using multiple medications, when communication is good.⁴⁰ When communication is poor, the risks for adverse patient outcomes increase.⁴¹ For concordance about prescription medications to be achieved, both patients and physicians need to take responsibility for ensuring that communication about prescription medications is open, honest, informative, and bidirectional.

One limitation of this study is the found nature of the data set. We could not interrogate participating voices to clarify the meaning of their posts, or follow up with them to elaborate on their thinking. A second limitation is that we do not have demographic data about the people who commented, only general information about *New York Times* readers. Finally, it is possible that the people who were motivated to comment felt provoked by some aspect of the article or other comments, creating a selection bias toward people who have negative feelings toward doctors or medicine. As we were interested in identifying barriers to concordance, this bias was found informative, but these views should not be interpreted as being generalizable. A review article concluded

that despite increasing access to the Internet and other societal changes, patients still prefer to discuss medications with their usual doctor and that they value their relationship with their doctors.⁴² A recent national survey showed that patients trust physicians more than other providers and information sources for information about medication efficacy, and are second only to pharmacists as an information source about medication costs.⁴³ These caveats notwithstanding, this analysis brings to light barriers to concordance that providers treating highly informed patients should be prepared for.

Conclusion

Distrust of physicians' recommendations about medications may be more widespread than physicians appreciate, particularly among well-educated patients, but this distrust is not always expressed. Practitioners may benefit from encouraging their patients to express dissent and even mistrust about medications and medical practice. It may be necessary to invite shared decision-making overtly and to encourage disclosure of opinions that may be perceived as taboo or threatening. Concordance about prescription medications is a worthy goal, but one that may be more difficult to realize than many, including patients and physicians, expect.

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