1 Harvard Medical School, Massachusetts, USA

2 Department of Global Health and Population, Harvard T.H. Chan School of Public Health, Massachusetts, USA

3 Department of Computer Science, Jacobs Technion-Cornell Institute at Cornell Tech, Cornell University and the Technion-Israel Institute of Technology

4 Department of Population Health Sciences, Weill Cornell Medical College, New York, USA

@leah_pierson

@2plus2make5

Cite this as: *BMJ* 2022;378:o1747

http://dx.doi.org/10.1136/bmj.o1747

Published: 15 July 2022

# Patients cannot consent to care unless they know how much it costs

## Given the impact that medical expenses have, disclosing them should be a part of the informed consent process, argue Leah Pierson and Emma Pierson

Leah Pierson, [1, 2] Emma Pierson[3, 4]

Americans rarely know how much their medical care will cost and most have received a medical bill that they did not expect.[1] The lack of transparency around medical costs leads people to avoid seeking necessary care, fosters distrust in the US healthcare system, and has implications for informed consent.[2] If patients do not know how much their care will cost—and the financial risk they may face as a result—can they really consent to it?

What information must be disclosed to patients in the process of acquiring consent has often been the subject of ethical debates. A widely accepted principle is the reasonable person standard, which requires divulging the details a reasonable patient would want to know about a procedure, including its risks, its benefits, and alternative treatment options.

How you decide which risks should be disclosed is also up for debate because it would be too burdensome to describe all the theoretically possible risks of a procedure or treatment. Yet two features are generally acknowledged to be relevant for assessing whether a risk should be disclosed: how frequently that risk occurs and how severe it is. A surgeon, for example, has a greater obligation to disclose a 10% risk of death associated with an operation than a 0.01% risk of death. Similarly, they have more of a duty to inform patients about a 10% risk of death than a 10% risk of a postoperative headache.

The financial risks associated with medical care are common enough and severe enough to warrant disclosure. Around 40% of Americans report being extremely or very afraid of the financial costs associated with a serious illness—astonishingly, that's more than the proportion who fear getting seriously ill in the first place.[1] Nearly one in five US households has medical debt.[3] Although courts disagree on how common a risk must be for physicians to be required to disclose it, 20% would exceed every numeric threshold that has been proposed.[4]

Moreover, among working age Americans who struggle to pay their medical bills, nearly half categorise the impact it's had on their families as "major," and 70% report that they or a member of their household have reduced spending on food, clothing, or basic household items as a result.[5]

Given how common and how devastating medical expenses are, a reasonable person would want to know how much they will be charged for their care. Failing to provide this information thus violates standards of informed consent.

Readers might raise two objections to this view. Firstly, some might argue that the financial hardships associated with care are distinct from the medical risks inherent to it. Perhaps, following this line of thought, informed consent only requires that patients understand the medical risks of treatment.

However, it is arbitrary to limit the risks clinicians must disclose to only risks of bodily harm, as financial harms can adversely affect patients' lives more than physical ones. Furthermore, financial risks and medical risks are intertwined. The anxiety and depression medical debt can inflict constitute side effects that, in other medical contexts, it would be obligatory to disclose. Weighty financial burdens can also compound existing medical risks, preventing or dissuading people from accessing care as they otherwise would. As one patient noted, "Charges for my insulin exceeded $1200 a month . . . I had to reduce the amount of insulin I took based on what I could afford; my health was negatively impacted as a result."[5]

A second objection is that patients can only have a right to information that it is possible to generate. Yet because of the US healthcare system's complexity, the financial costs associated with medical care are hard to estimate. Consequently, it would presently be impossible for the clinicians responsible for obtaining consent to perfectly estimate a patient's financial risk.

But the bar for informed consent is not a perfect estimate of risk. After all, it is impossible to perfectly estimate the medical risk of an operation, either—a surgeon cannot know how well each team member slept the night before or how many sutures a patient will need. As with medical risks, valid informed consent can still be obtained when the relevant financial risks are disclosed as accurately and precisely as possible.

It's within the grasp of policy makers, hospitals, and healthcare professionals to improve the disclosure of financial risk. Policy makers have already recently implemented two laws aimed at tackling this problem: the Centers for Medicare and Medicaid Services' price transparency rule and the No Surprises Act. Although the price transparency rule requires that hospitals publish their prices online, early data suggest that most hospitals have resisted, and it is too early to tell whether the No Surprises Act—which came into effect in January 2022 with the aim of eliminating common types of unexpected medical bills—will be more successful.[6]

Enforcing and promoting adherence to the price transparency rule and No Surprises Act would be

good first steps to take towards mending a healthcare system that consistently violates a basic tenet of medical ethics. A system that routinely fails to inform patients about financial risks is one that routinely provides care without informed consent.

Competing interests: We have read and understood BMJ policy on declaration of interests and declare the following interests: none.

Provenance and peer review: not commissioned, not peer reviewed.

1 The West Health Institute and NORC at the University of Chicago. Americans' views of healthcare costs, coverage, and policy. 2018. https://www.norc.org/PDFs/WHI%20Healthcare%20Costs%20Coverage%20and%20Policy/WHI%20Healthcare%20Costs%20Coverage%20and%20Policy%20Issue%20Brief.pdf.

2 Makary M. *The price we pay: what broke American health care—and how to fix it.* Bloomsbury Publishing, 2019:-51.

3 Bennet N, Eggleston J, Mykyta L, et al. 19% of US households could not afford to pay for medical care right away. The United States Census Bureau. 2021. https://www.census.gov/library/stories/2021/04/who-had-medical-debt-in-united-states.html.

4 Wheeler R. The numeric threshold for the disclosure of risk: outdated and inapplicable to surgical consent. *Ann R Coll Surg Engl* 2012;94:-2. doi: 10.1308/003588412X13171221501023 pmid: 22391361

5 Hamel L, Norton M, Pollitz K, et al. The burden of medical debt: results from the Kaiser Family Foundation/*New York Times* Medical Bills Survey. KFF. 2016. https://www.kff.org/report-section/the-burden-of-medical-debt-section-3-consequences-of-medical-bill-problems/.

6 Gondi S, Beckman AL, Ofoje AA, Hinkes P, McWilliams JM. Early hospital compliance with federal requirements for price transparency. *JAMA Intern Med* 2021;181:-7. doi: 10.1001/jamainternmed.2021.2531 pmid: 34125138