

# How Much Will It Cost?

November 2022, Volume 24, Number 11: E1029-1106

From the Editor Ethical Dimensions of Pricing Transparency Seth Scheetz, MD and Marshall H. Chin, MD, MPH	1031
Case and Commentary How Might Patients and Physicians Use Transparent Health Care Prices to Guide Decisions and Improve Health Care Affordability? Annika Brakebill, A. Mark Fendrick, MD, and Jeffrey T. Kullgren, MD, MS, MPH	1034
How Should Cost-Informed Goals of Care Decisions Be Facilitated at Life's End? Jing Li, PhD, Robert Tyler Braun, PhD, Sophia Kakarala, and Holly G. Prigerson, PhD	1040
What Should Clinicians Do When Health Services Are Improperly Billed in Their Names? Sharon Griswold, MD, MPH, Mustfa K. Manzur, MD, MPH, MS, and Wendy Dean, MD	1049
Policy Forum  If Patients Don't Use Available Health Service Pricing Information, Is Transparency Still Important? Christopher Whaley, PhD and Austin Frakt, PhD	1056
Informed Consent as a Means of Acknowledging and Avoiding Financial Toxicity as latrogenic Harm Kevin Schulman, MD and Barak Richman, PhD, JD	1063
Necessity for and Limitations of Price Transparency in American Health Care Harold A. Pollack, PhD, MPP	1069
Medicine and Society Which Price Should Be Transparent and Why?	1075

# Sherry Glied, PhD and Grace Kim, MHA

What Should US Policymakers Learn From International Drug Pricing Transparency Strategies?  Sarosh Nagar, Leah Z. Rand, PhD, and Aaron S. Kesselheim, MD, JD, MPH	1082
Art of Medicine Another Future We Create Christa J. Prentiss	1091
Bank Cards Might as Well Be Tarot Cards Julia O'Brien	1094
If You Have to Ask How Much It Costs, You Probably Can't Afford It Laura Kostovich, MS	1097
Viewpoint What Should "Shopping" Look Like in Actual Practice? Nisha M. Patel, MD, MPH, Jesse M. Ehrenfeld, MD, MPH, and Brian J. Miller, MD, MBA, MPH	1099

# Podcast

How Consumer Advocacy Groups Advance Health Equity: An Interview With Dr Mark Rukavina

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# **AMA Journal of Ethics®**

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# FROM THE EDITOR

# **Ethical Dimensions of Pricing Transparency**

Seth Scheetz, MD and Marshall H. Chin, MD, MPH

As clinicians, we aim to deliver high-quality care to every patient. We are guided by standards of care that are informed by evidence. In daily practice, however, we might be abruptly led to recontextualize clinical recommendations when patients ask, "How much will this cost?" This is a nuanced question. Patients are typically asking about the price they will pay for services—and, more specifically, the out-of-pocket price—rather than the cost, which has different meanings for different parties but typically refers to expenses incurred to produce and distribute services. Patients may be billed unpredictable amounts for health services we deliver. In the United States, high prices for services have fueled discussions of financial harm and financial toxicity. 1,2 In 2018, 2 of 3 adults were worried about affording unexpected bills. High health care bills likely contribute to social distrust of health professionals. As researchers, clinicians, and organizations grapple with how to discuss cost-conscious care and what care will cost patients, accurate pricing information is often not reliably, directly, or promptly available.

Several ethical values underlie calls for pricing transparency. First, transparency is a value in itself. An open society values knowledge rather than ignorance and generally prefers data and explanations that illuminate mechanisms of action to a proverbial black box. Second, autonomous informed consent depends—or should depend—upon transparency, since pricing transparency could increase efficiency and improve the value of care within a presumably free-market system of health care. Third, pricing transparency, in theory, could not only lead to more efficient decisions by purchasers, consumers (clinicians or patients), and policymakers, but also promote justice by better aligning resource utilization with social preferences and values to keep health care expenses from driving the sick and injured into poverty. Specifically, pricing transparency could help improve equitable access to high-quality care for marginalized populations by increasing competition and thereby reducing prices and preventing price discrimination. Pricing information could also help policymakers design and reform payment and delivery streams to be more user friendly and to better meet needs, thereby encouraging patients to become involved in their own care.

Pricing transparency has bipartisan political support. In 2014, the Healthcare Financial Management Association's Price Transparency Task Force defined price transparency as "readily available information on the price of healthcare services that, together with other information, helps define the value of those services and enables patients and

other care purchasers to identify, compare, and choose providers that offer the desired level of value."<sup>4</sup> Executive Order 13877 of June 2019 aimed to improve pricing transparency by requiring health care organizations to post specified pricing information in both machine-readable and patient-accessible formats to encourage patients to "shop" for nonurgent services.<sup>5</sup> However, professional associations have resisted regulation, believing that the requirements were overly burdensome and would not provide meaningful information to patients.<sup>6,7,8</sup>

Defining and implementing pricing transparency is a complicated process requiring cooperation and coordination among insurance companies, pharmaceutical companies, and health centers. Even when pricing information is readily available, traditional free-market, utilitarian economic principles don't often neatly or tidily apply, as neither clinicians nor patients can be assumed to be rational actors in an economic sense. For example, demand for unnecessary services can be driven by clinicians as well as patients. Moreover, variable insurance plans, with differing levels of maximum out-of-pocket costs and cost-sharing agreements, can influence clinicians' and patients' motivations to utilize pricing data or seek high-value care. All of these factors influence how feasibly health systems can achieve pricing transparency goals.

This issue of the *AMA Journal of Ethics* explores what pricing transparency means for patients, clinicians, health sector administrators, and policymakers. It illuminates tension among ethical and economic values that underly pricing transparency and the integrity of payment systems and care delivery streams. Contributors propose pricing transparency policies that express the ethical values of transparency, efficiency, and equity. The issue explores equitable access to high-quality care, shared decision making that incorporates patient values, and a complex health care market's ongoing search for value and efficiency. We hope this theme issue will guide future endeavors and policies to better support patients and clinicians when discussing pricing to motivate good health outcomes for patients and communities.

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# CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

How Might Patients and Physicians Use Transparent Health Care Prices to Guide Decisions and Improve Health Care Affordability?

Annika Brakebill, A. Mark Fendrick, MD, and Jeffrey T. Kullgren, MD, MS, MPH

### **Abstract**

Many Americans face high cost-sharing demands from their health insurers. While there is hope that prices for health services are becoming more and more transparent, even increased availability of price information will not always translate into optimal, equitable health and financial outcomes for patients. This commentary on a case argues why transparent pricing is an ethical imperative and identifies steps that health sector stakeholders should take to help patients and clinicians use pricing information to inform health decision making.

#### Case

NN is a 54-year-old woman with congestive heart failure, type 2 diabetes, hypertension, and chronic kidney disease who is enrolled in a marketplace health insurance plan with a \$6000 annual deductible. Last year, NN was hospitalized for decompensated heart failure. Her out-of-pocket (OOP) expenses for this hospitalization were high, which led to increased credit card debt and required her to spend less on food. Thus, even when NN experiences shortness of breath and leg swelling, she is reluctant to refill her prescribed diuretic. Furthermore, because of her concerns about the costs of her care, she often does not attend follow-up appointments with her physicians and only occasionally completes the laboratory testing they recommend. In her local newspaper, NN reads that hospitals are now required to publicly report to patients their negotiated prices for health care services. She is curious about this information and wonders if it could help with her financial concerns, but she isn't sure where to find this information or how to use it.

### Commentary

To benefit from price transparency, NN and the clinicians caring for her should discuss NN's insurance deductible, confirm indications for and the necessity of recommended services, canvass which necessary services should have their quality and prices compared in NN's regional market, and consider challenges that could emerge if NN were to receive services at different locations. Using OOP cost estimates from NN's health plan for medications, routine labs, and nonurgent imaging studies (eg, transthoracic echocardiograms), NN's clinicians could revisit her hesitancy to pursue treatment in light of the affordability of available options. Although the kind of

"shopping" needed to take advantage of pricing and quality information that is available and interpretable would not be practical in the case of unpredictable, urgently needed, expensive hospital services, potential benefits of comparing costs for nonurgent services is likely worthwhile.

Health care price information is now more available than ever. A 2019 executive order requiring hospitals to publicly report negotiated prices for health care services became effective on January 1, 2021, and motivates 2 major policy goals. First, greater price transparency would allow patients to better predict OOP costs and to decrease OOP spending and might mitigate surprise billing. Second, greater price transparency could have supply-side effects (eg, higher-cost services drop in price to match lower-cost services) and demand-side effects (eg, patients gravitate toward lower-cost services). Both could help constrain health care spending. Regardless of its capacity to further these policy goals, transparent pricing is, we argue, an ethical imperative. We also identify steps that health sector stakeholders should take to help patients and clinicians use this information to inform health decision making. We also identify steps that health sector stakeholders should take to help patients and clinicians use this information to inform health decision making.

### **Ethics and Equity**

Ethical reasons to support greater transparency about what health care services cost patients are numerous and include those discussed here.

Deferred care. As of 2017, nearly half of privately insured adults aged 18 to 64 in the United States were enrolled in a high-deductible health plan (HDHP).<sup>4</sup> Enrollees in HDHPs who have chronic conditions like NN face high OOP costs and commonly delay or forgo necessary services; in 2020, patients experiencing worse health were twice as likely as patients in better health to delay or forgo care due to cost.<sup>5</sup>

Inequitable cost burden. Prior to federal rules mandating price transparency, it was routine for patients to receive a health service without knowing how much it would cost. Financial burdens are disproportionately borne by members of historically marginalized groups, especially patients with low income, no insurance, and multiple chronic conditions. For example, Hispanic adults are more likely to delay or forego care than other groups. Requirements to disclose services' prices would promote equity by requiring what is a fundamental aspect of transactions in other sectors: people who will pay wholly or partially for a service will know in advance what it will cost.

Financial harm as iatrogenic harm. Physicians are key brokers of a patient's access to health services and should act in a patient's best interest. The landscape of modern US health care, beneficence requires incorporating financial information in health decision making, since ignorance of a patient's financial situation and treatment options' potential financial consequences can result in adverse outcomes. For example, informed consent to novel therapeutics requires consideration of clinical benefits and harms, a patient's goals and values, and risk of financial toxicity. Health care organizations and insurers—who influence OOP costs and seek payments from patients—should inform patients about services' prices and quality before patients consent to a service.

### **Limitations of Price Disclosure**

Despite an ethical imperative for transparency, simply providing price information to patients is not enough to reduce OOP cost to patients or decrease overall health spending. 12,13,14,15 Although the 2019 executive order improved on a prior one that only required charges (rather than payer-specific negotiated rates) to be publicly reported, price comparison tools already offered in many health insurance plans were sparsely used. 12 This finding suggests that patients need user experience support to take advantage of price information that is listed.

Imagine diagnosing a patient with diabetes and recommending medications, supplies, and lifestyle changes without counseling that patient about how to implement those recommendations; we could hardly blame the patient for failing to meet their hemoglobin A1c and self-management goals without adequate support. Aside from direct effects on patients, transparency rules have an as-yet unknown influence on price negotiations and aggregate health care spending. Notably, fiscal transactions in the health sector are more complex than in other areas of commerce. Moreover, price negotiations have ramifications for costs patients face and therefore how much patients spend, regardless of whether patient demand prompts competition in local markets (eg, through patient shopping).<sup>16</sup>

# **Applying Transparency to Practice**

The possible market impacts of price transparency, while important, are difficult to predict and will not be discussed further here; we focus instead on price transparency as an opportunity for clinicians and patients to work together to reduce OOP spending, enhance equity, and improve patient-centered outcomes. To realize the promise of greater price transparency, changes will be needed in health care at multiple levels.

