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## PEER-REVIEWED CME ARTICLE

### How Medicine May Save the Life of US Immigration Policy: From Clinical and Educational Encounters to Ethical Public Policy

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*Editor's Note: To claim one AMA PRA Category 1 Credit™ for the CME activity associated with this article, you must do the following: (1) read this article in its entirety, (2) answer at least 80 percent of the quiz questions correctly, and (3) complete an evaluation. The quiz, evaluation, and form for claiming AMA PRA Category 1 Credit™ are available through the [AMA Education Center](#).*

#### Abstract

Medicine has a conceptual contribution to make to the immigration debate. Our nation has been unable to move forward with meaningful immigration reform because many citizens seem to assume that immigrants are in the United States to access benefits to which they are not entitled. In contrast, when medicine encounters undocumented immigrants in the health care or medical education setting, it is obvious that their contributions to our health care system are denied by exclusionary laws. When the system is amended to be inclusive, immigrants become contributors to the systems that they access. I illustrate this thesis concerning the benefits of inclusion through an examination of the issues of forced medical repatriation, access to health insurance, and the access of undocumented students to medical education.

#### Introduction

For better or worse, virtually every person needs to access medical care at some time, and this means that there is no social problem that will not enter the health care system and need to be addressed in some way by clinicians. When policymakers refuse to address particular social issues, e.g., poverty, hunger, homelessness (and immigration), health care facilities may have to address the problems as they manifest on a case-by-case basis. In short, the burden of addressing such issues may be transferred to an already stressed health care system. This generally means that individual physicians and other health care professionals, their clinics and hospitals, and their communities must work creatively to address the needs of these patients. In some cases, reasonable options for patients afflicted by these issues may be few or none, as adequate resources may not be available. In such instances, it would also seem to be the responsibility of health care professionals to advocate for needed policy changes. In the United States,

our immigration system has been the focus of needed reform for several decades, but little progress has been made. As a result, the problems created by the immigration system's inadequacies have impacted health care and require policy interventions. This may require that medicine attempt to inform the nation's perspective on immigrants.

### **Context and the Life of Ethics**

Fortunately, medicine and medical ethics are up to the task. The late, renowned philosopher Stephen Toulmin described in 1982 how medicine had saved the life of ethics [1]. Ethics had lapsed into relativism paradoxically because it took universal principles as its starting point. These principles are abstracted from all particular content in a quest for certitude. But once such content is removed, the basis for deciding among choices is also nullified. Thus all positions become equal. Toulmin argued that medical ethics, a.k.a., bioethics, made progress during this period when philosophical ethics was barren because the problems medicine posed are within a rich context that can be analyzed and mined to assist in the solution. In particular, medical ethics starts by looking at cases in a broad sense, i.e., common situations. Within such situations, stakeholders have interests that are somewhat objective. Included in those interests are role-specific responsibilities within institutions that have been forged over time.

Toulmin's approach is similar to that of social philosophers such as Michael Walzer [2] in asserting that socially established institutions such as those that serve health care contain an internal logic, values, and wisdom that address the needs of the community. Solutions to problems that preserve these professional enterprises and serve the community present themselves as ethically and morally choice worthy. This methodology, which became best known as the revival of casuistry (i.e., case-based reasoning) in its further development with the venerable bioethicist, Albert Jonsen [3], takes historical context and embedded wisdom seriously. It is an inductive method that can build outward to higher levels of generality and elucidate our communal "forms of life" [1]. That is, we can harvest the lessons we learn in the medical sphere of endeavor to shed light on other aspects of our shared life [3].

### **Where Immigration-Related Challenges (and Opportunities) Present to Medicine**

Three immigration-related issues are virtually unavoidable in the clinical setting for medicine and for intimately related enterprises such as medical education. They simply present within medical and medical education facilities and require a response. First, clinicians have occasionally found themselves confronting the phenomenon of potentially forcing "medical repatriation" of an immigrant patient. Some of these cases have captured media attention, and a small medical and legal literature has developed [4, 5]. Such cases usually involve an undocumented immigrant in need of long-term care. The patient lacks any means of financing the care. His or her immigration status pre-empts most of the usually available ways by which low-wage workers might secure insurance, either through private purchase or through the provision of [Medicaid](#). Thus,

the health care institution seeks to discharge the patient to the only place that will accept him, i.e., the country of his birth. Closely related is the more general relationship between immigration status and health insurance. The exclusion of undocumented immigrants from the reforms occasioned by the Affordable Care Act not only poses problems when a patient cannot be discharged, but also frustrates the goals of the health care system. Finally, young undocumented immigrants, a.k.a. "DREAMers," have sought and, to a very limited degree, matriculated in medical schools. The needs of the physician workforce should prompt us to advocate for equality in the admissions and access to federal financial aid for this population.

Medicine confronts and responds to these issues each day in the best ad hoc manner available within the situation and inductively develops approaches and best practices that make use of the values and experience available within health care institutions because these situations demand a response. My conclusion from an analysis of these issues from that developing health care perspective reveals that public policy regarding undocumented immigrants and health care has been made from a mistaken paradigm. This paradigm starts with a universal rule that breaking laws is wrong and lawbreakers must not be rewarded for doing so. In attempting to apply the rule, every good is viewed through the lens of a potential reinforcement to the undocumented immigrant (i.e., the lawbreaker) that must be denied. This view uncritically comes to see access to health care and education as benefits to the individual and rightfully only available to citizens. In this presumptive worldview, citizen-contributors are pitted against those who come to the US illicitly to take such "benefits."

This rigid and mistaken framing of issues concerning immigrants has developed over several decades and was first made explicit in the debate concerning "welfare reform." As a result, the welfare reform law (Personal Responsibility and Work Opportunity Reconciliation Act of 1996) and a related act that specifically applied to immigrants called the Illegal Immigration Reform and Immigrant Responsibility Act (IIRIRA) of 1996 restricted access to a wide variety of "benefits" for authorized immigrants and undocumented immigrants, including health care [6, 7]. And, of course, this exclusion has continued in the Affordable Care Act [8, 9] and financing for higher education, such as student loans, by limiting such access to citizens [10]. These policies restricted access to benefits because policymakers believed that immigrants were being attracted to the metaphorical US "welfare magnet" [11, 12]. Thus, significant amounts of policy toward immigrants are premised on the image of immigrants as in pursuit of benefits being given to them [13]. This line of reasoning was translated and updated into the vernacular four years ago by then-presidential candidate Mitt Romney, who espoused a theory of "makers versus takers" at a private fundraiser [14], and he also suggested in public debates that, as takers, undocumented immigrants would "self-deport" if they were not able to access benefits [15]. While much has happened in four years, similar thinking

underlies a significant amount of the current public policy dialogue, and illicit “taking” is put forward in more virulent and noxious forms, e.g., “rapists,” “bringing drugs” [16, 17].

### **Makers, Takers, and Health Care**

Medicine implicitly understands the artificiality of this maker-versus-taker dichotomy. Medicine historically starts within the context of a one-on-one relationship of physicians to patients that operates within health care institutions and systems. These institutions are party to an implicit social contract and professional ethos of caring for patients and for the public health in a humane and efficient way [18]. In what follows, we will apply the procedure of medical ethics as it has evolved from Jonsen and Toulmin and other practical ethicists in order to provide recommendations that address the ethical issues that sometimes arise in the encounters between medicine and undocumented immigrants. We will see that a certain pattern emerges. Namely, the problems arise in the clinical or educational setting because undocumented immigrants are excluded from the common ways that such issues are addressed with citizens. We will see that policies that exclude undocumented immigrants from full participation in society actually serve to turn them into “takers” from the health care system. The obvious conclusion will be that developing inclusive social policies toward this population will ameliorate the issues by allowing undocumented immigrants to contribute to the solutions to these problems. Such a finding undermines the maker-versus-taker distinction and thereby helps to reframe the larger social policy debate.

### **The View from Health Care**

*Rejecting forced medical repatriation.* [Forced medical repatriation](#) is perhaps the most dramatic encounter involving unauthorized immigrants within our medical system. And a quick analysis of this issue shows how leaving particular health care facilities to address the needs of undocumented patients in an ad hoc manner threatens much of what medicine and the public value. These episodes begin with an injured patient, oftentimes a construction worker or other laborer, whose injury is so severe that the patient’s rehabilitation and care needs will continue for a significant period after the acute phase, perhaps for the remainder of the patient’s life. Acute care hospitals wish to discharge patients to the next appropriate level of care when it becomes feasible for obvious reasons, e.g., lower levels of care are less costly and patients are vulnerable to hospital-acquired infections when they remain as inpatients. But discharge to another facility requires a method of payment. The hospital opens its doors to all who need emergent care under the Emergency Medical Treatment and Active Labor Act (EMTALA) [19], which requires that patients presenting be examined and stabilized when they present to an emergency room. However, other facilities, such as a rehabilitation hospital or a skilled nursing facility, do not need to accept transfers of such patients when they have been effectively stabilized. In paradigmatic instances of medical repatriation, the worker lacks insurance because his employer does not provide it and, being undocumented, he will not qualify for Medicaid, which would commonly be the insurer covering long-term care in a

similar case involving a US citizen. So the hospital lacks the usual discharge options [20]. Deportation of the patient seems the obvious way to end the situation, and some hospitals have engaged in this practice over the objections of the patients or their families.

The literature on this topic reflects a consensus against forced medical repatriation, i.e., medical repatriation against the will of the patient [21, 22]. Forcing medical repatriation essentially risks making a health care facility into an arm of the immigration enforcement apparatus. It is a dramatic and high-profile activity. In overriding the will of the patient and family, it brings a kind of violence to the healing relationship. Immigrant communities can learn of such unfortunate practices, adding to the general fear that encountering public institutions and authorities can place one at risk. These fears extend beyond persons who are undocumented, as many families are of mixed status and those with an authorized immigration status can still fear placing their families at risk by interacting with the institutions. Furthermore, these practices that are based on lack of a lawful immigration status contribute to the perception by members of immigrant communities that they are treated with suspicion and should fear interactions with health care institutions [23]. Widespread mistrust can mean that large numbers of persons will not voluntarily present at the health care institution or will only present at a point of desperation.

The practice of forced medical repatriation undermines our health care institutions by eroding some of their fundamental values and aims. Our health care institutions, especially those designated as nonprofit entities, are supposed to be caring institutions where anyone in the community can present when in distress. We have noted that, as a society, we have codified this premise in EMTALA, which opens the door to the hospital to all in emergent situations [19]. While we can claim that this law is based on fundamental human rights, it also represents the settled intuition in our society that we do not want people dying in the streets. The hospital is a place where they are welcome to present. And if people believe they are unwelcome, this belief will undermine the ability of the institution to respond efficiently to their needs. Patients will present later in the course of their illness when they are sicker, and it will require more resources to treat [24, 25]. This will also mean that should they bear a communicable disease, they will place the community at additional risk by delaying treatment of it. So, forced medical repatriation has been rejected as ethically untenable, as it undermines the key value of the institution of medicine, that of caring for patients and the community.

For the time being, hospitals and health systems must act creatively to provide care for such patients without resorting to forced medical repatriation. But preservation of the values and functions of our health care institutions obviously would be better facilitated by the extension of the usual health insurance options to this population. Being insured would enable these patients to be transferred to a lower, more appropriate, level of care

with the same efficiency as any other patient. Thus, health insurance certainly benefits the patient, but it is an even greater benefit to the health care system. Inclusion within the system enables the system to fulfill its functions and live up to its values rather than introducing the distortion of the patient being eligible only for care at a fairly high level of care, i.e., emergency care, on the care continuum.

*Rethinking health insurance and immigration.* Health insurance from this vantage point of its implicit medical ethic is a way of enabling an undocumented patient to contribute to the system in advance. One can continue to deny access to insurance but to do so means that when these patients present, the financing of their care will need to be entirely absorbed by others. If they are enabled to buy insurance, they contribute by prepaying into the risk pool of the community. The community benefits in addition to any benefit the purchasers utilize. Some progressive organizations such as the American College of Physicians (ACP) have recognized this point and argued that undocumented immigrants should be able to purchase private insurance on the new insurance exchanges, as it seems foolhardy not to accept prepayment for care that will be utilized [26]. However, the ACP statement then falls prey to the conventional misunderstanding regarding who benefits whom by asserting that undocumented immigrants should remain ineligible for any of the sliding scale subsidies the government provides to enable persons of lower and lower-middle incomes to afford the purchase. While one can easily fall into the trap of seeing the subsidies as benefits to the purchaser and therefore deny them, the subsidies enable the purchase. If the potential purchaser does not buy insurance because of the lack of a subsidy, the person is denied the ability to make the contribution to the system that he or she can and again becomes a free rider should he or she need health care [27, 28].

At this point, we see that health insurance parallels other progressive practices in regard to undocumented immigrants [29]. In particular, sanctuary cities apply this same type of reasoning to “benefits” such as access to law enforcement. Enabling undocumented persons to call the police without fear that their immigration status will be challenged benefits the community by not allowing criminal activity to go unchecked [30]. Similarly, many states will issue drivers licenses regardless of immigration status [31]. Ensuring that all drivers on the road have received proper training and are identifiable benefits all who are on that same road. Of course, all of these measures have secondary benefits to the undocumented persons. Drivers’ licenses make increased economic activity realistic for the bearers. Being able to call police officers when in danger or victimized by criminals makes life safer for them as well. And being able to visit health care facilities when ill helps one to maintain one’s health and quality of life. Inclusion increases the degree to which an undocumented resident is a contributor to rather than a taker from the system. This forms a virtuous circle in which undocumented persons increasingly contribute to the community and the community increasingly benefits the undocumented person [29]. This virtuous circle, in which benefits to the society and inclusion of persons who are



immigrants reinforce each other, can be even more clearly seen in the issue of undocumented doctors.

*Dreamer MDs.* In the fall of 2012, the Loyola University Chicago Stritch School of Medicine became the first medical school in the United States to amend its admissions criteria to explicitly note that a specified group of undocumented immigrants is eligible to apply for admission [32]. These young people have been known as DREAMers, which is an acronym formed from the never-passed piece of legislation called the Development, Relief, and Education for Alien Minors (DREAM) Act [33], which would have provided them with a path to citizenship. (They are increasingly rejecting this acronym for separating them from solidarity with the larger undocumented immigrant community [32].) This population consists of undocumented immigrants who were brought to the United States before the age of 16 by their parents and have been raised and educated in the United States for a substantial period of their development.

When these students who had outstanding undergraduate academic qualifications began asking in the first decade of the twenty-first century if they could apply to medical schools, it was obvious to the leadership of the Stritch School of Medicine that it would be highly desirable to entertain these applications [34]. In addition to the usual academic qualifications, these applicants bring a variety of qualifications that are highly desirable in terms of the mission of medical schools to produce a physician workforce that meets the needs of society. For instance, such applicants are typically bilingual and bicultural. While they have grown up in the United States—with the result that in most respects they are not especially different from their citizen-peers—they also have a firsthand acquaintance with the experience of immigrants in the United States. Thus, when they successfully compete for admission on their merits, they also bring all the well-recognized benefits of diversity to their class [35]. They enrich the educational experience of their peers and their demographic profiles indicate that they are more likely to understand and choose to serve underserved communities similar to those in which they grew up [35].

As undocumented immigrants, DREAMers were excluded from working lawfully in the United States until the creation of a new status, Deferred Action for Childhood Arrivals (DACA), by the executive branch on June 15, 2012 [36]. With conferral of such status, one receives an Employment Authorization Document (EAD), also known as a work permit, and can apply for a social security number. However, they are still barred from receiving any federal financial aid, as that would seem to be a federal “benefit” [37]. Aside from the financial aid difficulty, there are few reasons for medical schools to reject the utilization of this talent pool. With the possibilities made possible by DACA, this talent pool should be stewarded for the benefit of the ends of the medical profession. For instance, their talents often include specific abilities such as linguistic skills and cultural knowledge that will enable them to meet particular needs of various segments of our

communities. They do not pose the usual concerns of international students that they might be likely to take their education and go back to a country of origin, thereby not benefiting the communities that help to support medical education in the United States. In this sense, these students are from here, from our communities [37].

