

# AMA Journal of Ethics®

**November 2018**

**Volume 20, Number 10: E1001-1112**

## **False Beliefs in Health Care**

### **From the Editor**

**The Internet, Ethics, and False Beliefs in Health Care** 1003  
Annie J. Tsay, MPH

### **Ethics Cases**

**Should a Physician Offer Recommendations Based on Experience but Contrary to Current Practice Guidelines?** 1007  
Beth A. Lown, MD and Karen Victor, MD

**How Should Clinicians Address a Parent's False Belief Generated by Denial or Grief About How to Care Well for a Child?** 1017  
Conrad Krawiec, MD and Benjamin Levi, MD, PhD

**How Should a Physician Counsel a Vegan Patient With IBD Who Might Benefit From Supplements?** 1025  
Elizabeth Southworth and Kayhan Parsi, JD, PhD

### **Medical Education**

**Should Crowdsourced Unvetted Content on Wikipedia Be Used in Health Sciences Teaching and Learning?** 1033  
Jennifer Meka, PhD and Alyssa Vigliotti

### **Health Law**

**Constitutional Regulation of Speech (and False Beliefs) in Health Care** 1041  
Scott J. Schweikart, JD, MBE

### **AMA Code Says**

**AMA Code of Medical Ethics' Opinions Related to False Beliefs in Health Care** 1049  
Danielle Hahn Chaet, MSB

## Policy Forum

**Why Health Professionals Should Speak Out  
Against False Beliefs on the Internet** 1052

Joel T. Wu, JD, MPH, MA and Jennifer B. McCormick, PhD, MPP

**How Should Clinicians Engage With Online Health Information?** 1059

Dónal P. O'Mathúna, PhD

## Medicine and Society

**Public Accommodation Laws and Gender Panic in Clinical Settings** 1067

Elizabeth Boskey, PhD, MPH, MSSW, Amir Taghinia, MD, and Oren Ganor, MD

**How Should Clinicians Respond When  
Patients Are Influenced by Celebrities' Cancer Stories?** 1075

Divya Yerramilli, MD, MBE, Alexandra Charrow, MD, MBE, and Arthur Caplan, PhD

## History of Medicine

**Ads and Labels From Early Twentieth-Century Health Fraud Promotions** 1082

Amber Dushman, MA, MLIS

## Art of Medicine

**When I Take Off My White Coat...** 1094

Joseph Gascho, MD

## Personal Narrative

**How Should a Research Ethicist Combat False Beliefs  
and Therapeutic Misconception Risk in Biomedical Research?** 1100

Jennifer B. McCormick, PhD, MPP

## Letter to the Editor

**Added Points of Concern About Caring for Dying Patients** 1107

Annette Hanson, MD, Ron Pies, MD, and Mark Komrad, MD

**Response to "Added Points of Concern About Caring for Dying Patients"** 1110

Alexander Craig, MPhil and Elizabeth Dzeng, MD, PhD, MPH

## Podcast

**Ethics Talk: How Should Clinicians Respond to False Beliefs in Health Care?**

## FROM THE EDITOR

### The Internet, Ethics, and False Beliefs in Health Care

Annie J. Tsay, MPH

False beliefs—those at odds with established bodies of evidence—have a number of origins, including the internet or personal experience. Such beliefs can be held by clinicians as well as patients; in the context of health care, they deserve clinical and ethical attention mainly because they can cause harm. The current preponderance of fake news, persistence of social media as a vehicle to disseminate it, and increasing abundance and easy availability of information—including health-related information—suggest the clinical and ethical importance of focusing on the role of *perspective*. According to which criteria ought we to evaluate a perspective and regard it as right or wrong? What makes a health care decision a “best” decision? Should personal and professional experiences have authority in decision making even if they are not consistent with clinical practice standards and the body of evidence that supports them? These questions will be explored from clinical, ethical, legal, and cultural perspectives in this issue of the *AMA Journal of Ethics*.

These cross-disciplinary perspectives offer guidance on how we should think about what constitutes evidence and facts and what kind of authority we grant them. For example, we generally expect members of guideline panels—be they clinical epidemiologists, physicians, researchers, or other professionals—to be capable of interpreting evidence and facts. However, given the same set of data, panel members’ conclusions about best practice recommendations can differ immensely.<sup>1</sup> Guideline panels are typically composed of generalists whose views on screening criteria are often more conservative than specialists<sup>1-3</sup> because “they have little to gain from the recommendations” and are “chosen for their skills in critical appraisal.”<sup>1</sup> In some instances, those who offer recommendations might not be the same professionals who use the guidelines to care for patients. Too often, guidelines use evidence-based data published in high-caliber journals, which we often take for granted as being unbiased though we must learn to critically appraise everything we read.<sup>4</sup> This issue is considered by the CMO of the Schwartz Center for Compassionate Healthcare, Beth A. Lown, and general internist Karen E. Victor, in responding to a case in which a physician offers [advice based on personal experience](#) and against current guidelines. The authors argue that in such circumstances, physicians should explain their rationale for deviating from clinical guidelines and respect a patient’s autonomy when that patient makes a different treatment decision. Clinicians’ false beliefs are also examined by researcher Elizabeth Boskey and surgeons Amir Taghinia and Oren Ganor. They discuss how health care

professionals' concerns about [public accommodation laws](#) intended to protect transgender persons from discrimination can be addressed through analogizing to discriminatory behavior in other contexts.

Two other cases examine a caregiver's or patient's false beliefs. Responding to a case of a parent who has false beliefs about her child's progressing illness, pediatricians Conrad Krawiec and Benjamin Levi show how clinicians can address a [parent's false beliefs](#) by understanding that parent's perspective, engaging in shared decision making, and, when necessary, reporting neglect. In a third ethical case about a patient with a [vegan diet](#) who refuses to take supplements, medical student Elizabeth Southworth and bioethicist Kayhan Parsi argue that taking a food history allows clinicians to provide quality care while respecting patient autonomy, although clinicians need to be honest with patients about the lack of regulation and risks of supplements.

In addition to one-on-one communication between private parties, the internet has emerged as a means for propagating and widely disseminating false beliefs. The need to gather (accurate) information quickly has created a niche for open-access sites like Wikipedia, whose host, the Wikimedia Foundation, has as its mission to contribute to "a world in which every single human being can freely share in the sum of all knowledge."<sup>5</sup> As a student, clinician, researcher, or private citizen with a question, it is tempting and often more efficient to get an answer from sources like Wikipedia rather than using a 2-step authentication process to access a subscription resource. The emergence of readily available information coupled with an abundance of web-based false information prompts the question: Should crowdsourced sources like Wikipedia be used in medical practice and education? Cognitive psychologist Jennifer Meka and medical student Alyssa Vigiotti discuss how medical educators can [teach students to appropriately assess and use information](#) from online sources. And health care ethicist Dónal P. O'Mathúna discusses ethical principles that have motivated Wikipedia's efforts to improve the quality of its content and [physicians' obligations](#) to help patients evaluate online information.

With the emergence of easily accessible information on the internet, one might wonder who should regulate online information and false speech. Public health law expert Joel T. Wu and public policy expert Jennifer B. McCormick not only discuss whether health-related internet-based information should be regulated through constitutional law but also suggest that [regulation by government alone is insufficient](#). Appealing to the American Medical Association (AMA) *Code of Medical Ethics*, they argue that health care professionals have ethical responsibilities to convey and help their patients obtain accurate health information. And AMA health law editor Scott J. Schweikart argues that false beliefs in medicine can be regulated by the legal doctrines of [false speech and professional speech](#).

Two articles discuss strategies for overcoming patients' false beliefs. While scientific articles are meant to present unbiased data, they can be difficult for the public to interpret. McCormick discusses her experience as an ethics consultant addressing false beliefs in translational science, especially [therapeutic misconception](#) (ie, research participants' belief that an experimental agent will personally benefit them) by repeatedly engaging participants in discussions of research risks and benefits. And resident physicians Divya Yerramilli and Alexandra Charrow collaborate with bioethicist Arthur Caplan to discuss how [celebrity cancer narratives](#) can influence patterns of care; they argue that clinicians should become familiar with these narratives and discuss with patients how they might be influencing their views and decisions.

Finally, 2 contributions highlight the role of visuals in combatting or perpetuating false beliefs. Cardiologist and photographer Joseph Gascho dispels the [false belief that physicians do not have time for personal pursuits](#) and self-care by juxtaposing images of physicians wearing white coats with images of physicians engaging in personal pursuits. And AMA archivist Amber Dushman presents images from the AMA Historical Health Fraud and Alternative Medicine Collection that provide insight into [medical quackery](#) and how the AMA responded to particular instances of it.

Finally, the podcast highlights what experts in public policy, innovative physician-scientists, and scientific representatives believe are possible avenues to address the [dissemination of false beliefs in health care](#). McCormick and Diane E. Griffin of Johns Hopkins Bloomberg School of Public Health and Albert I. Ko of the Yale School of Public Health will share theoretical, practical, and personal perspectives to address this emerging issue.

We hope that this theme issue provides fresh perspectives on false beliefs in medicine, as technology and crowdsourced online resources that tend to enable their rapid propagation are here to stay. New challenges include ways to appropriately utilize and regulate the vast amount of data and web-based information readily available, which can interfere with patient-physician relationships. This issue highlights how clinicians and educators can address these challenges by striving to form productive alliances with patients and by motivating patients' and students' critical thinking about the information they consume to prevent false beliefs' propagation in communities.

## References

1. Woolf SH. The price of false beliefs: unrealistic expectations as a contributor to the health care crisis. *Ann Fam Med*. 2012;10(6):491-494.
2. Kahan JP, Park RE, Leape LL, et al. Variations by specialty in physician ratings of the appropriateness and necessity of indications for procedures. *Med Care*. 1996;34(6):512-523.
3. Hutchings A, Raine R. A systematic review of factors affecting the judgments

produced by formal consensus development methods in health care. *J Health Serv Res Policy*. 2006;11(3):172-179.

4. Greenhalgh T, Howick J, Maskrey N. Evidence based medicine: a movement in crisis? *BMJ*. 2014;348:g3725. doi:10.1136/bmj.g3725.
5. Wikimedia Foundation website. <https://wikimediafoundation.org/>. Accessed September 21, 2018.

**Annie J. Tsay, MPH** is a third-year medical student at Penn State College of Medicine in Hershey, Pennsylvania. She majored in public health studies with an emphasis on international health at Johns Hopkins University and earned a master of public health degree in the epidemiology of microbial diseases from the Yale School of Public Health. Her primary interest is in infectious diseases, specifically emerging pathogens and their social implications. Her current research interest is in harmonizing clinical and basic science data to improve patient care and outcomes.

#### **Citation**

*AMA J Ethics*. 2018;20(11):E1003-1006.

#### **DOI**

10.1001/amajethics.2018.1003.

#### **Acknowledgements**

I wish to thank all the contributors to this theme issue and the editorial team at the *AMA Journal of Ethics* for their support in making this issue possible. I would also like to thank my advisor, Jennifer B. McCormick of Penn State College of Medicine, Department of Humanities, who encouraged me to think outside the box and to challenge the status quo and Mary E. Wilson of the University of California, San Francisco School of Medicine and Harvard School of Public Health for insightful comments and guidance. I also wish to thank Glenna M. Wong for unwavering friendship and Todd Felix, Milind Kothari, Eileen Moser, and Terry Wolpaw of the Penn State College of Medicine for support. Finally, I wish to thank George R. Simms, emeritus professor of Penn State College of Medicine, Department of Family and Community Medicine, for motivation and creative inspiration.

#### **Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

**Copyright 2018 American Medical Association. All rights reserved.  
ISSN 2376-6980**

## CASE AND COMMENTARY

### Should a Physician Offer Recommendations Based on Experience but Contrary to Current Practice Guidelines?

Beth A. Lown, MD and Karen E. Victor, MD

#### Abstract

This case of a patient whose physician refuses to prescribe statins for high cholesterol raises ethical issues about a physician's decision to offer clinical recommendations contrary to current practice guidelines. Our response summarizes social forces that have led to the rise of evidence-based medicine, the development of clinical guidelines, and the evolution of the roles of physicians and patients in decision making. We conclude that there are times when a physician can justifiably make a recommendation to a patient that contravenes a current clinical guideline. In making such a recommendation, we suggest that a physician should communicate a rationale for deviating from clinical guidelines and respect a patient's autonomy. We consider the need for and limitations of clinical guidelines, numerous factors influencing shared decision making, and key ethical principles of nonmaleficence and respect for patient autonomy.

#### Case

Mr S is a 50-year-old man who presents to his primary care physician in rural Pennsylvania. He is here to see Dr O for his annual physical examination. Dr O took care of Mr S's parents and now cares for Mr S's wife and their 3 adult children. Mr S has known Dr O for a long time and considers him not just his physician, but a friend.

Mr S and Dr O begin with some social conversation, then discuss his current health and concerns and proceed to the physical exam, which suggests no abnormalities. Dr O reviews Mr S's recent bloodwork. Despite 6 months of lifestyle modifications, Mr S continues to have elevated low-density lipoprotein (LDL) and total cholesterol levels, and lower than normal high-density lipoprotein (HDL) cholesterol. Dr O thinks that Mr S should continue with the current plan and recheck his lipid panel in 6 months. However, Mr S is concerned that his high cholesterol will not significantly improve in another 6 months and asks Dr O, "Shouldn't I be taking statins or some kind of medication for my high cholesterol at this point, Doc?" Dr O answers as follows: "I don't prescribe statins, which are a class of cholesterol-lowering medications recommended by the American Heart Association. I have taken them myself and experienced terrible muscle pain, which

is a well-documented side effect, to the point where it affected my ability to walk. I have had a couple of other patients who were on statins and stopped taking them because of severe side effects. Given my personal experiences with statins, I've stopped prescribing them altogether. My role as a good physician is to help improve your quality of life, not worsen it. Statins negatively affected my quality of life and I think they will negatively affect yours, too. Rather than statins, I recommend that you continue with lifestyle changes including increased exercise and a low-fat diet."

Mr S sat in silence contemplating his response. Dr O has been his trusted physician for nearly all his adult life, but he wonders why Dr O is recommending something inconsistent with well-established practice guidelines.

### **Commentary**

This case raises 2 fundamental and interrelated issues of doctoring: On what basis should physicians make treatment recommendations? And what is the role of the patient and the physician in formulating treatment decisions? These questions pertain to the epistemology and relational foundations of medicine. Epistemology is a branch of philosophy concerned with sources of knowledge and what constitutes truth. Philosophers diverge on the question of which criteria should be regarded as justifying a belief. Some ("evidentialists") require evidence sufficient to prove that the cause of a phenomenon is not the result of chance.<sup>1</sup> Others ("reliabilists") maintain that a belief is justified if it arises from reliable cognitive faculties and considers the probability of a phenomenon's occurrence.<sup>1</sup> These ideas have important applicability to health care. For example, ideally a physician should make treatment recommendations based, at a minimum, on a thorough understanding of the best available evidence of potential benefits and harms of treatment options while considering the patient's goals, preferences, and social context. A physician also needs to maintain awareness of how his or her own cognitive and affective biases might affect his or her decision making. We conclude that Dr O would be justified in making a recommendation contrary to clinical guidelines if he accomplished all the above and met specific obligations to his patient. We do not believe Dr O met these requirements in this case.

### **Statin Guidelines and Possible Explanations of Dr O's Recommendation**

The relevant guidelines are the 2013 American College of Cardiology/American Heart Association (ACC/AHA) statin guidelines.<sup>2</sup> These guidelines changed the previous risk assessment model and lowered the risk threshold considered sufficient to warrant primary prevention statin therapy to levels below those of other leading international guidelines. Per the ACC/AHA guidelines, statins are recommended for persons without clinical atherosclerotic cardiovascular disease (ASCVD) or diabetes who are 40 to 75 years of age, have LDL cholesterol levels between 70 and 189 mg/dL, and have an estimated 10-year ASCVD risk of  $\geq 7.5\%$ . The guidelines also advise against specific cholesterol target levels, advocating instead for treatment intensity according to risk



category.<sup>2</sup> The US Preventive Services Task Force advises therapy based on the presence of 1 or more CVD risk factors and a 10-year CVD risk of 10% or greater.<sup>3</sup> There is no consensus among national or international guidelines about these recommendations.<sup>4</sup> Disagreement among experts rightfully raises questions among practicing physicians about whether a specific treatment recommendation consistent with one of these guidelines would be based on a justified belief.

The case does not indicate whether Dr O believes there is sufficient evidence to support the ACC/AHA guidelines. Assuming he does and that Mr S falls within recommended treatment thresholds, recommending a statin would be based on Dr O's justified belief that this would be beneficial. Alternatively, suppose Dr O does not agree that sufficient evidence supports the guidelines or is skeptical in view of differences in guideline risk models and treatment thresholds. He would not be obliged to recommend statins in this situation, as a recommendation would not be based, in his mind, on a justified belief. In this case, however, Dr O seems unaware that his exclusive focus on his negative personal experiences with statins may reflect cognitive bias, hijacking his decision-making process and influencing his recommendations. More specifically, his personal experience as a patient may have generated cognitive availability bias (judging a phenomenon as more likely to occur because it springs readily to mind) and base rate neglect (ignoring the known prevalence of a condition because one is focused on a specific case).<sup>5,6</sup> Both possibilities may have led him to weigh the harms of statins more heavily than their benefits. If so, his recommendations would not rest on a justified belief and would be unsupported. It is also possible that Dr O is not familiar with the guidelines.

Regarding the second question about the role of patient and physician in decision making, although Dr O seems genuinely concerned for the patient's quality of life, he fails to integrate the patient's concerns and preferences into his recommendations. This omission does not emerge from issues related to the evidence upon which the guidelines are based. Rather, it may emerge from a physician-centered orientation to decision making, lack of knowledge about the impact of patients' active involvement in their care on health outcomes, or lack of interpersonal and communication skills.

As we discuss next, the challenge of justifying clinical recommendations led to the evolution of clinical practice guidelines.

### **Challenges in the Development of Medical Standards**

The American College of Surgeons published the first professional guidelines regarding cancer care services and fracture management in 1931, followed by the American Academy of Pediatrics, which produced practice guidelines regarding immunizations for children in 1938.<sup>7</sup> After World War II, the evolution of randomized, controlled trials offered new tools to assess the efficacy of newly developed therapeutics.<sup>8</sup> Subsequent expansion of federal funding for research and the expanded role of government as health

care provider, purchaser, and overseer of the public's health contributed significantly to the mandate for standards to ensure the quality of care.<sup>7</sup>

Professional standards review organizations, established in 1972 through amendments to the Social Security Act, enabled the development of data systems that uncovered wide variations in practice and care quality,<sup>7</sup> leading to calls for more rigorous application of research-based evidence to clinical care. David Sackett, acknowledged as the father of [evidence-based medicine](#) (EBM), defined it as "the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients."<sup>9</sup> The practice of EBM involves integrating the physician's clinical expertise (knowledge, proficiency, and judgment acquired through experience and reflective practice) with the best available evidence from systematic research.<sup>9,10</sup> EBM pioneers acknowledged that appropriate variations in practice might arise from physicians' using their clinical judgment and knowledge of patients' circumstances in addition to the results of rigorous research to guide care.<sup>9</sup> Some variations, of course, might arise from lack of awareness of research findings.

Proponents of EBM and clinical guidelines encountered considerable backlash from physicians who objected to formulaic, "cookbook medicine."<sup>9,11</sup> Tensions emerged among those who viewed [evidence-based guidelines](#) as a means to consolidate professional power and others who viewed them as impinging on physicians' autonomy.<sup>12</sup> Nevertheless, the convergence of rapidly expanding medical knowledge, technology, and treatments and the desire to reduce variation and improve quality of care has led to the development of myriad clinical practice and prevention guidelines by medical organizations and specialty societies.<sup>7</sup> The relationship between physicians and guidelines has become even more complex as guidelines have become measures of accountability, enforced and incentivized by insurers, governmental agencies, and the courts.<sup>13</sup>

Physician adherence to guidelines remains low, and interventions to enhance adherence have yielded mixed results.<sup>14,15</sup> One review suggests that this lack of adherence is attributable to multiple factors: skepticism about guidelines in general, lack of familiarity with guidelines, lack of belief that a guideline will result in expected outcomes, presence of contradictory guidelines, and lack of self-efficacy or motivation to implement guidelines.<sup>16</sup> External barriers also impede physicians' adherence to guidelines, including lack of time and resources, organizational constraints, and inability to reconcile patient preferences with guideline recommendations.<sup>14</sup> In this case, it's Dr O's preference, not the patient's, that contradicts current guidelines. This difference in preferences brings us to a discussion of the relational foundations of medicine and how the evolution of the patient-physician relationship has affected decision making.

## Decision Making in the Patient-Physician Relationship

Scholars and researchers have described various models of the patient-physician relationship and proposed recommendations about what might be “ideal,” particularly regarding the decision-making process.<sup>17</sup> For years, the beneficent *paternalistic* model prevailed, with physicians making decisions and presenting patients with information sufficient to obtain assent to the intervention she or he believed best. In the late 20th century, at around the time that the EBM movement was gaining steam, the rise of consumerism and consumer protections motivated patients and physicians to begin considering other approaches that expanded patients’ involvement in making decisions about their medical care.<sup>17</sup>

Although many models of the patient-physician relationship have been proposed, we discuss two here. In the *informative* model, the physician serves as a technical expert who provides relevant information and implements the patient’s choice of treatment.<sup>17</sup> This model overlooks the physician’s need to participate in decisions in caring relationships with patients and patients’ needs to feel they have a supportive guide when decisions are difficult.<sup>18,19</sup> The *shared decision making* model evolved to address how to find balance between physician power and patient choice.<sup>20</sup> The process involves, at a minimum, sharing of information and preferences by both physician and patient and an attempt to reach a shared understanding about the nature of the problem and what to do.<sup>20,21</sup> The physician’s [communication tasks in shared decision making](#) include building a partnership with the patient (or family); understanding the patient’s social circumstances, preferences, and expectations; and providing information about the patient’s condition as well as the benefits and potential harms of available treatments. Communication tasks also include discussing uncertainty about how available research evidence might apply to the patient, explaining the rationale for one’s recommendations, checking for understanding, and reaching agreement with the patient about how to proceed.<sup>22-25</sup> [Applying population-based guidelines to an individual patient](#) while integrating a patient’s preferences can be daunting. This task, however, is the essence of patient-centered care.<sup>26</sup>

The steady increase in people accessing medical information on the internet is changing the physician-patient relationship. For example, research based on the 2015 Health Information National Trends Survey notes that, among all racial groups, the internet is the most utilized first source of health information; health care practitioners come in second.<sup>27</sup> Mr S, who wonders why his physician is recommending “something inconsistent with well-established practice guidelines,” probably read about them on the internet if he did not receive information about them from Dr O. Physician responses to patients asking about health-related internet information have been mixed. Some are threatened, some view interpretation of this information as their responsibility, and others view it as an opportunity for partnership, particularly with activated patients.<sup>28,29</sup> Researchers define patient “activation” as having the knowledge, skills, and confidence

to manage one's health.<sup>30</sup> They posit that positive health behaviors emerge, in part, from actively seeking information to inform choices and behavior change.<sup>31</sup> Current evidence suggests that highly activated patients are significantly more likely to be aware of treatment guidelines for their condition and have improved health outcomes compared with less activated patients.<sup>31,32</sup>

### **The Physicians' Obligations and the Patient's Options**

Dr O has several obligations. He is obligated to remain informed about developments in medical knowledge, treatments, and guidelines. He is obligated to be self-aware and transparent. Dr O should acknowledge—to himself and to his patients—areas in which he has overwhelming cognitive and affective biases and that his personal experience may not be generalizable to others. Of course, biases are not always accessible to our conscious awareness, which makes acknowledging them and uncoupling them from decision making difficult.<sup>6</sup> Dr O is also obligated to respect patient autonomy and to involve the patient in decisions when the patient so desires. He should acknowledge that Mr S may weigh the potential benefits and harms of a statin differently than he does. Dr O might choose to say something like this: "First and foremost, I want you to enjoy good health. The research I'm aware of supports recommending a statin in your case to reduce your risk of cardiovascular disease. Some people who take statins develop muscle pains, which is a known side effect. My own experiences with muscle pains while on statins have made me sensitive to that problem, but the published statistics say that most patients take statins without any problems. What's most important is how *you* weigh the benefits and harms of taking a statin. Let's talk about that and make a decision about what might be best for you."

If, however, Dr O has reviewed the research and disagrees with the guidelines (because he believes the evidence is flawed, for example), has addressed any personal biases influencing his interpretation of the data, and has explained the reasoning behind his recommendations to the patient, he is not obligated to prescribe a medication or follow guidelines which he believes, professionally, are not in the best interest of his patient.<sup>33</sup> Under these circumstances, he can choose, following the ethical principle of nonmaleficence, to "do no harm."

Mr S is an informed, activated patient who is perplexed by his physician's deviation from recommended guidelines. What might he do in this situation? Mr S might respond to Dr O's recommendations by saying, "I appreciate that you are looking out for me, but I'm still worried about having a heart attack or stroke. Is there someone else I could talk to who might have a different opinion?" Or, if highly activated, he might say, "I'm willing to try a statin medication, even though you're not enthusiastic about prescribing one." However, unless Dr O explicitly invites his input, Mr S might simply contemplate Dr O's bias and wonder if it is time to change physicians.

### **Obligations, Evidence-Based Guidelines, and the Physician-Patient Relationship**

The convergence of EBM and incentivized guidelines, patient-centered care, and shared decision making, consumerism, and patient engagement is changing our concepts of agency for both patients and physicians. Competent physicians remain well informed about scientific developments and new evidence in their field of practice and strive to be aware of the influence of their cognitive and affective biases. They are obliged to provide high-quality care and to uphold the ethical principles of beneficence, nonmaleficence, and respect for autonomy and to do so within the context of caring, compassionate relationships. For reasons perhaps not fully elucidated, Dr O was unable to fulfill these obligations. We do not agree with his decisions or recommendations but would hope to discuss this with him if he were a colleague.

In summary, in cases in which physicians recommend deviating from a guideline, they are obligated to ensure, to the best of their ability, that their recommendations are based on justified belief, not driven by bias or conflict of interest. They are obligated to present clear information about risks and benefits of available treatment options and alternatives to patients. Physicians and patients may then share the responsibility to reach agreement on decisions that are best for the patient. Done well, clinical decision making integrates the physician's expertise, the best evidence relevant to the patient's needs, and the patient's preferences to arrive at a shared plan. Ultimately, of course, the patient is responsible for the decision about whether to act on the plan.

### **References**

1. Lemos N. *An Introduction to the Theory of Knowledge*. Cambridge, UK: Cambridge University Press; 2007.
2. Stone NJ, Robinson JG, Lichtenstein AH, et al; American College of Cardiology/American Heart Association Task Force on Practice Guidelines. 2013 ACC/AHA guideline on the treatment of blood cholesterol to reduce atherosclerotic cardiovascular risk in adults: a report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines. *Circulation*. 2014;129(25)(suppl 2):S1-S45.
3. Pagidipati NJ, Navar AM, Mulder H, Sniderman AD, Peterson ED, Pencina MJ. Comparison of recommended eligibility for primary prevention statin therapy based on the US Preventive Services Task Force Recommendations vs the ACC/AHA guidelines. *JAMA*. 2017;18;317(15):1563-1567.
4. Naylor M, Vasan RS. Recent update to the US cholesterol treatment guidelines: a comparison with international guidelines. *Circulation*. 2016;133(18):1795-806.
5. Croskerry P. The importance of cognitive errors in diagnosis and strategies to minimize them. *Acad Med*. 2003;78(8):775-780.
6. Croskerry P, Singhal G, Mamede S. Cognitive debiasing 1: origins of bias and theory of debiasing. *BMJ Qual Saf*. 2013;22(suppl 2):ii58-ii64.