Macro-level changes. Patient education initiatives must encourage patients to shop for nonurgent care. One study identified "not having considered" price and quality comparisons as the most common barrier to patient engagement in consumer behaviors. The Importantly, after January 1, 2023, health plans will be required to provide personalized OOP cost information and negotiated rates for 500 "shoppable" interventions (eg., prescription drugs, laboratory tests, imaging) that tend to vary little in quality but substantially in price. In January 2024, this requirement will be extended to all health services, necessitating availability to patients and clinicians of quality metrics and aids for interpreting them. Underscoop how to use available metrics—particularly when decisions are made at a point of service during nonemergent clinical encounters—is critical to patients' ability to maximize the value of their OOP spending. Clinicians-intraining, patient navigators, and social workers should learn to become more comfortable in conducting cost conversations. 19,20

Micro-level changes. Cost discussions and price comparison tool use should be incorporated routinely into clinical workflows and service delivery streams. In the absence of new tools created by health care organizations to meet federal transparency requirements,<sup>21</sup> clinicians should investigate prices for labs and interventions on a case-by-case basis, facilitated by business units responsible for billing and insurance contracts—from which price information for specific interventions by specific clinicians in specific organizations is drawn—so that they can efficiently incorporate relevant, up-to-date cost information in health decision making with patients. Electronic health records should be enhanced to leverage publicly available price information, payer-specific organizational negotiated costs, and insurance plan information to yield accurate,

personalized OOP costs estimates at the point of service. Quality metrics and interpretive guides should be provided, along with price information, so that patients and clinicians can assess costs and benefits of services, given a patient's needs and a clinician's judgment. Such point-of-care assessment will likely influence clinician ordering practices to help reduce costs.<sup>22</sup>

### Conclusion

In a health system in which patients with minimal health literacy or financial literacy and few resources struggle to afford health care, federal price transparency rules alone are unlikely to reduce financial burdens of care for patients who do not already use price information when care planning.<sup>23</sup> As HDHP enrollment continues to rise and as health services' prices become more transparent, organizations and clinicians should support patients in making cost-informed decisions to maximize affordability of service. By constraining OOP spending, HDHP enrollees' chronic conditions can be more adequately managed to delay, if not prevent, the need for more expensive interventions or hospitalizations.

Clinicians who help patients access needed services have a duty to support patients' access to and interpretation of price and quality information. As interventions to enhance patients' experiences of using transparent information are implemented, data on patients' responses to greater price transparency will be generated; such data should be evaluated to refine transparency strategies. For now, leveraging newly transparent price and quality information to improve access to health services and adherence to recommendations is a step toward promoting equity and affordability of care for all US residents.

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### Editor's Note

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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA. This article is the sole responsibility of the author(s) and does not necessarily represent the views of the US Department of Veterans Affairs or the US government.

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# **CASE AND COMMENTARY: PEER-REVIEWED ARTICLE**

How Should Cost-Informed Goals of Care Decisions Be Facilitated at Life's End?

Jing Li, PhD, Robert Tyler Braun, PhD, Sophia Kakarala, and Holly G. Prigerson, PhD

#### Abstract

Interventions near patients' deaths in the United States are often expensive, burdensome, and inconsistent with patients' goals and preferences. For patients and their loved ones to make informed care decisions, physicians must share adequate information about prognoses, prospective benefits and harms of specific interventions, and costs. This commentary on a case discusses strategies for sharing such information and suggests that properly designed advance care planning incentives can help improve communication and decision sharing.

### Case

DD is the designated durable power of attorney for health care, who has served well in this capacity by prioritizing her mother's previously expressed wishes to the best of her ability. DD has also, to this point, represented all DD's siblings as they discuss with care teams the care of their elderly parent in hospital and nearing death. DD and the health care team have discussed initiation of life-sustaining interventions (eg, mechanical ventilation, intubation, artificial nutrition and hydration), as well as a hospice care referral, given the patient's diagnosis and impending death.

DD explains to the health care team that her mother had previously indicated she wanted all lifesaving therapies but that she values quality of life over extended life. The patient had also expressed a desire not to become a family burden. While sharing this sentiment, DD expresses, "For long hospital stays, no one needs to know the price of services to know it's expensive and that it will leave us bankrupt—\$100 a day, \$1000 a day out of our pockets. That is too much for most American families and it's too much for us. Our kids won't be able to go to college, and we won't have enough to pay for my father's medicines.

### Commentary

Health care in the United States, especially near the end of life (EoL), is extremely expensive. Medicare is the primary payer for health services rendered to patients over age 65 in the United States, and an estimated one-quarter of total Medicare spending is on about 5% of Medicare beneficiaries in their last year of life. 1,2 These statistics are

retrospective, however—the fact that much has been spent on patients in the last year of life *ex post* does not necessarily mean that the spending was futile *ex ante*,<sup>2</sup> as these care decisions were made when patients were still alive, often with the hope that the (expensive) care could rescue them from imminent death or at least prolong their lives for an extended period of time. While cost is important for care decisions across the lifespan, it takes on special significance and meaning in the context of EoL care, which we define as care received for either life-prolonging or palliative purposes by patients with a high likelihood of dying, such as those with advanced-stage cancer or heart disease. In this context, as recovery to full health is not realistic, cost-informed goals of care should mean goals of care informed by broader definitions of cost and benefit, including not only clinical benefits and harms but also out-of-pocket monetary costs and their financial implications for patients and families, taking into account patients' prognosis and preferences.

Cost-informed goals-of-care decisions are especially important, as concordance between patient preferences and care received is widely recognized as the hallmark of high-quality EoL care.<sup>3</sup> Moreover, these decisions are made against a backdrop of a fragmented health care system that often promotes aggressive care, especially for patients near death, which is costly for several reasons.<sup>4,5</sup> Despite recent reforms emphasizing paying health care practitioners for performance,<sup>6</sup> much of the US health care system (including Medicare) is still dominated by fee-for-service incentives, wherein a higher volume of services is financially rewarded.<sup>7,8</sup> The relatively rapid adoption of health care innovations, including new or experimental treatments (such as the recent approval of a new drug for treating Alzheimer's<sup>9,10</sup>), and the high prices paid for them also distinguish the United States from many other developed countries.<sup>11,12</sup>

In this commentary, we discuss the opportunities and challenges for individual physicians (both generalists and specialists) in providing patients near the EoL and their families and caregivers with sufficient information regarding prognosis, potential benefits and risks, and out-of-pocket costs to make cost-informed goals-of-care decisions. We also discuss the role of advance care planning (ACP)—the ongoing process in which the patient, their family, and health care practitioners reflect on the patient's goals and values (eg, extending life vs improving quality of life) and discuss how these should inform the patient's current and future medical care<sup>13</sup>—in facilitating cost-informed goals-of-care decisions. Improved decision-making processes regarding EoL care is particularly important for socially disadvantaged patients, who often lack both adequate information and the financial resources needed to receive quality health care concordant with own preferences.

### **Prognosis**

Prognosis is crucial to informing patients' or their health care proxies' evaluation of care options. Studies on patients with advanced cancer have found that the majority of patients are unaware of their prognosis, <sup>14</sup> despite having a desire to discuss it with their physicians, <sup>15,16</sup> likely because many physicians do not explicitly discuss prognosis or life expectancy with their patients at EoL. <sup>16</sup> Studies show that terminally ill patients who have a clear understanding of their prognosis (that they likely have months, not years, to live) are more likely to (a) engage in ACP<sup>17</sup> and to (b) receive less burdensome, aggressive, and unbeneficial care <sup>16,17,18,19</sup> and (c) more value-consistent care. <sup>18</sup> Knowledge of prognosis also better equips patients to navigate the complexity of Medicare benefits and eligibility for certain types of care, such as hospice care, which requires that the patient be certified by 2 independent physicians as having less than 6

# **Prospective Benefits and Harms**

It is well documented that aggressive and burdensome treatments with few proven benefits are frequently used at EoL, such as intubation of patients with advanced dementia<sup>21,22</sup> and chemotherapy for patients with metastatic cancer.<sup>23</sup> Research shows that physician beliefs and preferences regarding aggressiveness of treatments strongly predict variation in EoL spending across regions in the United States, whereas patient preferences for treatment at EoL (eg, comfort care vs aggressive care) have very little relation to EoL spending.<sup>24</sup> This finding is likely attributable to patients either not being actively involved in the care decision process or not understanding the pain and suffering they would need to endure merely to be kept alive in a seriously debilitated state, not to mention their not understanding the ambiguous survival benefits (or lack thereof).<sup>25</sup> In fact, a large body of literature has documented the significant barriers to effective physician-patient communication in the context of EoL, such as physicians' lack of communication training and skills and the exclusive focus on clinical parameters.<sup>25,26,27</sup>

For most patients near the EoL, as in the case of DD's elderly parent, a decreased quality of life is part of the broader definition of patient "cost" that needs to be taken into account. We thus advocate for adequate focus on the impact of treatments on quality of life, such as on acceptable health states and valued life activities<sup>26</sup> (in addition to survival), as an integral part of medical decision making and physician-patient communication at EoL. For patients or their health care proxies with sufficient numeracy, quality-adjusted life years could be used as a guide to compare treatments, as the measure explicitly incorporates both quality of life and length of survival. Furthermore, clinicians should promote a deeper understanding of side effects (eg, specific toxicities or common side effects such as nausea, vomiting, headache) associated with each treatment among all patients or their health care proxies. We acknowledge, however, that health care system-wide reforms, including better communication education and palliative care guidelines, are essential to improve the shared decision-making process regarding EoL care.<sup>27</sup>

### **Financial Burden**

Physicians might feel that they should promote the most effective care regardless of cost. However, in the US health care system, out-of-pocket cost is a consideration for most patients, and discussing it better equips them to make informed decisions.<sup>28</sup> Even with Medicare coverage, patients are still responsible for 20% of copayment for physician services (unless they have supplemental coverage, which many do not), which can be substantial. For instance, for chemotherapy infusions, the copay could approach \$10 000 for certain brand-name cancer drugs.<sup>29</sup> Riggs and Ubel suggest that "a useful rule of thumb is to consider a trade-off related to the cost of care reasonable if the physician would endorse the same trade-off in response to a strong patient preference that was not related to out-of-pocket costs."30 In the context of EoL, since treatment "effectiveness" in terms of curing the condition is no longer a realistic goal, the emphasis in goals-of-care discussions should be put on weighing the goals of prolonging life, quality of life, and cost concerns in a way consistent with patient preferences, if such preferences are documented or can be elicited. Extending life by days or weeks should not be assumed to be the only or even the most important criterion for decision making.

While it is unrealistic to ask physicians to be well-informed about patient-specific cost information, there are a few things physicians could do to improve communication with patients about costs. These include (1) initiating the conversation about costs by discussing general "expensiveness" of treatments, since physicians usually have some idea about which treatment option may be most expensive; (2) asking about patients' or families' financial circumstances or hardship and insurance coverage; and (3) directing patients or health care proxies to financial assistance programs if appropriate and to price transparency platforms (if available).<sup>30</sup> Additionally, social workers and case managers can play an important role in helping patients understand the financial consequences of treatments and direct them to resources as needed. It is important to note that while federal legislation mandating hospital price transparency is in place,<sup>31</sup> existing evidence suggests that price transparency tools have had little effect on reducing patient out-of-pocket costs.<sup>32,33</sup> They are thus unlikely to be effectively utilized by patients without proper guidance from clinicians and case managers.

Patients from vulnerable groups, who lack the financial resources to pay higher health care costs, may especially benefit from cost discussions.<sup>34,35</sup> Other families like DD's might still benefit from cost-saving strategies, such as switching to lower-cost alternative treatments. Although fear of harm to the patient-physician relationship has been cited as a barrier to conversations about cost of care,<sup>36</sup> recent research shows that patients prefer physicians who discuss cost over those who do not,<sup>37</sup> and inclusion of cost information has been shown to inform patients' hypothetical decisions regarding treatments without changing their attitude toward physicians.<sup>37</sup>

### **Planning**

As discussed above, comprehensive information on prognosis, clinical benefits and harms of treatments, and treatment costs are all indispensable components of ACP, which gives patients the opportunity to put in place advance directives that document their wishes regarding medical treatment and to appoint a surrogate decision maker (ie, health care proxy).<sup>38,39</sup> Simply having an ACP conversation or intervention without adequately communicating all of the above aspects of care can limit its effectiveness. Communication failures may explain the mixed findings regarding the effect of ACP interventions on care quality and patient satisfaction.<sup>40</sup> Adequate communication between patients and their proxies is just as important as the communication between patients and their physicians to ensure that the proxies properly understand patient preferences and to resolve any potential conflicts of interest (especially if family asset reallocation is involved in paying for medical treatments).<sup>41</sup> In the case of DD's family, for example, early ACP discussions could potentially facilitate agreement among DD's parent, DD, and DD's siblings regarding the optimal treatment.

