



Access, Affordability, and Sustainability: Barriers to High-Quality Care in a High-Income Country

Toms Vengaloor Thomas¹  Aju Mathew²

¹ Department of Radiation Oncology, University of Mississippi, Mississippi, United States

² Department of Oncology, Malankara Orthodox Syrian Church Medical College Kolenchery, Kochi, Kerala, India

Address for correspondence Aju Mathew, MD, Department of Oncology, Malankara Orthodox Syrian Church Medical College Kolenchery, Kochi, Kerala 682311, India (e-mail: cancerkerala@gmail.com).

Ind J Med Paediatr Oncol 2022;43:285–288.

Introduction

There is a perception among oncologists that the field of global oncology pertains only to matters related to low- and middle-income countries (LMICs). It stems from a perception that considers lack of access to cancer care and unaffordability of therapy as problems that plague the less affluent regions of the world. In this commentary, we aim to shed light on the fact that these issues do not respect the dichotomies of high-income versus low-income countries or the global north versus south.

When physicians from high-income countries were surveyed about the access to cancer medicines deemed essential by the World Health Organization, a large majority of them felt that these medicines, including immunotherapy, were universally accessible (i.e., no substantial out-of-pocket expense for >90% of patients).¹ Unfortunately, the inaccessibility and unaffordability of cancer care are profound even in high-income countries, although we perceive it as otherwise. This inaccurate fact stated by practicing oncologists makes it clear that their current understanding of the accessibility and affordability of cancer care as oncologists is faulty.

Almost 27 million (8.6%) Americans were still uninsured in 2016.² A large proportion of cancer survivors experience financial hardships due to cancer.³ Even if we falsely assume that the out-of-pocket expense for the individual is marginal, the economic burden of cancer care is steadily rising. It is definitely not sustainable for the economy in the long run.

The US Healthcare System: An Eagle's Eye View

In the United States, the government provides two types of health coverage for patients under the supervision of the Center for Medicare and Medicaid Services (CMS). Medicare for patients more than 65 years of age and Medicaid for the disabled. Most private and public sector employers provide health insurance as part of the employee benefits.⁴ A private health insurance coverage can be bought for a monthly fee from the marketplace for the self-employed. Health insurance does not cover all healthcare expenses (referred to as “cost-sharing”). Health insurance would start covering the costs after an initial “deductible” is being met by the patient, which can be ranging from hundred to a few thousand dollars depending on the plan. Then, once the patient goes for a doctor visit, he/she may have to pay a small fee (referred to as co-pay) at the respective offices, usually about 25 to 100 dollars.

Even after the patient meets the deductible, most insurance plans pay only a part of the cost, ranging from 60 to 80%. The patient has to pay the remainder of the price (“co-insurance”). All these costs are covered by the patient account for the “out-of-pocket-maximum,” which is usually in the order of a few thousand dollars. Once the patient meets the “out-of-pocket-maximum,” the subscribed health insurance plan usually covers the remainder of the cost. The “Donut hole” is the gap in insurance coverage when a patient is responsible for the cost of the drugs after an initial period

DOI <https://doi.org/10.1055/s-0042-1748798>.
ISSN 0971-5851.

© 2022. Indian Society of Medical and Paediatric Oncology. All rights reserved.

This is an open access article published by Thieme under the terms of the Creative Commons Attribution-NonDerivative-NonCommercial-License, permitting copying and reproduction so long as the original work is given appropriate credit. Contents may not be used for commercial purposes, or adapted, remixed, transformed or built upon. (<https://creativecommons.org/licenses/by-nc-nd/4.0/>)

Thieme Medical and Scientific Publishers Pvt. Ltd., A-12, 2nd Floor, Sector 2, Noida-201301 UP, India

where the plan pays for the medications. If the patient is “uninsured” or “self-paid,” they have to depend on the safety net hospitals that may provide some financial assistance.

Pharmaceutical benefits managers (PBMs) manage the prescription drug benefits for private insurers and government health plans.⁵ Even though the PBMs were introduced to decrease the cost of prescription medicines, in reality, they work as a middleman, leading to increased cost of drugs, lower value, and increased administrative burden.

The Three-Legged Problem

We can categorize the problems in the American healthcare system into three major parts.

First, it is inaccessible. The inaccessibility of cancer care can be due to multiple reasons—regional, geographic, ethnic, racial, or socioeconomic disparities. For instance, the survival of breast cancer patients is adversely affected by where they live; patients who live in poorer neighborhoods have reported decreased survival rates.⁶ The racial disparities, Black, Hispanic, and Native American patients have more inadequate access to cancer care and consequently reported worse survival rates, have been well established in multiple cancers, including prostate cancer,^{7,8} cervical cancer,⁹ and head and neck cancers.¹⁰ Geographical disparities in cancer care have been well documented in various cancers, including breast cancer, colon cancer, and prostate cancer.^{11,12} For instance, geographical differences and socioeconomic deprivation lead to late-stage diagnosis and worse survival in colon cancer.¹³ Unfortunately, all of these disparities work hand-in-hand to make timely cancer care inaccessible to the most vulnerable population.