The case of DREAMers shows that communities are once again best served by enabling the full participation of those present rather than artificially restricting that participation. It is difficult to see why they should be prevented from using their talents to benefit patients in need. Again, we see the self-fulfilling nature of the maker-versus-taker distinction. If the conditions of inclusion exist, these people become contributors. If they are excluded from participation in the mainstream life of the community, they are limited in the kinds of contributions that they may make. As we noted earlier, DREAMers in medical school cannot secure federal student loans because our system does not wish to give a “benefit” to an undocumented immigrant [37]. But we must again recall why student loans are provided to medical students and students in higher education at all. Such loans have been historically seen as helpful to overall economic development and enhancing the quality of life and security of the nation [38]. And medical student loans have enabled the expansion and diversification of the physician workforce to comprise a group better able to address a growing and diversifying population [39]. Of course, a student who can become a doctor is benefitted. But that benefit is ancillary to meeting the need for a talented and qualified physician workforce.

### **Ethics, Policy, and the Community**

The conclusion from our overview is simple. Our health care institutions are undermined when clinicians are forced to treat some patients and potential colleagues differently simply because of immigration status. These institutions and clinicians are forced to act contrary to their values and to discriminate in ways contrary to the established norms of medicine and health care for nonmedical reasons that are extrinsic to the profession.

This conclusion also seems to yield a corollary: namely, the degree to which undocumented persons contribute to our institutions is largely determined by the degree to which systems enable and accept their contributions. Seeking to exclude their participation from health insurance or health care professions as punishment for unlawful entry or overstaying a visa limits their contributions. Of course, as people who are motivated to leave their homeland and immigrate to the United States often possess great determination, they sometimes find ways to overcome these barriers despite the intended obstacles. Such considerations call into question the prudence and practicality of exclusionary policies. Is the absolutizing of laws regarding authorized immigration worth undermining our cherished values and institutions and denying our communities the contributions of undocumented immigrants? Toulmin reminds us that morality is to a large extent that which preserves and furthers our institutions and forms of life rather than undermines them [1].

## Conclusion

Our survey of the ways in which undocumented immigrants interact with the health care system illustrates that the common way of framing issues related to undocumented immigrants is highly artificial. That is, the maker-versus-taker focus abstracts a particular individual from the social and institutional context and does not consider the person as part of larger communities and human ecology. As a result, such artificial thinking makes prescriptions that damage the community and its institutions. Medicine starts from cases within institutions and asks for policy solutions that preserve the goods that we value within our institutions and communities.

The conclusion that our health care institutions are undermined when clinicians are forced to treat some patients and potential colleagues differently simply because of immigration status and that policies inclusive of this population benefit our institutions seems to have immigration policy implications as it underscores the self-reinforcing nature of public policy. That is, undocumented immigrants who have lived, studied, and worked within a community participate within that community. The community functions best when that participation is not truncated but fosters inclusion. That is in the community's interest. And as the undocumented immigrant contributes to the community, he or she becomes still more a part of that community by developing a kind of equity interest in these social institutions and their values. Reciprocally, with the passage of time, the community gains an equity interest in the individual whose good it also has at least tacitly fostered.

Medicine and its ethics contribute to our thinking about the treatment of undocumented immigrants who live and work within our borders. We must treat such people in accordance with the inclusive norms of our institutions—institutions that promote the good of the community. But can medicine and its ethics tell us exactly how to alter our immigration policies such that we know exactly how many people and who they are that should be given entry visas? Of course not. But it provides a starting point and a methodology. We must begin from within the ecology of our institutions and relationships rather than begin with an empty and negative characterization of immigrants.

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## FROM THE EDITOR

### To Understand and Be Understood: The Ethics of Language, Literacy, and Hierarchy in Medicine

Clear communication and understanding between patients and physicians is essential to the practice of medicine. And yet approximately 80 million Americans have limited health literacy—the ability to process and understand medical information in order to make decisions about health care [1]. Low health literacy can be the byproduct of differences in spoken language, underlying knowledge about medical conditions, and cultural beliefs about health and sickness. Demographically, low health literacy is associated with educational level, ethnicity, socioeconomic status, and age [2]. The tragedy of linguistic failures with respect to health outcomes is well known: low health literacy among patients is consistently associated with more hospitalizations, greater use of emergency care, lower receipt of critical preventative interventions such as mammography screening and influenza vaccination, poorer ability to take medications properly, and, among seniors, poorer overall health status and higher mortality rates [1]. In fact, poor health literacy partially explains the existence of racial disparities in some health outcomes [1]. The prevalence of low health literacy and its association with poor health outcomes create ethical challenges for medical practitioners.

Caring for patients with low health literacy is further complicated by existing social and administrative hierarchies that structure relations between patients and health care practitioners and among practitioners themselves. Rank within medical hierarchies is based on level of authority and experience, creating constraints concerning who speaks up, when to speak up, and how to speak in order to be heard [3].

Mindful of the fact that communication across barriers of health literacy and hierarchical status is a central challenge in the practice of medicine [4], this month's issue of the *AMA Journal of Ethics*® considers the theme of language and hierarchy in medicine. It seeks to characterize potential sources of miscommunication in medical settings, draws attention to the social disparities that complicate existing differences in spoken language and level of health literacy, and explores the conventions of language use within medicine.

Our foray into the topic begins with the most obvious question: Who must bear the burden to facilitate communication within the medical encounter? Alexander R. Green and Chijioke Nze note that while the law is very clear in placing [responsibility for interpreter services](#) on health care providers, there should be institutional programs to support them, which would require culture change in hospital medicine on the order of



what occurred with the introduction of hand hygiene. Gaurab Basu, Vonessa Phillips Costa, and Priyank Jain discuss [patients' right to language services](#), noting that whoever serves as a translator must be both a competent and an impartial individual within the medical hierarchy. Similarly, in the podcast, Donald A. Barr emphasizes clinicians' legal and ethical obligation to rely on [professional translators](#) rather than family members in clinical settings and discusses how lack of health literacy and language barriers can negatively affect health care outcomes.

Medical education has a role to play as well in ensuring that adequate numbers of future physicians are able to meet the linguistic needs of this country's diverse population. Green and Nze show how residents' underutilization of interpreter services—even when available—is due to lack of incentive, time pressures, and indifferent attitudes towards limited English proficiency (LEP) patients. Barret Michalec, Maria Athina (Tina) Martimianakis, Jon C. Tilburt, and Frederic W. Hafferty argue that the responsibility for [working in underserved areas](#) with large numbers of patients with LEP falls on all future medical professionals and not just students belonging to underrepresented minority groups.

In addition to macro-level interventions, we must also consider implementing small-scale changes that can help surmount language barriers within a given clinical encounter. As Lara Killian and Margo Coletti note, even when a patient and clinician are speaking the same mother tongue, the use of [medical jargon](#) can be a formidable barrier. The authors advocate the use of Health Literacy Universal Precautions, a set of tools that enhance shared decision making by facilitating clear communication and ensuring that patients understand the health information they are given [5]. Overcoming linguistic and cultural barriers also has a great deal to do with reconstructing patients' stories in a way that is authentic and respectful. Annie Le, Kara Miller, and Juliet McMullin note that [illness narratives](#), once promising in their ability to shed light on diverse cultural beliefs, can lead to stereotyping about patients of different backgrounds if, in reading them, certain particularities are focused on. Rather than falling into that pit, they argue that medical practitioners should guard against reductionist thinking by asking follow-up questions of patients that clarify the contexts of illness.

In seeking to implement these communication practices, we confront the issue of transparency. Noting that the mental health record is becoming increasingly available to patients, Robyn P. Thom and Helen M. Farrell argue that hesitancy to embrace [transparency](#) out of a desire to spare patients having to face labels and judgments contained in their medical record goes against the ethical principles of justice, autonomy, and beneficence. Focusing on the opportunities for communication and transparency that the electronic health record (EHR) provides, Angus Roberts explains that while there have been several efforts to uniformly structure medical information, the EHR is still dominated by unstructured natural language that traffics in nuances,

negations, temporal expressions, and hedging phrases. He argues that the tension in the EHR between easily coded “hard” data, which aims to narrowly characterize the population, and free text, which aims to comprehensively describe the individual, might be resolved—if incompletely—through [linguistic analysis](#) (i.e., natural language processing).

So what is the way forward? MaryKatherine Brueck and Angelique M. Salib discuss the [legal implications](#) of physicians’ poor verbal and nonverbal communication, arguing that, in cases of physician error, the possibility of adverse legal action can be reduced through “apology statutes” that protect physicians from penalties for disclosing medical errors. Unsurprisingly, emphasis has been placed on training medical students to practice effective communication and cultivate empathy and reflectiveness. One method for doing this is through narrative training. Marcia Day Childress examines the relevance of Kathryn Montgomery’s *Doctors’ Stories* [6], which excavates medicine’s narrative foundations. Childress believes that having medical students [write stories](#) can school them in the reflection, ethical awareness, and resilience needed to practice medicine.

To understand the importance of language to the practice of medicine, we must first appreciate the narrative aspect of medicine. As Ross Kessel writes in a review of Kathryn Montgomery’s *How Doctors Think* [7], “using doctors’ aphorisms, maxims and rules of thumb, as well as patients’ often inchoate ‘histories,’ she shows us how physicians arrive at a clinical judgement about the person in front of them” [8]. This narrative encounter between patient and physician, which is at the heart of the practice of medicine, cannot serve the needs of patients if they are unable to communicate their symptoms, unable to understand how to take their medications, or are too intimidated by the medical hierarchy and medical jargon to speak up. The goal of this issue is to learn from this state of affairs and offer insights to medical professionals both for restructuring the way they record and disseminate information and for ensuring the success of each medical encounter.

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## ETHICS CASE

### Why It's Unjust to Expect Location-Specific, Language-Specific, or Population-Specific Service from Students with Underrepresented Minority or Low-Income Backgrounds

Commentary by Barret Michalec, PhD, Maria Athina (Tina) Martimianakis, PhD, Jon C. Tilburt, MD, MPH, and Frederic W. Hafferty, PhD

#### Abstract

In this case we meet Amanda, a medical student of Native and Latin American ethnicity who receives financial aid. Her friends are surprised by her interest in an elite residency program. They suggest, rather, that with her language skills, ethnic background, and interest in social justice, she has a responsibility to work with underserved patient populations. In our commentary, we consider issues raised by the case and explore Amanda's friends' underlying expectations and assumptions that perpetuate the very inequities that the resolution of the case purports to address. We also identify the role of privilege and address the "burden of expectation" that appears to be associated with underrepresented minority (URM) medical students and normative assumptions about their career paths.

#### Case

Amanda is a second-year medical student at a private Midwestern medical school, which she is able to attend thanks to an institutional scholarship and federal financial aid. She has been seriously engaged with campaigns on campus for health equity and social justice in the community and in the country at large. Amanda grew up in a family with mixed Native American and Latin American roots and was a first-generation college graduate in her family; thus, issues of access to education and health care are very important to her.

Amanda grew up speaking Spanish fluently and studied medical Chinese in her first year of medical school. She has used her language skills in a medical student-run clinic that provides free basic clinical services to those with limited English proficiency (LEP), which includes Spanish and Chinese speakers. As a second-year medical student, she has begun thinking about clinical years and plans for a successful residency match. During her recent visit with her family over Christmas, her parents and maternal grandmother

expressed their pride in her accomplishments and their desire that she match into a competitive specialty and residency program.

At school, she is having a discussion with friends about their current career interests. When she expresses her anxieties about what it takes to match into a competitive specialty in an elite residency program, her friends express surprise. "I thought since you were so passionate about social justice, you'd be more interested in working with minority populations back home." Others concur and express the opinion that, as someone with the cultural competencies and language skills to work with immigrants in her home state, she has a responsibility to utilize her skills for LEP populations. She wonders what to say.

### **Commentary**

*Talk of "ethical dilemmas" diverts attention from the structural conditions that have produced the problem in the first place.*

*Daniel Chambliss [1]*

As a team of three social scientists and a physician bioethicist—and following De Vries' [2] distinction between sociologists *in* medical ethics (e.g., functioning as "collaborators") and sociologists *of* medical ethics (e.g., functioning as "outsiders" and "debunkers")—we will problematize as well as address issues raised by the case. In both respects, we pay special attention to the concept of *expectations*, exploring where expectations about "paying back" may originate along with the impact these expectations may have on (medical) career pathways and professional identities. Within this discussion, we introduce the concept *burden of expectation* in exploring the assumed responsibility of underrepresented minority (URM) students regarding specialty choice, type of practice, patient population, and practice location.

### **How Ethical Is the Ethical Dilemma?**

The opening paragraph of this case is a sociological smorgasbord. Nested within the case are not only tacit messages suggesting privilege for some and obligation for others but also assumptions associated with typical gender norms; ethnicity biases; medical students' socialization and professional development (most notably in regards to career expectations); and explicit, implicit, and even hidden institutional-level barriers and hurdles for URM students. However, the lightning rod in Amanda's case is text specifying that she is able to attend medical school "thanks to an institutional scholarship and federal financial aid." We will begin our comments, therefore, by discussing the (explicit and implicit) institutional and societal expectations that can be associated with this kind of support for students, specifically those who are members of underrepresented minority groups.

The language of the case itself depicts Amanda as a subordinate and essentially indebted social actor. An explicit and contractual agreement with a financial institution to repay a monetary loan seems now to have been stretched by others to include a more implicit expectation that she go into a particular field or specialty and focus her studies, training, and skills on certain geographic areas or patient populations, thus metaphorically continuing to pay back her debt as an “indentured” activist: one whose debt can only be repaid by meeting gender- and/or ethnicity-specific *de facto* service requirements.

Furthermore, the above case implicitly positions (and quite favorably) the medical school as a neutral bystander (or perhaps even a benefactor) in this relationship. This case obviates the fact that Amanda’s type of scholarship also helps lure or retain URM applicants—which, in turn, improves the rankings of the school, including its diversity profile and identity as a socially responsible institution. Helping students from URM groups attend medical school raises the reputation of the university at a time when there are growing social responsibility expectations of all higher education institutions. Furthermore, support programs exist such as institutional scholarships, separate admissions tracks for those interested in rural medicine or nontraditional majors, and even loan-repayment programs funded through the Affordable Care Act that recruit medical students to work as primary care clinicians in underserved areas, with varying service commitments [3]. In turn, these programs’ expectations as well as gender- and ethnicity-related assumptions can restrain students’ (especially URM students’) self-determination and agency, possibly pushing them down professional pathways other than those the students originally envisioned.

### **The Fortitude of Expectations**

Our theme of how expectations may limit self-determination continues as we consider how the case characterizes Amanda’s friends. In directing our attention to a micro issue (i.e., Amanda struggling with “what to say” to her friends), the structure of the case itself diverts our attention from much larger, meso (institutional) and macro (sociocultural) issues. We read that Amanda’s friends are surprised by her desire to pursue a competitive specialty, as they express their expectation that she would return home and pursue a route more directly tied to working with underserved patients given her interest in social justice, her language skills, and her apparent competence in various cultures. What is important (ethically) here is that these expectations reflect and express implicit biases [4, 5]—subconscious stereotypes—that are cultivated through [socialization processes](#) (including those associated with medical professional development) that guide beliefs, perceptions, and even interactions. A prominent theoretical stance in the sociology literature known as the conflict perspective suggests that socialization represents a powerful means of social control because people are implicitly and explicitly taught norms, values, and perspectives that reflect the hegemony of those in positions of power and authority [6]. Therefore, through more systems-level socialization

processes (e.g., education, family, peers, media, faith-oriented), and through socialization processes and mechanisms nested within and associated with the institution of medicine specifically, trainees internalize the values, beliefs, and practices of their profession—for better or for worse—and perpetuate them through their own actions, beliefs, and assumptions. Socialization processes often unfold without the learner necessarily being aware of their impact and influence or reflecting upon how things are versus how things *should* or *could* be. As a result, ethically problematic assumptions and expectations about colleagues' backgrounds and callings can arise and persist over time.

Within this case specifically, expectations held by Amanda's friends reflect a set of particular overarching societal-level stereotypes that linger within medicine and its educational culture: (a) women *should* desire work in more patient-centered specialties and (b) ethnic minorities, if given opportunities through education and/or employment, *should* "pay it forward" (through particular career paths) [7, 8]. These stereotypes underpin the ethical dilemma. Amanda is portrayed as deviating from the norm when she dares to consider a career that does not involve working with URM patient groups. The reaction of her friends who expect that Amanda would want to go this particular professional route as well as the framing of these expectations as "responsibilities" acts as a powerful reproduction, a safeguarding of sorts, of the norm's power over Amanda and what she *could* do and be in the world.