None of the aforementioned components of ACP would be realistic if clinicians did not have sufficient time or incentives to have these discussions with patients. To overcome these barriers, on January 1, 2016, Medicare began reimbursing clinicians (both physicians and nonphysicians) for having ACP discussions with patients. Early evidence suggests that ACP billing was associated with significantly less intensive EoL care (eg, hospitalizations, emergency department visits, intensive care unit stays). However, the uptake of ACP billing codes remains low among providers. Recent research identifies a number of barriers to ACP billing, Including low reimbursement (\$80 to \$86 for the first 30 minutes and \$75 for each 30 minutes thereafter, although ACP codes could be billed as often as needed)

While explicitly incentivizing clinicians to have ACP conversations is a necessary first step to improving clinician-patient communication, it is clear that further reforms are needed, such as revising the ACP reimbursement structure and incorporating ACP in existing quality payment programs to allow for a more streamlined billing process and improved incentives. The latter could be accomplished by extending the Medicare reimbursement scheme for care planning for patients with cognitive impairment, which requires a written care plan for billing, to ACP.<sup>47</sup> Potential benefits of ACP reform include incentivizing utilization of advance directives for both clinicians and patients, ensuring that patient preferences are properly documented, and promoting annual updates of advance directives documents during annual wellness visits, for example.

### Conclusion

Meaningful shared decision making among patients, family members, and clinicians requires improved communication about patient prognosis, clinical benefits and harms of treatment options, and treatment costs. Knowledge of all these aspects of care would help patients at the EoL express their preferences or help their health care proxies, such as DD and her family, better express patient preferences and make informed care decisions. Shared decision making is especially critical for patients who are socially disadvantaged or cognitively impaired. Incentives for ACP, if properly designed, hold the promise of facilitating the shared decision-making process and improving quality of care and quality of life for patients at the EoL.

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### Editor's Note

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

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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. This article is the sole responsibility of the author(s) and does not necessarily represent the views of the National Institutes of Health or the US government. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

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# **CASE AND COMMENTARY: PEER-REVIEWED ARTICLE**

What Should Clinicians Do When Health Services Are Improperly Billed in Their Names?

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#### Abstract

The Centers for Medicare and Medicaid Services mandates physicians' responsibility for making sure that reimbursement for services physicians provide to patients is accurate and appropriate. Yet the shift of physician practice ownership to various employment models has amplified a dilemma. Physicians working as employees for some US health care companies might not know about services billed in their name, much less be able to review or contest when, which, to whom, or at what costs services were billed. Although such practices violate legal standards, many employed physicians are now accountable without transparency or agency. This commentary on a case considers this set of problems in contemporary billing and reimbursement structure and practice.

### Case

Dr L completed residency training 4 years ago and continues to pay down a balance of over \$300 000 in loans used to finance college and medical education. Dr L practices medicine as an employee of Urban Health Care (UHC). Upon hire, Dr L was required to agree to grant UHC exclusive rights to bill for, collect, and retain reimbursement payments for Dr L's professional services. The agreement does not indemnify Dr L for erroneous or fraudulent billing by UHC on Dr L's behalf but does specify that UHC report speed and efficiency productivity targets called *work relative value units* (wRVUs) to Dr L, which inform Dr L's performance reviews, incentives, and compensation.

Dr L recently noticed that salary deposits during the last few months do not seem to track with wRVU productivity reported by UHC. Dr L has also been asked by UHC billing staff, with increasing frequency during these months, to revise documentation of some services to some patients. Dr L asks other physician colleagues about their experiences with UHC's billing practices and finds that several suspect that UHC is upcoding services they have provided to patients. Dr L learns that a few who have questioned UHC about this apparent irregularity have been terminated or had their hours reduced. One colleague expressed frustration, "We're personally and professionally liable for the accuracy of bills sent in our names, yet we can't question UHC without reprisal." The

Centers for Medicare and Medicaid Services (CMS) Medical Learning Network posts instructions for reporting suspected fraudulent or erroneous billing,<sup>1</sup> but none of Dr L's colleagues have yet done so.

Dr L wonders whether to contact CMS.

### Commentary

Society's contract with clinicians requires that they provide complex health care services it cannot otherwise obtain and expects that they will be truthful,1 "competent, altruistic. and moral" in executing such services. Society accordingly grants health professions, especially medicine, status and privilege. In billing and claims submissions, specifically, the CMS Medicare Learning Network expresses another social contract expectation: "Medicare and other Federal health care programs rely on physicians' medical judgment to treat patients with appropriate, medically necessary services, and to submit accurate claims for Medicare-covered health care items and services" (italics added).3 CMS regulations were written when most physicians practiced independently and exercised direct control over those who did their billing. Now, however, only one-third of physicians younger than 40 years of age own their labor.4 Clinician agency is generally confined to the point of service, and clinicians' authority in claims matters has been surrendered to billing departments of health care organizations that employ them. Although the Physician Self-Referral Law names physicians, the regulations apply to all health care billing entities that have financial conflicts of interest.<sup>5</sup> Despite significant changes to the health care system over the last 2 decades, the social contract remains in place, and we do well to remember that physicians "have a legitimate right to expect to work in a system which supports, not subverts, the traditional values of the healer and the professional."2

Yet "the traditional values of ... the professional" may not be supported in a system in which *physicians* are responsible for accurate Medicare claims submitted by their employers. According to the Office of Inspector General (OIG), US Department of Human Services:

Payers trust you, as a physician, to provide necessary, cost-effective, and quality care. You exert significant influence over what services your patients receive, you control the documentation describing what services they actually received, and your documentation serves as the basis for bills sent to insurers for services you provided. The Government's payment of claims is generally based solely on your representations in the claims documents.

Because the Government invests so much trust in physicians on the front end, Congress provided powerful criminal, civil, and administrative enforcement tools for instances when unscrupulous providers abuse that trust.... When you submit a claim for services performed for a Medicare or Medicaid beneficiary, you are filing a bill with the Federal Government and certifying that you have earned the payment requested and complied with the billing requirements.<sup>6</sup>

This dogma implies that clinicians are not indemnified when erroneous or fraudulent claims are submitted to payers in their name by their employers. Yet, unless they own their practice, most physicians will rarely, if ever, see what is billed for or submitted for payment in their name. The result is an untenable situation in which physicians are responsible for the accuracy of billing—without transparency, agency, or authority over it—in what is known as the *double-bind paradox*.

# **Trade Secrecy**

The Code of Federal Regulations (CFR) carries the force and effect of federal law, mandating that, in circumstances in which clinicians assign billing responsibility to an employer or external vendor for reimbursable services rendered to patients insured by Medicare, they have unrestricted access to claims data submitted in their names. Yet health care organizations operating in competitive markets have staked out negotiated billing rates as "trade secrets," even though "to date, no court has definitively held that negotiated rates between health care [organizations] and insurers constitute trade secrets." In this environment, clinicians are unable to ascertain the downstream value of services they render because such knowledge might undermine their organizations' competitive advantage in specific health care marketplaces. Clinicians are thus put in a double-bind: they have responsibility to ensure the accuracy of bills and claims submitted in their name, but their agency and authority to do so is undermined by de facto trade secret protection practices in everyday payment and billing operations in the US health care sector. This double-bind is worsened by improper billing and reprisals.

# Improper Billing and Reprisals

Improper billing. Perhaps the lack of transparency would be less of an ethical and financial problem were there not so many ways to bill and code improperly. Upcoding is one kind of improper billing practice that happens when the complexity of services rendered is exaggerated. Less common are overtly false claims that impose phantom charges (ie, for services never rendered), bills for services not clinically indicated, duplicate charges, unbundled charges for a group of services that are standardly billed together, or excessive quantities of itemizable charges.<sup>3,9</sup> Unless physicians have access to and time to review billing and claims data connected to their names, they cannot identify irregularity, error, or fraud for which they are legally liable, according to 2021 CDC guidance.<sup>3</sup>

Reprisals and moral injury. Even with whistleblower and due process protections, physicians who have refused to sign off on charts of patients seen by another clinician for whom reimbursement rates are lower (eg, physician assistants) have reported retaliation (eg, losing hospital privileges or being removed from a clinical schedule). Minutes of a 2021 American College of Emergency Physicians Board meeting reported that physicians who speak up regarding inappropriate billing concerns face high risk of career-jeopardizing reprisals and only rarely resort to legal action against their employers. Literature on reprisal is sparse, however, so the extent of the problem is difficult to quantify. When professionals have responsibilities but work in environments in which they lack agency or control in executing their responsibilities, such as ensuring billing accuracy, they can suffer moral injury. This issue is of tremendous ethical importance. Improvement of systems that create such double-binds can be key to mitigating the widely documented and numerous harms of moral injury. In what follows, we canvass relevant information and options for clinicians faced with their employers' nontransparent billing and claims practices.

# Self-Disclosure

Currently, CMS recommends that physicians address potential concerns about billing fraud or errors by following the OIG's Health Care Fraud Self-Disclosure Protocol.<sup>3</sup> The term *self-disclosure* might be an artifact from the era when physicians were directly responsible for their own billing. The Figure also lists other options delineated in the resource.

**Figure.** Centers for Medicare and Medicaid Services Recommendations to Address Suspected Personal or Organizational Billing Fraud

### What to Do if You Think You Have a Problem

If you think you are engaged in a problematic relationship or have been following billing practices you now realize are wrong:

Immediately stop submitting problematic bills

- Seek knowledgeable legal counsel
- Determine what money you collected in error from patients and from the Federal health care programs and report and return overpayments
- Unwind the problematic investment by freeing yourself from your involvement
- Separate yourself from the suspicious relationship
- Consider using OIG's or CMS' self-disclosure protocols, as applicable

Reproduced from Medicare Learning Network.3

A clinician denied access to billing and claims information can notify the OIG or CMS. If a clinician's organization does not comply with a clinician's request for review access, it cannot receive Medicare claims reimbursement funds until the issue is resolved. Given the evidence of reprisals discussed above, self-disclosure to a federal agency requires courage, and clinicians should be aware that unemployment or reprisals are risks of disclosure.

## Liability

In the case, Dr L's and colleagues' concerns about liability for irregular billing and claims submission done in their names by Urban Health Care is appropriate. In 2012, the OIG announced that physicians might be liable for false claims submitted by entities billing and receiving CMS payments in their names. <sup>14</sup> Unfortunately, there is precedent for physician-owners of billing services being exposed to legal and financial liability (eg, fines) for false claims. In 1998, Emergency Physicians Billing Service (EPBS) and its leadership were found liable for false Medicare claims submitted to and collected by the billing company, which was owned by a physician. The federal government subsequently negotiated a settlement with 25 emergency physician practice groups that utilized EPBS to bill for services rendered by their clinicians. <sup>15</sup> Although we do not know of a legal precedent for clinicians who rendered services (but were not owners) being held liable by a court of law for improper billing or claims practices, neither do we know of legal precedent absolving clinicians of liability for services improperly billed in their names.

# How Else Can Clinicians Defend Themselves?

In 2021, the American Medical Association (AMA) examined the issue of physician billing transparency in its Report of the Board of Trustees. <sup>16</sup> First, the board recommended that that the AMA advocate for physicians to have "unrestricted access" to their billing records and associated patient medical records. Second, the board recommended that "the AMA adopt policy stating that, after termination of employment or other contractual arrangement, physicians should be given access to their billing records and associated medical records" so that they can defend themselves against any malpractice or other formal investigatory proceedings or claims brought against them. Third, the board recommended that the AMA "advocate for legislation or regulation to eliminate contractual language that bars or limits the treating physician's access to his or her

billing records and associated medical records, such as treating these records as trade secrets or proprietary." <sup>16</sup> Finally, the board cited policy advising that employers indemnify clinicians they employ from liability for erroneous, fraudulent, or otherwise inaccurate billing or claims submission when they are not at fault.

Additionally, federal, state, and organizational policies should promote billing transparency and at least be incentivized to (1) meet minimum requirements to share relevant proprietary information with clinician-employees who need to access billing and claims data submitted in their name or (2) transfer the full burden of billing and claims accuracy accountability to organizations.

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# **POLICY FORUM: PEER-REVIEWED ARTICLE**

If Patients Don't Use Available Health Service Pricing Information, Is Transparency Still Important?

Christopher Whaley, PhD and Austin Frakt, PhD

### Abstract

The US health system is replete with health service pricing idiosyncrasies and opacity unrelated to quality. Online tools intended to make health care purchasing resemble consumerism by making prices transparent have had little if any effect on improving health care market functioning and changing patient behavior. Although price transparency is still in its infancy, it holds promise to be as useful to patient-consumers as it has been to large purchasers (eg, employers) of health services and policymakers. But even if price information is not routinely used by patients, transparency of such information still has ethical importance in a market in which patients pay increasingly high out-of-pocket costs.

# Introduction

Apart from some public programs (eg, Medicare), US health care prices are subject to negotiation and dictated by providers' and insurers' market power. In this sense, health care is a market, but one that is different for consumers than other markets, such as for breakfast cereal or cellular phones. In particular, quality of service is difficult to assess, consumption is often not optional, and most consumers don't pay the full price (ie, they are insured).