Second, it is unaffordable. Financial toxicity in cancer care is defined as the harmful personal financial burden faced by patients receiving cancer care.⁴ Catastrophic health expenditure refers to any medical expense that can threaten the household's financial stability.¹⁴ One in three Americans experiences financial burden as a result of medical care.¹⁵ The risk of a high financial burden is significantly greater in patients with cancer than patients with other chronic medical conditions.¹⁶ Thirteen percent of the nonelderly patients with cancer spend at least 20% of their income, and 50% of the elderly (Medicare beneficiaries) spend at least 10% of their income on cancer treatment-related out-of-pocket expenses.^{16,17} Patients with cancer had a nearly threefold more significant risk of declaring personal bankruptcy. Those bankrupt patients had a 79% higher mortality risk than those who did not.^{15,18} Zafar et al explained the three possible reasons behind the relationship between financial distress and a higher risk of mortality¹⁵: poorer subjective well-being,¹⁹ impaired health-related quality of life,²⁰ and subpar quality of care.²¹

Finally, it is unsustainable. The US healthcare expenditure is almost 3 trillion dollars/year (almost equal to the gross domestic product [GDP] of India in 2021).²² It is nearly identical to 18% of the GDP of the United States. The cost of healthcare is rising year by year. Cancer care costs are

Table 1 Contributing factors for financial toxicity in the United States

1. Overdiagnosis
2. Overtreatment
3. Unnecessary use of diagnostic testing
4. Use of low value practices
5. Injudicious use of expensive treatment modalities
6. Lack of pricing competition and choice
7. High price of innovative therapeutic techniques
8. Use of extended course radiation treatment and indiscriminate use of proton therapy
9. Excess burden of billing and insurance-related administrative cost
10. Lack of awareness of the cost among physicians and the patients
11. Lack of price transparency

estimated to grow by 34 to 246 billion dollars by 2030.²³ It is unsustainable for the country's economy.

Contributing Factors for Financial Toxicity

Multiple factors contribute to financial toxicity in the United States (► **Table 1**). Unnecessary use of diagnostic testing leads to wastage of almost 210 billion dollars per year.²⁴ Overdiagnosis (when a condition is diagnosed that would otherwise not go on to cause symptoms or death during a patient's lifetime) and overtreatment (when medical services are provided with a higher volume or cost than appropriate) are also pervasive problems.^{25,26} It is estimated that up to 30% of the US healthcare cost is wasted money.²⁷ The use of low-value practices, including the injudicious use of expensive treatment modalities that offer a marginal benefit at best, also leads to substantial financial toxicity. A lack of pricing competition and choice also leads to increased cost of healthcare products and technologies.²⁸ The CMS is banned from negotiating drug prices which affects the medication cost for millions of Americans. A study that reviewed the cost of cancer medicines (e.g., rituximab and bevacizumab) found that Americans are paying almost twice the price compared with Norway, likely due to the lack of negotiating power for CMS.²⁸ The high cost of innovative therapeutic techniques is also a contributing factor, especially when used in terminal disease.²⁸ The use of more extended course radiation treatment and indiscriminate use of proton therapy may also contribute to financial toxicity.²⁹ Another cause is the excess burden of billing and insurance-related administrative cost—both by the insurer and the provider. It was estimated by a recent study in 2017 by Woolhandler and Himmelstein that the United States spends 1.1 trillion dollars on administrative costs, which is almost one-third of the healthcare expenditure.³⁰

Lack of awareness of the cost of various therapies contributes tremendously to financial toxicity. Significant numbers

of physicians in the United States believe that cancer care is accessible and affordable to the whole population, but in reality, it is not.¹ Physicians' knowledge about the cost of diagnostic tests, medicines, or healthcare visits is poor.³¹ It was found that when the data on the fees were provided to the physicians, they cut down the use of ordering tests.³² So, it is crucial to educate the physician community about this cost of healthcare. Another pervasive problem pertains to the lack of price transparency. It is challenging for patients to determine how much a medical intervention will cost them. Sadly, even physicians are in the same boat.

Solutions

The Institute of Medicine in the United States has called for attention to the "waste in healthcare" and came up with suggestions to provide "best care at lower cost" in 2013.³³ "Choosing wisely" campaign has been initiated as a part of this effort to curtail the use of low-value practices and thereby to decrease the cost of health care.²⁷ Various organizations of physicians involved in cancer care, like the American Society of Clinical Oncology and the American Society of Radiation Oncology, have come forward with their recommendations to help in this regard.^{27,34} These efforts may have improved the awareness of low-value practices among oncologists; but there is no definitive evidence that these have successfully curtailed the cost.

