

# P R A K A R S A *Policy Brief*

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## Cancer Patients and Their Families Bear the Brunt of Out-of-pocket Cost: A Stumbling block for UHC in Indonesia?

### Key Points:

- Patients and their families continue to endure both medical and non-medical expenses (out-of-pocket) during the course of cancer treatment.
- While the JKN covers catastrophic cost of cancer treatment, it has not yet comprehensively covered some critical medication and targeted therapy, leaving a notable out-of-pocket gap for patients and their families.
- Informal caregivers assume a pivotal role in providing palliative care which bolster cancer patients' recuperation, yet, the absence of palliative care policy in Indonesian healthcare system have caused multiple burdens for them.



### Existing Healthcare Policies and Cancer Treatment in Indonesia

Cancer has become a pressing global health issue, exerting a substantial influence on both mortality and morbidity rates. In 2018, the World Health Organization's Global Cancer Statistics (GLOBOCAN) reported 348,809 cancer cases in Indonesia, resulting in 207,210 deaths. Furthermore, this distressing trend has witnessed a notable escalation in 2020, with the number of newly diagnosed cancer cases in Indonesia surging to 396,914, accompanied by an alarming death toll of 234,511 cases.

In 2020, Indonesia experienced a significant increase in cases for three types of cancer. Breast cancer saw the highest increase at 16.6 percent, followed by cervical cancer at 9.2 percent, and lung cancer at 8.8 percent (Globocan, 2020). In terms of gender distribution, men constituted the highest proportion of lung cancer patients, accounting for 14.1 percent or 25,943 cases. Whereas, women comprised the highest proportion of breast cancer patients, representing 30.8 percent or 65,858 cases, and cervical cancer, amounting to 17.2 percent or 36,633 cases.

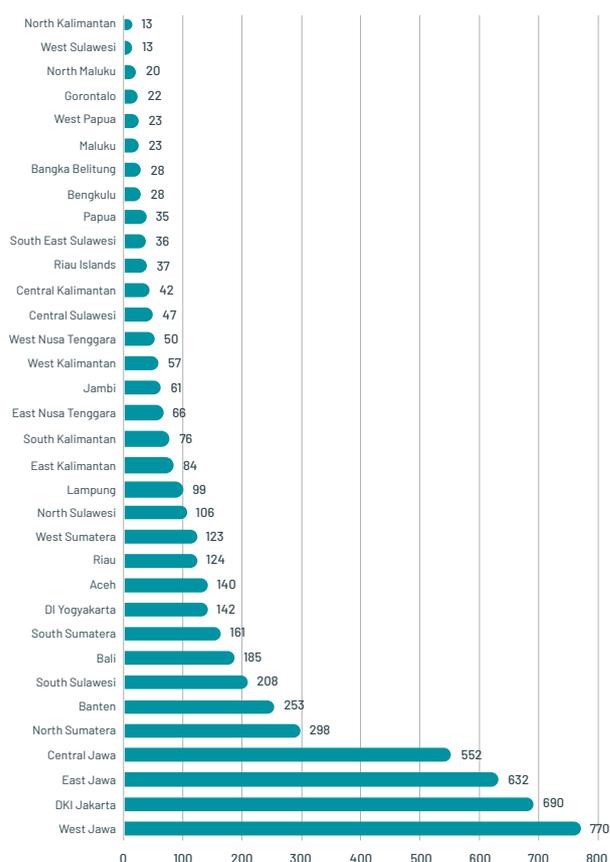
Indonesia already has measures aimed at preventing cancer through strategies such as health promotion, case management, and early detection. One example is the Healthy Living Community Movement or the so-called GERMAS, which was established under Presidential Instruction No. 1 of 2017. This policy aims to promote healthy lifestyle practices and prevent cancer cases by encouraging individuals to adopt and maintain healthy habits.

Moreover, the Indonesian government has been implementing the Chronic Disease Management Program (PROLANIS) policy since 2014 as an attempt to provide support for individuals living with chronic diseases, enabling them to attain an optimal quality

of life. This initiative aims to facilitate access to top-notch healthcare services and enhance knowledge concerning health and prevention of chronic diseases, specifically targeting patients with type 2 diabetes mellitus and hypertension. Additionally, the government has made concerted strategies to curb the progression of level 2 chronic diseases through screening and early detection measures. However, participation rates in screening remain alarmingly low. A study conducted by Wahidin et al. (2022) revealed that only 9.8% of women, approximately only 3.6 million out of a total of 37.4 million women aged 30-39 years in 2007 to 2018, actively participated in cervical and breast cancer screening.

