Crowdfunded Cancer Care—A Reflection on Health Care Delivery in the US

S. Yousuf Zafar, MD, MHS

In September 2020, a simple search on GoFundMe.com for the term cancer treatment yielded more than 300,000 results, each one a plea for financial assistance. These crowdsourced fundraising, or crowdfunding, campaigns seek to “ease the financial burden of cancer,” or more urgently, suggest that without assistance, a family “could lose their shelter, not have reliable transportation or food to eat.” Since its founding in 2010, GoFundMe, currently one of the largest crowdfunding platforms, claims to have raised more than $9 billion in donations. To understand the true impact of these campaigns, we must acknowledge that crowdfunding campaigns are not just consigned to a dusty corner of the internet—in reality, they take center stage. According to the Pew Research Center, in 2015 more than 1 in five Americans had donated to an online fundraising project, and 68% of those had donated to help a person in need. Yet, questions remain as to who benefits most and how equitably those funds are raised.

To address these questions with a particular focus on cancer-related financial assistance, Silver et al analyzed 144,061 GoFundMe crowdfunding campaigns from 2010 to 2019. The authors found that cancer-related financial assistance campaigns raised the most money if they originated in US counties with higher socioeconomic status and they had sufficient internet literacy to describe their beneficiaries as worthy of donation. Together, the data suggest that characteristics of successful campaigns serve to exacerbate disparities in cancer care.

To what degree is crowdfunding a reflection on cancer care delivery in the US? To answer this question, we must first acknowledge that these campaigns are driven by a combination of factors, including the increasing cost of treatment, prolonged use of treatment, and increasing cost-sharing in health insurance plans.

First, the price tag of cancer treatment has been increasing for decades, such that the cost of a month of anticancer therapy today is (in inflation-adjusted dollars) orders of magnitude more expensive than it was 30 years ago. Today, 1 month of a single anticancer drug can cost tens of thousands of dollars. Although drug costs are most visible and easiest to single out, other components of care contribute to costs, including inpatient care, professional fees, and facility fees, among others. Indeed, for a subgroup of patients, nondrug costs can actually exceed drug costs within the total cost of care calculation.

Second, these costly drugs are dosed every few weeks, sometimes for years at a time. The increasing duration of therapy is due, in many cases, to the improved effectiveness and tolerability of that treatment. Although that topic is beyond the scope of this commentary, important debates continue as to the added value of extended therapy with these drugs, when considering the incremental improvement in cancer survival weighed against the exorbitant and steady increases in price.

Third, as prices and duration of therapy continue to increase, insurers have been searching for ways to reduce the total cost of cancer care. One commonly used tool in the health plan design arsenal is cost-sharing, wherein a portion of cost is shifted from the insurer to the patient in the form of copayments, deductibles, and coinsurance. According to the Kaiser Family Foundation, out-of-pocket health care spending increased by 67% from 2008 to 2018. Theoretically, cost-sharing was designed to increase a patient’s skin in the game, such that awareness of and partial responsibility for cost should decrease health care utilization. In reality, patients with cancer unquestioningly shoulder the burden of high out-of-pocket costs, with subsequent impacts on their family budgets, adherence to treatment, and emotional health. This negative impact of out-of-pocket costs is framed as the...
financial toxicity of cancer care and is, for the most part, what drives the cancer crowdfunding movement.

Although, at face value, crowdfunding campaigns might seem like a harmless means of reducing a family’s treatment-related financial burden, evidence of potential harm from these campaigns is growing. These harms include fake accounts, loss of privacy, and fundraising for unproven interventions. Silver et al add to this list by revealing biases in fundraising favoring those with greater socioeconomic status and internet literacy. Where do we go from here? The cost of cancer treatment—and along with it, the patient’s financial burden—will continue to increase. More than likely, patients and families will continue to seek alternative sources of financial aid including crowdfunding campaigns. We should not impede access to these resources for patients in need; just a quick scroll through any one of these websites will crystalize the much-needed assistance that is generously donated, in many cases by strangers. However, that giving is in some cases skewed away from those with the greatest need. Rather than limiting access to these resources, important questions must be asked of crowdfunding platforms. How will they hold campaigns to the highest standards to ensure they are verified? How will they ensure campaigns are highlighted and funds are distributed with equity? To what extent are they now a part of the health care financing industry, and to what degree should they be regulated as such?

Arguably, crowdfunding platforms are a reflection on the state of modern health care delivery in the US. We live in a country where some patients have to crowdsource their health care expenses, and even in the midst of generosity, we face growing disparities between the have-nots and the haves-even-less.

ARTICLE INFORMATION


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Corresponding Author: S. Yousuf Zafar, MD, MHS, Duke Cancer Institute, DUMC 2715, 2424 Erwin Rd, Ste 602, Durham, NC 27710 (yousuf.zafar@duke.edu).

Author Affiliations: Duke Cancer Institute, Durham, North Carolina; Duke-Margolis Center for Health Policy, Durham, North Carolina.

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REFERENCES