### **Assumptions and Expectations (or Lack Thereof) Associated with Privilege**

Consistent with these implicit biases about women and ethnic minorities and their potentially limiting impact on these groups' professional options, Amanda's friends (and others) apparently believe that because of her ethnic background and language skills, Amanda has a responsibility to serve a patient population of similar ethnic and linguistic background. This expectation is supported by Amanda's purported avowed and embodied interest in issues of access to education and health care. It also reflects the protective shroud of privilege—[social advantages](#) (often race or ethnicity and gender) that protect certain people and provide a more clearly paved path to upward social mobility in comparison to others who encounter explicit and implicit hurdles and pitfalls (e.g., institutionalized sexism and racism).

In this case, Amanda's friends' privilege is reflected in their apparent assumption that they do not have responsibility to work with underserved patient populations and that they somehow see themselves as more free than Amanda to explore their own professional interests. Furthermore, they hold this assumption despite the fact that medicine, foundationally, is a service profession and that all medical professionals have a fiduciary responsibility to serve diverse patient populations. In contrast to her friends, Amanda is attributed a burden of service because of her ethnic identity, language skills, and having previously worked to alleviate health inequities.

From her friends' viewpoint, Amanda's skills stemming in part from her ethnicity make her more *naturally* suited for work in URM communities. Thus, whereas Amanda is chained to an expectation of altruistic medical "servitude," her friends (note the text does not say that they expect Amanda to *join them* in service to minority, immigrant, and LEP patients) are protected from this mantle of responsibility because of their privilege.

Students who are members of URM groups are indeed more likely to practice in underserved areas and work with disadvantaged patient populations. As Bennett, Phillips, and Teevan [9] noted in an earlier issue of this journal, "students with rural backgrounds are much more likely to practice in rural settings, and African American students more often choose inner-city practice. ... Women ... disproportionately choose primary care." In turn, the authors articulate support for premedical pipeline programs that encourage students from disadvantaged and minority groups to enter the medical profession: "because these students are more likely to work with underserved populations after graduation, increasing their interest in health professions and investing in academic support may help correct the current physician maldistribution."

In this quotation, once again, we encounter evidence for connecting the admission of URM students to implicit expectations that these students work in underserved areas. This is emblematic of the very same set of biasing assumptions that are shared among Amanda's friends, particularly since the authors of the quoted source provide no evidence about why these students "choose" to work with these particular patient populations. These same assumptions can impact admissions and recruitment strategies—which can be reflected in financial aid and scholarship offerings and eventually become nested within institutional culture and practice as they become reinforced through faculty-student and student-peer interactions.

### **The Fairness of Expectations**

We were tasked with the following question in relation to the case: "Which criteria should be used to assess the fairness of expecting location-specific, language-specific, or population-specific service from students or graduates from underrepresented minority or low-income backgrounds?"

We believe it is fundamentally unfair to differentially *expect* URM students—because of their underrepresented, disadvantaged, or underprivileged minority status—to work in underserved areas or with specific populations. Likewise, as we have argued, we believe it is unfair to *expect* these students to follow this specific professional track because they are assumed to be better prepared for it because of their ethnicity, cultural practices, or language skills. Moreover, such biases have created a burden of expectation that, when left unchallenged, can become institutionalized and limit the capacity of URM students to imagine or pursue upward mobility. This burden of expectations, which disproportionately falls on the shoulders of URM medical students, reflects a corruption



of the adage, “To whom much is given, much is expected.” Rather, when discussing any “criteria” that should be used to assess fairness of expecting medical students to serve, we suggest that medical education institutions pose the following question to *all* of their community members, “If not me, then who?”

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## ETHICS CASE

### **Clinicians' Obligations to Use Qualified Medical Interpreters When Caring for Patients with Limited English Proficiency**

Commentary by Gaurab Basu, MD, MPH, Vonessa Phillips Costa, and Priyank Jain, MD

#### **Abstract**

Access to language services is a required and foundational component of care for patients with limited English proficiency (LEP). National standards for medical interpreting set by the US Department of Health and Human Services and by the National Council on Interpreting in Health Care establish the role of qualified medical interpreters in the provision of care in the United States. In the vignette, the attending physician infringes upon the patient's right to appropriate language services and renders unethical care. Clinicians are obliged to create systems and a culture that ensure quality care for patients with LEP.

#### **Case**

Shiv is a fourth-year medical student hoping to match into dermatology. He knows what program he wants to rank as his top choice and is currently doing a month-long, hospital-based dermatology rotation. He is excited to get additional exposure to a field he genuinely enjoys, and naturally he also feels pressure to do well. One morning while Shiv is rotating with a couple of residents, the attending physician wants to demonstrate some skin findings on a patient, a Haitian woman with an immunologic condition who has limited English proficiency. The attending physician briefly explains, in English, to her and the residents what they will be looking for. As she is giving a hesitant nod to his request, he abruptly pulls down her hospital gown exposing her breasts. She seems to be acutely uncomfortable, her eyes widen, and her arms remain paralyzed at her sides. She doesn't say anything. Having spent a year working on tuberculosis (TB) in Haiti, Shiv happens to speak Haitian Creole and, sensing her discomfort, asks her in Creole if she is OK and explains that it is a teaching session. This seems to calm her somewhat. The attending physician chides Shiv for carrying on a conversation with the patient that the rest of the group can't understand and accuses him of detracting attention from his teaching time. Shiv wonders how to respond.

## Commentary

The Haitian patient in this case has a right to language services. In failing to communicate through a qualified interpreter, the attending physician probably exacerbates the patient's emotional distress from having her breasts abruptly exposed.

We will use a rights-based framework to explore the legal and ethical responsibilities that health care professionals have to their patients with limited English proficiency (LEP). We will then describe national standards for language services established by the United States government and the National Council on Interpreting in Health Care (NCIHC). Analysis of these standards will show that, in this case, a qualified interpreter was required to provide appropriate care to the patient. Shiv, the medical student in this case, is placed in a challenging circumstance and feels compelled to act as an ad hoc interpreter. We detail why use of Shiv as an ad hoc interpreter is inappropriate. Finally, we present systems-based solutions that can help mitigate harm to patients with LEP.

## Patient Care

*A rights-based framework.* Access to health care services is a human right, as defined in numerous international health rights covenants [1-3]. The United Nations Committee on Economic, Social and Cultural Rights' General Comment 14 states, "Health is a fundamental human right indispensable for the exercise of other human rights. Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity" [4]. The right to health care should be an organizing principle in our health systems. The use of appropriate language services and the right of a patient with LEP to access health care are inextricably linked. For patients with LEP, the only way to meaningfully access health services is by clearly communicating with health care professionals using their preferred language of care.

In the United States, patients with LEP have a legal right to access health care in their preferred language. The foundation of this right is established in Title VI of the landmark Civil Rights Act of 1964 [5], which prohibits discrimination on the basis of race, color, and national origin in programs and activities receiving federal financial assistance. In health care, Title VI—as enforced by Executive Order 13166, entitled "Improving Access to Services for Persons with Limited English Proficiency"—is a cornerstone for the provision of oral interpretation and written translation services to patients with LEP [6, 7].

Health care institutions can provide appropriate language services to their patients with LEP by hiring qualified bilingual staff [8]. However, since it is not always possible to hire qualified bilingual staff in all patients' preferred languages, it is essential to have systems for accessing professional language assistance services in place rather than relying on ad hoc interpreters such as Shiv. One solution is for hospitals to employ qualified medical

interpreters in the major languages of their patient populations and contract with telephonic or videoconference services for access to additional languages on demand.

In this vignette, the Haitian patient's right to access language services was ignored, and the patient experienced unnecessary emotional distress. We believe that some of the patient's emotional distress could have been avoided by trying to more meaningfully and clearly communicate with her via use of a qualified medical interpreter.

*Informed consent.* The American Medical Association's (AMA's) *Code of Medical Ethics* states, "The process of informed consent occurs when communication between a patient and physician results in the patient's authorization or agreement to undergo a specific medical intervention" [9]. The concept of informed consent tends to be referenced mostly in cases of written consent for treatments or procedures. However, performing an invasive examination also requires consent, even if not by a formal written process [10]. In this case, the attending physician needs a qualified interpreter to obtain consent prior to conducting a skin evaluation of the breasts and should certainly be modeling this practice robustly for students (and probably the practice of more gently exposing a patient for examination and teaching purposes). In failing to do so, the attending physician undermines the patient's autonomy and informed decision making. Shiv tries to intervene, but even if he had been interpreting from the beginning of the encounter, the AMA *Code of Medical Ethics* statement on informed consent still would not have been upheld. We've argued here that good informed consent is impossible without the use of a qualified medical interpreter.

### **Medical Interpreting**

*Standards of practice for medical interpreting.* A concern of clinical and ethical importance relates specifically to the risk of errors during a verbal consent process for a patient with LEP that does not involve a qualified medical interpreter [11]. In the United States, the Department of Health and Human Services (HHS) establishes competencies required of a "qualified interpreter" [12]. These competencies include the knowledge of specialized terminology and interpreter ethics and the skills to interpret accurately, effectively, and impartially. HHS requires that hospitals conduct an assessment of individuals claiming to have competencies prior to designating an individual as a qualified interpreter. HHS does not require that hospital staff serving as interpreters possess national certification, which is currently available in just a handful of spoken languages [13]. However, HHS clarifies that "the fact that an individual has above average familiarity with speaking or understanding a language other than English does not suffice to make that individual a qualified interpreter for an individual with limited English proficiency" [14].

The case does not indicate that Shiv has demonstrated the required competencies for a qualified interpreter, so we assume he is acting as an ad hoc interpreter. While current HHS guidelines do allow for the use of an ad hoc interpreter in situations involving an

imminent threat to the safety or welfare of a patient with LEP when no qualified interpreter is immediately available [12], this case does not seem to represent urgent circumstances in which use of an ad hoc interpreter would be endorsed by HHS. Health care professionals should use extreme caution when using ad hoc interpreters. The use of ad hoc interpreters—a broad category that includes a patient’s friends or family members and unqualified bilingual staff—can significantly increase medical errors [11]. Health care professionals face potential civil liability when they fail to provide qualified interpreters, if such failure leads to a tort cause of action, such as lack of informed consent, breach of duty to warn, or improper medical care [15]. In contrast, the use of professional interpreters while providing medical care for patients with LEP improves comprehension, service utilization, clinical outcomes, and patient satisfaction [16].

*Conflict of interest.* The National Council on Interpreting in Health Care has developed standards of practice for interpreters in health care [17]. The standards relevant to this vignette have to do with scope of practice as an interpreter (particularly if one has other roles in a clinical setting), one’s obligation to be impartial, and one’s potential role as an advocate for the patient with LEP. Specifically, an interpreter with an additional role in a clinical setting: (1) must adhere to all interpreting standards of practice while interpreting, (2) should disclose potential conflicts of interest that may hinder patient care and withdraw from assignments when necessary, and (3) may advocate on behalf of a party or group to correct mistreatment or abuse of a patient with LEP.

Shiv finds himself with a complicated [conflict of interest](#) due to his dual roles as a clinician-in-training and possible interpreter. He probably could have prevented some harm to the patient by asking his attending physician to use a qualified medical interpreter at the beginning of the encounter. He did not do this, presumably because such interference could have angered the attending physician, thereby negatively impacting his career ambitions.

It is important to highlight that this dynamic was a direct consequence of the failure of the attending physician as a medical educator. Medical educators have a responsibility to [role model](#) medical professionalism, to teach students about patient rights, and to create a healthy learning environment. The attending physician failed as a medical educator when he did not use a qualified medical interpreter—not to mention when he abruptly disrobed the patient—and then chided Shiv when he attempted to respond to her vulnerability. While Shiv could possibly have done more to intervene, including requesting a qualified medical interpreter, we believe the poor outcome of this encounter is squarely the attending physician’s responsibility.

### **Solutions**

Traditionally, the locus of power in a medical team resides in the attending physician’s capacity for good role modeling and demonstration of collaborative leadership, and we

have examined how he used that authority without regard to legal or ethical standards. We shall now explore how systems-based solutions can check such abuses of power and help create safer environments for patients and students.

We believe that institutions providing health care and training should have processes to prevent transgressions such as those represented in this case. First, patients should be made aware of their rights, and this information should be accessible to patients who are most vulnerable, such as patients with LEP. At our hospital, patients are informed of their rights through programs such as interpreter rounds, in which patients with LEP receive daily visits from an interpreter services representative to verify that the patient's communication needs are being met. Patients with LEP learn how to directly access language services on demand while getting care within our health system, and they are given permission to do so, even if a health care professional does not initiate a request for a qualified interpreter. Second, interpreter services should be easily accessible at all points of care via in-person, telephone, or videoconference technologies, and these services should be advertised to the clinicians and patients. HHS now requires hospitals to include multilingual nondiscrimination notices ("taglines") on significant patient documents and to include information on their websites indicating how patients can access language assistance services [12]. Third, teaching students and providing care to patients with LEP takes significant time and effort. Health care institutions should recognize this and provide employees, particularly clinicians, the resources and time needed to appropriately care for patients with LEP. Fourth, health care delivery systems and financing must reflect the legal and ethical responsibilities health care institutions have to patients with LEP.

The institution should also anticipate its response when the above processes fail. Does the patient have access to an advocate? Are students empowered to report unprofessional behaviors of their supervisors or instructors? Does the attending physician have access to remediation? In our institution, we have a patient advocate and medical students have access to an ombudsperson. Medical students are also given guidance during orientation about how to respond to instances in which patients' or students' rights are violated.

We have argued here that clinicians' responsibilities to patients with LEP extend beyond the walls of a health care institution. The professional societies for medical interpreters should advocate for expanding the access, utilization, and reimbursement for medical interpreters' services. Also, medical education and medical interpreter professional societies should promote interprofessional education that improves attitudes, skills, and collaboration as they relate to the care of patients with LEP. Lastly, we must recruit more underrepresented minorities and professionals who speak languages other than English to serve as clinical staff and faculty and provide them with training in how to request an interpreter or the resources needed to gain competency in interpreting.

## Conclusion

Patients with LEP in the United States have a legal right to access language services, and clinicians have legal and ethical responsibilities to communicate through qualified interpreters when caring for these patients. This case highlights the importance of developing health care delivery and financing systems that honor the rights of patients with LEP and facilitate quality care.

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## ETHICS CASE

### When and How Should Clinicians Share Details from a Health Record with Patients with Mental Illness?

Commentary by Robyn P. Thom, MD, and Helen M. Farrell, MD

#### Abstract

Stigma associated with mental illness—a public health crisis—is perpetuated by the language used to describe and document it. Psychiatric pathology and how it can be perceived among clinicians contribute to the marginalization of patients, which exacerbates their vulnerability. Clinical documentation of mental illness has long been mired in pejorative language that perpetuates negative assumptions about those with mental illness. Although patients have the legal right to view their health record, sharing mental health notes with patients remains a sensitive issue, largely due to clinicians' fears that review of this content might cause harm, specifically psychiatric destabilization. However, the ethical principles of justice, beneficence, and autonomy as well as nonmaleficence must be considered by clinicians in determining when and how to share psychiatric details from a health record with their patients.

#### Case

Dr. Kelly, a psychiatrist, has been seeing Maya, a 36-year-old woman, for management of a personality disorder for several years. Based on her symptom profile, Dr. Kelly has diagnosed her with borderline personality disorder. He has noted her fragile self-image, volatility, and frequent displays of anger, intense paranoia, unstable relationships, substance abuse, and serious threats of self-injury as well as suicidal ideation. Despite the difficulties in caring for a patient with a personality disorder, Dr. Kelly has managed to develop a working relationship with Maya using psychodynamic psychotherapy.

One day after a session that was a bit awkward, Maya—who had recently met with a friend who had suffered a medical error in an emergency department—became suspicious of Dr. Kelly and requested access to her health record in order to see what had been written about her.

Dr. Kelly worries that if Maya sees her record, it will disrupt all the progress she has made so far in identifying perceptual distortions and developing healthier modes of perception and response. In the past, he has written in his notes about how Maya can be

“manipulative,” is an “addict,” and has several “failed relationships.” He worries that Maya’s already fragile self-image could be further damaged after reviewing her record and wonders what to do.