7. Weisz G, Cambrosio A, Keating P, Knaapen L, Schlich T, Tournay VJ. The emergence of clinical practice guidelines. *Milbank Q.* 2007;85(4):691-727.
8. Bothwell LE, Podolsky SH. The emergence of the randomized, controlled trial. *N Engl J Med.* 2016;375(6):501-504.
9. Sackett DL, Rosenberg WMC, Gray JAM, Haynes RB, Richardson WS. Evidence based medicine: what it is and what it isn't. *BMJ.* 1996;312. doi:10.1136/bmj.312.7023.71.
10. Epstein RM. Mindful practice. *JAMA.* 1999;282(9):833-839.
11. Sur RL, Dahm P. History of evidence-based medicine. *Indian J Urol.* 2011;27(4):487-489.
12. Smith R, Rennie D. Evidence based medicine—an oral history. *BMJ.* 2014;348:g371. doi:10.1136/bmj.g371.
13. Timmermans S. From autonomy to accountability: the role of clinical practice guidelines in professional power. *Perspect Biol Med.* 2005;48(4):490-501.
14. Chan WV, Pearson TA, Bennett GC, et al. ACC/AHA special report: clinical practice guideline implementation strategies: a summary of systematic reviews by the NHLBI Implementation Science Work Group: a report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. *J Am Coll Cardiol.* 2017;69(8):1076-1092.
15. Flodgren G, Eccles MP, Shepperd S, Scott A, Parmelli E, Beyer FR. An overview of reviews evaluating the effectiveness of financial incentives in changing healthcare professional behaviours and patient outcomes. *Cochrane Database Syst Rev.* 2011;(7):CD009255.
16. Cabana MD, Rand CS, Powe NR, et al. Why don't physicians follow clinical practice guidelines? A framework for improvement. *JAMA.* 1999;282(15):1458-1465.
17. Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. *JAMA.* 1992;267(16):2221-2226.
18. Quill TE, Brody H. Physician recommendations and patient autonomy: finding a balance between physician power and patient choice. *Ann Intern Med.* 1996;125(9):763-769.
19. Quill TE, Cassel CK. Nonabandonment: a central obligation for physicians. *Ann Intern Med.* 1995;122(5):368-374.
20. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med.* 1997;44(5):681-692.
21. Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Soc Sci Med.* 1999;49(5):651-661.
22. Epstein RM, Alper BS, Quill TE. Communicating evidence for participatory decision making. *JAMA.* 2004;291(19):2359-2366.

23. Towle A, Godolphin W, Greenhalgh T, Gambrill J. Framework for teaching and learning informed shared decision making. *BMJ*. 1999;319(7212):766-771.
24. Lown BA, Clark WD, Hanson JL. Mutual influence in shared decision making: a collaborative study of patients and physicians. *Health Expect*. 2009;12(2):160-174.
25. Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med*. 2012;27(10):1361-1367.
26. Epstein RM, Street RL Jr. The values and value of patient-centered care. *Ann Fam Med*. 2011;9(2):100-103.
27. Nguyen AB, Robinson J, O'Brien EK, Zhao X. Racial and ethnic differences in tobacco information seeking and information sources: findings from the 2015 Health Information National Trends Survey. *J Health Commun*. 2017;22(9):743-752.
28. Eysenbach G, Jadad AR. Evidence-based patient choice and consumer health informatics in the Internet age. *J Med Internet Res*. 2001;3(2):e19. doi:10.2196/jmir.3.2.e19.
29. McMullan M. Patients using the Internet to obtain health information: how this affects the patient-health professional relationship. *Patient Educ Couns*. 2006;63(1-2):24-28.
30. Hibbard JH. Patient activation and the use of information to support informed health decisions. *Patient Educ Couns*. 2017;100(1):5-7.
31. Hibbard JH. Using systematic measurement to target consumer activation strategies. *Med Care Res Rev*. 2009;66(1)(suppl):S9-S27.
32. Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Aff (Millwood)*. 2013;32(2):207-214.
33. Morris AH, Ioannidis JPA. Limitations of medical research and evidence at the patient-clinician encounter scale. *Chest*. 2013;143(4):1127-1135.

**Beth A. Lown, MD** is a general internist affiliated with Mount Auburn Hospital in Cambridge, Massachusetts. She is also an associate professor of medicine at Harvard Medical School and the chief medical officer of the Schwartz Center for Compassionate Healthcare. Her professional interests include health professional education, empathy and compassion, health care communication, and organizational change.

**Karen E. Victor, MD** is a general internist at Mount Auburn Hospital in Cambridge, Massachusetts, and an assistant professor of medicine at Harvard Medical School in Boston. Her professional interests include patient engagement and communication between patients and physicians.

**Editor's Note**

The case to which this commentary is a response was developed by the editorial staff.

**Citation**

*AMA J Ethics.* 2018;20(11):E1007-1016.

**DOI**

10.1001/amajethics.2018.1007.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*



## CASE AND COMMENTARY

### How Should Clinicians Address a Parent's False Belief Generated by Denial or Grief About How to Care Well for a Child?

Conrad Krawiec, MD and Benjamin Levi, MD, PhD

#### Abstract

Parents of children with complex health needs are often both vigilant and very knowledgeable about their child's disease state. That said, sometimes parents' hyperfocus, combined with their strong emotional attachment, can result in both false beliefs regarding their child's capacities and disagreements with clinicians about what is and is not clinically indicated. We examine ethical and professional responsibilities clinicians should consider when working with parents who hold false beliefs about their child with complex health needs.

#### Case

Joan K is a 10-year-old with Lennox-Gastaut syndrome, which entails recurrent seizures, severe cognitive and developmental deficits, and often progressive difficulties with swallowing.<sup>1</sup> Joan's mother, Ms K, is a single parent and has always been her daughter's primary caregiver. Despite Joan's developmental and motor deficits, she has been able to eat and maintain normal height and weight—which her mother believes is due to herbal supplements she includes in Joan's diet. For the third time in 6 months, however, Joan has been diagnosed with pneumonia and is now hospitalized for respiratory distress. It is apparent to the clinical team that Ms K, a licensed nurse practitioner, is devoted to meeting her daughter's needs, but also that Ms K has a view of her daughter that is at odds with Joan's actual abilities. The disconnect comes to a head when a nurse comes to Joan's bedside to administer intravenous antiseizure medication.

Ms K objects, stating, "No, Joan takes this as a paste. I crush the pills, mix them with water, and spoon feed her."

When the nurse responds, "I can't do that if she's having difficulty swallowing," Ms K states matter-of-factly that Joan leads a normal life and has no trouble swallowing. "I have been doing this for years, and there's no reason to change now."

The young attending physician, Dr D, overhears this exchange and intervenes. "Ms K, as I think you know, difficulty swallowing is a sign of Lennox-Gastaut syndrome progression<sup>2</sup> and could be the underlying reason for her recurrent pneumonia. We can do a swallow

study to see if that's the case. But, in the meantime, your daughter needs her medication to control her seizures—particularly since she still has a fever. Given Joan's respiratory distress and risk for aspiration, the medicine is best given intravenously." Ms K grudgingly agrees, and over the next few days Joan responds well to the antibiotics. A subsequent swallow study shows significant dyscoordination and aspiration.

When Dr D recommends placing a feeding tube prior to discharge, Ms K responds, "Joan doesn't need a feeding tube. I'm a nurse, and I can take care of her just fine the way she is."

Dr D wonders what to say next.

### **Commentary**

Typically, surrogate decision makers' responsibility is to consider what their loved ones would choose if they had decisional capacity. But for patients who have never had the ability to formulate their own values or express autonomous preferences (which includes young children and persons with severe, life-long neurological impairment), such substituted judgment is not possible. For Joan, this means that her mother (Ms K) has needed to make health care decisions based on what she thought was in Joan's best interests.<sup>3</sup> Because many parents like Ms K devote their lives to caring for and protecting their children, they rightly can be considered experts regarding their child's condition.<sup>4</sup> By respecting this expertise, health professionals can gain parents' trust and reach a shared understanding with parents of what is best for the child.<sup>5</sup>

In some cases, however, conflict is unavoidable, particularly when parents' requests run counter to best practice. On its face, Ms K's [objection to the feeding tube](#) appears to be mostly an "emotionally grounded belief" that is resistant to evidence.<sup>6</sup> Ms. K has devoted her life to taking care of Joan and might see her daughter's ability to eat as not only a means of nourishment but also a measure of success. If so, a change in Joan's nutritional situation coupled with the team's recommendation of a feeding tube might trigger both distress and counterproductive reactions for Ms K, as parents who perceive their role as important prefer to be involved in treatment decision making and can be distressed by the need for further intervention.<sup>7,8</sup> Assuming that the clinical team's clinical assessment is accurate, Ms K is clinging to a (now) false belief and unrealistic expectation that she can continue to feed her child without risking Joan's well-being.

Faced with this kind of situation, clinicians should exercise caution to avoid straining their relationship with the parent, which is needed (long term) to promote effective care. Here we will discuss how clinicians can support a parent while ensuring that the child with complex needs is protected from harm. We will highlight how to address false beliefs, engage in shared decision making, take a multidisciplinary approach to communication, and deal with the ethical challenges of conflicts engendered by false beliefs.

### **How Should Clinicians Address a False Belief?**

When faced with a clinical situation like this, the team must practice both the art and the science of medicine. This requires exercising compassion, sound medical reasoning, and strong interpersonal and partnering skills. Developing effective partnerships with surrogate decision makers usually involves shared decision making, which allows surrogate decision makers' values and preferences to be considered without displacing the patient from being the focus of care.<sup>9</sup> Because parents of a child who has never had the ability to express preferences typically know their child best *and* have decision-making authority, it makes sense to rely on them to achieve patient-centered care, whereby care is individualized in light of the patient's unique situation. But parents' decision-making authority is predicated on their acting in the best interests of the child, particularly for major health decisions.<sup>10</sup> Accordingly, to engage in shared decision making, Joan's clinical team has a complex set of responsibilities: (1) to truly understand and appreciate Ms K's perspective; (2) to engage Ms K respectfully while assessing her and Joan's specific needs and preferences; (3) to share the information needed to make patient-centered decisions, clearly explaining what is known, what is uncertain, and what are the risks, benefits, and likely consequences of different plans of treatment; and (4) to share in deliberations with Ms K about which option is best for Joan. Here, we discuss responsibilities 1, 2, and 4.

*Understand Ms K's perspective.* To begin, the team should recognize that Ms K could be struggling to reconcile the objective health data with her desire to maintain established behavior patterns in Joan's life. Additionally, Ms K's training as a nurse might lead to some role confusion, insofar as it blurs the line between "caring for" Joan and "treating" Joan. It is precisely because personal feelings can influence one's professional judgment that clinicians are strongly advised against **treating family members**.<sup>11</sup> As such, the team should affirm Ms K's expertise and role as Joan's advocate but also help Ms K appreciate that her emotional attachment to Joan could be compromising her objectivity.

*Engage Ms K respectfully.* Clinicians are under no obligation to provide futile treatment, even when demanded.<sup>12</sup> But, for Joan, the question is whether treatment—the feeding tube—can be imposed over and against her mother's objection. The team's responsibilities to treat Joan originated with the patient-physician relationship that was established when Ms K brought Joan to the hospital for care. It being determined that Joan's swallowing dysfunction puts her at high risk for multiple complications if oral feeding is continued,<sup>13,14</sup> the question arises whether there is a reasonable alternative to placing a feeding tube. If not, the team has a professional and ethical responsibility to ensure that Joan receives appropriate care in the form of a feeding tube.

For most parents, feeding their child is a profoundly meaningful activity. Acknowledging this value and how emotionally fraught it can be for some parents to consent to a feeding tube can be helpful. Doing so might validate Ms K's reluctance to give consent without

discounting the clear need to protect Joan. By pointing to the natural course of Lennox-Gastaut syndrome,<sup>2</sup> the team can further commend Ms K for her years of hard work and her ability to continue to feed Joan until now.

If Ms K holds firm to her (arguably) false belief about the safety of continued oral feeding, it would be important to explore the origins of this belief. Is it rooted in fear? Misunderstanding? Guilt? Magical thinking? Does Ms K need to have the health data presented in a different way?

*Engage in shared decision making.* Because people sometimes process information quite differently, the team might need to reconsider how best to explain Joan's worsening condition. It is easy to mistakenly assume that a parent interprets clinical information in the same way as clinical team members, especially when the parent is a fellow health professional. It can be particularly helpful to absolve Ms K of any self-imposed culpability by reminding her that Joan's current condition reflects the disease process, not any failing on her part. The central message should embody a reasoned, evidence-based assessment of Joan's present condition, combined with an empathic recommendation for treatment and a clear explanation of the potential consequences of declining a feeding tube.

Shared decision making involves engaging Ms K not only to assess her understanding but also to convey respect and [build trust](#). Many intractable conflicts can be traced to breakdowns in communication and trust, which lead to mistaken assumptions, suspicion, and often vilification on either side. Without trust, the entire clinical enterprise breaks down, as clinicians can no longer rely on the information provided by patients and families, who in turn dismiss clinicians' recommendations for treatment. With this in mind, social workers and case managers often can play an important role in helping everyone involved work as a team to promote Joan's well-being.

### **How Should Clinicians Respond if Parents' Refusal of Recommended Treatment Endangers a Child?**

Although respectful, empathic engagement will resolve most conflicts, there are instances in which disagreement persists. In these situations, the issue is whether the potential harm to the child is sufficient to warrant overriding the parents' decision.<sup>15</sup> Parents are not required, or even expected, to make decisions that prioritize a child's interests over and against all other interests. Parents' decisions invariably take into account the interests of a child's siblings, those of their community, and even their own interests. Ethical, social, and legal norms, however, demand that children be protected from significant, undue harm; protections for children in the United States include the mandate to report abuse or neglect.<sup>16,17</sup>

In the present case, if Ms K persistently refuses a feeding tube for Joan, the team must

decide whether the risk and severity of harm are great enough to constitute **medical neglect**.<sup>18</sup> When to report possible child abuse or neglect is a complex question.<sup>18</sup> If a clinician has “reasonable suspicion” that a child is being abused or neglected, there is an ethical and legal obligation to make a report to child protective services.<sup>19</sup> While there is no specific definition for what counts as “reasonable suspicion,” a good rule of thumb is that physicians should report whenever they either *believe* or have the nagging feeling that abuse might have happened or is likely to happen.<sup>20</sup> It would count as neglect if a parent’s failure to adhere to prescribed care causes (or creates significant risk for) serious harm to the child.<sup>21</sup> Accordingly, Ms K needs to understand that her continued refusal of a feeding tube would constitute neglect because it puts Joan at risk for repeated aspiration and life-threatening respiratory compromise.<sup>13,14</sup> That said, invoking “neglect” has the potential to undermine the team’s relationship with Ms K. Hence, careful consideration is needed about how to frame the concern about neglect and when to introduce it. Because case managers and social workers are often very skilled at handling emotionally charged situations and nuanced relationships, they can be very helpful in resolving disputes involving **refusal of recommended treatment**. Although it can be helpful to consult with child abuse specialists or social workers experienced in such cases, ultimately the clinician with the concern is responsible for the decision to report.

If, despite the team’s best efforts, Joan’s mother continues to refuse placement of a feeding tube, medical neglect would need to be reported to child protective services.<sup>22</sup> Ideally, such a report would not only ensure Joan’s safety but also initiate social services that would help Ms K provide care to Joan.

In acting to ensure Joan’s well-being, the team should also do its best to address Ms K’s own needs and concerns. Relationships between parents and health professionals are often strained by the need to report neglect. That said, these relationships are more likely to be preserved when clinicians are transparent about their actions and motivations and respond empathically to parents’ reactions, which often include anger, sadness, and frustration. Compassion and reinforcement of shared goals concerning Joan’s well-being might help Ms K better appreciate both the reality of Joan’s condition and the team’s need to act. It also might be helpful to acknowledge that we all lose perspective at times, be it from exhaustion or the intense focus required to care for children with complex medical needs—and that even the most competent, knowledgeable, and caring people need outside, expert direction at times.

### **Strategies for Engaging Parents About False Beliefs**

Parents of children with complex medical needs are typically knowledgeable and well positioned to help guide care for their child. Various circumstances can compromise their ability to make sound health decisions for their child, however, including holding a fixed false belief. When a false belief leads to disagreements about necessary treatment, the

team needs to respectfully engage the parent in discussion, provide education and support to help the parent make sound decisions, focus discussion on everyone's shared interests in the child's well-being, and, when necessary, exercise its authority to protect vulnerable children from harm.

## References

1. Gallop K, Wild D, Verdian L, et al. Lennox-Gastaut syndrome (LGS): development of conceptual models of health-related quality of life (HRQL) for caregivers and children. *Seizure*. 2010;19(1):23-30.
2. Ogawa K, Kanemoto K, Ishii Y, et al. Long-term follow-up study of Lennox-Gastaut syndrome in patients with severe motor and intellectual disabilities: with special reference to the problem of dysphagia. *Seizure*. 2001;10(3):197-202.
3. Macklin R. Return to the best interests of the child. In: Gaylin W, Macklin R, eds. *Who Speaks for the Child: The Problems of Proxy Consent*. New York, NY: Plenum Press; 1982:265-301.
4. Woodgate RL, Edwards M, Ripat JD, Borton B, Rempel G. Intense parenting: a qualitative study detailing the experiences of parenting children with complex care needs. *BMC Pediatr*. 2015;15(1):197. doi:10.1186/s12887-015-0514-5.
5. McCann D. Parenting children with complex needs [published online ahead of print December 30, 2015]. *J Child Health Care*. doi:10.1177/1367493515624008.
6. Halpern J. When concretized emotion-belief complexes derail decision-making capacity. *Bioethics*. 2012;26(2):108-116.
7. Pyke-Grimm KA, Stewart JL, Kelly KP, Degner LF. Parents of children with cancer: factors influencing their treatment decision making roles. *J Pediatr Nurs*. 2006;21(5):350-361.
8. Miller VA, Luce MF, Nelson RM. Relationship of external influence to parental distress in decision making regarding children with a life-threatening illness. *J Pediatr Psychol*. 2011;36(10):1102-1112.
9. Kon AA, Davidson JE, Morrison W, Danis M, White DB. Shared decision making in intensive care units: an American College of Critical Care Medicine and American Thoracic Society policy statement. *Crit Care Med*. 2016;44(1):188-201.
10. Baumrucker SJ, Sheldon JE, Stolick M, Morris GM, Vandekieft G, Harrington D. The ethical concept of "best interest." *Am J Hosp Palliat Care*. 2008;25(1):56-62.
11. American Medical Association. Opinion 1.2.1 Treating self or family. *Code of Medical Ethics*. <https://www.ama-assn.org/delivering-care/treating-self-or-family>. Accessed April 18, 2018.
12. Misak CJ, White DB, Truog RD. Medically inappropriate or futile treatment: deliberation and justification. *J Med Philos*. 2016;41(1):90-114.
13. Kim JS, Han ZA, Song DH, Oh HM, Chung ME. Characteristics of dysphagia in children with cerebral palsy, related to gross motor function. *Am J Phys Med Rehabil*. 2013;92(10):912-919.

14. Sullivan PB. Gastrointestinal disorders in children with neurodevelopmental disabilities. *Dev Disabil Res Rev*. 2008;14(2):128-136.
15. Diekema DS. Parental refusals of medical treatment: the harm principle as threshold for state intervention. *Theor Med Bioeth*. 2004;25(4):243-264.
16. Child Welfare Information Gateway; Children's Bureau. Mandatory reporters of child abuse and neglect. <https://www.childwelfare.gov/pubPDFs/manda.pdf>. Published August 2015. Accessed April 2, 2018.
17. Holder AR. Circumstances warranting court-ordered medical treatment of minors. In: *American Jurisprudence Proof of Facts*. Vol 24. 2nd ed. Rochester, NY: Lawyers Cooperative Publishing; 1980:169-210.
18. Levi BH, Loeben G. Index of suspicion: feeling not believing. *Theor Med Bioeth*. 2004;25(4):1-34.
19. Levi BJ, Portwood SG. Reasonable suspicion of child abuse: finding a common language. *J Law Med Ethics*. 2011;39(1):62-69.
20. Levi BH, Crowell K. Child abuse experts disagree about the threshold for mandated reporting. *Clin Pediatr (Phila)*. 2011;50(4):321-329.
21. Keeshin BR, Dubowitz H. Childhood neglect: the role of the paediatrician. *Paediatr Child Health*. 2013;18(8):e39-e43. doi:10.1093/pch/18.8.e39.
22. Jenny C; Committee on Child Abuse and Neglect, American Academy of Pediatrics. Recognizing and responding to medical neglect. *Pediatrics*. 2007;120(6):1385-1389.

**Conrad Krawiec, MD** is a pediatrician, internist, pediatric critical care physician, and member of the Division of Pediatric Critical Care Medicine at Penn State Health Children's Hospital in Hershey, Pennsylvania. His research focuses are on improving the care of critically ill pediatric patients with pulmonary disease and the medical education of all learners within his institution.

**Benjamin Levi, MD, PhD** is a philosopher and pediatrician in the Division of General Academic Pediatrics at Penn State Hershey Medical Center and the Department of Humanities at Penn State College of Medicine in Hershey, Pennsylvania. His research focuses on human decision making, with particular attention to reporting suspected child abuse and advance care planning for adults.

#### **Editor's Note**

The case to which this commentary is a response was developed by the editorial staff.

#### **Citation**

*AMA J Ethics*. 2018;20(11):E1017-1024.

**DOI**

10.1001/amajethics.2018.1017.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*



**CASE AND COMMENTARY**

**How Should a Physician Counsel a Vegan Patient With IBD Who Might Benefit From Supplements?**

Elizabeth Southworth and Kayhan Parsi, JD, PhD

**Abstract**

Veganism has grown in popularity in recent years. We argue that physicians should share the best available evidence on the efficacy of such diets while respectfully trying to understand the perspectives of patients who choose vegan diets. The first section establishes the need for physicians to understand reasons behind patients' dietary and health preferences. The second section considers evidence, or lack thereof, for nutritional supplementation in special populations, such as those practicing veganism.

**Case**

Kate is a 29-year-old with inflammatory bowel disease (IBD) who has visited her family physician, Dr C, about involuntary weight loss, fatigue, agitation, and lethargy over the past month. As an animal lover, Kate adopted a vegan diet a little over 6 months ago after watching a documentary about veganism's environmental benefits. She also brought a copy of an article published by the Academy of Nutrition and Dietetics that states that a well-planned vegan diet "can be healthful, nutritionally adequate and may provide health benefits in the prevention and treatment of certain diseases."<sup>1</sup> The article also spoke about the health benefits of a vegan diet, including decreased risk for type 2 diabetes, high cholesterol, and hypertension. Kate is devoted to maintaining a vegan diet and has never felt better, until recently.

"Well, Kate, your bloodwork from last week looks pretty normal except for your iron, calcium, and folic acid levels. I think these below-normal numbers might point to the reasons why you feel tired," notes Dr C.

"That's good. So what kinds of vegan foods can I eat to get those specific nutrients? I really want to stick to my diet. It's environmentally kind, and I believe it will help me avoid getting diabetes, which runs in my family," says Kate firmly.

"I understand your commitment and fears. The fastest way to get you into the normal range for these nutrients is to have you take iron, calcium, and folic acid supplements," Dr C offers with reassurance.

“But I do not want to take supplements because I have read that supplements can contain animal products. Besides, what’s the evidence that supplements work? I might be better off drinking kombucha tea as a natural way of boosting my energy without interfering with my vegan diet.”

Dr C considers how to respond to Kate.

### **Commentary**

In this case, we have a young patient (Kate) who is a committed vegan. Vegans represent a very small group—about 1% of the US adult population, according to a 2009 poll<sup>2</sup>—who eschew all animal products in their diet. While vegans represent a small portion of the patient population, appropriate nutritional intake of vitamins and minerals and supplementation of nutrients is a critical issue for physicians and vegan patients. Physicians have responsibilities to understand the unique health needs of those who eliminate specific foods from their diets and thus must have a working knowledge of nutrition. To this end, a patient interview should probably begin with an in-depth exploration of that patient’s dietary habits. In taking Kate’s history, it is important for the physician, Dr C, to explore with Kate the values that inform her relationship with food and, if relevant, their connection to her broader sense of spirituality. Many people adopt diets strictly for their own health improvement. Others might do so out of a sense of vanity. Indeed, the fitness industry often markets products by appealing to people’s sense of vanity rather than their desire to pursue a healthy lifestyle. But, in Kate’s case, we have someone committed to veganism because she feels obligated to animals, to the environment, and to her own health.

### **Ethical and Spiritual Reasons for Veganism**

Many activists, scholars, and other individuals espouse a vegetarian or even vegan diet because of their commitment to the welfare of animals. Philosophers such as Mylan Engel have argued forcefully against the meat industrial complex (that is, the large-scale industrialization of meat processing).<sup>3</sup> They believe that raising, killing, and consuming millions of sentient animals is immoral *per se* and should be abandoned for a plant-based diet. If Kate subscribes strongly to an ethical commitment to animals, Dr C should ask about her commitment.

Environmental stewardship can also motivate individuals to adhere to veganism. The meat industry has a large carbon footprint and is a significant source of greenhouse gases.<sup>4</sup> A vegetarian diet greatly reduces one’s carbon footprint, thus reducing one’s impact on the environment and contribution to greenhouse gas production.<sup>5</sup> Based on these facts, Dr C might understand why Kate would think it reasonable to reduce her carbon footprint and negative impact on the environment through a vegan diet.

For many committed vegetarians and vegans, an ethical commitment to animals and to their own better health is part of their [spiritual framework](#). Indeed, the vegetarian movement was started in the 19th century by people like John Harvey Kellogg, who was a committed Seventh Day Adventist.<sup>6</sup> It would be essential for Dr C to better understand how Kate's veganism is part of her spiritual identity.

At our medical school (Loyola University Chicago Stritch School of Medicine), we have small group sessions on both spirituality and integrative medicine. Medical students learn the importance of gathering a spiritual history that aims to identify sources of support and essential values that the patient holds. Ultimately, this history is used to care for the whole patient and allows a clinical team to consider accommodations and modifications that can be made to a care plan that offers quality care and expresses respect for patient autonomy.

### **Taking a Food History**

Next, Dr C should explore Kate's food history. Dr C might hold a misconception that a vegan diet does not meet common dietary recommendations, but he should recognize that there is no overt risk to the patient simply based on her dietary practices. For clinicians, it is easier to discount a practice that is not well understood or mainstream and even more difficult to support a practice that lacks evidence. In the case of veganism, there are few clinical trials that specifically explore the health effects of vegan diets, which limits our understanding of how veganism impacts health. Some studies that have linked veganism to potential health benefits assert that the mechanism could be an improved microbiota balance.<sup>7</sup> Another observational study, however, demonstrated the need for [supplementation of essential vitamins](#) and minerals in those practicing strict nonmeat, vegan, and lactovegetarian diets, thus illustrating the potential risk of deficiency.<sup>8</sup> Overall, we do not have sufficient scientific data that would irrefutably support a statement for or against veganism (although there exist many anecdotal reports by persons who report greater weight loss and improved health on a vegan diet).

Through a detailed food history, any potential barriers to eating healthy food can be identified. A popular misconception among some patients is that adopting a vegan diet will automatically lead to improved health outcomes. However, following a vegan diet does not necessarily mean "healthy" foods are being consumed. For example, some who practice veganism eat foods high in sugar or that are processed. Exploring what Kate eats on a daily basis would provide Dr C with a better understanding of why her blood levels of calcium, iron, and folic acid are low. Through this history, Dr C would also be able to demonstrate to Kate a commitment to her health and understanding of her values. As a result, Dr C would be able to better tailor nutrition recommendations to Kate based on her vegan diet and to work with her to identify what she would be willing to do to ensure her health is maintained.

### **Supplements and a Physician's Role in Counseling Patients**

Ideally, patients should, and can, consume essential vitamins and minerals through their diet as opposed to relying on the use of supplements. A study in Finland, however, demonstrated an increased need for vitamin D supplementation during the winter months for vegans, which further supports close monitoring of blood levels of vitamins and minerals to prevent overt deficiency.<sup>8</sup> Nevertheless, few situations of extreme deficiency, such as megaloblastic anemia, warrant rapid correction with supplementation, and in this case a more conservative approach could be appropriate. In addition, there is a lack of information about optimal blood levels of many vitamins, making it difficult to interpret subtle deficiency states.<sup>9</sup> Therefore, physicians must take into consideration the full clinical picture before them when counseling a patient with "suboptimal" lab levels and recognize situations in which patient autonomy should be respected with regard to supplementation preferences. In this case, Kate's concern regarding the physician's recommendation for supplementation is 2-fold—she's concerned that the recommended supplements have animal products, and she's also concerned about their efficacy. A cursory search online reveals that many vegan websites recommend paying attention to essential vitamins and minerals. Some of these sites advocate getting essential nutrients through supplements and cite plant-based capsule options. With this knowledge, the physician can educate Kate on available vegan-friendly supplements, if she wishes to take them, to address the lab results.

