The NEW ENGLAND JOURNAL of MEDICINE

Perspective

Full Disclosure — Out-of-Pocket Costs as Side Effects

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N Engl J Med 2013; 369:1484-1486 | October 17, 2013 | DOI: 10.1056/NEJMp1306826

Article

Few physicians would prescribe treatments to their patients without first discussing important side effects. When a chemotherapy regimen prolongs survival, for example, but also causes serious side effects such as immunosuppression or hair loss, physicians are typically thorough about informing patients about those effects, allowing them to decide whether the benefits outweigh the risks. Nevertheless, many patients in the United States experience substantial harm from medical interventions whose risks have not been fully discussed. The undisclosed toxicity? High cost, which can cause considerable financial strain.

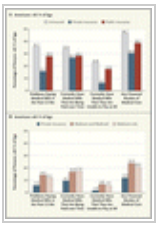
Since health care providers don't often discuss potential costs before ordering diagnostic tests or making treatment decisions, patients may unknowingly face daunting and potentially avoidable health care bills. Because treatments can be "financially toxic,"[1] imposing out-of-pocket costs that may impair patients' well-being, we contend that physicians need to disclose the financial consequences of treatment alternatives just as they inform patients about treatments' side effects. Health care costs have risen faster than the Consumer Price Index for most of the past 40 years. This growth in expenditures has increasingly placed a direct burden on patients, either because they are uninsured and must pay out of pocket for all their care or because insurance plans shift a portion of the costs back to patients through deductibles, copayments, and coinsurance. The current reality is that it is very difficult, and often impossible, for the clinician to know the actual out-of-pocket costs for each patient, since costs vary by intervention, insurer, location of care, choice of pharmacy or radiology service, and so on; nonetheless, some general information is known, and solutions that provide patient-level details are in development.

Consider a Medicare patient with metastatic colorectal cancer. Commonly, a component of first-line therapy for this disease is bevacizumab. The addition of bevacizumab to chemotherapy extends life by an average of approximately 5 months over chemotherapy alone. The drug is fairly well tolerated, but among other risks, patients receiving bevacizumab have a 2% increase in the risk of severe cardiovascular toxic effects. Over the course of a median of 10 months of therapy, bevacizumab costs $44,000.[1] A patient with Medicare coverage alone would be responsible for paying 20% of that cost, or $8,800, out of pocket, and that price tag doesn't include payments for other chemotherapy, doctor's fees, supportive medications, or diagnostic tests. Most physicians insist on discussing the 2% risk of adverse cardiovascular effects associated with bevacizumab, but few would mention the drug's potential financial toxicity.

This example is not isolated, and the consequences for patients are grim. The problem is perhaps starkest in cancer care, but it applies to all complex illness. The Center for American Progress has estimated that in Massachusetts, out-of-pocket costs for breast-cancer treatment are as high as $55,250 for women with high-deductible insurance plans; the out-of-pocket costs of managing uncomplicated diabetes amount to more than $4,000 per year; and out-of-pocket costs can approach $40,000 per year for a patient with a myocardial infarction requiring hospitalization.[2] The Centers for Disease Control and Prevention estimates that, owing in part to such high out-of-pocket costs, in 2011 about a third of U.S. families were either struggling to pay medical bills or defaulting on their payments (see graphs).[3]

This health care–related financial burden can cause substantial distress, forcing people to cut corners in

ways that may affect their health and well-being. In our research, we discovered that many insured patients burdened by high out-of-pocket costs from cancer treatment reduce their spending on food and clothing to make ends meet or reduce the frequency with which they take prescribed medications.[4]


Financial Burden of Medical Care.

Whether because of insufficient training or time, many physicians don't include information about the cost of care in the decision-making process.[5] But discussing costs is a crucial component of clinical decision making. First, discussing out-of-pocket costs enables patients to choose lower-cost treatments when there are viable alternatives. Patients experience unnecessary financial distress when physicians do not inform them of alternative treatments that are less expensive but equally or nearly as effective. We discovered this phenomenon when interviewing a convenience sample of breast-cancer survivors who had participated in a national study of financial burden. Many women reported discussing treatment-related costs with their physicians only after they had begun to experience financial distress. One woman reported that only after she told her clinician “I am not taking this if it is going to be $500 a month” did the clinician inform her that “We can put you on something [less expensive] which is just as effective.”

Second, such discussions could assist patients who are willing to trade off some chance of medical benefit for less financial distress. Admittedly, the trade-off between cost and potential benefit is complex and ethically charged. Yet when costs are not included in decision making, patients are deprived of the option, and patient engagement is harmed. Presenting this trade-off to patients makes clinical sense if we think of financial costs as treatment side effects.

Third, discussing out-of-pocket costs could benefit patients by enabling them to seek financial assistance early enough in their care to avoid financial distress. One of the patients we interviewed explained, “My husband died and we were in debt. I was sick, he was sick. I lost my house . . . . And I told [my doctor] that I could not afford to take the Femara. She said, `Well, you can apply for help' . . . and I got help!” One has to wonder whether an earlier discussion of out-of-pocket costs might have prevented the patient from losing her home.

Fourth, a growing body of evidence suggests that including consideration of costs in clinical decision making might reduce costs for patients and society in the long term.

Although we believe that physicians should discuss out-of-pocket costs with their patients, we recognize that such discussions will not always be easy. As previously acknowledged, it is often difficult to determine a patient's out-of-pocket costs for any given intervention. Efforts are under way to address this informational barrier: insurance companies are developing technologies to better estimate patients' costs, and several states have passed price-transparency legislation. But these efforts are imperfect and incomplete, so for now, physicians and patients will often have a difficult time estimating cost differentials between viable treatment options. In addition, patients and physicians face social barriers to discussing costs of care. No doubt, many doctors and patients find discussions of money uncomfortable; they have not been coached in ways of having the conversation. Patients worry that asking about costs will put them at odds with their doctors or result in subpar treatment. And some physicians believe that their duty is to provide the best medical care regardless of cost.

We believe that given the distress created by out-of-pocket costs, it is well within physicians' traditional duties to discuss such matters with our patients. Admittedly, out-of-pocket costs are difficult to predict, but so are many medical outcomes that are nevertheless included in clinical discussions. Policymakers need to continue the push for greater transparency in medical costs, especially those borne by patients. Health care stakeholders should advocate for high-value care that reduces cost while improving outcomes. But that change will not occur overnight, and in the meantime, patients will continue to suffer from treatment-related financial burden. Physicians should discuss what is known about these costs with our patients, so that the personal financial impact of medical care is incorporated into the selection of the best care for any given patient, in the same way that any other potential toxic effect is considered. We can no longer afford to divorce costs from our discussion of patients' treatment alternatives.

Disclosure forms provided by the authors are available with the full text of this article at NEJM.org.

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Comments (30)

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CONTRIBUTORS

Data by Profession and Location