Economic Burden of Cancer Treatment in Kerala: Experiences of Patients Under Public Health Care Funding with Special Reference to Regional Cancer Centre Thiruvananthapuram

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Abstract

The central and state governments have instituted several schemes and subsidies to assist underprivileged patients, particularly those undergoing cancer treatments. The efficacy of these initiatives in fulfilling their intended objectives holds equal importance to their establishment. Hence, to alleviate patients' economic burdens, it is crucial to determine how to manage factors such as awareness, experience, and outcomes of implementing the schemes. Main objective of the study is to understand the extent of awareness among cancer patients about governmental schemes and subsidies. Second, identifying the treatment-related expenditures incurred by cancer patients at regional cancer centres. Third, assessing the economic strain that impacts patients' families. A sample of 250 patients from the Regional Cancer Centre in Thiruvananthapuram was carefully selected for this study. The study's findings revealed that a majority of patients and their families become acquainted with public schemes and financial aids primarily through social media and hospital inquiries. At the same time, many patients received financial assistance from different schemes, but most of them had to spend more than 100000 rupees on medications to prevent recurrence. However, shortcomings were identified in the reimbursement system at the RCC, where the processing of fund transactions spanned from 15 days to two months. As a result, patients expressed discontent with the efficiency of the public funding mechanism.

Keywords

Cancer treatment, RCC, Public funding

1. Introduction

Among the general population of Kerala, 1.1% of people have cancer annually. The number of cancer cases in Kerala in 2014 reached 31,400, leading to a mortality toll 13,816 (ICMR, 2018).

Despite notable advancements in cancer treatment, these advancements have been accompanied by escalating expenses. Among the costs associated with cancer treatment are the time and effort invested by patients and

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their families, diminished productivity due to cancer-linked disabilities, and untimely deaths. Treatment costs for cancer are substantial, resulting in a significant financial burden. Many factors influence this decision, including the income of the family, the socioeconomic status of the family, the health insurance coverage, and the stage of the disease. Additionally, treatment-associated expenses include consultation fees, accommodations, diagnostic tests, medications, and procedural costs. Aside from medical expenses, non-medical expenditures include expenses for sustenance, income loss, and transportation to treatment centres. Necessities like childcare, domestic assistance, medical apparatus, specialized diets, and nutritional supplements also compound the burden. Cancer care may become even more expensive in the future due to the adoption of advanced, costly treatment modalities. This assumes significance in light of national health policies striving to realize accessible and reasonably priced healthcare services. Many families suffer from financial constraints, and the cost of treatment negatively affects their financial security. As such, India's central and state governments have introduced several initiatives and financial aids to support individuals from underprivileged backgrounds, particularly in the context of cancer treatment. The effectiveness of these schemes in delivering their purpose is equally vital to their implementation. To effectively address patients' economic burden, it is crucial to understand and manage various factors such as awareness, experience, and the outcomes of implementing government schemes. This research aims to investigate the level of comprehension among cancer patients and their first-hand encounters with government schemes and subsidies. By examining these aspects, we can gain valuable insights into the effectiveness and impact of these initiatives on alleviating the financial struggles of cancer patients in Kerala. This research delves into the extent of comprehension among cancer patients and their encounters concerning governmental initiatives and financial aid.

The study also centres on the duration of these initiatives' assistance to impoverished and disadvantaged cancer patients in Kerala and the extent to which they alleviate their economic burdens. This research study primarily examined the financial implications of cancer treatment in Kerala. The study aims to shed light on the economic burden faced by individuals undergoing cancer treatment and assess how government funding alleviates this financial burden. Thus, the primary objectives of the study are to 1. To study the awareness of cancer patients regarding government schemes and subsidies 2. To understand the treatment-related expenditure incurred by cancer patients undergoing treatment at regional cancer centres 3. To assess the financial burden which influences the family life of patients.

2. Review of literature

Numerous scholars in the realm of public finance have made efforts to determine the efficacy of public funding for healthcare treatments. The allocation of funds from various initiatives and policies implemented by the state and central government proves highly advantageous for patients undergoing treatment, particularly those battling multiple stages of cancer. This is primarily attributed to the financial burden of each treatment, which is significantly alleviated through public funding. Some significant studies on the effectiveness of public funding for medicines in the healthcare sector in the Indian context are discussed below.

In a study conducted by Purohit in 2001, an investigation was carried out to examine the impact of private initiatives and policy decisions on the healthcare sector in India. The study's findings demonstrated that the existing policy strategies introduced after the liberalization period require improvement to safeguard consumers from being taken advantage of and to provide increased coverage for the rising costs of healthcare services for the general public. Similarly, in a study conducted by Rao et al. (2002) in India, an in-depth investigation was

carried out to examine the control measures implemented at both the state and central levels. The study's main aim was to improve the existing cancer treatment facilities and assess the effectiveness of palliative care for patients with advanced-stage cancer. Using narrative analysis, a total of 178 cancer-controlling units were analyzed. The study's outcomes suggested that enhancing the execution of current strategies and policies could yield greater effectiveness.

