



Financial Toxicity and Societal Costs of Cancer Care: Distinct Problems Require Distinct Solutions

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Recent years have seen a shift in attitudes among clinicians toward addressing the costs of cancer care in the oncology clinic. Where once discussing costs directly with patients was viewed as taboo and potentially detrimental to the ideal patient-doctor relationship [1, 2], it is now described by professional organizations such as the American Society of Clinical Oncology as a component of high-quality patient-centered care [3]. This represents a historic change in the professional perception of the physician's role, and it comes with a need to recognize the forces driving this change and clarity regarding the goals of discussions of costs with patients. Our concerns with the financial toxicity that patients may encounter at the individual level as a result of cancer treatment must not serve as a fig leaf obscuring the major challenges we face in confronting the rising costs of cancer care, nor should it jeopardize our fiduciary duty to advocate for our patients' access to beneficial care.

Recent discussion of costs in oncology often begin with a discussion of rising and potentially unsustainable societal costs of care and then pivot to a focus on direct costs to patients, frequently described as "financial toxicity" [3–6]. Major policy papers by both the American Society of Clinical Oncology and the European Society for Medical Oncology emphasize a need for clinicians to consider value in treatment decisions as a means to control both direct costs and societal costs of cancer care [4, 7].

These are important but distinct issues. Societal costs are a product of the incidence of cancer, increasing diagnostic and therapeutic options (innovation), and rising costs for both new and older interventions. Direct costs to patients are a product of both the cost for the selected intervention or test and the amount the patient is required to pay out-of-pocket to gain access. These direct costs are due to lack of health insurance or cost-sharing by their specific insurance policy.

Direct costs to patients and societal costs are often linked, making the call for physicians to broadly consider and discuss "costs" more politically palatable. As costs rise and patients bear a growing percentage of costs through cost-sharing mechanisms (copayments, coinsurance, and deductibles), it may seem preferable to address concerns that stem from rising drug prices or for-profit health insurance by focusing simply

on the costs confronted by patients. Clinicians can retain our patient focus while avoiding contentious political debates. However, this may yield unintended consequences. Conflating societal costs of cancer care with direct costs to patients and emphasizing discussions of costs as a solution risks unnecessarily compromising the patient-doctor relationship, increasing the burdens of a cancer diagnosis, and increasing disparities in cancer care.

WHAT IS DRIVING THE CONCERN WITH COSTS OF CANCER CARE?

The forces driving the current focus on costs include rising drug prices, increases in cost-sharing, and economic changes in cancer care that affect clinicians and patients directly. Oncology has experienced a marked increase in new interventions, including molecularly targeted and immunotherapy drugs that are expanding options and improving outcomes for thousands of patients. Being able to do more, for more people, increases the societal costs of care. At the same time, oncology drug prices are high, often more than \$100,000 per year, roughly double the median U.S. household income, with costs seemingly based on what the market will bear rather than the incremental value of the new drug [8].

Rising costs from drugs and other services, such as hospitalization and imaging, have been met by efforts from for-profit private insurers to shift more of the economic burden of treatment to patients [9]. This is effective in limiting health care utilization but reduces the use of both low-value and high-value aspects of health care [10]. In addition, cost-shifting has coincided with rising health insurance industry profits [11]. Compounding these challenges, a large part of cancer care is funded by government programs, such as Medicare for older patients and Medicaid for the very poor. These large payers are prohibited by statute from considering cost-effectiveness or negotiating lower drug prices. Finally, we must acknowledge the increased financial pressure on physicians and their practices due to changes in oncology reimbursement [12]. These shifts have resulted in declining income and closure for many practices. Further financial challenges are seen on the horizon as bundled payments for oncology services are proposed. While recent economic changes in oncology practice are rarely mentioned in discussions of

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financial toxicity, these pressures may contribute to a change in the historical willingness of physicians to discuss costs with patients and to rising concern with societal costs of care [13, 14].

DISTINGUISHING BETWEEN DIRECT COSTS TO PATIENTS AND SOCIETAL COSTS OF CARE

Recognizing some of the forces that may contribute to the current focus on financial toxicity does not mean that we can or should ignore the real effect of costs on patients. The financial consequences of cancer treatment decisions can result in distress beyond that imposed by the disease and even lead to personal bankruptcy [15–17]. They can also affect access to care and adherence to essential therapy [18, 19]. However, financial toxicity is also an artifact of drug prices that may have little to do with the value of an intervention for a given patient and a health insurance system based on a private for-profit model or an inadequately financed public model that shifts costs to patients regardless of value or elasticity of demand. Financial toxicity implies a need to inform patients of the consequences of treatment decisions, analogous to education regarding health-related side effects of therapy. We must be careful, in doing so, that we not forget that these costs are not an inherent “toxicity” but a byproduct of our health care system. If we eliminated all out-of-pocket expenses for patients tomorrow, we would still face the societal challenge of rising costs of care.