Having the influence and power for negotiation curtails the cost of drugs to some extent.³⁵ There have been some efforts to control prescription drug pricing, but more efforts are needed at a policy level.³⁶ Recently, there has been an effort to have online pharmacies that can cut the cost for the patients (e.g., the cost-plus drug company). We believe this will result in competitive pricing among the various PBMs. The medical community and policymakers are having more discussions about the lack of price transparency.³⁷ Allowing CMS to have the power for price negotiation will help curtail the cost of drugs. At the level of physicians and patients, education efforts are needed to improve the awareness of the problem and the potential solutions.³²

Take a Leaf Out of the Indian Scene

Cancer care in India is burdened by financial toxicity, much more than in the United States.¹⁴ There are multiple reasons for this, including the lack of insurance, poverty, and lesser spending by the government on healthcare. It is often suggested that the average Indian middle-class family is one medical bill away from poverty. But there are some silver linings in India; there are multiple options for generics and biosimilar drugs, which have helped decrease the cost for the patients.³⁸ For instance, Nair et al reported that the availability of rituximab biosimilars in India tremendously cuts costs, leading to increased access to this life-saving therapy (35% in 2010 to 95% in 2020).³⁸ Greater access to generics and biosimilars can help reduce the price of cancer therapy in the United States, with no detrimental impact on outcomes.

Conclusion

There are critical challenges to delivering cost-sensitive cancer care in high-income countries. Understanding the issues and applying best practices in other parts of the world would help address some pervasive problems. We believe that such bidirectional learning would improve patient care and exemplify the true meaning of global oncology.

Conflict of Interest

None declared.

References

- 1 Fundytus A, Sengar M, Lombe D, et al. Access to cancer medicines deemed essential by oncologists in 82 countries: an international, cross-sectional survey. *Lancet Oncol* 2021;22(10):1367–1377
- 2 American Society of Clinical Oncology. The State of Cancer Care in America, 2017: a report by the American Society of Clinical Oncology. *J Oncol Pract* 2017;13(04):e353–e394
- 3 Gordon LG, Merollini KMD, Lowe A, Chan RJ. A systematic review of financial toxicity among cancer survivors: we can't pay the co-pay. *Patient* 2017;10(03):295–309
- 4 Zafar SY, Peppercorn JM, Schrag D, et al. The financial toxicity of cancer treatment: a pilot study assessing out-of-pocket expenses and the insured cancer patient's experience. *Oncologist* 2013;18(04):381–390
- 5 Royce TJ, Schenkel C, Kirkwood K, Levit L, Levit K, Kircher S. Impact of pharmacy benefit managers on oncology practices and patients. *JCO Oncol Pract* 2020;16(05):276–284
- 6 Beyer KMM, Zhou Y, Laud PW, et al. Mortgage lending bias and breast cancer survival among older women in the United States. *J Clin Oncol* 2021;39(25):2749–2757
- 7 Mahal BA, Chen YW, Muralidhar V, et al. Racial disparities in prostate cancer outcome among prostate-specific antigen screening eligible populations in the United States. *Ann Oncol* 2017;28(05):1098–1104
- 8 Underwood W, De Monner S, Ubel P, Fagerlin A, Sanda MG, Wei JT. Racial/ethnic disparities in the treatment of localized/regional prostate cancer. *J Urol* 2004;171(04):1504–1507
- 9 Yoo W, Kim S, Huh WK, et al. Recent trends in racial and regional disparities in cervical cancer incidence and mortality in United States. *PLoS One* 2017;12(02):e0172548. Doi: 10.1371/journal.pone.0172548
- 10 Albert A, Giri S, Kanakamedala M, et al. Racial disparities in tumor features and outcomes of patients with squamous cell carcinoma of the tonsil. *Laryngoscope* 2019;129(03):643–654
- 11 Goodwin JS, Freeman JL, Mahnken JD, Freeman DH, Nattinger AB. Geographic variations in breast cancer survival among older women: implications for quality of breast cancer care. *J Gerontol A Biol Sci Med Sci* 2002;57(06):M401–M406
- 12 Jemal A, Ward E, Wu X, Martin HJ, McLaughlin CC, Thun MJ. Geographic patterns of prostate cancer mortality and variations in access to medical care in the United States. *Cancer Epidemiol Biomarkers Prev* 2005;14(03):590–595
- 13 Lin Y, Wimberly MC. Geographic variations of colorectal and breast cancer late-stage diagnosis and the effects of neighborhood-level factors. *J Rural Health* 2017;33(02):146–157
- 14 Boby JM, Rajappa S, Mathew A. Financial toxicity in cancer care in India: a systematic review. *Lancet Oncol* 2021;22(12):e541–e549
- 15 Zafar SY. Financial toxicity of cancer care: it's time to intervene. *J Natl Cancer Inst* 2015;108(05):djv370. Doi: 10.1093/jnci/djv370
- 16 Bernard DS, Farr SL, Fang Z. National estimates of out-of-pocket health care expenditure burdens among nonelderly adults with cancer: 2001 to 2008. *J Clin Oncol* 2011;29(20):2821–2826