### **Commentary**

Language used to describe mental illness has long been mired in what can be viewed as pejorative terminology. Historically, mental illness was described as “madness,” “insanity,” and “lunacy” [1]. The term “borderline personality disorder,” a more contemporary example, suggests someone who is marginal in quality of character or altogether lacking character. [Stigmatizing language](#) in a health record can have far-reaching effects that clinicians should consider from ethical and clinical standpoints. A patient’s mental health record is not only used as a reference by clinicians but also available to health professionals from multiple disciplines for the purposes of coordinating care. Furthermore, the emergence of electronic health records offers opportunities to provide patients with real-time access to their records. In this commentary, we describe how mental illness can be documented with neutral language and offer suggestions to patients requesting access to their record.

### **An Increasing Number of Patients Are Accessing Electronic Health Records**

Although patients have had the right to review their medical records since the Health Insurance Portability and Accountability Act (HIPAA) was passed in 1996 [2], the practical challenges of accessing paper records limited access. As of 2014, however, 76 percent of US hospitals had adopted electronic health record systems [3]. With this change, health care systems and clinicians are revisiting the issue of how best to share the content of health records with patients.

In 2010, OpenNotes, a pilot study of shared primary care notes, was rolled out across multiple institutions in the United States [4]. Over 100 primary care physicians and about 25,000 patients were enrolled in an observational study in which patients had real-time access to their record through a secure internet portal. Overall, both patients and primary care physicians were pleased with the initiative: 99 percent of patients wanted OpenNotes to continue and no physicians wanted it to stop. Advantages included patients feeling more in control of their care and increased medication adherence. Only 1-8 percent of patients reported that viewing their online health record caused confusion, worry, or offense [5]. Although results from this pilot study within the primary care population were quite positive, the extent to which it is generalizable to a psychiatric population is unclear.

### **Research on Increasing the Transparency of Mental Health Notes**

In the case, Maya is not being offered routine access to her record; rather, she is requesting access to her health record after a specific incident that caused suspicion.

Furthermore, her record contains stigmatizing language such as “addict,” “manipulative,” and “failed relationships.” How might Maya be affected by reading her record?

Although the OpenNotes pilot study showed that transparent primary care notes was relatively successful, it did not address increasing the [transparency](#) of or patient access to mental health notes, in particular. A different pilot study is ongoing at Beth Israel Deaconess Medical Center in Boston, which allows mental health clinicians to “opt-in” to allow high-functioning patients access to their record through a secure internet portal [6]. Although it is unclear how the team defined “high functioning,” it is probable that some patients, particularly those who are not severely impaired by their mental illnesses and who have achieved clinical stability or a good therapeutic alliance with their clinicians, would be less likely to be adversely affected by reading their record. We know little about Maya’s level of functioning related to important social and health determinants—for example, her employment status, housing status, and social support are not discussed. These would be factors for Dr. Kelly to consider when deciding how to proceed.

Initially, at least, Beth Israel clinicians participating in this pilot felt that bringing transparency into the mental health field was not without risk [6]. Specific concerns included whether patients would be upset by reading aspects of their record—say, a diagnosis of a personality disorder, or, for patients with schizophrenia, that their firm convictions are seen as delusional—and how standard psychiatric terminology could be perceived as judgmental, dismissive, or reductionist. Dr. Kelly’s concern that sharing the record with Maya could cause harm and destabilize her is certainly a valid one.

Retrospective studies that have reviewed mental health records for stigmatizing language reveal that such language is common. Crichton et al. [7] had both study staff and patients review 50 sets of psychiatric case notes for offensive content. “Offensive” was defined as “annoying” or “insulting” and reviewers were deliberately instructed to interpret “offensive” broadly. They found that more than 80 percent of case notes contained content that was either moderately or extremely offensive when rated by two professionals. In comparison, only 24 percent of medical case notes from a matched sample contained offensive content when rated by two professionals.

### **An Ethical Argument for Increasing the Transparency of Mental Health Notes**

Reticence concerning increasing the transparency of the psychiatric record likely stems from the ethical principle of nonmaleficence, which means “do no harm.” As discussed previously, note contents can evoke feelings of confusion, anxiety, worry, or offense in patients [5, 7], which in turn can cause psychiatric decompensation. Furthermore, if clinicians knew that patients would read their notes, they might exercise censorship in documentation, such as not including a diagnosis of borderline personality disorder, not clearly conveying that the patient’s thought content might be delusional, or not

documenting a patient's pattern of suspected lying. From a clinical perspective, withholding this kind of diagnostic or clinical detail from a record could negatively affect a patient's care if that patient seeks care in the emergency department or from another clinician.

There are other ethical justifications for increasing transparency. With the trend of mental health professionals sharing notes with primary care professionals, it could be argued from the standpoint of justice that mental health patients should also be able to read their notes. Furthermore, allowing a mental health patient to view or perhaps even collaborate in creating his or her health record by reviewing it in real-time and discussing inaccuracies or need for amendments with the clinician suggests that such an approach might enhance that patient's autonomy during a clinical encounter. Finally, a transparent health record might actually be therapeutic and therefore motivate beneficence and the therapeutic capacity of the patient-clinician relationship. For example, patients can feel mystified about what their clinician is thinking about them; allowing them to read their clinical notes takes away this mystery [8] and perhaps some anxiety associated with it. Furthermore, if patients help their therapists accurately formulate and represent what they experience, it might help them feel better understood by their therapists. For example, in our experience, patients might be relieved to receive a diagnosis of borderline personality disorder, particularly if they take comfort in knowing that the chaos and unhappiness they experience stems from a known, treatable clinical entity rather than being due to a fault in themselves [9]. In the case, Dr. Kelly can do two important things: (1) use descriptive, nonjudgmental language in Maya's health record that can illustrate how Maya meets diagnostic criteria for borderline personality disorder and (2) discuss with her the formulation of this diagnosis, which might lead to a deepening of their therapeutic alliance.

### **How to Move Towards Transparency**

As an increasing number of health care systems adopt electronic health records, mental health documentation will likely also move towards more transparency. What are practical considerations for transitioning to more transparent electronic record maintenance that have important clinical and ethical relevance in the context of mental health care?

First, as in much of clinical medicine, clinicians should carefully consider how a transparent record might impact each individual patient. We would suggest a "why, when, where, and how much?" approach. Clinicians should explore with their patients why they are interested in reviewing their health record, including what they are hoping to learn and what they might fear reading. Timing is also important when determining how to disclose records' content. For example, it would be inappropriate for acutely psychotic patients to review their records, and it would be prudent to achieve clinical stability before sharing the record. Patients and clinicians should also collaboratively

determine whether it would be more therapeutic for the patient to review the record in private or with the clinician present. Finally, there are aspects of health records that should not be shared with patients. These include sensitive information, such as information about violent behavior or substance use, obtained by a third party.

Second, as health records become more transparent, we believe that clinicians will need to become more cognizant of the language they use to describe patients. Accurate, precise, fact-based descriptions of behavior rather than subjective or opinion- or assumption-based labeling should be used. For example, rather than writing "Mr. A is a known addict," one could write "Mr. A continues to drink two pints of vodka daily." This type of writing might lead to less clinical prejudice on the part of a clinician and decrease diagnostic anchoring that can lead clinicians to jump to a diagnosis based on a clinical buzzword rather than considering a patient's complete clinical presentation. For example, while "paranoia" may be considered a buzzword for schizophrenia, the full clinical presentation should be taken into consideration when making this diagnosis. That said, descriptive language should not replace a clear diagnosis. Although one could argue that many diagnostic terms in the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* remain offensive or stigmatizing, for the present, this volume contains the contemporary shared language among health professionals on mental health diagnostics. Descriptive terminology should be used to nonjudgmentally substantiate a diagnosis, which should be clearly documented in the record using the currently recognized and accepted *DSM* terminology. Finally, the National Alliance on Mental Illness [10] and individual psychiatrists [11] have begun analyzing and cataloging specific words that should be avoided when writing about persons with mental illness. For example, "schizophrenic" should be replaced with "person with schizophrenia," and rather than writing a patient "suffers" from mental illness it is preferable to replace this word with a value-neutral word that does not express assumptions about a patient's feelings.

### **Conclusion**

From what we know, Dr. Kelly has been acting in good faith as Maya's clinician, has therapeutically aligned with her, made a diagnosis, and recommended a treatment plan of psychotherapy. The case illustrates areas for improved sensitivity and objectivity when documenting delicate details about a patient's pathology. While Maya has expressed interest in seeing her record, Dr. Kelly would do well to adopt the "why, when, where, and how much?" approach that we recommend to explore her interest in reviewing her record. If Maya remains interested in reading the record, they could then formulate a plan together for when and where it should be shared. They could consider sharing the notes during an office session so that there is a built-in context for immediate discussion and clarification. As we've argued, she might find this helpful in terms of rebuilding trust with her psychiatrist who has expressed intent to act in her best interest and cause no harm. Finally, depending on Maya's goals for reviewing the record,

Dr. Kelly should determine how much of her record should be shared. For example, if she is simply looking to better understand his formulation of her diagnosis, a case summary might be sufficient.

The bottom line for mental health care professionals and other clinicians to keep in mind is that this is a time of opportunity. Electronic health records are more accessible to patients and health professionals alike. Although both the language traditionally used in psychiatric documentation to describe clinical observations and the use of diagnostic terms themselves can be stigmatizing, this shift in accessibility affords us an opportunity to modify the ways we write and think about patients. As an initial step, we should take care to use as much nonjudgmental and factually descriptive language as possible while continuing to use accurate diagnostic terminology. And though diagnostic terms will likely be slower to change, they eventually will need to be replaced with less stigmatizing language, too.

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## THE CODE SAYS

### **AMA Code of Medical Ethics' Opinions Related to Language and Hierarchy in Medicine**

Danielle Hahn Chaet, MSB

Language is a very powerful element of the patient-physician relationship. At the most basic level, patients and physicians need to understand the information they are exchanging with one another simply to establish mutual understandings of an illness or injury and treatment recommendations. Many exchanges, however, are not this simple. Patients come from a range of backgrounds: their literacy and [health literacy](#)—and, in particular, their socioeconomic status, health beliefs, and past health and health care experiences—all contribute to patients' narratives. A physician's background can influence the patient's narrative as well, but the physician will always be in a position of knowledge and power relative to a patient because of her or his education, skills, and knowledge. When a physician speaks with a patient, most often, it is as an expert in the language of medicine speaking with a nonexpert. Patients can't generally be expected to speak this language, and so a physician must translate appropriately.

The *AMA Code of Medical Ethics* speaks to this notion of facilitating patients' understanding of medical language in several places. Opinion 1.1.3, "Patient Rights" [1], states that patients have a right to "receive information from their physicians and to have opportunity to discuss the benefits, risks, and costs of appropriate treatment alternatives, including the risks, benefits and costs of forgoing treatment" and "to ask questions about their health status or recommended treatment when they do not fully understand what has been described and to have their questions answered." For patients to *fully* understand could mean that a [barrier to understanding](#) should be addressed, whether it's language—in which case, in keeping with Title VI [2] and Office for Civil Rights guidance [3], calling a certified interpreter would be appropriate—or health literacy, in which case a clinical situation should be explained in simpler terms. Opinion 2.1.1, "Informed Consent," goes deeper into the nuances of what is meant by full understanding.

Informed consent to medical treatment is fundamental in both ethics and law. Patients have the right to receive information and ask questions about recommended treatments so that they can make well-considered decisions about care. Successful communication in the patient-physician relationship fosters trust and supports shared decision making.

The process of informed consent occurs when communication between a patient and physician results in the patient's authorization or agreement to undergo a specific medical intervention. In seeking a patient's informed consent (or the consent of the patient's surrogate if the patient lacks decision-making capacity or declines to participate in making decisions), physicians should ... assess the patient's ability to understand relevant medical information and the implications of treatment alternatives and to make an independent, voluntary decision [4].

This opinion clarifies that valid informed consent hinges on the patient's ability to understand the information presented about a diagnosis or treatment—including risks and benefits of undergoing or foregoing treatment—and that it is the physician's responsibility to make sure that this is so. Opinion 2.1.5, "Reporting Clinical Test Results," also addresses a physician's obligation to facilitate a patient's understanding.

To ensure that test results are communicated appropriately to patients, physicians should adopt, or advocate for, policies and procedures to ensure that ... test results are conveyed sensitively, *in a way that is understandable to the patient/surrogate*, and the patient/surrogate receives information needed to make well-considered decisions about medical treatment and give informed consent to future treatment (emphasis added) [5].

Finally, sensitivity to these issues of language and understanding is essential to eliminating disparities in health care. Opinion 8.5, "Disparities in Health Care" [6], states that, as part of fulfilling this professional obligation, physicians should "cultivate effective communication and trust by seeking to better understand factors that can influence patients' health care decisions, such as cultural traditions, health beliefs and health literacy, language or other barriers to communication and fears or misperceptions about the health care system."

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## MEDICAL EDUCATION

### Language-Based Inequity in Health Care: Who Is the “Poor Historian”?

Alexander R. Green, MD, MPH, and Chijioke Nze

#### Abstract

Patients with limited English proficiency (LEP) are among the most vulnerable populations. They experience high rates of medical errors with worse clinical outcomes than English-proficient patients and receive lower quality of care by other metrics. However, we have yet to take the issue of linguistic inequities seriously in the medical system and in medical education, tacitly accepting that substandard care is either unavoidable or not worth the cost to address. We argue that we have a moral imperative to provide high-quality care to patients with LEP and to teach our medical trainees that such care is both expected and feasible. Ultimately, to achieve linguistic equity will require creating effective systems for medical interpretation and a major culture shift not unlike what has happened in patient safety.

#### Case of a 56-Year-Old “Poor Historian” with Acute Renal Failure

The most memorable experiences of my third year as a medical student in the US were the ones in which I (the second author, CN) actually contributed something meaningful to the care of a patient. One such experience involved Mr. S, a 56-year-old Brazilian construction worker, who had recently undergone hip replacement surgery elsewhere and presented with several days of nausea, vomiting, food intolerance, and general malaise. He was found to have abnormal kidney function tests and elevated potassium. His English was fair at best, and his medical record was already thoroughly marked with the label of “poor historian.” I met Mr. S after he had been triaged by the emergency department (ED) physicians and seen by nephrology for his renal failure, with the result that a work-up was already in motion. It was a busy night, and no one had yet involved a medical interpreter in his case, so, as a medical student—despite not speaking Mr. S’s language—I thought I might contribute. I had low expectations, however. After all, multiple experienced clinicians had been unable to gain much from talking to Mr. S, and they seemed frustrated and doubted that the extra time would be worthwhile. I was not encouraged by my resident to call for an interpreter, but neither was I dissuaded, so I went ahead. During our conversation, I discovered that Mr. S had been taking high doses of meloxicam for his postsurgical pain. Not understanding what it was, he hadn’t mentioned it previously. It turned out that he had nephritis induced by nonsteroidal anti-inflammatory drugs (NSAIDS) and a bleeding gastric ulcer. I remember feeling partly

triumphant and partly shocked that a student's effort had prevented a missed (or at least delayed) diagnosis. Would this have happened had the patient been a native English speaker?

This case vignette illustrates the potentially serious consequences of language barriers for the care of patients with limited English proficiency (LEP). In this article, we discuss how it is that linguistic inequities in health care persist, how they are propagated by medical education, and what we can do about it.

### **Linguistic Inequities in Health Care and the Moral Imperative**

People with LEP, defined by the US census as those who speak English less than "very well," represented 8.7 percent of the US population five years and older in 2011 [1]. They have been consistently shown to receive lower quality care than English-proficient patients on various measures: understanding of treatment plans and disease processes, satisfaction, and incidence of medical errors resulting in physical harm [2-6]. These disparities are rooted in obvious [communication barriers](#) but also may reflect cultural differences, clinician biases, and ineffective systems (i.e., structural barriers) [7]. Medical interpreter services can help overcome some of these barriers, but they have associated costs—both financial and in terms of physician time [8, 9]. Title VI of the Civil Rights Act of 1964—as enforced by Executive Order 13166 [10]—requires that health care providers receiving federal funds implement Department of Justice guidance on providing competent interpreter services when needed [11]. However, this legislation has not been strongly enforced [12]. For example, one study found that 43 percent of hospitalized patients with LEP had communicated without an interpreter present during admission, and 40 percent had communicated without an interpreter present after admission [13]. In general, use of formal interpreter services (telephonic or live) is relatively low compared to the use of [ad hoc interpreters](#) (family members or other untrained individuals) [14, 15], a practice fraught with potential for errors [16]. Although health systems are challenged by the volume of visits, diversity of languages, and lack of reimbursement for medical interpretation [17], physicians often have interpreter services available but choose not to use them [18]. This confluence of factors may have contributed to the suboptimal care in the case of Mr. S.