Considering the nature of Kate's symptoms and her request to avoid supplementation, it might be acceptable either to propose a short course of supplements with purposeful increased dietary intake of foods rich in calcium, iron, and folate or to allow her to try dietary modifications alone with a follow-up appointment to check blood levels. If Kate plans to get pregnant, it is also important for Dr C to understand vitamin recommendations specific to this patient population. Because a deficiency in folate has been linked to neural tube defects in newborns, it is recommended that women of childbearing age maintain appropriate folic acid levels.<sup>10</sup> To this end, many food products, such as cereal, are fortified with folic acid and provide sufficient supplementation to address potential deficiency. Dr C should explore Kate's relationship status and any plans for pregnancy to assess the need for folic acid supplementation, as she might not be consuming fortified foods, and educate her about the health consequences of deficiency.

When addressing Kate's question about efficacy of supplements, Dr C should recognize the complexity of the topic, the history of the supplement industry, and the power physicians have when discussing supplements with patients. Physicians serve as an intermediary between patients and the vast array of medical information available online. Furthermore, they are responsible for distilling medical knowledge, tailoring it to a specific patient's needs, and communicating this information in an effective way. It is the clinician's ethical responsibility to practice evidence-based medicine using the best and most up-to-date data possible.<sup>11</sup> When it comes to the use of supplements, physicians

should have a basic knowledge of nutrition, essential vitamin and mineral deficiencies, and supplement risks and recommendations.

The pharmaceutical industry spends millions of dollars each year on drug discovery, development, and clinical trials regulated by the Food and Drug Administration (FDA). At the root of this process is ensuring patient safety and gathering scientific evidence to inform clinical practice. In contrast, the supplement industry is free of stringent FDA evidentiary standards.<sup>12</sup> Moreover, the supplement industry is “a multibillion-dollar a year industry” with an estimated 85 000 dietary supplements for sale in the US; 50% of Americans take a supplement daily.<sup>13</sup> While supplementation of essential vitamins and minerals in cases of overt deficiency is clinically indicated, in well-nourished adults there is no clear benefit and even potential harm associated with vitamin use.<sup>14</sup> In 2013, the Children’s Hospital of Philadelphia (CHOP) tested Vitamin D drops being given to newborns and found that some formulations contained “more than double” the international units stated on the label, raising concerns about toxicity.<sup>13</sup> Many supplements contain doses that exceed the daily recommended allowance as set by the FDA, and thus dosing must be carefully considered when “prescribing” supplements to patients. A common misperception is that if a certain amount of a supplement is good, then more would be better. Additionally, people might believe that because supplements are “natural,” they are healthy or better than nonnatural substances. This is an example of the naturalistic fallacy.

Finally, identifying reputable supplement companies is essential to ensuring quality and purity of vitamins and minerals that physicians endorse through their recommendations. Informed consent requires a physician to disclose risks and benefits of and alternatives to any proposed treatment or intervention. If Kate’s vegan diet causes certain vitamin deficiencies, it’s incumbent upon Dr C to inform Kate about potential risks of these vitamin deficiencies. If the data is uncertain, then that should be shared as well. Because Kate is already skeptical of supplements, it is important that Dr C properly inform her of these risks.

### **A Role for Physician Advocacy in Food Supplementation**

This case can be construed as highlighting issues surrounding the medical field’s lack of scientific understanding about nutrition. In a world of evidence-based medicine, it is difficult for physicians to make [recommendations about supplementation and different diets](#) with few rigorous studies on which to base their clinical decisions. It is the ethical responsibility of the physician and the medical profession to recognize this lack of information and call for research that aims to address questions about different diets and the use of supplements. Due to lack of regulatory oversight of the supplement industry, patients are especially vulnerable to the persistent misconception that overconsumption of supplements can lead to better health outcomes without risk. This is a fallacy that physicians can work to rectify with their patients. There is a growing body

of literature and clinical cases demonstrating that supplements are not harmless interventions. The Drug-Induced Liver Injury Network, a community charged with identifying toxicity associated with herbal products and supplements, found that 20% of liver injuries were due to supplements.<sup>15</sup> It is the physician's responsibility when recommending supplements to determine if good clinical data exist and to weigh the risks and benefits. Physicians promoting supplement use must be open and honest with their patients about the lack of regulation of the supplement industry and disclose risks associated with supplements. Finally, physicians must recognize their own limitations in the area of nutrition. [Nutrition education](#) is only recently getting more attention in the medical school curriculum.<sup>16</sup> Acknowledging scope of practice is important and consulting dietitians when appropriate is essential to quality health care.

### References

1. Caspero A. Building a healthy vegetarian meal: myths and facts. Academy of Nutrition and Dietetics. <https://www.eatright.org/food/nutrition/vegetarian-and-special-diets/building-a-healthy-vegetarian-meal-myths-and-facts>. Published July 20, 2017. Accessed August 21, 2018.
2. Vegetarian Resource Group. How many vegetarians are there? *Vegetarian Journal*. May 15, 2009. <https://www.vrg.org/press/2009poll.htm>. Accessed August 21, 2018.
3. Engel M Jr. The commonsense case for ethical vegetarianism. *Between Species*. 2016;19(1). <http://digitalcommons.calpoly.edu/cgi/viewcontent.cgi?article=2139&context=books>. Accessed May 9, 2018.
4. Center for Sustainable Systems, University of Michigan. Carbon footprint factsheet. <http://css.umich.edu/factsheets/carbon-footprint-factsheet>. Published 2018. Accessed August 23, 2018.
5. Fiala N. How meat contributes to global warming. *Scientific American*. February 2009. <https://www.scientificamerican.com/article/the-greenhouse-hamburger/>. Accessed August 23, 2018.
6. Potter-Dunlop JA, Tse AM. Dietary issues inpatients face with being vegetarian: an integrative review. *Holist Nurs Pract*. 2012;26(1):30-37.
7. Glick-Bauer M, Yeh MC. The health advantage of a vegan diet: exploring the gut microbiota connection. *Nutrients*. 2014;6(11):4822-4838.
8. Outila TA, Kärkkäinen MU, Seppänen RH, Lamberg-Allardt CJ. Dietary intake of vitamin D in premenopausal, healthy vegans was insufficient to maintain concentrations of serum 25-hydroxyvitamin D and intact parathyroid hormone within normal ranges during the winter in Finland. *J Am Diet Assoc*. 2000;100(4):434-441.
9. Dawson-Hughes B. Vitamin D deficiency in adults. UpToDate. <https://www.uptodate.com/contents/vitamin-d-deficiency-in-adults-definition->

- [clinical-manifestations-and-treatment](#). Updated October 25, 2017. Accessed May 9, 2018.
10. Pitkin RM. Folate and neural tube deficits. *Am J Clin Nutr*. 2007;85(1):S285-S288. Accessed August 23, 2018.
  11. American Medical Association. AMA Principles of Medical Ethics. *Code of Medical Ethics*. <https://www.ama-assn.org/sites/default/files/media-browser/principles-of-medical-ethics.pdf>. Revised June 2001.
  12. Dietary Supplement and Education Act of 1994, Pub L No. 103-417, 108 Stat 4325.
  13. Supplements and Safety [video]. *Frontline*. Public Broadcasting Service. January 19, 2016. <https://www.pbs.org/wgbh/frontline/film/supplements-and-safety/>. Accessed May 9, 2018.
  14. Guallar E, Stranges S, Mulrow C, Appel LJ, Miller ER III. Enough is enough: stop wasting money on vitamin and mineral supplements. *Ann Intern Med*. 2013;159(12):850-851.
  15. Navarro V, Khan I, Björnsson E, Seeff LB, Serrano J, Hoofnagle JH. Liver injury from herbal and dietary supplements. *Hepatology*. 2017;65(1):363-373.
  16. Saddick B. Doctors not taught to discuss diet, nutrition with patients. *Chicago Tribune*. August 1, 2016. <http://www.chicagotribune.com/lifestyles/health/sc-doctors-diet-nutrition-health-0803-20160801-story.html>. Accessed May 9, 2018.

**Elizabeth Southworth** is a third-year medical student at Loyola University Chicago Stritch School of Medicine in Maywood, Illinois. Her research interests include medical student leadership, teaching development, and academic medicine.

**Kayhan Parsi, JD, PhD** is a professor and the director of graduate programs in the Neiswanger Institute for Bioethics and Health Policy at Loyola University Chicago Stritch School of Medicine in Maywood, Illinois. His research interests are in clinical ethics, ethics education, global health, media and bioethics, and professionalism and professional ethics.

#### **Editor's Note**

The case to which this commentary is a response was developed by the editorial staff.

#### **Citation**

*AMA J Ethics*. 2018;20(11):E1025-1032.

**DOI**

10.1001/amajethics.2018.1025.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*



## MEDICAL EDUCATION

### Should Crowdsourced, Unvetted Content on Wikipedia Be Used in Health Sciences Teaching and Learning?

Jennifer Meka, PhD and Alyssa Vigliotti

#### Abstract

Internet technology makes information from both peer-reviewed sources and crowdsourced content, such as Wikipedia, instantly accessible. Health sciences education must adapt by providing learners with the skills needed to effectively and appropriately access and use information. In this article, we introduce a conceptual framework for teaching and learning using crowdsourced content. Using this framework, we show how educators can help learners develop the skills they need for critically assessing information quality, acquiring knowledge, and making clinical decisions.

#### Using Digital Sources as a Resource in Medical Education

In our digital age, there is a plethora of medical information of varying reliability instantly available. This phenomenon encouraged the coining of the term “e-health,” which was first defined in 2001 as “the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet.”<sup>1</sup> The World Health Organization redefined this term in 2005 as “the cost-effective and secure use of information and communications technologies [ICT] in support of health and health-related fields, including health care services, health surveillance, health literature, and health education, knowledge and research.”<sup>2</sup> Since the emergence of e-health, it is estimated that 1 in 3 American adults have used the internet to try to figure out a medical condition.<sup>3</sup> The internet is also widely used by children and adolescents, with a significant number of them actively seeking health information online.<sup>4,5</sup>

It is no surprise that current health professions students, many of whom were born in this digital era, are using the internet as a resource throughout their education. Marc Prensky coined the terms “digital natives” and “digital immigrants” to describe those who were born into the digital world and those who were not.<sup>4</sup> He discusses the dichotomy in learning and teaching methodologies between the two groups and argues that educators must “learn to communicate in the language and style of their students” who are digital natives.<sup>4</sup>

Many educators are concerned about students' reliance on crowdsourced information as a starting point for learning. Crowdsourcing is the practice of soliciting group contributions, often from an online community or forum, to guide selection of services or products or to gather ideas and suggestions. Often crowdsourced material, such as that seen on Wikipedia, is anonymous and might not be written by experts. Rather than dissuading students from using such material, we propose helping students learn how to effectively navigate resources such as Wikipedia.

### **The Changing Landscape of Information and Resources**

Students consult online sources for a number of reasons, whether to supplement lecture material, clarify unfamiliar terms or disease processes, or answer an attending physician's questions during rounds. Guidelines are available to students describing how to effectively evaluate websites' merits and reliability. One university's library system has a specific "rubric" to evaluate websites. The rubric suggests appraising the website's currency ("When was the site last updated?"), authority ("Who is the author or creator?"), validity ("Is the information accurate or valid?"), point of view or bias ("What is the website's point of view?"), and audience ("Who was the website created for?").<sup>6</sup> Together, these proposed criteria are intended to help students evaluate important information regarding the accuracy, perspective, and relevance of information on websites, which should inform their decision about whether to use them.

Many medical schools provide students with similar guidance on how to evaluate online information and how to search for online peer-reviewed sources using the UpToDate<sup>®</sup> and PubMed databases. However, even with this guidance, crowdsourced resources such as Wikipedia continue to supplement peer-reviewed sources in students' education. Consider the following experiences students shared with us about using crowdsourced resources.

When I had difficulty understanding a problem-based learning [PBL] case, I would use Wikipedia to get an overall sense of the topic. For example, I struggled initially with learning about Cushing's syndrome. When I first googled Cushing's syndrome, the first link was to Wikipedia. I used that to get an overview of the topic before I went to my other sources (textbooks, Pathoma). I often found Wikipedia was easier to understand than some of my medical textbooks.

I had several apps on my phone to help with drugs and mechanisms of action. However, if the apps weren't working or I was short on time, I would quickly google drugs. I typically did this if I needed information that I thought was common knowledge—drug classes, side effects, etc. I never used Wikipedia for things such as current guidelines or recommendations; I instead referenced UpToDate or the USPSTF [US Preventative Services Task Force] guidelines because I trusted those more.

These examples of students' use of Wikipedia provide both evidence that students are using crowdsourced information throughout medical school and insight into how they are using this information.

Consistent with these examples, one study suggests that Google and Wikipedia are frequently used as starting points for locating information, even though students rate these platforms as having significantly lower quality and reliability than peer-reviewed sources.<sup>7</sup> A 2012 survey conducted at one medical institution found that 94% of medical students reported using Wikipedia, stating its articles were both easy to access and easy to understand.<sup>8</sup> Although ease of access and understandability are typically not used as criteria to determine a website's merit, it appears these criteria are still important for students when they are searching for information online. Although there is little information available as to what medical information students are specifically searching for on Wikipedia, one study found that there was "a significant correlation between the year of medical school and the use of Wikipedia as the initial resource, with older years less likely to use Wikipedia as the first resource,"<sup>8</sup> suggesting that as students progress through their graduate education they rely less on crowdsourced material found online. This evidence of students' use of Google and Wikipedia highlights the need for faculty understanding of when and how students use a variety of information sources to augment their learning.

There has also been some debate as to how accurate crowdsourced resources such as Wikipedia are. Physicians and faculty often dissuade students from using resources like Wikipedia since they appear to be inaccurate and lack a traditional fact-checking system.<sup>9</sup> Anecdotal evidence highlights this theme. One student told us:

I never wrote a paper in college or medical school where I cited Wikipedia because I knew Wikipedia was typically frowned upon. If a student included information in our PBL discussion from Wikipedia, it was usually said in a joking manner. "Oh, I know this is from Wikipedia, but..." It was always qualified first with, "I'm not sure how accurate this is."

Several articles have examined Wikipedia's accuracy. In 2005, the peer-reviewed journal *Nature* compared the accuracy of scientific articles in Wikipedia to those in Encyclopaedia Britannica.<sup>10</sup> While both are considered encyclopedias, Wikipedia is a free online encyclopedia that anyone can edit as compared to an established source such as Encyclopaedia Britannica. Analysis of 42 scientific articles determined that both references contained 4 serious errors.<sup>10</sup> Another review conducted in 2011 on the accuracy of Wikipedia's [medical entries](#) found mixed results.<sup>10</sup> Despite the warnings that crowdsourced resources are unreliable because they contain inaccuracies, such sources continue to be used by students, physicians, and the general public.<sup>10</sup> Medical content on Wikipedia, which contained over 155 000 articles by the end of 2013, was viewed more than 4.88 billion times that year alone.<sup>11</sup> One study even suggests that "the creation of a

Wikipedia article leads scientists to use similar words in later scientific work," which is ultimately influencing the state of scientific literature.<sup>12</sup> This study also found evidence to suggest that the scientific articles referenced in Wikipedia receive more citations, suggesting Wikipedia is a complement to the traditional journal system.

It is clear that, despite this controversy, students use crowdsourced information such as that found on Wikipedia. For this reason, it is helpful for educators to consider how they might best use these resources in their teaching to help learners understand the benefits and pitfalls of using these resources throughout their medical education.

### Frameworks for Incorporating Online Content Into Education

Rather than dwelling on the source, we propose that educators focus on the skills students need for acquiring knowledge in general and for critically appraising the reliability of information presented in the source. When considering reliability, students should be looking at accuracy, consistency, and completeness of information (or "sufficiently sound quality").<sup>13</sup> Several competency models or frameworks are useful for thinking through what [critically appraising knowledge](#) might look like in practice for educators and future clinicians.

The Technological Pedagogical Content Knowledge (TPACK) is a framework that expands on the work of Lee Shulman<sup>14</sup> by including the knowledge beneficial for educators to teach effectively with technology.<sup>15</sup> The TPACK framework brings together 3 primary forms of knowledge necessary for educators to demonstrate: content knowledge (CK), pedagogical knowledge (PK), and technological knowledge (TK) (see table). In effectively combining these 3 forms of knowledge in their teaching, educators can provide optimal learning experiences for students and help learners begin to be cognizant of the best ways to use various resources.

**Table.** Descriptions of Types of Knowledge Presented in the Technological Pedagogical Content Knowledge Framework

Knowledge Area	Types of Knowledge Represented
Content knowledge	"Knowledge of concepts, theories, ideas, organizational frameworks," and knowledge of "established practices and approaches toward developing such knowledge." <sup>16</sup>
Pedagogical knowledge	"Knowledge about the processes and practices or methods of teaching and learning.... This generic form of knowledge applies to understanding how students learn, general classroom management skills, lesson planning, and student assessment." <sup>16</sup> It also includes understanding of the materials, programs, and resources that comprise the curriculum and how to develop and manage the curriculum based on students' needs.

Technological knowledge	"Knowledge about certain ways of thinking about, and working with technology, tools and resources. This includes understanding information technology broadly enough to apply it productively at work and in everyday life, being able to recognize when information technology can assist or impede the achievement of a goal, and being able continually [to] adapt to changes in information technology." <sup>15</sup>
Adapted from Kohler, <sup>15</sup> Kohler, Mishra. <sup>16</sup>	

Shulman discusses the importance of contextual understanding in teaching and learning<sup>14</sup>; this understanding emphasizes the need for educators to have knowledge of the contexts in which learning occurs (eg, classroom, clinic, hospital) and the character of the communities and cultures within which learning occurs. This approach is especially important in dispelling myths that only certain sources can or should be used for learning, especially in health professions education where just-in-time learning is important. Instead of shying away from using nonpeer-reviewed sources throughout health professions education, educators need to understand the context in which students learn and to help students better navigate the digital landscape.

As digital natives move through our health professions programs, it is critical that educators learn from their students how to address students' preferences and needs. In discussing millennials in academic medicine, Waljee<sup>17</sup> describes opportunities for flattening the hierarchy through various mentoring activities. Reverse mentoring is one such approach that serves as an effective way to empower learners. It provides students with opportunities to impart their perspectives, skills, and guidance to more senior colleagues while promoting a collaborative environment.<sup>17</sup> Engaging in conversations about information sources and resources can open a dialogue between faculty and students in which all parties benefit. Moreover, given that patients are likely using some of the same sources of information, using a reverse mentoring approach in discussing these sources can be a powerful learning experience for all and preparation for future practice.

### **Strategies for Moving Forward**

While it is helpful for educators to use the TPACK framework to determine students' current level of knowledge and skills, as we begin to cultivate the additional skills we want students to apply when using online resources, it is equally important for students to take ownership of their learning. Charles Friedman is one educator with a deep interest in how individuals and groups interact with information technology. He has described a 3-competency framework to help prepare health professions students, most of whom are digital natives, navigate their futures as physicians in this digital era.<sup>18</sup> First, it is important that students understand what they do and don't know. Friedman describes a process of "calibration," by which students and clinicians have sense when

they have reached their limit of knowledge and need to seek help.<sup>18</sup> The second competency is the ability to ask a good question. With access to unlimited information, this competency helps to ensure that students are using resources to “improve their incomplete knowledge.”<sup>18</sup> Finally, the third competency highlights the skills necessary to evaluate and weigh evidence and to make clinical decisions based on the strengths or weaknesses of that evidence.

Together, these competencies provide students a solid framework to further their learning and give educators opportunities to be innovative in their planning, instruction, and assessments. The TPACK framework inspires educators to think in practical terms about how students access and use information in their daily practice. This reflective process provides opportunities not only for students but also for educators to respond in ways that foster growth and learning. Ultimately, students’ and educators’ use of nonpeer-reviewed sources is not going away anytime soon. For this reason, we believe it is important for educators to help students feel comfortable and competent navigating nonpeer-reviewed sources throughout their education and future careers. By learning together, we can create effective teaching and learning experiences for all.

## References

1. Eysenbach G. What is e-health? *J Med Internet Res*. 2001;3(2):e20. doi:10.2196/jmir.3.2.e20.
2. World Health Organization. WHA58.28: eHealth. <http://www.who.int/healthacademy/media/WHA58-28-en.pdf>. Published May 25, 2005. Accessed August 24, 2018.
3. Fox S, Jones S. Health online 2013. Washington, DC: Pew Research Center; January 15, 2013. <http://www.pewinternet.org/2013/01/15/health-online-2013/>. Accessed September 20, 2018.
4. Prensky M. Digital natives, digital immigrants. *On Horiz*. 2001;9(5):1-6.
5. Gray NJ, Klein JD, Noyce PR, Sesselberg TS, Cantrill JA. Health information-seeking behaviour in adolescence: the place of the internet. *Soc Sci Med*. 2005;60(7):1467-1478.
6. Penn State University Libraries. Evaluating information rubric. <https://libraries.psu.edu/services/research-help/evaluating-information-rubric>. Accessed August 24, 2018.
7. Judd T, Kennedy G. Expediency-based practice? Medical students’ reliance on Google and Wikipedia for biomedical inquiries. *Br J Educ Technol*. 2011;42(2):351-360.
8. Allahwala UK, Nadkarni A, Sebaratnam DF. Wikipedia use amongst medical students—new insights into the digital revolution. *Med Teach*. 2012;35(4):337.
9. Metcalfe D, Powell J. Should doctors spurn Wikipedia? *J R Soc Med*. 2011;104(12):488-489.

10. Giles J. Internet encyclopaedias go head to head. *Nature*. 2005;438(7070):900-901.
11. Heilman JM, West AG. Wikipedia and medicine: quantifying readership, editors, and the significance of natural language. *J Med Internet Res*. 2015;17(3):e62. doi:10.2196/jmir.4069.
12. Thompson N, Douglas H. Science is shaped by Wikipedia: evidence from a randomized control trial. [https://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=3039505](https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3039505). MIT Sloan School of Management research paper 5238-17. Published September 20, 2017. Updated February 19, 2018. Accessed May 9, 2018.
13. Haigh CA. Wikipedia as an evidence source for nursing and healthcare students. *Nurse Educ Today*. 2011;31(2):135-139.
14. Shulman LS. Knowledge and teaching: foundations of the new reform. *Harv Educ Rev*. 1987;57(1):1-21.
15. Koehler M. TPACK explained [What is TPACK? tab on TPACK website]. <http://tpack.org/>. Published September 24, 2012. Accessed April 16, 2018.
16. Koehler MJ, Mishra P. What is technological pedagogical content knowledge? *Contemp Issues Technol Teach Educ*. 2009;9(1):60-70.
17. Waljee JF, Chopra V, Saint S. Mentoring millennials. *JAMA*. 2018;319(15):1547-1548.
18. Friedman CP, Donaldson KM, Vantsevich AV. Educating medical students in the era of ubiquitous information. *Med Teach*. 2016;38(5):504-509.

**Jennifer Meka, PhD** is the director of the Woodward Center for Excellence in Health Sciences Education and the director of the Cognitive Skills Program at Penn State College of Medicine in Hershey, Pennsylvania, where she is also an assistant professor of psychiatry and humanities. Prior to joining academia, she served for 5 years as vice president for educational systems development at an international company for educational technology. She is interested in designing comprehensive systems for supporting student learning and faculty development to provide the best possible learning experiences for students.

**Alyssa Vigliotti** is a fourth-year medical student at Penn State College of Medicine in Hershey, Pennsylvania, where she is also the vice president of her class. She graduated from New York University with a degree in sociology. As an undergraduate and medical student, she conducted research focusing on pediatric and geriatric populations, and she plans to pursue a career in pediatrics.

**Citation**

*AMA J Ethics.* 2018;20(11):E1033-1040.

**DOI**

10.1001/amajethics.2018.1033.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*



## HEALTH LAW

### Constitutional Regulation of Speech (and False Beliefs) in Health Care

Scott J. Schweikart, JD, MBE

#### Abstract

False beliefs in medicine can be regulated by constitutional doctrines of false speech and professional speech, whereby government can restrict professionals' false beliefs or impose its own false beliefs on professionals. In our allegedly "post truth" society, such regulations and their foundations can have an important influence on health care practice.

#### False Beliefs and Health Care

There has been a resurgence of false beliefs in American society. These false beliefs range from scientific in nature, such as the "flat-earth" paradigm<sup>1</sup>; to the politically motivated and influenced, such as the "birther" movement<sup>2</sup>; to the conspiratorial, such as claims that the moon landings were an elaborate hoax.<sup>3,4</sup> False beliefs have also found their way into health care, sometimes with dire consequences. For example, false beliefs about cures for AIDS have long been problematic<sup>5</sup>; another example is the anti-vaccine beliefs of Somali and Orthodox Jewish communities to which recent measles outbreaks in Minnesota and Los Angeles have been attributed.<sup>6,7</sup>

What happens when health care professionals are sources of false beliefs that influence their practices, patients' care, and public health? How can government regulate clinicians' false beliefs? What if government itself is a source of false belief and compels clinicians to express these beliefs to patients? In this article, I explore these questions from the perspective of American jurisprudence, which, for this issue, is nominally First Amendment constitutional law governing freedom of speech.<sup>8</sup>

#### Government Regulation of Clinicians in the Speech Context

Clinicians are not free to practice without limitations from the government. Health care practice engages constitutional speech, so regulations on clinicians' conduct and practice can be viewed as limitations on their freedom of speech. Although clinician speech on its face is less obvious than speech seen in other more verbally intensive professions, such as the practice of law, when a clinician advises a patient, she is engaging in speech.<sup>9</sup> Viewed through the lens of First Amendment jurisprudence, there are broadly 2 different categories of speech relevant to adjudicating laws and regulations governing clinicians' practices: false speech and professional speech.