- 17 Davidoff AJ, Erten M, Shaffer T, et al. Out-of-pocket health care expenditure burden for Medicare beneficiaries with cancer. *Cancer* 2013;119(06):1257–1265
- 18 Ramsey S, Blough D, Kirchoff A, et al. Washington State cancer patients found to be at greater risk for bankruptcy than people without a cancer diagnosis. *Health Aff (Millwood)* 2013;32(06):1143–1152
- 19 Hanratty B, Holland P, Jacoby A, Whitehead M. Financial stress and strain associated with terminal cancer—a review of the evidence. *Palliat Med* 2007;21(07):595–607
- 20 Fenn KM, Evans SB, McCorkle R, et al. Impact of financial burden of cancer on survivors' quality of life. *J Oncol Pract* 2014;10(05):332–338
- 21 Dusetzina SB, Winn AN, Abel GA, Huskamp HA, Keating NL. Cost sharing and adherence to tyrosine kinase inhibitors for patients with chronic myeloid leukemia. *J Clin Oncol* 2014;32(04):306–311
- 22 Patel MS, Reed DA, Loertscher L, McDonald FS, Arora VM. Teaching residents to provide cost-conscious care: a national survey of residency program directors. *JAMA Intern Med* 2014;174(03):470–472
- 23 Mariotto AB, Enewold L, Zhao J, Zeruto CA, Yabroff KR. Medical care costs associated with cancer survivorship in the United States. *Cancer Epidemiol Biomarkers Prev* 2020;29(07):1304–1312
- 24 Clarke JL, Laskowski RJ, Coons C, et al. Proceedings of the Christiana Care Health System Value Institute Value Symposium. *Am J Med Qual* 2012;27(6, Suppl):3S–20S
- 25 Welch HG, Black WC. Overdiagnosis in cancer. *J Natl Cancer Inst* 2010;102(09):605–613
- 26 Lyu H, Xu T, Brotman D, et al. Overtreatment in the United States. *PLoS One* 2017;12(09):e0181970. Doi: 10.1371/journal.pone.0181970
- 27 Schnipper LE, Smith TJ, Raghavan D, et al. American Society of Clinical Oncology identifies five key opportunities to improve care and reduce costs: the top five list for oncology. *J Clin Oncol* 2012;30(14):1715–1724
- 28 Prasad V, De Jesús K, Mailankody S. The high price of anticancer drugs: origins, implications, barriers, solutions. *Nat Rev Clin Oncol* 2017;14(06):381–390
- 29 Santos PMG, Mathis NJ, Lapen K, et al. Assessment of Guideline-Nonconcordant Radiotherapy in Medicare Beneficiaries With Metastatic Cancer Near the End of Life, 2015– 2017. *JAMA Health Forum* 2022:e214468–e214468
- 30 Woolhandler S, Himmelstein DU. Single-payer reform: the only way to fulfill the president's pledge of more coverage, better benefits, and lower costs. *Ann Intern Med* 2017;166(08):587–588
- 31 Allan GM, Lexchin J. Physician awareness of diagnostic and nondrug therapeutic costs: a systematic review. *Int J Technol Assess Health Care* 2008;24(02):158–165
- 32 Feldman LS, Shihab HM, Thiemann D, et al. Impact of providing fee data on laboratory test ordering: a controlled clinical trial. *JAMA Intern Med* 2013;173(10):903–908
- 33 Institute of Medicine. 2013. *Best Care at Lower Cost: The Path to Continuously Learning Health Care in America*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/13444>.
- 34 Hahn C, Kavanagh B, Bhatnagar A, et al. Choosing wisely: the American Society for Radiation Oncology's top 5 list. *Pract Radiat Oncol* 2014;4(06):349–355
- 35 Carrera PM, Kantarjian HM, Blinder VS. The financial burden and distress of patients with cancer: Understanding and stepping-up action on the financial toxicity of cancer treatment. *CA Cancer J Clin* 2018;68(02):153–165
- 36 Sachs R. Administration finalizes most-favored nation drug pricing rule at the last minute. *Health Aff Blog* 2020
- 37 Butcher L. Price transparency. *Hosp Health Netw*. Jun 2014;88(6):32–7, 1.
- 38 Nair R, Radhakrishnan VS, Mallath MK. Rituximab biosimilars for B-cell lymphomas: a decade of real-world experience from India. *Lancet Haematol* 2021;8(08):e548–e549