A descriptive study on healthcare financing in India was conducted by Acharya and Ranson (2005). The research sought to investigate the viability of community-based health insurance as a potential method for funding healthcare expenses. The study identified elements of financial viability, underscoring the significance of international donor organizations, government insurance entities at both central and state levels, and non-governmental organizations in exploring the promising potential of the Central Bureau of Health Intelligence (CBHI) as an alternative avenue.

Subramanian et al. (2009) employed an activity-based methodology in their research, focusing on cost as the primary factor, demographic aspects, program activity expenses, research expenditures, diagnostic outlays, and treatment costs in the Indian context. The study aimed to assess the effectiveness of visual inspection-based oral cancer screening, utilizing an activity-based cost analysis framework. The study's findings indicate that the most economically efficient strategy for oral cancer screening through visual inspection involves targeting high-risk populations. This targeted approach ensures that screening can be provided at a reasonable expense within the constraints of limited resources. The research places a significant emphasis on the cost aspect of cancer patients while acknowledging the role of public funding in providing financial support to patients.

Karikkan and Gangadharan (2010) performed a detailed examination at the micro level of the Karunya benevolent fund scheme

initiative, demonstrating its efficacy in catering to the requirements of individuals below the poverty line and other susceptible segments of the population.

Kulkarni and Divati (2013) conducted an additional descriptive investigation utilizing a bottom-up approach, focusing on the expenditures associated with intensive care for cancer patients in India. The study employed a cost analysis technique to assess the total daily expenses, encompassing the charges for hospital wards, operating rooms, and the overall cost per survivor. The primary objective was to ascertain the financial outlay for intensive care within Indian cancer hospitals. The study's outcomes reveal two key findings: Firstly, the costs associated with intensive care units (ICUs) pose a significantly heavier financial burden on patients due to the comparatively lower Indian GDP and per capita income. Secondly, the study underscores the necessity for an enhanced selection process for admitting chemo-oncology patients into the ICU, aiming to optimize the utilization of scarce resources. The central focus of this research was to comprehensively explore the financial implications and expenditures linked with intensive care services for individuals undergoing cancer treatment.

In their study, Nair et al. (2013) examined how cancer patients were being treated and the costs they incurred while receiving treatment at a government tertiary hospital in India. This research involved a cross-sectional analysis involving a substantial sample size of 508 cancer patients. The findings from this study illuminated the program's shortcomings in effectively screening and detecting cancer at an early stage. Consequently, this failure resulted in delayed diagnoses, increasing patient expenses.

MacLeod et al. (2016) conducted an empirical investigation concerning the expenses associated with cancer drugs in India, with a particular emphasis on public funding and the age of the patients. The study also concentrated on the financial backing originating from the public sector. The primary objective was to

discern and contrast the preferences for funding between cancer patients and the general population, as opposed to the criteria adopted by decision-makers who allocate funds for cancer drug procurement. The study's findings are twofold: Advocating for equitable access to cancer medications, regardless of their cost or efficacy. Secondly, citizens prioritize certain factors that funding decision-makers might overlook, resulting in their exclusion from public funding. The study also offered insights into the utilization of public funds for drug procurement and the accompanying expense burdens on the patients.

In his research, Joe (2014) conducted a case study to investigate the prevalence and associated factors of healthcare financing difficulties in India. The study's conclusion highlighted the necessity for implementing social protection policies and enhancing healthcare coverage as crucial measures to mitigate the occurrence of financial distress in the context of healthcare financing in India.

Chackrabathy et al. (2017) undertook extensive research examining the economic impact of cancer in India, grounded in the analysis of costs and expenditures. The study encompassed the entire population of cancer patients in the country. The research investigated the financial obligations faced by individuals affected by cancer and their families, containing direct and indirect expenses. The study indicated that cancer patients and their families are financially burdened. This burden is particularly pronounced among those in advanced stages of the disease, those in rural areas, and those with limited socioeconomic status. The study's primary focus was to elucidate how cancer places strain on the Indian economy, and it effectively delineates the processes of cost and expenditure involved in this phenomenon.