*False speech.* False speech is a category of law wherein government regulates and sanctions false statements. Some categories of false statements include fraud, defamation, perjury, and false commercial speech.<sup>10</sup> Government authority to regulate false speech is founded in the squaring of law and morality, which resulted in generally accepted ethical prohibitions against falsehoods being incorporated in the legal sphere.<sup>11</sup> A false statement may be impermissible under regulations or statutes, but there are limitations on [government's authority to restrict false speech](#). The Supreme Court has repeatedly recognized that falsity alone is not enough to warrant regulation and that there must be some extenuated circumstance attached to the falsity—like malice or perjury, for example—for government sanction of false speech to be valid.<sup>12-14</sup>

In the context of health care, consider the situation of a clinician practicing with a false belief—such as the belief that vaccines cause autism—who counsels patients against receiving vaccines. This belief is counter to established evidence-based medicine and causes appreciable harm. For this reason, some legal scholars note that true and false speech regarding scientific facts—such as what might be exchanged during a clinical encounter, for example—should be separate First Amendment speech categories, thereby allowing greater regulation of false scientific speech.<sup>12,15</sup> Scientific speech is different from other kinds of false speech because of the nature of evidence-based logic; that is, it is easier to determine which statements are actually true or false. As Christopher Guzelian explains, “false scientific speech meets the predictable definition of false speech better than other forms of speech because the speech’s falsity is knowable.”<sup>12</sup> Currently, constitutional law that restricts false speech does not take into account this unique aspect of scientific speech—that its truth is verifiable—and is instead a patchwork of rules and standards, such as the standard that public officials must demonstrate that false statements were made with “actual malice” in order to prevail in a defamation suit.<sup>13</sup> This hodgepodge of rules and standards creates unpredictability in determining false-speech liability.<sup>12</sup> Hence, Guzelian argues that scientific speech (which would be largely applicable to health care practice because of the profession’s scientific underpinnings), because of its “knowable” character, should be subject to additional scrutiny and evidentiary standards relative to other forms of false speech (like defamation), thus enabling false scientific speech to be held to account and its liability to be predictable.<sup>12</sup>

*Professional speech.* As opposed to the more general doctrine of false speech, professional speech is directly related to clinicians’ speech, and there is an existing body of case law involving physicians. Claudia Haupt describes professional speech as communication of “insights through the professional to the client, within a professional-client relationship.”<sup>16</sup> A defined professional speech doctrine has not yet been articulated by the Supreme Court, and the degree of First Amendment protection for professional speech currently remains undeveloped and is provisional in nature.<sup>17-19</sup> While the legal

contours of a professional speech doctrine are unclear, there is a body of cases relating to the professional speech of a range of groups, from traditional professionals—such as physicians, nurses, pharmacists, and lawyers—to quasi-professionals, such as fortune tellers.<sup>20,21</sup>

Professional speech cases relevant to clinicians fall into 2 common types. First, there are the cases in which [government imposes a strict ban or limit](#) on certain practices of clinicians, circumscribing how they may practice their profession. This is the most straightforward way government can restrict a professional's practice. Famous recent examples are the homosexual [conversion therapy](#) bans in California and New Jersey. These bans, fundamentally identical in both states, outlawed any clinician from engaging in "reparative" therapies for homosexual minor patients.<sup>19,22,23</sup> Notably, the courts in both cases differed on whether the ban was regulating the "speech" or "conduct" of the therapist, illustrating the debate about whether a clinician's practice is considered speech. The bans were challenged by professionals in both states, who argued that such bans violated their First Amendment freedom of speech rights. The California case went to the 9th Circuit Court of Appeals, where the ban was ultimately upheld in *Pickup v Brown*; the Court upheld the ban as a constitutional restriction on the professional's conduct and did not view the ban as a limit on professional speech.<sup>22</sup> In New Jersey, the case went to the 3rd Circuit Court of Appeals, where, in *King v Governor of New Jersey*, the Court upheld the ban but, differing from the 9th Circuit, viewed the ban as a restriction on professional speech, which is subjected to a higher level of scrutiny.<sup>23</sup> As Timothy Zwick explains, the 3rd Circuit reasoned that the "ban was permissible only if it directly advances the state's substantial interest in protecting minor clients and is not more extensive than necessary to serve that purpose."<sup>19</sup> The 3rd Circuit explained that "the reason professional speech receives diminished protection under the First Amendment [is] because of the State's longstanding authority to protect its citizens from ineffective or harmful professional practices."<sup>23</sup> The Court further explained that the validity of New Jersey's conversion therapy ban (ie, the validity of a state's ability to restrict professional speech) should be reviewed with a level of scrutiny such that the New Jersey legislature, in its attempt to protect its citizens from harmful and ineffective professional practices, has "drawn reasonable inferences based on substantial evidence."<sup>23</sup> The 3rd Circuit ultimately found that the New Jersey legislature met this burden, as there was substantial evidence in the legislative record that conversion therapy was both harmful and ineffective.<sup>23</sup> *King* demonstrates that such bans on professional speech, when weighed against free speech rights of health professionals, can (and should) survive constitutional scrutiny.<sup>23</sup>

The second common type of case regarding physician professional speech is compelled speech, in which the government compels clinicians to express its viewpoint. A classic example of how the state compels professional speech is mandatory ultrasound laws or other similarly penned laws designed to thwart abortion. Many of these laws came after

the Supreme Court's ruling in *Planned Parenthood of Southeastern Pennsylvania v Casey*, which challenged Pennsylvania law requiring disclosure of medical information and alternatives to abortion at least 24 hours before the abortion was performed.<sup>24</sup> David Orentlicher explains that the Supreme Court upheld the law in this case "on the grounds that [Pennsylvania] mandated information that was truthful and nonmisleading and that would make for a fully informed decision by the woman."<sup>25</sup> In this sense, the restriction, though ideologically motivated, was constitutionally valid as a codification of lawful informed consent goals. As Orentlicher notes, "the state need not remain neutral, but was free to promote an interest in the preservation of fetal life, as long as its speech mandates were truthful and not misleading."<sup>25</sup> Another case involving compelled speech is *Planned Parenthood Minnesota, North Dakota, South Dakota v Rounds*, wherein a 3-judge panel on the 8th Circuit struck down an abortion informed consent statute that compelled clinicians to inform patients that women who have an abortion have an increased risk of suicide.<sup>26</sup> The panel noted that no studies or evidence supported an increased risk of suicide and concluded that such a statute "violates doctors' First Amendment right to be free from compelled speech that is untruthful, misleading, or irrelevant."<sup>26</sup> The panel's decision was eventually overturned by an *en banc* decision by the 8th Circuit,<sup>27</sup> but Orentlicher argues that the 3-judge panel got its decision correct, as informed consent mandates "must be truthful and not be misleading [and t]he goal is to inform not misinform."<sup>25</sup> Therefore, in an ideal sense, truthfulness of speech is key for constitutional validity of statutes that compel speech of health professionals. Courts are wise to follow the truthfulness standard set by the Supreme Court in *Casey*, as it allows a clinician to further, rather than hinder, patients making "wise" and "informed" decisions,<sup>24</sup> while a "compelled medical statement that contradicts in unequivocal terms the leading associations of experts in relevant fields does not serve that end."<sup>26</sup>

## Discussion

The battles over restricting clinician speech related to the false beliefs of either clinicians or government become more controversial and high profile when the speech act in question is related to a politicized issue, such as conversion therapy or abortion. However, not all cases of false beliefs in health care are of this type. For example, as noted by Steven Woolf, "[p]hysicians are not immune to false beliefs about clinical efficacy"; studies have shown that "patients, clinicians, and society often hold unrealistic expectations about the effectiveness of tests and treatments," thus creating an "appetite for procedures of dubious effectiveness."<sup>28</sup> In such instances, the forces that help perpetuate the false belief are not so much political as they are economic or psychological.<sup>28</sup>

Additionally, it is important to remember that history has shown that some accepted norms in health care are products of incorrect conclusions that were later found to be wrong. A famous example is the long-held notion that stomach ulcers were caused by stress and anxiety. This notion was refuted by Australian scientists Barry Marshall and

Robin Warren, who proved that ulcers are actually caused by an *H pylori* bacterial infection, not stress.<sup>29</sup> This example serves as a reminder that sometimes clinicians and the medical community get things wrong and that incorrect notions can become, for a time, established norms. In other words, today's established norms (or false beliefs) may become tomorrow's false beliefs (or established norms).

Critics of restrictions on clinician speech might point to the *H pylori* case as a cautionary tale in that what is currently deemed a false belief could actually be true. For example, if a physician treating a patient's ulcer before the *H pylori* discovery had believed in a bacterial cause of stomach ulcers and decided to treat the patient using antibiotics, while eschewing any treatment related to stress or anxiety, such treatment would have been deemed based on a false belief that was not backed by the scientific community. Such a physician would have been providing, at the time, a medically unsupported treatment that would someday become universally supported by the medical profession; the physician would in actuality be a pioneer. In such a scenario, one might argue that any law or regulation that would bar or limit the physician's practice and speech would be unjust and indicative of the hazards of limiting a physician's speech, as doing so could stifle new practice knowledge that is legitimate and necessary.

While the risk of stifled truth always exists, reducing that risk is a joint responsibility of the medical profession and the government. The medical profession needs to continually strive for evidence-based guidelines, and the government should ideally follow and apply the profession's collective wisdom founded on evidence-based knowledge. The government can accomplish this goal via the legislative and executive branches creating laws and regulations that restrict false professional speech and via the judicial branch adequately upholding and applying such rules while striking down or limiting improper ones.

When considering restrictions on scientific speech (like medical speech), larger questions come into view: Is false scientific speech always harmful? Might there be some false scientific speech that is not harmful? The answer is that false scientific speech of professionals is always harmful. This is because, as Claudia Haupt explains, professions are "knowledge communities," meaning that professions are a "network of individuals who share common knowledge and experience as a result of training and practice" and are "engaged in solving similar problems by drawing on a shared reservoir of knowledge, which, at the same time, they help define and to which they contribute."<sup>9</sup> If knowledge upon which a profession builds its foundation is flawed or incorrect, then the profession cannot perform its services to society as intended. This is especially true of the scientifically based professions, like medicine, wherein the foundational knowledge is biologically based science. If the medical professional is operating under false scientific principles, the result is harmful; at best, the resultant flawed treatments will be ineffective, at worst, such flawed treatments can directly injure patients.

The uniqueness of scientific knowledge is such that, as long as rigorous scientific method is continually applied to test hypotheses, past misunderstandings—such as the belief that stomach ulcers are stress induced—can be resolved. Scientific knowledge is thus more likely than other types of information debated as false speech to reflect ultimate truths and falsehoods.<sup>12</sup> Pursuit of truth is fundamental in health care; the state should regulate clinicians' false beliefs, just as the state should not compel its own false speech through clinicians.

### Summary

In an era of numerous false beliefs in society and in medicine, it is important to understand how false beliefs can be regulated. False beliefs that exist in medicine can be regulated by 2 legal doctrines: false speech and professional speech. The false speech doctrine is based on an analysis of the constitutionality of government restrictions on false statements. The professional speech doctrine is based on an analysis of the constitutionality of laws that may either restrict or compel the speech of professionals. Ultimately, a legal doctrine that allows a clinician to speak most truthfully to patients and the community is the best outcome for the health professions and society.

### References

1. Poole S. Why bad ideas refuse to die. *Guardian*. June 28, 2016. <https://www.theguardian.com/science/2016/jun/28/why-bad-ideas-refuse-die>. Accessed March 30, 2018.
2. Robertson L. Indeed, born in the USA. FactCheck.org. <https://www.factcheck.org/2011/04/indeed-born-in-the-u-s-a/>. Published April 27, 2011. Accessed March 30, 2018.
3. Davis S. How do we know the moon landing really happened? *National Space Centre Blog*. June 16, 2017. <https://spacecentre.co.uk/blog-post/know-moon-landing-really-happened/>. Accessed March 30, 2018.
4. van der Linden S. Moon landing faked!!!—Why people believe in conspiracy theories. *Scientific American*. April 30, 2013. <https://www.scientificamerican.com/article/moon-landing-faked-why-people-believe-conspiracy-theories/>. Accessed March 30, 2018.
5. Brink S. Fake cures for AIDS have a long and dreadful history. *NPR*. August 17, 2014. <https://www.npr.org/sections/goatsandsoda/2014/07/15/331677282/fake-cures-for-aids-have-a-long-and-dreadful-history>. Accessed March 30, 2018.
6. Belluz J. Minnesota's measles outbreak is what happens when anti-vaxxers target immigrants. *Vox*. October 26, 2017. <https://www.vox.com/science-and-health/2017/10/26/16552864/minnesotas-measles-outbreak-immigrants-anti-vaxxers>. Accessed on March 30, 2018.

7. Karlamangla S. Measles outbreak grows in LA's orthodox Jewish community despite California's strict new vaccination law. *LA Times*. January 21, 2017. <http://www.latimes.com/local/california/la-me-ln-measles-20170120-story.html>. Accessed on June 25, 2018.
8. US Const amend I.
9. Haupt CE. Professional speech. *Yale Law J*. 2016;125(5):1238-1303.
10. Guzelian CP. False speech: quagmire? *San Diego Law Rev*. 2014;51(1):19-80.
11. Goodman DR. Ethical falsehood: towards a moral values paradigm in false-speech adjudication. *South Texas Law Rev*. 2013;55(1):71-112.
12. Guzelian CP. True and false speech. *Boston Coll Law Rev*. 2010;51(3):669-718.
13. *New York Times v Sullivan*, 376 US 254 (1964).
14. *US v Alvarez*, 567 US 709 (2012).
15. Guzelian CP. Scientific speech. *Iowa Law Rev*. 2008;93:881-928.
16. Haupt CE. Professional speech and the content neutrality trap. *Yale Law J*. 2017;127:150-172.
17. Keighley JM. Physician speech and mandatory ultrasound laws: the First Amendment's limit on compelled ideological speech. *Cardozo Law Rev*. 2013;34(6):2347-2405.
18. Smolla RA. Professional speech and the First Amendment. *West VA Law Rev*. 2016;119:67-112.
19. Zwick T. Professional rights speech. *Ariz State Law J*. 2015;47(4):1289-1360.
20. Jones NB. Did the fortune tellers see this coming? Spiritual counseling, professional speech, and the First Amendment. *Miss Law J*. 2014;83(3):639-670.
21. *Moore-King v County of Chesterfield*, 708 F3d 560 (4th Cir 2013).
22. *Pickup v Brown*, 740 F3d 1208 (9th Cir 2014).
23. *King v Governor of New Jersey*, 767 F3d 216 (3rd Cir 2014).
24. *Planned Parenthood v Casey*, 505 US 833 (1992).
25. Orentlicher D. Abortion and compelled physician speech. *J Law Med Ethics*. 2015;43(1):9-21.
26. *Planned Parenthood Minn, ND, SD vs Rounds*, 653 F3d 662 (8th Cir 2011).
27. *Planned Parenthood Minn, ND, SD vs Rounds*, 686 F3d 889 (8th Cir 2012).
28. Woolf SH. The price of false beliefs: unrealistic expectations as a contributor to the health care crisis. *Ann Fam Med*. 2012;10(6):491-494.
29. Abbasi J. Barry Marshall, MD: *H pylori* 35 years later. *JAMA*. 2017;317(14):1400-1402.

**Scott J. Schweikart, JD, MBE** is a senior research associate for the American Medical Association Council on Ethical and Judicial Affairs in Chicago, Illinois, where he is also the legal editor for the *AMA Journal of Ethics*. Previously, he worked as an attorney editor and reference attorney at Thomson Reuters and practiced law in Chicago. Mr. Schweikart earned his MBE from the University of Pennsylvania, his JD from Case Western Reserve

University, and his BA from Washington University in St. Louis. He has research interests in health law, health policy, and bioethics.

**Citation**

*AMA J Ethics.* 2018;20(11):E1041-1048.

**DOI**

10.1001/amajethics.2018.1041.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*



## AMA CODE SAYS

### **AMA Code of Medical Ethics' Opinions Related to False Beliefs in Health Care**

Danielle Hahn Chaet, MSB

#### **Abstract**

Principle V, Opinion 1.1.6 ("Quality") and Opinion 5.5 ("Medically Ineffective Interventions") are explored here to briefly explain physicians' responsibilities when it comes to false or medically inappropriate interventions.

Physicians practicing today are living in an age in which there is more publicly available information than at any other point in history. Such information can be based on solid and thorough evidence, anecdotal evidence (ie, individual experience rather than studies done on large numbers of patients), or ineffective or inappropriate guidelines; or it can be misinterpreted or patently false. It is physicians' duty to think critically about what they read and learn and to ensure that information they use comes from credible sources. These efforts help keep physicians from unwittingly disseminating outdated or false information and can help them challenge patients' or their own false beliefs.

The *AMA Code of Medical Ethics* underscores this idea. The fifth Principle of Medical Ethics states, "A physician shall continue to study, apply, and advance scientific knowledge, maintain a commitment to medical education, make relevant information available to patients, colleagues, and the public, obtain consultation, and use the talents of other health professionals when indicated."<sup>1</sup> Principle V is referenced throughout the *AMA Code*, reminding readers of physicians' duties to use evidence-based information when caring for patients. Notably, Opinion 1.1.6, "Quality," states that as "professionals dedicated to promoting the well-being of patients, physicians individually and collectively share the obligation to ensure that the care patients receive is safe ... [and] effective."<sup>2</sup> The opinion outlines how physicians can fulfill this obligation, which largely depends on maintaining current knowledge of best care practices and implementing measurable practice improvement strategies by:

holding themselves accountable to patients, families, and fellow health care professionals for communicating effectively and coordinating care appropriately ... [and] monitoring the quality of care they deliver as individual practitioners—e.g., through personal case review and critical self-reflection, peer review, and use of other quality improvement tools.<sup>2</sup>

Patients, professionals, or other decision makers could also [glean information from the internet](#) and might not have sufficient expertise to critically examine the content. Opinion 5.5, “Medically Ineffective Interventions,”<sup>3</sup> discusses situations in which patients or their family members request [treatment that is not medically appropriate](#). It states that these requests “challenge the physician to balance obligations to respect patient autonomy and not to abandon the patient with obligations to be compassionate, yet candid, and to preserve the integrity of medical judgment.”<sup>3</sup> The opinion goes on to explain that, in essence, good communication between a physician, patient, and any decision makers is the most useful and important tool in these situations. Often, goals of care need to be clarified or reaffirmed. Other times, patients, professionals, or family members might be acting out of fear, desperation, grief, or other complex emotions that could interfere, in some cases, with the capacity to assess information and make decisions. These situations require physicians to make context-sensitive assessments of their own and others’ beliefs and how those beliefs can shape specific decisions in individual cases.

Whether proposing or responding to a request for a medical intervention, physicians have responsibilities to base their recommendations on their best medical judgment, which, generally, should be evidence based and patient centered.

## References

1. American Medical Association. AMA Principles of Medical Ethics. *Code of Medical Ethics*. <https://www.ama-assn.org/sites/default/files/media-browser/principles-of-medical-ethics.pdf>. Revised June 2001.
2. American Medical Association. Opinion 1.1.6 Quality. *Code of Medical Ethics*. <https://www.ama-assn.org/delivering-care/quality>. Accessed August 21, 2018.
3. American Medical Association. Opinion 5.5 Medically ineffective interventions. *Code of Medical Ethics*. <https://www.ama-assn.org/delivering-care/medically-ineffective-interventions>. Accessed August 21, 2018.

**Danielle Hahn Chaet, MSB** is a research associate for the American Medical Association Council on Ethical and Judicial Affairs in Chicago, Illinois. Her work involves researching, developing, and disseminating ethics policy and analyzing current issues and opinions in bioethics. She obtained her master of science degree in bioethics, with a focus on clinical policy and clinical ethics consultation, from the joint program of Union Graduate College and the Icahn School of Medicine at Mount Sinai.

### Citation

*AMA J Ethics*. 2018;20(11):E1049-1051.

### DOI

10.1001/amajethics.2018.1049.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

## POLICY FORUM

### Why Health Professionals Should Speak Out Against False Beliefs on the Internet

Joel T. Wu, JD, MPH, MA and Jennifer B. McCormick, PhD, MPP

#### Abstract

Broad dissemination and consumption of false or misleading health information, amplified by the internet, poses risks to public health and problems for both the health care enterprise and the government. In this article, we review government power for, and constitutional limits on, regulating health-related speech, particularly on the internet. We suggest that government regulation can only partially address false or misleading health information dissemination. Drawing on the American Medical Association's *Code of Medical Ethics*, we argue that health care professionals have responsibilities to convey truthful information to patients, peers, and communities. Finally, we suggest that all health care professionals have essential roles in helping patients and fellow citizens obtain reliable, evidence-based health information.

#### The Growing Problem of False Health Information on the Internet

Over the course of the past century, causes of disease and social conceptions of health have evolved from an infectious-agent theory of disease, to a behavioral theory of disease, to a social-ecological model.<sup>1,2</sup> The social-ecological model recognizes that social and environmental conditions, including the information environment and health-related speech, affect health outcomes for both individuals and populations.<sup>3,4</sup>

A problem our society currently faces is the pervasive availability and consumption of false health information,<sup>5,6</sup> which can cause individual and social harm by nurturing false beliefs about medicine, disease, and prevention.<sup>7</sup> One major source of health-related information is the internet.<sup>8-11</sup> The internet has democratized health information, but, as a result, health care professionals are no longer perceived as authorities with exclusive knowledge about health-related content.<sup>12</sup> Search engines like Google allow anyone to easily find information about anything. Social media sites like Twitter, Reddit, and Facebook provide forums for private citizens to freely express their views, including about medicine and health care. Yet the content disseminated through websites and online communities is largely unregulated. Thus, it is largely [up to consumers](#) to determine the quality and reliability of the information.

The question this raises is whether the proliferation of health-related information on the internet should be regulated and, if so, by whom. An argument might be made for government oversight because the wide circulation of false health information can lead to real injuries and harms. After all, a well-established role of the government in a democratic society is to “promote the general welfare” of its citizenry.<sup>13</sup> Yet, in the United States, the government also has an obligation to protect private citizens’ right to free speech. Thus, there exists a tension between the government’s commitment to general welfare and its duty to affirm individuals’ right to free speech.

This article will explore this tension. First, we review our society’s commitment to protecting the free speech of private citizens in the public sphere, although the content of private speech might be false and even harmful. Second, we briefly describe commercial and [professional speech](#) as a specific category of speech that can be regulated by the government for the purposes of public health and welfare. Finally, in recognizing the Constitutional boundaries on free speech in society, we discuss the professional and ethical obligations of health care professionals to provide truthful and accurate health information both in clinical practice and in the community. We suggest that all engaged in the biomedical and scientific enterprise have an ethical and social responsibility to share truthful information about health and to correct falsehoods when possible.

### **Free Speech and the Internet**

The First Amendment states, “Congress shall make no law ... abridging the freedom of speech.”<sup>14</sup> Supreme Court jurisprudence interpreting the First Amendment has affirmed that private citizens have a constitutionally protected right to articulate personal views and beliefs in public spaces without unnecessary government regulation or censorship, including public spaces on the internet. The right to free speech prevents the government from suppressing speech even if the content is false or offensive, including when the content is health related.<sup>15</sup> Examples of constitutionally protected false, health-related speech in both physical and virtual public spaces include advocacy groups’ assertions that vaccines are ineffective and cause autism<sup>16</sup> and prolife advocacy groups’ assertions that abortions cause breast cancer.<sup>17</sup> In the context of online but not health-related information, the Supreme Court ruled in *Reno v ACLU* that government-instituted, content-based restrictions on nonobscene speech were unconstitutional.<sup>18</sup> As such, it is unlikely that any health-related internet speech that is not obscene can be regulated by the government. Moreover, given the unpredictability of internet expansion and changes in consumer preferences, whether the government can develop long lasting and enforceable solutions to the problem of false health information remains a difficult and unresolved challenge.<sup>19</sup>

## Commercial and Professional Speech

There are, however, 2 categories of speech for which the government might have authority to constrain or compel speech to promote the health and welfare of the community: commercial speech and professional speech. Commercial speech is a category of speech defined as speech that (1) identifies a product for sale, (2) is a form of advertising, and (3) confers economic benefits.<sup>3</sup> Courts can uphold regulation of commercial speech based on a 4-part test articulated in *Central Hudson Gas and Electric Corporation v Public Service Commission of New York*.<sup>20</sup> Historically, examples of the regulation of commercial speech include advertisements for tobacco, alcohol, and gambling.<sup>1</sup> However, since *Central Hudson*, courts have demonstrated increasing reluctance to regulate commercial speech, emphasizing the rights of speakers rather than the state's interests in the health and welfare of community members.<sup>4</sup> We believe this places an increased burden on physicians to correct inaccurate or false health-related information that can be found in commercial sources, including on the internet.

Professional speech is a category of speech that scholars have defined as speech "uttered in the course of professional practice."<sup>21</sup> The Supreme Court indicated in *Planned Parenthood of Southeastern Pennsylvania v Casey* in 1992 that physicians' First Amendment rights not to speak are implicated, but only as part of the practice of medicine, subject to reasonable licensing and regulation by the state.<sup>22</sup> While this case involved the constitutionality of a law requiring, among other things, that at least 24 hours before performing an abortion (except in an emergency) physicians inform the woman of the nature of the procedure, the health risks of the abortion and of childbirth, and the "probable gestational age of the unborn child," it set the stage for state regulation of professional speech between physicians and their patients. Since then, courts have struggled to articulate a consistent approach to defining the scope and limitations of a state's power to regulate health care professional speech on a range of issues, including physician speech regarding firearm ownership and sexual orientation change efforts.<sup>23</sup>

While the government has some powers to regulate health-related speech, those powers are very limited and are not comprehensive or consistent. Recognizing the constitutional limits on the government's powers to regulate private citizens' free speech in the public sphere, we suggest that government regulation cannot be expected to resolve the problem of false and harmful health-related information that is perpetuated on the internet by private citizens who are speaking with their private citizen rather than their professional "hat" on. Furthermore, the government cannot be relied upon to be the sole speaker of truthful and accurate health information. As recently demonstrated by politically motivated prohibitions of certain words in official documents, the government can publish biased or incomplete statements or refrain altogether from saying anything at all.<sup>24,25</sup> Since the government cannot be relied upon to resolve the problem of false health information found on the internet, it is important for anyone involved in the

biomedical enterprise to participate in public discourse. Furthermore, we suggest that physicians, as part of their professional code, have an ethical duty not only *not* to share bad or false information but also to actively participate in conversations about health and help correct false or harmful information that can be found on the internet.

### **Implications for Health Care Professionals**

Medical professionals have a unique responsibility to confront false or misleading beliefs by virtue of their specialized knowledge and professional obligations. First, medical professionals are members of a community that possesses specialized knowledge about and training in health. Second, licensed professionals are the only people in our society who are allowed to practice medicine. The professional obligation to confront false health beliefs and information is more straightforward within a clinical setting: when patients express false or misinformed beliefs, it is professionally and ethically appropriate to attempt to correct and redirect the patients so that they can hopefully use evidence-based information to make an informed decision about their care. But outside an individual patient-clinician relationship, what is the obligation of a health care professional to the broader community to confront false beliefs and information?

We would suggest that health care professionals have an ethical obligation to correct false or misleading health information, share truthful health information, and direct people to reliable sources of health information within their communities and spheres of influence. After all, health and well-being are values shared by almost everyone. Principle V of the AMA Principles of Ethics states: "A physician shall continue to study, apply, and advance scientific knowledge, maintain a commitment to medical education, *make relevant information available to patients, colleagues, and the public*, obtain consultation, and use the talents of other health professionals when indicated" (italics added).<sup>26</sup> And Principle VII states: "*A physician shall recognize a responsibility to participate in activities contributing to the improvement of the community and the betterment of public health*" (italics added).<sup>26</sup> Taken together, these principles articulate an ethical obligation to make relevant information available to the public to improve community and public health. In the modern information age, wherein the unconstrained and largely unregulated proliferation of false health information is enabled by the internet and medical knowledge is no longer privileged, these 2 principles have a special weight and relevance.

To withdraw or refrain from public discourse in an environment where false and harmful health information is pervasively disseminated would be an abdication of the ethical obligation to make "relevant information" (or accurate information) available to improve community and public health, as medical and public health professionals possess reliable and truthful information about the nature of health and the causes of disease. For example, educated professionals can embrace invitations to speak at local groups about a particular health-related topic or respond to a blog posting. Another venue is Twitter; some use Twitter in their professional capacity to share news releases and articles and

to participate in organized, moderated Twitter chats. Even in their own social circles, health care professionals can have a positive impact by directing people to accurate sources of information and correcting misperceptions when possible. We recognize that this obligation of health care professionals extends outside the clinical setting and into the sphere of their lives. However, as the causes of death and disability extend beyond the boundaries of the clinic, so do the obligations of health care professionals. This is an obligation they take on when they choose the profession of medicine.

## References

1. Gostin LO, Wiley LF. *Public Health Law: Power, Duty, Restraint*. Oakland, CA: University of California Press; 2016.
2. Institute of Medicine. *The Future of the Public's Health in the 21st Century*. Washington, DC: National Academy Press; 2003.
3. Gostin LO, Javitt GH. Health promotion and the First Amendment: government control of the informational environment. *Milbank Q*. 2001;79(4):547-578.
4. Parmet WE, Smith JA. Free speech and public health: a population-based approach to the First Amendment. *Loyola Law Rev*. 2006;39(1):363-446.
5. Ruiz JB, Bell RA. Understanding vaccination resistance: vaccine search term selection bias and the valence of retrieved information. *Vaccine*. 2014;32(44):5776-5780.
6. Mashiach R, Seidman GI, Seidman DS. Use of mifepristone as an example of conflicting and misleading medical information on the internet. *BJOG*. 2002;109(4):437-442.
7. Lo NC, Hotez PJ. Public health and economic consequences of vaccine hesitancy for measles in the United States. *JAMA Pediatr*. 2017;171(9):887-892.
8. Fiksdal AS, Kumbamu A, Jadhav AS, et al. Evaluating the process of online health information searching: a qualitative approach to exploring consumer perspectives. *J Med Internet Res*. 2014;16(10):e244. doi:10.2196/jmir.3341.
9. Hesse BW, Nelson DE, Kreps GL, et al. Trust and sources of health information: the impact of the Internet and its implications for health care providers: findings from the first Health Information National Trends Survey. *Arch Intern Med*. 2005;165(22):2618-2624.
10. Benigeri M, Pluye P. Shortcomings of health information on the Internet. *Health Promot Int*. 2003;18(4):381-386.
11. Cline R, Haynes KM. Consumer health information seeking on the Internet: the state of the art. *Health Educ Res*. 2001;16(6):671-692.
12. Allmark P, Tod A. How should public health professionals engage with lay epidemiology? *J Med Ethics*. 2006;32(8):460-463.
13. US Const preamble.
14. US Const amend I.
15. Noah L. Truth or consequences?: commercial free speech vs. public health promotion (at the FDA). *Health Matrix Clevel*. 2011;21(1):31-95.



