AMA Journal of Ethics

Formerly Virtual Mentor

November 2015

Volume 17, Number 11: 1007-1101

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American Medical Association Journal of Ethics

November 2015, Volume 17, Number 11: 1009-1018

PEER-REVIEWED ARTICLE

Why Can't We Be Friends? A Case-Based Analysis of Ethical Issues with Social Media in Health Care

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"A George Divided Against Itself Cannot Stand!" [1]

This quote comes from the ever-popular '90s sitcom *Seinfeld*. In this classic scene, the always-put-upon George Costanza complains to his best friend Jerry about his two selves—Independent George and Relationship George. Independent George is the George that both George and Jerry love (bawdy, lying, etc.), whereas Relationship George is the identity that George maintains with his girlfriend, Susan. His concern is that if he does not create a firewall between these two identities, Relationship George will subsume Independent George. The exchange between George and Jerry humorously illustrates the real-life challenges of our brave new world of social media. Like George, who wants to maintain a boundary between his two personal ("bawdy" and relationship) identities separate from their personal identities online [2]. The issue of boundaries is but one of many that the use of social media raises. In fact, the ubiquitous use of social media has created a number of potential ethical and legal challenges, some of which we will cover in this article. Specifically, we will:

- 1. Define social media;
- 2. highlight some recent instances of the good, bad, and ugly—social media used for good purposes, bad purposes, and plain ugly purposes;
- 3. outline salient professional and ethical issues;
- 4. review some illustrative case examples; and
- 5. highlight where to find recent policy recommendations.

In many ways, social media is a liberating tool for millions of people throughout the world. The challenge for health care professionals is how to use social media in a responsible and thoughtful way. In this essay, we hope to foster a more reflective dialogue on both the benefits and potential risks of using social media in the health care context, particularly through a series of case vignettes.

What is Social Media?

A technical description of how social media works is as follows:

social network sites...[are] web-based services that allow individuals to (1) construct a public or semi-public profile within a bounded system, (2)

articulate a list of other users with whom they share a connection, and (3) view and traverse their list of connections and those made by others within the system. The nature and nomenclature of these connections may vary from site to site [3].

The term "social media" includes such personal and professional platforms as Facebook, Twitter, LinkedIn, Tumblr, and Pinterest, to name just a few. Although Facebook is still the social media juggernaut with more than a billion active users [4], new social media technologies appear on an almost daily basis.

The existence of social media has not-so-quietly revolutionized the way human beings interact and connect with one another both personally and professionally. For thousands of years, geographic distance and lack of technologies for communication across that distance posed significant barriers to how people connected with one another. The invention of the Gutenberg printing press in the fifteenth century was the beginning of the revolution that made the printed word accessible. The second revolution was the creation in the nineteenth and twentieth centuries of mass communication technologies such as the telephone, radio, and television. The third revolution was the recent creation of social media outlets through which anyone with a smart phone can circulate a story or update to anyone else in the world. As of October 2014, 64 percent of US adults had a smartphone [5].

The Good, the Bad, and the Ugly

Social media has the potential to truly improve health behaviors, allow governments to respond to public health emergencies, and even alert pharmaceutical companies to adverse drug reactions more rapidly than current reporting mechanisms (perhaps even in real time). It also allows those with rare diseases to have more expansive <u>networks</u> to learn about their condition and treatments and gain helpful psychosocial support. As one disease advocate put it, "the internet has made our small disease larger and we are able to educate many more people now" [6]. These groups can be a much-needed source of emotional support and information exchange.

Unfortunately, irresponsible use of social media is fraught with hazards. There have been reports of patients stalking their physicians [7], health care professionals disclosing private information about patients [8], and students <u>blogging</u> denigrating descriptions of patients under their care [9]. A 2009 study published in *JAMA* revealed that 60 percent of medical schools surveyed "reported incidents of students posting unprofessional online content" [10]. The now-infamous *Yoder* case highlighted the hazards of students inappropriately blogging about their patients [9]. There have even been reports of medical residents losing their jobs for taking inappropriate photos, none perhaps more salaciously than the *BBC News* headline, "US 'Penis Photo Doctor' Loses Job" [11]. As one ethics commentator in the *Journal of Clinical Ethics* stated: "You can't make this stuff up.

And unfortunately, you don't have to" [12]. These behaviors are ethically problematic and could possibly trigger libel suits or other legal actions.

Professional Ethical Issues

The use of social media in the health care setting raises a number of professionalism issues including concerns related to privacy and confidentiality; professional boundaries; recruitment; the integrity, accountability, and trustworthiness of health care professionals; and the line between professional and personal identity [13]. Below we discuss the first issue, which is foundational to the others.

Privacy and confidentiality are often used interchangeably but they have some crucial differences. Privacy is typically focused on the person—how and when an individual may share of him or herself. This is patient-controlled. Confidentiality, on the other hand, is focused on information that has been shared with someone else in a relationship of trust. This is controlled by the physician (or other health care professional).

Maintaining privacy and confidentiality are integral to the patient-health care professional relationship, since preserving patient trust is essential for competent clinical care. Without some commitment to confidentiality, many patients would be disinclined to share intimate information about themselves or their health histories, which could compromise the delivery of health care. With the advent of the Health Insurance Portability and Accountability Act (HIPAA) enacted in 2003 [14], health care entities were legally allowed to disclose protected health information (PHI) only to facilitate "treatment, payment, and health care operations" [15].

In the remaining part of this essay, we consider several case studies (some taken from the news and some hypothetical) that highlight the more salient ethical and legal issues that arise with the proliferation of social media use in health care.

Case Study One: The Global Health Student

A medical student is on an immersion trip to the Dominican Republic during the summer after her first year. She wishes to document her experience with the patients she encounters by photographing them in the clinical setting. She speaks fluent Spanish and asks for verbal consent from a patient to take her picture before doing so. She does not tell the patient what she plans to do with it. She uploads the photo to her Facebook account, describing the patient's clinical issues.

What are some of the issues this case raises? Although legal norms governing privacy and confidentiality in the US and the Dominican Republic may differ, one could argue that ethical norms should not. The first question to ask is what does consent mean here? Is it a simple verbal consent that is not documented? Does the patient have a right to know the intended use of the photos and whether it is public or relatively private? Will the photos be used for educational purposes or will they simply be shared through a personal Facebook account? These are all important considerations to reflect upon before the student takes these photos during her immersion trip, and they highlight the necessity of distinguishing between personal use and professional use of social media. Opinion 5.045 of the American Medical Association (AMA) *Code of Medical Ethics* discusses filming patients in health care settings. Although it does not squarely address social media, one could look to it for some guidance. For instance, this opinion states that "filming patients without consent is a violation of the patient's privacy." By this logic, taking a photo of a patient and then uploading it to Facebook without consent is also a violation of the patient's privacy. In a recent *AMA Journal of Ethics* article, <u>Terry Kind</u> cites the American College of Physicians and the Federation of State Medical Boards guidelines' injunction to pause: "Trust yourself, but pause before posting to reflect on how best to protect and respect patients, their privacy, and your professional relationships and responsibilities" [16]. This student would do well to do likewise.

Case Study Two: The Tweeting Physician

A physician who works in a private practice is openly critical of health care reform. He tweets: 'I don't support Obamacare or Obama; patients who voted for him can seek care elsewhere." His colleagues are concerned that his political views may hurt their practice; moreover, they wonder if it's ethical for a physician to refuse to see someone because of his or her political views [17].

This scenario raises many concerns. First of all, we have a First Amendment-protected right to free speech. Various forms of social media have facilitated the ability of many more people to publicly exercise this right. And, indeed, this physician has a First Amendment right to express his political views. For instance, a physician may submit a letter to the editor of a newspaper, expressing his or her political views. Presumably such a letter would be vetted by an editor. Social media has no editor. Therefore, it's even more incumbent upon a practicing physician to be careful about expressing political views online. The AMA Code of Medical Ethics allows physicians to discuss political matters directly with their patients unless "patients and their families are emotionally pressured by significant medical circumstances" [18], but "communications by telephone or other modalities with patients and their families about political matters must be conducted with the utmost sensitivity to patients' vulnerability and desire for privacy." Current patients of this physician may find his behavior contrary to sensitivity to their vulnerabilities. And the physician's own colleagues may view such behavior as inappropriate or even contrary to whatever contractual terms the physician signed. Furthermore, the AMA *Code* also proscribes discriminating against patients because of their "race, gender, sexual orientation, or any other criteria that would constitute invidious discrimination" [19]. Is it permissible, then, for a physician to refuse to care for someone because of his or her political views?

Case Study Three: The Googling Program Director

A residency program director is overwhelmed with resident applications. He has started to search applicants on Google to learn about their online identities. He discovers that a few of the students applying to his program have photos in their Facebook profiles that show them in an unflattering light. One is holding a drink at a party, appearing to be inebriated. Most disturbing is one set of photos in which the students (and even some physicians) are brandishing weapons on what appears to be an international immersion trip [20].

Human resources departments and hiring committees are increasingly turning to the Internet to learn more about <u>applicants' online activities</u>. They may acquire certain personal information via social media outlets such as Twitter or Facebook or they may even learn about an applicant's professional disciplinary history. Indeed, employers routinely retain services to check an applicant's criminal background. They also follow up with references supplied by applicants.

This scenario raises questions about conducting such searches through the use of social media: Are such searches ethically permissible? How reliable is the information found? Do job applicants have any expectations of privacy? It may be incumbent upon an employer to screen applicants by doing a simple Google search to ensure that nothing troubling is uncovered, but the reliability of the information remains questionable, and it may be that such information should not be used in decision making without first allowing the applicant the opportunity to provide an explanation. Perhaps, then, prospective applicants should be notified that such searches will be conducted. We must all remember that no consent is required for someone to post photos of another person on Facebook, so, even if an applicant is not a Facebook user, others still may post identifying information and photos that are not all that flattering.

Case Study Four: Connecting on LinkedIn

A young pediatrician has recently finished his training and is now a newly minted attending physician. He is building his practice and has active accounts with Facebook and LinkedIn. A mother of one of his patients has recently sent a request to be his "friend" on Facebook. He declines this friend request, believing that this may impair his clinical judgment. He wonders, however, if it would be appropriate to connect with this patient's mother through LinkedIn, since it is a site for professional networking as opposed to personal friendships.

As the opening anecdote about George Costanza suggests, the boundaries between our professional and personal lives have become increasingly blurred. Nonetheless, many people will attempt to construct some kind of boundaries with various forms of social media. For instance, many think of LinkedIn as strictly a professional networking site and would never post personal information there. The pediatrician in this scenario may think that connecting with a patient's mother on LinkedIn is purely a professional connection. A challenge arises, however, if the mother of the child reaches out to the pediatrician

through LinkedIn with a question about her child's health. Is the pediatrician obligated to respond? If he does not, is he potentially liable? Are privacy issues raised if various patients are connecting with the physician through social media and all become aware of one another's identity and that they are, in fact, patients? Although they are voluntarily connecting with their physician, it may not be transparent to users that they may be connected to that physician's other patients.

Case Study Five: Patient Targeted Googling [21]

A physician treating an elderly woman for shortness of breath began looking for the cause of her worsening condition. He sent for a drug screen, on which she tested positive for cocaine. She told him she had no idea how cocaine could be in her system, which made him concerned she might be a victim of abuse. One of the nurses involved in her care Googled her and discovered that she had a previous police record for cocaine possession [22].

This kind of activity has garnered increasing attention, especially among psychiatrists and other practitioners in mental health. The situation is not unlike the residency program director Googling applicants—information on the Internet is freely available. Why shouldn't a responsible health care practitioner Google a patient to learn more <u>potentially helpful information</u> about him or her? The issue here is one of trust. Currently, patients expect that what they share with a physician is the sum total of the doctor's information about them. It has been argued that such online research about patients should be avoided, unless there is a significant health or safety issue at stake [23].

Guidelines for the Responsible Use of Social Media

In response to the proliferation of social media use among health professionals and students in training, various educational institutions and professional organizations have developed guidelines. For instance, Loyola University Chicago Stritch School of Medicine [24], Northwestern University Feinberg School of Medicine [25], and the Mayo Clinic [26] have all responded with formal policies on the use of social media by students, faculty, and staff. In addition, both the <u>American Medical Association</u> [27] and the British Medical Association [28] have developed formal guidelines on the use of social media in health care.