Nevertheless, the plurality and power of providers and insurers lead to price variation for the same service across and within markets. For example, private insurance average prices for lower-back magnetic resonance imaging vary by more than \$500 across US metropolitan areas, but, in Dallas, the difference between the price at the 75th percentile and the 25th percentile is \$799.¹ Yet the association between health care cost and quality is inconsistent and moderate at best.²

Moreover, clinicians frequently do not have information about their own organization's prices.<sup>3</sup> Even when they have access to price information, clinicians are unlikely to incorporate prices in their treatment decisions.<sup>4</sup> If, unlike virtually every other market, sellers—in this case, health care professionals—do not know the prices of the services they offer, it is unreasonable to expect that their customers—in this case, patients—will make decisions based on prices. Yet moving patients from higher-priced to lower-priced provider organizations would represent a sizable savings opportunity for patients and

health care purchasers, such as employers.<sup>5</sup> While making prices more transparent has not yet been successful in achieving these savings, increased price transparency is still economically and ethically important.

### **Limited Economic Impact**

In the last few years, several online tools have been developed to provide patients with health care prices. These tools, often tailored to a patient's benefit design and insurance networks, provide patients with their estimated out-of-pocket costs for a given service or procedure.<sup>6,7,8</sup> Some initially thought that increased price transparency would spur market competition and make health care purchasing resemble consumerism in other markets.<sup>9</sup> However, while some patients who use these tools do go to lower-priced providers,<sup>6</sup> use of these tools has not been sufficient to lower overall spending.<sup>7,8</sup> Price transparency tools so far have led to only modest provider price competition.<sup>10,11</sup>

There are several possible reasons for this finding. Even with full information on provider prices, patients have limited reason to care about prices if their insurance pays the majority of costs. <sup>12</sup> Indeed, studies have found that consumer-facing price transparency information is only effective when it is paired with patient incentives to select lower-priced providers. <sup>13</sup> Assuming patients are cost conscious, they still face barriers to accessing lower-priced providers because many services require referrals from a physician. <sup>14,15,16</sup> In addition, patients may lack the ability to interpret price information and determine a procedure's appropriateness when selecting providers, much less assess quality differences among providers.

### **Federal Policies**

As of January 1, 2021, US hospitals are required to disclose their prices on their website. The However, implementation and enforcement of this policy has been challenging, with many hospitals not complying 20 months after it went into effect. In addition, media reporting has highlighted that some hospitals use blocking code to prevent pages with price lists from appearing in internet searches. Efforts to extend price transparency requirements to insurers have been met with industry opposition; both hospital and insurer lobby groups have filed lawsuits to prevent price disclosure.

The initial evidence of modest impacts of price transparency raises a natural question of what role price information should play in the US health care system. After all, even with full price information, most patients will still require referrals and have to interpret quality to select providers. Does expanded price transparency still have economic and ethical value?

### Price Transparency Still Has Economic Value

Despite current disappointments,  $^{22}$  price transparency is still economically important for the US health care system for 3 reasons.

First, price transparency is in its infancy. It is possible that future health care practice or price transparency tools will more effectively change patient behavior. In other countries, such as Singapore, price information is regularly incorporated in medical decision making.<sup>23</sup> Perhaps in the United States, as price transparency tools become more commonplace, patient behavior will similarly adapt. Several other digital tools, including online shopping and restaurant review sites, grew slowly but are now commonplace. Likewise, it is possible that the small number of patients who currently avail themselves of price transparency information will grow.<sup>7,24,25</sup>

Second, price transparency can be used by purchasers other than patients. Employers purchase health insurance for over 150 million people in the United States but often have little insight into the prices negotiated on their behalf.<sup>26</sup> Appropriately designed price transparency tools can inform employers of these prices. In fact, some innovative employers have already used pricing information to redesign health benefits and inform purchasing decisions.<sup>27</sup> For example, the California Public Employees Retirement System used price information to direct patients to lower-cost surgical providers for joint replacement and outpatient surgery.<sup>28</sup> Similarly, the Montana state employee health plan used price information to negotiate lower prices for hospital services.<sup>29</sup>

Third, policies—such as limiting market concentration, implementing public options, and potentially regulating provider prices—require transparent information on prices. As highlighted in several recent media stories, price transparency can also be used to "name and shame" higher-priced providers and create more general awareness of health care prices. 30,31,32 Recent price transparency reforms have been motivated by rising provider prices and media reports of provider price variation. 33 Understanding the necessity of and designing these policies is not possible without transparent information on prices.

# **Autonomy and Collective Efficiency**

As economists, we view price transparency as a necessary, but not a sufficient, condition for enabling patient (consumer) autonomy in voluntary market transactions, as well as for more effective collective action on health care spending. Below we elaborate on both considerations.

Autonomy. In nearly every market, prices are the key economic signal that are used to allocate resources. US consumers are accustomed to having price information and rightfully expect it, even for regulated services for which they have no choices, such as utilities like water, gas, or electricity. In most markets, prices for a good or service are reflective of the value of that good or service. Through their choices (when they have them), consumers can and often do drive down the prices of lower-quality or less-valued goods and services and drive up the prices of higher-quality or more-valued ones. In the United States, all enrollees in employer-sponsored coverage or individual market plans pay something for their care (ie, premiums, deductibles, copays) and can experience price variation (ie, different prices from different providers). Even within Medicare and Medicaid, a large proportion of enrollees are in private plans for which prices are negotiated and can vary for the same service within markets. Although this market dynamic will always be attenuated in health care because of its unique features (eg, third-party payment), it is impossible for consumers to exercise their autonomy—or for health care to fully benefit from market forces—without price transparency.

It is important to note that consumer autonomy is limited to voluntary (ie, nonurgent) health care transactions. Studies have found that up to 43% of health care services for people with private health insurance is "shoppable" in the sense that the timing and the provider of that care are elective, providing the opportunity for patients to respond to prices, if available.<sup>34</sup> For voluntary transactions such as these, it is immoral not to inform patients of prices before the transactions are made. Arguably, transactions cannot actually be voluntary without the consumer possessing (or having the ability to possess) full information, including information about out-of-pocket prices, analogous to informed consent in health care. Therefore, even if price information is not routinely used, it still has ethical import. Failure to disclose relevant price information—and charging the

consumer hidden prices after the fact—are characteristics of a dysfunctional market that we can remove through policy. There is no other market in which we tolerate, prior to purchase, not knowing prices of goods and services we buy.

Collective efficiency. Not only does the consumer have a right to know the prices of health care goods and services, so does the general public. Although incurred by individual patients, health care spending is largely borne by individuals beyond the patient, whether through taxes, premiums, or forgone wages.<sup>35</sup> Therefore, members of the general public have a right to know the prices of what they are collectively paying for. Analogously, regulated monopoly utility companies must transparently disclose and justify the prices they charge. Doing so helps government hold utilities accountable for what they provide relative to their costs. Thus, an additional upstream benefit of price transparency in health care is that it would allow employers, insurers, and public programs to better manage the benefits they provide (eg, by designing networks and cost sharing that encourage enrollees to use lower-priced providers).

#### Conclusion

The consequences of these ethical considerations are twofold. First, consumer-specific prices should be transparent to individuals, reflecting the prices they face as determined by their insurance coverage. Second, the prices paid by taxpayers and premium-paying policyholders should also be observable to decision makers responsible for crafting, regulating, and managing public and private plans. Note that changes in prices and spending need not occur for price information to be useful. Patients and other payers might reasonably conclude that a health care price is appropriate, but they can only do so if it is known to them. Apart from payment rates for public programs (eg, Medicare and Medicaid), transparency on health care prices paid by individual consumers and by the general public has not been fully implemented. This leaves most consumers, employers, and policymakers in the dark about one of the most important aspects of health care services.

Due in part to improvements in technology and provider consolidation, prices for common health care services will undoubtedly continue their upward trend. As health care becomes more expensive, patients and purchasers will face an increasing burden of health care costs. While currently not a meaningful feature of the US health care system, price transparency can be important for assessing and ensuring health care affordability. Nevertheless, barriers to realizing the full potential of price transparency, such as limited information about procedure quality or limitations in accessing lower-priced providers due to the referral process, will always exist. As we continue to wrestle with the cost and value of health care in the United States, we can no longer afford—economically or ethically—to remain in the dark about the prices we pay.

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# **POLICY FORUM: PEER-REVIEWED ARTICLE**

Informed Consent as a Means of Acknowledging and Avoiding Financial Toxicity as latrogenic Harm

Kevin Schulman, MD and Barak Richman, PhD, JD

### Abstract

Negative health consequences stemming from the financial burden of care on patients and their loved ones are documented as *financial toxicity* in the literature, and these consequences should be included in informed consent discussions during patient-clinician interactions. However, codes of medical ethics have yet to require obtaining consent to financial costs, even as the No Surprises Act, effective on January 1, 2022, requires some clinicians to facilitate informed financial consent prior to an out-of-network elective service as a means of avoiding arbitration. This article discusses how this requirement can be more broadly applied to informed consent for any intervention.

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# **Envisioning Informed Financial Consent**

The uncomfortable reality that the financial toxicity of medical care is a significant source of patient harm is increasingly recognized in the medical literature. 1,2,3,4,5,6,7,8 In fact, clinicians' failure to disclose the likely cost of care during informed consent discussions has fueled the disreputable business practice of surprise medical bills, which charge well above market-level prices for services that the patients never assented to; indeed, surprise bills often demand payment amounts to which no informed purchaser would ever agree and are frequently followed by aggressive collection actions.9

The financial burden of health care remains an ethical blind spot for the entire US health care sector. One of the paramount tenets of medical ethics is to ensure that patients are adequately informed before consenting to medical treatment. The doctrine of informed consent, along with communication with patients and shared decision making, constitutes the entirety of the second chapter of the American Medical Association (AMA) Code of Medical Ethics.<sup>10</sup> Although this chapter speaks frequently of treatment (mentioned 34 times) and intervention (mentioned 21 times), there is not a single reference to cost, price, or pay. Even AMA Code Opinion 11.3.1, "Fees for Medical Services," does not require disclosure of a payment amount in advance.<sup>11</sup> Thus, there is

a gap between how costs are handled in medical ethics and how much real harm costs inflict on patients' health and well-being. The consequences are even more profound, given the uncomfortable reality that the nation spent approximately 19.7% of its gross domestic product on health care in 2020—and more than double the average of 11 other wealthy Organisation for Economic Co-operation and Development (OECD) countries in 2015—thereby crowding out socially needed investments in education, childcare, and other social determinants of health. 12,13,14,15

It is time for the medical profession to double down on its long-standing and admirable commitment to patient autonomy by including informed financial consent as a critical component of its foundational definition of informed consent. In other words, a physician's ethical obligation to a patient should include adequately informing the patient of any financial consequences of nonurgent medical care before that care is provided. Informed financial consent has been described by Richman et al "as an essential element of medical practice [that] would both fulfill the profession's ethical commitment to patient autonomy and provide a much-needed market-based counterforce to price escalation." Richman et al argue that patients and their clinicians and provider organizations have an implied contract when clinical services are provided and that an essential element of any contract is the price for a service. If a price is not established before a service is provided, providers should be compensated based on the market price of a service, not their charge for that service.

The No Surprises Act, effective on January 1, 2022, requires some clinicians to facilitate informed financial consent prior to an out-of-network elective service as a means of avoiding arbitration. Here, we discuss how this requirement can be more broadly applied to informed consent for any intervention.

### Harms of Inadequate Informed Consent

The lack of an informed financial consent obligation is acutely evident in today's health care marketplace. Receiving health care in the United States places a patient at significant, and often undisclosed, financial risk. The charges for health care services are calculated in arrears after the services have occurred. The financial obligations of patients vary significantly based on the provider charge (or the list price for the service set by the physician or hospital), whether the provider was contracted with the health plan (as an in-network provider and at a contracted in-network price), and the details of the plan provisions for payment. Financial toxicity can be further exacerbated by benefit designs, such as high-deductible health plans that place first-dollar payment responsibility on patients, even when they have health insurance. The financial sequela of medical debt can include considerable distress, 1,2,3,4 personal bankruptcy,5 and lasting impacts on the patient and their family members.<sup>6,7</sup> Severe financial distress can also have direct and long-term health effects on patients, as it is a risk factor for mortality in cancer patients.8 In sum, financial obligations have been documented to have adverse health effects, just like complications from a medical service or procedure, and they should be disclosed to enable full patient autonomy in decision making.

