Financial Toxicity, Part II: How Can We Help With the Burden of Treatment-Related Costs?

Published on Cancer Network (http://www.cancernetwork.com)

April 15, 2013 | Practice & Policy [1], Oncology Journal [2]
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Just as high-quality research has focused on limiting the physical toxicity resulting from successful treatment, future research should focus on mitigating the negative effects of financial toxicity without affecting disease-related outcomes.

Janet is a 67-year-old woman with metastatic breast cancer. Despite having insurance, Janet has been saddled with life-altering out-of-pocket expenses from her cancer treatment. In Part I of this two-part series, we described how Janet’s struggle with out-of-pocket expenses was not unique; a growing body of evidence has detailed the negative impact of costs on insured patients receiving cancer treatment.[1] The cost of cancer care, overall, is increasing. Innovations in therapy are more expensive now than ever before.[2] These innovations are less toxic than older drugs, so the elderly and frailer patients are more likely to get treated. And our population is aging—thus, more patients are being treated with more expensive drugs for longer periods. Due to the exorbitant price tag on cancer treatment, third-party payers have shifted a portion of costs to patients in the form of rising premiums, coinsurance, higher prescription drug copayments, and tiered drug formularies.

Don’t get us wrong; we, too, celebrate the innovations that have made cancer treatments more effective, less toxic, and less physically burdensome. But now a new burden from these treatments is emerging—personal and societal “financial toxicity.”

The manifestations of cost sharing for cancer treatments are not intangible expenses borne by society. Rather, the story of the palpable impact of cost sharing in cancer is voiced through patients like Janet. In order to defray cancer-related out-of-pocket costs, patients are altering their lives and their care: they are nonadherent with their medications; they are opting out of expensive treatment; they are spending less on basics like food; and they are spending down their retirement savings.[3] Patients are experiencing “financial toxicity” as a direct result of their cancer treatment. As Janet explained, she felt “caught between a rock and a hard spot” when it came to paying for cancer care. Mounting evidence has described the negative implications of cost sharing from the patient’s perspective; we know that many patients receiving cancer treatment experience both an objective financial burden and subjective financial distress. However, little is known about whether or how patients want costs included in treatment-related decision making. For instance, do patients want to talk about costs with their doctors? Can we identify patients at greatest risk for experiencing financial toxicity? If we can identify those patients, how can we help?

Despite a lack of knowledge with regard to patient preferences, communicating with patients about costs has been advocated.[4] Still, an important distinction should be made between patients reporting financial distress and patients wanting to adjust treatment plans as a result of financial distress. A study from the general medicine literature found that while 63% of study participants reported a preference for discussing costs with their doctors, 85% had never actually had the discussion.[5] Few studies have addressed the issue of patient communication specifically in regard to costs and cancer. Bullock et al found that while most cancer patients wanted to talk to their doctors about costs, they did not consider costs when making treatment decisions and did not want their physicians to consider costs either.[6] These data present an interesting conundrum: patients want to discuss costs, but they prefer that their physicians do not make any treatment decisions based on costs. Yet, talking about costs after the fact eliminates the possibility of decreasing out-of-pocket expenses before they accrue. If we follow this strategy, we are left with trying to sort out untenable medical bills that might have been avoided, or at least minimized. Why might patients be reluctant to discuss costs as a part of treatment decision making? First, patients receiving treatment might be more willing than we realize to take on costs for marginal potential benefits. According to prospect theory, patients facing loss or harm will take on greater risk in decision making if they perceive a likelihood of benefit.[7] Although it does not involve costs, the literature regarding phase I trial participation serves as an excellent example of this general
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principle: in one study, 44% of patients stated that they would be among those who benefited from a trial with only a 20% expected benefit rate.[8] Thus, if a patient expects to benefit from therapy, perhaps he or she perceives the financial burden to be bearable. Additionally, patients might feel pressure to get the “best care” regardless of cost; they might not want to risk getting sub-par care because of cost cutting.[4] Patients might not believe their physicians are the right people with whom to discuss cost concerns, or they might feel that their physicians do not have the time to have that discussion. Finally, patients might be embarrassed to bring up financial distress with their doctors. Interestingly, these are the same barriers that many oncologists report when asked why they do not initiate a cost discussion with their patients.[9] Despite these barriers to including costs in decision making, a slice of the literature suggests that cancer patients are indeed very sensitive to costs in relation to value.[10] While patients might outwardly claim they do not want costs taken into consideration when treatment decisions are made, some patients still make cost-based decisions after the fact: these decisions are manifested through nonadherence to drugs, avoidance of recommended procedures, and skipping of physician appointments, all to save money.[3,11]