There is still a significant disparity in accessing cancer treatment across different regions in Indonesia, especially for patients outside Java Island. These patients face difficulties to access healthcare facilities like hospitals, specialist doctors, and necessary medical equipment. For instance, in some areas, biopsy samples need to be sent to Jakarta, causing a month-long wait for results due to the lack of proper equipment locally (PRAKARSA, 2023). Additionally, there is a shortage of medical personnel and specialized doctors. The number of oncology specialists in Indonesia is limited, with only 139 internal medicine specialists and hematology/oncology consultants spread across 17 provinces (Machmudi, 2021). There are also low numbers of surgical oncology specialists (217), radiation oncology specialists (118), and pediatric hematology/oncology specialists (80) available across various provinces (Machmudi, 2021). A study by Hiswara (2017) highlighted the shortage of radiation oncologists, projecting a need for 1,300 radiation oncologists and approximately 730 radiotherapy facilities by 2023, considering population growth and the expected increase in new cancer cases.

Figure 1: Number of Internal Medicine Specialists in Hospitals by Province in 2021



Source: Health Profile of the Republic of Indonesia 2021

Currently, cancer treatment in Indonesia remains centralized in DKI Jakarta, requiring cancer patients from other regions to be referred to hospitals in Jakarta. Data from the Ministry of Health, as cited in PRAKARSA's study (2023), indicates that Type C hospitals largely dominate advanced-level healthcare facilities in Indonesia. There are 1,593 Type C hospitals, followed by Type D hospitals (905 hospitals), Type B hospitals (437 hospitals), and a mere two percent of Type A hospitals (47 hospitals). Unfortunately, Type C hospitals lack adequate equipment for treating cancer patients.

### Medical and non-medical out-of-pocket cost during cancer treatment

The Indonesian National Health Insurance (JKN) scheme has included coverage for cancer treatment costs related. However, not all types of cancer medications are included in the treatment benefits package. This is primarily due to the limited funds managed by BPJS Kesehatan, the Indonesian National Health Insurance administrator. The 2020 BPJS Kesehatan report indicated that total claims for cancer treatment amounted to 3.1 trillion rupiah. Consequently, the drugs financed under the scheme must adhere to the principles of cost-effectiveness as outlined in Permenkes 71 of 2013, which governs health services in the JKN. This means that the incurred costs should be proportional to the clinical benefits obtained (Nadjib et al., 2020). Thus, the objective of the JKN system is to provide treatment of good quality while ensuring "value for money."

The JKN benefit package falls short in covering all cancer medications, resulting in patients and their families encountering significant out-of-pocket cost for their healthcare. A study conducted by PRAKARSA (2023) highlights patients of lung, cervical, and breast cancer face various out-of-pocket costs, including medical expenses, non-medical expenses, and numerous other related costs, such as:

First, one of the medical expenses required by lung cancer patients is the targeted therapy known as Avastin (Bevacizumab), which is not covered by JKN. Avastin used to be covered by JKN for treating metastatic colorectal cancer. However, it was later removed from the coverage list because it didn't show significant clinical benefits and was too expensive, making it not cost-effective and potentially affecting the efficiency of the JKN system (Kristin et al., 2021). As a result, patients with different types of cancer now must buy the drug on their own and face high medical costs. For instance, lung cancer patients are required to pay 14 million rupiah to obtain Avastin (Bevacizumab). In addition, patients and their families bear non-medical expenses amounting to 5 to 7 million rupiah, which covers transportation, accommodation, meals, and other incidental costs for each treatment session, which can last 1-2 weeks.

Second, cancer patients often need to seek treatment outside their hometowns due to inadequate healthcare facilities. This is a common situation, especially for patients from regions outside Java, as highlighted by our research (PRAKARSA,2023). Limited availability of specialist doctors and advanced diagnostic technology for cancer symptoms contribute to the need for patients to travel. For example, patients and their caregivers from Bangka Belitung may face transportation costs of up to 7 million rupiah for a single treatment session. The duration of treatment varies depending on the type of cancer, with lung cancer patients mentioning that they have to travel to Jakarta for one to two weeks for treatment.

