

Cancer care and economic burden—A narrative review

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ABSTRACT

Cancer care poses a significant economic burden in India, where noncommunicable diseases contribute to a large number of deaths and disability-adjusted life-years. Despite economic growth, equitable wealth distribution remains a challenge, leading to inequalities in healthcare access. India's healthcare system is primarily privatized, financed through out-of-pocket expenditure (OOPE), and lacks coverage for a majority of the population. As a result, individuals without financial means face catastrophic health consequences when seeking necessary healthcare. OOPE in India's healthcare system is a major concern, with medicines accounting for a significant portion of expenses, followed by diagnostic tests and consultation fees. Nonmedical expenses also contribute to the financial burden. Cancer care specifically faces substantial financial challenges, with high treatment costs, reduced workforce participation, and the need for distress financing. Cancer-related OOPE is predominantly borne by patients and their families, leading to significant financial strain. The lack of comprehensive health insurance coverage and limited access to publicly funded healthcare services exacerbate the problem. Catastrophic health expenditure (CHE) in cancer care is prevalent, pushing households into financial distress and potentially impoverishment. Efforts have been made to address this issue, such as increasing public spending on healthcare and implementing health insurance schemes. However, challenges remain in ensuring their effectiveness and reach. The role of family care physicians is crucial in supporting patients and their families during catastrophic health expenditures related to cancer-related palliative care. They coordinate care, provide advocacy, emotional support, symptom management, and facilitate end-of-life discussions. Comprehensive measures are needed to strengthen healthcare infrastructure, improve access to affordable cancer care, enhance health insurance coverage, and implement supportive measures for cancer patients. Additionally, promoting preventive measures and early detection can help reduce the need for expensive treatments and decrease the risk of catastrophic health expenditures.

Keywords: Cancer care, CHE, India, OOPE

Introduction

In 2017, India witnessed a staggering number of 9.7 million deaths and 486 million disability-adjusted life-years (DALYs), with noncommunicable diseases accounting for 46.6% of national DALYs.^[1] This escalating burden emphasizes the urgent need for effective economic and resource management to address the growing healthcare crisis. Despite significant economic

growth in the country, achieving equitable wealth distribution remains a persistent challenge.^[2] The advent of advanced diagnostics and modern technologies in disease treatment has contributed to the rising expectations for quality care and prolonged patient survival.^[3] However, this progress has come at a steep cost, leading to a significant increase in healthcare expenditure. As a result, there is an inherent inequality in the distribution of healthcare services. India's healthcare system is largely privatized, functioning in a corporate fashion, and primarily financed through out-of-pocket expenditure (OOPE).^[4] Unfortunately, more than 90% of the working population in India belongs to underprivileged sections of society and lacks a stable, formal source of income. Consequently, many individuals

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are not covered under any public health scheme.^[5] When faced with health-related challenges, individuals who lack the financial means to access necessary healthcare facilities often experience catastrophic health consequences.^[6] According to the National Sample Survey Organisation (NSSO) 75th Round Annual Report, the average medical expenditure per hospitalization varies across different types of hospitals. Government hospitals record an approximate average expenditure of 61,216 rupees, whereas private hospitals account for a higher expenditure of 93,305 rupees.^[7] This disparity highlights the gaps in healthcare delivery, management, guidance, and the actual implementation of economic considerations, particularly for those who are not covered under any healthcare scheme. Addressing these issues requires comprehensive reforms that ensure affordable and accessible healthcare for all segments of society. Efforts should focus on improving wealth distribution, strengthening public health schemes, and enhancing the overall delivery and management of healthcare services. Only through inclusive and equitable measures can India effectively tackle the economic challenges associated with healthcare delivery and ensure better health outcomes for its population.

What is the Indian scenario in terms of OOPE?