16. Naprawa AZ. Don't give your kid that shot: the public health threat posed by anti-vaccine speech and why such speech is not guaranteed full protection under the First Amendment. *Cardozo Public Law Policy Ethics J.* 2013;11(3):473-527.
17. *Christ's Bride Ministries Inc v Southeastern Pennsylvania Transportation Authority*, 148 F3d 242, 247 (3d Cir 1998).
18. *Reno v American Civil Liberties Union*, 521 US 844 (1997).
19. Brotman SN. Twenty years after *Reno v. ACLU*, the long arc of internet history returns. Brookings Institute.  
<https://www.brookings.edu/blog/techtank/2017/06/26/twenty-years-after-reno-v-aclu-the-long-arc-of-internet-history-returns/>. Published June 26, 2017. Accessed April 29, 2018.
20. *Central Hudson Gas and Electric Corp v Public Service Commission of New York*, 447 US 557, 561 (1980).
21. Halberstam D. Commercial speech, professional speech, and the constitutional status of social institutions. *Univ Penn Law Rev.* 1999;147(4):771-874.
22. *Planned Parenthood of Southeastern Pennsylvania v Casey*, 505 US 833, 844 (1992).
23. Parmet WE, Smith JA. Free speech and public health: unraveling the commercial-professional speech paradox. *Ohio State Law J.* 2017;78(4):887-915.  
[https://kb.osu.edu/bitstream/handle/1811/85762/OSLJ\\_V78N4\\_0887.pdf](https://kb.osu.edu/bitstream/handle/1811/85762/OSLJ_V78N4_0887.pdf). Northeastern University School of Law research paper 313-2018. Accessed September 19, 2018.
24. Sun LH, Eilperin J. CDC gets list of forbidden words: fetus, transgender, diversity. *Washington Post*. December 15, 2017.  
[https://www.washingtonpost.com/national/health-science/cdc-gets-list-of-forbidden-words-fetus-transgender-diversity/2017/12/15/f503837a-e1cf-11e7-89e8-edec16379010\\_story.html?utm\\_term=.7d055eabc34d](https://www.washingtonpost.com/national/health-science/cdc-gets-list-of-forbidden-words-fetus-transgender-diversity/2017/12/15/f503837a-e1cf-11e7-89e8-edec16379010_story.html?utm_term=.7d055eabc34d). Accessed April 29, 2018.
25. Gostin LO. Language, science, and politics: the politicization of public health. *JAMA.* 2018;319(6):541-542.
26. American Medical Association. Principles of Medical Ethics. <https://www.ama-assn.org/delivering-care/ama-principles-medical-ethics>. Accessed April 29, 2018.

**Joel T. Wu, JD, MPH, MA** is a clinical ethics fellow at Children's Minnesota and Abbott Northwestern Hospital in Minneapolis, Minnesota. He is also a senior lecturer at the University of Minnesota School of Public Health in the Division Health Policy and an affiliate faculty member of the Center for Bioethics at the University of Minnesota. He previously conducted health policy development and research at the Institute of Medicine and the Brookings Institution. His work focuses on clinical ethics practice, organizational ethics and policy in health care, and justice issues in public health.

**Jennifer B. McCormick, PhD, MPP** is a member of the Penn State Clinical and Translational Science Institute's program leadership and the American Society of Human Genetics' Social Issues Committee. She completed a doctoral degree in molecular and cellular biology, a postdoctoral fellowship in biological chemistry, master's degree in public policy, and a National Human Genome Research Institute Centers of Excellence in ELSI (Ethical, Legal and Social Implications) Research fellowship. She lectures frequently on topics related to research ethics and science policy, responsible conduct in research, informed consent, translational research ethics, translational genomics and policy, and social responsibility in science.

**Citation**

*AMA J Ethics.* 2018;20(11):E1052-1058.

**DOI**

10.1001/amajethics.2018.1052.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

## POLICY FORUM

### How Should Clinicians Engage With Online Health Information?

Dónal P. O'Mathúna, PhD, MA

#### Abstract

Many adults, physicians, and medical students search the internet for health information. Open access has many benefits, but the variable quality of internet health information—ranging from evidence based to false—raises ethical concerns. Using Wikipedia as a case study, this article argues that everyone engaging with internet health information has ethical responsibilities. Those hosting and writing for health websites should ensure that information is evidence based, accurate, up to date, and readable and be transparent about conflicts of interest. Health care professionals, including medical students, have both ethical responsibilities to help patients avoid false or misleading health information and practical opportunities to improve the quality of internet health information. All users of such information—professionals and patients alike—should develop critical appraisal skills and apply them to internet health information to distinguish the good from the junk.

#### Internet Health Information

The convenience, accessibility, and (often) free availability of internet health information makes it highly attractive. The information is found in many formats, including specialized websites, blogs, and social networking sites. In 2012, an estimated 72% of US adult internet users searched online for health information.<sup>1</sup> Most users (77%) began their searches for health information using search engines; only 13% began their searches using specialized health websites, such as WebMD.<sup>1</sup> However, concerns have been raised about people's abilities to effectively search for information, comprehend what they find, and cope with the volume and variable quality of information.<sup>2-4</sup>

Moreover, the accuracy of internet health information varies greatly. For example, in a study of the quality of online information on mental health, two-thirds of the websites had content rated as good quality using DISCERN, an objective, validated instrument for measuring the quality of written health information.<sup>3</sup> A systematic review of information about preoperative fasting on 87 websites, including health care institution websites, found that 55% included at least one recommendation that contradicted evidence-based guidelines.<sup>4</sup> Of great concern, websites of health care institutions were more likely to

have inaccurate information. Overall, the researchers assessed the quality and readability of the information as poor using validated instruments.

In addition to general health information, research has examined the quality of internet health information about specific conditions. In a United Kingdom (UK) study, online information on rhinoplasty, one of the most common surgical procedures performed, was found to be generally of low quality, unreliable, and difficult to read on the basis of objective measures.<sup>5</sup> Another study examined the portrayal of online health information in US and UK newspaper articles about health, most of which referenced a website. The coders rated 47% of the articles as excellent quality, 33% as average or good quality, and 20% as poor quality.<sup>2</sup> Yet another study examined information on dengue, a significant health problem in developing countries.<sup>6</sup> Among the websites examined, 46% were evaluated as excellent, 15% as good, 18% as fair, 9% as poor, and 11% as very poor using an objective measure of quality. Other studies could be cited to show that the quality of health information on the internet is highly variable.<sup>3</sup>

Given this variability in quality, online health information must be critically appraised to distinguish between what is reliable and what is not. Clinicians—especially those using the internet for informal professional education<sup>7</sup>—have an ethical obligation to use their critical appraisal skills to help patients avoid false or misleading health information. One of the most common sources of online health information is Wikipedia, with over 70% of physicians using it for health care information,<sup>8</sup> as well as over 90% of medical students.<sup>9</sup> Given its popularity, Wikipedia provides an interesting case to examine the ethical obligations of clinicians regarding internet health information.

### **The Wikipedia Case**

Since launching in 2001, Wikipedia has become the fifth most popular website in the world, containing millions of articles in hundreds of languages.<sup>10</sup> As of March 2017, medical topics were covered in 30 000 English-language articles and 164 000 articles in other languages.<sup>9</sup> As a “wiki,” anyone can add, delete, or edit pages, raising concerns about the quality of its information. Some studies have found Wikipedia to be of comparable quality to other sources of general health information, but others have not been so positive. One study focused on the 10 most costly US health conditions and whether Wikipedia made assertions that conflicted with evidence in peer-reviewed articles.<sup>11</sup> Using Wikipedia articles from 2012, the research found statistically significant disagreement between Wikipedia and peer-reviewed sources for 9 of the 10 conditions. The one exception was an article on concussions, which the researchers noted was contributed by those with more expertise than the contributors of the other 9 articles.

Findings like these have led some to discourage the use of Wikipedia for health information, while Amin Azzam, MD, who teaches a course on editing Wikipedia for medical students, argues that physicians “have a moral obligation” to engage actively

with such websites.<sup>12</sup> The openness of Wikipedia can thus be seen as an opportunity to address its limitations. In 2004, WikiProject Medicine was founded by a physician to engage those with medical training in editing Wikipedia medical articles.<sup>9</sup> It continues to be one of Wikipedia's most active editing groups, primarily composed of health care professionals, researchers, and students.<sup>9</sup> Around the same time, medical students at some universities were offered course credit to edit Wikipedia pages for courses [teaching critical appraisal skills](#).<sup>12</sup>

Wikipedia also sought to improve its quality through collaborations. Since 2012, Wikipedia has collaborated actively with the Cochrane Collaboration and its over 30 000 contributors, mostly health care professionals and researchers. Cochrane is an international nonprofit organization that produces systematic reviews of health interventions that are seen by many as the gold standard for rigor and reliability.<sup>13</sup> Other collaborations have been developed with Wikipedia to encourage active engagement by those with relevant expertise. For example, some peer-reviewed journals encourage, or sometimes require, authors to develop a Wikipedia page to accompany their published article; the Public Library of Science dual publishes broad review articles in its journals and in Wikipedia; and Translators without Borders, a nonprofit organization, has translated Wikipedia medical pages into over 100 languages.<sup>9</sup> Other initiatives have been internal to Wikipedia, such as checks on the quality of both the content and the editing of medical articles. While the quality across the massive website remains variable, recent assessments are showing improvements.<sup>9</sup> This finding demonstrates how an ethical commitment to promoting the accuracy of health information on the internet can bring demonstrable improvements that help protect patients from false or misleading information.

### **Ethical Principles**

The types of improvements that Wikipedia has sought are motivated by a number of ethical principles that should apply to all internet health information. Foremost among these is the importance of promoting the general good and avoiding harm to users of the information. One way to do this is by ensuring that the best available evidence informs the content.

High-quality health care involves core commitments to safety, effectiveness, patient-centeredness, and equity, among others.<sup>14</sup> Each of these commitments can be linked to ethical principles: for example, patient-centeredness is based on respect for persons, and safety is based on nonmaleficence.<sup>15</sup> Such commitments and ethical principles apply equally to clinical practice and internet health information. Patient-centeredness, for example, should lead authors of website content to provide health information in clear and easily readable ways. To ensure that patients spend their limited resources on effective interventions and are not harmed by false claims, authors of website content should also ensure that information comes from credible sources that are backed up by

high-quality evidence and references. When relevant, authors of website content should identify the type of study design and link to a description of it so that readers can inform themselves of the strengths and limitations of each type of evidence. Most elements of evidence-based practice can thus be shown to be informed by ethical principles and values.<sup>15</sup>

A number of ethical principles similar to those discussed above were articulated in the 2000 e-Health Code of Ethics.<sup>16</sup> The guiding principles are summarized in the table. In addition, the document accompanying the Code discusses several ways to put these principles into practice.

**Table.** Guiding Principles of the e-Health Code of Ethics

Ethical Principle	Description
Candor	"Disclose information that if known by consumers would likely affect consumers' understanding or use of the site or purchase or use of a product or service."
Honesty	"Be truthful and not deceptive."
Quality	"Provide health information that is accurate, easy to understand, and up to date. <i>and</i> Provide the information users need to make their own judgments about the health information, products, or services provided by the site."
Informed consent	"Respect users' right to determine whether or how their personal data will be collected, used, or shared."
Privacy	"Respect the obligation to protect users' privacy."
Professionalism in Online Health Care	"Respect fundamental ethical obligations to patients and clients. <i>and</i> Inform and educate patients and clients about the limitations of online health care."
Responsible Partnering	"Ensure that organisations and sites with which they affiliate are trustworthy."
Accountability	"Provide meaningful opportunity for users to give feedback to the site. <i>and</i> Monitor their compliance with the e-Health Code of Ethics."

© Helga Rippen, Ahmad Risk. Adapted from Table 1 in "e-Health Code of Ethics," originally published in the *Journal of Medical Internet Research* (<http://www.jmir.org/2000/2/e9/>)<sup>16</sup> and distributed under the terms of the Creative Commons Attribution License (<http://www.creativecommons.org/licenses/by/2.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Although not explicitly mentioned in the Code, conflict of interest is another important ethical consideration. Users of internet health information must determine if the content is trustworthy, so authors should disclose any conflicts of interest that can intentionally or unintentionally introduce bias into the content. One of the reasons Wikipedia introduced stricter oversight policies for medical content was that employees of companies with commercial interests were found to be adding and deleting information so that articles portrayed their products in more favorable ways.<sup>17</sup> While such marketing strategies might be acceptable in some commercial realms, there are reasons to regard applying such strategies to health information as unethical.

The potential for conflicts of interest to introduce bias into online health information reached a new level in 2014 as a new group of top-level internet domain names (like the familiar “.com” and “.edu”) were being released. Among these were “.health” and 17 other health-related names.<sup>18</sup> Despite objections from the World Health Organization and many medical informatics experts, the names were allocated “to the highest bidders,” according to critics, rather than by what would best promote and safeguard public health.<sup>19</sup> According to the CEO of DotHealth, the company that eventually won the contract to administer domain names with .health in them, removing anything other than harmful and illegal information “in the name of ‘quality’ is a dangerous precedent that amounts to potential censorship of free speech at worst and favoritism at best.”<sup>19</sup> Critics claimed they were not arguing for censorship but that, given the credibility and trust inherent in a .health website name, transparency should be the guiding ethical principle for health information websites.<sup>19</sup> This means that those hosting and writing for health websites should be transparent about who they are and any conflicts of interest they might have so that readers can evaluate the trustworthiness or potential bias of the information. Those hosting interactive websites should also be transparent about how the privacy and confidentiality of any user-provided information will be protected.<sup>19</sup>

Justice is another important ethical principle in the context of the internet. The widespread availability of the internet is frequently noted, but not everyone has easy, affordable, and reliable access to it. This disparity can occur for several reasons, including poor infrastructure, the costs of access or equipment, or lack of internet technology or health literacy. If only those with certain incomes can access “free” health information, websites can unfairly or unjustly give preferential prominence to the health concerns of those with higher incomes and neglect the concerns of those with lower incomes. Some attempts have been made to counteract these tendencies. For example, while Wikipedia medical content is still skewed towards English, a collaboration with Translators without Borders is helping to ensure articles are available in a wider range of languages.<sup>9</sup>

Other practical approaches to addressing quality include ways to credential health websites. The Health on the Net Foundation (HON) is a Swiss nongovernmental organization seeking to improve the reliability and credibility of health and medical

information on the internet.<sup>20</sup> It does this via a code of conduct that provides HONcode certification to websites that agree to adhere to these ethical standards. Each year, websites need to be re-evaluated and recertified, although HON does not evaluate the quality of the information on the website.<sup>21</sup> HONcode certification is widely used as an indicator of higher-quality information, for which some independent research has found supportive evidence.<sup>22</sup> However, researchers have found that some websites displaying HONcode certification were not in compliance with all of the code's principles,<sup>22</sup> and another study found a weak correlation between HONcode certification and the quality of website health information.<sup>3</sup>

Other deeper and less tangible ethical issues arise in the context of internet health information, which will only be mentioned here.<sup>18</sup> One issue is how patients using the internet instead of engaging with clinicians to diagnose, investigate, and possibly treat their health conditions will impact their health and [how they view their conditions](#). It would be problematic if patients engaged in endless internet searching for explanations of their symptoms or conditions or came to hold false beliefs about them, especially if consultation with health care professionals could provide clearer answers. For example, the term "cyberchondria" has been coined for the exacerbation of health anxiety following frequent internet searching for health information.<sup>1</sup> A second issue is how the internet will impact [patient-professional interactions](#) and relationships as patients come to professionals with more information gleaned from the internet. While information gathering can be beneficial, it can also lead to problems if patients come to hold false beliefs and adamantly adhere to them despite strong evidence to the contrary.

## **Conclusion**

Health information on the internet highlights the value of access to information. As such, it is a public resource that should be used for the public good. Health information can promote health, but it also has the potential for harm if it promotes false beliefs or is misleading. To the degree information is evidence based, honest, reliable, and understandable, it can promote good. To the degree it is misleading, biased, or inaccurate, it can lead to harm—either by giving readers incorrect recommendations or by diverting them from good courses of action. The variable quality of information on the internet creates ethical responsibilities for all involved with internet health information: providers, professionals, and the public. Providers of online health information should ensure their websites adhere to ethical standards like those discussed here. Health care professionals should engage with patients about the information they access and help them critically appraise it so that they can evaluate health information better themselves. It is important not only to critique low-quality websites but also to become involved in initiatives to help improve what is available online. Many opportunities exist to improve internet health information, enabling medical professionals to contribute to public health and public good. The flip side of open access to so much health information is the ethical responsibility to critically appraise that information. The internet has



reaffirmed for another generation the Latin aphorism *caveat lector* (let the reader beware).

## References

1. Fox S, Jones S. Health online 2013. Washington, DC: Pew Research Center; January 15, 2013. <http://www.pewinternet.org/2013/01/15/health-online-2013/>. Accessed September 20, 2018.
2. McCaw BA, McGlade KJ, McElnay JC. Online health information—what the newspapers tell their readers: a systematic content analysis. *BMC Public Health*. 2014;14:1316. doi:10.1186/1471-2458-14-1316.
3. Grohol JM, Slimowicz J, Granda R. The quality of mental health information commonly searched for on the Internet. *Cyberpsychol Behav Soc Netw*. 2014;17(4):216-221.
4. Roughead T, Sewell D, Ryerson CJ, Fisher JH, Flexman AM. Internet-based resources frequently provide inaccurate and out-of-date recommendations on preoperative fasting: a systematic review. *Anesth Analg*. 2016;123(6):1463-1468.
5. Haymes AT. The quality of rhinoplasty health information on the internet. *Ann Plast Surg*. 2016;76(2):143-149.
6. Rao NR, Mohapatra M, Mishra S, Joshi A. Evaluation of dengue-related health information on the internet. *Perspect Health Inf Manag*. 2012;9:1c. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3392950/>. Accessed September 20, 2018.
7. Schmidt T. Informal education of medical doctors on the Internet. *Stud Health Technol Inform*. 2013;190:92-94.
8. Hughes B, Joshi I, Lemonde H, Wareham J. Junior physician's use of Web 2.0 for information seeking and medical education: a qualitative study. *Int J Med Inform*. 2009;78(10):645-655.
9. Shafee T, Masukume G, Kipersztok L, et al. Evolution of Wikipedia's medical content: past, present and future. *J Epidemiol Community Health*. 2017;71(11):1122-1129.
10. Collins J. The top 10 most popular sites of 2018. *Lifewire*. April 12, 2018. <https://www.lifewire.com/most-popular-sites-3483140>. Accessed May 1, 2018.
11. Hasty RT, Garbalosa RC, Barbato VA, et al. Wikipedia vs peer-reviewed medical literature for information about the 10 most costly medical conditions. *J Am Osteopathic Assoc*. 2014;114(5):368-373.
12. Beck J. Doctors' #1 source for healthcare information: Wikipedia. *Atlantic*. March 5, 2014. <https://www.theatlantic.com/health/archive/2014/03/doctors-1-source-for-healthcare-information-wikipedia/284206/>. Accessed May 1, 2018.
13. Smith R. The Cochrane Collaboration at 20: much has been achieved, but much remains to be done. *BMJ*. 2013;347(7938):3-4.
14. Baily MA, Bottrell M, Lynn J, Jennings B. The ethics of using QI methods to improve health care quality and safety. *Hastings Cent Rep*. 2006;36(4):S1-S40.

15. O'Mathúna DP. Ethical considerations for evidence implementation and evidence generation. In: Melnyk B, Fineout-Overholt E, eds. *Evidence-Based Practice in Nursing & Healthcare: A Guide to Best Practice*. 3rd ed. Philadelphia, PA: Wolters Kluwer; 2015:515-530.
16. Rippen H, Risk A. e-Health Code of Ethics. *J Med Internet Res*. 2000;2(2):e9. doi:10.2196/jmir.2.2.e9.
17. Fleck F. Online encyclopedia provides free health info for all. *Bull World Health Organ*. 2013;91(1):8-9.
18. Solomonides AE, Mackey TK. Emerging ethical issues in digital health information. *Camb Q Healthc Ethics*. 2015;24(3):311-322.
19. Eysenbach G. The new health-related top-level domains are coming: will cureforcancer.health go to the highest bidder? *J Med Internet Res*. 2014;16(3):e73. doi:10.2196/jmir.3358.
20. HON (Health On the Net) website. <https://www.hon.ch/en/>. Accessed September 7, 2018.
21. HON (Health On the Net). HONcode. <https://www.hon.ch/HONcode/Webmasters/>. Accessed September 7, 2018.
22. Chumber S, Huber J, Ghezzi P. A methodology to analyze the quality of health information on the internet: the example of diabetic neuropathy. *Diabetes Educ*. 2015;41(1):95-105.

**Dónal P. O'Mathúna, PhD, MA** is an associate professor in the College of Nursing at the Ohio State University in Columbus, Ohio, and an associate professor in the School of Nursing and Human Sciences at Dublin City University in Dublin, Ireland. His research interests include conducting Cochrane systematic reviews and examining ethical issues in disaster research and humanitarian crises.

#### **Citation**

*AMA J Ethics*. 2018;20(11):E1059-1066.

#### **DOI**

10.1001/amajethics.2018.1059.

#### **Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

**Copyright 2018 American Medical Association. All rights reserved.  
ISSN 2376-6980**

## MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

### Public Accommodation Laws and Gender Panic in Clinical Settings

Elizabeth Boskey, PhD, MPH, MSSW, Amir Taghinia, MD, and Oren Ganor, MD

*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

Public accommodation laws (PALs) are used to address discrimination against minorities. There is broad discussion about using such laws to either protect or prohibit access to sex-segregated spaces for transgender people. Health care facilities are subject to PALs, which affect rooming assignments and access to sex-segregated environments. Around the time that a Massachusetts transgender PAL went into effect in October 2016, the first author (EB) facilitated 18 professional trainings at 5 health care facilities in greater Boston. During these trainings, staff repeatedly brought up 2 areas of moral concern reflecting public conversations about transgender rights: risk posed by the presence of transwomen in sex-segregated spaces and feelings of unpreparedness for dealing with anti-trans bias. This article discusses the role of education in responding to gender panic in inpatient settings.

#### Public Accommodation Laws and Gender Panic in the Inpatient Setting

Public accommodation laws (PALs) are used to address discrimination against minority groups. Currently, there is broad public discussion about using PALs to either protect or prohibit access to sex-segregated spaces for transgender people.<sup>1-3</sup> Transgender people have a gender identity that is different than the one typically associated with their assigned sex at birth, in contrast to cisgender people, whose gender identities are congruent with their assigned sex at birth.

PALs can have significant implications for health care professionals. Since October 2016, Massachusetts has guaranteed transgender people, as a civil right, access to sex-segregated facilities that are consistent with their sincerely held gender identity, regardless of their histories of medical or surgical care.<sup>4</sup> Health care facilities, including hospitals, nursing homes, and substance abuse treatment facilities, all qualify as public accommodations under this law. Between 2016 and 2018, the first author (EB)

facilitated 18 trainings on [gender-affirming care](#) for health care practitioners and support staff at 5 facilities in greater Boston—2 city hospitals, 2 suburban satellite centers, and 1 urban, inpatient addiction facility. Trainings ranged in size from 5 to over 50 participants. During those trainings, clinical and nonclinical staff repeatedly brought up 2 areas of moral concern about dealing with transgender patients. This paper describes inpatient staff experiences of moral concern based on the first author’s recollection of these conversations, likely antecedents for the development of such concerns, and the importance of addressing such concerns through education.

### **Staff Experiences of Gender Panic**

The primary concern expressed by staff during the aforementioned trainings reflected moral panic<sup>5</sup> over fear that a heterosexual, cisgender man could present as a transgender woman to prey on women in a sex-segregated space.<sup>6</sup> Specifically, during several trainings, staff members stated that they thought it was inappropriate to house transgender women with cisgender women, justifying that statement with some variation on the hypothetical question, “How do we know that they [transgender women] are not men pretending to be women in order assault them [cisgender women]?” This concern expresses one kind of gender panic<sup>7,8</sup> and was brought up in more than half of all trainings, usually by support staff rather than clinical staff.

This kind of gender panic is also cited as the reason for a number of so-called “[bathroom bills](#)” proposed or enacted in the United States. Bathroom bills require people to access facilities concordant with a gender listing on their birth certificate or their sex assigned at birth.<sup>15</sup> In other words, transgender women are expected to use men’s facilities and transgender men, women’s facilities, until and unless they are able to change the sex named on their birth certificate. A few states do not allow birth certificates to be changed in this way.<sup>16</sup> Even where allowed, states may require people to undergo genital-affirmation surgery,<sup>16</sup> which can be financially prohibitive, even for those people who wish to undergo such procedures.<sup>16,17</sup>

Such bills are often described in ways that indirectly or directly position transgender women as a sexual threat, including referring to transgender women as men and describing them as perverse or unnatural.<sup>9-11</sup> Media have also historically positioned transgender women as dangerous, predatory, or objects of disgust, although such portrayals have become more positive in recent years.<sup>11</sup> Lack of broad public discussion about transgender identities as normal variation and not dangerous, combined with the fact that many people do not know anyone who is transgender, enable fear and negative media portrayals to shape transphobic beliefs,<sup>11-14</sup> which further nourish gender panic, including in clinic office settings.

Discussions about bathroom bills almost entirely focus on threats perceived to accrue when transgender women, who might still have male genitalia, are allowed to enter

women's-only spaces. Rarely are similar concerns expressed about transgender men.<sup>15,18</sup> This asymmetry in the perception of transgender women and transgender men is presumably because cisgender women are seen as vulnerable to being taken advantage of in ways that cisgender men typically are not and because transgender men are more likely to "pass" in men's-only spaces.<sup>19</sup> During trainings, pointing out this asymmetry in the perception of transgender men and women seemed to be an effective way to help people begin to question their feelings of gender panic, as it encouraged them to consider how their concerns about transgender women might be a reflection of broader issues of gender in society. Ironically, the way that femininity is associated with sexual vulnerability in American culture means that the very transgender women being framed as threats in gender panic discourse are themselves at high risk of sexual victimization.<sup>20</sup>

The gender stereotypes that position women as inherently sexually vulnerable and men as inherently sexually threatening have led to widespread acceptance of the notion that, given access and opportunity, men will be sexually aggressive towards women—something often shorthanded by the term *rape culture*.<sup>21</sup> No evidence known to the authors supports the concern that cisgender men masquerade as transgender women to access women's-only spaces. However, transgender women are at demonstrably elevated risk of sexual assault relative to cisgender women: in a large 2015 national survey, 47% reported having been sexually assaulted during their lifetime,<sup>22</sup> a rate more than double that for cisgender women.<sup>23</sup> Transgender women are also at known risk for sexual assault in public restrooms, which can cause health problems due to bathroom avoidance.<sup>24</sup> What helped to address the staff's concern about rape culture was linking the elevated risk of assault, stigma, and discrimination faced by transgender women to the lack of evidence of cisgender men pretending to be transgender as a ploy to gain access to women's spaces.

Those who disagree with transgender PALs seem to sincerely believe that such regulations put cisgender women at risk, generally due to multiple misconceptions about gender, sex, and power common in society and reinforced by transphobic narratives.<sup>7,10,11,15,18</sup> As such, professional education about gender-affirming care must not simply dictate inclusive behavior but should explore reasons why people might be tempted to resist such behavior. The authors' experience suggests that discussion of each of the aforementioned factors—rape culture, disproportionate focus on transgender women, sexual assault risk experienced by transgender women, and health effects of bathroom avoidance—can help ameliorate clinician and support staff concerns.

### **Staff Concerns About Patient Bias**

The second concern that was repeatedly brought up, more often by clinic support staff members than by clinicians, was that they did not know how they would deal with people who expressed transphobic viewpoints or discomfort about transgender patients.

This concern took the form of the hypothetical question, “How am I supposed to deal with it if my patients freak out because their roommate is transgender?” In other words, these staff members were concerned about dealing with others’ gender panic. Whereas staff members’ gender panic was generally defended as being based on rational beliefs, others’ panic—known as secondary panic—was more often construed as an emotional issue. This could be because nurses and other health care practitioners frequently witness, or are victims of, discriminatory behavior. There have been numerous reports of patients refusing or demanding to be cared for by someone of a specific race, religion, or sex.<sup>25-29</sup> Anecdotal reports of patients protesting their assigned roommate in inpatient settings also tend to include allusions to perceived race, religion, and sexual orientation.