We believe that health care professionals, leaders, and medical educators have a moral imperative to address these persistent linguistic inequities (caused in part by communication barriers) by developing effective systems for medical interpretation, shifting the organizational culture, and educating health professionals.

### **Interpreter Services from the Physician's Perspective**

Most physicians would deem it unfair for a certain group of patients (those with LEP) to receive worse care; they might assume that unfairness is unavoidable and not take responsibility to change it, but they would not consider linguistic disparities in health care

to be fair. Indeed, a large survey of residents found that 96 percent indicated a patient's culture was an important consideration in providing care [19]. A smaller group of physicians might place responsibility to learn English on patients and point to their personal choice to come to the US and not learn the language. Regardless of one's opinion, physicians' standards of professionalism hold that we not base our care on judgments about patients [20]. A trauma surgeon, for example, has a moral imperative to treat the injuries of the drunken driver in an automobile accident just as he does the innocent victim.

How, then, do we prevent adverse events due to inadequate communication, such as missing a diagnosis of NSAID-induced nephritis and a bleeding gastric ulcer in the case of Mr. S or allowing a patient to take too much warfarin due to confusion about dosing [21]? Live interpreters, including professional interpreters and trained staff, are an option for large hospitals and smaller providers that serve a few predominantly immigrant populations. In the case of less common languages for which live interpreters are not a practical option, a wide variety of telephonic and video interpreter services are readily available in the more than 100 languages spoken in the US [8], but they are used relatively infrequently due in large part to a lack of organizational commitment and training of staff on the use of these services [22].

In practice, physicians may recognize that they are unintentionally providing worse care to patients with LEP but justify it in various ways [18]. In a qualitative interview study, internal medicine and emergency medicine residents in two hospitals where interpreter services were readily available blamed their failure to fully utilize these services on time constraints, the hassle of involving interpreters, and minimal incentives from supervisors, and they tended to shift responsibility to others [18]. One resident said:

I guess I feel like someone is talking to [the patient] and getting a good history at some point.... It's okay if I kind of come in and do a little bit more of a perfunctory exam and history, knowing that I will at some point talk to them with an interpreter when time is available. But in some ways ... it does not seem all that fair because English-speaking patients—I talk to them in their own language easily even on-call, even when I am busy [23].

One concerning aspect of this approach was the lack of standardization, which left decisions to individual discretion. Residents often assessed the cost-benefit ratio of using interpreter services for each interaction (the time it would take versus the perceived benefit to patient care) and reserved interpreters for particularly important conversations like goals-of-care discussions [18].

Mr. S was almost a casualty of this kind of rationalization. He had been seen by several physicians, all pressed for time and either deferring proper communication to someone else or writing it off altogether due to language barriers and the patient's low health literacy. In the murky waters of clinical medicine and documentation, labeling the patient as a "poor historian" or having communication difficulties due to language barriers may be seen by some physicians as absolving them of responsibility for taking a complete history with a competent interpreter. In fact, it does not—the law is very clear on this point, as described above. However, it is also evident that placing responsibility solely on individual physicians, with no effective system in place to guide them, is a recipe for failure. Complex problems have complex solutions.

### **Medical Education and Implicit Messages about Care of LEP Patients**

If residents accept and rationalize substandard care for patients with LEP, then clearly medical students, for whom residents are the most influential teachers [24-26], will learn the same attitude and approach. One of the authors (ARG) and colleagues carried out a qualitative study of medical students and nursing students to explore their experiences learning about the care of patients with LEP during their clinical rotations. Our findings described a powerful "[hidden curriculum](#)" (teaching that is not part of the formal curriculum but is transmitted through experiences and interactions) in which supervisors role-modeled an indifferent, and sometimes negative, attitude towards care of patients with LEP [27]. Supervisors often did not involve professional interpreter services or expect students to do so, nor did they teach how to effectively work with an interpreter. A hierarchy of values was conveyed to students whereby good communication, especially if it took extra time, was valued much lower than clinical knowledge and even fairly mundane tasks [27], which contravenes the "ethics of caring" [28]. One student said:

It just seemed to be an extra step or just take longer to use a phone or to call an interpreter up to the floor or something like that. It just seemed, "Oh, if we can get by with just speaking a little bit of the language or using some other form of communication, it would be easier than taking the time to make the phone calls and go through somebody else" [29].

Additionally, students' efforts to work with interpreters were not appreciated by supervisors, and students blamed systems barriers in conjunction with time pressures for what they recognized as suboptimal care for patients with LEP. This hidden curriculum forces a moral conflict for many students whereby their own personal values (some of which were shaped during their formal curriculum) come in conflict with what is expected of them in practice.



## **We Can Do Better**

In order to ensure high-quality, equitable care for patients with LEP, our health care system will either need to find a way to connect all patients to health care professionals who speak their preferred language or implement effective systems for medical interpretation. Numerous studies have demonstrated that language concordance improves the patient satisfaction, engagement, perceived understanding, utilization of preventative services, and outcomes of patients with LEP [30-34]. Improving the diversity of our health care workforce and expanding (and expecting) second language training would help optimize the care of patients with LEP. However, adopting this approach would be slow and unlikely to meet demand. Turning to interpreter systems, the expectations and resources for communicating with patients with LEP vary widely across health care organizations [7], and while some guidance for hospitals is available [7], we are a long way from standardized and effective systems.

We need to align our laws with our policies, and our policies with our expectations. Many physicians remember a time when hand washing before entering a patient's hospital room was not expected or enforced, but the system has changed. Hand sanitizer is available and obvious in front of each room. Signs are posted everywhere and staff members monitor one another. The culture itself within the hospital has shifted. Something similar needs to happen to address language barriers. This will not be an easy process. It will require full commitment by leadership, consistent messaging and promotion, and policy setting and enforcement to change organizational culture. Some steps in this direction include: (1) investing in high-quality interpreter services using technologically advanced solutions (e.g., video remote interpreting) and automating the process to reduce the barriers to use, (2) training faculty and staff to use these services efficiently and effectively, (3) enforcing clear rules that remove ambiguity from the decision-making process and tracking enforcement openly, (4) creating a culture of equity in which excellent care is expected for patients with LEP as it is for all patients, and (5) sending a strong message to our medical trainees that good communication with patients with LEP is part of good clinical practice and that suboptimal care is unacceptable.

Looking ahead, as health care moves to a value-based model and patient-centered medical homes promote a team approach to care, medical interpreters may take on expanded roles. For example, they may serve also as patient navigators who help guide patients through the complexities of the health care system [35], cultural brokers [36, 37] who help to bridge the different perspectives of patient and clinician [38, 39], and safety checkers who ensure that dangerous miscommunications are caught before errors occur [7]. Interpreters will be valued not on a dollars-per-minute basis but as important team members who improve quality of care and outcomes, thereby generating revenue rather than adding cost. Ultimately, with all due respect to the moral imperative, it will be this financial equation that drives real change.

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## IN THE LITERATURE

### From *Doctors' Stories* to Doctors' Stories, and Back Again

Marcia Day Childress, PhD

Montgomery K. *Doctors' Stories: The Narrative Structure of Medical Knowledge*. Princeton, NJ: Princeton University Press; 1991.

#### Abstract

Stories have always been central to medicine, but during the twentieth century bioscience all but eclipsed narrative's presence in medical practice. In *Doctors' Stories*, published in 1991, Kathryn Montgomery excavated medicine's narrative foundations and functions to reveal new possibilities for how to conceive and characterize medicine. Physicians' engagement with stories has since flourished, especially through the narrative medicine movement, although in the twenty-first century this has been challenged by the health care industry's business-minded and data-driven clinical systems. But doctors' stories—and Montgomery's text—remain crucial, schooling clinicians in reflection, ethical awareness, and resilience. Physicians who write even short, 55-word reflective stories can hold to humanistic and ethical understandings of patient care and of themselves as healers even as they practice in systematized settings and employ evidence-based expertise.

#### Introduction

Stories have always been central to medicine, but the meteoric rise of bioscience during the twentieth century all but eclipsed narrative's enduring presence in medical practice. The 1910 Flexner report put US medical education on a scientific footing [1], and the biomedical innovations that followed—from antibiotics to transplant surgeries—enabled doctors to treat many conditions. Science was key to medical progress, arguably to the neglect of medicine's art. Clinical encounters trended ever more scientific: diagnosis depended on objective testing; treatment, on research-based clinical protocols; and wellness, on patients achieving or maintaining certain "numbers."

From mid-century on, doctoring tended to overlook, even screen off, medicine's core uncertainty: medical practice is a *human* endeavor, each patient an *n* of one. With science supreme, the clinical encounter's narrative elements had but shadowy status. "Anecdote" was a derisive term. The patient's story shrank to a single sentence in the chart, the subjective chief complaint cordoned off by quotes. Doctors' stories—

chronicles of careful observation and judgment starting with “What’s the matter?” or “Where does it hurt?”—often seemed just the gate- or record-keeping mechanisms that ushered patients into medical care and then documented their management from hospital admission to discharge.

### ***Doctors’ Stories and the Case for Narrative in Medicine***

In 1991, Kathryn Montgomery published *Doctors’ Stories*, a meticulous excavation of medicine’s narrative foundations and functions [2]. A literary scholar teaching in a medical school, Montgomery was an outsider, a self-described “licensed trespasser in clinical territory” [3], who cast a keen yet compassionate eye on medical learning and practice. Her inquiry discovers medicine’s narrative epistemology and acknowledges the generic narrative form—the individual medical case—at the heart of clinical practice. Her study also exposes medicine’s aversion to its own fundamental uncertainty: if only biomedical science could override each patient’s human particularity, each illness’s idiosyncratic expression in an individual life!

Montgomery makes a compelling case for narrative ways of conceiving and characterizing medical practice. In both *Doctors’ Stories* and her later volume, *How Doctors Think*, she clarifies that medicine is not itself a science but rather “a rational, *science-using* . . . interpretive activity” (my emphasis) that depends on the physician cultivating clinical judgment through practical reasoning and experienced knowing. Such an interpretive practice, she suggests, “takes the patient as its text and seeks to understand his or her malady in the light of current biological, epidemiological, and psychological knowledge” [4].

Montgomery’s explanatory model borrows from literary study—close reading (a form of close observation directed at texts), analysis, and interpretation—and turns these methods to the myriad “texts” of clinical medicine, including, especially, patients’ stories, patient-physician encounters, and doctors’ “translations” of those interactions into histories, diagnoses, [chart notes](#), and treatment plans. Montgomery gives us license and a lexicon with which to parse medicine’s narrative principles and practices. She reminds us that patients and clinical situations are made meaningful and memorable in story form as individual narratives replete with descriptive particularity, plot twists, idiosyncratic turns of phrase, and points of emotional connection.

She focuses not only on clinical judgment as acquired and used by doctors but also on the exchange between patient and physician, a crucial human dynamic at once rationally governed (by patterned clinical reasoning and protocols for interviews and physical exams) and emotionally felt (as empathy, compassion, and trust), for doctor and patient alike. She finds both clinical judgment and the patient-physician encounter to be narratively based, founded in the exchange of stories, attentive listening, interpreting and meaning-making, and active response. To illustrate her claims, Montgomery invokes

literature's iconic detective, Sherlock Holmes. This master of close observation, dispassionate analysis, and inductive reasoning—born of Scottish physician Sir Arthur Conan Doyle's imagination and medical experience—is, she says, something of a model clinician [2].

For clinicians steeped in medicine-as-science, Montgomery's work legitimizes "storying" language in and about medicine. Indeed, her conclusions inform and are consistent with the "narrative medicine" movement more recently championed by physician and literary scholar Rita Charon [5]. As defined by Charon [6], narrative medicine is clinical practice grounded in the physician's "narrative competence"—that is, "the competence that human beings use to absorb, interpret, and respond to stories" [7]. Charon contrasts what she calls medicine's "narrative knowledge" with its more widely known "logicoscientific knowledge" [8] but insists that both are necessary—and necessarily in balance—if doctors are to practice "with empathy, reflection, professionalism, and trustworthiness" [7]. As a theoretical construct advanced by Montgomery and Charon (and as a systematic practice taught by Charon and others in narrative-medicine curricula), narrative medicine in recent years has given physicians, patients, scholars, and medical educators alike new approaches to practicing, experiencing, and reflecting on medicine [9].

### **Do Doctors' Stories Matter Now?**

Fast forward to 2017, a quarter-century after *Doctors' Stories* appeared. Health care is among the US's largest industries, with health-related spending reaching \$3.2 trillion in 2015 and projected to surpass one-fifth of the nation's total economy by 2025 [10]. Organized medicine remains bioscientifically based but now also invokes business models, methods, and metaphors as it seeks to grow—in services provided, patients served, profits realized—and to manage costs. Within clinical systems, evidence-based protocols and treatment algorithms are the rule, with laudable objectives to affirm best practices, achieve efficiencies, reduce error, and standardize good care, all to improve patient outcomes. Clinicians are expected to follow practice guidelines, their compliance charted quantitatively in terms of practice patterns and clinical outcomes [11]. Now-ubiquitous electronic health records best capture numbers, not narratives.

Amid the clinical data deluge, the checklist-rich electronic charts, and the buzzwords of bioscience and business, where now is "story"? Is the narrative medicine movement just a rearguard cry of resistance? Or do the stories of medicine—including doctors' stories—still thrive, still count? And is Montgomery's landmark text still helpful as we try to understand better what transpires between patient and physician, what ethical doctoring is all about, and how doctors reflect and take care of themselves?



### Teaching Twenty-First-Century Doctors to Write Stories

As a longtime teacher of physicians-in-training, I unequivocally affirm that doctors' stories remain at the heart—indeed, may be the beating heart—of clinical medicine. Like Montgomery, I am a literary scholar and another “licensed trespasser” in the medical domain. Like her, I appreciate—because I observe this almost daily—that physicians know, remember, and learn from patients and practice situations *as stories*. They process clinical experience as Charon's narrative knowledge—as “pearls” or lessons, epiphanies, or cautionary tales. The doctors' stories I know best are those I ask clinically active medical students and residents to write.

Reflective story writing differs from oral tale-telling among peers, as when doctors swap stories from the clinical trenches, each narrator one-upping the other. Rather, story *writing* is work that calls for a different, perhaps more authentic kind of ego investment. It requires discriminating attention to lived experience and a slew of deliberate compositional choices—about genre and form, point of view, plot, chronology, character, voice, tone, a way of beginning, and a sense of an ending. Writing orders experience and in doing so mines it for meaning and practical wisdom. And writing out a signal memory can actually make a new memory.

*What medical students learn from narrative writing.* My students' stories capture memorable moments in their learning and make them available for scrutiny. Their stories represent opportunities to exercise compassion and humanity toward patients and peers, cultivate moral awareness and a vocabulary for moral discourse, interrogate ambiguity and uncertainty, and engage in self-care, including reflecting on their own and others' attitudes and actions and realigning their professional and personal lives—all practices that novice practitioners will need in order to sustain themselves against the pressures of twenty-first-century clinical work. As internist Kate Scannell observes in “Writing for Our Lives: Physician Narratives and Medical Practice” [12], clinicians' storying can sometimes be life-saving. Writing about their work can preserve practitioners' morale, reconnect them with their sense of purpose, and “so fully expand and engage the personal and professional dimensions of doctoring [as to] expressly remind us of the vast range of human and transcendental experiences available to us” [13].

Richly detailed stories about patients anchor physicians ethically as well as existentially. Patients, after all, really make a doctor a doctor. As Montgomery notes, “Only with the examined and reflective care of patients do well educated students of human biology become physicians” [14]. To know patients as whole persons, to apprehend their worlds and advocate for them, and then to tailor care to their circumstances—these ethical actions are fundamental to good doctoring and well addressed through storytelling.