In 2020, Congress finally recognized the ethical and social harms caused by surprise medical bills and enacted legislation designed to halt this most egregious incursion on patient autonomy. The No Surprises Act (NSA), effective January 1, 2022, prohibits certain out-of-network providers from billing patients inflated charges.<sup>17</sup> Although some have argued that engaging in surprise billing was a violation of state contract and consumer protection laws,<sup>18</sup> the NSA was a significant step forward in protecting

patients from surprise medical bills. Critically, the NSA might also represent a major step forward in recognizing informed financial consent as a clinician obligation.<sup>17</sup> In some circumstances, the act requires out-of-network clinicians to disclose prices to patients 72 hours in advance of an elective procedure if those clinicians want to avoid the payment dispute provisions of the act.<sup>17</sup> This provision, together with the regulations implementing the NSA, provide a real-world template for the requirements of informed financial consent from a patient.

# **Achieving Informed Financial Consent**

Adequate informed financial consent should include a legal commitment to providing patients with a price quote at or before the point of service. This commitment might seem like a sea change for US clinicians and provider organizations, but the concept of pledging to a price prior to providing a service should sound familiar to all of us—it is how we pay for goods and services in every other aspect of our lives. It is also a "common practice for self-pay clinical services such as direct primary care, elective plastic surgery, and laser-assisted in situ keratomileusis (LASIK) eye surgery."<sup>17</sup>

We do not suggest that arriving at a specific price quote will be easy. Imagine that your physician offers you a colonoscopy for cancer screening. She describes the procedure and the risks, but she never provides a full description of the resources needed to administer the procedure: professional services, anesthesia, sterile supply, procedure room, recovery room, and pathology, if required. In truth, a colonoscopy is a specific bundle of services offered by different professionals and potentially different organizations (if the physicians are not employed by the hospital or ambulatory surgery center). Given the organizational complexity of care delivery, the United States has adopted a system of unbundling services and billing for each component of a service separately after the services have been provided. Thus, were prices to be bundled, all the clinicians and organizations providing a service would have to agree to the financial terms in providing the service. (Such an effort could be coordinated by the clinician or by the facility where the service is provided and could be negotiated on a period basis rather than for individual patients to make the process most efficient.)

Accordingly, requiring providers—both clinicians and provider organizations—to satisfy informed financial consent could lead to beneficial structural reforms in the broader payment system, as bundling payments would make obtaining financial informed consent much easier. For most services, the individual elements are predictable in a statistical sense, so constructing a standard bundle of services and charging for the bundle would not be challenging for most provider organizations. Provider organizations understandably worry that complications arising from a procedure could require additional resources. However, they should know how frequently such complications arise, and clinicians already address complication risk as part of their disclosure, so the financial implications of possible complications could be disclosed to patients as well as the bundled cost of the procedure. For example, if there were to be a perforation during a colonoscopy—a rare complication of the procedure—the fixed price for the procedure would not apply. In discussing the limits of the binding disclosure, the clinician could explain the potential cost implications of such complications. Depending on the risk of a procedure, deviations from the fixed-price estimate should be infrequent.

# **Pricing Transparency in Practice**

In truth, even though discussions and knowledge of health care prices have been categorically separated from the delivery of care in the United States, making prices

available should not be difficult. Payments for medical services, including a patient's financial responsibility, are typically set by the contract between the hospital and the health plan. Many provider organizations now have a process to estimate the actual cost to the patient based on their health plan. These tools typically have a disclaimer that the estimates are not a price guarantee (eg, "Please note that pre-service estimates are based on average charges from similar patients. Your bill will be based on services you actually receive and may differ significantly from the average." 19). Moving from a cost estimate to a fixed priced thus would require minimal additional effort. One surgery center in Oklahoma has built an attractive business model around fixed, transparent pricing for clinical services. 20

The US Department of Health and Human Services imposes similar price disclosure requirements on hospitals, which must "provide clear, accessible pricing information online about the items and services they provide in two ways: 1. As a comprehensive machine-readable file with all items and services. 2. In a display of shoppable services in a consumer-friendly format." Although required postings are averages across patients and not a commitment to any individual patient, they still signal how price information can be compiled and disseminated. Within 20 months of the effective date, however, fewer than 20% of hospitals had meaningfully complied with these directives—let alone fully embraced the opportunity to inform patients seeking to economize on health care costs. <sup>22,23</sup> Nevertheless, enforcement of these requirements could alleviate both financial distress and patient ignorance.

Informed financial consent can have other positive impacts on the health care system and the cost of care. Price transparency could empower consumers to shop for lower-cost services, and physicians and hospitals in turn would be under additional pressure to manage the costs and quality of individual clinical services. Finally, price transparency could exert pressure to lower costs from within organizations (eg, physicians trying to grow their practice needing a competitive price in the market) or from outside organizations (eg, shaming physicians and hospitals for excessive pricing schemes).

#### **Need for Physician Leadership**

Ultimately, the financial toxicity of health care is a problem that will never be solved without physician leadership. Patients are dependent on the skill of their physicians, and society relies even more heavily on the public spiritedness and scientific knowledge that the medical profession supplies. No amount of regulation can protect lay people from their dependence on physicians, which is ultimately why an ethical code of conduct emerged in the very earliest days of medicine as a profession.<sup>24</sup> For the same reason, we now need physicians to assume their ethical obligations in matters of finance. Government regulations will not substitute for physician self-policing and ethical leadership. It's time to address the harms associated with financial toxicity of health care by revising the AMA *Code of Medical Ethics* to address informed financial consent.

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# POLICY FORUM: PEER-REVIEWED ARTICLE

**Necessity for and Limitations of Price Transparency in American Health Care** 

Harold A. Pollack, PhD, MPP

#### Abstract

Price transparency is an ethical and policy imperative for American health care. More transparent pricing would allow patients and families to make better decisions and would allow clinicians to deliver care with greater simplicity and integrity. This article also considers transparency's real-world patient care limitations and the extent to which price transparency is a reliable pathway to service delivery efficiency and market discipline.

#### Consensus

I pondered a version of this essay in the waiting area of an outpatient surgical center. I was waiting for my wife, who was undergoing endoscopy to rule out a primary cancer that might have produced an anomalous mass detected in the parietal lobe of her brain. Although I teach health economics, I did not comparison shop for these services. I had no idea how much my wife and I or our insurer would be charged. My out-of-pocket bill could be \$100 or \$1000. Who knew? In that difficult moment, we were experiencing the uncertainty of health care as so many others do. We were blessed that no cancer was found.

Cases in which a patient receives emergency services or important surgical care at an in-network hospital—only to later discover that their particular anesthesiologist or surgeon is out of network (ie, not fully covered by their insurance)—demonstrate how daunting billing surprises can be for patients. Nearly 20% of patients undergoing innetwork elective surgery or giving birth receive surprise bills,¹ often for thousands of dollars. In many cases, out-of-network prices are not only unexpected but also markedly higher than prices charged for similar in-network services. Such billing practices undermine public confidence in health care, particularly when surprise billing becomes a business model used by physician groups to charge more for their services² than patients and payers would likely tolerate in more transparent exchanges. One indicator of Americans' consensus on the value of price transparency is bipartisan support for the No Surprises Act, which went into effect on January 1, 2022. 1.3.4

This article discusses variation in health care prices that drives calls for price transparency, the benefits and limits of price transparency, and the extent to which price transparency is a reliable pathway to service delivery efficiency and market discipline.

# **Pricing Variation**

Vast, seemingly random variation across clinicians' and organizations' pricing and billing practices and some hospitals' lack of compliance with the No Surprises Act have attracted widespread media coverage. A 2021 New York Times article, "Hospitals and Insurers Don't Want You to See These Prices," offered many examples of seemingly irrational variation in what patients covered by insurers are charged. At the University of Mississippi, a colonoscopy costs \$2144 for patients with an Aetna plan, \$1463 for patients with a Cigna plan, and \$782 for patients without insurance. University of Pennsylvania hospitals charged \$93 for a pregnancy test for patients insured by New Jersey Blue Cross PPO, \$18 for Pennsylvania Blue Cross patients, and \$10 for patients with no insurance.

Some pricing variation might be justifiable on economic or policy grounds. It's not surprising that a hospital would charge less to patients who belong to its own vertically integrated health maintenance organization. Some differences might also be justified as helping cross-subsidize care for patients without insurance. Moreover, Medicare and Medicaid pay lower prices than private insurers, which provides a valuable counterweight to hospitals and other provider organizations that leverage their pricing power against fragmented private insurers to charge insurers (and ultimately patients) prices that far exceed marginal costs.

Other species of price dispersion are more difficult to justify. The pastiche of covert discounts, surprise charges, and opaque billing practices hinders individual patients who are seeking to make sensible decisions or simply understand what they will pay, given their insurance and diagnostic realities. The sheer opacity and complexity of health care prices wastes patients' time and, at times, undermines the legitimacy of the health system itself.

#### Benefits of Price Transparency

Price transparency could help align patient-consumer welfare and health equity: more simplicity and transparency would allow patients and payers to comparison shop and to bear predictable costs. For example, health insurance decision support tools that provide personalized out-of-pocket cost estimates across plans could help patients navigate the challenges of managing care costs, and the results of trials of such tools have been reported. These tools' developers, however, acknowledge their limitations, noting that "system-level interventions are needed to lower financial toxicity and help patients manage care costs." One also hopes that transparent pricing would increase competition, thereby lowering prices of services that are amenable to comparison shopping (eg., hip replacement, hernia surgery, colonoscopy).

# **Limitations of Price Transparency**

When price transparency does not lower prices, control costs, or discipline a health care market in other ways, overreliance on it to curb predatory pricing and billing practices might prove disappointing, and it sometimes has unintended consequences. Price transparency can, for example, facilitate collusion, a happened when the Danish government posted prices of concrete. Neither would price transparency address

differences in resources or bargaining power between patients and organizations or between affluent and resource-poor patients.

Another limitation of price transparency is that patients don't or can't always make efficient use of price information to advance their interests on their own or without support in interpreting and applying the information. Patients experiencing the greatest financial need are not always well positioned to benefit from transparency. In nursing home markets, for example, proliferation of quality and pricing information hinders equity when more affluent patients and families are positioned to respond more aggressively to such information. Patients with the most serious illnesses also might not be well positioned to benefit from price transparency, as the burden of comparison shopping falls to ill patients or their loved ones who might be already-overworked caregivers.

Although the No Surprises Act seeks to address out-of-network service billing abuses, several organizations, with the backing of bipartisan support, oppose regulating median in-network reimbursement rates to offer benchmarks for out-of-network billing. <sup>16</sup> These groups argue, implausibly, that such regulations unfairly favor insurers by incentivizing them to lower rates paid to in-network providers and thereby lower out-of-network reimbursement to in-network rates. Such pushback provides a timely reminder that physicians and health care organizations are self-interested political and economic actors within our \$4 trillion health sector. <sup>17</sup>

Price transparency also requires us to address diagnostic and procedure upcoding, a practice that inflates prices, especially when used by noncritical-access hospitals that treat rural Medicare beneficiaries. <sup>18</sup> Upcoding Medicare Advantage enrollees' diagnoses is common, especially in vertically integrated plans. <sup>19</sup> Such overt departures from price transparency exacerbate pressures on public budgets, violate patient-clinician trust, and are financially toxic to patients.

#### **Policy Solutions**

Acknowledging all of price transparency's limitations, greater price transparency might nonetheless improve our health care delivery system, bolster its ethical operation, and improve our health care system's public legitimacy if the following actions are taken.

Clinicians and organizations must recognize their economic self-interests. Clinicians and organizational leaders must acknowledge their roles as economic actors who respond to financial incentives that do not always promote health equity or their patients' interests. Organizations that limit services to Medicaid patients and offer more lucrative reimbursement to affluent patients able to pay higher prices<sup>20</sup> have great influence on excess expenditures, patients' and communities' well-being, and health equity. Provider organizations should thus exercise their leverage over medical prices transparently—but, more importantly, in a fair and equitable way.

Supplement price transparency with other measures. Measures to promote greater transparency are valuable complements to, not substitutes for, expanding insurance coverage, increasing Medicaid reimbursement rates, and applying pressure to achieve more disciplined pricing and billing practices, promote efficiency, and protect and support vulnerable patients. When health care expenditures account for one-fifth of the US gross domestic product,<sup>21</sup> American society requires lower overall prices, not merely more transparent ones.

Implement effective, fair price transparency regulations. Policymakers must exercise their supply-side leverage in health care marketplaces to promote transparency and economy that do not require or presume individual clinicians' or health care organizations' self-restraint (eg, to not upcode or deny service to patients insured by Medicaid). Public regulation can implement price transparency more reliably and fairly than unilateral action by clinicians and organizations. Health equity demands that we push these levers hardest and first rather than expecting patients, clinicians, and organizations to address this challenge on their own.

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# **MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE**

Which Price Should Be Transparent and Why?