Our experience suggests that secondary gender panic is easier to address with staff members than their own gender panic, due to their experience addressing discriminatory behavior in other contexts. For example, we found that prompting staff members to recognize the similarity of gender identity discrimination to racial or religious discrimination helped them realize that they already had the skills and experience to intervene. We also found it helpful to remind staff that this issue could be more of a theoretical concern than an actual one, as patients are not typically exposed to other patients’ genitals and might have no idea about the gender identity of their roommate.

### **Gender Panic as a Patient Safety Concern**

Conservative dialogue about PALs tends to treat PALs as sources of safety concerns. As public accommodations, health care spaces are locations with potential for controversy about transgender issues.<sup>30,31</sup> For example, during training, some health care practitioners and staff members were observed to question repeatedly whether PALs, particularly those that allow transgender women to access women’s-only spaces, put cisgender women at risk.

To date, there is no known published data suggesting that PALs pose a risk to cisgender patients. However, there is substantial evidence that gender panic and discrimination pose risks to transgender patients. Numerous studies document discrimination against transgender patients in clinical settings.<sup>30,32-35</sup> Types of discrimination include verbal, physical, and sexual harassment; refusal of care; and even unnecessary forced treatment.<sup>36</sup> These experiences pose direct risks to the health of transgender patients and serve as barriers to their seeking health care in future.<sup>33,34,37</sup>

PALs have potential to significantly improve the lives of transgender people. However, education for clinicians and support staff is needed to address gender panic that can lead to hostility and other concerns described here. Research has shown that explicit [education on transgender issues](#) increases staff members’ comfort and decreases bias in patient care.<sup>38-41</sup> As such, understanding and addressing fears that lead to gender panic has potential to improve clinician satisfaction, patients’ experiences, and patients’ health.

## References

1. Schuster MA, Reisner SL, Onorato SE. Beyond bathrooms—meeting the health needs of transgender people. *N Engl J Med*. 2016;375(2):101-103.
2. Scout N. Transgender health and well-being: gains and opportunities in policy and law. *Am J Orthopsychiatry*. 2016;86(4):378-383.
3. Zaidi D. Transgender health in an age of bathroom bills. *Acad Med*. 2018;93(1):9.
4. Mass Gen Laws Ch 272, §98 (2016).
5. Klocke BV, Muschert GW. A hybrid model of moral panics: synthesizing the theory and practice of moral panic research. *Sociol Compass*. 2010;4(5):295-309.
6. Gordon G. Transgender legal advocacy: what do feminist legal theories have to offer? *Calif Law Rev*. 2009;97(6):1719-1762.
7. Mathers LAB. Bathrooms, boundaries, and emotional burdens: cisgendering interactions through the interpretation of transgender experience. *Symbolic Interact*. 2017;40(3):295-316.
8. Lorber J. Why do bathrooms matter? *Contemp Sociol*. 2012;41(5):598-602.
9. Maza C. This is what conservative media think a transgender woman looks like. *Equality Matters Blog*. August 19, 2013. <http://equalitymatters.org/blog/201308190001>. Accessed April 30, 2018.
10. Moffitt RE. Keeping the john open to Jane: how California's bathroom bill brings transgender rights out of the water closet notes. *Georgetown J Gend Law*. 2015;16(2):475-504.
11. Solomon HE, Kurtz-Costes B. Media's influence on perceptions of trans women. *Sex Res Soc Policy*. 2018;15(1):34-47.
12. Rodenborg NA, Boisen LA. Aversive racism and intergroup contact theories: cultural competence in a segregated world. *J Soc Work Educ*. 2013;49(4):564-579.
13. Gillig TK, Rosenthal EL, Murphy ST, Folb KL. More than a media moment: the influence of televised storylines on viewers' attitudes toward transgender people and policies. *Sex Roles*. 2018;78(7-8):515-527.
14. Flores AR. Attitudes toward transgender rights: perceived knowledge and secondary interpersonal contact. *Polit Groups Identities*. 2015;3(3):1-19.
15. Platt LF, Milam SRB. Public discomfort with gender appearance-inconsistent bathroom use: the oppressive bind of bathroom laws for transgender individuals. *Gend Issues*. 2018;35(3):181-201.
16. Ross J. How easy is it to change the sex on your birth certificate? *Washington Post*. May 18, 2016. [https://www.washingtonpost.com/news/the-fix/wp/2016/05/18/the-next-frontier-in-the-bathroom-law-debate-changing-birth-certificates/?utm\\_term=.8a5468eac6b7](https://www.washingtonpost.com/news/the-fix/wp/2016/05/18/the-next-frontier-in-the-bathroom-law-debate-changing-birth-certificates/?utm_term=.8a5468eac6b7). Accessed May 10, 2018.
17. Lee EJ, Gurr D, Van Wye G. An evaluation of New York City's 2015 birth certificate gender marker regulation. *LGBT Health*. 2017;4(5):320-327.
18. Westbrook L, Schilt K. Doing gender, determining gender: transgender people, gender panics, and the maintenance of the sex/gender/sexuality system. *Gend Soc*. 2014;28(1):32-57.

19. Nuttbrock L, Hwahng S, Bockting W, et al. Psychiatric impact of gender-related abuse across the life course of male-to-female transgender persons. *J Sex Res.* 2010;47(1):12-23.
20. Yavorsky JE, Sayer L. "Doing fear": the influence of hetero-femininity on (trans)women's fears of victimization. *Sociol Q.* 2013;54(4):511-533.
21. Herman D. The rape culture. *Cult.* 1988;1(10):45-53.
22. James SE, Herman JL, Rankin S, Keisling M, Mottet L, Anafi M. *The Report of the 2015 US Transgender Survey.* Washington, DC: National Center for Gender Equality; 2016.  
<https://www.transequality.org/sites/default/files/docs/usts/USTS%20Full%20Report%20-%20FINAL%201.6.17.pdf>. Accessed September 14, 2018.
23. Breiding MJ, Smith SG, Basile KC, Walters ML, Chen J, Merrick MT. Prevalence and characteristics of sexual violence, stalking, and intimate partner violence victimization— National Intimate Partner and Sexual Violence Survey, United States 2011. *MMWR Surveill Summ.* 2014;63(8):1–18.
24. Herman JL. Gendered restrooms and minority stress: the public regulation of gender and its impact on transgender people's lives. *J Public Manage Soc Policy.* 2013;19(1):65-80.
25. Deacon M. How should nurses deal with patients' personal racism? Learning from practice. *J Psychiatr Ment Health Nurs.* 2011;18(6):493-500.
26. Popper-Giveon A, Keshet Y. The secret drama at the patient's bedside-refusal of treatment because of the practitioner's ethnic identity: the medical staff's point of view. *Qual Health Res.* 2018;28(5):711-720.
27. Estacio EV, Saidy-Khan S. Experiences of racial microaggression among migrant nurses in the United Kingdom. *Glob Qual Nurs Res.* 2014;1:2333393614532618. doi:10.1177/2333393614532618. Accessed May 10, 2018.
28. Singh K, Sivasubramaniam P, Ghuman S, Mir HR. The dilemma of the racist patient. *Am J Orthop (Belle Mead NJ).* 2015;44(12):e477-e479.  
<https://www.amjorthopedics.com/article/dilemma-racist-patient>. Accessed September 20, 2018.
29. Padela AI, Schneider SM, He H, Ali Z, Richardson TM. Patient choice of provider type in the emergency department: perceptions and factors relating to accommodation of requests for care providers. *Emerg Med J.* 2010;27(6):465-469.
30. Rodriguez A, Agardh A, Asamoah BO. Self-reported discrimination in health-care settings based on recognizability as transgender: a cross-sectional study among transgender US citizens. *Arch Sex Behav.* 2018;47(4):973-985.
31. White Hughto JM, Reisner SL, Pachankis JE. Transgender stigma and health: a critical review of stigma determinants, mechanisms, and interventions. *Soc Sci Med.* 2015;147:222-231.



32. Jaffee KD, Shires DA, Stroumsa D. Discrimination and delayed health care among transgender women and men: implications for improving medical education and health care delivery. *Med Care*. 2016;54(11):1010-1016.
33. Seelman KL, Colón-Díaz MJP, LeCroix RH, Xavier-Brier M, Kattari L. Transgender noninclusive healthcare and delaying care because of fear: connections to general health and mental health among transgender adults. *Transgend Health*. 2017;2(1):17-28.
34. Macapagal K, Bhatia R, Greene GJ. Differences in healthcare access, use, and experiences within a community sample of racially diverse lesbian, gay, bisexual, transgender, and questioning emerging adults. *LGBT Health*. 2016;3(6):434-442.
35. White Hughto JM, Murchison GR, Clark K, Pachankis JE, Reisner SL. Geographic and individual differences in healthcare access for US transgender adults: a multilevel analysis. *LGBT Health*. 2016;3(6):424-433.
36. Lambda Legal. When health care isn't caring: Lambda Legal's survey of discrimination against LGBT people and people with HIV. [https://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-report\\_when-health-care-isnt-caring.pdf](https://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-report_when-health-care-isnt-caring.pdf). Published 2010. Accessed May 10, 2018.
37. Cruz TM. Assessing access to care for transgender and gender nonconforming people: a consideration of diversity in combating discrimination. *Soc Sci Med*. 2014;110:65-73.
38. Sekoni A, Gale N, Manga-Atangana B, Bhadhuri A, Jolly K. The effects of educational curricula and training on LGBT-specific health issues for healthcare students and professionals: a mixed-method systematic review. *J Int AIDS Soc*. 2017;20(1):1-13.
39. Lelutiu-Weinberger C, Pollard-Thomas P, Pagano W, et al. Implementation and evaluation of a pilot training to improve transgender competency among medical staff in an urban clinic. *Transgend Health*. 2016;1(1):45-53.
40. Park JA, Safer JD. Clinical exposure to transgender medicine improves students' preparedness above levels seen with didactic teaching alone: a key addition to the Boston University model for teaching transgender healthcare. *Transgend Health*. 2018;3(1):10-16.
41. Jaffer M, Ayad J, Tungol JG, MacDonald R, Dickey N, Venters H. Improving transgender healthcare in the New York City correctional system. *LGBT Health*. 2016;3(2):116-121.

**Elizabeth Boskey, PhD, MPH, MSSW** is a social worker and researcher in the Center for Gender Surgery at Boston Children's Hospital in Boston, Massachusetts. As a certified sexuality educator and certified health education specialist, she has been engaged in research and education about gender and sexuality for more than two decades. She has contributed to numerous books and articles on sexual health and related fields and is on the editorial board of the *American Journal of Sex Education*.

**Amir Taghinia, MD** is a plastic and microvascular surgeon at Boston Children’s Hospital, where he is also the co-director of the Center for Gender Surgery, and an assistant professor of surgery at Harvard Medical School in Boston, Massachusetts. He completed medical training, residency, and fellowship in hand and microsurgery at Harvard and affiliated hospitals in Boston. His fields of interest include congenital hand surgery and complex microvascular reconstruction.

**Oren Ganor, MD** is a plastic and reconstructive surgeon at Boston Children’s Hospital in Boston, Massachusetts, where he is the founder and co-director of the hospital’s Center for Gender Surgery. He was trained in medicine at the Hebrew University of Jerusalem and completed Harvard fellowships in breast reconstruction and microsurgery at Beth Israel Deaconess Medical Center and a craniofacial and pediatric plastic surgery fellowship at Boston Children’s Hospital. He has presented to various audiences on gender-affirming surgery and transgender health.

**Citation**

*AMA J Ethics.* 2018;20(11):E1067-1074.

**DOI**

10.1001/amajethics.2018.1067.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

## MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

### How Should Clinicians Respond When Patients Are Influenced by Celebrities' Cancer Stories?

Divya Yerramilli, MD, MBE, Alexandra Charrow, MD, MBE, and Arthur Caplan, PhD

*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

Despite the prodigious medical literature on cancer care, some patients rely on celebrity narratives as frameworks for understanding their experiences of cancer and as benchmarks for decision making.

Regardless of whether these narratives are appropriate sources of health information for patients, it has been shown that celebrity narratives influence patterns of care. Three cases—John McCain, Angelina Jolie, and Jimmy Carter—are presented to illustrate how media coverage of cancer can have unforeseen consequences on individual patients exposed to these kinds of stories. For this reason, clinicians should become familiar with these narratives and comfortable with discussing how celebrity narratives can shape patients' views and decisions.

#### Importance of Patient Cancer Narratives

The internet has drastically changed the landscape of medicine in general and cancer care in particular.<sup>1</sup> While the medical profession continues to communicate scientific advances in a top-down manner through medical journals, celebrity narrative has come to matter more as a source of information for the public, as people use the internet for bottom-up "organic advocacy."<sup>2</sup> In the past decade, several high-profile figures have publicly dealt with their cancer diagnoses and in turn shaped the [evolving narrative of cancer](#) in the media. Celebrity cancer stories range from exceptional, nongeneralizable narratives to stories of cancer management that align closely with scientific recommendations. For example, in the case of Senator John McCain's diagnosis of glioblastoma, an incurable cancer, media coverage focusing on triumph obfuscated factual information regarding prognosis, which could inhibit other patients from addressing their goals of care. In the case of Angelina Jolie, who attempted to address breast and ovarian cancer prevention in women with BRCA mutations, the nuances of individual risk were misinterpreted by the public and impacted patterns of care. Finally,

the case of former President Jimmy Carter shows that success with novel therapies can also create expectations for excellent outcomes, although researchers are still actively studying the side effects and benefits of these new agents. Regardless of whether celebrities' experiences are generalizable, physicians cannot ignore the power celebrities have either to perpetuate or to neutralize false impressions of cancer management.

### **John McCain**

Before his death in August 2018, John McCain, the former Republican senator from Arizona, publicly revealed his diagnosis of glioblastoma (a form of brain cancer) and returned to Congress for critical votes regarding US health care and taxes.<sup>3,4</sup> Glioblastoma, unfortunately, is a terminal disease, with the best treatment option consisting of maximal surgical removal of the tumor followed by chemoradiation, with only about a quarter of patients surviving 2 years after diagnosis.<sup>5</sup> McCain's story demonstrated that celebrity can reinforce entrenched, simplified views of cancer as manageable with aggressive, cutting-edge treatment. Media coverage of McCain—a war veteran and then-US senator in the midst of political crisis—focused on his innate character, resilience, and stoicism in his fight against cancer.<sup>6,7</sup> The media, quoting prominent US politicians, leveraged McCain's courage in war to reassure the public that he could overcome an unpredictable and a devastating illness.<sup>8</sup> While messages of positivity and strength are certainly important in helping patients cope, patients facing similar diagnoses might have interpreted such coverage as a promise of their own chances of recovery, although the majority of patients experience fear, weakness, and the very real comorbid psychiatric symptoms and illnesses that can accompany cancer. Unfortunately, in an effort to show support for the senator, these narratives might perpetuate false hope for many patients suffering from glioblastoma, preventing patients and their families from pursuing appropriate care and psychological support.

### **Angelina Jolie**

In another case, Angelina Jolie attempted to alter the depiction of cancer in the media when she wrote about her own concerns about breast cancer risk, given that she had a mutation of the BRCA1 gene.<sup>9</sup> She tried to empower women at risk of breast cancer by discussing her decision to undergo the preventative measure of removing both her breasts and by encouraging awareness of familial risk for breast cancer and exploration of therapeutic options in order to make informed choices.<sup>9</sup> In a follow-up piece about the preventative removal of her ovaries and fallopian tubes, Jolie tempered the generalizability of her story, stating, "There is more than one way to deal with any health issue.... [C]hoose what is right for you personally."<sup>10</sup> Multiple studies have found that the mere publication of Jolie's narrative impacted patterns of care on a broad level, with patients seeking information regarding risk-reducing double mastectomy and asking for genetic testing.<sup>11-13</sup> As is commonly observed by oncologists, patients frequently misinterpret double mastectomy as a recommended safe and precautionary treatment for all women worried about breast cancer, regardless of pre-existing risk, without

realizing Jolie's decision reflected the fact that she had an 87% lifetime risk of breast cancer from a genetic mutation.<sup>9</sup> This misunderstanding of medical facts in many cases leads women to pursue unnecessarily aggressive surgical options when they might otherwise pursue less invasive and less morbid preventative and treatment options.

### **Jimmy Carter**

While Angelina Jolie focused attention on cancer prevention, former President Carter used his celebrity to call attention to novel therapies, such as immunotherapy, for patients with advanced cancers. He described the multidisciplinary care he received—including surgery, immunotherapy, and radiation—as well as the multi-institutional care he received, all of which are in no way restricted to former presidents or Nobel Prize winners.<sup>14,15</sup> His uneditorialized description of the logistics of his care were perhaps the most generalizable. However, access to novel therapeutic agents is not easily obtained, and while former President Carter had a wonderful response to his treatment, there is still a great deal that is unknown about the benefits and risks of new agents such as immunotherapy.<sup>16</sup> These kinds of success stories are important and of scientific merit, but the treatments they describe are not guaranteed miracle cures on which every patient can pin hopes.

### **Influence of Celebrity Cancer Narratives**

These cancer stories matter because they influence care. Several studies have shown that information seeking, cancer screening, and primary prevention are influenced by celebrity narratives of cancer care.<sup>11,13,17-20</sup> However, these studies did not measure the fear and psychological distress that also might accompany excessive screening or drastic unnecessary medical procedures. Furthermore, we know that patients with advanced cancer who do not understand their prognosis are more likely to choose aggressive treatments instead of considering treatments that might better subserve their quality of life.<sup>21,22</sup> Therefore, we can infer that celebrity stories that further perpetuate false understandings of prognosis might lead cancer patients to seek care that might not align with their true wishes had they possessed a realistic understanding of their disease. Mostly, these studies underscore a terrifying reality: patients find scientific evidence generated by rigorous clinical trials less compelling than anecdotes by or about celebrities.

Ultimately, famous people have no legal or ethical obligations to other cancer patients. They are not physicians, and the general public is not their collective patient. They have a right to express their experience of care and how it impacts their lives in the way they choose. Technically, they owe nothing more than any other cancer patient owes in the public domain. To this point, even ordinary people can leverage social media to impact public understanding of cancer.<sup>23</sup> However, celebrities do not have the scientific expertise to give medical advice and to highlight nuances in different cases. This unfortunately

means that, when they do tell their stories, falsehoods and myths can become entrenched in the public understanding of cancer care.

However, to ignore the impact celebrity words have on other patients would be akin to denying that tobacco advertisements have no impact on smoking and, therefore, cancer risk. Celebrity narratives can have powerful effects both in favor of evidence-based medicine and against it.<sup>24</sup> Celebrities communicate how cancer impacts their work, the role of faith as a source of support, and their fear of the possibility of cancer returning. These ambassadors of cancer care share how they struggle to lift life, work, and family out of the sea of medical jargon, appointments, and side effects that become routine. They destigmatize the diagnosis, promote self-empowerment, and help people find support in common experiences.

Celebrity power in the media makes public figures both ideal and necessary partners.<sup>24</sup> Experts in cancer care, whose research is scientifically sound and grounded in data, need to cultivate voices that are strong and emotionally resonant and whose message is accessible to the public as well as evidenced based.

### **Advice for Physicians**

Physicians should be aware of the stories to which patients gravitate before they ever enter the office and should consider reading media in conjunction with medical journals. Relying on the media for health information can be considered a structural risk factor in the same way that a neighborhood with high air pollution and poor access to healthy food and low vaccination rates are structural risk factors. Physicians take into account information about the health environment of the individual—which should include social media—in order to improve communication, narrow differential diagnoses, and make realistic health plans. There could be barriers, biases, limitations, and health literacy discrepancies that form in the online space. It is helpful to know what patients read and to address the impact of this content on how patients view their health.

Ultimately, the best space to engage with patients is still the office. Physicians are limited in their freedom of speech in the office by privacy laws (eg, the Health Insurance Portability and Accountability Act [HIPAA] of 1996) and possibly by liability policies. However, as physicians recognize misconceptions perpetuated online regarding cancer care—such as the belief that extensive surgery is required for low-risk, early stage breast cancer—there might be opportunities in physician-mediated forums to encourage people to discuss their personal medical decisions with their own physicians who understand their clinical case.

The impact of celebrities on cancer care exists, regardless of whether physicians believe it should. In fact, the impact of celebrities on patients' newfound engagement with media extends far beyond cancer and has been shown to impact screening for infectious

diseases as well.<sup>25</sup> In response, medicine must find its way to the information mainstream if patients are to receive the most helpful and accurate information. Physicians can partner with celebrities to ensure accurate information is available online by linking anecdotes with standard guidelines. Furthermore, physicians should understand that relying on media for health information is a structural risk factor and warn patients about the potential effects of the media on their perceptions of cancer and decisions regarding their own health care and bodies.

## References

1. Hesse BW, Nelson DE, Kreps GL, et al. Trust and sources of health information: the impact of the Internet and its implications for health care providers: findings from the first Health Information National Trends Survey. *Arch Intern Med*. 2005;165(22):2618-2624.
2. Leas EC, Althouse BM, Dredze M, et al. Big data sensors of organic advocacy: the case of Leonardo DiCaprio and climate change. *PloS One*. 2016;11(8):e0159885. doi:10.1371/journal.pone.0159885.
3. Hulse C. John McCain has brain cancer, senator's office says. *New York Times*. July 19, 2017. <https://www.nytimes.com/2017/07/19/us/politics/john-mccain-brain-cancer.html>. Accessed November 29, 2017.
4. Oberlander J. Repeal, replace, repair, retreat—Republicans' health care quagmire. *N Engl J Med*. 2017;377(11):1001-1003.
5. Stupp R, Mason WP, van den Bent MJ, et al; European Organisation for Research and Treatment of Cancer Brain Tumor and Radiotherapy Groups; National Cancer Institute of Canada Clinical Trials Group. Radiotherapy plus concomitant and adjuvant temozolomide for glioblastoma. *N Engl J Med*. 2005;352(10):987-996.
6. Morris J. John McCain's brain cancer, and mine. *New York Times*. July 20, 2017. <https://www.nytimes.com/2017/07/20/opinion/john-mccain-brain-cancer-glioblastoma.html>. Accessed November 20, 2017.
7. Charen M. Appreciating John McCain. *National Review*. September 21, 2017. <http://www.nationalreview.com/article/451563/john-mccain-cancer-hero-fights-his-last-battle-perhaps>. Accessed November 29, 2017.
8. Horton A. "Give it hell, John": Washington reacts to Sen. McCain's cancer diagnosis. *Washington Post*. July 20, 2017. [https://www.washingtonpost.com/news/powerpost/wp/2017/07/19/tougher-than-a-2-steak-washington-reacts-to-john-mccains-tumor-diagnosis/?utm\\_term=.80cb27f25edc](https://www.washingtonpost.com/news/powerpost/wp/2017/07/19/tougher-than-a-2-steak-washington-reacts-to-john-mccains-tumor-diagnosis/?utm_term=.80cb27f25edc). Accessed June 28, 2018.
9. Jolie A. My medical choice. *New York Times*. May 14, 2013. <https://www.nytimes.com/2013/05/14/opinion/my-medical-choice.html>. Accessed September 13, 2018.
10. Jolie A. Diary of a surgery. *New York Times*. March 24, 2015. <https://www.nytimes.com/2015/03/24/opinion/angelina-jolie-pitt-diary-of-a-surgery.html>. Accessed November 29, 2017.

11. Evans DGR, Barwell J, Eccles DM, et al. The Angelina Jolie effect: how high celebrity profile can have a major impact on provision of cancer related services. *Breast Cancer Res.* 2014;16(5):442. doi:10.1186/s13058-014-0442-6.
12. Juthe RH, Zaharchuk A, Wang C. Celebrity disclosures and information seeking: the case of Angelina Jolie. *Genet Med.* 2014;17(7):545-553.
13. Noar SM, Althouse BM, Ayers JW, Francis DB, Ribisl KM. Cancer information seeking in the digital age: effects of Angelina Jolie's prophylactic mastectomy announcement. *Med Decis Making.* 2015;35(1):16-21.
14. Almendrala A. Why President Carter's melanoma announcement was groundbreaking. *HuffPost.* August 21, 2015. [https://www.huffingtonpost.com/entry/president-carter-press-conference-groundbreaking\\_us\\_55d63eb0e4b0ab468da07167](https://www.huffingtonpost.com/entry/president-carter-press-conference-groundbreaking_us_55d63eb0e4b0ab468da07167). Accessed November 29, 2017.
15. CSPAN. *Former President Jimmy Carter News Conference on Cancer Diagnosis* [video]. Atlanta, GA: August 20, 2015. <https://www.c-span.org/video/?327705-1/president-jimmy-carter-news-conference-cancer-diagnosis>. Accessed September 13, 2018.
16. Hildebrandt M, Peggs K, Uharek L, Bollard CM, Heslop HE. Immunotherapy: opportunities, risks and future perspectives. *Cytotherapy.* 2014;16(4)(suppl):S120-S129.
17. Ayers JW, Althouse BM, Noar SM, Cohen JE. Do celebrity cancer diagnoses promote primary cancer prevention? *Prev Med.* 2014;58:81-84.
18. Brigo F. Impact of news of celebrity illness on online search behavior: the "Robin Williams phenomenon." *J Public Health.* 2014;37(3):555-556.
19. Chapman S, McLeod K, Wakefield M, Holding S. Impact of news of celebrity illness on breast cancer screening: Kylie Minogue's breast cancer diagnosis. *Med J Aust.* 2005;183(5):247-250.
20. Cram P, Fendrick AM, Inadomi J, Cowen ME, Carpenter D, Vijan S. The impact of a celebrity promotional campaign on the use of colon cancer screening: the Katie Couric effect. *Arch Intern Med.* 2003;163(13):1601-1605.
21. Temel JS, Greer JA, Admane S, et al. Longitudinal perceptions of prognosis and goals of therapy in patients with metastatic non-small-cell lung cancer: results of a randomized study of early palliative care. *J Clin Oncol.* 2011;29(17):2319-2326.
22. Weeks JC, Cook EF, O'Day SJ, et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA.* 1998;279(21):1709-1714.
23. Noar SM, Leas E, Althouse BM, Dredze M, Kelley D, Ayers JW. Can a selfie promote public engagement with skin cancer? *Prev Med.* 2018;111:280-283.
24. Hoffman SJ, Tan C. Following celebrities' medical advice: meta-narrative analysis. *BMJ.* 2013;347:f7151. doi:10.1136/bmj.f7151.



25. Allem JP, Leas EC, Caputi TL, et al. The Charlie Sheen effect on rapid in-home human immunodeficiency virus test sales. *Prev Sci*. 2017;18(5):541-544.

**Divya Yerramilli, MD, MBE** is a resident in the Harvard Radiation Oncology Residency Program in Boston, Massachusetts. She earned a BS in biology from Duke University, and an MBE and MD from the University of Pennsylvania Perelman School of Medicine. Her academic interests include palliative care in oncology, resource allocation, and end-of-life care.

**Alexandra Charrow, MD, MBE** is a fifth-year resident in the Harvard Combined Dermatology Residency Program in Boston. She graduated from Yale University with a degree in philosophy and from the University of Pennsylvania Perelman School of Medicine with an MD and an MBE. Her bioethical writing and research focus on the limitations of medical norms, body modification and enhancement, and the ethics of body-related identity politics.

**Arthur Caplan, PhD** is the Drs William F. and Virginia Connolly Mitty Professor and founding head of the Division of Medical Ethics at the NYU School of Medicine in New York City. Prior to joining the NYU School of Medicine, he was the Sidney D. Caplan Professor of Bioethics at the University of Pennsylvania Perelman School of Medicine, where he created the Center for Bioethics and the Department of Medical Ethics. He is the author or editor of 35 books and more than 725 papers in peer-reviewed journals.

**Citation**

*AMA J Ethics*. 2018;20(11):E1075-1081.

