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Price Transparency for Whom? In Search of Out-of-Pocket Cost Estimates to Facilitate Cost Communication in Cancer Care

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EDITORIAL

High costs of cancer drugs have repeatedly provoked a public outcry over the affordability of cancer care in news media and journal articles.[1–4] Especially for patients diagnosed with cancer in the United States, the sustained increase in the cost of cancer care is believed to cause tremendous distress for patients and their families to the extent that the term “financial toxicity” has been used to describe patients’ cost-related experiences,[5, 6] and coping strategies are being discussed.[7, 8] One such strategy is patient-physician cost communication, which was advocated in a Guidance Statement endorsed by the American Society of Clinical Oncology (ASCO) Cost of Care Task Force in 2009.[9] ASCO took a strong stand on the importance of cost communication, affirming that it is a key component of high-quality care in cancer. This view was supported by the Institute of Medicine Committee on Improving the Quality of Cancer Care.[10]

A recently published review article on cost communication in oncology reported that a major barrier for patient-physician cost communication is a lack of accurate and accessible information on costs, especially out-of-pocket costs.[11] Ideally, this barrier of cost communication can be alleviated by making price information public. Price transparency in healthcare sector has been the focus of legislation in many states. These state laws mandate healthcare providers to make price information available to all consumers, either upon request or posted on-line. According to a report card on state price transparency laws published by the Health Care Incentives Improvement Institute in 2016, only 7 states have no statutes addressing price transparency at the time of the report.[12] The private sector echoed state legislatures’ efforts in promoting price transparency, as evident by an increasing number of “price estimator tools” offered by insurers or employers.[13] However, currently available price estimator tools have limited utility in accurately estimating out-of-pocket cost

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for cancer patients since pricing information available from these tools is usually for “most commonly used” procedures and services, and often only covers “shoppable services” such as elective outpatient surgeries, imaging services, and lab tests.[13, 14]. Oncology services are neither common procedures nor shoppable services.

The complex, multidisciplinary nature of oncology care makes estimation of out-of-pocket costs challenging. Patients with cancer often undergo treatments that consist of a combination of surgery, chemotherapy, radiation therapy, and supportive care. The exact combination of treatment modalities and the duration of each depend on a multitude of factors, such as cancer diagnosis, stage, and comorbidity. Even if a treatment pathway is mapped out upfront, the pathway often needs to be modified based on patients’ response to treatment and sometimes patients’ ability to pay. Efforts to improve price transparency in oncology have led to the development of several web-based resources. Eviti ADVISOR (<https://connect.eviti.com/evitiAdvisor/>) is a web-based tool that can be used to compare expected costs, outcomes, and toxicities of different treatments. However, this resource is not directly available to patients. Access is limited to healthcare providers with a registered account; a Tax ID and National Provider Identifier number are required to complete the registration. It is important to note that while the terms cost and price are often used interchangeably, price transparency from the perspective of providers or policy makers does not necessarily lead to transparency in the type of “prices” or “costs” most relevant to patients – the out-of-pocket costs. Indeed, even if patients can gain access to eviti ADVISOR through their providers during their clinical encounters, its cost estimation function reports costs to the healthcare system but does not provide estimates of out-of-pocket costs.

DrugAbacus (<https://drugpricinglab.org/tools/drug-abacus/>) is an interactive, public-accessible on-line tool to allow policy makers and consumers to compare prices of cancer drugs. This platform presents the monthly cost of cancer drugs in two ways: current price and abacus price. Current prices reflect reimbursement from three payment systems: Medicare, US Department of Veterans Affairs, and the United Kingdom National Health Service. The abacus price attempts to provide an estimate of “value-based prices” by incorporating the following eight attributes in its calculation: efficacy, tolerability, novelty, research and development costs, rarity, population burden, unmet need, and prognosis. Users are able to personalize their abacus price by weighing each attribute per their own preference and value. As of November 2017, DrugAbacus included 52 cancer drugs approved by the US Food and Drug Administration between 2001 and 2015, covering both oral and intravenous anticancer drugs. Despite the excitement over the potential of this tool to facilitate the communications on drug prices among stakeholders and to empower users to explicitly quantify their value judgment,[15, 16] DrugAbacus, like eviti ADVISOR, does not provide information on out-of-pocket costs either.