Sherry Glied, PhD and Grace Kim, MHA

#### Abstract

Prices private insurers negotiate with health care organizations and clinicians have historically been confidential. Since the early 2000s, privately insured patients have faced increasing out-of-pocket costs and demanded more information about variability in negotiated prices, some of which has slowly become available. This article argues that fragmentation in US health care delivery streams and shortcomings in formal quality measures mean that the value of making prices transparent is in its usefulness as a tool for policymakers and regulators rather than for patients.

### Federal Action on Price Transparency

Price transparency in health care has long been a goal of consumer advocates. In 2019, the Trump administration promulgated 2 regulations enabled by the legal authority afforded under Section 1311(e)(3) of the Affordable Care Act and Sections 2715A and 2718 of the Public Health Act to promote price transparency. 1.2 The first rule, which went into effect in January 2021, requires heath care organizations to reveal negotiated prices in a consumer-oriented display and to produce a machine-readable file of these prices. Initial studies have found uneven compliance overall and evidence of selective compliance among the highest revenue heath care organizations.<sup>3,4,5</sup> The second rule, which has been delayed by 6 months but is expected to take effect in July 1, 2022, requires insurers to make publicly available standardized and updated machinereadable data files of negotiated prices, including in-network and out-of-network allowed amounts and billed charges.6 Effective January 1, 2023, insurers will also be required to offer an online shopping tool for consumers to access both negotiated rates and personalized estimates of out-of-pocket costs for 500 of the most shoppable health care services (ie, services that can be scheduled in advance and are routinely conducted in nonurgent situations).7

This article argues that fragmentation in US health care delivery streams and shortcomings in formal quality measures mean that the value of making prices transparent is in its usefulness as a tool for policymakers and regulators rather than for patients.

# Why Price Transparency Now?

Although the opaque nature of health care prices has long been noted as problematic,<sup>8</sup> the use of price transparency as a strategy to address rising health care costs is a relatively new development.<sup>9</sup> The rising profile of price transparency reflects changes in the structure of private health insurance plans. Under 1990s style-managed care contracts, patients' out-of-pocket liability was either transparent—fixed copayments for specific services—or limited by relatively low deductibles and out-of-pocket maximums. In the early 2000s, tax policy began to encourage the adoption of high-deductible insurance plans. Under these plans, patients' potential liability for the cost of care increased substantially.<sup>10</sup> By 2020, average deductibles for single coverage in employer-sponsored plans were 4.6 times higher than in 2000 after adjusting for inflation (see Table 1).<sup>11,12,13</sup>

Table 1	Avorage Annu	al Daduatible fo	r Single Coverage in	2000 and 2020
Table 1.	Average Annu	ai Deductiole to	Silible Coverage III	L ZUUU AHU ZUZU

Deductible	2000	2020	Fold Increase
Average annual deductible, single coverage	\$23911	\$164412	6.879
Inflation-adjusted amount (2020 dollars) <sup>a</sup>	\$358	\$1644	4.595

<sup>&</sup>lt;sup>a</sup> Using the CPI inflation calculator from the US Bureau of Labor Statistics, \$239 in December 2000 was estimated to have the same buying power as \$357.78 in December 2020.<sup>13</sup>

In response to concerns that patients could not appropriately balance the costs and benefits of care without further information, insurers and self-insured employers began in the 2010s to provide price transparency tools within their health plans. While available evidence suggests low utilization of these tools, they offered a proof of concept for the idea of price transparency in the context of empowering consumers. 14,15,16

The potential value of price transparency was confirmed by an analysis of data on health care prices published in 2013. As part of the Affordable Care Act, a committee of the Institute of Medicine was tasked with analyzing geographic variation in health care spending. The committee identified significant variation in the negotiated prices paid to physicians and health care organizations by commercial insurers across the country.<sup>17</sup> This study spurred a series of such analyses, which showed that negotiated prices varied substantially, even within narrow geographic regions, and often even for the same service provided in the same hospital.<sup>18,19</sup> Moreover, prices were systematically higher in concentrated markets where a few health professionals had stronger negotiating power. This evidence of price variation suggested that reinforcing price-shopping behavior would have the potential to reduce overall health expenditures. It also suggested that unless price was correlated with real differences in quality, markets are not competitive and alternative price-setting mechanisms should be established.

As this history suggests, there can be different rationales for promoting price transparency. Some posit that awareness of prices might lead consumers to budget appropriately and make more efficient choices about service utilization or to favor lower-cost clinicians and health professionals.<sup>20</sup> Others argue that price transparency might improve the negotiating position of private insurers in markets with few clinicians (ie, concentrated provider markets).<sup>21</sup>

# Which Price Should Be Transparent?

Different rationales for price transparency imply that different kinds of prices need to be made transparent. If price transparency is intended to help consumers with household

budgeting or with choosing whether to use a given service or not, knowledge of the average cost of a bundle of services might be sufficient for consumers to make decisions about how to finance their care. For all but the simplest health care services, a consumer's out-of-pocket liability will depend on prices of a series of products and services, suggesting the need to make transparent a single price for a predefined bundle of services, which might include inpatient services, clinician time, laboratory tests, diagnostic services, anesthesia, and postacute care. This level of transparency would be very difficult to achieve unless there is a consensus on which services are included in each of a defined set of bundles that combine the services needed to appropriately address a health condition (see Table 2).<sup>22,23,24</sup> While there are efforts to create such bundles (for example, in the Medicare program),<sup>25,26</sup> more typically the components of treatment for specific conditions are offered by different health care professionals, the exact components of an individual patient's care are not fixed in advance of a treatment or procedure, and alterations in the course of treatment during an episode of care will affect a patient's out-of-pocket liability.

Table 2. Cost Components of a Typical Bundle of Services for a Surgical Episode				
Hospital Services				
Facility costs				
Room and board				
Supply costs				
Operating room				
Prescription drugs				
Intensive care unit				
Blood				
Durable medical equipment				
Implant				
Physical therapy				
Recovery room				
Laboratory				
Radiology				
Professional fees				
Postacute Care				
Inpatient rehabilitation facility				
Skilled nursing facility				
Home health agencies				
Long-Term Acute Care Facilities				
Outpatient visits				
Professional and physician fees				
Hospital readmission				

However, if price transparency is intended to enable patients who plan to go ahead with a course of care make an informed choice among provider organizations, they need information on actual prices, or negotiated reimbursement rates, that different provider

organizations will ultimately charge across various services. An out-of-pocket price faced by an individual insured patient in the United States (in most situations) will depend on that patient's insurance plan at a specific point in time (eg, whether the clinician performing the service is in-network, co-insurance and copayment structures, or whether the patient has met a deductible amount or out-of-pocket maximum). Even among patients with the same insurance plan, net out-of-pocket costs can vary significantly.

Finally, if the goal of price transparency is intended to inform public policy (eg, by providing information to policymakers who might impose regulatory limits on unusually high prices), prices of specific services (rather than bundles) might be most informative. Prices at this level can inform our understanding of the effects of market consolidation, competition across geographies, and price-setting behavior.

# **Unintended Consequences**

Although the obstacles to releasing meaningful price information are daunting, analysts also have qualms about the consequences were such data indeed available.<sup>27,28</sup> Patients have more difficulty judging the quality of health care services than the quality of most other goods and services for which they shop. If reliable quality information is not available, patients may inappropriately prioritize low prices over the quality of the services offered by different physicians or heath care organizations. The opposite possibility is also a concern: some patients may interpret high prices as indicative of high quality (as they have been shown to do in other low-information contexts), which would subvert the cost-reduction goals of price transparency initiatives.<sup>29,30</sup> Price transparency thus must be integrated with meaningful quality information to enable informed and patient-centric choices.<sup>31</sup>

A second concern is that information about stand-alone prices may lead to price *increases*. Under current standards, physicians and health care organizations are likely unaware of the precise rates their competitors have negotiated with commercial insurers. Access to new information on their competitors' rates might lead some high-priced physicians and health care organizations to lower their rates, as has been observed in some studies,<sup>32,33</sup> but it could also lead lower-priced physicians and health care organizations to raise their rates, as is evident in other studies.<sup>34</sup> Economists are also concerned that revealing price information could enhance health care systems' efforts to collude in rate setting, as violators of implicit rate-setting agreements will be easily identifiable if negotiated prices are transparent.<sup>35</sup>

#### What We Need

Under optimal price transparency, patients would have ready access to information on the personal cost of a bundled treatment for a given condition across a range of local physicians and health care organizations, combined with trusted information regarding relative quality. The price transparency rule mandating that insurers compute memberand plan-specific out-of-pocket prices<sup>7</sup> would provide patients with one component of this information. Although information about comparative quality of services would remain limited and contested, patients might be able to combine plan-specific and clinician- and provider-specific price information with external sources of quality information (eg, advice from a primary care physician).

A big worry, from a patient perspective, is uncertainty about how much a bundle of services will cost. It is possible to imagine a hospital offering a binding, pretreatment price for a bundle of services—for example, in England, some heath care organizations

offer an all-inclusive fixed price for knee replacement surgery to private paying customers, including postdischarge care encompassing outpatient care and treatment of complications for 30 days postprocedure<sup>36,37</sup>—but this is not currently the norm in the United States, except under a few demonstration programs of public and private payers.<sup>38,39,40</sup> Construction and pricing of bundles, or episode payment models, involve complex decisions and calculations and requires adequate infrastructure and data, along with constant monitoring and patient education.

Without binding prices for bundles of care, it is hard to see how price transparency will meaningfully change patient behavior. Even for this purpose, rules making negotiated prices transparent will not be a panacea and may have significant side effects. Negotiated health care prices are an imperfect measure of the underlying costs of producing health care goods and services. Prices reveal little about the quality of services or access to care for varied populations. There will likely be substantial variation in the ability of patients to make use of these data. The availability of new data, however, should enable researchers to uncover information on price variation, better understand the pricing structure of the commercial insurance market, and identify potential policy levers to address the costs of care. Regulations on price transparency would likely be most useful in providing information that can be used by public policymakers seeking to address price variation resulting from market inefficiencies rather than by patients struggling with high out-of-pocket costs.

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# **MEDICINE AND SOCIETY 2: PEER-REVIEWED ARTICLE**

What Should US Policymakers Learn From International Drug Pricing Transparency Strategies?

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#### Abstract

This article analyzes differences in prescription drug pricing transparency practices among 3 Organisation for Economic Co-operation and Development member nations: the United Kingdom, Germany, and Canada. Specifically, this article compares these countries' policies on list and net price disclosures and on how international reference pricing is used to evaluate merits and drawbacks of different pricing transparency approaches. Finally, the article summarizes what policymakers in the United States should learn from these comparisons.

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#### **Transparency Cuts Both Ways**

High prescription drug prices in the United States (US) are driven by the fact that brandname drug manufacturers are freely able to set prices at the time of launch, whereas in other industrialized countries around the world, prices are more systematically negotiated on the basis of the benefits that the drugs provide. The distinct approach to drug pricing in the US has spurred debate over reforms to bring US drug prices more in line with those in other industrialized countries, since the US spends far more per capita on pharmaceuticals than all other members of the Organisation for Economic Cooperation and Development (OECD).<sup>1</sup>

One area of substantial debate is prescription drug pricing transparency reforms, or efforts to improve the disclosure of drug prices and price-establishment mechanisms.<sup>2</sup> Prescription drug price transparency can be a powerful tool for competition, negotiation by insurers, and patient information and drug selection. However, such measures can also weaken the negotiation positions of certain payers by preventing manufacturers from granting additional, confidential rebates or discounts to certain insurers and not others, as is currently done.

Here, we discuss issues in drug pricing transparency, analyze differences in prescription drug pricing transparency practices among 3 OECD member nations—the United

Kingdom, Germany, and Canada—and summarize what US policymakers should learn from these comparisons.