Lastly, the Federation of State Medical Boards has developed "Model Policy Guidelines for the Appropriate Use of Social Media and Social Networking in Medical Practice" [29]. Although ethics and law often lag behind technological innovation, we now have a burgeoning set of policies to help health care professionals more thoughtfully use social media in their work and in their private lives. These new policies address a number of issues raised by the cases discussed here: privacy, boundaries, professional identity, and one's reputation. We highly recommend that such policies be promoted and that institutions seriously consider developing their own internal policies. Various forms of social media have transformed the way human beings interact with one another. Anyone with Internet access or a smartphone can now transmit tweets, Facebook postings, and Instagram images to hundreds, even thousands, of other people, all of whom can share this same information with their own network of contacts. This kind of technology can be liberating, but it also can create potential ethical and legal challenges for health care professionals. To address some of these challenges while availing our profession of some of the benefits, we recommend the following:

- Have a clear understanding of local, state, and national laws concerning privacy.
- Have a working knowledge of professional society guidelines.
- Know your institutional culture.
- Be prepared to make changes to stay current with the rapid developments in technology.
- Circulate policies, including updates, in writing to all who are required to abide by them.
- Differentiate between guidelines for education and guidelines for practice, if appropriate.
- Educate all (students, staff, faculty) about the policies.

Because all forms of social media have become so integrated into the social fabric, managing social media use on both a personal and professional level has become imperative. As Greysen et al. have concluded in an article in the *Journal of General Internal Medicine*:

Certainly, the principle of "first, do no harm" should apply to physicians' use of social media, but we can do better. Just as we must look beyond harm reduction towards health promotion in clinical practice, we must go farther than curtailing unprofessional behavior online and embrace the positive potential for social media: physicians and health care organizations can and should utilize the power of social media to facilitate interactions with patients and the public that increase their confidence in the medical profession. If we fail to engage this technology constructively, we will lose an important opportunity to expand the application of medical professionalism within contemporary society. Moreover, a proactive approach on the part of physicians may strengthen our patients' understanding of medical professionalism [30].

As health care professionals, we all need to accept, adapt, and amend policies, practices, and professional obligations to use social media with good outcomes and avoid the bad or even the ugly.

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American Medical Association Journal of Ethics

November 2015, Volume 17, Number 11: 1019-1021

LETTER FROM THE EDITOR

The Era of High-Value Care

High-value care has emerged as a new ethos for practicing medicine, with a greater focus on minimizing waste, containing costs, reducing medical errors, and improving adherence to quality metrics. It emphasizes nonmaleficence, or doing no harm to patients, by reducing overutilization of tests—which may lead to false positives and unnecessary invasive procedures—and unnecessary care. Indeed, high-value care is not only about reducing cost, but also about improving quality and reducing harm. Incentives and curricula are increasingly being designed to focus on maximizing value, which is generally defined as quality divided by cost.

Ethical tensions may arise when practicing high-value care. While value-based care can further the principle of justice by facilitating consideration of how to distribute limited resources fairly, some may argue that it can conflict with the principles of beneficence and respect for autonomy, which have been interpreted as doing the most good and securing the most self-determination for an individual patient without thinking about resource limitations. This issue of the *AMA Journal of Ethics* explores these ethical tensions. We are fortunate to have experts and thought leaders in the field of high-value care contributing to this issue.

Three case commentaries highlight common ethical questions related to high-value care. Often, clinicians must decide whether diagnostic imaging and procedures should occur while a patient is hospitalized or may be deferred to an outpatient setting. In <u>their</u> <u>commentary</u>, Christopher Moriates, MD, and Josué A. Zapata, MD, examine hospital and physician incentives to contain costs within a medical ethics framework. Physicians also are frequently faced with a choice between high-value and low-value care when confronting patient expectations and requests for diagnostic imaging. Bjorg Thorsteinsdottir, MD, Annika Beck, and Jon C. Tilburt, MD, MPH, <u>analyze</u> factors that might influence a physician's recommendation in a case of a patient who expects a screening mammogram when guidelines suggest that it is most likely not indicated. The <u>last case</u> concerns a clinician-educator who obtains extensive laboratory testing for educational and diagnostic purposes and a resident trainee who feels these tests are not indicated. Maggie K. Benson, MD, discusses how they might navigate this disagreement through mutual understanding and compromise. Two other articles discuss the place of high-value care considerations in medical education. In <u>his piece</u>, Hyung J. Cho, MD, recalls his experiences with clinical conferences in residency, reflecting that consideration of the appropriateness of work-up, costs, and value were often lacking. He also highlights solutions, such as monthly conferences that connect overuse to patient harm by labeling it a medical error. Today, high-value care is increasingly incorporated into medical education and recognized as a core competency of training by professional societies. Aditya Ashok and Brandon Combs, MD, <u>describe</u> novel methods for educating medical students, residents, and attending physicians about high-value care.

The question of how to structure medical payment and care delivery to promote highvalue care is also a pressing one. Jeffrey Clemens, PhD, and Stan Veuger, PhD, <u>discuss</u> the implications of the repeal of the Medicare Sustainable Growth Rate (SGR) and its replacement with the merit-based payment incentive system (MIPS), a pay-forperformance model intended to encourage high-value care among provider organizations. Eva Luo, MD, MBA, <u>examines</u> two other approaches to increasing value: the "focused factory" model, in which efficiency is increased to extreme levels to lower the costs per patient, and the "high-touch" model, which focuses on improving outcomes by increasing interaction between the provider organization and the patient.

One of the goals of the high-value care movement is to prevent financial harm not only to the system but also to individual patients by containing costs. Vineet Arora, MD, MAPP, Christopher Moriates, MD, and Neel Shah, MD, MPP, <u>explain</u> the difficulty of identifying the true costs of health care and describe the price transparency movement, which aims to make charges more accessible to both patients and clinicians. Reshma Gupta, MD, MSHPM, Cynthia Tsay, MPhil, and Robert L. Fogerty, MD, MPH, <u>examine</u> the history of costs of care from the nineteenth century to the present day. New standards were adopted over time to improve quality, health expenses rose at a dramatic rate, and price transparency disappeared. The authors conclude by suggesting steps to screen patients for financial harm.

As <u>this month's featured opinion</u> on physician stewardship from the AMA *Code of Medical Ethics* points out, both systemic changes and individual physicians' actions are needed to create a fiscally sustainable health care system. One area in which both are pertinent is end-of-life care for patients with advanced cancer. Ali John Zarrabi, MD, Ran Huo, MD, and Diane Meier, MD, <u>argue</u> that palliative care interventions, supported by increased education and targeted policy, will decrease costs and improve outcomes and quality of life. In the <u>podcast</u>, Wendy Levinson, MD, discusses the challenges to high-value care and Choosing Wisely's efforts to stimulate discussion about overuse of tests and treatments that don't add value or may be harmful.

Practicing medicine responsibly in a complex and rapidly changing era poses challenges to both the patient and clinician. The new paradigm of value-consciousness is being adopted in culture, patient care, and policy; we hope this issue of the *AMA Journal of Ethics* provides a useful lens through which to consider it.

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American Medical Association Journal of Ethics

November 2015, Volume 17, Number 11: 1022-1027

ETHICS CASE

The High-Value Care Considerations of Inpatient versus Outpatient Testing Commentary by Josué A. Zapata, MD, and Christopher Moriates, MD

Dr. Cordova is a hospitalist at a busy New York City hospital. One Thursday morning she admits Mr. Finlay, a 64-year-old man with a history of coronary artery disease and myocardial infarction with a significant cough. His chest x-ray shows a pulmonary infiltrate, and he is treated for community-acquired pneumonia with intravenous antibiotics.

Dr. Cordova plans to discharge Mr. Finlay as soon as he was breathing well on room air. On Friday morning, however, she receives a call from Mr. Finlay's cardiologist, saying that Mr. Finlay is due for a repeat stress test and repeat echocardiogram and asking her to order them during Mr. Finlay's admission. The cardiologist explains that Mr. Finlay lives alone in Brooklyn without strong family or social support. It is difficult for him to travel to and from the hospital to get these tests done on an outpatient basis. Furthermore, he does not keep all his appointments because of the financial constraints of travel and because public transportation is challenging, so performing these tests while he is in the hospital might help ensure that they happen.

The stress test and echocardiogram cannot be scheduled until Monday or Tuesday of the following week. Keeping Mr. Finlay in the hospital for additional days puts him at risk of hospital-acquired infections and hospital-associated disability and delirium. Additionally, in the back of her mind, Dr. Cordova also knows that some of her salary, as well as general advancement in the department, depends on metrics such as keeping patients' length of stay to a minimum.

All things considered, Dr. Cordova feels that keeping Mr. Finlay in the hospital, awaiting repeat testing which could be done on an outpatient basis, would not be the best use of hospital and health care resources, so she discharges the patient.

Commentary

This case reflects a common tension experienced by virtually all well-meaning and valueconscious clinicians practicing in an inpatient setting. Providing this patient with an echocardiogram and stress test in the inpatient setting (for the sake of this discussion, we will assume that these tests are indicated) may delay or affect diagnosis and treatment for other patients who are awaiting these tests or perhaps boarding in the emergency department awaiting a hospital bed. Furthermore, in addition to the uncertainty about the patient's best interest, this physician has a direct conflict of interest, in that she benefits both professionally and financially from limiting his length of stay. While it is clear that personal incentives should definitely not play a role in medical decisions, is it reasonable to expect physicians to consider costs to others and to society while caring for individual patients?

An Ethical Basis for Considering Value

In the same way that conventional frameworks help us deal with common clinical complaints, a well-established set of principles forms the core of modern Western medical ethics: respect for patient autonomy, beneficence, nonmaleficence, and justice. In practice, these ethical principles often conflict with each other, and balancing them is necessary for ethical decision making. We will examine the case in light of these principles and the concept of value, which is commonly defined as quality of care divided by overall costs.

Respect for patient autonomy. In this case, one could propose prioritizing respect for the patient's autonomy by allowing Mr. Finlay to decide whether he would prefer to have these tests done while he is in the hospital or whether he would rather return and have them done as an outpatient. Although the scenario reports that he lives alone and has difficulty returning for tests and visits, he still might in fact prefer not to spend an extra weekend in the hospital. Engaging Mr. Finlay in discussion of the potential benefits and harms of these different options and allowing him to choose could maximize his autonomy. Shared decision making can be an important strategy for ensuring ethical and high-value care decisions when there is not one clearly superior treatment option, since achieving greater alignment of care with patients' values has the potential to improve patient understanding and satisfaction, result in better outcomes, and reduce unwarranted variation in care and costs [1, 2]. However, in this case, prioritizing the patient's preferences may conflict with other important interests, including stewardship of limited health resources and nonmaleficence.

Beneficence and nonmaleficence. Beneficence, or the obligation of the physician to act in the best interest of the patient, suggests that the physician has a duty to make decisions based solely on the benefit to the single individual without consideration of other interests, including societal interests. The American Medical Association (AMA) specifically warns that physicians' "first duty must be to the individual patient. This obligation must override considerations of the reimbursement mechanism" [3]. In this case, Dr. Cordova could argue that her fiduciary duty to Mr. Finlay is to be his unwavering advocate and act exclusively in his best interest. Indeed, she may agree that, although every health care system needs a method for limiting health care overuse, to respect the fundamental principle of beneficence she cannot be expected to simultaneously consider both the interests of the health system (high-value care) and those of her patient (access). She may decide to order the echocardiogram and stress tests while Mr. Finley is

in the hospital because she believes that they will help Mr. Finlay, even if she also believes this may not be the most efficient use of hospital resources.

On the other hand, considering the case from a nonmaleficence (or the classic "first do no harm") perspective, Dr. Cordova may decide that keeping Mr. Finlay in the hospital for a nonurgent diagnostic workup would expose him to unnecessary risks (e.g., infection and delirium) that do not outweigh the benefits. According to a large study by the Centers for Disease Control and Prevention, nearly 650,000 hospitalized patients each year develop a hospital-acquired infection [4], and other studies indicate that delirium occurs in up to one of every five noncritically ill hospitalized adults [5, 6], resulting in serious harms, including increased mortality [7]. Additionally, while the intricacies of inpatient billing are extremely complex and beyond the scope of this commentary, some privately insured patients are responsible for significant co-pays and co-insurance; in a 2007 study, 62 percent of personal bankruptcies were due to medical expenses, and hospital bills were the largest single out-of-pocket expense for nearly half of medical debtors [8]. Thus, Dr. Cordova may be concerned about exposing Mr. Finlay to possible "financial harm" [9] with a longer stay.