An economic survey conducted in 2020 predicted that increasing public spending on health to 3% of the gross domestic product (GDP) could eventually lead to a 30% decrease in out-of-pocket expenses (OOPE).^[8] However, the current government expenditure on healthcare in India stands at approximately 1% of GDP,^[9] leaving a substantial burden on individuals and their families. Recent reports indicate that OOPE in India's healthcare system remains a major concern. Medicines alone account for a significant portion, ranging from 40 to 50% of total OOPE, placing a considerable financial strain on patients.^[10-17] Additionally, around 10% of OOPE is attributed to diagnostic tests, and approximately 13% is allocated to consultation fees. Moreover, nonmedical expenses, including accommodation and travel, have witnessed a sharp increase, rising from 7 to 17% over the past two decades.^[16,18] These additional costs further contribute to the overall financial burden faced by individuals seeking healthcare services. While subsidized care and insurance coverages are available, they often fall short of fully alleviating the burden of out-of-pocket expenses.^[19,20] The National Health Policy, in alignment with the Sustainable Development Goals, aims to address this issue and reduce the financial burden on patients.^[21] However, more comprehensive measures and increased public spending on health are crucial to ensure affordable access to healthcare and mitigate the impact of out-of-pocket expenditures on individuals and their households.^[22-26]

Cancer and OOPE in India

The allocation of financial resources for cancer-specific spending in India has shown a substantial increase over the years. In the 6th plan (1980–1985), the expenditure was INR 115 million, which rose to INR 28,719 million and INR 60,000 million in the 11th and 12th five-year plans, respectively.^[27,28] The

Government of India has also pooled a significant amount of money toward cancer care through publicly sponsored health insurance schemes.^[29] Additionally, certain states with high cancer prevalence have dedicated subsidies for cancer diagnosis and treatment.^[30] However, there is a lack of published comparative studies assessing the long-term cost-effectiveness of these schemes for cancer patients. Even in the public sector, the cost of cancer treatment can be prohibitively high. While government schemes and insurance policies may cover some of these expenses, the discussion around out-of-pocket expenses (OOPE) for indirect costs is often overlooked. In the pursuit of providing the best possible therapy, clinicians may prescribe high-end treatments without explicitly considering the cost-benefit ratio. Caregivers, driven by their concern for the patient, often request the best treatment without realizing the potential for “Catastrophic Health Expenses” (CHE) and “Distress Financing” (DF).^[31] A study by Wani *et al.* (2013)^[32] highlighted that the major cost components of in-patient cancer chemotherapy are drug and material costs (46.88%) and labor costs (48.45%). The average unit cost per patient per bed day for in-patient chemotherapy was found to be Rs. 5725.12 (\$125.96), which includes expenditures incurred by both the hospital and the patient (out of pocket). In their study conducted in Kashmir, they observed that patients bore 40.48% of the drug costs out of their own pockets, while the hospital covered approximately 5.91% of the expenses. In contrast to developed countries where over 70% of pharmaceuticals are publicly funded, patients in developing economies bear the burden of paying for 50–90% of drug costs. This places a significant financial strain on poor patients in most developing countries.^[32] Mahal *et al.* (2013)^[33] conducted a study on the burden of cancer on households' out-of-pocket health spending in India in 2004. They found that cancer-affected households experienced higher outpatient visits, hospital admissions, and increased out-of-pocket health expenditures per member compared to control households. Cancer-affected households spent between INR 66 and INR 85 more per member on healthcare over a 15-day reference period, and the additional expenditures on in-patient care annually equated to 36% to 44% of the annual household expenditures of matched controls. Members without cancer in cancer-affected households used less healthcare and spent less on healthcare. The study also revealed lower adult workforce participation rates among cancer-affected households compared to control households. Furthermore, cancer-affected households had significantly higher rates of borrowing and asset sales to finance outpatient and in-patient care. A more recent study in 2021 focused on metastatic breast cancer patients indicated that the average monthly expenditure for cancer patients increased by 32% during the COVID-19 pandemic, while mean monthly household income decreased by a quarter. More than two-thirds of the patients had no income during the lockdown, and more than half of the patients resorted to borrowing money to meet their expenses. Distress financing was notably higher among patients receiving treatment in Mumbai compared to those in their native cities.^[34] Another study conducted in South India in 2021 reported that the average out-of-pocket expenditure