Provided learners have time, space, and careful mentoring, my experience has been that writing about their clinical lives significantly affects young physicians' formation as reflective practitioners. Young physicians have a nascent moral awareness about their work, derived as much from observing how medicine is practiced as by actually performing it. Learning to story about what they have noticed shapes their clinical style: it is good practice for how to practice. In storying, apprentices refine their sense of [practical ethics](#). They find words for moral hazards and quandaries they witness and any moral queasiness they feel. Their narratives are repositories for humanistic observations, actions, and attitudes that receive scant attention on rounds or in patients' records.

Whether doctors write to remember cherished patients, revisit challenging ones, try to decipher clinical puzzles, rail against uncertainty, forgive themselves, or record flashes of insight, they are exercising moral imagination and elucidating moral lessons. They reinhabit crucial experiences and hunt for the right words to represent and interpret themselves and their own and others' actions, all against a backdrop of professional ethics and [personal values](#). In the process, they may ruminate on what it is and what it means to be a doctor.

*The 55-word story.* Time being short for medical students, and shorter for residents, the 55-word story is a powerful tool for busy clinicians' reflective writing. This tiny narrative template seems to have been first described in 1995 [15]. Now well used in medicine [16-18], it has been championed in *JAMA*, three "A Piece of My Mind" essays offering guidance and examples [19-21]. As a literary form, it is simple. As an assignment, it may or may not be written to a prompt. As a task, it is blessedly brief—also game-like, distractingly, even addictively, so. Here is the trick: the story must be *55 words exactly*, no more and no fewer (not counting an optional title). There are no other rules. The exercise involves words and numbers, composing and counting—a lively combination of mental functions. The story may be written fast (in under ten minutes) or slow (take a week); it need not use complete sentences; it may be arranged on the page any which way; its word count may be edited down or built up to the magic 55; in topic and tone it may be dark or droll, silly, sweet, or stunning. Perhaps most importantly, anyone can write a 55-word story. Also, in my experience, more doctors than not love this exercise and many make it a permanent addition to their medical toolkit.

The 55-word story has long had a place in my literature and medicine course, where senior medical students write to remember significant moments from their clerkships and then share their narratives with classmates. More recently, students in our Gold Humanism Honor Society chapter collected peers' 55-word tales about clinical life and bound them into a pocket-sized booklet for presentation to the new clinical clerks titled *Don't Forget—Stories from the Clerkship Year*. Here are two, by two of the story project's leaders.

### Don't Forget

The resident you (almost) followed into the bathroom.

All the times you felt completely clueless about where you were supposed to go or what to do.

The physics equation you couldn't remember.

The residents who made you feel like part of the team.

All the incredible patients you had the opportunity to take care of.

(© 2017 Claire Montaigne, class of 2016)

Written at the close of the clerkships, this story looks back on a momentous year with a potent mix of disbelief (did I really do that?) and relief (I made it!). In choosing moments to remember, the writer charts her growing competence and balances naïve embarrassment against newfound clinical confidence. Tellingly, the narrative arc trends positive, the young clinician's last lines focusing on the patients she served and the house staff who welcomed her rather than on the times her ineptitude made her cringe.

### An Avocado Tree in Monterrey

In his CCU bed with a failing heart, he told me about when that now sickly organ had driven a farm boy from Virginia to Monterrey, where he sat beneath an avocado tree with Elena. I plied him for more each day, treating his heart as he treated mine, unsure who was the greater beneficiary.

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This story draws deftly on the manifold meanings we attach to the human heart. While centered on an older man in cardiac failure, it quickly reveals the apprentice doctor's heart-felt, transformative engagement with his patient, who had shared a vivid tale of an intrepid journey and romantic encounter many miles and years ago. Patients matter to their doctors: they teach and even help to take care of their doctors; in turn, physicians honor and remember patients by holding their rich, idiosyncratic stories. The student supplemented his 55 words with a small sketch depicting his patient (as a young man) in faraway Mexico, sitting under the avocado tree alongside Elena. Imaginatively, compassionately, my student was there too, and this changed him, as well as the care he gave in the coronary care unit.

In my experience, apprentice doctors are schooled and soothed by what they write. If we instill in them a habit of regular narrative practice, trainees may learn to manage stressful careers more adroitly, better tolerate medicine's uncertainties, maintain healthy self-regard, and find greater satisfaction and meaning in their life and work. And

writing stories about being a clinician also makes explicit, and discussable, what Montgomery affirms: the narrative nature of medical knowledge, learning, and practice.

### Conclusion

With concerns about practitioner burnout and associated patient-safety risks [22], medical schools now give priority to reflection and self-care, which can help doctors-to-be cultivate emotional resilience for a lifetime's practice. Reflection is increasingly considered a core clinical competency [23-26]. Reflective physicians are likely more self-aware, more open to self-improvement—even, potentially, more wise. But reflection and self-care are disciplined practices, ones that we in medical education are challenged to inculcate in trainees via traditional methods of medical learning and assessment. Storying, though, is a time-honored mode of reflection and self-examination, and, increasingly, medical schools are turning to narrative-writing strategies to help learners cultivate self-awareness and become reflective practitioners [27]. Storying early, storying often, in 55 words or more, physicians can hold to humanistic and ethical understandings of patient care and of themselves as healers even as they work in high-pressure, systematized settings and employ evidence-based expertise. Montgomery still matters: *Doctors' Stories* licenses twenty-first century practitioners to affirm the value of their narrative knowledge and practice and to confidently, compassionately care for patients and for themselves.

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## STATE OF THE ART AND SCIENCE

### Language, Structure, and Reuse in the Electronic Health Record

Angus Roberts, PhD

#### Abstract

Medical language is at the heart of the electronic health record (EHR), with up to 70 percent of the information in that record being recorded in the natural language, free-text portion. In moving from paper medical records to EHRs, we have opened up opportunities for the reuse of this clinical information through automated search and analysis. Natural language, however, is challenging for computational methods. This paper examines the tension between the nuanced, qualitative nature of medical language and the logical, structured nature of computation as well as the way in which these have interacted with each other through the medium of the EHR. The paper also examines the potential for the computational analysis of natural language to overcome this tension.

#### Introduction

The past few decades have seen a shift away from paper-based medical records towards computerized electronic health records (EHRs). Whereas paper-based records had their roots in a largely textual representation, the digital nature of computers lends itself more readily to the structuring and organization of data. The shift to the EHR has therefore been accompanied by a pressure on clinicians to record patient information in a structured way by choosing options such as diagnosis, medications, and symptoms from lists and completing onscreen forms. Structured information is computationally tractable, unlike the natural language of the textual portion of the record. Structured information, it is argued, can be reused to support research, audit, and the clinical process [1].

Very few would argue against the reuse of medical data. From the mid-sixteenth century, physicians increasingly recorded their cases, often indexed or ordered by disease or cure, in order to reuse them as a record of their practice and to extend medical knowledge. Thomas Willis, the seventeenth-century neuroanatomist, wrote that he would “weigh all the symptoms, and to put them, with exact Diaries of the Diseases, into writing; then diligently to meditate on these, and to compare some with others; and then [begin] to adopt general Notions from particular Events” [2].

Computer technology magnifies the efforts of Willis by many degrees, giving us the potential for reuse at scale. Structuring data allows the computer to aggregate, generalize, classify, sort, and search—powerful tools in building medical knowledge. We can imagine Willis leafing through his diaries to find a remembered patient, while the modern data analyst calls up 100 such cases. Whereas Willis could review his notes and compare one patient with another to find a pattern, a modern EHR-based study can crunch through tens of thousands of records to find small but statistically significant relationships [3].

There is, however, a problem. The EHR exposes a fundamental conflict between the needs of software and the needs of human users. The EHR tries to bridge two worlds: the human, “analogue,” cognitive world and the formal, logical, “digital” world of the machine [4]. There are many ways in which EHR design tries to overcome this conflict and bridge the analogue and digital worlds. I examine some of these below and argue that such designs fail to capture a full record of the patient. This leaves clinicians falling back on recording clinical encounters in analogue, through the use of natural language text. If we are to reuse the data of the EHR, then we must find ways to analyze this text. I look at how natural language processing—the computational analysis of natural language text—offers a way to do this.

### **Bridging the Digital World of the EHR and the Analogue World of the Clinician**

One attempt to bridge the analogue and digital worlds can be seen in the use of medical terminologies in the EHR. Such terminologies are not intended to replace clinical narratives but rather to allow the coding of events alongside the narrative text of the record. In their simplest form, these are lists of codes, each associated with a human language term for some disorder or class of disorder, often arranged in taxonomies. A simple terminology, however, no longer satisfies the needs of administrative coding, leading to the introduction of ever more complex terminologies. This problem is illustrated in the following description of the ICD-10 terminology, recently introduced in the United States. “Coding for medical encounters used to be haphazard” says the author, but this will change as “ICD-10 has a new structure and more room (up to seven characters, from five)” and includes “details, such as laterality and etiology” [5]. Such a coding scheme allows for grouping and analysis of clinical encounters, but we would clearly need other techniques if we wanted to capture all the detail of those encounters in structured form. While ICD-10 may be more powerful at coding than its predecessor, seven characters and a few added details are never going to have the expressivity of even a single sentence of natural language. Coding, both intentionally and as a result of the limits of what can be practically described, is about generalizing. While coding schemes might accurately describe a patient as a member of some group, they were never designed to describe the individual patient in detail.



Accordingly, there have been several efforts to provide ways of structuring the record of the clinical encounter. In computer-based documentation (CBD) systems, documentation is driven by the completion of onscreen templates: picking items for diagnosis, symptoms, interventions, and medications from drop-down boxes; check lists; and other computer interface components. The selection of the appropriate templates for completion might be driven by computerized workflows and care pathways [6, 7]. For example, entering that a patient smokes may lead to questions about how many cigarettes per day are smoked and for how long the patient has been smoking. Or recording a specific test result may prompt the user to consider other investigations. In the closely related structured data entry (SDE) approach, the user creates documentation by selecting clinical concepts from interfaces constructed from some underlying knowledge model, usually based on standard medical terminologies. Concepts may be further qualified and adapted by selecting modifiers, anatomical location, and so on [8]. Selecting “abdominal pain,” for example, may lead to the user being given a choice of more precise localization and a choice of onset.

SDE and CBD may well provide a rich and convenient way of describing patients. Yet, however data are structured, the clinician can only consider the fixed set of patient characteristics and features allowed by the structured representation and has no way to stray beyond those parameters. Clinicians cannot easily describe the personal, social, and cultural circumstances of patients; the interplay between their disease, life, and treatment; or the particular way in which they experience their disease. Nor can clinicians give a detailed description of the clinical encounter and of their personal reaction to it. Instead, patients are described as members of a population that share the same limited structured representation. Swinglehurst, talking about the UK primary physician record, which has been highly structured since the 1990s, describes a “dilemma of attention” [9]. On the one hand, medicine frames the patient as an individual and, on the other, as part of a population. The EHR brings this dilemma into sharp focus with easily structured and easily coded “hard” data pushing the dilemma’s resolution towards framing the patient as part of a population and representing an increase in the bureaucratization of health care. Should patients be treated only as members of populations, or is there some value in considering them as individuals? And, if we need to consider them as individuals to give the best care for their circumstances, is structured data able to convey all of the information necessary to support this care?

### **Analyzing the Text of the EHR**

Despite the efforts put into structuring the clinical narrative, the fact that structured representations are not able to give the level of description and convenience required by the clinician means that the medical record is still dominated by unstructured natural language. While CBD and similar ideas have a place in many EHR systems, the addition of free-text notes and the uploading of documents remain common EHR functionalities. Indeed, many important observations go unrecorded in the structured record, only

appearing in the free text stored alongside the empty fields and forms. In one UK case register derived from a forms-based EHR, for example, dealing with free text has been a major concern of reuse [10].

Why do clinicians prefer text and insist on using it? Meystre et al. note that free text is convenient to express clinical concepts and events, such as diagnosis, symptoms, and interventions [11]. Reviewing the few studies that look at the expressivity of CBD systems compared to natural language notes, Rosenbloom et al. report that prose can be more accurate, reliable, and understandable [12]. Powsner, Wyatt, and Wright refer to structured data as freezing clinical language and restricting what may be said [13]. Much of medical language is nuanced and makes heavy use of negation, temporal expressions, and hedging phrases. These are all difficult to represent as structured data. For example, when saying that something happened “a few months ago,” or that it is “more or less resolved,” the time and resolution cannot easily be accommodated by structured elements. Greenhalgh et al. say that free text is tolerant of ambiguity, which supports the complexity of clinical practice [14].

One way in which this tension may be resolved is through a linguistic analysis of the free text: an area of computer science known as natural language processing (NLP). NLP of medical records is nearly as old as the computerization of those records. Sager’s Linguistic String Project, for example, implemented NLP in radiology reports in 1976 [15]. The last few years have seen a big growth in medical NLP—paralleling the growth in the EHR—stimulated by government investment in health information technology (IT) internationally. Uses include automated coding of episodes, extraction of facts such as symptoms and confounding factors to support epidemiology, and extraction of clinical events to drive decision support [11, 16].

NLP does not provide a complete answer to the problem of extracting information from natural language, though, as the very reason clinicians value language—its expressivity—makes it difficult to analyze. The challenges that NLP faces are technical, organizational, and social. Specific technical challenges for NLP include ambiguity, uncertainty, complex temporal reasoning, complex terminology, heavy use of abbreviations, and a wide range of texts from prose-like letters to terse reports. All of these are active areas of NLP research [11]. There are also social and organizational challenges to its adoption. For example, the development of an NLP system usually requires example texts with the phenomenon of interest already identified, for the purpose of both training by example and evaluation. Marking the phenomenon of interest in the data requires expert human resources, often scarce in a health setting. Moreover, exporting the data from its source EHR and sharing it with software developers and the NLP research community raises [privacy issues](#). And, finally, after all the effort, the NLP system will still make mistakes. The end user—perhaps a data

analyst, perhaps a clinician using a decision support tool—has to deal with the system’s inevitable errors.

Much of medical NLP is targeted at extracting quantifiable facts expressed directly in the text, such as finding test results and medications discussed in an encounter note or finding a patient’s symptoms and smoking status from a clinic letter. We may, however, go beyond extraction of bare facts from individual records and study variation in the corpus as a whole, finding information that the writer may not have consciously intended to reveal. For example, McCoy et al. [17] studied sentiment expressed in discharge notes by looking at occurrences of words related to polarity (positive or negative), subjectivity, intensity, and negation. They found that, for psychiatric patients, public insurance was associated with significantly lower levels of positive sentiment while greater comorbidity was associated with significantly lower levels of both positive and negative sentiment. Additionally, self-identification as Hispanic was associated with significantly higher levels of both positive and negative sentiment. A similar approach has been used to study suicide risk, with one study finding that the clinic notes of outpatients who later died from suicide showed an increase in distancing language—for example, an increase in the use of third-person pronouns by the clinician [18].

These examples expose the power of natural language communication and give an insight into why clinicians value it. There is a sense in which the language of the record—particularly the narrative parts such as letters between clinicians—carry more information than could ever be conveyed by structure alone. When physician and anthropologist Cecil Helman describes reading a “fat file ... filled with the frustrated letters of a dozen doctors” and goes on to talk about the “tone” of those letters and the “hints” they contain [19], he is describing how communication through narrative text goes beyond a stream of facts. Through natural language, we communicate thoughts and feelings that we may only be dimly aware of ourselves. The implication is that by getting rid of the natural language text of the EHR, we will remove that communication and all of its benefits.

## **Conclusion**

While structuring EHRs is a valuable way to bring benefit by allowing their reuse, we also need to recognize the importance of natural language in human communication and allow for it when building EHRs and when deploying technologies, such as NLP, to analyze those EHRs [12].

What will the future EHR bring to the language of the medical record? One possibility is that records will no longer be confined to communication between clinicians and that patients will join in the conversation. Legislation now allows patients to see their records in many countries. For example, in the UK, this is enshrined in the Data Protection Act [20]. With the buff folder hidden away in a basement medical records library, it was

impractical for patients to regularly review their own record. Unlike paper records, however, the EHR is instantly portable and can be viewed at any location and at any time. We might expect that patients will increasingly access their own notes by browsing them on the web or swiping through them on their phone. This accessibility has implications for [how records should be best presented](#) to patients in order to aid their understanding and to avoid unnecessary alarm. It is as yet unclear how patient access will change the way in which physicians interact with the record, although there is evidence that, once again, physicians will not feel the need to change their language [21].