Justice. The principle of justice in medical ethics refers to a fair and equitable distribution of health resources. One part of seeking justice is promoting the fiscal sustainability of the health system for the greater good of society, which is where value comes into play. The medical professionalism charter endorsed by the American Board of Internal Medicine (ABIM) Foundation, the American College of Physicians (ACP)-American Society of Internal Medicine Foundation, and the European Federation of Internal Medicine states that "While meeting the needs of individual patients, physicians are required to provide health care that is based on the wise and cost-effective management of limited clinical resources" [10]. In addition, the ACP calls for physicians to "choose interventions and care settings that maximize benefits, minimize harms, and reduce costs" [11]. To comply with this principle, Dr. Cordova must consider whether the benefit to Mr. Finlay warrants occupying a hospital bed and a slot with an echocardiographer and a cardiologist in the stress lab, which may mean that another patient (perhaps even a patient who needs these tests more) has delayed or reduced access to such services. Moreover, performing these tests in the inpatient setting may be more expensive, adding to overall health care system expenses. Considering this case from the standpoint of social justice, Dr. Cordova should not offer a prolonged hospital stay for these nonurgent tests to be performed.

Beyond Low-Hanging Fruit—When Patient and Societal Interests May Not Be Congruent

We can illustrate the potential conflicts between beneficence and justice (which subsumes value) and help clinicians understand how to consider value ethically by classifying tests and treatments according to whether or not they are good for the patient and whether or not they are good for society [12]. If an intervention is good for both (e.g., vaccination programs, prenatal screening), it is easy to decide to perform it. If a test or procedure is bad for both (e.g., screening mammography or colonoscopy for an 85-year-old patient with stage-IV cancer), then the decision is similarly straightforward. The conflict arises when patients' and society's interests are not aligned, resulting in a situation in which something is good for the patient but bad for society as a whole, or bad for the patient but good for society as a whole. When either of these situations occurs it becomes necessary to weigh the values of beneficence and justice simultaneously and attempt to arrive at an ethically acceptable balance.

In this case, performing the tests in the hospital—assuming they are necessary and will help Mr. Finlay—is good for his health and will save him money and difficulty but will generate additional expense and potentially disadvantage other patients who need the same services, thus possibly making it detrimental to other individuals and society as a whole. Consequently, Dr. Cordova must decide between a tragedy of the commons, in which she places the interest of Mr. Finlay above that of the need to safeguard health resources, and the bitter pill for the patient, in which Mr. Finlay subordinates his personal needs for the overall benefit of the public. Indeed, all clinicians are implicitly forced to make these calculations routinely, whether they view them as an ethical conundrum or not.

What's the Right Thing To Do?

Ultimately, Dr. Cordova elected to discharge Mr. Finlay without providing the tests. In making her choice, she considered Mr. Finlay's best interest, thought about how to minimize harm to him, and reflected on the overall needs of the health care system—for cost-effective care, in this case—and alternative costs to other patients. After deliberation, she felt that the benefit to the individual patient did not outweigh the overall harm done to the health care system and other patients.

Although not every medical decision should value justice above beneficence, these types of complex ethical challenges deserve a clear and explicit process similar to what we have described above to serve both the interests of the patient and society. By taking the time to thoughtfully navigate these clashing ethical principles, Dr. Cordova performed her professional duty as a physician.

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American Medical Association Journal of Ethics

November 2015, Volume 17, Number 11: 1028-1034

ETHICS CASE

Grow a Spine, Have a Heart: Responding to Patient Requests for Marginally Beneficial Care

Commentary by Bjorg Thorsteinsdottir, MD, Annika Beck, and Jon C. Tilburt, MD, MPH

Dr. Perry is a primary care physician in a busy urban clinic in East Harlem in New York City. He is already behind schedule and has been somewhat apprehensive about seeing his next patient, 42-year-old Ms. Hollowell, whose medical problems are prediabetes and obesity. Ms. Hollowell comes to clinic for both scheduled visits and urgent care walkins. Dr. Perry has seen her perhaps once a month for the past several years.

Today, she asks Dr. Perry for a referral for a mammogram. She is concerned that breast cancer may run in her family. An aunt of hers had breast cancer in her 60s, and two years before Ms. Hollowell had convinced Dr. Perry that she should get a "baseline" mammogram. That test was indeterminate, and she then was sent for a right breast ultrasound and diagnostic mammogram, which were both negative.

Dr. Perry believes that, because Ms. Hollowell is between 40 and 50 and is in a low-risk group based on the new screening guidelines, a mammogram is unnecessary at this time. Still, he recognizes that Ms. Hollowell is anxious and wants to get a mammogram to "make sure everything is alright." He explains the risks of false positives again, but Ms. Hollowell points out the "close call" and "cancer scare" she had two years ago and her desire to be reassured. He fears that not referring her will hurt the therapeutic relationship that has been built over the years. Perhaps she will seek out another physician if he refuses her request for a referral. Dr. Perry quickly checks the computer and sees that he is running behind schedule; there are three other patients waiting to be seen.

Commentary

Through the power of their prescriptions and orders for tests and procedures, physicians are the de facto gatekeepers of medical resources. In the era of health maintenance organizations and the Patient Protection and Affordable Care Act (ACA) [1], physicians face renewed pressure to practice parsimonious medicine [2]. The Choosing Wisely campaign orchestrated by the American Board of Internal Medicine Foundation encourages doctors to limit the use of minimally beneficial services [3]. The Patient-Centered Outcomes Research Institute aims to compare the effectiveness of different treatment options to allow physicians to choose the most beneficial and effective care

for their patients [4]. International and domestic awareness of the harms and costs associated with overdiagnosis and overtreatment [5, 6] is increasing, challenging medicine to have a smaller footprint [7]. These are good and important developments that will help patients and the profession. But how should the doctor at the bedside navigate these currents? What is the right thing to do when a <u>patient requests</u> services that are judged by the physician to be <u>unnecessary</u> or even harmful?

Here we will deconstruct the current case by focusing on the physician's ethical obligation as a gatekeeper of health care resources in an environment in which minimizing overutilization is a priority but outright <u>rationing</u> is dismissed. The ethical issues raised by the current case are broader than those of resource utilization; other ethical principles come into play when addressing patients' requests for minimally beneficial or even harmful tests or procedures. Physicians have never been obliged to offer nonbeneficial care and they can confidently recommend against marginally beneficial care that they believe is not worthwhile. The principle of nonmaleficence is particularly pertinent in the case of this young woman, inasmuch as many have called attention to the risk of harm from overdiagnosing breast cancer in women her age [8, 9]. Since 2009 the United States Preventive Services Task Force guidelines no longer unequivocally recommend mammograms for women younger than 50 but rather defer to shared decision making based on individual risk-to-benefit assessments [10], and in 2015 the American Cancer Society updated its guidelines, recommending that women with average breast cancer risk begin regular screening mammograms at age 45 [11].

While recommending against testing in this case is parsimonious practice, good clinicians also have a heart and recognize that all requests are coming from somewhere. Ms. Hollowell is clearly fearful that she is at risk for breast cancer and needs reassurance from her physician that it is safe not to pursue further tests. Navigating such concerns skillfully can stem the tide of requests for marginally beneficial tests and procedures. Appeasing the patient through ordering more tests may not help; diagnostic tests for symptoms with a low risk of serious illness do little to reassure patients and decrease their illness anxiety [12]. On the contrary, false positive mammogram results and recalls for further testing often result in lingering anxiety, as may have been the case for Ms. Hollowell [13].

The role of the individual physician in limiting overtreatment or allocating valuable resources is a particularly divisive subject in the fragmented US health care system. In the US, physician restraint with an individual patient, even one with government insurance, will not reliably redistribute those resources to benefit other patients [14]. Bedside rationing is a reality in many countries [15], and some argue that physicians are uniquely positioned to determine which patient would benefit from treatment and thus have a duty to ration marginally better treatments [16, 17]. This role raises the concern that rationing makes a doctor a "double agent" and risks compromising her ability to

fulfill her duty as a patient advocate when tasked with allocation of a limited resource [18, 19]. In a recent survey, the majority of US doctors seemed to agree: respondents felt that the responsibility for limiting access to care and rationing lies more with insurance companies, health systems, trial lawyers, and even patients than with physicians. The majority of those surveyed, however, still emphasized both the need to adhere to guidelines that discourage the use of marginally beneficial care and the role of doctors in limiting the use of unnecessary tests [20]. These sentiments highlight the difference between rationing and parsimonious care [2].

To alleviate the concerns about dual agency and conflict of responsibilities, an intermediate way of ethically limiting access to health care resources at the bedside, so-called administrative gatekeeping, has been recommended [18]. Therein, the physician is required to act out fair policies adopted at higher levels within the health care system while at the same time being prohibited from considering cost in clinical deliberation. This approach relies on the development of agreed-upon processes for determining coverage and dealing with requests for treatment that is not covered [21]. Debating these issues is necessary so physicians can maintain fidelity to patients' best interest within the constraints of available resources.

While we endorse parsimonious medicine, we agree that physicians should not serve as self-appointed negative gatekeepers at the bedside. Below we outline why it is hard to justify such a role for the physician in the US context using Ms. Hollowell's case as an example. To adequately address the question of how Dr. Perry should respond to Ms. Hollowell's request, we need more information about her breast cancer risk and insurance status. For the purposes of this discussion we will assume that Dr. Perry's estimate of low risk of breast cancer is accurate. We will address the ethical question in the US context for three different insurance status introduces unique resource allocation concerns.

If Ms. Hollowell pays out of pocket then there would be no ethical concerns about overutilization unless there was limited access to mammography, in which case the fairness of allocation of scarce resources by ability to pay could be questioned. Ability to pay is currently an accepted form of rationing—a kind of "soft" rationing—in US health care [22]. Mammograms are widely available in the US, so *it is hard to invoke an obligation to withhold a mammogram if Ms. Hollowell is willing to pay*.

If she has private insurance, the ACA mandates that her plan cover a screening mammogram without cost sharing [1]. (This is interesting given the weak evidence supporting mammograms for women 40-50 years old [10] and points to the strong political sensitivities surrounding breast cancer screening.) Refusing to refer an insured patient for mammography will not reliably benefit other patients more in need of

services since the money is just as likely to increase the takings of insurance company shareholders. Such savings offer little justification to withhold the service [23]. If all physicians restricted the use of mammograms for this low-risk group, it could possibly decrease the cost of insurance and thus benefit other patients. Given the universally mandated insurance coverage for breast cancer screening and fear of litigation for delayed breast cancer diagnosis, however, there would have to be a paradigm shift in both insurance coverage and tort reform for the practice patterns of physicians to change. *Thus Dr. Perry has no ethical obligation based on resource allocation to limit Ms. Hollowell's access to a mammogram covered by her insurance in accordance with the law. Best interest or nonmaleficence arguments could be used to justify not yielding to Ms. Hollowell's autonomous request and limiting her access because of the risk of harm from overtreatment as outlined above. However, in the current environment, in which mammograms are considered standard of care, Dr. Perry would be incurring significant personal liability were Ms. Hollowell to be diagnosed with breast cancer at a later stage.*

Finally, if Ms. Hollowell has government insurance, the gatekeeper role becomes more relevant since money saved by withholding services might plausibly be reallocated toward services for other patients. In this context, one could argue that the cost effectiveness of tests and procedures should influence resource allocation at some level. This is done in many countries and has been tried in the controversial Oregon Medicaid experiment [14, 24]. However, the use of cost effectiveness to govern coverage decisions is explicitly prohibited in the US Medicare system [25], which covers screening mammograms for Ms. Hollowell's age group [26]. Thus our question becomes: should Dr. Perry feel ethically obliged to go beyond what clinical guidelines and government insurance policy state and withhold the desired screening mammogram from Ms. Hollowell? As a physician acting in Ms. Hollowell's best interest and trying to protect her from the stress of another "cancer scare," Dr. Perry is justified in counseling her against doing the mammogram based on his assessment of the risk-benefit balance. Going beyond that and refusing to refer her for desired services that are covered by her insurance, however, would require appeal to an ethical principle other than fair resource allocation. While we hold physicians to high standards of professionalism and ethical conduct, the physician cannot be expected to make up for unfair insurance and government policies at the bedside. Thus, it is hard to assign Dr. Perry an ethical obligation rooted in fair resource allocation to withhold the mammogram from Ms. Hollowell under the present US system, even if she has government insurance. Rather, physicians collectively should actively participate in shaping policies and guidelines to help address the problem of overtreatment.