incurred by a cancer patient was INR 35,817 (USD 523.6) for males and INR 20,496 (USD 299.6) for females, with males having significantly higher out-of-pocket expenses than females. Overall, these findings highlight the substantial financial burden faced by cancer patients in India, despite the availability of government schemes and insurance policies. Out-of-pocket expenses, high treatment costs, reduced workforce participation, and the need for distress financing contribute to the financial strain experienced by individuals and their families.

Catastrophic health expenditure (CHE)

Cancer can indeed lead to a significant loss of income for affected individuals and their families due to various factors.^[35] The challenges faced by cancer patients in maintaining employment and the subsequent financial strain can be substantial.

1. **Treatment and Recovery Time:** Cancer treatments, such as chemotherapy, radiation therapy, or surgery, often require a significant amount of time and may result in extended periods away from work. This absence can result in reduced or no income during the treatment and recovery phases.
2. **Reduced Work Capacity:** Cancer and its treatments can lead to physical and emotional challenges, including fatigue, pain, cognitive difficulties, and emotional distress. These factors can impact an individual's ability to perform their job effectively and may necessitate reduced work hours or even a leave of absence.
3. **Medical Expenses:** Cancer treatments can be expensive, involving costs for hospital stays, surgeries, medications, laboratory tests, imaging scans, and doctor visits. Even with health insurance, individuals may face out-of-pocket expenses, deductibles, co-pays, and co-insurance, which can quickly accumulate and strain household finances.
4. **Limited Insurance Coverage:** While health insurance is crucial, coverage limitations and exclusions can significantly impact financial stability. Some treatments, experimental therapies, or supportive care options may not be covered, placing an additional financial burden on patients and their families.
5. **Loss of Job and Insurance:** In some cases, cancer may lead to job loss if individuals are unable to continue working or if they are terminated due to extended absences. This loss of employment may also result in the loss of employer-sponsored health insurance, creating further financial difficulties.
6. **Additional Expenses:** Cancer can bring about additional expenses beyond medical costs. These may include transportation to treatment centers, home care services, modifications to living spaces, and the need for specialized equipment or supplies. These costs can quickly add up, exacerbating the financial strain.
7. **Emotional and Psychological Impact:** Dealing with cancer and its treatment can take an emotional toll on individuals and their families. The stress and anxiety associated with the diagnosis and treatment process can affect mental well-being, making it challenging to focus on work and maintain productivity.

The combination of these factors can lead to a significant decrease in household income for cancer patients and their families. This loss of income, coupled with the increased financial burdens, can create a considerable strain on their overall financial stability, making it difficult to cover basic living expenses, such as housing, utilities, transportation, and daily necessities.

It is important for cancer patients and their families to seek support and explore available resources. These may include financial assistance programs, social services, nonprofit organizations, and employer benefits such as disability insurance or workplace accommodations. These resources can help alleviate some of the financial challenges and provide support during the cancer journey.

