Financial Toxicity as an Unforeseen Side Effect of Inflammatory Bowel Disease

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“Financial toxicity” refers to the adverse impacts of cost on a patient’s disease experience and outcomes. Although the focus of financial toxicity thus far has been in the context of cancer care, it is reasonable to suspect that other chronic illnesses are afflicted by this same concept. In this article, we discuss a case of financial toxicity in a patient with ulcerative colitis, which ultimately lead to not only insufficient disease management, but also paradoxically increased cost. Our case serves to illustrate the phenomenon of financial toxicity and its consequences in patients with inflammatory bowel disease.

Key Words: adverse event; crohn’s; cost; financial toxicity; Inflammatory Bowel Disease; ulcerative colitis.

INTRODUCTION

“Financial toxicity” refers to the idea of patients dealing with cost implications as a part of their disease experience.¹ The term was originally coined by S. Yousuf Zafar, MD, and Amy Abernethy, MD, from the Duke Cancer Institute in Durham, NC, to describe an adverse event increasingly experienced by patients with cancer.¹ According to Zafar and Abernethy, there are 2 aspects of financial toxicity: objective financial burden and subjective financial distress. Much more is published on objective financial burden, with nonadherence as one of the best-studied outcomes resulting from higher costs.¹² Subjective financial distress has been linked to changes in treatment-related decision making, with patients deciding for or against treatments based on primarily on cost.¹³ Like our patient with ulcerative colitis in the vignette, these cancer patients are spending their savings, canceling vacations, and working more unintended hours to be able to afford their care.¹

DISCUSSION

Inflammatory bowel disease (IBD) is a heterogeneous group of chronic inflammatory disorders, including ulcerative colitis and Crohn disease, that affects nearly 2 million Americans.⁴ Treatment tends to be multifaceted and disease course tends to be variable, with a large portion of IBD patients requiring costly hospitalization (24%–83%), surgery (39%–82%), or aggressive medical therapy (39%–82%).³ Furthermore, IBD is often diagnosed during the most...
economically productive years of adulthood such that nearly a third of costs stem from indirect sources, including lost productivity. The nebulous nature of these indirect or “hidden” costs make them easier to overlook, and the downstream effects of these losses are difficult to calculate. For example, economic distress may lead to financial coping behaviors (e.g., skipping medications due to cost) and psychosocial distress may lead to increased psychosomatic complaints or behavior change, thus further increasing costs. Like with cancer care, there are relatively few studies that focus on the subjective financial distress faced by patients with IBD. Though our understanding of the outcomes of this distress is limited, there is evidence to demonstrate its existence. For example, a 2017 survey study captured responses from 3608 Crohn’s and Colitis Foundation of America (CCFA) members, and 66.3% of respondents reported health care–related financial worry. Another survey study from 2018 of 48 patients with Crohn disease identified that most of these patients experienced at least mild financial distress.

Conversely, the objective financial burden of IBD care is well documented in the literature. Compared with those without IBD, these patients are incurring higher costs due to both treatment-specific and disease-specific features. A large 2019 study from the CCFA found that patients with IBD incurred a greater than 3-fold higher direct cost of care per annually compared to non-IBD controls ($22,987 vs $6956) and absorbed more than twice the out-of-pocket costs ($2213 vs $979). Key drivers of cost include treatment with specific therapeutics, especially biologics; emergency department use; and health care services associated with relapsing disease, anemia, or mental health comorbidity. Furthermore, the costs of care for IBD have been steadily increasing for more than a decade, largely driven by rising pharmaceutical expenditures from increased biologic use.

Although providers may ultimately have limited control over the cost of treatment, a component of their care should include monitoring the burden of these costs given the negative clinical outcomes that they impose on patients. Universal financial toxicity screening has been proposed for cancer patients as standard of care and may be beneficial for IBD patients as well. This is especially true given the complex and chronic nature of IBD treatment. Identification of high-risk patients allows for triage to financial resources and individual case management that can improve IBD care delivery and prevent downstream effects. For example, in our vignette, intensified management with biologics—which was initially deferred due to cost, ironically—may have prevented his acute flare. More specific, streamlined consideration of financial realities a priori could have prevented a paradoxical increase in cost in the form of another hospitalization and more lost time.

Although concern over cost is not novel, what is novel is the degree of attention focused on conversations and decision making as a major locus of control. Whereas before, directly discussing costs with patients was considered unconventional and potentially harmful to the ideal patient–doctor relationship, it is now considered a component of high-quality patient-centered care. Considering the financial feasibility of treatment connotes both a sense of respect and empathy for patients’ individual journeys. Furthermore, in general, patients want to discuss their cost of care and expect and prefer that their physician begin the conversation. Ultimately, addressing financial toxicity makes physicians better advocates for beneficial care, and decreasing financial toxicity may lead to improved outcomes long term. Of course, patient and health care worker awareness is the first step toward this goal, and our report serves to illustrate this phenomenon at the individual level.

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