Conclusion

The lack of consistency and accountability in US insurance policy, and the lack of reliable and fair redistribution of resources on a societal level, ought not to be compensated for by individual physicians' actions to limit care at the bedside. We believe instead that, collectively, physicians have a social responsibility to share their knowledge and experience at the policy level for the benefit of society at large and move our society toward fair and equitable systems [27]. This is best achieved through a fair process in open democratic deliberations. At the bedside, the physician should be focused on the individual patient's welfare and be willing to say "no" based on her best interests alone. The art of medicine lies in balancing respect for patient autonomy against beneficence and nonmaleficence.

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American Medical Association Journal of Ethics

November 2015, Volume 17, Number 11: 1035-1039

ETHICS CASE

Cost-Consciousness in Teaching Hospitals

Commentary by Maggie K. Benson, MD, MS

Paul, who graduated with a joint MD/PhD and an interest in quality improvement and high-value care, is a second-year internal medicine resident in an academic hospital in a large city. He started his first month on the general medicine floor two weeks ago.

He had been looking forward to working with Dr. Rivers, a hematologist and one of the most senior attending physicians in the department, who had performed groundbreaking research in the 1970s in cellular biology. But Paul has found that he disagrees with Dr. Rivers on a number of clinical decisions, particularly in the ordering of lab tests. Often for any laboratory abnormality, such as a slightly elevated calcium, Dr. Rivers wanted a full workup to be performed, including hormone levels and various other tests. Recently, for example, a patient on the service had a prolonged partial thromboplastin time (PTT), a measure of the blood's ability to clot. An enthusiastic believer in the dual patient care and education roles of the teaching hospital, Dr. Rivers saw prolonged PTT as an opportunity to teach the utility of various lab tests, and he recommended ordering a full panel, including mixing studies, fibrinogen, factor levels, and several other tests.

Paul felt that, since many of these lab tests would not change the clinical care of the patient, they were unnecessary. He found it difficult, however, to bring up his views with Dr. Rivers, either on rounds or in the afternoon, because Dr. Rivers was a senior physician and so enthusiastic about explaining the lab results to the residents.

Dr. Rivers had noticed that Paul seemed to disagree with some of his decisions on rounds and was not as enthusiastic about the workup of certain patients. He did not know whether Paul disagreed with the clinical decisions or was simply disinterested.

Commentary

It is common knowledge that the United States spends more money on health care per capita than any other country in the world, yet achieves health outcomes that do not surpass its peer countries [1]. Acknowledging this discrepancy between health care spending and health outcomes, the Institute of Medicine in 2012 published a report, *Best Care at Lower Cost*, which estimated that 30 percent of health care costs in the US were wasteful, i.e., did not contribute to improved health outcomes [2]. As gatekeepers of health care spending, physicians play a critical role in health care use and have an ethical imperative to provide high-quality care that avoids the medical and <u>financial harms</u> of

unnecessary care for both individual patients and society. Proponents advocate that practicing high-value care be considered a universally necessary competency for physicians [3].

Accordingly, there have been many calls to establish high-value care as an <u>educational</u> <u>priority</u> [4-6]. The question posed to medical educators now is not "*should* we teach high-value care," but rather "*how* do we teach our trainees to practice high-value care?" This question has spurred various curricular efforts across specialties and training levels [7, 8]. While formal curricula in high-value care are a starting point, the <u>daily experiences</u> of residents on the wards and in clinics, such as those described in the case of Paul and Dr. Rivers, are in all likelihood more powerful in influencing resident behavior with regard to high-value care. As one study demonstrated, the spending environments in which residents train impact their spending patterns for years after entrance into independent practice [9]. To create a workforce of physicians prepared to practice high-value care, medical training programs must teach trainees to be thoughtful stewards of limited health care resources.

At the University of Pittsburgh, we conducted focus groups with residents in which we inquired about the barriers they face to practicing high-value care in their training [10]. One of the most common barriers to emerge was attending physicians and consultants. Mirroring Paul's experience, our residents reported observing variable attention to value among attending physicians and cited this as a powerful barrier to reducing unnecessary tests and procedures. In this case, Paul's interest in health policy enhances his motivation to practice high-value care on the wards. Despite his enthusiasm, Dr. Rivers has not reinforced the importance of high-value care, and his actions undermine the educational mission of high-value care.

Paul is in his first month as a second-year resident and eager to make a good impression. Creating conflict with the attending physician is most likely not on his agenda. Dr. Rivers's seniority may be intimidating to Paul and make him even less likely to engage in a dialogue about test-ordering practices and the value of various tests. Paul may even fear that showing restraint in ordering tests may lead Dr. Rivers to form a poor impression of his clinical judgment and prompt a negative evaluation at the end of the month. In defense of Dr. Rivers, he appears to have good intentions and enthusiasm. He is focused on the educational mission of demonstrating medical knowledge but less focused on how each test may impact the clinical care of the patient at hand.

The least effective path forward is for Paul and Dr. Rivers to move through the month in silent tension, risking a poor teaching evaluation for Dr. Rivers, a poor resident evaluation for Paul, and a lost opportunity to improve for both. It is also not in Paul's best interest to create an adversarial relationship with Dr. Rivers on rounds, in front of other learners.

The most productive next step in this scenario would be an in-person discussion between Paul and Dr. Rivers about high-value care and the rationale for the various tests that Dr. Rivers recommends. Although he is a senior physician, it's possible that highvalue care is a novel concept to Dr. Rivers. For this conversation to occur, Paul would have to feel confident enough in his relationship with Dr. Rivers, his clinical acumen, and his communication skills to broach the subject. This conversation would be best held away from the rest of the team so that neither Paul nor Dr. Rivers feels self-conscious in front of other junior learners. There is also an opportunity for Dr. Rivers to initiate the dialogue with Paul during mid-rotation feedback.

The ideal outcome of a conversation would be for Dr. Rivers and Paul to agree to practice and teach high-value care as a team. Dr. Rivers would need to be receptive to practice change and it would help if he were familiar with the concept of high-value care. He could embrace the learning opportunity presented by an abnormal lab value by discussing a broad differential diagnosis with the team, but advocate most often restricting further testing to that which is relevant to the particular patient under their care. Paul would need to acknowledge that there may be rare times when extra testing is ordered strictly for educational value rather than advancement of patient care, so long as the intent is made transparent to learners and not showcased as the standard of care.

There are ways to overcome the barriers both Paul and Dr. Rivers confront to engaging in such dialogue. If Paul is uncomfortable approaching Dr. Rivers directly, he could voice his concerns through other available avenues. Having a private conversation first with the program director or a chief resident may enable him to apply more nuanced communication strategies in speaking with Dr. Rivers directly, or it may open other avenues in which the program leadership could discuss practice change with Dr. Rivers.

To pursue practice change, Paul's training program could prime the educational environment to foster high-value practice. Placing high-value care education on the agenda for faculty retreats or faculty development sessions would help to establish it as an educational priority. The wealth of recent literature on teaching value [3, 6, 7, 8] and general consensus on the importance of high-value care education should serve as a meaningful way to build faculty buy-in for practice change.

Programs could also design novel, or adapt existing, teaching tools to help faculty members teach high-value care on the wards or in clinic, which would help develop faculty knowledge and teaching skills. This approach would be less of a burden to faculty than designing a teaching activity on high-value care on their own would be, especially if they view it as outside of their content expertise. At the University of Pittsburgh, for example, a clinician educator designed a patient bill-reflection exercise that all faculty rotating on the wards are expected to use for one teaching session each month [11].

Ward attending physicians are provided with easy access to a patient bill and a discussion guide to help facilitate dialogue.

Finally, by incorporating the practice and teaching of high-value care into the resident evaluation of attending physicians, Paul's program could signal the importance of this concept, provide learners with safe and anonymous means of providing feedback on it, and enable program leadership to monitor the practice and teaching of high-value care on the wards.

With health care costs unsustainable and unnecessary health care placing patients at risk of medical and financial harm, physicians must fulfill their responsibility to provide care that is effective, safe, and efficient. Medical educators must guide future physicians in the nuanced, evidence-based clinical decision making that high-value care requires. While serving as ward attending physicians, faculty have a responsibility to learners and patients to serve as role models by teaching high-value care, and training programs have a responsibility to prepare faculty for success in high-value care education.

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American Medical Association Journal of Ethics

November 2015, Volume 17, Number 11: 1040-1043

MEDICAL EDUCATION

Teaching High-Value Care

Aditya Ashok and Brandon Combs, MD

Introduction

The United States spends more money on health care than any other country and yet lags in most performance assessment dimensions, according to a recent report by the Commonwealth Fund [1]. Donald M. Berwick and Andrew D. Hackbarth estimated that, in 2011, between \$158 and \$226 billion was spent on the provision of health care that was unneeded or unwanted [2]. In a nationally representative survey of US primary care physicians, 42 percent reported believing that their own practices' patients are getting excessive care [3].

Following Michael E. Porter and Thomas H. Lee, we define value as "health outcomes achieved that matter to patients relative to the cost of achieving those outcomes" [4]. It is important, however, to distinguish between value and cost. High-cost care, such as antiretroviral therapy for HIV infection, can still deliver good value if the net benefits justify the costs [5]. And some low-cost interventions may provide low value. Amir Qaseem and colleagues identify preoperative chest radiography in patients who are healthy and without symptoms as both low-cost and low-value [5].

There is growing enthusiasm for incorporating high-value care (HVC) curricula into the training of medical students, <u>resident physicians</u>, and attending physicians. High-value care has been recognized as an important teaching topic by the Alliance for Academic Internal Medicine (AAIM), the American College of Physicians (ACP), and the American Board of Internal Medicine (ABIM) [6]. Furthermore, prominent centers such as the Institute for Strategy and Competitiveness at Harvard Business School and the Center for Healthcare Value at the University of California, San Francisco (UCSF) study value in health care. By 2017, the AAIM, the ABIM, the ABIM Foundation, and the ACP aim to establish the practice of high-value care as a key competency within medical education [7]. The Accreditation Council for Graduate Medical Education (ACGME) and the ABIM have also indicated that cost awareness is an important component of residency training [8]. Steven E. Weinberger has proposed separating cost awareness from the competency of "systems-based practice" and making it the basis of a seventh ACGME core competency that would also include resource stewardship [9].

Here, we explore initiatives that incorporate HVC principles into medical training.

Medical Students as Change Agents

UCSF recently awarded a proposal to better integrate value assessments into undergraduate medical education [10]. The proposal's goal is to give third-year medical students on internal medicine rotations an assigned role in promoting high-value care: that of HVC officers empowered to start discussions about HVC with other medical staff. The training emphasizes interventions based on the ABIM Foundation's "Choosing Wisely" campaign, and the curriculum will accord with the current goals of the UCSF Division of Hospital Medicine. The students will receive a 30-minute orientation lecture, short videos, and training at the beginning of the internal medicine clerkship [10].

Martin Muntz piloted a similar program at the Medical College of Wisconsin, for which he and his team were recognized in the Costs of Care and ABIM Foundation Teaching Value and Choosing Wisely Challenge [11]. In that program, students are educated on instances of overuse, such as unnecessary telemetry monitoring or avoidable blood transfusions, and then asked to serve as high-value care officers on internal medicine clerkships [12].

This program and others like it help make the students' role in promoting value more explicit. Buy-in from clerkship directors, residents, and attending physicians on rounds will be important in growing such initiatives. It would be unfortunate if time pressures, a focus on hierarchy, or resistance to change led to team members' being dismissive of the HVC officers' suggestions. In other words, the learning environment itself must be considered.

Taking Advantage of the Crowd

Crowdsourcing ideas may also be a way to effect change on this issue. Neel Shah and colleagues employed crowdsourcing methods to identify novel approaches to teaching value from across North America in the Teaching Value and Choosing Wisely Challenge [13]. They received 74 submissions from students, residents, faculty members, and nonclinical administrators. Of the submissions, 15 addressed undergraduate medical education, 39 addressed graduate medical education, and 20 addressed both [13].

The Do No Harm Project at the University of Colorado School of Medicine also takes advantage of others' experiences. Through this initiative, medical trainees are asked to submit clinical vignettes that highlight the avoidable harms that can result from medical overuse to facilitate a culture change in the practice of medicine [14]. Similarly, in 2014, *JAMA Internal Medicine* launched a section called Teachable Moments that features clinical vignettes describing examples of low-value care submitted by clinical trainees around the world [15]. This series is available to individuals at all stages of training, which allows for broad engagement.

Conclusion

Clinical trainees are the future of health care delivery, and failure to engage them in pursuing high-value care may perpetuate wasteful health care spending and avoidable patient harms. Further research is required to demonstrate the efficacy of educational interventions in improving quality and reducing costs and to identify the most promising approaches.