Ramireddy et al. (2017) conducted a retrospective investigation focusing on treating oral cancer within tertiary care facilities in India. The study incorporated cost as a variable, encompassing both indirect and direct expenses and medical costs. The study's primary objective was to ascertain the approximate fees associated with oral cancer treatment by considering various cost factors. The study's findings underscored several crucial recommendations: 1) The establishment of a centralized oral cancer registry for India, 2) The expansion of tertiary care centres, 3) The initiation of funding initiatives and organizations to support cancer treatments across India, and 4) The establishment of awareness clinics, cancer screening programs, and prevention camps. The study concentrated predominantly on oral cancer diseases, centred around the service performance of hospitals and the provision of care to oral cancer patients. Existing literature presented a scarcity of research exploring the awareness levels of cancer patients regarding government initiatives and their influence on alleviating financial and economic burdens. The present study aims to bridge this gap by investigating the awareness of cancer patients in Kerala concerning specific schemes and subsidies and how these measures impact their financial burdens and family life.

Existing research has indicated a lack of comprehensive studies that evaluate the extent of cancer patients' awareness about government initiatives and how such awareness contributes to alleviating their financial and economic challenges. This study intends to fill this void in the academic discourse by investigating the awareness levels among cancer patients in Kerala pertaining to specialized schemes and subsidies. Furthermore, the study aims to examine how this awareness influences the economic burdens faced by patients and the subsequent impact on their family dynamics.

3. Research Methodology

The research was carried out among individuals diagnosed with cancer who were undergoing treatment at the Regional Cancer Centre situated in Thiruvananthapuram, Kerala. This facility provides various treatment options for seven specific types of cancer, specifically throat cancer, breast cancer, lung cancer, renal cancer, prostate cancer, blood cancer, and

paediatric cancer treatments. In order to prioritize patient safety and reduce the risk of infection, the collection of data specifically pertaining to blood cancer and paediatric cases was omitted. The data collection procedure was carried out with great care, following a systematic approach. Initially, the researcher identified the cancer treatment departments. Next, each department was classified according to its characteristics. A total of 50 samples were then selected from each department in a methodical manner. The researcher employed a convenience sampling technique to select the samples for this study. With the help of bystanders accompanying each cancer patient, a total of 250 survey schedules were completed and collected. This systematic method ensured thorough and pertinent data collection from the participants of the study.

4. Analysis, Results and Discussion

Descriptive Statistics was performed by using SPSS 25. The study's primary objective was "To study the awareness of the cancer patients regarding government schemes and subsidies". To understand the awareness of schemes among patients from various dimensions were explored. The first statement of the schedule was aimed at studying the awareness of different schemes among patients and was collected by YES/NO questions. The response pattern for this item is as interpreted below.

Table 1. *Awareness about the public schemes for cancer treatment*

Response	Frequency	Percentage
Yes	246	98.4
No	4	1.6
Total	250	100

Source: Primary data

In this study, the table1 shows that 98.4 per cent of patients are aware of the schemes for cancer treatment, and only 1.6 per cent of them are unaware of the public schemes for treatment. The second part of the same objective was to analyse the source of awareness about government schemes using three media options: media, neighbours and

relatives. Here the schedule aimed to study the sources from which the information about the schemes was availed to the patients. The response pattern was also interpreted below.

Table 2. *Source of awareness about government schemes*

Labels	Frequency	Percentage
Media	122	49
Neighbours	44	17.5
Relatives	29	11.6
Hospital	55	21.9
Total	250	100

Source: Primary data

Table 2 shows that 49 per cent of patients were aware of the schemes through media. 21.9 per cent of patients get awareness through hospitals. Only 17.5 per cent of patients were aware of neighbours, and few were familiar with relatives. Here, most of the patients get more awareness from media than other platforms. The last part of the same objective also analysed the availment of schemes. Here, the statement aimed to study schemes' availment among patients collected by YES/NO questions. The response pattern for this item is as interpreted below.

Table 3. *Availment of schemes*

Response	Frequency	Percentage
Yes	238	95
No	12	5
Total	250	100

Source: Primary data

In this study table, 3 shows that 95 per cent of patients availed of different government schemes during their treatment, and 5 per cent of patients did not avail of any benefits from such schemes.

The study's second objective was "To understand the treatment-related expenditure incurred by cancer patients undergoing treatment at regional cancer centres". To understand the cost of treatment, the first statement of the schedule was structured by the cost of treatment for curing cancer at a regional cancer centre by using different expenditure levels, starting from below 30000

rupees to above 120000 rupees. The response pattern for this item is as interpreted below.

Table 4. *Cost of Treatment*

List	Frequency	Percentage
Below 30000	4	2
30000-60000	7	2.8
60000-90000	32	12.7
90000-120000	125	49.8
Above 120000	82	32.7
Total	250	100

Source: Primary data

Table 4 explains that 49.8 per cent of patients spent 90000-120000 of costs for their treatment., 32.7 per cent of patients were spending more than 120000 for treatment, 12.7 per cent of them were spending 60000-90000, and the remaining 5 per cent of patients were paying below 60000 for treatment.