Professional societies, such as ASCO, National Comprehensive Cancer Network (NCCN), or European Society for Medical Oncology, have established their own home-grown version of “value framework” or “evidence block” as in the case of the NCCN.[17–20] Only the ASCO value framework acknowledges the role of out-of-pocket costs in its value assessment criteria. However, no guidance is provided regarding how to obtain such information, aside from a comment that patient cost is “*highly variable depending on the patient’s insurance*

benefits.” [20] Indeed, the wide variety of health insurance benefit design under the complex, segmented health care system in the United States renders it extremely difficult to produce a price estimator tool to inform consumers of their out-of-pocket costs. The insurance benefit design covers intravenous chemotherapy administered at office settings under medical benefit and oral chemotherapy under pharmacy benefit. Not only does the cost-sharing requirement (i.e., deductible, copayment, coinsurance, out-of-pocket maximum) differ between medical and pharmacy benefits, there are also some fundamental differences between Medicare and private insurance. Specifically, many private insurance plans have copayment but no coinsurance in its pharmacy benefit whereas the Medicare Prescription Drug Plan (also known as Medicare Part D) includes both in its benefit design with the rate of coinsurance varies by benefit phases. Studies have found substantially higher out-of-pocket costs for cancer patients receiving oral chemotherapy who were enrolled in Medicare vs. those in private insurance.[3] Without knowledge of patients’ insurance benefit design, along with access to proprietary, negotiated health system pricing, it is nearly impossible to produce reliable estimates of out-of-pocket costs.

Should we halt patient-physician cost communication until more reliable information on out-of-pocket costs becomes available? Absolutely not! Cost discussions allow patients to select lower-priced alternatives when available, make a trade-off between medical benefit and cost based on their preference, and identify financial assistance resources earlier rather than later. [21] A recently published qualitative study offered important insights on topics that were covered during cost communication.[22] The study found that only less than 10% of the discussions were related to out-of-pocket costs, with time off work and insurance being the two dominating topics in cost-related discussions. While findings from this study needs to be interpreted with caution to avoid over-generalization as the sample size was small and the vast majority of the study cohort were African Americans breast cancer patients with annual household income less than \$40,000, these findings point to the importance of continuing working during treatment for many patients, both from a financial perspective (to keep insurance coverage and be able to cover out-of-pocket costs) and a psychosocial perspective (to feel a sense of normalcy during a difficult time in one’s life). Additionally, the findings suggested that cost communication could open the opportunity to start a conversation to better understand the non-clinical aspects of cancer care so as to make a patient feel like s/he is being treated as a whole person, not simply a tumor or disease. Another study found that, in a small sample of patients, when a cost discussion occurred between patient and oncologist, out-of-pocket costs were reduced 57% of the time. In most cases, costs reduction was achieved primarily by navigating patients to financial assistance and by negotiating with the patient’s insurance company without having to change treatment.[23] While waiting for a price estimator tool tailored for oncology care, promoting screening for financial toxicity among cancer patients should be standard of care, especially since resources already exist to reasonably lower patient cost.

It is our opinion that it will take a system-wide approach to tackle financial toxicity in cancer. The success in tobacco control achieved under the Ask Advise Refer (AAR) approach recommended by the US Department of Health and Human Services offers a promising road map ahead.[24] This three-step approach should start with an open dialogue between patients and their cancer care team asking about the potential financial impact of

cancer to the patient. Next, treatment decision should be made by advising patients of the treatment considered to be most valuable to patients given the evidence, patient's goals and values, prognosis, and financial standing. Lastly, if the treatment of choice could place patients at high risk for financial toxicity, it should trigger an automatic referring mechanism to direct patients to patient financial assistance programs. Having easily accessible resources with understandable estimates of out-of-pocket cost for patients is a critical step toward system readiness for the cancer care delivery system to implement the AAR approach to tackle financial toxicity.

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