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American Medical Association Journal of Ethics

November 2015, Volume 17, Number 11: 1044-1045

THE CODE SAYS

AMA Code of Medical Ethics' Opinion on Physician Stewardship

Opinion 9.0652 - Physician Stewardship of Health Care Resources

Physicians' primary ethical obligation is to promote the well-being of individual patients. Physicians also have a long-recognized obligation to patients in general to promote public health and access to care. This obligation requires physicians to be prudent stewards of the shared societal resources with which they are entrusted. Managing health care resources responsibly for the benefit of all patients is compatible with physicians' primary obligation to serve the interests of individual patients.

To fulfill their obligation to be prudent stewards of health care resources, physicians should:

- (a) base recommendations and decisions on patients' medical needs;
- (b) use scientifically grounded evidence to inform professional decisions when available;
- (c) help patients articulate their health care goals and help patients and their families form <u>realistic expectations</u> about whether a particular intervention is likely to achieve those goals;
- (d) endorse recommendations that offer reasonable likelihood of achieving the patient's health care goals;
- (e) choose the course of action that requires fewer resources when alternative courses of action offer similar likelihood and degree of anticipated benefit compared to anticipated harm for the individual patient, but require different levels of resources;
- (f) be transparent about alternatives, including disclosing when resource constraints play a role in decision making; and
- (g) participate in efforts to resolve persistent disagreement about whether a costly intervention is worthwhile, which may include consulting other physicians, an ethics committee, or other appropriate resource.

Physicians are in a unique position to affect health care spending. But individual physicians alone cannot and should not be expected to address the systemic challenges of wisely managing health care resources. Medicine as a profession must create conditions for practice that make it feasible for individual physicians to be prudent stewards by:

- (h) encouraging health care administrators and organizations to <u>make cost data</u> <u>transparent</u> (including cost accounting methodologies) so that physicians can exercise well-informed stewardship;
- (i) ensuring that physicians have the <u>training</u> they need to be informed about health care costs and how their decisions affect overall health care spending; and
- (j) advocating for policy changes, such as medical liability reform, that promote professional judgment and address systemic barriers that impede responsible stewardship.

Issued November 2012 based on the report "<u>Physician Stewardship of Health Care</u> <u>Resources</u>," adopted June 2012.

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American Medical Association Journal of Ethics

November 2015, Volume 17, Number 11: 1046-1052

STATE OF THE ART AND SCIENCE

The Challenge of Understanding Health Care Costs and Charges

Vineet Arora, MD, MAPP, Christopher Moriates, MD, and Neel Shah, MD, MPP

Health care prices are opaque, and patients and clinicians are equally in the dark about them. As Americans enroll in high-deductible health plans at unprecedented rates, the affordability of health care has received significant attention [1]. In 2015, "how much does it cost?" is an increasingly familiar question from clinical trainees. The problem is that right now it is not clear who has the answers. The costs of delivering care are obscured in layers of jargon and complex accounting [2].

Speaking the Same Language: Health Care Cost Terms

The first step in understanding health care costs is to be able to distinguish between terms such as "cost," "charge," "price," and "reimbursement" (table 1).

Term	Definition
Cost	To providers: the expense incurred to deliver health
	care services to patients.
	To payers: the amount they pay to providers for
	services rendered.
	To patients: the amount they pay out-of-pocket for
	health care services.
Charge or price	The amount asked by a provider for a health care
	good or service, which appears on a medical bill.
Reimbursement	A payment made by a third party to a provider for
	services. This may be an amount for every service
	delivered (fee-for-service), for each day in the
	hospital (per diem), for each episode of
	hospitalization (e.g., diagnosis-related groups, or
	DRGs), or for each patient considered to be under
	their care (capitation).

Table 1: Defining Costs, Charges, and Reimbursement (adapted from Understanding Value-Based Healthcare [3])

These terms have specific meanings, but their interpretation often depends on whose perspective is being considered. To patients, cost usually represents the amount they have to pay out-of-pocket for health care services. This cost is very different from the amount that providers (i.e., health care organizations or clinicians) incur to deliver that

service. Further complicating matters, the cost to the provider is often calculated by including costs from categories like personnel and equipment that may seem disconnected from an individual patient's care.

The need for all of this terminology reflects the complexity of health care transactions. This complexity is largely a product of having multiple participating parties—the patient, the provider organization, and the "third-party" payer (insurer). Sometimes, a fourth party, such as a large employer that offers health insurance as a benefit (often referred to as the "purchaser"), is also involved. When discussing health care costs, it is important to ensure that the correct terminology is being used and that it is clear from whose perspective costs are being considered (i.e., payer, patient, provider, or purchaser).

So, how do costs relate to the "charge," or the "price," that health care providers put on the bill? Well, unfortunately, often there is <u>no clear relationship</u>. The relationship would be clearer and costs-per-service more easily calculated if costs were assigned to categories such as "patient check-in" and "collecting history" [4]. Although this is not impossible, it would be a lot of work, requiring direct observation of each "labor input," i.e., the number of person-hours involved in completing each task for an episode, as well as accounting for the costs of space, nonconsumable equipment, and administrative overhead on a minute-to-minute basis. Very few provider organizations are willing to put in this kind of effort.

Most hospitals have a "chargemaster," an itemized list of prices, similar to a restaurant menu [5]. Health care facilities often set chargemaster prices at many times the amount for which they are reimbursed or paid by insurers. While this may sound strange at first, it allows hospitals to set a high starting point for ensuing closed-door bargaining with different commercial insurers and very high charges for the small fraction of self-pay patients who can and will pay the chargemaster or "sticker" price. (Of course, the group of "self-pay" patients is heterogeneous. While it may include the wealthiest of patients who seek care regardless of the price, it also includes those who lack insurance altogether, such as illegal immigrants.)

What Do Patients Actually Pay?

Most patients have health insurance and, as a result, are not paying the full charge on the bill but, instead, a "copayment" (i.e., a fixed small amount for a given service, often paid at the time it is received) or a percentage of the charge, depending on their insurance plans [6]. This makes life fairly challenging for anyone trying to answer the question, "Doc, how much is this going to cost me?" Even if the doctor knew the charge, he or she would be unlikely to know the specifics of a particular patient's insurance plan. The amount that a patient may owe is further affected by the setting or location of the health care good or service. For example, Medicare patients often pay a deductible of \$1,260 for acute hospitalization, and then Medicare covers the rest up to 60 hospital days. But if a Medicare patient is seen in the emergency department and not admitted, or is "kept under observation status," he or she is technically an outpatient, for which the copayment for hospital services may be as much as 20 percent of the total charge... so you can see how difficult it might be to predict what a given patient will pay for a particular intervention or treatment episode [7, 8].

The Price Transparency Movement

There is currently a national movement to make charges easily available to patients—an idea often referred to as "price transparency." This movement has been made possible in recent years by a variety of new websites and tools that provide information directly to patients about the charges that they could face.

In February 2013, *Time* magazine published an exposé on health care costs, "Bitter Pill: Why Medical Bills are Killing Us," by journalist Stephen Brill [9]. Shortly after, the then-Secretary of the Department of Health and Human Services, Kathleen Sibelius, took the unprecedented step of making available online the 2011 chargemaster prices of the 100 most common inpatient treatment services of all hospitals that treat Medicare patients [10]. This enabled Medicare patients, for the first time, to compare the prices of procedures across hospitals in their areas. This data also confirmed what several recent studies have demonstrated: there is wide variation in the prices of tests and procedures, even in the same geographic location [11].

Other websites use a variety of methods, including crowdsourcing, to identify the prices of health care goods and services. For example, at HealthcareBlueBook.com, one can search for the lowest prices for health care goods or services based on zip code [12]. Fairhealth.org, which makes available to clients a database of doctors' fees contributed by payers nationwide, grew out of a legal investigation in New York into how insurance companies were setting reimbursements for out-of-network services [13, 14]. Castlighthealth.com contracts with employers to provide their employees access to prices of health care goods and services covered by the company-sponsored insurance. Its initial public offering received a valuation of more than \$3 billion, reflecting the keen interest in this burgeoning area [15].

There is also great interest within health care in using the electronic health record (EHR) to display prices for various goods and services to physicians and physicians-in-training. Initial studies of this strategy showed mixed results, and the conventional wisdom became that prices in the EHR quickly turn into "white noise" that is ignored [16, 17]. However, more recent studies have found that clinicians are now more likely to react to price information [18, 19], perhaps due to the recent global attention to the importance of health care costs. In one controlled study at Johns Hopkins, displaying the Medicare Allowable Rates for lab tests to hospital physicians in the order-entry system led to substantial decreases in orders for certain higher-cost lab tests and resulted in a more-

than-\$400,000 net cost reduction over the course of a six-month intervention period [18]. Similarly, a study using dollar signs (\$-\$\$\$) to indicate the relative costs of antibiotics on culture and antibiotic susceptibility testing reports resulted in a significant decrease in prescriptions for high-cost antibiotics [19].

What Can Physicians Do?

While price transparency is an important element of helping patients receive more affordable care, it may be unreasonable to expect clinicians to master the specific details of what each patient may pay, particularly given the large number of plans and reimbursement rates set by insurance companies.

So, what should physicians do? While there may be an understandable initial instinct to throw our hands up [20], we propose an alternative strategy.

First, we physicians should take ownership of <u>our clinical decisions</u> and make sure they are actually going to make our patients better. Currently, more than one-third of the health care services we deliver do not help patients get better [21], so there is clearly room for improvement. For those looking for a place to start, the <u>Choosing Wisely</u> campaign has convened an unprecedented collaboration among numerous medical specialty societies to identify lists of wasteful practices, i.e., those that provide little clinical benefit [22].

In addition, doctors can and should play a role in <u>screening</u> patients for financial harm. Simple questions like "Do you have difficulty paying for your medications?" have been shown to help identify patients at risk for cost-related nonadherence [23]. Having a conversation with a patient about his or her finances is more likely to result in switching the patient to a cheaper alternative prescription drug [24]. Even if these conversations are uncomfortable and even if you don't have all the answers, simply being aware of your patients' financial concerns is a critical starting point.

Although the costs may not always be clear, and the price may not always be "right," doctors still have an ethical obligation to "do no harm" by reducing waste and identifying and helping patients who are at risk for financial harm [25].

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American Medical Association Journal of Ethics

November 2015, Volume 17, Number 11: 1053-1058

POLICY FORUM

Repeal of the Medicare Sustainable Growth Rate: Direct and Indirect Consequences

Jeffrey Clemens, PhD, and Stan Veuger, PhD

In 2013, US health care spending totaled about \$3 trillion, or more than \$9,000 per person [1]. This corresponded to 17.4 percent of GDP, a much larger share than one sees in other countries [1, 2]. The largest financer of this medical care was the federal government: the Medicare program for the elderly and disabled accounted for 26 percent of all hospital expenditures and 22 percent of all outpatient care [1], and states' Medicaid programs received \$265 billion in federal funding [3]. Beyond this direct role, the federal government influences health care and health insurance markets through their tax treatment, subsidy arrangements, and regulation.

The federal government's role as the largest financer of health care, which has expanded in recent years through the <u>Medicare Modernization Act of 2003</u> and the <u>Patient</u> <u>Protection and Affordable Care Act</u> of 2010, positions it to substantively shape the sector's long-run trajectory. As the single largest purchaser of health care services, its decisions regarding the generosity and structure of payments exert systemwide influence. In this context, we consider the implications of the recent repeal and replacement of the Medicare Sustainable Growth Rate (SGR) through the enactment of the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) [4].

From SGR to MACRA

The SGR. The SGR, enacted through the Balanced Budget Act of 1997, was the product of a congressional effort to constrain growth in Medicare's spending on physician services. The underlying formula was meant to generate reductions in fee-for-service payment rates when Medicare's total spending on physicians' services grew more quickly than a target growth rate. It made allowances for modest fee increases, changes in the number of Medicare beneficiaries, and GDP growth, among other factors [5].

For most of the SGR's existence, actual expenditures grew faster than target expenditures. The SGR's formula has thus typically called for reductions in Medicare's fee-for-service payment rates [6]. Political pressure from physician organizations wary of reduced compensation [7] and from beneficiaries concerned about access to care [8] led Congress to enact a series of temporary measures to keep these cuts from materializing. These so-called "doc fixes" were typically legislated to last for a single year, making their renewal an annual or more frequent event. Because they did not alter the underlying SGR formula, the divergence between doc fix payments and those called for by the formula gradually widened. The reductions in Medicare fee-for-service payment rates that would occur if there were a lapse in the doc fix thus became increasingly dramatic over time, approaching 30 percent in some years [9].