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## HEALTH LAW

### Strategies for Acing the Fundamentals and Mitigating Legal and Ethical Consequences of Poor Physician-Patient Communication

MaryKatherine Brueck and Angelique M. Salib, JD

#### Abstract

This article explores how the absence of effective verbal and nonverbal communication in the physician-patient encounter can lead to poor outcomes for patients and physicians alike. The article discusses legal and ethical topics physicians should consider during a medical encounter and provides educational and practical suggestions for improving effective communication between physicians and their patients.

#### Introduction

Consider the hypothetical case of a young university student, Patient Johnson, who enters the doctor's office experiencing frequent headaches and anxiety. After checking in and waiting in the main office, Johnson is greeted by a nurse and taken back to an exam room, where she anxiously sits and waits for 20 minutes for the physician to arrive. Dr. Smith enters the room, quickly glances at the chart, remains standing, and begins asking a series of general questions using a slew of medical terminology—particularly psychological and neurological vocabulary—when responding to Johnson's concerns about headaches. While Dr. Smith does not appear concerned, the use of unfamiliar terms leaves Johnson uneasy and unclear about her current health status.

Over the course of a career, a physician may have as many as 150,000 patient interviews, making a patient interview one of the most common components of a physician's practice [1]. Although communication is recognized as an important physician competency, physicians are not well trained to communicate effectively [2]. Additionally, physicians' position of authority in the physician-patient relationship may intimidate some patients, rendering them overly deferential or susceptible to undue influence in health care decision making. However, patient satisfaction is largely dependent on a physician's ability to communicate empathetically and to include patients in the decision-making process [3].

Physician communication is also associated with patient health outcomes, which includes both self-reported [4] and objectively measured outcomes [5]. Studies have shown that certain physician behaviors are linked with negative patient health outcomes, including using medical jargon the patient does not understand, an uninviting posture,

standing rather than sitting, interrupting the patient, making assumptions, asking leading questions, and wearing a white coat or medical uniform [3, 6, 7]. While this list is not exhaustive, it highlights common examples of language—including nonverbal communication—that can negatively impact patients' care experience and, ultimately, their health outcomes.

This article will explore the ethical and legal implications of physicians' verbal and nonverbal communication with patients in addition to techniques that can improve communication styles.

### **Ethical Dimensions of Communication in the Physician-Patient Encounter**

In conversations between a patient and physician, there exists an inherent imbalance of power, as the patient, compromised by illness, turns to the physician for answers, medical advice, and treatment [8]. This imbalance of power is present—and necessary—due to the conditions of the clinical encounter wherein the physician holds the medical knowledge and skills the patient wishes to access. While the imbalance of power does not threaten the physician's ability to provide quality care intrinsically, it may be exacerbated through ineffective communication. Failed verbal and nonverbal communication runs the risk of distorting the ideal collaborative physician-patient relationship: the physician may fall into involuntary paternalism, controlling medical decision making in the belief that he or she knows what's best for the patient; or, contrarily, the patient may become distrustful of the medical profession in cases in which the physician was not transparent or clearly understood [9, 10]. In both instances, a patient may become unable or unwilling to participate in shared decision making, compromising quality care. A physician may not necessarily be morally culpable for the patient's withdrawal in these cases, as the patient also bears responsibility for participation in decision making; however, the physician maintains responsibility for treating the patient and delivering quality care. With this goal in mind, the physician has a duty to mitigate the threats to effective clinical decision making that result from ineffective communication.

Poor communication in the physician-patient relationship may not only introduce a barrier to practicing medicine effectively but also raise concerns about the appropriate allocation of health care resources. Although more research needs to be done on this topic, patients who feel that the physician does not respect their concerns, show empathy, or provide relevant information may have lower rates of compliance with recommended treatment options, leading to greater costs and expenditures, including those associated with increased hospital admissions [10]. Physician communication, then, impacts not only the trajectory of the individual patient's care, but also the health care system as a whole. Recognizing that health care resources are limited and valuable, physicians should participate in a system that maximizes efficiency and quality of care, starting at the root of care in the physician-patient encounter [11].



### **Legal Consequences of Poor Communication**

Studies indicate that a breakdown in communication between a physician and patient is the “root cause” of malpractice claims [12]. In one analysis of claims data from 2004–2008, communication failures in test result notification accounted for 4 percent of malpractice claims by volume and 7 percent of the total cost [13]. This data underscores the importance of effective communication during the physician–patient encounter and the potential for detrimental effects of legal action on a physician’s practice in its absence.

What types of breakdowns in communication can lead to adverse legal action? Studies have shown that, in cases of medical error, patients’ uncertainty about whether they have received all the relevant information and physician dishonesty [12] can lead to litigation. Lawsuits have also resulted from failure to obtain informed consent and breach of a patient’s privacy rights [14].

To err is human. Although it is inevitable that there will be some breakdowns in communication over the course of a physician’s career despite his or her best efforts, it is still possible for the physician to remediate the situation. In the case of medical errors, physicians may be reluctant to discuss how “things went wrong” for fear of liability, retaliation, or being perceived as incompetent. In an effort to reduce physicians’ fear of being transparent with patients and their families, policymakers have passed “[apology statutes](#),” whereby physicians can express sympathy, apologies, or condolences without fear of those statements being used against them in court. To date, 36 states plus the District of Columbia have passed such laws [15]. For example, the medical apology statute in Connecticut provides that any statement or gesture expressing apology, fault, or compassion made by a health care professional as a result of an unanticipated outcome of care is inadmissible as evidence in a civil action brought by an alleged victim [16]. Studies to date have shown that apologies in cases of medical error reduce the cost of litigation and facilitate faster settlement times [17]. Although errors inevitably happen, acknowledgment of fault and expressions of apology can be a means to remediate the physician’s relationship with the patient and lessen the possibility of adverse legal action.

### **Making a Change: Methods to Improve Communication with Patients**

Having addressed ethical and legal considerations that result from failed communication in the clinical encounter, we now identify what physicians can do in order to proactively prevent these concerns from arising.

[Patient-centered communication](#) (PCC) that promotes shared decision making has been widely endorsed, including by the National Academy of Medicine (formerly the Institute of Medicine) [18], as a key aspect in improving the quality of care delivered in the clinical

encounter. PCC involves (1) considering patients' needs, wants, perspectives, and individual experiences; (2) offering patients opportunities to provide input into and participate in their care; and (3) enhancing partnership and understanding in the patient-physician relationship [19]. Additionally, Opinion 2.11 of the AMA *Code of Medical Ethics*, "Informed Consent," discusses the importance of creating a space that encourages shared decision making [20]. The opinion notes that a physician should be actively engaged in assessing a patient's ability to understand and process information (to the best of his or her ability), presenting relevant information accurately and sensitively, and documenting the conversation. Yet, comprehensive utilization of these guidelines must also take into consideration the effects of nonverbal communication—facial expression, voice tone, body position—that accompany verbal information sharing [21]. All of these recommendations take time to put into practice but are essential to collecting accurate information and fostering a collaborative relationship. Especially in cases in which ample time is not allowed to thoroughly establish the clinical relationship due to institutional constraints and pressures, physicians should pay careful attention to their demeanor, presentation, and delivery of relevant information [22]. Although physicians see many patients each day—often witnessing similar symptoms, cases, and behaviors—it is important for them to recognize that each patient is unique and should be approached with the same attitude of care, whether it is the first or last patient seen that day.

Another way to improve physician-patient communication is to enhance the teaching of communication skills during undergraduate medical education [2]. This is particularly important, as studies have shown that students become more cynical and less empathetic during medical school [23]. [Reflective writing](#) is one established method for teaching medical students empathy, as are general courses in medical humanities [24]. Another way to improve communication skills is to implement an alternative communication model in clinical practice. The Studer Group developed the AIDET® model for physicians to improve effectiveness in the patient encounter [25]. The five fundamentals of communication include:

Acknowledge—greet the patient by name, make eye contact, smile.

Introduce—your name, title.

Duration—give time expectations for tests, next steps.

Explanation—what to expect, answer questions, how patients can contact you.

Thank you—express gratitude and support [25].

## Conclusion

Physicians are frequently pressed for time as they care for many patients and fulfill other responsibilities of their job. However, by employing patient-centered communication using a model such as AIDET, physicians' investment in communicating effectively can

pay off in several dimensions of their practice, legally and ethically, and also contribute to providing quality care for their patients.

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## POLICY FORUM

### The Role of Universal Health Literacy Precautions in Minimizing “Medspeak” and Promoting Shared Decision Making

Lara Killian, MA, MLIS, and Margo Coletti, AMLS

#### Abstract

Shared decision making (SDM), a collaborative process whereby patients and professionals make health care decisions together, is a cornerstone of ethical patient care. The patient-clinician communication necessary to achieve SDM depends on many factors, not the least of which is a shared language (sometimes with the aid of a medical interpreter). However, even when a patient and clinician are speaking the same mother tongue, the use of medical jargon can pose a large and unnecessary barrier. This article discusses how health care professionals can use “universal health literacy precautions” as a legal, practical, and ethical means to enhance SDM and improve health care outcomes.

#### Case of Language Barrier’s Impact on Patient Autonomy

Patient X, a 56-year-old construction worker, visits the emergency department (ED) with pain and swelling in his right calf. He can walk on his leg with a limp and considers the pain to be bearable. He would prefer to just “power through” whatever is causing the discomfort. This is his first ED visit. He is here to placate his wife, who was alarmed at the progression of the swelling over the last 24 hours.

A physical exam reveals a slightly elevated temperature of 99 degrees and blood pressure of 150/110. Blood cultures, a creatine phosphokinase (CPK) test, and a C-reactive protein (CRP) test are ordered. When asked about any previous trauma to his leg, Patient X is confused. Has he had “trauma”? He considers himself a calm person, not easily alarmed or “traumatized.” He asks the physician (Dr. Y) why they need his blood and is told that the cultures may reveal the agent or pathogen responsible for his condition. Patient X is becoming alarmed. To him, an “agent” sounds like a person. A “pathogen” sounds like a “psychopath” but it can’t mean that, except the doctor said something about the “culture.”

Dr. Y is running behind; it will be at least two hours before she can return with the bloodwork results to confirm her diagnosis, prescribe appropriately, and either discharge or admit Patient X. This leaves Patient X with two hours to worry and try to explain the situation to his wife over the phone.

When Dr. Y returns, Patient X is fearful and distressed, and his head is full of confusing words: culture, pathogen, agent, and trauma. Next is a new word: cellulitis. Dr. Y tells him cellulitis is an “inflammation of the skin and subcutaneous tissues.” Patient X looks at his leg with alarm. What does “subcutaneous” mean? And “inflammation”—does that mean his leg is on fire? It certainly feels like it is. The physician recommends treatment: the cellulitis is severe enough to warrant observation for 24 hours. Dr. Y tells Patient X that he can either go home with a prescription for oral antibiotics and bed rest, or he can stay for IV antibiotics and observation. She asks him if he has any questions about this choice. His head is swimming with half-formed questions but all he can come up with is, “What do *you* think I should do?”

Coming from a place of confusion and fear, Patient X has ceded his autonomy and all decision making to the physician. Fear and confusion can be especially prevalent in EDs and ICUs, and communication barriers exist in all health care settings. This article examines not only how language barriers occur and interfere with shared decision making, but also how health care staff can remedy this problem by using new communication tools.

### **Medical Terminology and Patient Lingo as Barriers to Shared Decision Making**

Every profession has its own vernacular. Contractors, computer engineers, attorneys, physicians—we all have a different jargon. The customer, client, or patient often struggles to understand important information conveyed in unfamiliar and technical terms, frequently at a fast pace. Medical terminology is collectively referred to by the Medical Library Association as “medspeak” [1]. Patients’ abilities to sift critical facts from insignificant details within this jargon jungle can have serious consequences for their decisions and actions regarding their health conditions.

Shared decision making (SDM), a collaborative process whereby patients and professionals make health care decisions together [2], is a cornerstone of ethical patient care. The patient-clinician communication necessary to achieve SDM depends on many factors, not the least of which is a shared language (sometimes with the aid of a medical interpreter). However, even when a patient and professional are speaking the same mother tongue, the use of medspeak can be an unnecessary barrier to SDM.

A patient who learns she has had a myocardial infarction (medspeak term) might hear the diagnosis, including lab results (more medspeak), as unintelligible. In fact, the patient might grasp the seriousness of the situation only from the expression on the physician’s face. When asked if she has any questions, the answer might be “no,” because the patient does not want to appear ignorant or is overwhelmed with questions and doesn’t know where to start. Patient X was only able to ask one question: “What do *you* think I should do?”

Another factor in patient-clinician communication is that patients often have their own lingo. A “deep study” (depression), “athletic fits” (epileptic seizures) [1], or a discharge from a patient’s “oven door” (vagina), are colloquial or even individual terms, each indicating a condition that needs to be addressed. The clinician sometimes has to act as a two-way interpreter, clinician-to-patient and patient-to-clinician. Patients’ anxiety and symptoms can add to the [communication barrier](#). When anxious, in pain, or compromised by illness, even patients and family members with high health literacy can mishear, misinterpret, or forget vital information—just at the time when it’s most critical to understand it.

### **Health Literacy and Health Literacy Universal Precautions**

Only 12 percent of adults in the US [3] are considered to have high health literacy proficiency. An even smaller number of American adults, 9 percent, have adequate numeracy skills [3] to ensure that correct medication dosages are taken, for example [4]. In Canada, by contrast, 46 percent of adults between 16 and 65 years of age are considered to have adequate health literacy, but that number falls to 12 percent for those older than 65 [5].

Health literacy at its core is being able to find, understand, and use information about health. Often, health care professionals assume that patients and families understand what they’ve been told [6]. However, it’s not enough to think that a nod or silence—or even a “yes”—means comprehension. A blank look—common when a person is overwhelmed—is a good indication that there has been a communication breakdown [7]. Tools are needed to translate confusing medical vocabulary, confirm understanding, fill in gaps, and ensure that patients are encouraged to ask questions and actively learn about their health conditions.

Health Literacy Universal Precautions, a toolkit created by the Agency for Healthcare Research and Quality (AHRQ), is a series of steps that health care professionals can take to ensure that patients understand information relevant to their health and can participate in their own health care. The toolkit, freely available online, includes 21 tools to help improve communication with and care for patients and families at all health literacy levels [8]. Designed for busy health care environments, the toolkit includes techniques such as encouraging questions in a non-shaming atmosphere, using educational materials effectively, and the “teach-back” method for assessing patient comprehension. The teach-back method is simple: after explaining a patient’s condition, options, or next steps—such as what medication will be taken, how much, and when—the clinician asks patients to state in their own words what they will do next or what they understood from the clinician’s statements. If patients have understood what the clinician has told them, they’ll be able to explain it back. If they haven’t, the clinician will know immediately that he or she needs to go over the important details again and try



again to confirm understanding. Much like routine hand washing, AHRQ recommends that clinicians use these tools on the assumption that every patient may have limited health literacy [8].

### **Why Should Health Care Professionals Use Health Literacy Universal Precautions?**

According to the *AMA Code of Medical Ethics*, “Physicians have a responsibility to adopt, or advocate for, policies and procedures to ensure that ... the patient/surrogate receives information needed to make well-considered decisions about medical treatment and give informed consent to future treatment” [9]. There are ethical, legal, and practical rationales for the use of universal health literacy precautions. We make our case, with the help of Patient X and Dr. Y, below.

*Dignity.* Respect for patient autonomy, a key principle of medical ethics, begins with respect for the intrinsic moral worth of the patient and his or her dignity. Thomas Nairn [10], senior director of ethics, Catholic Health Association, states that “Health literacy is also—and perhaps even primarily—an ethical issue involving the dignity of the patient and the very integrity of health care” [11]. He further notes that “the relationship between the patient and the health care professional necessarily entails a difference in power. The power of the health care professional can be used to enhance the dignity of the patient or contribute to his or her denigration” [12]. The use of technical jargon in any profession can be a means of wielding power over the listener. Sociologist Karen Sternheimer argues that “Social groups create special language—like jargon—in part to make communication short cuts, but mostly to clearly delineate who is a member and who is not” [13]. Using med speak can undermine the patient’s dignity by creating boundaries between the patient and the clinician. Avoiding med speak altogether, or explaining terminology when its use is unavoidable, respects patient dignity and is the ethical choice. When Patient X asks why his blood is being taken and Dr. Y tells him that the cultures may reveal the agent or pathogen responsible for his condition, she has not answered his question in any meaningful way, given his low level of health literacy. He may feel ignorant or “less than” because he does not understand her answer.