The third objective of the study was "To assess the economic burden on the family of patients". Here the first part of the schedule focused on other sources of funds for the treatment with different categories like health insurance, borrowed funds, bank deposits, salary in advance and other sources. In this section, the schedule aimed to study the other sources of funds for treatment other than government funds. The responses from patients for this statement were interpreted as below.

Table 5. *Other sources of funds for the treatment*

Response	Frequency	Percentage
Health insurance	29	11.6
Borrowed fund	141	56.5
Bank deposits	2	.8
Salary in advance	3	1.2
Others	75	29.9
Total	250	100

Source: Primary data

Table 5 illustrates additional sources of financing for cancer treatment. Among these, 56.5 per cent of patients resorted to borrowing funds, while 29.9 per cent used alternative financial means for their treatment. Within this category, 11.6 per cent of patients relied on health insurance, and a mere 1.2 per cent

used their salary in advance. Considering the respondents' socio-economic background, it is essential to note that their bank balances and deposits might not be substantial, leading to only 0.8 per cent of patients utilizing bank deposits. The data extracted from Table 5 highlights that most patients opted for borrowed funds to cover their treatment expenses. The study's objective also delved into assessing how patients and their families reacted to the costs associated with treatment. The participants' responses to these inquiries were measured using a five-point Likert scale, classifying their reactions, such as the perceived necessity of treatment expenses, attitudes towards medical benefits, anticipated costs, and family responses to treatment expenses. The response pattern for this questionnaire ranged from strongly agreeing to strongly disagreeing. The ensuing feedback from the patients is interpreted as follows.

The research discovered that most patients and their families know about public treatment schemes (98.4%). This awareness primarily stemmed from media sources (49%) and hospitals (21.9%). Furthermore, the study unveiled that 95% of patients use various public financial assistance programs, while over half (more than 50%) incur treatment costs exceeding 100,000 rupees. Around 37% of patients spend over 100,000 rupees on medications to prevent recurrence. Regarding financial aid, half of the patients receive between 50,000 to 100,000 rupees through schemes during their initial courses of treatment. However, a notable portion (26%) of patients do not accept any financial support from the government. The research highlights that most patients (33%) receive their reimbursement within 15 days to a month, whereas 28.3% experience a delay of over two months from the admission date. Furthermore, the study observed that 93% of patients express dissatisfaction with public funding. The investigation also delved into patient experiences during registration, revealing substantial discontent with the process. Borrowed funds (56.5%) and other sources, encompassing health insurance and advance

salary, emerged as the primary avenues for treatment financing.

Based on the study's outlined objectives, it was revealed that many patients and their families possess knowledge about public schemes and financial aids obtained through diverse social media platforms and inquiries made at hospitals. This aligns with the findings of Penchas and Shani (1995), who determined that a substantial portion of patients and their families gain awareness of public schemes and funding policies through engagement with social media. This underscores the crucial role of media in disseminating essential information to the public. Furthermore, most patients took advantage of financial assistance provided by various schemes. However, a significant proportion of patients incur expenses exceeding 100,000 rupees to procure medications to prevent recurrence. The reimbursement process within the context of RCC entails a duration ranging from 15 days to two months for fund transactions. Due to this extended timeframe, patients express dissatisfaction with the effectiveness of public funding.

5. Conclusion

The study's results indicated that most patients had accessed financial assistance through various treatment schemes, yet they were also incurring costs exceeding 100,000 rupees for medications to prevent recurrence. The reimbursement process within RCC exhibited a timeframe of 15 days to two months for fund transactions, contributing to patient dissatisfaction with public funding. Challenges with registration and securing adequate funds were also evident, leading to a reliance on borrowing and health insurance as primary sources of financial support. The analysis consistently emphasized that augmenting public funding and schemes for patients would alleviate the economic strain associated with treatment. The economic burden on individuals living with cancer and their families was substantial. Due to their constrained scope, existing programs targeting cancer prevention and treatment costs demonstrated limited efficacy in reducing this burden. Consequently, the government and hospital management must take decisive actions and implement solutions to alleviate this issue. This initiative would effectively address the needs of economically disadvantaged individuals, including those below the poverty line and other vulnerable segments of society.

The study underscores that the current programs designed to tackle cancer prevention and treatment costs have not effectively mitigated the burden due to their inadequate scale of implementation. As a result, the government should enhance these programs to address these challenges effectively. Additional factors such as geographical distance from homes, psychological distress, and difficulties in arranging funds can contribute to delays in treatment decisions among low-income families. Therefore, it is recommended that state governments intervene to alleviate these fundamental issues patients face. This intervention should involve providing necessary funds at the time of treatment itself.

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