The large size of the cuts implied by the SGR made permanent repeal look costly. Simultaneously, the implied cuts' size made it unpalatable, to physicians and Medicare beneficiaries alike, for Congress to allow them to be implemented. It is precisely these forces that sustained the doc fix "ritual" for so long. Recognizing its annual inevitability, the Congressional Budget Office (CBO) incorporated these fixes into its (more realistic) "alternative" fiscal scenario for forecasting deficits and debt [6]. The CBO's forecast of the cost of long-term repeal finally decreased, however, when the growth rate of medical spending declined in recent years. In 2015, Congress finally repealed the SGR (or, technically, turned it into a mechanism that produces fixed annual updates, explained below) [4].

The MACRA. What, then, replaces the SGR? There are two key elements of the MACRA that will directly affect physicians' payments and practices. The first is a new procedure to determine the updates to Medicare's physician fees: instead of annually improvised updates, fees are now scheduled to increase by 0.5 percent per year through 2019 and then to remain flat from 2020 through 2025 [4]. The SGR repeal thus brings an end to the recurring uncertainty in Medicare physician pay and the need for congressional intervention to avert sudden, large payment rate cuts.

The repeal's second element is the introduction of a "merit-based incentive payment system" (MIPS). Starting in 2019, the MIPS will fold a number of current incentive systems into a single, modified approach to rewarding physician groups that excel according to its criteria for providing high-value care. These bonuses and penalties are cost-neutral; money flows from underperformers to outperformers [10]. The goal of these new incentive payments is, of course, to induce physician groups to provide higher-quality care without increasing resource usage. The measures upon which groups will be scored include the "meaningful use" electronic health record (EHR) program, the Physician Quality Reporting System (PQRS), and the Value-Based Payment Modifier (VBPM) program. The scoring will also incorporate an evaluation of clinical practice improvement activities [11]. As of September 2015, the secretary of the Department of Health and Human Services (HHS) had yet to announce more detailed implementation guidance and assessment criteria. But the size of bonus payments and penalties derived from MIPS scores is written into the law: they will grow to range from +27 percent to -9 percent in 2022. Physician groups will also be offered the chance to opt out of the MIPS. To do so, a large enough percentage of their revenue must come from qualifying alternative payment mechanisms (APMs). Qualifying alternative mechanisms must more tightly link physician income to performance and require "sufficient" quality reporting.

The range of mechanisms that will be deemed qualifying remains to be fully determined by the secretary of HHS.

Presumably the MIPS will bear a significant similarity to Medicare's Pioneer accountable care organizations (ACOs), which, thus far, appear to have delivered promising savings [12]. Because the Pioneer ACOs voluntarily participated in the initiative, however, the extent to which these first-movers' successes will be replicated by later entrants is unclear [13, 14]. In general, of course, it is quite difficult to design mechanisms that make it pay to reduce revenue [15].

Probable Effects

The repeal of the SGR and the expansion of the MIPS will have direct, wide-ranging impacts on physician payments and practices. Importantly, these changes are likely to exert influence beyond the Medicare program.

As practitioners are well aware, Medicare's fee schedule plays a central role in many contracts between physicians and private third-party payers [16, 17]. Specifically, contracted payments are regularly negotiated relative to Medicare's payment menu, typically with relatively high payment rates for physician groups with substantial market power and relatively low payment rates for small group practices. Recent research [18] finds that, consistent with the conventional wisdom, Medicare's payments do indeed exert significant influence over private payments. The study, conducted by one of us and another coauthor, investigated how private payments responded to Medicare's substantial 1998 change in payments for surgical procedures relative to "other" medical services [18]. Using a large database of private sector claims, the study found that private payment changes tracked Medicare's payment changes virtually dollar for dollar with essentially no lag. The relationship was particularly strong in markets dominated by relatively small group practices. Anecdotal evidence suggests that other sorts of reforms, for example Medicare's Multiple Procedure Payment Reduction policy for diagnostic imaging services, have also been incorporated into private payment models [19].

It may only be a matter of time, then, until the elimination of the SGR and the introduction of the MIPS influence both the overall generosity and the underlying structure of private-sector payments. These changes in payments should, in turn, be expected to influence both the overall quantity and kinds of care physicians provide [20]. Further, it is likely that the reduced uncertainty about future compensation will induce higher levels of investment and an increased willingness to hire [21] (also S.R. Baker, N. Bloom, S.J. Davis, unpublished data, 2015).

That said, other elements of the law may make future policies and regulations less predictable. The changes packaged into the MIPS, for example, may affect physician

incentives in subtle ways. Little can be said, however, until the components of the new incentive system have been more completely designed and revealed. Where significant revenues are at stake, one would certainly expect physicians' practices to organize in ways that are likely to be rewarded. The system's capacity to measure and reward true underlying quality, whatever one believes that is, will thus be crucial. The effectiveness of these efforts and their impacts on care quality for both the publicly and privately insured remain to be seen.

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American Medical Association Journal of Ethics

November 2015, Volume 17, Number 11: 1059-1063

POLICY FORUM

Increasing Cost Efficiency in Health Care without Sacrificing the Human Touch Eva Luo, MD, MBA

On the beach, the traditional summer challenge is to build the most elaborate sand castle. Those with towers and moats are easily identifiable "high-value" constructions that achieve beachwide admiration. When the challenge is, however, to build the highest-value health care system, the characteristics equivalent to towers and moats are less obvious. Michael Porter simplified the definition of value in health care with the equation *value* = *outcomes/cost*—equating value with achieving the best outcomes at the lowest costs [1, 2]. But how best to optimize value in a well-designed delivery system for a population is still not well understood. The sand castle we will try to construct in this article is for the population of pregnant women.

The High-Volume Approach

One way value can be optimized is reducing the denominator of the health care value equation: cost. It is an oft-quoted statistic that 30 percent or more of health care spending may be wasteful [3]. As a result, the effort to increase value in health care has been dedicated to improving efficiency and thereby reducing cost. One type of delivery system that has emerged from these efforts is the "focused factory model," surgical centers that specialize in care for a very specific condition or population. Shouldice Hospital [4] for hernia care and Martini Klinik [5] for prostate cancer care are well-regarded examples. These focused factories sustain high volumes that help build clinical expertise and standardization of care, thus achieving high value by reliably increasing both positive outcomes and cost savings. They optimize operations through the adoption of process improvement methodologies like LEAN and Six Sigma to improve the efficiency and flow of the system.

On the other side of the Pacific Ocean, we can get a glimpse of a "factory-style" health care system. With 1.3 billion people to serve, China's national health care system is by necessity high-volume [6]. Spending a month at Ruijin Hospital in Shanghai provided me with an insider's view of the operations in place at one of the busiest teaching hospitals in all of China. Clinicians routinely see upwards of 50 and sometimes as many as 100 patients a day in the outpatient setting just to scratch the surface of the country's high demand.

Routine prenatal care appointments in China are best compared to an assembly line. Patients queue outside the office door to see whichever obstetrician is available (clinicians do not have their own panels of patients) and file in one by one at the call of "next!" The patient's chart is quickly handed to the obstetrician for review. The medical assistant immediately begins to conduct a physical exam and calls out rapid-fire findings to be recorded by the obstetrician, who then makes recommendations. Each appointment lasts no more than five minutes, which allows patients to ask just one or two questions; there is no time for chitchat. If further testing is needed, the medical assistant quickly ushers the patient into an adjacent exam room, where all swabs and collection tubes are prepared for the obstetrician's examination so that he or she can return to the consultation room within five minutes. Patients are given their collected samples and specific instructions on where to drop them at the hospital labs.

Is this high-volume system high-value? It is difficult to comment on the clinical outcomes quantitatively and holistically, given significant access challenges in China's more rural areas and practice variations rooted in cultural differences [7]. If a healthy baby and healthy mother at delivery are the desired outcomes, China's factory-like health care system, with its efficient and standardized care, does produce just that. Maternal mortality and infant mortality rates have dropped dramatically since 1990 [8-10].

However, China's extreme form of factory-like medicine, with its clinician-centric focus on efficiency for episodic care, does seem to neglect the long-term patient outcomes. China's cesarean section rate in some places is greater than 50 percent [11, 12], and anecdotal evidence suggests it is approaching 70 percent at Ruijin Hospital. (One of the several hypotheses about China's high cesarean section rate is that it is a reaction to the extremely large population's high demand for obstetrical services [11].) Given evidence that cesarean sections are inferior to vaginal deliveries for both the health of mother and baby, a 50 percent cesarean section rate indicates that there is room for improvement on clinical outcomes, at least from the patient experience and longitudinal care perspectives [13].

"High-Touch" Approaches

At the other end of the spectrum from high-volume delivery models are those that are "high-touch." Such models optimize health care value by focusing on the numerator of the equation: patient outcomes. This optimization is often achieved by reducing complications, aiming at restoration of health, or preventing disease and costly care interventions through a patient-centered, community-based, and even consumer-driven approach. Ultimately, with greater adherence to care plans and sustainable behavioral change, cost savings are also achieved.

lora Health, a Cambridge startup that seeks to transform primary care, is a high-touch care delivery system [14, 15]. Each patient is assigned a health coach who maintains and encourages all lines of communication—phone calls, text messages, emails, office visits, and house calls—to help patients achieve their individual health goals. Health coaches and physicians at lora Health practices develop relationships with patients beyond a

focus on disease states, laboratory tests, and biometric markers. These relationships become woven into the fabric of the community to shape behavioral and lifestyle changes that influence health outcomes. Community-tailored group exercise and wellness classes offered at each clinical site are examples. Payment is per patient rather than per encounter, which encourages clinicians to focus on overall health and prevention to reduce the use of more expensive forms of care. Iora Health has been able to achieve impressive outcomes, like reduction of emergency room visits for a generally sick population of patients who have several chronic diseases [15].

The CenteringPregnancy model of group prenatal care visits is a high-touch approach to prenatal care. Women of similar gestational age within a community are grouped together, and over the course of about ten prenatal visits they gain each other's support as they learn about and experience the clinical changes of pregnancy and prepare for labor and delivery [16]. Each 90-minute visit begins with a woman's self-assessment of vital signs while she mingles with others in the group and their invited family members. There is then teaching and discussion that follows a standard curriculum. Sessions are facilitated by a nurse-midwife or physician [16]. A growing body of research suggests that group prenatal care produces comparable if not better outcomes than traditional visits [16-18]. It also seems to be a clinically effective model for at-risk populations such as adolescents and low-income women [17].

While there is not yet much evidence about the connection between high-touch models of health care and overall clinical outcomes, the growing body of literature on "etiquettebased medicine" demonstrates a correlation between effective physician-patient communication and improved patient outcomes [19-21]. Behavioral change research also suggests that, because a healthy lifestyle may require significant behavior modification, the creation of physician-patient relationships with the development of a web of accountability that promotes behavioral change [22] also points to the value of a "high-touch system."

The Best of Both Worlds: Segmenting a Population and Then Scaling Care

Strong arguments can be made in favor of both high-touch and high-volume approaches. Both have led to model systems that achieve improvements in outcomes and reductions in cost. The advantage high-touch has is its population-based approach. Patients and their health conditions are heterogeneous. Health care needs range from psychiatric therapy sessions to prenatal care to transplant surgery. Similarly, patient communities include young millennials who communicate almost exclusively over mobile devices and the sickest of the "dual-eligibles" (those eligible for both Medicare and Medicaid), who are oftentimes homebound. Upon closer examination, all of the successful models mentioned earlier—Shouldice Hospital, Martini Klinik, and Iora Health—actually employ both high-touch and high-volume approaches. All three are sensitive to the needs of specific segments of their patient population and designed ways to address those needs in an efficient and scalable manner. As these successful models indicate, creating a highvalue health care system must begin with a high-touch understanding of the patient population.

Re-envisioning prenatal care through the lens of value would transform our current onesize-fits-all approach. A high-touch approach would help us segment the pregnant population by degrees of risk. A high-volume approach would help us develop scalable solutions best suited for each segment of that population. The future of prenatal care would reflect the heterogeneity in the population and include characteristics that allow us to optimize outcomes within each segment. Low-risk expectant mothers may only need a few in-person appointments and can receive the rest of their care via mobile phone, while high-risk pregnancies may necessitate more frequent visits, group prenatal care, and/or remote monitoring. Prioritizing certain needs and outcomes for each segment of the population means that solutions and interventions can then be tailored to the patients' needs and, when scaled up, remain efficient.