Catastrophic health expenditure (CHE) in cancer care poses a significant challenge in India, placing a heavy financial burden on individuals and families. The high costs associated with cancer diagnosis, treatment, and supportive care contribute to this issue, pushing many households into financial distress. A substantial portion of cancer-related expenses in India are borne out-of-pocket by patients and their families. The lack of comprehensive health insurance coverage and limited access to publicly funded healthcare services further exacerbate the problem. As a result, individuals face the risk of incurring CHE, which is defined as healthcare expenses that exceed a certain threshold of their income or household budget. The consequences of CHE are far-reaching and can have a profound impact on individuals and their families. The financial strain caused by excessive healthcare expenditures can lead to impoverishment, loss of assets, and even catastrophic consequences such as selling property or taking loans with high-interest rates. Moreover, the psychological and emotional stress of managing the financial burden alongside the physical and emotional challenges of cancer treatment can further deteriorate the overall well-being of patients and their families. Efforts have been made by the Indian government to address this issue. The increase in public spending on healthcare and the implementation of publicly sponsored health insurance schemes aim to alleviate the financial burden on cancer patients. However, challenges remain in ensuring the effectiveness and reach of these initiatives, particularly for vulnerable populations and those residing in remote areas. The study conducted by Singh *et al.*^[36] (2020) revealed alarming statistics regarding the financial burden faced by cancer patients, particularly those undergoing cervical cancer treatment. The prevalence of catastrophic health expenditure (CHE) was found to be 61.6% when considering the 40% threshold for the capacity to pay (CTP). Surprisingly, patients who utilized insurance schemes actually had a higher prevalence of CHE compared to those who did not use insurance schemes (65.5% vs. 60.7%), although the difference was not statistically significant (*P* value 0.351).^[35] Singh *et al.*^[36] also assessed the health system costs associated with different treatment modalities for cervical cancer, such as radiotherapy, brachytherapy, chemotherapy, and surgery. The cost ranged from INR 19,494 to 41,388 (USD 291–617) for these treatments.

Additionally, patients incurred out-of-pocket expenses (OOPE) ranging from INR 4,042 to 23,453 (USD 60–350). Distressingly, nearly 62% of patients experienced catastrophic health expenditure, and 30% resorted to distress financing to cover the costs.^[35] The study further highlighted that the poorest-income quintile faced significantly higher odds of CHE (OR: 25.39, *P*value: <0.001) and distress financing (OR: 15.37, *P*value: 0.001). This indicates that individuals with lower income levels are disproportionately burdened by the financial implications of cancer treatment. The cost of brachytherapy and radiotherapy under the Health Benefit Package (HBP) varied from INR 45,364 to 64,422 (USD 676–960). These findings underscore the substantial financial strain experienced by cancer patients. The high prevalence of catastrophic health expenditure, coupled with distress financing, highlights the urgent need for measures to alleviate the financial burden and ensure access to affordable cancer care for all individuals, regardless of their income level. To address catastrophic health expenditure in cancer care, a comprehensive approach is necessary. This includes strengthening the healthcare system infrastructure, improving access to quality and affordable cancer treatments, enhancing health insurance coverage, and implementing supportive measures such as financial assistance programs for cancer patients. Additionally, promoting preventive measures, early detection, and screening programs can help reduce the need for expensive treatments and ultimately decrease the risk of catastrophic health expenditures.

Role of family care physicians in case of catastrophic health expenditure for cancer-related palliative care

Family care physicians play a crucial role in supporting patients and their families during catastrophic health expenditures related to cancer-related palliative care.^[37] While the primary responsibility for cancer treatment and palliative care often falls on oncologists and specialized palliative care teams, family care physicians can provide invaluable assistance in various ways:

1. **Coordination and Communication:** Family care physicians act as the central point of contact between the patient, their family, and the multidisciplinary healthcare team. They ensure effective communication among all parties involved, facilitating the exchange of information, treatment plans, and goals of care.
2. **Patient Advocacy:** Family care physicians advocate for their patients by helping them navigate the complex healthcare system, ensuring that they receive appropriate and timely care. They can assist in obtaining necessary referrals, coordinating appointments, and advocating for insurance coverage or financial assistance.
3. **Emotional Support:** Dealing with catastrophic health expenditures and palliative care for cancer can be emotionally challenging for patients and their families. Family care physicians provide emotional support, empathetic listening, and counseling to help patients cope with the psychological and emotional impact of their situation.
4. **Symptom Management:** Palliative care focuses on alleviating symptoms, improving quality of life, and providing comfort to patients. Family care physicians, in collaboration with the palliative care team, can assist in managing pain, controlling symptoms, and addressing the side effects of treatments to enhance the patient's well-being.
5. **Care Planning and Decision Making:** Family care physicians play a crucial role in facilitating discussions about treatment options, advance care planning, and end-of-life decisions. They help patients and their families understand the available choices, potential benefits, and risks, allowing them to make informed decisions aligned with their values and goals.
6. **Long-Term Follow-up:** Family care physicians continue to provide ongoing care and support beyond the immediate palliative care phase. They ensure regular follow-up visits, monitor the patient's health, manage chronic conditions, and provide continuity of care throughout the cancer journey.
7. **Referrals and Resource Identification:** Family care physicians have extensive knowledge of local healthcare resources, support services, and community organizations. They can connect patients and families with appropriate resources for financial assistance, psychological support, home healthcare, and other services that can help alleviate the financial burden associated with catastrophic health expenditures.

By actively participating in collaborative care for palliative therapy in cancer, family care physicians ensure that patients receive comprehensive, patient-centered, and multidimensional support throughout their palliative journey. Their involvement strengthens the coordination of care, enhances communication among the healthcare team, and ultimately improves the patient's quality of life.

The Indian Association of Palliative Care (IAPC) and the Association of Family Physicians of India (AFPI) jointly proposed an integrated community palliative care model. They published a position paper in 2018, stressing the significance of incorporating primary palliative care into the regular clinical practice of PCPs/FPs.^[38] Additionally, in 2019, they released another paper discussing the necessary competency framework for PCPs/FPs to deliver primary palliative care in the community.^[39] While the integrated model can vary in its nature and implementation, a systematic review examining this model identified five essential elements for its success. These elements include effective interpersonal communication, enhancing knowledge and skills, clearly defined roles and responsibilities, establishing a smooth referral and back-referral process between specialists and PCPs/FPs, and ensuring continuous and coordinated support.^[40] Collaborative care between specialists and PCPs/FPs has shown positive outcomes in terms of symptom control, improved quality of life, and a higher likelihood of patients expressing a preference to spend their final hours at home.^[41]

Conclusion

In conclusion, cancer care in India presents significant challenges, particularly in terms of out-of-pocket expenditure (OOPE). The burden of cancer and the increasing costs associated with its treatment underscore the need for comprehensive measures to address the financial strain faced by patients and their families. The privatized nature of healthcare in India, coupled with the lack of comprehensive coverage under public health schemes, leaves a substantial portion of the population vulnerable to high healthcare expenses. The reliance on OOPE as the primary source of funding for cancer care further exacerbates the financial burden. Studies have highlighted the substantial proportion of household income spent on cancer treatment, including expenses for medications, diagnostic tests, consultations, and nonmedical costs such as travel and accommodation. These expenses can push individuals and families into catastrophic health expenditure, leading to distress financing and adverse economic consequences. Efforts are being made by the government to increase public spending on healthcare and expand insurance coverage. However, more needs to be done to ensure equitable access to affordable cancer care and reduce the financial strain on patients. Policy interventions should aim to enhance the effectiveness and efficiency of healthcare delivery, promote transparency in pricing and billing, and explore innovative financing mechanisms to alleviate the burden of OOPE. Furthermore, public awareness campaigns and education on the importance of early detection and prevention can help reduce the incidence of cancer and minimize the need for costly treatments. Strengthening support systems and providing financial assistance to cancer patients, particularly those from low-income backgrounds, is crucial to ensure that no individual is denied essential care due to their financial status. Addressing the issue of out-of-pocket expenditure in cancer care requires a multi-faceted approach that combines policy reforms, improved healthcare infrastructure, and enhanced social support systems. By alleviating the financial burden on individuals and families, India can strive toward a more equitable and accessible cancer care system that prioritizes the well-being and financial security of its citizens.

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Conflicts of interest

There are no conflicts of interest.

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