**DOI**

10.1001/amajethics.2018.1075.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

**Copyright 2018 American Medical Association. All rights reserved.  
ISSN 2376-6980**

**HISTORY OF MEDICINE**

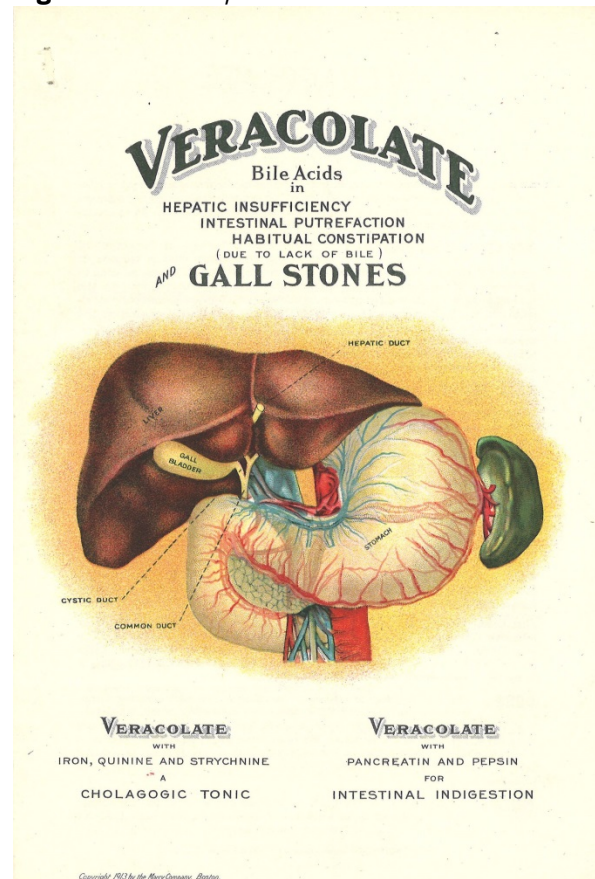
**Ads and Labels From Early 20th-Century Health Fraud Promotions**

Amber Dushman, MA, MLIS

**Abstract**

Ten advertisements and labels from the American Medical Association (AMA) Historical Health Fraud and Alternative Medicine Collection illustrate false health beliefs perpetuated in 20th-century medical quackery promotions. This article canvasses some of the claims made and responses to these ads and labels.

**Figure 1.** *No Relief From Veracolate or the AMA's Chemists*



Courtesy of the American Medical Association Archives.<sup>1</sup>

Veracolate, made by the Marcy Company of Boston, Massachusetts, claimed to aid indigestive problems with iron, quinine, and strychnine. Upon review of Veracolate's

actual chemical composition in 1915, the American Medical Association (AMA) found it to be “semisecret in composition, unscientific in combination.”<sup>2</sup> The AMA noted that Veracolate’s claims were “unwarranted” and wrote to an inquiring woman from Chicago, “A person who continually uses Veracolate ... has simply developed the cathartic habit... They [Veracolate tablets] contain two digestive ferments that are utterly incompatible when given in one tablet.”<sup>3</sup> Veracolate tablets claimed to contain 2 ingredients: pepsin and pancreatin; however, when taken in a tablet form, they were ineffective. Pepsin, a palliative ingredient in Veracolate, is only active in an acid medium, and pancreatin has to act in an alkaline medium, rendering these tablets ineffective for real digestive issues when taken in tablet form.

**Figure 2.** *The Cry of the Cells*, 1917



Courtesy of the American Medical Association Archives.<sup>4</sup>

From the early 1910s through World War II, Oak Balm was advertised as a women’s at-home treatment for ailments of the vaginal tract, allowing customers to treat themselves in the privacy of their own homes. The manufacturer, Hager Medical Company in South Bend, Indiana, used a free booklet to sell Oak Balm through a dramatic storytelling of a history of the body, pain, and remedies. The booklet declares, “When the cells are congested and they cannot find relief locally, they cry for help and this CRY OF THE CELLS is called ‘Pain.’”<sup>5</sup> The Oak Balm manufacturer claimed to remedy pain in females due to menstrual cramps or a rigid cervix, which caused infertility.<sup>6</sup> According to AMA Propaganda Department chemists, who were responsible for gathering and disseminating information concerning health fraud and quackery, the preparation consisted of 2 suppositories made up of boric acid, alum, and cacao butter, but no tannin. Therefore, no oak constituent was present, which was ironic considering the product was named “Oak Balm.”

The AMA did not recommend Oak Balm and questioned its claims of “prompt, pleasant and permanent” cures of all diseases of women, including cancer, gall stones, and arthritis.<sup>7</sup> The Propaganda Department was later renamed the Department of Investigation and answered inquiries from physicians, local Better Business Bureau

offices across the United States, the news media, and members of the public. In the process of preparing answers to these inquiries, the Department also corresponded with federal and state regulatory agencies, state and county medical societies, and experts in the field to verify the legitimacy of promoters' claims. This work was done long before the Food and Drug Administration (FDA) took it over in 1975.

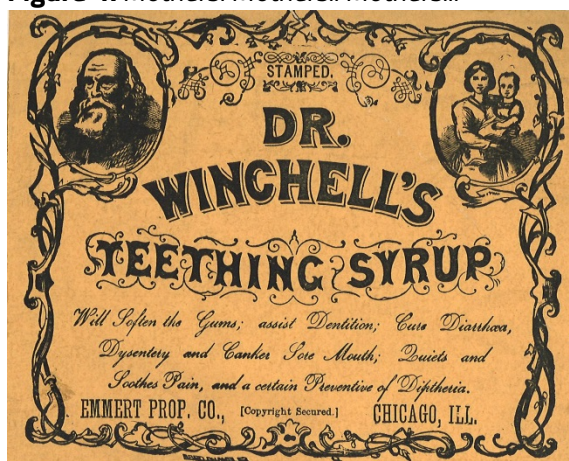
**Figure 3.** *You'll Feel Like a New Person*



Courtesy of the American Medical Association Archives.<sup>8</sup>

This common device of the early 20th century purported to cure most ills of the flesh by means of a violet-colored electrical discharge, which gave a mild superficial stimulation to the part of the body to which it was applied. "Violet-Rays applied by the Violetta reach every cell, tissue and organ of your body—reviving, vitalizing and energizing every atom of your make-up.... From the first treatment you'll feel like a new person," claimed the Vi-Rex Company of Chicago.<sup>9</sup> The company promised consumers increased mental and physical energy and more general success if they used the Violetta. The AMA deemed these claims false in a 1929 letter to Mr K. B. Williamson at the National Better Business Bureau.<sup>10</sup>

Figure 4. Mothers! Mothers!! Mothers!!!



Courtesy of the American Medical Association Archives.<sup>11</sup>

The Emmert Proprietary Company of Chicago, Illinois, sold this deadly product during a brief 2-year period from 1910 to 1912, making claims directed toward mothers that it "was the best medicine for diseases incident to infancy." Manufacturers claimed that the syrup "quiets and soothes all pain," "cures diarrhea and dysentery in the worst forms," and "cures ... diphtheria."<sup>12</sup> The AMA reported very little on Dr Winchell's Teething Syrup but disputed the above claims as false and misleading and reported in *Nostrums and Quackery* that the tonic was misbranded.

Figure 5. Mail Order Cure

A vertical, rectangular advertisement for Dr. W. O. Coffee's World-Famous Home Treatment for Deafness. The top half features the text "Sensational OFFER!" in large, bold, red letters. Below this, a large black number "5" is prominently displayed, with "ONLY \$5" to its left and "Pays for the full 3 Months' Course of" to its right. The product name "Dr. W. O. Coffee's World-Famous Home Treatment for DEAFNESS" is written in bold, black and red text. The bottom section contains a detailed offer: "Just think of it—only \$1.66 a month for this marvelous three months' home treatment which has benefited thousands of men and women from Ear Tubal Deafness. This is our last offer to you—only \$5 pays in full for the same wonderful treatment for which thousands are now paying \$30 (or \$10 a month for three months). To introduce Dr. Coffee's Home Treatment in your community, we make you this very special limited offer. You simply cannot afford to be without this remarkable treatment at this ridiculously low price. Think what it will mean to you. Fill in the coupon at bottom of enclosed large pink sheet, cut out and mail with \$5 (money order or check) today." The advertisement concludes with "Our Last Special Offer for a Limited Time Only—ACT!" and "DR. W. O. COFFEE CO. : : : DAVENPORT, IOWA, U. S. A." A vertical signature "W. O. Coffee" is written on the right side of the ad.

Courtesy of the American Medical Association Archives.<sup>13</sup>

Dr W. O. Coffee's advertisement is an example of 20th-century quackery and mail-order fraud. Proprietor William O. Coffee was a long-time practitioner of fraud who died in 1927; however, not wanting the profitable business to die with his father, his son, P. E. Coffee, carried on his legacy. P. E. Coffee held a degree in homeopathy but was never licensed to practice medicine in the United States and operated the business out of Davenport, Iowa. The W. O. Coffee Company used well-established mail-order methods—in particular, a follow-up system by which several letters were sent to persons who did not act on earlier mailings.

The so-called deafness treatment in this advertisement consisted of 2 powders, an inhalant, oils for the ear, a salve for the nose, another ointment for the ears, and laxative tablets. In a hearing that was part of a lawsuit against Coffee, the company revealed that 2 women without medical training working for the company would “diagnose” deafness in patients and furnish treatments. In one response, Arthur Cramp of the AMA addressed the American Federation of Organizations for the Hard of Hearing and explained that the number of deafness-cure quacks was large in comparison with medical charlatans in general because the patient, after receiving a discouraging verdict from scientific medicine, often turned hopefully to the allure of false claims.<sup>14</sup>

**Figure 6.** *Hair Grows Like a Plant*



Courtesy of the American Medical Association Archives.<sup>15</sup>

Recommended for use a few minutes a day, the Modern Vacuum Cap of Baldness allegedly stopped hair loss and dandruff. According to advertisers who actively promoted the apparatus between 1915 and 1930, all it took was science and common sense. In reality, the vacuum cap was a rubber head piece from which air was removed by a hand pump. “It’s bunk,” stated the AMA in a 1927 letter to the National Better Business Bureau.<sup>16</sup> The device produced a passive hyperemia, an increase—equivalent to mild stimulation—in the amount of blood in scalp vasculature but did not grow hair. The AMA furthered explained to the Better Business Bureau, “In the vast majority of cases of

baldness, the hair follicle is destroyed, and you might just as well expect to grow a new finger when a finger has been cut off as to grow new hair where the hair is actually gone.”<sup>16</sup> The AMA condemned the cap as injurious to the scalp, hair, and head.

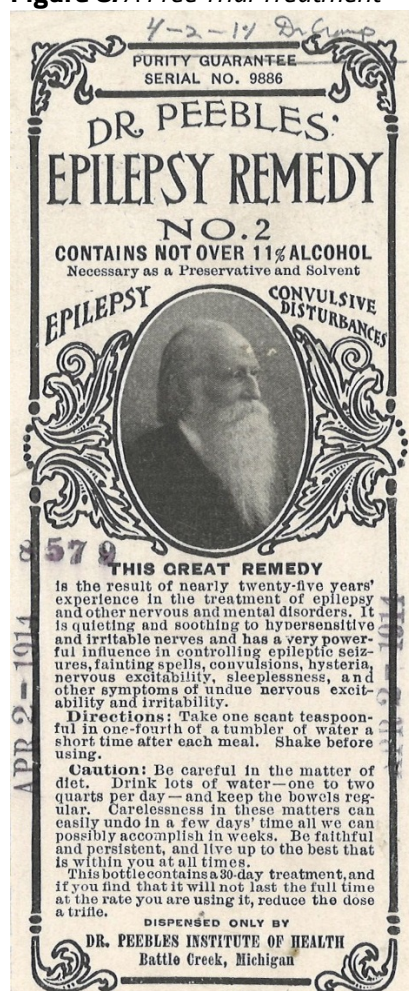
**Figure 7.** *The Natural Way to Health*



Courtesy of the American Medical Association Archives.<sup>17</sup>

This early health food vendor advertised to prospective customers through [chiropractors](#) and other “drugless healers” during the post-World War I years through the Depression years of the 1930s. The manufacturer of Normalettes claimed to cure all in the “the Family Group of Ten: Catarrh, constipation, indigestion, tonic, rejuvenation, underweight, goiter, female diseases, overweight and the growing child.”<sup>18</sup> The nostrum itself was a tablet containing ground plant material coated with chalk and sugar. Other formulas included small amounts of phenolphthalein (laxative) and bile salts, starch digestant, charcoal, and baking soda. According to letters to inquiring physicians and members of the public, the AMA noted that it did not analyze Normalettes so it could not comment on the effects of the pills, but it did warn of the company’s quackish claims and advised that results sought by taking Normalettes could be achieved by a well-balanced diet full of vitamins and minerals. Normalettes does not seem to have advertised beyond Southern California, and the AMA received very few requests for information, which explains why the AMA Bureau of Investigation did not analyze the nostrum.

Figure 8. A Free Trial Treatment

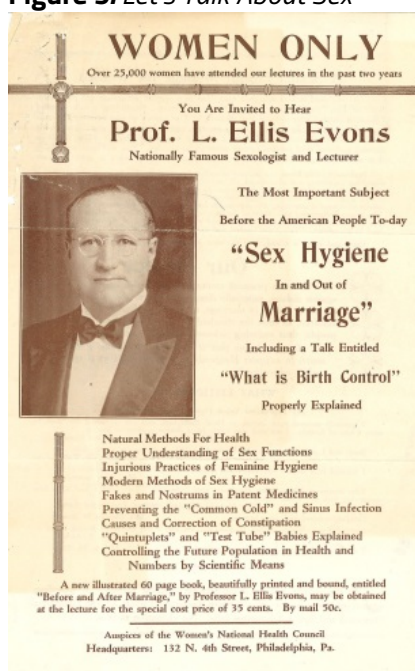


Courtesy of the American Medical Association Archives.<sup>19</sup>

J. M. Peebles of Dr Peebles' Epilepsy Remedy received a fraudulent degree from Philadelphia University of Medicine and Surgery and operated out of Battle Creek, Michigan, during the first quarter of the 20th century. He reached his victims in the usual manner through advertisements placed in newspapers and magazines. He offered a "free trial treatment," which, combined with scare tactics and claims of cures, acted as bait to desperate members of the public who suffered seizures. The chemical breakdown of Dr Peebles' Epilepsy Remedy was 8.4% alcohol and roughly 22% ammonia, potassium, sodium, bromide, and chloride.<sup>20</sup> As the AMA noted, "The use of bromid[e]s in the treatment of epilepsy has been known for years" but was, at best, palliative—a far cry from Peebles' claim that the compound offered a cure. The drug acted as a sedative, generally tending to suppress some seizures. Despite this effect, the AMA did not recommend Dr Peebles' Epilepsy Remedy to epileptics because the "indiscriminate use" of bromides was dangerous.<sup>20</sup> Early studies had found that long-term use of bromides caused irritability, depression, hallucinations, and homicidal tendencies.<sup>20</sup>



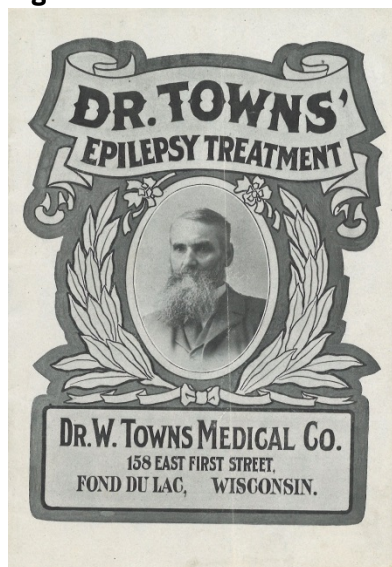
**Figure 9.** *Let's Talk About Sex*



Courtesy of the American Medical Association Archives.<sup>21</sup>

Professor Evons operated out of Philadelphia, Pennsylvania, and was widely known for his lecture series on sex. But sex talks weren't the only thing Professor L. Ellis Evons was selling. He was peddling oxylin antiseptic tablets for guarding against vaginal infections.<sup>22</sup> This poisonous drug was found to contain over 50% boric acid by an FDA inspector. Gearing his products towards women, he also used these lectures to distribute contraceptives. He advertised himself as a "noted biologist and sexologist." However, according to correspondence between the AMA and the Better Business Bureau of Philadelphia in 1934, the Bureau of Investigation revealed "he was wholly unknown to [the] science world."<sup>23</sup> Professor Evons was operating during a time when the Comstock Laws made discussion and distribution of contraceptives illegal. He used the "Women's National Health Council," a sham operation, as a front to arrange his well-attended lectures. Although they were ostensibly free, he did ask for donations from the women who attended. It's believed that he secretly sold his contraceptives in a back room after these lectures. In 1935, he was fined for distributing contraceptives in Philadelphia. Just one year prior, he had been arrested in Albany, New York, for giving a lecture on birth control as part of a sting operation that involved the AMA. At the June 1938 annual meeting, the AMA passed policy "so that physicians may legally give contraceptive information to their patients,"<sup>24</sup> reflecting the changing laws and acceptance of dispensing contraceptives as a valid medical practice in the United States.

**Figure 10.** *You Cured Me*



Courtesy of the American Medical Association Archives.<sup>25</sup>

Dr Towns' Epilepsy Treatment purported, "Most physicians claim there is no cure.... We claim there is a positive, permanent and speedy cure."<sup>26</sup> The Dr W. Towns' Medical Company of Fond Du Lac, Wisconsin, was one of many providers of fake cures for epilepsy during the early 20th century. As reported in *JAMA*, Towns circulated a leaflet giving what he called "endorsements" of his nostrum and published a celebratory editorial about his nostrum in the *American Journal of Health*.<sup>27</sup> However, this editorial meant little to those who knew that the *American Journal of Health* would endorse any fake willing to pay its publication fee.<sup>27</sup> Federal chemists found that Towns' nostrum consisted of sweetened, flavored ammonium bromide and salt, a sugar-coated pill of sulphonyl mixed with talcum and tolu, and black pills composed of charcoal, sugar, phosphorus, and inorganic matter, with a small amount of strychnine-bearing material. These chemists declared Towns' Epilepsy Treatment misbranded as a "cure" for epilepsy.<sup>27</sup> Federal authorities prosecuted Towns for making false and misleading claims; Towns pleaded guilty and was fined.

### References

1. Marcy Company. Veracolate [advertisement]. 1913. Historical Health Fraud and Alternative Medicine Collection; Box 879, Folder 26. Chicago, IL: American Medical Association Archives.
2. DWA. Queries and minor notes: Veracolate. *JAMA*. 1919;72(17):1245.
3. McIntyre letter. September 1, 1925. Historical Health Fraud and Alternative Medicine Collection; Box 879, Folder 26. Chicago, IL: American Medical Association Archives.

4. Hager Medical Company. Oak Balm [advertisement]. 1917. Historical Health Fraud and Alternative Medicine Collection; Box 305, Folder 06. Chicago, IL: American Medical Association Archives.
5. Hager Medical Company. Cry of the cells [booklet]. 1912. Historical Health Fraud and Alternative Medicine Collection; Box 305, Folder 06. Chicago, IL: American Medical Association Archives.
6. Hager Medical Company. Promotional letter. 1925. Historical Health Fraud and Alternative Medicine Collection; Box 305, Folder 06. Chicago, IL: American Medical Association Archives.
7. Hager Medical Company. Female weakness cures [pamphlet]. 1928. Historical Health Fraud and Alternative Medicine Collection Box; 305 Folder 06. Chicago, IL: American Medical Association Archives.
8. Bleadon-Dun Company. Free VI-REX ozone generator [advertisement]. 1928. Historical Health Fraud and Alternative Medicine Collection; Box 884, Folder 05. Chicago, IL: American Medical Association Archives.
9. Bleadon-Dun Company. Promotional letter. August 23, 1919. Historical Health Fraud and Alternative Medicine Collection; Box 884, Folder 05. Chicago, IL: American Medical Association Archives.
10. American Medical Association. KB Williamson to the National Better Business Bureau [letter]. 1929. Historical Health Fraud and Alternative Medicine Collection; Box 884, Folder 05. Chicago, IL: American Medical Association Archives.
11. Emmert Proprietary Company of Chicago. Dr Winchell's teething syrup [advertisement]. 1910-1912. Historical Health Fraud and Alternative Medicine Collection; Box 392, Folder 14. Chicago, IL: American Medical Association Archives.
12. Miscellaneous nostrums pamphlet. 1910. Historical Health Fraud and Alternative Medicine Collection; Box 392, Folder 14. Chicago, IL: American Medical Association Archives.
13. Coffee WO. Dr W.O. Coffee's world-famous home treatment for deafness [advertisement]. [n.d.] Historical Health Fraud and Alternative Medicine Collection; Box 154, Folder 06. Chicago, IL: American Medical Association Archives.
14. Cramp A. Warns against quacks offering deafness cures. June 18, 1930. Historical Health Fraud and Alternative Medicine Collection; Box 154, Folder 06. Chicago, IL: American Medical Association Archives.
15. Modern Vacuum Cap Company. Showing the modern vacuum cap in use [advertisement]. September 18, 1915. Historical Health Fraud and Alternative Medicine Collection; Box 516, Folder 11. Chicago, IL: American Medical Association Archives.
16. American Medical Association. KB Williamson to the National Better Business Bureau [letter]. October 8, 1927. Historical Health Fraud and Alternative

Medicine Collection; Box 516, Folder 11. Chicago, IL: American Medical Association Archives.

17. Health Laboratories, Inc. Normalettes [advertisement]. 1926-1935. Historical Health Fraud and Alternative Medicine Collection; Box 582, Folder 01. Chicago, IL: American Medical Association Archives.
18. Health Laboratories, Inc. Normalettes [pamphlet]. [n.d.] Historical Health Fraud and Alternative Medicine Collection; Box 852, Folder 01. Chicago, IL: American Medical Association Archives.
19. Dr. Peebles Institute of Health. Dr. Peebles' epilepsy remedy [advertisement]. [n.d.] Historical Health Fraud and Alternative Medicine Collection; Box 643, Folder 04. Chicago, IL: American Medical Association Archives.
20. American Medical Association. The propaganda for reform: Dr Peebles' Institute of Health: a fraudulent and dangerous "cure" for epilepsy. *JAMA*. 1915;64(5):455-456.
21. Women's National Health Council. Sex talks [flyer]. [n.d.] Historical Health Fraud and Alternative Medicine Collection; Box 787, Folder 11. Chicago, IL: American Medical Association Archives.
22. Evons LE. Lecture flyer. [n.d.] Historical Health Fraud and Alternative Medicine Collection; Box 787, Folder 11. Chicago, IL: American Medical Association Archives.
23. American Medical Association. Letter to the Better Business Bureau of Philadelphia. June 20, 1934. Historical Health Fraud and Alternative Medicine Collection; Box 787, Folder 11. Chicago, IL: American Medical Association Archives.
24. American Medical Association. Resolutions from the section of nervous and mental disease recommending alternation of existing laws relative to contraceptive information In: Proceedings from the 89th House of Delegates of the American Medical Association Session; June 13-17, 1938; Chicago, IL. [http://ama.nmtvault.com/jsp/viewer.jsp?doc\\_id=ama\\_arch%2FHOD00001%2F0000030&page\\_name=89](http://ama.nmtvault.com/jsp/viewer.jsp?doc_id=ama_arch%2FHOD00001%2F0000030&page_name=89). Accessed July 5, 2018.
25. Dr W. Towns Medical Company. Dr Towns' epilepsy treatment [advertisement]. [n.d.] Historical Health Fraud and Alternative Medicine Collection; Box 853, Folder 8. Chicago, IL: American Medical Association Archives.
26. Dr W. Towns Medical Company. Dr Towns' epilepsy treatment [brochure]. 1911. Historical Health Fraud and Alternative Medicine Collection; Box 853, Folder 8. Chicago, IL: American Medical Association Archives.
27. American Medical Association. The propaganda for reform: convictions under the Food and Drugs Act: more frauds exposed by the Bureau of Chemistry. *JAMA*. 1912;58(1):51-52.

**Amber Dushman, MA, MLIS** is the manager of the American Medical Association's Department of Records Management and Archives in Chicago, Illinois, where she has managed the organization's historical collections since 2010. She holds a master's degree in public history from Loyola University Chicago and a master's of library and information science degree from Dominican University.

**Citation**

*AMA J Ethics.* 2018;20(11):E1082-1093.

**DOI**

10.1001/amajethics.2018.1082.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

## ART OF MEDICINE

### When I Take Off My White Coat...

Joseph Gascho, MD

#### Abstract

Lay persons might think physicians spend all their time in hospitals or clinics or that physicians fly their private jets to exclusive resorts for long weekends. But physicians are regular people just like their patients, and, when not on the job, they do many of the same things for the same reasons: playing with pets and doing sports, music, and art. Physicians might not have a blue-ribbon dog, might not have played varsity basketball in college, might not have gone to Julliard before medical school, might not have had one-person exhibits at the Metropolitan Museum of Art, but what they do when they are not wearing their white coats can make them better physicians when they put the coats back on again.

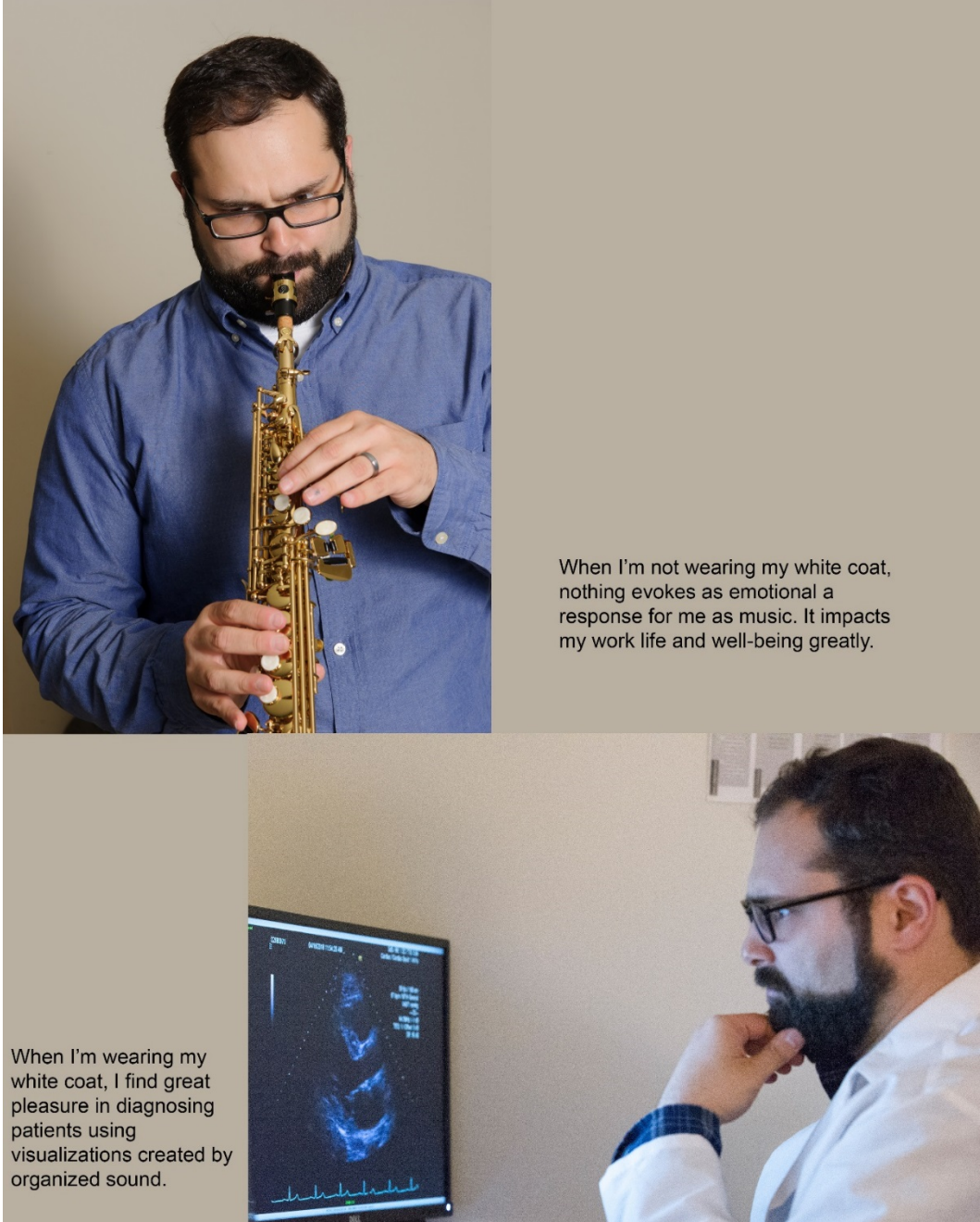
**Figure 1.** Dwight Davis, MD With Dog and With Students and Residents on Rounds



When I'm not wearing my white coat, I try to enjoy and give thanks for the many simple pleasures of life.