Ultimately, health care value needs an approach that is both high-touch and highvolume, and, above all, population-specific. Before we embark on building new sand castles for health care, we must identify whom we are building them for.

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American Medical Association Journal of Ethics

November 2015, Volume 17, Number 11: 1064-1072

POLICY FORUM

High-Value Palliative Care for Cancer Patients

Ali John Zarrabi, MD, Ran Huo, MD, and Diane E. Meier, MD

I will remember that I do not treat a fever chart, a cancerous growth, but a sick human being, whose illness may affect the person's family and economic stability. My responsibility includes these related problems, if I am to care adequately for the sick. Hippocratic Oath, Modern Version

Although the Hippocratic Oath was written in antiquity, American medical students for generations have sworn to "apply, for the benefit of the sick, all measures which are required, avoiding those twin traps of overtreatment and therapeutic nihilism" [1]. As physicians we are bound by this oath to provide all measures to increase both the length and quality of our patients' lives. For patients with advanced cancer, we advocate for a balance between therapeutic nihilism—a philosophy that would exclude these patients from clinical trials and the advancement of science—and overtreatment, which could result in physical, psychological, and financial harm. In this paper, we call on our fellow physicians to reaffirm their commitment to the Hippocratic Oath. We argue that integration and early adoption of palliative care for patients with advanced cancer is the optimal approach to maximizing their quantity and quality of life while reducing the physical and financial toxicities that neither extend life nor improve living.

What Is Palliative Care?

Palliative care, also known as palliative medicine or supportive care, "is specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness—whatever the diagnosis" [2]. Palliative care can be offered to anyone with serious illness, regardless of age or stage of disease, and it can be provided to patients who are undergoing active treatment with curative intent. For the purpose of this paper, we will focus on palliative care for cancer patients who have advanced or incurable disease.

Palliative care is provided by an interdisciplinary team of palliative care doctors, nurses, social workers, and other specialists who work together with a patient's other doctors to provide extra support and improve quality of life for the patient and his or her family [3]. All physicians who have attained basic core competencies in symptom management, psychosocial interventions, communication, and care transitions can practice primary palliative care [4]. Specialty palliative care is a consultative service dedicated to assisting

other clinicians using an interdisciplinary team for patients requiring more complex supportive care.

High-Value Palliative Care Interventions for Patients with Cancer

Although we are not accustomed to considering value in health care, there is a method of calculating it by dividing the quality of care by its cost [5]. The assumption underlying the effort to improve value in health care is that the cost should be proportional to the benefit. When we talk about value, we must ask whether the medical intervention that we are proposing improves the quality and quantity of life enough to justify its cost (financial, temporal, and symptomatologic). The financial cost can be grave: health care expenditures are cited as a major cause of personal bankruptcy [6].

The physical, psychological, and social costs of treatment are onerous for patients with advanced cancer, and the financial costs are particularly high; chemotherapeutic regimens frequently enter the market that are several times more expensive than similarly efficacious medicines [7]. Unfortunately, few comparative effectiveness studies exist in oncology [8], and expensive medications that provide little value over cheaper ones are depleting the financial resources of many Americans [9].

Low-value interventions are common in treating advanced cancer. A medical oncologic intervention known as palliative chemotherapy (which, despite its name, does not originate in palliative care as we describe it below) is offered to patients with advanced cancer to improve cancer-related symptoms and, potentially, survival, even if the cancer itself is incurable. More than half of all patients with incurable cancer receive palliative chemotherapy in their last months of life [10]. However, a recent prospective cohort study by Prigerson et al. of patients with end-stage metastatic cancer and life expectancy of less than six months found that palliative chemotherapy did not lengthen survival, irrespective of functional status, nor did it improve or worsen quality of life for patients with good functional status, even when controlling for clinical setting.

Skilled, sensitive, and honest communication about the limitations and burdens of palliative chemotherapy may improve quality of care and reduce the costs of potentially deleterious toxic therapies. This topic is especially relevant because patients occasionally opt for chemotherapy because they prefer to feel as if they are "doing something." This may mean they believe the chemotherapy will have curative intent: up to 69 percent of patients with lung cancer and 81 percent of patients with colorectal malignancy receiving palliative chemotherapy were not aware that they could not expect to be cured of their diseases [12], suggesting that oncologists are not trained to speak to patients about the potential benefits and tradeoffs of palliative chemotherapy. Offering palliative chemotherapy is only appropriate if the patient understands that the benefits of

treatment might be minimal and that they may feel worse from it, particularly near the end of life. Equating treatment with hope in these cases is unethical.

Oncologists are uncertain about whether and how the cost of care should <u>affect their</u> recommendations [13]. Some oncologists feel that consideration of cost conflicts with their duty to individual patients and that cost should not enter into the discussion of whether or not to offer a therapy. Those oncologists may be more comfortable discussing whether the therapies offer any value in terms of quality or duration of life rather than discussing cost burden. For doctors who feel uncomfortable <u>discussing costs</u> of care, the Prigerson study [11] provides a rationale for focusing instead on reduced quality of life when discussing value with their patients and colleagues.

Palliative care can offer high-value alternatives in care of advanced cancer. Palliative care not only decreases costs but, more importantly, improves quality of care. It has been shown to improve quality of life, patient satisfaction, caregiver burden, and survival in patients with serious illness [14]. In cancer care specifically, palliative care improves several key metrics of quality by alleviating pain, depression and psychosocial distress, fatigue, and dyspnea and by providing information and care planning [15]. Expertise in communication, complex decision making, and care transition makes palliative care clinicians ideal partners for oncologists who are weighing the benefits and risks of a given intervention in the context of a patient's goals [15]. By focusing on what is important to the patient, palliative care may temper unrealistic patient and family expectations that sometimes lead clinicians to offer services without evidence of utility or benefit.

Evidence supports the value of integrating palliative care into oncologic care at the time of diagnosis of advanced cancer. Introducing palliative care earlier in advanced cancer patients' illness results in higher utilization of hospice, reduction in futile aggressive care in intensive care settings, and extension of life for some patients [14, 16]. For example, Temel et al. [14] showed that patients with metastatic non-small-cell lung cancer who were randomly assigned to early palliative care concurrently with standard oncology care had significantly higher quality-of-life scores, fewer depressive symptoms, less aggressive end-of-life care, and a modest survival benefit compared to those who received standard oncology care. Furthermore, average hospice stay in the palliative care intervention group was eleven days, while the standard care group stayed only four [14]. One explanation for these differences is that patients who had simultaneous palliative care were better able to understand and process their prognoses and chose less chemotherapy near the end of life, which may account for their relatively longer survival period.

Early intervention is valuable not only for improvements in quality of life, but also for cost savings. The evidence demonstrating that early palliative care interventions reduce

cost is convincing. A multicenter prospective cohort study of patients admitted to the hospital with a diagnosis of advanced cancer found that earlier consultation was associated with estimated cost savings of 14 percent (if palliative care consultation occurred within six days) and 20 percent (if palliative care consultation occurred within two days), attributable to the reduced length of hospital stay and reduced intensity of hospital care [17]. Another study found that total average health care costs were \$6,766 lower for patients randomly assigned to usual care plus interdisciplinary care service (IPCS) than for those assigned to usual care alone [18]. Patients in the IPCS group also reported greater satisfaction with their care experiences and clinicians' communication [18]. These studies support early palliative care intervention for patients with advanced cancer as a means to raise quality and decrease the cost of care, thereby improving the value of care.

Barriers to High-Value Palliative Care for Cancer Patients

Despite the evidence for improved quality and reduced cost, many barriers to the implementation of high-value practices remain. Palliative care is often stigmatized as being synonymous with end-of-life or hospice care, when these are only components of what palliative care can offer to patients and their families [19]. In a culture in which Americans employ military metaphors [20] in referring to cancer patients who "battle," "fight," and sometimes "lose" their "wars" with cancer, patients, families, and clinicians may feel obliged to aggressively treat the disease even when the harms of treatment clearly outweigh the potential benefits. American values can conflict with pursuing a natural death, and dying is sometimes seen as the failure of the medical system rather than as the natural ending to every life.

The national anxiety surrounding death and dying [21] could explain why some oncologists believe that palliative care referrals destroy hope [22] and that providing potentially futile therapies is a means of tempering patient anxieties about death. These beliefs may be caused by a dearth of adequate primary palliative care education in medical school and residency programs, lack of proper reimbursement for the often lengthy and sensitive conversations about advance care planning (which we hope will soon change), and even differences in attitudes and opinions about palliative care within the oncologic community. For example, in a survey of hematologic and solid tumor specialists at MD Anderson Cancer Center, researchers found that hematologic specialists were more likely than solid tumor specialists to favor prescribing systemic therapy with moderate toxicity and no survival benefit for patients with poor functional status and an expected survival of one month. They also felt less comfortable discussing death and dying [23]. These practices are consistent with data showing that hematologic malignancy patients have high rates of ICU admission and prolonged hospitalizations in the last 30 days of life [23]. Politically, palliative care has been stigmatized as health care rationing. Fear mongering led to palliative care being likened to "death panels," a strategy which was successful in quelling much of the national debate about health care reform [24]. Six years after reimbursement for advance care planning was removed from the Affordable Care Act [25] following Sarah Palin's infamous Facebook post likening goals-of-care conversations to governmental execution of seniors [26], the Centers for Medicare and Medicaid Services announced that they will reimburse doctors for these conversations beginning in 2016 [27]. This development provides hope that, while some politicians may delay popularization of palliative care, ultimately, policymakers embrace it as valuable to the health of our nation.

Lack of a robust workforce of palliative care physicians is yet another barrier to providing Americans with access to good supportive care. Despite sound evidence of palliative care's efficacy, only 66 percent of large hospitals had a palliative care program and just 59 percent of National Cancer Institute (NCI)-designated cancer centers and 22 percent of non-NCI-designated cancer centers had an outpatient palliative care clinic or team in 2013 [28]. To increase the ranks of palliative care specialists, it is imperative that we train more physicians in the specialty and that basic palliative care training become a standard component of medical school, residency, and continuing medical education. Below we summarize the barriers to high-value palliative care for cancer patients:

Table 1. Barriers to high-value palliative care for cancer patients		
•	Stigma of palliative care as synonymous with end-of-life or hospice care	
•	Politicization of palliative care ("pulling plug on grandma")	
•	Lack of adequate primary palliative care education	
•	Paucity of palliative care specialists	
•	Some oncologists' preference to give systemic therapies at the end of life	

Promoting High-Value Practices in Palliative Care for Cancer Patients

To encourage high-value palliative care, we urge the adoption of high-value standards in diverse health care settings [29]. For example, one recent retrospective cohort study of patients with advanced solid tumors diagnosed and followed at Veterans Affairs (VA) hospitals found that study patients only received appropriate nonhospice palliative care 49.5 percent of the time, even within a health delivery system into which palliative care is deeply penetrated and well integrated [30]. Further research clarifying the barriers to

appropriate implementation of high-value palliative care in health systems is imperative so that sustainable programs can develop and flourish nationally.

Palliative care quality standards should result in increased revenue for payers, and we argue that penalties should be considered for failure to do so. If giving chemotherapy at the end-of-life has been shown not only to have no effect on increasing the quantity of life but also to worsen its quality, then why are physicians reimbursed for these harmful practices? When a given intervention's potential for no benefit or even harm is greater than its potential for benefit, then why should it be the default treatment [31]? More research examining the value of specific interventions for specific malignancies might strengthen the existing evidence base showing that more harm than benefit results from physicians offering toxic therapies near the end of life. This research ultimately might help guide decision making for clinicians and payers.

Cultural change is, of course, more difficult to achieve. Over time we hope that emerging evidence in favor of palliative care, along with development of sustainable and efficient care delivery models, will encourage oncology to embrace palliative care as the fourth pillar [32] of comprehensive cancer care alongside medical oncology, surgical oncology, and radiation oncology. Integrating palliative care into the medical curriculum would be the most effective way to produce a generation of physicians who embrace the principle and practices of palliative care. We also believe that training "palliative oncologists" [33], physicians with specialty training in both hematology/oncology and palliative care, would supply our health care system with physicians who can serve as experts and ambassadors for both fields, generating novel research questions and designing models of care integration. Training successive generations of health care professionals to practice palliative care will require coordinated effort from educators, institutions, policymakers, and payers to create an environment in which palliative care is part of the standard of care for patients with advanced malignancy. Below we summarize these and other recommendations for improving high-value palliative care for cancer patients.