#### Information and Its Uses

Debates over drug pricing transparency tend to focus on 2 key issues: (1) disclosure of *list* vs *net* prices and (2) how publicly available prices should be or are used. A drug's list price is set by a drug's manufacturer but can be decreased through rebates and discounts to payers to a so-called net price. Rebating or discounting processes might be required by law (eg, as they are for Medicaid, the US state-based health insurer for poor patients) or be implemented by a private insurer or its pharmacy benefit manager.<sup>3</sup> Although net prices are closer to actual prices to payers for drugs, only list prices are disclosed in the US.<sup>2</sup> Broader drug price transparency might come in the future, given the issuance of the Transparency in Coverage final rule, which mandates disclosure of historical net and current list prices for prescription drugs (which became effective on January 1, 2022<sup>4</sup>) and a later executive order granting the US Department of Health and Human Services (HSS) authority to enforce price transparency rules in health care organizations.<sup>5</sup>

How price transparency is implemented could affect both US drug prices and drug prices in other countries if the US were to adopt international reference pricing. International reference pricing is the practice of citing a "basket" (eg, a collection of prices) from other countries, usually with comparable economies, to regulate domestic drug prices. The practice gained notoriety in the US when a federal judge blocked an HSS rule that would have used international reference pricing to control spending on prescription drugs paid through Medicare Part B, the US federal government's insurance programs for hospital-or physician-administered drugs to patients over age 65.6 Congress later focused on a legislative approach to negotiating drug prices. International reference pricing could decrease drug spending by tying US drug prices to lower prices in other countries where they are negotiated based on the clinical benefits those drugs provide. Importantly, the use of international reference pricing could also lead to unintended complications, such as delaying drug entry in other nations and raising list, or even net, prices abroad.

When designing pricing transparency reforms, US policymakers should consider lessons learned from systems in the United Kingdom (UK), Germany, and Canada.§ These countries are particularly apt comparators due to the distinctive approaches taken in each setting and their similar levels of economic development to the US. Germany and Canada spend the third- and fourth-highest amount per capita, respectively, on pharmaceuticals in the OECD, while the UK spends roughly the OECD median.¹ We sought to evaluate how pricing transparency factors into these countries' price regulation systems and what lessons these cases have for the impact of pricing transparency reforms in the US.

# **United Kingdom**

In the UK, drug prices are regulated by the Voluntary Scheme for Branded Medicines Pricing and Access.<sup>9</sup> Under the Voluntary Scheme, drug prices are controlled through the UK's National Institute for Health and Care Excellence (NICE).<sup>9</sup> For each product with a new active ingredient, NICE conducts a health technology assessment comparing the cost-effectiveness of the product to existing alternatives to determine whether the National Health Service (NHS) should cover the drug.<sup>9,10</sup> NICE recommendations are binding on the NHS and constrain drug prices by forcing manufacturers to either avoid

selling the drug in the UK or to lower list prices and offer discounts until NICE deems the drug cost-effective. 10,111

Alternatively, a minority of manufacturers of branded drugs choose to participate in the Statutory Scheme instead of the Voluntary Scheme. <sup>12</sup> Under this scheme, NICE does not evaluate a new drug; the government instead determines a maximum price for the drug, taking into account factors like the drug's development cost, the manufacturer's profit margin, and more. <sup>12</sup>

For generic medications, the UK relies solely on market competition to lower prices, resulting in slightly higher generic prices than in the US.<sup>12,13,14</sup> However, for all drugs, if spending on certain medications causes major budgetary strain for the NHS, prices may further be negotiated down or subjected to competitive bidding.<sup>12</sup>

The UK's pricing mechanisms result in certain price disclosure practices. List prices paid to NHS pharmacy contractors are disclosed in the monthly Drug Tariff released by the government. List prices for NICE-reviewed drugs are also disclosed, and if the drug is deemed cost-effective, the list price becomes the net price. However, for pharmaceuticals with non-cost-effective list prices or with prices negotiated by the government or priced through bidding or special discounts, net prices are not disclosed due to the confidentiality of these processes. Additionally, the UK does not use international reference pricing but instead relies solely on NICE's framework of tying a product's price to its assessed clinical value—an arrangement known as value-based pricing. Many high-income countries that use international reference pricing reference UK prices, so UK list prices (or disclosed net prices) affect prices beyond its borders.

#### Canada

In Canada, drug prices undergo government review through a variety of different mechanisms. Patented brand-name medications are regulated at the federal level by the Patented Medicine Prices Review Board (PMPRB), an agency that sets ceilings for drug prices. <sup>17</sup> Net prices are set at the provincial level through negotiations between drug companies and the provinces. <sup>21,22</sup> The Canadian Agency for Drugs and Technologies in Health (CADTH) may make recommendations to payers about the cost-effectiveness of certain medications—an approach similar to NICE in the UK, although, unlike NICE, CADTH's decisions are nonbinding and do not reflect actual net prices. <sup>23,24</sup>

In terms of transparency, in Canada, as in the UK, list prices for drugs are available, while net prices are not because of confidential discounting and negotiations. <sup>18</sup> Canadian list prices for medications can be found in online formularies released by each province. <sup>25</sup> Canada does rely on international reference pricing through the PMPRB, which uses a basket of 11 peer industrialized countries to establish price ceilings for patented medicines. <sup>26</sup> Often, only list prices are available to inform the PMPRB price. The final price ceilings from the PMPRB are also confidential. <sup>26</sup>

# Germany

In Germany, manufacturers independently set a new brand-name product's price for the first year of market availability. In subsequent years, prices are negotiated between drug manufacturers and the National Association of Statutory Health Insurance Funds ("Sickness Funds"), an association representing German insurers. For a new product, the Gemeinsame Bundesausschuss (G-BA)—an independent body governing German physicians, hospitals, and health insurers—commissions a government health

technology assessment agency to issue a nonbinding, advisory opinion on whether a new drug is innovative or offers a therapeutic benefit over current products.<sup>27,28</sup> This process of evaluation is similar to the health technology assessment and value-based pricing standards used by CADTH and NICE. If the drug is deemed innovative and has comparators, the Sickness Funds and the drug manufacturer will directly negotiate the maximum reimbursement that insurers will pay for the product, creating a maximum price for the product.<sup>10,27,29</sup> If the product is not deemed innovative, however, the G-BA classifies the drug in an existing therapeutic class and then references the German prices of other current drugs in that class to set the maximum reimbursement for the product—a process of domestic therapeutic reference pricing.<sup>10,27,29</sup>

The nature of the German drug pricing system results in several distinct pricing transparency practices. Unlike in the UK and Canada, in Germany, both list and net prices are publicly available in the Rote Liste, a comprehensive database of drug prices.<sup>29,30</sup> This transparency leads other countries to reference some, but not all, German net prices when negotiating their drug prices,<sup>19</sup> since Germany also selectively uses international reference pricing, like Canada.<sup>27</sup> For example, Germany uses international reference pricing to set ceilings or maximum reimbursements—as proposed in the US and done in Canada—and, in negotiations over the prices of innovative products that lack therapeutic competitors, German negotiators reference a basket of prices from 15 European countries as one factor in negotiations.<sup>14,31</sup>

In sum, different price transparency practices exist across the UK, Canada, and Germany. While these countries release list prices, 2 key differences relate to net price disclosure and reliance on disclosure of prices in other countries.

# Lessons for US Policymakers

These examples of pricing transparency regulations abroad contain important lessons for US policymakers. In recent years, political actors have claimed that reforms to price transparency disclosure could help lower US drug prices.<sup>2</sup> For example, efforts to disclose domestic list and net prices in the US could provide information to strengthen insurer negotiating positions and allow cost-exposed US patients to make more cost-effective decisions, resulting in lower drug spending.<sup>2</sup> Disclosure could also put public pressure on policymakers to take evidence-based steps to contain prices.<sup>32</sup> Furthermore, as Germany's example shows, net price disclosure can have positive collateral effects, as other countries can reference net prices negotiated on the basis of drugs' clinical value, which are more realistic than list prices.<sup>33</sup> It is estimated that US use of international reference pricing could save the federal government billions of dollars each year.<sup>34</sup> Lastly, although confidentiality can enable manufacturers to maintain higher net prices, some manufacturers argue that confidential negotiations allow them to give larger discounts to certain insurers and improve payers' ability to negotiate lower prices.<sup>2</sup>

However, important practical complications limit the potential of these pricing transparency reforms. First, insurers might misrepresent rebates to prevent disclosure of true net prices.<sup>2,35</sup> Second, despite the fact that many US patients bear direct costs for high-priced drugs, they are often unfamiliar with the nuances of drug pricing and insurance, which hampers their ability to choose cheaper drugs or insurance plans regardless of price transparency.<sup>36</sup> Third, the evidence is inconclusive as to whether drug pricing transparency results in lower drug spending due to several factors, including confidential agreements between various insurers and manufacturers,

nondisclosure of select rebates and discounts, and improper reporting of prices.<sup>2,37</sup> As a result, nations with more reasonable drug pricing systems, such as the UK, Germany, and Canada, do not rely on price transparency alone to limit drug prices. Rather, these states supplement transparency with other approaches, such as negotiations like those led by the German Sickness Funds or health technology assessments like those done by NICE or CADTH. In all 3 cases, price transparency is used as part of a centralized, multimodal approach to tie prices to a drug's clinical value.

Similar implementation challenges would emerge with US efforts to use international reference pricing to cap prices directly. Although US international reference pricing could lower drug spending by using foreign prices to set price ceilings or inform price negotiations,38 the lack of international net price disclosure in most foreign countries would force US policymakers to reference high foreign list prices, hindering potential benefits from international reference pricing and underscoring the importance of accounting for various price transparency regulations in other nations.<sup>39,40</sup> Moreover, international reference pricing can create delays in market entry abroad, as pharmaceutical manufacturers try to ensure that higher prices are referenced first.<sup>39</sup> One study found that, in the European Union, drugs usually first appear in Germany, followed by either the UK, Austria, or Denmark (not necessarily in that order), and then other countries because this arrangement ensures that other European states reference the high German prices.<sup>39</sup> International reference pricing use in certain countries has also been linked to collateral price increases.38 US use of international reference pricing could similarly cause delays or collateral drug price increases in foreign drug markets, as the size of the US market could lead drug manufacturers to either delay market entry or to try to hike prices for medications in countries referenced by the US.39

Thus, international reference pricing and net price disclosure reforms alone will be insufficient to meaningfully address excessive drug prices in the US. The US should pair these efforts with other reforms to lower net prices more directly. For example, the US could permit national payers like Medicare to negotiate lower drug prices or, ideally, employ value-based pricing frameworks to decrease net prices by tying them to drugs' clinical value. These efforts should supplement pricing transparency reforms to address unnecessary spending on brand-name drugs more effectively.

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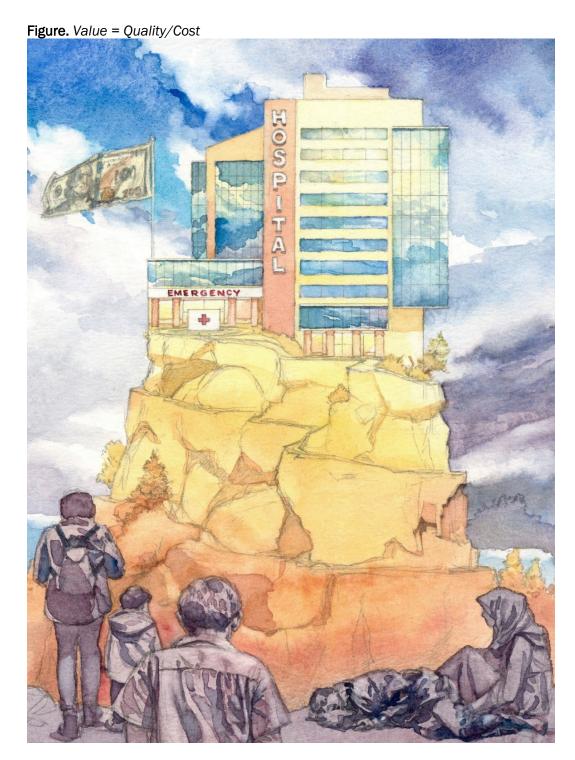
# AMA Journal of Ethics® November 2022, Volume 24, Number 11: E1091-1093 ART OF MEDICINE

**Another Future We Create** 

Christa J. Prentiss

# Abstract

The second of 2 drawings exploring the changing financial climate of the US health sector, this watercolor visually considers which values our words and actions endorse.



**Media**Watercolor and graphite on cold press paper, 7" x 10".

Value, quality, and cost are 3 key factors in a complex health care industry. As of June 2020, about 18% of individuals in the United States had medical debt "in collections." For many ill or injured people in the United States, treatment will make them or their

families bankrupt. Even when health care is of high quality, should it be regarded as "valuable" when it generates more poverty?

This watercolor drawing illustrates an imposing, perhaps impressive, but distant hospital perched atop a hill bathed in golden light, a glowing promise of aid for some. Its flag is a US \$100 bill. Shadowy foreground figures seem to hesitate. Those still standing are uncertain whether to approach or enter.

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Christa J. Prentiss is a fourth-year medical student at Oregon Health & Science University in Portland, Oregon, whose interests include health care access, intersections of the arts and sciences, and rock climbing.

#### Editor's Note

The first of Prentiss' 2 drawings appears in the October 2022 issue of the journal.