When I'm wearing my white coat, I remind our residents and students about the unique responsibility we have to provide humanistic care to our patients during difficult times in their lives.

**Figure 2.** Michael Farbaniec, MD Making Sound and Reading Images of Sound



When I'm not wearing my white coat, nothing evokes as emotional a response for me as music. It impacts my work life and well-being greatly.

When I'm wearing my white coat, I find great pleasure in diagnosing patients using visualizations created by organized sound.



**Figure 3.** Faisal Aziz, MD Holding a Painting and Gowned in Operating Room



When I'm not wearing my white coat, the world is beautiful and despite using all the colors that I use to paint, I can only capture a tiny portion of its beauty.

When I'm wearing my white coat, the whole universe stops and the only thing that matters is the patient on the operating table.

**Figure 4.** Anisa Chaudhry, MD Serving a Tennis Ball and Examining a Patient



When I'm not wearing my white coat, I enjoy sun, fun, and exercise. Tennis allows me to do all three while never "taking my eye off the ball."

When I'm wearing my white coat, I think about the physical exam. It might be a dying art, but it will always remain an integral part of clinical assessment in adults with congenital heart disease.

**Joseph Gascho, MD** is a cardiologist at Penn State College of Medicine in Hershey, Pennsylvania. A published poet and photographer, he has portraits of patients, physicians, and support staff on permanent display at Penn State Health Milton S. Hershey Medical Center.

**Citation**

*AMA J Ethics.* 2018;20(11):E1094-1099.

**DOI**

10.1001/amajethics.2018.1094.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

**Copyright 2018 American Medical Association. All rights reserved.  
ISSN 2376-6980**

**PERSONAL NARRATIVE**

**How Should a Research Ethicist Combat False Beliefs and Therapeutic Misconception Risk in Biomedical Research?**

Jennifer B. McCormick, PhD, MPP

**Abstract**

Therapeutic misconception can be especially challenging at large research-intensive academic medical centers, where boundaries between clinical care and research can become murky. In early stage clinical trials, for example, physicians often encourage patients to enroll in a drug or an intervention study as part of a treatment plan. As a research ethicist, I have found myself having to temper researchers' enthusiasm to prevent their overemphasizing positive benefits to participants. One strategy I've used is to encourage researchers to collaborate with treating physicians and to continually engage participants in assessing risks and benefits. This strategy has been helpful not only in early stage trials but also in translational genomic studies in which research can be used in part as a means of making costly testing available to patients.

**Mistaking Research for Treatment**

What do we mean by misconception? Essentially, a misconception is an erroneous or mistaken belief about how something works, what something is, or why something occurs; it is a species of falsehood. In research settings, a particular false belief has been described by the term *therapeutic misconception*.

The notion of therapeutic misconception was first defined in the 1980s as a research participant's mistaken belief that decisions about her personal medical care are being made solely for her benefit while she is a participant in a research study.<sup>1,2</sup> That is, participants might not appreciate the distinction between their roles as research participants contributing to the creation of generalizable knowledge and their roles as patients receiving personalized medical care. Since the introduction of the concept, others have conducted empirical studies of this phenomenon and have refined what constitutes therapeutic misconception.<sup>3-8</sup> There has been recognition that it is not only patient-subjects who have misconceptions about the goals of the study in which they are enrolled but also researchers and clinicians.<sup>9-13</sup> Therapeutic misconception, a concept that has been discussed and studied for several decades, is increasingly a challenge in

the current era of translational science (which has been referred to as research going from “bench to bedside to backyard”).<sup>14</sup>

### **Curbing Enthusiasm**

For the last 10 years, I have been a member of research ethics consultation services (RECS), first at the Mayo Clinic and currently at Penn State College of Medicine. RECS began appearing in large academic research institutions in the middle of the last decade of the 20th century and aim to maximize the benefits while at the same time minimizing the harms of science for research participants, patients, researchers, and the public.<sup>15-17</sup> In this role, I have been asked to participate on studies—specifically, to be involved in the [consent process](#). Good informed consent is not a one-time event; it is a continuous discussion during which a participant is reminded of the voluntary nature of her participation, the potential risks and benefits to her, and the purpose of her participation. Reiterating that research goals are based on research questions—not the participant’s condition—and that benefits to her are not expected can help minimize therapeutic misconception and the false beliefs it can generate. Investigators who have requested my participation have wanted assistance in addressing therapeutic misconception and in ensuring that research participants appreciated that the chief goal of the study was to generate generalizable knowledge.

One of the first studies on which I was consulted was an early adipose-derived human mesenchymal stromal cell trial for [amyotrophic lateral sclerosis](#) (ALS) patients.<sup>18,19</sup> The major purpose of my presence was to observe the consent process with patients. I would debrief with the investigator, who obtained participants’ consent, to share my reflections on how the conversation went; not uncommonly, I would point out participants whom I felt might not have understood ethically and clinically relevant distinctions between their participation in research and their parallel clinical care. Investigators also sought my expertise to assure themselves that they were keeping their own enthusiasm about potential benefits in check. Because ALS patients are vulnerable and desperate for a cure and because this was a stem cell trial and stem cells are considered new cutting-edge technology with complex risks, they believed it was critical to have my involvement and guidance.

### **Trading False Beliefs for False Hope?**

Over time, my role became smaller because this investigative team was particularly sensitive to the nature of its participant population: desperate patients and families who might be vulnerable to even mere hints of hyperbole. This experience occurred about 7 or 8 years ago, but it stands out because while there was great potential for consent conversations to be muddled and unintentionally misleading—due to technical complexity and power imbalances among clinicians, investigators, and patient-subjects—they weren’t. That is, the team’s awareness of participants’ desperation, the hype around the technology, and their own enthusiasm and excitement about their novel

approach actually led to some of the best informed consent conversations I have witnessed. However, despite the thoughtful and deliberate steps the team took in recruiting and enrolling participants and in conducting informed consent discussions, some participants who enrolled held the false belief that they might benefit directly from participation. Indeed, because this was an early phase 1 trial with a novel approach to stem cell therapy, the chance for any kind of benefit to a participant was, as the saying goes, “slim to none, and slim was out of town.” The existence of therapeutic misconception and the extremely low chance of personal benefit raised an important ethical question about communication: How should one communicate clearly, truthfully, and compassionately to patient-subjects who have very little hope? One goal was to try to eliminate false beliefs without creating false hope.

My experience as a consultant on the ALS study has led me to assess more closely the role of hope in medicine versus research and to consider in more detail how to protect the good that comes from providing hope. How do we mitigate an unfounded hope in families and in patient-subjects whose prognosis is frightening—with no relief in sight except death—while not squashing an informed optimism, or what some have called therapeutic optimism?<sup>6</sup> These types of discussions continue to be important for researchers to engage in with research ethicists and social scientists who study research participant attitudes, perceptions, and understanding, particularly in large research-intensive academic medical centers. Here, in the epicenters of translational biomedical research, the difference between being a patient and a research participant is not always clear cut or black and white.

### **Translational Genomic Research Challenges**

This gray space, where the [boundaries between clinical care and research](#) are blurry, can be complicated to navigate because of the custom of maintaining research and clinical care as two distinct activities, with no overlap.<sup>20,21</sup> Maintaining a firm wall between the two is increasingly challenging, including in translational genomics. Translational genomic research, eg, studying the use of genome sequencing for diagnosis, identification of potential therapies, or prescribing medications is moving forward at a rapid pace.<sup>21</sup> While these studies have clear research objectives about creating generalizable knowledge, findings with potential medical benefits to participants or their relatives can also be generated. As Churchill et al. have noted, such findings are “necessarily a secondary aim, a felicitous by-product of the major research purpose, and not the chief agenda.”<sup>22</sup> It’s also a gray space because participation typically involves not much more than a blood draw or permission to use blood or other tissue left over from a clinical procedure, with the physical risks from a blood draw or clinical procedure that would be (or that had been) performed regardless of research participation seeming almost nonexistent. However, the lack of a tangible research intervention might make therapeutic misconception even more of a concern. My second example is a translation genomic study in oncology for which I was asked to join a research team as co-

investigator, with my primary role being the “curber of enthusiasm” (C Rentmeester, written communication, April 2018).

The specific translational genomic study—a clinical study in the view of the institutional review board but really a discovery study with no intervention—was aimed at seeing whether any targetable genomic changes in participants’ tumors could be identified with mate-pair sequencing.<sup>23</sup> Mate-pair sequencing and analysis allow for ready identification of large deletions, duplications, and other structural changes to chromosomes that can affect gene function. The study team was specifically after targetable changes to the genome that would not otherwise be considered in clinical decision making about what chemotherapies to use for treatment. It was a discovery study, but it also had potential benefit to the individual participants because (1) most participants had failed standard therapy and (2) the sequencing might identify a molecular genetic target for a therapy that would not otherwise be used.

The investigators were cognizant of their limitations; that is, they knew they were extremely excited about the potential clinical benefit to individual participants. This exuberance, they knew, could possibly lead to biased informed consent discussions by overemphasizing potential benefits to participants. Similar to the ALS study, many of these participants were desperate for a beneficial treatment or cure. The investigators asked me to join the team to oversee the consent process as well as any “return of research results” communications to participants. As it happened, I ended up obtaining consent from many of the participants. I also participated in most of the communications with individual participants and with the participants’ oncologists when a research result rose to the level of being potentially clinically useful. My personal goal was to make the communications clear and explicit about what was actually known and had evidence behind it versus what was anecdotal and speculative. This task was challenging: the investigators were incredibly optimistic about their work, the oncologists were determined to find something for these patients, the technology was exciting, and we all wanted to do something for these research participants who were desperate patients. As biomedical scientists, bioethicists, and clinicians, we had each gotten into the business to help patients.

One participant whom I will likely remember for some time is AH, a woman in her mid-thirties with ovarian cancer. She had undergone several rounds of chemotherapy with limited success in shrinking the tumor. I had engaged her in the process of consent to the study and was involved in several subsequent conversations. In all of these interactions, I was challenged by my own desire to help AH remain optimistic while at the same time being realistic about the very small chance that this discovery research would identify her silver bullet. Even if a pathogenic variant in her tumor genome was identified that was targeted by a drug AH had not tried (because that gene was not usually targeted for her type of cancer), a number of steps would need to be taken in both research and

clinical labs to validate the finding. Then we would have to get access to the drug (likely for off-label use) or find a clinical trial for which AH qualified. Balancing optimism with realism was a continual challenge, especially with AH. I spoke with AH several times about her role as a research participant (not as a patient) in this discovery research project (with an emphasis on discovery) while also keeping her abreast of the study's progress, hoping that hearing about it might help maintain her therapeutic optimism. I still sometimes wonder how successful I was in balancing optimism with realism.

### **Conclusion**

Therapeutic misconception might not often be thought of as species of falsehood. Falsehood is about misunderstanding or thinking inaccurately about something. In therapeutic misconception, that "something" is the distinction between research participation, in which the relationship is between the investigator or study team and the participant, and clinical care, in which the relationship is between the patient and the clinician or clinical team. While some have argued that worrying about therapeutic misconception can undermine rather than promote participants' understanding and informed consent,<sup>24</sup> others argue that being concerned about therapeutic misconception and its clinical and ethical relevance is more important than ever because the assumptions of and relationships between researchers and participants (and clinicians and patients) can be rather muddled in translational research, learning health systems, and research-intensive academic medical centers,<sup>20</sup> where clinicians are also investigators, patients are also participants, and research results can have clinical usefulness to participants.

Therapeutic misconception is a unique type of false belief, yet it is an important one in medical research and medicine. Clinicians and researchers alike need to continue being in tune to its challenges and should be able to recognize when they themselves are vulnerable to it. As I—and investigators who have pulled me into their studies—have discovered, individuals like me can fill a niche helping patients and investigators navigate the translational blurriness.

### **References**

1. Appelbaum PS, Roth LH, Lidz C. The therapeutic misconception: informed consent in psychiatric research. *Int J Law Psychiatry*. 1982;5(3-4):319-329.
2. Appelbaum PS, Roth LH, Lidz CW, Benson P, Winslade W. False hopes and best data: consent to research and the therapeutic misconception. *Hastings Cent Rep*. 1982;17(2):20-24.
3. National Bioethics Advisory Commission. *Ethical and Policy Issues in International Research: Clinical Trials in Developing Countries*. Vol 1. <https://bioethicsarchive.georgetown.edu/nbac/clinical/Vol1.pdf>. Published April 2001. Accessed May 14, 2018.



4. National Bioethics Advisory Commission. *Ethical and Policy Issues in International Research: Clinical Trials in Developing Countries*. Vol 2. <https://bioethicsarchive.georgetown.edu/nbac/clinical/Vol2.pdf>. Published May 2001. Accessed May 7, 2018.
5. Henderson GE, Churchill LR, Davis AM, et al. Clinical trials and medical care: defining the therapeutic misconception. *PLoS Med*. 2007;4(11):e324. doi:[10.1371/journal.pmed.0040324](https://doi.org/10.1371/journal.pmed.0040324).
6. Horng S, Grady C. Misunderstanding in clinical research: distinguishing therapeutic misconception, therapeutic misestimation, and therapeutic optimism. *IRB*. 2003;25(1):11-16.
7. Miller FG, Brody H. A critique of clinical equipoise. Therapeutic misconception in the ethics of clinical trials. *Hastings Cent Rep*. 2003;33(3):19-28.
8. Kimmelman J, Levenstadt A. Elements of style: consent form language and the therapeutic misconception in phase 1 gene transfer trials. *Hum Gene Ther*. 2005;16(4):502-508.
9. Joffe S, Cook EF, Cleary PD, Clark JW, Weeks JC. Quality of informed consent in cancer clinical trials: a cross-sectional survey. *Lancet*. 2001;358(9295):1772-1777.
10. Joffe S, Weeks JC. Views of American oncologists about the purposes of clinical trials. *J Natl Cancer Inst*. 2002;94(24):1847-1853.
11. Taylor KM, Kelner M. Interpreting physician participation in randomized clinical trials: the Physician Orientation Profile. *J Health Soc Behav*. 1987;28(4):389-400.
12. Taylor KM. Integrating conflicting professional roles: physician participation in randomized clinical trials. *Soc Sci Med*. 1992;35(2):217-224.
13. Taylor KM, Feldstein ML, Skeel RT, Pandya KJ, Ng P, Carbone PP. Fundamental dilemmas of the randomized clinical trial process: results of a survey of the 1,737 Eastern Cooperative Oncology Group investigators. *J Clin Oncol*. 1994;12(9):1796-1805.
14. Murtagh MJ, Demir I, Harris JR, Burton PR. Realizing the promise of population biobanks: a new model for translation. *Hum Genet*. 2011;130(3):333-345.
15. Cho MK, Tobin SL, Greely HT, McCormick J, Boyce A, Magnus D. Strangers at the benchside: research ethics consultation. *Am J Bioeth*. 2008;8(3):4-13.
16. Cho MK, Tobin SL, Greely HT, McCormick J, Boyce A, Magnus D. Research ethics consultation: the Stanford experience. *IRB*. 2008;30(6):1-6.
17. McCormick JB, Sharp RR, Ottenberg AL, Reider CR, Taylor HA, Wilfond BS. The establishment of research ethics consultation services (RECS): an emerging research resource. *Clin Transl Sci*. 2013;6(1):40-44.
18. Lindner U, Kramer J, Rohwedel J, Schlenke P. Mesenchymal stem or stromal cells: toward a better understanding of their biology? *Transfus Med Hemother*. 2010;37(2):75-83.

19. Staff NP, Madigan NN, Morris J, et al. Safety of intrathecal autologous adipose-derived mesenchymal stromal cells in patients with ALS. *Neurology*. 2016;87(21):2230-2234.
20. Beauchamp TL, Saghai Y. The historical foundations of the research-practice distinction in bioethics. *Theor Med Bioeth*. 2012;33(1):45-56.
21. Wolf SM, Burke W, Koenig BA. Mapping the ethics of translational genomics: situating return of results and navigating the research-clinical divide. *J Law Med Ethics*. 2015;43(3):486-501.
22. Churchill LR, King NM, Henderson GE. Why we should continue to worry about the therapeutic misconception. *J Clin Ethics*. 2013;24(4):381-386.
23. Harris FR, Kovtun IV, Smadbeck J, et al. Quantification of somatic chromosomal rearrangements in circulating cell-free DNA from ovarian cancers. *Sci Rep*. 2016;6:29831. doi:10.1038/srep29831.
24. Wendler DS. Time to stop worrying about the therapeutic misconception. *J Clin Ethics*. 2012;23(3):272-287.

**Jennifer B. McCormick, PhD, MPP** is a member of the Penn State Clinical and Translational Science Institute's program leadership and the American Society of Human Genetics' Social Issues Committee. She completed a doctoral degree in molecular and cellular biology, a postdoctoral fellowship in biological chemistry, master's degree in public policy, and a National Human Genome Research Institute Centers of Excellence in ELSI (Ethical, Legal and Social Implications) Research fellowship. She lectures frequently on topics related to research ethics and science policy, responsible conduct in research, informed consent, translational research ethics, translational genomics and policy, and social responsibility in science.

**Citation**

*AMA J Ethics*. 2018;20(11):E1100-1106.

**DOI**

10.1001/amajethics.2018.1100.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

**Copyright 2018 American Medical Association. All rights reserved.  
ISSN 2376-6980**

## LETTER TO THE EDITOR

### Added Points of Concern About Caring for Dying Patients

Annette Hanson, MD, Ron Pies, MD, and Mark Komrad, MD

*This correspondence responds to "How Should Physicians Care for Dying Patients With Amyotrophic Lateral Sclerosis?" which appeared in the August 2018 issue of the AMA Journal of Ethics.*

If there is any doubt that the legalization of assisted suicide has changed the ethos of medicine, that question should be settled by Craig and Dzung's article, "How Should Physicians Care for Dying Patients with Amyotrophic Lateral Sclerosis?" As psychiatrists and ethicists, we appreciate Craig and Dzung's attempt to highlight some central ethical issues involved in end-of-life care. However, we are deeply troubled by the article's implicit message: namely, that physicians are acting ethically when they help patients kill themselves in such a way as to avoid legal liability. In our view, that self-serving calculation serves physicians' interests—not patients' well-being. We are also troubled by several critical omissions in the fictional Dr S's evaluation and clinical management of "Donald"—a patient with [amyotrophic lateral sclerosis](#) (ALS) and extreme physical limitations who is requesting what the American College of Physicians rightly terms "physician-assisted suicide" (PAS).<sup>1</sup>

In the case, Dr S worries that despite these extreme physical limitations, Donald might somehow still be able to kill himself in a protracted or violent way, and he considers a lethal prescription to be an acceptable alternative means of death. Some proponents of assisted suicide assert that patients who seek medically assisted death are so determined to die that they will merely find another method if denied a prescription. Jones and Paton<sup>2</sup> tested this method-substitution theory and found, on the contrary, that having an assisted suicide law on the books did nothing to reduce the rate of "natural" (ie, nonassisted) suicides. States that offered physician-assisted suicide had no reduction in nonassisted suicides.<sup>2</sup> Conversely, states without assisted suicide laws had similar increases in nonassisted suicides as states with the laws.<sup>2</sup> However, having an assisted suicide law on the books does increase total state suicide rates by 11.79% when a range of factors are controlled for.<sup>2</sup> Indeed, evidence from Oregon suggests there might be a "contagion" effect, owing to highly publicized cases of PAS, such as that of Brittany Maynard.<sup>3</sup>

Craig and Dzung write that their fictional patient must pass through "rigorous psychological testing" in order to obtain a lethal script. Yet neither Washington State nor Oregon have legislated mandatory psychological evaluation or testing for patients who

request assisted suicide.<sup>4,5</sup> In reality, only 3.5% of Oregon patients given prescriptions were referred for psychiatric evaluation in 2017.<sup>4</sup> In *The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals*, the Task Force to Improve the Care of Terminally-Ill Oregonians acknowledges that, in practice, the act's statutory safeguards do not adequately protect people with mental illness.<sup>6</sup> Nor do assisted suicide laws require a voluntary referral for mental health care as part of the informed consent process.

In the fictionalized vignette, Dr S never explores factors in Donald's request that could stem from subtle forms of coercion, such as pressure from family members to end his life. Nor is there any assessment of **cognitive distortions** that might be clouding the patient's judgment. Instead, in the case, Donald's apparent motivations are rather credulously accepted at face value. Nor does Dr S offer Donald mental health care and counseling in his discussion of treatment alternatives. This is particularly worrying, given that 35% to 50% of ALS patients have cognitive deficits related to decision-making capacity.<sup>7</sup>

The authors are concerned about the "significant harm" that can come from denying a patient's autonomy and agency, and "the potential harms of refusing to prescribe lethal drugs." Yet they cite no empirical data showing that a physician's refusal to prescribe lethal medication leads to any type of "significant harm." As psychiatrists, we recognize that temporary limitations on patient autonomy and agency—coupled with empathic counseling—can lead to continued life, re-engagement, and a renewed sense of meaning even in the face of a terminal illness.

## References

1. Sulmasy LS, Mueller PS. Ethics and the legalization of physician-assisted suicide: an American College of Physicians position paper. *Ann Intern Med*. 2017;167(8):576-578.
2. Jones DA, Paton D. How does legalization of physician-assisted suicide affect rates of suicide? *South Med J*. 2014;108(10):599-604.
3. Dore MK. In Oregon, other suicides have increased with the legalization of physician-assisted suicide. Choice Illusion Montana. <http://www.choiceillusionmontana.org/2017/09/by-margaret-k.html>. Published August 18, 2017. Accessed August 9, 2018.
4. Oregon Health Authority. Oregon Death with Dignity Act 2017 data summary. <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf>. Published February 9, 2018. Accessed August 14, 2018.
5. Washington State Department of Health. Washington State Death with Dignity Act report. <https://www.doh.wa.gov/Portals/1/Documents/Pubs/422-109-DeathWithDignityAct2017.pdf>. Published March 2018. Accessed August 14, 2018.

6. Task Force to Improve the Care of Terminally-Ill Oregonians. *The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals*. Center for Ethics in Health Care, Oregon Health & Science University.  
<http://www.ohsu.edu/xd/education/continuing-education/center-for-ethics/ethics-outreach/upload/Oregon-Death-with-Dignity-Act-Guidebook.pdf>.  
Published March 1998. Updated December 2008. Accessed August 14, 2018.
7. Irwin D, Lippa CF, Swearer JM. Cognition and amyotrophic lateral sclerosis (ALS). *AM J Alzheimers Dis Other Demen*. 2007;22(4):300-312.

**Annette Hanson, MD** is an assistant professor of psychiatry at the University of Maryland in Baltimore, Maryland, where she is also the director of the forensic psychiatry fellowship.

**Ron Pies, MD** is professor emeritus of psychiatry at State University of New York (SUNY) Upstate Medical University in Syracuse, New York. He attended SUNY Upstate Medical University, where he also completed his residency in psychiatry.

**Mark Komrad, MD** is an assistant professor of psychiatry at the University of Maryland School of Medicine in Baltimore, Maryland.

#### **Citation**

*AMA J Ethics*. 2018;20(11):E1107-1109.

#### **DOI**

10.1001/amajethics.2018.1107.

#### **Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

**Copyright 2018 American Medical Association. All rights reserved.  
ISSN 2376-6980**

## LETTER TO THE EDITOR

### Response to “Added Points of Concern About Caring for Dying Patients”

Alexander Craig, MPhil and Elizabeth Dzeng, MD, PhD, MPH

*This correspondence responds to a letter to the editor, “[Added Points of Concern About Caring for Dying Patients](#),” which was written in response to “[How Should Physicians Care for Dying Patients With Amyotrophic Lateral Sclerosis?](#)”*

We are grateful to Hanson, Pies, and Komrad for raising important issues regarding the mental health aspects of Donald’s case. The issues presented are indeed ethically challenging, and this case conjures strong views and emotions on all sides.

It is unfortunate that this letter’s authors perceive Dr S’s careful scrutiny of the laws to be motivated by avoiding liability instead of by protecting Donald’s best interests. We could equally claim that Dr S is attempting to navigate the law in order to provide physician aid in dying (PAD) for a patient whom he thinks should be eligible. We agree that the framing presented by these authors appears self-serving, but there is no reason to assume this is Dr S’s primary motivation. Certainly, Dr S’s motives should be considered and evaluated, but we suggest they are not a central feature of the case.

The issue specifically raised by the case is not whether PAD is ethically, morally, or legally justifiable, although this is certainly a worthy question for another forum. Rather, the issue is whether a physician who agrees that PAD can be acceptable acts ethically by agreeing to provide PAD for a patient who lacks the physical capacity to fulfill an explicit dictum of the law. Dr S’s personal views on PAD notwithstanding, we stress that whether a physician decides to prescribe lethal drugs under [PAD laws](#) is a deeply personal and moral decision. Refusing PAD could damage the physician-patient relationship and continuity of care, as well as contribute to potential feelings of abandonment, as described in our paper—harms that are as important to account for as they are difficult to quantify empirically. The Dale lawsuit against the University of California Board of Regents, University of California, San Francisco (UCSF) Health, and other defendants is one example in which a patient and family felt egregiously harmed by the physician’s refusal to provide PAD.<sup>1</sup> Indeed, patients’ stress and confusion as a result of their inability to find a prescribing physician represents a challenge not infrequently encountered during the short time that PAD has been legal in California.

We acknowledge that the mental health aspects of PAD generally are significant, but it would be a miscalculation to assume that patients only seek PAD because of [underlying](#)

mental illness. There is therefore no reason to suppose that compassionate psychiatric counseling will suffice for all patients seeking PAD. Referral for psychiatric evaluation might sometimes be warranted, but clinicians should recognize that mental health is but one important feature in cases like Donald's. Safeguards such as whether to mandate mental health evaluations must balance patient protection and patient access to PAD.<sup>2</sup>

We reiterate the importance of exploring other potential motivations Donald might not have disclosed, including limited financial resources and inadequate palliative care services. We agree that familial coercion would be ethically troubling and should be regarded as a source of worry about how requests for PAD are considered. Clinicians must likewise remember that though potential mandated mental health screening might identify impaired cognition, decision-making capacity can still be intact in patients with cognitive deficits.

It is not difficult to imagine a situation in which a patient like Donald—even with extreme physical limitations—turns to violent methods of suicide when convinced that no other options exist. While Dr S must consider this possibility, and while suicide rates are certainly important to consider, it is inappropriate to reduce the calculation of whether to offer PAD, where legal, to a mere weighing of one method of death versus another. Not all patients who obtain PAD prescriptions end up using them<sup>3</sup>; perhaps patients see the main benefit not solely in their use but in reclaiming a measure of autonomy and control over their lives. Focusing mainly on depression in end-stage disease ironically omits from deliberation the patient's experience and "sense of meaning" that the letter's authors, and we ourselves, would agree must remain the primary focus.

## References

1. Bodley M. Family sues UCSF following death of cancer patient. *SFGate*. July 19, 2017. <https://www.sfgate.com/bayarea/article/Family-sues-UCSF-following-death-of-cancer-patient-11298115.php>. Accessed August 22, 2018.
2. Buchbinder M, Pope TM. Medical aid in dying in Hawaii: appropriate safeguards or unmanageable obstacles? *Health Affairs Blog*. August 13, 2018. <https://www.healthaffairs.org/doi/10.1377/hblog20180808.14380/full/>. Accessed August 22, 2018.
3. Ganzini L, Nelson HD, Schmidt TA, Kraemer DF, Delorit MA, Lee MA. Physicians' experiences with the Oregon Death with Dignity Act. *N Engl J Med*. 2000;342(8):557-563.

**Alexander Craig, MPhil** is a second-year medical student at the University of California, San Francisco School of Medicine. His bachelor's and master's theses in classical philosophy explored medicine as a developing field of knowledge in ancient Greece and Rome. He is broadly interested in medical ethics and the philosophy of science.

**Elizabeth Dzeng, MD, PhD, MPH** is an assistant professor at the University of California, San Francisco (UCSF) in the Division of Hospital Medicine and Social and Behavioral Sciences, Sociology program, where she directs the ethics curriculum for medical students. She has also been involved in the statewide and UCSF response to the legalization of physician aid in dying in California. Her current research is focused on understanding the systemic factors that contribute to burdensome care for older adults with advanced dementia at the end of life, physician moral distress, and ethical challenges at end of life.

**Citation**

*AMA J Ethics.* 2018;20(11):E1110-1112.

**DOI**

10.1001/amajethics.2018.1110.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*