Table 2. Recommendations for expanding high-value palliative care for cancer patients	
•	Early consultation
•	More research on implementation of palliative care for patients with malignancies
•	Improved primary palliative care education
•	Increased workforce of palliative care specialists
•	Payment systems in which meeting of palliative care quality metrics is rewarded

Conclusion

We advocate for a reaffirmation of the Hippocratic Oath, to ensure that patients do not suffer needlessly and to make sure that we do not cause iatrogenic suffering with toxic medicines that do not improve or extend life. We believe that innovation can occur at the intersection of palliative care and medical oncology. We can create a space for new approaches to treating serious illness that maximize the quantity and quality of life while reducing physical, psychological, and financial harm.

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Acknowledgements

We would like to thank Suzy Goldhirsch for her skillful editing of this paper.

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American Medical Association Journal of Ethics

November 2015, Volume 17, Number 11: 1073-1078

HISTORY OF MEDICINE

Promoting Cost Transparency to Reduce Financial Harm to Patients

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Medical care is continuously evolving as new drugs are discovered and new technologies are mastered. Along with these strides, however, come added costs. With nearly one in every five dollars spent in the United States going to health care [1], the sheer volume of money that changes hands in the health care sector is enormous. How did we get here?

Early Twentieth Century

Up until the end of the nineteenth century, most doctors' visits took place in patients' homes. Charges for treatments and procedures were determined through a negotiation between the physician and patient [2]. With the development (by Joseph Lister) and widespread adoption of aseptic techniques by the 1890s [2], the modern hospital emerged as a place of medical advancement and treatment. People previously treated at home were now seeking treatment at hospitals [2], which had to recoup building and operating costs. Estimates suggest that the percentage of an average US family's medical bill dedicated to hospital charges almost doubled in the first third of the twentieth century—from 7.6 percent in 1918 to 13 percent in 1929 [3, 4]. And in 1929, hospital expenses drove up the average annual health care charges (\$67) by nearly 400 percent per family—to \$261 [4]. These alarming statistics, coupled with the end of World War I and the Great Depression, led reformers to call for a national health insurance system or an appropriate community agency focusing on the promotion of group practice, equitable distribution of costs of medical care among social groups and over time, and an emphasis on preventative medicine [5].

In the early 1900s, established professional standards for physicians had emerged, and Abraham Flexner helped to incorporate them into medical education [6]. The profession responded to these improvements in medical science, education, and training with division of labor and an increase in medical specialization [5]. The Committee on the Costs of Medical Care (CCMC) argued in 1933 that variation in health care use and more frequent contact with medical practitioners were leading to increased health care expenditures for individual families [5]. Physicians' decisions about what to charge patients for services were influenced by a wide variety of factors—such as the rising cost and length of medical education, hospital and administrative fees, and increased competition—not directly related to providing what we now call "high-value care," a scenario that some would argue is continuing today [6].

Mid-Twentieth Century

After the world wars, the field of medicine grew rapidly, employing much experience gained from treatment of battlefield wounds and mental conditions. Health care began to approach what we know it to be today. For example, antibiotics came into wide use, childbirth was increasingly a hospital event, and chemotherapy was first used clinically in 1942 [7]. Medicine was fully entrenched as a science, and, as medical knowledge grew, so too did cost, that is, the monetary burden of providing a service [8]. (This term is distinct from charges—the amount billed by the entity providing the service—and payments or reimbursements—the monetary amount received by the entity providing the service.)

However, though costs were rising, cost information was sometimes made available to patients so they could make informed financial decisions about their care. In 1954, for example, Grace-New Haven Hospital presented all expectant mothers with the cost of room and board for the upcoming delivery [9]. The prices of different types of rooms were handed to the patient the same way we today place identification bands on patients and have them sign informed consents. As the costs increased and care became more complex, this transparency has disappeared.

Today

Since the last third of the twentieth century, the doctor's toolkit has grown to encompass more technology, treatments, and tests, and costs have grown with it. Organ transplantation, elaborate cardiac surgeries, and life-sustaining technology not only increase cost of care enormously, but also keep people alive to incur even more charges in the future. In 2004, \$1.9 trillion was spent on health care in the United States—a 36fold increase from 1947 when adjusted for inflation [10]—or \$6,508 per person [11]. In 1960, US health care expenditures were only \$27.4 billion, or \$147 per person [11]. The increasing resources dedicated to health care are becoming so expensive that financial harms are visited upon patients, who often do not have information to make fully <u>informed financial decisions</u> about their care. Prominent authors have discussed these financial "side effects" or "toxicities" and exhorted medicine to "do no (financial) harm" [12-14].

Financial Harms

Health care is the fourth largest share of household expense for the typical family in this country, behind housing, food, and transportation [15]. More than three-quarters of polled Americans with health insurance in 2005 reported being concerned about their ability to pay medical bills for routine care, and, in 2006, 32 percent of polled Americans reported worrying about financial harm in the event of a serious illness or accident [16]. Recently, it has been reported that more than half (52.1 percent) of all debts in the US are due to medical expenses [17]. These debts may in part be incurred because of a lack

of price transparency and communication between patients and physicians concerning medical prices [18]. Patients have reported wanting to have these conversations with their clinicians [19].

Why has cost control only recently become a rallying cry among clinicians, given what is at stake for our patients and the nation? Major reasons include a <u>lack of information</u> <u>about costs</u> among both physicians and patients and gaps in physician training about financial harms.

Cost negotiations have changed over time. Prices are no longer distributed to patients in advance. Now, closed-door negotiations between hospitals, clinics, and other provider organizations and insurance companies set complex fee schedules, a practice that results in physicians' ignorance of costs and patients' making purchases without knowing the prices or completely understanding the services they are receiving. As a result, the cost of a medical service may be drastically lower than the charges sent to the insurance company for reimbursement and the charges that patients see in their medical bills [20, 21].

We suggest that medical centers take the following steps to promote cost transparency and to train physicians and patients how to have open discussions about costs and the risks of financial harm:

- Provide medical professionals and patients with local cost information about tests, procedures, and medications.
- Publicize data on <u>costs and quality</u> made available by the federal government through Hospital Compare [22].
- Increase monitoring of patients who are at high risk for financial harms.
- Increase access to community resources to assist patients at high risk for financial harms, including financial coaching, vocational training, and housing and food security programs.
- Promote institutional discussions about <u>system-level changes</u> to improve care coordination, population health, and preventative care.

Conclusions

Patients and physicians have a joint ethical responsibility to discuss medical costs and to avoid financial harms for patients and society at large. Simply put, the United States cannot withstand the escalating cost of health care indefinitely. However, we believe that the recommendations outlined above, in combination with national policies and incentives, can improve cost transparency, help avoid financial harms, and promote ethical medical practice. Moving forward, we must reflect on these cost trends, identify key lessons, and promote efforts to rapidly evaluate and scale interventions that improve the delivery of high quality care at lower costs.

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American Medical Association Journal of Ethics

November 2015, Volume 17, Number 11: 1079-1081

MEDICINE AND SOCIETY

Countering Medicine's Culture of More

Hyung J. Cho, MD

Not long ago, I trained at an internal medicine primary care residency at Yale-New Haven Hospital. I had hopes of becoming a great diagnostician, and for that I was in the right place. The program had some of the best clinician-educators in the area, possibly in the country. What I remember most vividly were the morning reports.

We would discuss an interesting case at these daily meetings. The chief residents would take turns preparing and presenting. The majority of the time, the presentation focused on an inpatient case that was a "zebra," a diagnosis or complication that we rarely encountered—lupus cerebritis, fungal pneumonia, or catastrophic antiphospholipid syndrome. We rarely discussed a classic case of congestive heart failure or syncope. Zebras only added to the awe and interest.

One morning, a young man presented with fevers, tachycardia, and a progressively worsening rash. We were in the usual conference room, large enough for about 30 people. It had a long table in the middle where residents sat, with an array of faculty seated all along the walls of the room. Eyes were drawn to the white board, where the case slowly unfolded. It was an inviting place, permeated by the smell of coffee for the weary souls who had been on call all night. The voices and laughter of colleagues were welcoming after those lonely hours.

The progressively unfolding case left opportunities for questions. Possible diagnoses would expand with each successive query: "Was the patient immunosuppressed? Any history of weight loss? Was the rash blanching?" We discussed possibilities like endocarditis, Epstein-Barr virus (EBV), cytomegalovirus (CMV), dengue fever, idiopathic thrombocytopenic purpura, syphilis, leptospirosis, and on and on. My imagination and interest would go wild, and the residents would think about the next set of tests and treatments to go with the possible diagnoses. When someone did mention the correct tests or treatments, eager approval came from the chief or the faculty. I can't remember the last time dengue fever was seen in New Haven, Connecticut, but nonetheless, the possibilities were endless and exciting. The wealth of knowledge the faculty possessed about these zebras was intoxicating; I worshiped their wisdom.

The diagnosis in this case turned out to be toxic shock syndrome from staphylococcus aureus. The appropriate treatment would be broad-spectrum antibiotics to start,

including clindamycin, and intravenous immunoglobulin. There was a long discussion about the consequences of missing this diagnosis, including the possibility of multiorgan failure and death. But it became apparent to me in hindsight that we didn't talk about the appropriateness of the workup and treatment. We left wild-eyed about the possibility of toxic shock presenting with a fever and rash, but how probable was toxic shock compared to the usual nonpurulent cellulitis with a fever? How often did we actually see leptospirosis in the US? <u>Perspective</u> was lacking, in the sense that most people admitted to the hospital with cellulitis can and should be treated with IV cefazolin and monitoring. In addition, we didn't discuss the probability of CMV, EBV, or leptospirosis. I could just imagine an intern saying the next day in rounds, "I remember the morning report yesterday, and so I ordered CMV and EBV titers and a urine leptospira test." Discussion of costs and value was lacking during these conferences. A culture of "more" was consistently reinforced.

We are in a <u>crisis of overuse</u>, in which an estimated \$750 billion per year, or up to 30 percent of health care spending, is considered <u>wasteful</u> [1]. In response to major initiatives like the American Board of Internal Medicine's Foundation's <u>Choosing Wisely</u> <u>Campaign</u> and the Lown Institute's RightCare Alliance, awareness of overuse is increasing. We know that there isn't a single test or treatment that hasn't been linked to patient harm in some way, whether it is physical, financial, or emotional. For our patients' well-being, we cannot afford to continue this trend of overuse. The unnecessary clindamycin doses used in case of unlikely toxic shock may cause clostridium difficile colitis days later. When you ask of any admission with cellulitis and a fever, "could this be toxic shock?" the answer is inevitably yes. Could low-back pain be cancer? The answer is always "yes it can." But evidence has shown that not all low-back pain, for example, needs to be imaged [2, 3]. Sometimes all we need is a good discussion with the patient.

I am currently an academic hospitalist at Mount Sinai Hospital in New York. The push toward overuse in a major academic center in a city of this size can be overwhelming. The patients often travel long distances to get "the best" testing and treatment, and the thought still prevails that more is better. Clinical uncertainty alone can cause a clinician to order a barrage of tests or call in many consultants. The paucity of time and the complexity of a place this large also propagate overuse.

To address this problem, we started a monthly conference at which students, residents, and faculty review cases of overuse, called OCCAM's (overuse clinical case morbidity and mortality) Conference. The name is a reference to Occam's razor, a principle of parsimony, economy, and succinctness used in problem solving, often phrased in medicine as, "When you hear hoof beats, think horses, not zebras." We discuss costs and value and connect overuse to patient harm by labeling it a medical error and performing root-cause analyses. The goal is to create a safe environment for open discussion, in the hopes of preventing patient harm from overuse from happening again. Identifying these

cases can be challenging; we weren't trained to look for them in the past. We readily recognize bad outcomes from underuse—the death from a case of sepsis for which appropriate antibiotics weren't started early, or the poor outcome from ischemic stroke that wasn't recognized earlier. However, tracing a case of clostridium difficile back to treatment for presumed bacterial bronchitis is difficult.

These days, however, I have a sense of renewed hope. Perhaps it's my longing for a change in the quality of care. Perhaps because my students and residents know that my research is in high-value care they make a concerted effort to change their practices. Regardless, I do enjoy an intern's reciting a long presentation and squeezing in at the end, "Dr. Cho, we decided not to check labs tomorrow because we think it's unnecessary." Sure, daily labs may not cost much, but it's the change in culture that makes this statement invaluable.

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American Medical Association Journal of Ethics

November 2015, Volume 17, Number 11: 1082-1097

Suggested Readings and Resources

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American Medical Association Journal of Ethics

November 2015, Volume 17, Number 11: 1098-1101

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