*Autonomy.* Exercising the right of self-determination is contingent on a patient’s understanding of relevant information. The clinician’s ensuring that the patient understands appropriate diagnostic and treatment information is an essential component of [informed consent](#), a process that is ongoing throughout the clinical encounter—whether or not a consent form is involved. Informed consent happens informally when the patient is directed to strip for an exam. (“Please take off your clothes from the waist down and put this robe over your bottom half, so the doctor can look at your leg.”) It is the patient’s understanding of the information presented and willingness to participate in his or her own care that enables SDM and informed consent to take place. A patient who doesn’t understand the possible next steps in his or her care or the risks of a particular treatment cannot give informed consent. Patient X did not

have enough understanding of his condition to participate in SDM and make an informed decision about his treatment. Dr. Y's explanations were a jumble of jargon to Patient X, not a foundation on which to base an informed consent.

*Risk management.* Breakdowns in patient-physician communication can lead to legal liability [14]. In this case, Dr. Y could have used the teach-back method to ask Patient X to explain to her what he understood his condition and options to be. If his preference was to go home with the prescription for oral antibiotics and the expectation of bed rest, Dr. Y could have asked him to explain his next steps, which should involve filling the prescription. Dr. Y would be managing the risk of a complaint being filed with the hospital (because Patient X wasn't adequately cared for), because she would have confirmed understanding with her patient. Studies have shown that improved communication between health care practitioners and patients leads to improved patient outcomes, fewer medical errors, and lower rates of malpractice claims [15]. In fact, primary care physicians with no [malpractice claims](#) differ significantly in their communication skills from those who have experienced malpractice claims [16].

*Regulatory compliance.* In the US, there are several accrediting bodies for health care organizations. Accreditation from at least one of these organizations may be essential for providers to obtain insurance reimbursement, fulfill state regulatory requirements, and acquire and maintain a competitive advantage, among other benefits [17]. Three of these organizations address health literacy concerns within their regulations: the Joint Commission, the National Committee for Quality Assurance, and the Utilization Review Accreditation Commission [18]. The AHRQ Toolkit maps tools to specific regulations of these three accrediting bodies and provides a "crosswalk" (i.e., tables) to navigate these regulations [18].

*Patient safety and practical implications.* Communication is a patient safety issue as well. Making sure patients understand their condition or treatment and that they know what the next steps are and what to watch out for means they're less likely to return to the health care professional's office or, worse, the ED [19]. In a research study context, patients with a firm grasp of the research steps, visits, and procedures are more likely to stay enrolled for the duration of the study [20]. Enabling people to take an active role in their own care through ensuring their comprehension of relevant information makes the health system more efficient for everyone and leads to better health outcomes overall [15].

### **How Could Patient X's Clinical Experience Have Been Better?**

The clinical encounter between Patient X and Dr. Y could have been improved with the use of Health Literacy Universal Precautions tools. Instead of asking the patient whether he had experienced trauma to his leg, Dr. Y could have used Tool #4, "using plain language," and asked if he'd had any cuts or scratches on it [8]. Before ordering the blood

draw, she could have told the patient his blood would be examined for germs that might be causing an infection in his leg. Before leaving the exam area, she might have asked him, "If your wife calls, what will you tell her about your leg? Can you explain to her why we are taking a sample of your blood?" This is an example of the teach-back method—Tool #5 in the AHRQ Toolkit [8]—whereby patients need to explain in their own words what they have understood about their condition. Dr. Y. will also need to outline the treatment choices and engage her patient in the decision-making process. Why might Patient X be better (or worse) off at home? Does he have to climb stairs several times a day to use the bathroom? Does he have help at home? Will he be able to remain autonomous and to take care of himself as he used to? Are there any concerns about Patient X retaining dignity if he needs to be bathed or toileted by his wife?

### Conclusion

Health care professionals can and should use Health Literacy Universal Precautions as an ethical, legal, and practical means to enhance SDM and improve health care outcomes. Not using health literacy precautions could add avoidable costs to a burdened health care system. In its Toolkit, the AHRQ provides a path. Can we find a way to follow it?

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## MEDICINE AND SOCIETY

### From Particularities to Context: Refining Our Thinking on Illness Narratives

Annie Le, MPH, Kara Miller, MA, and Juliet McMullin, PhD

#### Abstract

This paper examines how illness narratives are used in medical education and their implications for clinicians' thinking and care of patients. Ideally, collecting and reading illness narratives can enhance clinicians' sensitivity and contextual thinking. And yet these narratives have become part of institutionalizing cultural competency requirements in ways that tend to favor standardization. Stereotyping and reductionistic thinking can result from these pedagogic approaches and obscure structural inequities. We end by asking how we might best teach and read illness narratives to fulfill the ethical obligations of listening and asking more informative clinical interview questions that can better meet the needs of patients and the community.

#### Introduction

Illness narratives are a genre wherein an illness and its effect on the patient's life are told as an autobiographical or biographical account. As Kleinman [1] and Frank [2] have argued, illness narratives are forms of meaning making. They provide insight into how patients and clinicians understand the why and how of illness causation and treatment, including how illness processes are linked to the broader social and structural contexts of patients, their communities, and their clinicians. As a form of meaning making, illness narratives can be created in a clinical encounter, wherein physicians and patients co-construct a therapeutic agenda [1, 3, 4] that weaves together what the patient and the clinician know about the illness and its context.

*The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures* [5] is an example of an illness narrative that illuminates cultural, economic, and ethical meanings in a patient's illness. *The Spirit* describes the beliefs and practices of the Lee family, Hmong immigrants living in Central California, and those of the health care and social service workers, who were, from their experience and cultural positions, attempting to provide excellent care for Lia, the young daughter who has epilepsy. The story gives us profound insight into how, despite a medical team's best efforts, inadequate care can arise from miscommunication, failure among clinicians to reflect on their own cultural and economic positions, rigid institutional policies and procedures, and systemic inequities.

In the 20 years since the publication of *The Spirit*, conversations about the role of illness narratives in medical training have abounded. In this article, we examine the use of illness narratives in cultural competency training and their implications for clinicians' thinking and care of patients. We argue that an approach to teaching narrative that tends toward standardization and reductionism may impede students' understanding of how to authentically engage with patients' stories and the structural inequities described in illness narratives. We end by asking how we might best teach and read illness narratives with a view to asking clinical interview questions that are more informative and better meet the needs of patient-centered and community-engaged care.

### **Teaching Cultural Competency with Illness Narratives in Medical Training**

Illness narratives such as *The Spirit* have become tools to demonstrate that medical students have acquired cultural competency [6], which is required by the Accreditation Council for Graduate Medical Education (ACGME) [7, 8]. At the heart of using illness narratives and teaching cultural competency is a desire to ensure excellent care for all patients—recognizing that patients face differential experiences and barriers to care—and to contribute to reducing health disparities related to race and ethnicity [9]. Nevertheless, given the demand on medical education to accommodate and standardize new scientific knowledge [10], individual and structural contexts of narratives can be reduced to lists of cultural attributes. Here, we show that the problem that *The Spirit* and similar illness narratives pose for medical training resides not in the narrative itself but rather in how such books are taught and interpreted [11, 12].

The theory and practice of cultural competency have been critiqued for the potential pitfalls of stereotyping and simplifying the meaning of culture and who “has” culture [13]. Similarly, DasGupta notes that a hallmark of cultural competency is a reliance on “lists” of fixed cultural characteristics [14]. Scholars in both the discipline of anthropology, whose ethnographies may be used to create such lists, and medicine, whose practice depends on sensibly and sensitively understanding a patient's narrative [15], argue that when reading illness narratives such as *The Spirit* we must do so as agile and complex thinkers who can move beyond lists [13, 15]. When reading illness narratives, teachers and students should attend to not only the cultural context but also the social and [structural contexts](#) that make complicated treatments nearly impossible for under-resourced patients to follow.

For the Lee family, “failures to comply” with the treatment regimen led to Lia being moved to foster care for several months. Lia Lee's physicians were regularly changing her medications, trying to find the right anticonvulsant for the progression of the seizures. This constant fine-tuning, however, never included a conversation about how Lia's parents understood the reason for the changes or their ability to repeatedly access different medications. Importantly, the physicians also did not take into account the

parents' knowledge of how each medication was affecting Lia. Rather than reading this moment of "noncompliance" as the failure of treatment comprehension by an immigrant family, the moment should be read with attention to economics, access, and the clinician's ability to listen with care [16].

To achieve this type of reading, teachers and students not only must focus on data points about their patient's culture or illness but also must critically reflect on their own assumptions and grapple with both structural conditions that produce inequitable access to resources and structural interventions that do not meet the needs of the patient [13, 14]. Engaging in [critical reflection](#) can lead clinicians to ask questions of their patients, clarifying and attending to the combined individual and contextual factors that might affect patients' health, such as how patients understand their medication and its effects, being unhoused, having multiple jobs to make ends meet, or living in neighborhoods that are subjected to greater amounts of pollution or violence [14, 17, 18]. These questions can provide an opening for creating an illness narrative with the patient and his or her family about a treatment plan that more appropriately meets the patient's health care needs.

When analyzed critically and holistically, illness narratives provide insight into the context of patients' lives, create and sustain empathy, and spark critical reflection on implicit biases and structural inequities. Teaching illness narratives to best effect involves expanding beyond the framework of cultural competency. An authentic engagement with the narrative can yield lessons for clinicians to engage with their health care team and with their patients and to provide care that broadens the scope of considered contexts. In this way, the scope of interventions with which clinicians can engage are similarly broadened.

### **Particularities, Peculiarities, and Pedagogy: Where It Goes Wrong**

Given the potential for illness narratives to bring attention to the nuances of social and structural context, how is it that the cultural competency lens seems to limit readers to *particularities* about their patients? In medical and anthropology courses, discussions about narrative and culture can revolve around cultural *particularities* as *peculiarities*. One such particularity is food. In *The Spirit*, Hmong foods are recurring motifs. The supposed peculiarity of their foods is mentioned by doctors who care for Lia's mother in the hospital after she gives birth to Lia. In anthropology classes using *The Spirit* taught by one of us (KM), students frequently focus their discussions on the descriptions of foods and other alluring or unfamiliar practices of the Lee family. Although food is indeed meaningful, the microscopic focus on this aspect of a patient's context alone can be problematic if it leads to exoticizing, pigeonholing, or simply distracting from care.

Similarly, a course guide familiar to one of us (AL) that introduces students to the topic of cultural competency opens by stating that our diverse society "offers us the chance to



enjoy many of the world's cuisines. It also means that we get to experience many of the world's languages." At best, this perspective only goes as far as recognizing that clinicians may encounter patients who have different backgrounds and life experiences than themselves. At worst, it may position the clinician as a mere recipient of information about his or her patients, rather than as an active participant in developing the patient-clinician dynamic. Medical students are accustomed to receiving a straightforward rubric for didactic science competencies, and this expectation of standardization may be inadvertently transferred to the expectations of their approach to clinical encounters with the result that cultural particularities may be gathered as data points, consistent with the clinical manner of collecting data points about a presenting illness. This scientific way of knowing is in direct contrast with understanding the meaning of the narrative [19] and the context in which that narrative occurs [1, 4, 13].

In this reductive framing of culture, cultural competency can slide into stereotyping and ultimately inadequate care. For example, the cursory reading and teaching of narratives regarding foods associated with different cultures, paired with the reductionist thinking that certain foods are always consumed by specific cultures, can lead to overly simplified questions in the clinic. One of the authors (AL) reports that, having taken several classes and workshops about cultural competency, a common refrain is that the patient must be questioned about assumed cultural food practices. Given the exact same example several times by instructors, she (AL) found herself asking a Latina patient with diabetes, "How many tortillas do you eat?" prior to asking broader questions about diet. The clinician missed the opportunity to open the conversation to nutrition in general, food access, and exposure to obesogenic environments. Importantly, this patient did not even like tortillas.

Indeed, the pedagogical framework within which illness narratives are taught has consequences for clinical practice. When illness narratives and cultural competencies are reduced to stereotypes, the constellation of forces that affect health outcomes beyond the individual level of behavior, beliefs, and attitudes are obscured, and the bounds within which the clinician is capable of addressing patient needs is constrained. More helpful for lifelong learners than a rubric of cultural competencies is initiating the exploration of broader contexts of care that foster partnerships with others, knowing oneself in a reflexive manner, and co-constructing illness narratives and therapeutic agendas.

### **Thinking about Care and Context**

To hear and listen to someone's story creates an [ethical obligation](#) [20]. This ethical obligation requires something of the listener in general and, in this context, of the physician in particular: a diagnosis, a referral, a space for expressing and bearing witness to suffering and social inequity. All of these actions require care—not just care in its commonly used sense of providing health care—but care as something considered by an

active, agile, and complex thinker [15]. To use illness narratives to achieve this kind of care and thinking requires instructors to carefully attend not simply to the descriptions of cultural attributes but to the contexts in which the medical encounters occur [1, 11, 12].

One of the roles of clinicians is to act as gatekeepers, as they command knowledge of and access to medical and social services resources. Consequently, clinicians' interpretations of and interactions with patients' narratives can amount to provision or denial of resources. When illness narratives are not co-constructed by clinician and patient, inappropriate or inadequate treatment can follow, as we see in *The Spirit*. An understanding of how one cares within broader contextual, structural perspectives would make material resources and power dynamics more explicit and ideally compel one to assume a role as advocate for one's patients, affirming their agency while providing access to available social service resources and advocating for access where it is limited.

### **Care and Context at the Core of Medical Practice**

Given the complexity of the narrative in *The Spirit*, to reduce it to lists of cultural attributes is to not completely teach or read the narrative. This text and other illness narratives [21-23] provide ample detail to examine the cultural context as well as the institutional, economic, and political structures that influence health care and health-related inequities. Expanding beyond the hyperfocus on cultural particularities to achieve a structural outlook could assist clinicians in becoming comfortable with the discomfort of not knowing and categorizing their patients offhand, committing to developing relationships through open-ended questions and listening, and seeking to co-create therapeutic agendas that better account for context [1, 3, 4, 20].

Teaching with illness narratives in medical education could be improved by explicit training in how to decipher and analyze cultural and structural contexts [24]. Several pedagogical approaches have been described that avoid the pitfalls of cultural reductionism. Kleinman and Benson [25] have proposed an ethnographic approach to considering culture beyond lists of particularities. DasGupta [14] provides a methodology for engaging students in open discussion of the cultural and structural contexts in illness narratives. Metzl and Hansen's [17] structural competency framework describes an approach to teaching about the structural conditions that shape the patient's world. Metzl and Hansen argue that this approach can improve the quality and comprehensiveness of clinicians' questions about patients' life circumstances and provide them with tools to make a difference in their patients' lives by preparing them to serve as advocates for social services and structural change. Integrating these approaches can provide a more comprehensive foundation within which illness narratives can be taught to their fullest potential, solidifying our obligation to engage with patients and their complex narratives [20], which hold potential for providing meaningful and excellent medical care.

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## **CORRECTION NOTICE**

### **Correction to “The Case of Dr. Oz: Ethics, Evidence, and Does Professional Self-Regulation Work?”**

Audiey C. Kao, MD, PhD, editor-in-chief

The following corrections were made to the article entitled “[The Case of Dr. Oz: Ethics, Evidence, and Does Professional Self-Regulation Work?](#)” published in the February 2017 issue, 19(2), of the *AMA Journal of Ethics*.

On page 200, changes were made to clarify the Food and Drug Administration’s findings by substituting a quotation from the cited reference: “found the ‘vast majority of apple juice tested to contain low levels of arsenic’ and given these levels was ‘confident in the overall safety of apple juice consumed in this country.’”

On page 200, “endorsed” was changed to “featured two guests on his show who claimed” to concur with the cited reference, and the sentence was moved to the second paragraph to address an error in chronology.

On page 200, changes were made to clarify that the ten physicians who wrote the letter were not colleagues of Dr. Oz at Columbia University College of Physicians and Surgeons.

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