Societal costs of cancer care are estimated to constitute at least 5% of total health care spending [20]. This percentage is projected to increase as a percentage of overall spending [21]. Health care spending in return, in both the United States and other nations, constitutes a growing and arguably unsustainable fraction of total gross domestic product [20]. The importance of “bending the cost curve” in health care has been well described [22]. Failure to do so risks not only sustainable access to cancer care but also other social priorities, including education, infrastructure, public health efforts, and scientific research. On this basis alone, there is an urgent need to consider the role of the frontline clinician in assessing value and identifying strategies to control societal costs while preserving or enhancing quality care.

Efforts such as the American Board of Internal Medicine Foundation’s “Choosing Wisely” campaign highlight opportunities to eliminate inappropriate care [23]. Other practices, such as wider implementation of hypofractionation of radiation therapy for breast cancer, that can reduce costs with no detriment to patients have been identified [24]. Value frameworks can be used to help clinicians recognize when a lower-cost regimen will achieve similar or even superior results [4]. However, none of these efforts to achieve cost control need to involve discussions of costs with patients in the clinic. In addition to working to control costs, physicians must play a role in identifying high-value aspects of cancer care in which further societal resource allocation is well justified; they should also serve as advocates to ensure that all patients in need have access, without prohibitive out-of-pocket costs.

HOW SHOULD WE APPROACH COSTS OF CARE IN THE CANCER CLINIC?

Most patients wish to be informed of direct costs they will face as a result of treatment decisions; they want to know what

their portion of the bill will be. Patients may not want considerations of direct costs to influence physicians’ recommendations, and most do not want considerations of societal costs to influence their treatment decisions [25].

Although we value shared decision-making and recognize that patient choices may affect societal costs of care, goals of care discussions should focus exclusively on the interests of the patient. Introducing costs as part of the basis for decision making can distract from a discussion of which interventions are actually beneficial and can result in patients receiving care based on socioeconomic status, not medical need.

In assessing the importance of this distinction, we can consider two models. In the first, decisions are based on discussion of the medical issues and the patient’s preferences, and then direct costs are considered and confronted, as we would any other barrier to access or adherence. The physician or others in the oncology clinic can assist patients with understanding and minimizing out-of-pocket costs (through assistance with insurance coverage or applications to industry patient support programs or charitable foundations). Financial toxicity is not ignored but is not the focus of decision-making. In the second model, costs are presented and considered up front as part of the pros and cons of various care options, analogous to how we might consider serious risks and toxicity from treatment. While this later “upfront” approach may be gaining traction in the growing literature on costs of care and financial toxicity, it is not clear that this is driven by demand from patients.

Decisions over cancer care do not occur in anything approaching an idealized marketplace, where considerations of cost and benefit are essential to determine utilization and price. Patients face an asymmetry of information regarding potential risks and benefits of health care decisions, and there is lack of transparency regarding overall cost and even direct costs that can be difficult to overcome. Perhaps most important, patients with cancer are under duress from their illness, and they rely on their clinicians to be their advocates for appropriate care, not brokers of all possible health care services. It is telling that when patients with cancer are asked to define “value,” they tend not to focus on economic factors but on relationships and communication with their clinicians [26]. These relationships can be undercut by raising questions of costs in the cancer clinic, particularly if patients feel that potentially beneficial care is being withheld to save money for the hospital or insurance company.

CONCLUSION

Concerns over costs of cancer care are not novel; they date back at least four decades [27]. What is novel is the degree of attention focused on the conversations and decision-making in the clinic as a major locus of cost control. The important distinction between patient costs and societal costs should be recognized so that discussions in the clinic can focus on informing patients of expected burdens complemented by efforts to ensure access to appropriate care. Serious questions regarding societal costs remain, even if we can minimize financial burdens for patients. Will we regulate drug pricing or let large government payers negotiate to lower prices? Will creative payment reform and incentivizing value and

outcomes help control total costs? Should we move further toward universal coverage and a single-payer system that might lower administrative costs and rely on a constrained budget to force hard choices? Control of societal costs can be addressed through clinician education, value-based guidelines and pathways, formulary restrictions, payment reform, and government regulatory decisions but should not be imposed on patients at the point of decision-making in the cancer clinic.

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