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# AMA Journal of Ethics® November 2022, Volume 24, Number 11: E1094-1096 ART OF MEDICINE

# Abstract

Julia O'Brien

**Bank Cards Might as Well Be Tarot Cards** 

This comic compares a lack of price transparency in health care billing to psychic card readings.

Figure. Mystic Money













#### Media

Procreate®.

This comic shows how a lack of price transparency in health services is about as linked to value as a psychic Tarot card reading. As the patient leaves the clinic office, she sorts her credit cards for selection and payment; her environment alters mysteriously, transitioning the cards' roles and meanings. From a patient's perspective, in the current health care billing climate, is it possible that how much she'll be billed and how much her insurance covers will be anything *but* a surprise at the point of service? If it's reasonable to expect a rational relationship between health care services and their value, then perhaps surprises should be few, not routine.

Not only is the patient surprised by her expensive bill, but she struggles to understand how this amount was calculated. Pricing is not really transparent at all, with both patients and clinicians unaware of final costs until long after services have been rendered. From a patient's perspective, out-of-pocket costs are rarely itemized—or itemized clearly—and so are about as structured and straightforward as psychic readings.

Julia O'Brien is a graduate student at the School of the Art Institute of Chicago in Illinois.

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November 2022, Volume 24, Number 11: E1097-1098

# **ART OF MEDICINE**

If You Have to Ask How Much It Costs, You Probably Can't Afford It Laura Kostovich, MS

#### **Abstract**

In health care, the cost of surgical procedures and medications often come across as items listed at market price, which is indicated as "MP" on menus of many upscale restaurants.



# Media

Digital painting.

# Caption

In health care, trying to determine the cost of surgical procedures and medications often feels like ordering food listed at market price (MP) in an upscale restaurant. Listing an item as MP doesn't tell the patrons much at all. Now they are left with a decision of whether to order it, gambling they will be able to afford the meal, putting themselves in a vulnerable position and risking judgment of their social standing by inquiring about the price or skipping the item altogether. The same 3 options are true for patients trying

to figure out the cost of procedures and medications. The first option is to blindly agree to a procedure or medication in hopes it is affordable. Secondly, you can uncomfortably ask your physician the exact cost, knowing they might not have that information available and that if you need to ask, you probably can't afford it. Lastly, you could skip the necessary procedure or medication because you aren't sure you can afford it but do not want to put yourself in the embarrassing position of inquiring about cost. Pricing transparency in health care would give patients necessary insight into cost and help them make decisions based on relevant information.

**Laura Kostovich, MS** is a freelance medical and scientific illustrator. She earned a BS in biology from St Xavier University and an MS in biomedical visualization from the University of Illinois at Chicago.

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#### Abstract

In health care, lack of transparency about the cost of health care services to patients during clinical encounters has contributed to increased costs and high out-of-pocket expenses. Federal policy has responded to the need for more transparency and spurred discussion about ethics and the clinician's role in being transparent with patients at the point of service. This article investigates and encourages state, private market, and federal policy efforts to address what health care costs patients. This article also applies the ethical framework of principlism to cases and considers what a "shoppable service" model would demand of clinicians in practice.

The American Medical Association designates this journal-based CME activity for a maximum of 1 AMA PRA Category 1 Credit™ available through the AMA Ed Hub™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

#### Necessity of Price Transparency

Health care delivery differs from other consumer-facing services, such as dental, legal, or veterinary services, due to limited price transparency at the point of service.¹ This opacity has contributed to increased costs and associated out-of-pocket expenses and affects patients' health care decisions, as nearly 33% of Americans in 2019 reported that they or a family member delayed treatment due to cost.² As a significant portion of health care costs result from physician-driven patient care decisions,³ clinicians must increasingly consider their responsibility to address cost. Providing high-value care and considering patients' financial well-being in shared decision making, especially for "shoppable services," expands the clinician's role as a steward of health care resources and as an advocate for patient-centered care.⁴ In 2017, shoppable services, defined as "service[s] that can be scheduled by a healthcare consumer in advance," composed an estimated 36% of medical spending and 43% of out-of-pocket spending. Recent policy efforts by the Centers for Medicare and Medicaid Services (CMS) support price reporting for shoppable clinical and diagnostic services to drive innovation; to facilitate informed, price-conscious decision making; and to promote competition.5

### The Current Landscape of Price Transparency

Under the Affordable Care Act of 2010, Congress mandated that US hospitals establish and annually update a public list of standard charges. Unfortunately, standard charges as exemplified by the "chargemaster" represent nondiscounted, fee-for-service list prices that bear little resemblance to negotiated prices, making them unhelpful and inaccurate for predicting patients' out-of-pocket expenses. Accordingly, Executive Order 13877 of June 2019 directed the Secretary of Health and Human Services to propose regulation requiring hospitals to publicly post charges based on negotiated rates for common shoppable items and services. The subsequent CMS Hospital Price Transparency Final Rule of November 2019 required hospitals to publish a consumer-friendly list of the 300 most shoppable services and expanded the definition of standard charges to include discounted cash prices and payer-specific negotiated rates.

Similar efforts at the state level have yielded mixed effects. Since 2004, California state law has required hospitals to make public chargemaster data, publish average charges for the 25 most common inpatient and outpatient procedures, and provide price estimates to uninsured patients who request them. 10,11 However, most hospitals do not comply with providing price estimates when requested, 12 and the legislation had minimal effect on hospital prices, at least in the first 18 months. 13 New Hampshire launched a HealthCost price transparency program in 2007, producing an estimated 5-year savings of \$7.9 million for individuals and \$36.0 million for insurers on imaging studies. 14 However, a subsequent analysis found no decrease in price variation for reported services, including imaging, during the first full year of the program. 15

Some insurance plans have developed cost estimator tools for their members. One study found that, during 2011-2012, users of Aetna's Member Payment Estimator were more likely to be younger, healthier, and have higher annual deductible spending and to most often search for preventive screenings (eg, mammography and colonoscopy), childbirth, imaging, and nonemergency outpatient procedures. Following implementation of Castlight Health's price transparency platform, 18 employers demonstrated a \$124.72 (13.2%) reduction in payment for advanced imaging for users of the platform, and Blue Cross Blue Shield's price transparency intervention reduced costs by \$220 (18.7%) per magnetic resonance imaging scan in 2012. Thus, the benefits of price transparency accrue to patients who generally have higher out-of-pocket spending for shoppable services. Challenges remain, as price transparency has not fully entered the exam room, where clinical decisions incurring patient expenses are made.

# Price Transparency Using the Framework of Principlism

Discussion of price transparency regulation must include its intentional and unintentional ethical consequences for patients, physicians, and health systems. We analyze these challenges using the 4 principles of bioethics applied to 4 cases.<sup>19</sup>

Respect for autonomy. Respect for autonomy assumes that rational agents (patients) are involved in informed and voluntary decisions. Consider a case of a woman with severe osteoarthritis contemplating a total knee replacement. As she plans financially, she would like to know that accepting the risk of surgery would be "worth it." She must choose if the risks and benefits of total knee replacement outweigh those of continuing conservative management with medications and exercise. Given the evidence that patients forgo care due to cost,<sup>2</sup> financial risk should be considered in shared decision

1100 journalofethics.org

making for this elective procedure. Yet, there are 3 barriers to patients being informed about prices.

First, studies reveal poor compliance with the Hospital Price Transparency Rule, with 65% of the 100 largest US hospitals unambiguously noncompliant and only 5.6% of 500 randomly sampled hospitals compliant with all requirements within the first 2 months of the rule taking effect.<sup>20,21</sup> During the first 5 months the rule was in effect, compliance was greater in for-profit, system-affiliated, large, nonurban facilities and those with greater information technology preparedness.<sup>22</sup> This finding is consistent with a June 2022 study of 5239 US hospitals, which reported that only 729 (5.7%) were compliant with requirements after 6 to 9 months and that greater compliance was associated with lower revenue per patient-day and within unconcentrated health care markets.<sup>23</sup> The general lack of industry compliance was likely in part due to the modest maximum penalty for hospitals who failed to comply, set at \$300 per hospital per day, or \$109 500 per year. 5 Hence, the policy was updated in 2022 by scaling the penalty for larger hospitals to \$10 per bed per day and raising the maximum annual penalty to \$2 007 500 per hospital.<sup>24</sup> In addition to recent legal requirements for price transparency, social contract theory suggests that the patient, the physician, and the profession engage in reciprocal agreements with the public, including an emerging fiduciary duty to provide cost-effective care. 25,26 To do so, health systems should support price transparency efforts and further develop their technology infrastructure to assist with effective implementation. In addition, greater scrutiny of concentrated health care markets and refinement of financial determinants of hospital adherence are needed.

Second, for the patient to be appropriately informed, pricing and associated quality information should be easily understandable and applicable to the decision-making process. Most individuals do not seek pricing information even when tools are available. For insured patients, copayments can be constant and hospitalizations might exceed the deductible, which shields insured patients from many of the medical costs and price differences. For this reason, price transparency efforts should focus on copayments and out-of-pocket costs so that patients can make decisions using personalized, salient, and consumer-friendly information. In this way, our health system could alleviate unjust or unrealistic burden on patients in navigating a complex system.

Lastly, patients often rely on physicians for advice about where to receive care and are frequently unwilling to go against a clinician's advice for a copayment difference of \$10 to \$35.28 Price information should thus be available at the point of care. To realize this goal, physicians will require a supportive environment with specific training and reflective practice.29

Nonmaleficence. Consider a man with chest pain who, suspicious of a heart attack, searches online for a hospital with the cheapest interventional cardiac procedure. This case highlights the need to focus price transparency on shoppable services, a distinction emphasized in the 2019 Hospital Price Transparency Final Rule. Price transparency can reduce the harms of unnecessary tests and procedures. In one study of primary care physicians, displaying the average Medicare reimbursement rate decreased ordering of 5 laboratory tests by 19% and improved physician knowledge of relative costs without increasing adverse events (although there was no metric to determine clinical appropriateness of forgoing a test).<sup>30</sup> Another controlled clinical trial at a tertiary care hospital presented fee data to clinicians at the time of order entry and reduced test

ordering by 8.6%.<sup>31</sup> Regardless of cost, clinicians should act according to standard of care while avoiding wasteful practice.

Beneficence. Beneficence emphasizes the duty to benefit the patient, as well as to take positive steps to prevent harm to and remove harm from the patient. Price transparency can potentially reduce cost, especially out of pocket, which benefits patients directly and potentially health care practitioners and systems operating under risk-based contracts or those directly partnered with a health plan. Consider an expectant mother planning a normal vaginal birth who factors price in her decision but would like to ensure a healthy outcome. To uphold the principle of beneficence, price transparency should be paired with transparency of quality and effectiveness data, which can be less accessible.<sup>32</sup> Publicly reporting quality in the context of price would empower this mother to shop for value and has been shown to stimulate quality improvement activity within hospitals.<sup>33</sup> Hospitals and clinicians committed to high-quality, cost-effective care would profit from increased patronage for these services. Policymakers should commit to promoting cost-effectiveness research in conjunction with price transparency.

Justice. Justice can be promoted using a variety of factors, including allocation to each person an equal share, or according to need, effort, contribution, merit, or free-market exchanges. Consider an uninsured man with low-back pain and intermittent numbness of his leg who wonders whether he should have an MRI for further evaluation. Empirical evidence suggests that price transparency leads to lower and more uniform prices, which would benefit this man. In theory, price transparency achieves lower and more uniform prices in 2 ways. First, transparency publicizes the practice of price discrimination, or selling a product at different prices to different groups based on willingness to pay, which primarily affects those who are uninsured or are poor. Secondly, transparency would reduce cost through increased price negotiation by providers.

Finally, adoption of "reference pricing" might incentivize patients to be more engaged consumers. In this model, an employer or insurer pays up to an established maximum price (the "reference price") for a health care service. Several studies have shown an effective reduction in prices paid by patients after implementation of reference pricing.<sup>34</sup> For knee or shoulder arthroscopy, there was \$2.3 million in savings over 2 years for one large retirement system.<sup>35</sup> Over 3 years, out-of-pocket costs were reduced by \$71 508 (13.8%) for computed tomography and magnetic resonance imaging scans<sup>36</sup> and by \$1.05 million (41.5%) for lab testing for one large employer.<sup>37</sup>

It should be noted that price transparency might not prevent discrimination. If displaying prices to clinicians affects ordering, certain patient groups may be systematically unfairly treated, especially if cost of care is higher for certain insurance types (with higher deductibles or out-of-pocket expenses) or for uninsured patients. However, these disparities exist currently, and the goal of transparent prices is to promote price competition and allow for more informed choices.

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