Whether or not they want to discuss costs with their doctors, patients are experiencing considerable financial distress as a result of the treatment we prescribe to them. Patients who want to talk about costs but leave the doctor’s office before doing so might be more likely to express dissatisfaction with care.[12] If patients are unwilling to bring up the subject of costs, how do we identify those at greatest risk for financial distress? Since a growing proportion of our patients are considered underinsured,[13] this question is of utmost importance. First, oncologists could rely on sociodemographics, singling out patients by age, ethnicity, income, or employment status.[13] However, this strategy could overlook a considerable proportion of at-risk patients. We could look for patients who have applied for copayment assistance, since they are at higher risk for experiencing financial distress[3]—but in these patients the financial damage has likely already been done. One approach to capturing financial toxicity mirrors the way in which any other treatment-related toxicity or patient-reported concern is captured: through the use of real-time patient-reported outcomes (PROs) data collected during clinical care to guide treatments and monitor impact. Patients are willing and able to report their symptoms routinely, and numerous studies have supported the use of electronic PROs (ePROs) as a standard part of clinical care, particularly in regard to sensitive topics.[14,15] Through the use of ePROs, patients could be screened for financial distress—along with fatigue, weight loss, and nausea—at each visit, allowing for longitudinal evaluation and timely intervention.

But what intervention? Now that we know that cancer care is expensive even for insured patients, and are aware that certain patients might be at greater risk for experiencing financial toxicity, how do we help them? These questions frame the next, critical step in the research interface between health policy and the patient. The development of an intervention to reduce costs might be best approached by understanding who could act as gatekeepers for expensive care. Policymakers come to mind, first, since they alone are tasked with crafting cost-saving health policies at the national level. Despite its name, the Affordable Care Act does much to increase access to care but little to reduce the financial burden. None of these entities by itself is likely to solve the problem of high costs. What is on the horizon to help decrease costs for patients? First, the most obvious change comes from the Affordable Care Act. By setting limits for out-of-pocket expenses and providing premium credits, the Affordable Care Act, by some estimates, will result in up to a 70% decrease in...
underinsured adults.[13] However, due to the shared responsibility requirement (also known as the individual mandate), more people will be required to purchase insurance. The Affordable Care Act might at best decrease costs by effecting a movement away from fee-for-service payments and toward an episode-based reimbursement approach, in which Medicare would reimburse providers a set amount to care for a patient’s condition for a period of time. This approach would allow health systems or providers to choose between equivalent treatment options based upon affordability and cost-effectiveness.[19] A second potential option for reducing the cost burden is the development of cost-conscious practice guidelines. For example, the American Society of Clinical Oncology (ASCO) has formed a working group to assess including cost and cost-effectiveness data in ASCO’s clinical practice guidelines.[20] The integration of cost into practice guidelines could help physicians make cost-conscious decisions that are still within the scope of acceptable, standard care. Third, much of the cost of cancer care is centered around drugs, and by some estimates up to 75% of oncology drugs are used off label.[21] Drug compendia are used to determine medically acceptable off-label use, but studies suggest that compendia are inconsistent in their listing of off-label use and in their reliance on evidence.[22] Greater efforts to make compendia development more consistent, and to link comparative-effectiveness and cost information to compendia monographs, might help guide health systems and clinicians in the use of drugs. Fourth, at the policy level, the inclusion of value in comparative assessments of medical technologies is warranted. While comparative-effectiveness research (CER) is currently promoted and funded by the Patient-Centered Outcomes Research Institute (PCORI), no link exists between the research generated by PCORI funding and the drug-approval process—unlike with the United Kingdom’s NICE, which integrates cost and value into coverage decisions.

A means by which many of these policy mechanisms can be brought to the bedside and produce more cost-effective care is (rapid) learning healthcare. This approach allows healthcare to “learn” by collecting extensive, multi-center clinical data in real time, analyzing the data, and implementing insights in clinical practice.[23] Rapidity is injected into the model through real-time analytics and point-of-care clinical decision support. This model could incorporate CER at the individual level; for example, if an individual patient’s personal information on expenses, insurance benefits, and sociodemographics were combined, in real time, with information on likely efficacy and potential toxicity, then the patient and doctor could make a tailored decision based on the individual’s personalized risk assessment along with consideration of potential benefits and costs of therapy. The treatment cost implications would be apparent to patients well before they opened an unexpected bill.

We oncologists and our patients are facing an era of medicine in which innovations are implemented at a rapid pace, costs are rising to keep up with innovation, and those costs are being shifted onto patients. As a result, we find ourselves at the front lines of the conflict between cost and effectiveness, and frankly, we are unprepared. Now that we are aware of Janet’s plight with her health care bills, we need to design interventions to help. We need to consider education for patients and providers, tools to identify those at greatest risk, and means for providing those experiencing financial toxicity with alternative care options. Cancer treatment is unlikely to become any less expensive in the coming years, and neither patients nor providers will risk the quality of care to eliminate all out-of-pocket costs for patients. However, just as high-quality research has focused on limiting the physical toxicity resulting from successful treatment, future research should focus on mitigating the negative effects of financial toxicity without affecting disease-related outcomes.
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