Moreover, patients who come from outside Java often bear significant additional expenses for their caregivers. Such expenses comprise of accommodation costs ranging from 1.2 to 3 million rupiahs per month, and a weekly meal allowance of about 700 thousand rupiahs. Some cancer survivor organizations and civil society organizations (CSOs) have been instrumental in providing subsidized accommodation or shelters for patients and their caregivers during treatment. However, the lack of coordination between these shelters management and hospitals means that patients are often unaware of their availability. Other costs patients have to consider include diapers, which can cost around 1.5 million rupiahs, and vitamins, which are typically around 50 thousand rupiahs.

Third, families and cancer patients also expense a large amount of indirect costs. These costs may include a loss of work productivity and income, as well as anxiety and psychological distress for both patients and their caregivers. Findings from interviews conducted in our study (PRAKARSA, 2023) revealed that lung cancer patients had to take extended sick leave for nearly a year. During the first three months, their salary was reduced by 25 percent. Some patients even mentioned the possibility of losing their jobs

altogether due to the extended and demanding nature of their treatment, which could last for weeks.

In addition to the economic burden, cancer patients also experience psychological challenges that can lead to symptoms such as anxiety and depression, significantly impacting their overall quality of life. This phenomenon is commonly referred to as "financial toxicity," where patients not only face financial difficulties that affect their household's economic status but also have a profound impact on their well-being and overall quality of life (Pangestu and Rencz, 2022).

The role of caregivers in the treatment of cancer patients is crucial, yet they often lack proper support, particularly in terms of psychological assistance. Additionally, caregivers generally overlook their own need for medical consultation and support. Our study finds that caregivers frequently experience feelings of hopelessness when patients fail to show signs of improvement. Moreover, caregivers also harbor fears about the future, contemplating the possibility of losing their loved ones who are battling cancer.

In general, caregivers who are participants of the National Health Insurance-Indonesian Health Card (JKN KIS) can access psychological assistance services as stipulated in Presidential Regulation Number 82 of 2018 regarding Health Insurance. These services are typically provided in a step-by-step manner, starting from the First Level Health Facility (FKTP) in domicile of card holder. If further treatment is required, caregivers may be referred to an Advanced Health Facility (Fasilitas Kesehatan Tingkat Lanjut/ FKTL). However, it is a common knowledge that caregivers often face challenges in seeking consultation at FKTPs due to their difficulty of finding time to consult, especially when they are out of town to take patients for treatment.

### The Urgency to Improve Palliative Care Policies to Support Cancer Patients' Treatment

Palliative care is a type of care that focuses on easing the suffering of cancer patients. It involves early identification, comprehensive assessment of the patient's condition, and the management of physical, psychosocial, and spiritual issues (WHO Palliative Care, 2020). The primary objective of palliative care is to enhance the quality of life of cancer patients throughout their journey, including the end stages of their lives.

Palliative care implementation in Indonesia is currently limited, reaching only 1% of terminal cancer patients (RI Ministry of Health, 2022). Palliative care can be provided either at an advanced referral health facility or at patient's home, as long as there is an informal or professional caregiver present. The policies governing palliative care in Indonesia are outlined in the Decree of the Minister of Health (KMK) number 812 of 2007 and National Guideline for Palliative Cancer Program 2015, which primarily focuses on professional caregivers or healthcare workers. However, family members can also play a crucial role as informal caregivers, assisting patients in coping with the various challenges that arise from a cancer diagnosis.

Accordingly, caregivers often lack the necessary training and information to provide proper care for cancer patients. Based on the study by PRAKARSA (2023), caregivers reported not receiving information about patient's cancer stage. Health workers tend to withhold this information, especially when the patient reaches advanced stages of the disease. However, knowing the stage of cancer is crucial for patients and their caregivers to prepare for palliative care and enhance patient's quality of life. It is important to provide caregivers with the necessary information and support to improve their capacity in caring for cancer patients effectively.

The stages of palliative care start when a cancer patient is diagnosed by a doctor and identified as requiring care. Palliative care is necessary for patients who experience various conditions, including physical discomfort, psychological challenges, and advanced-stage treatment (Ministry of Health, 2015). Its purpose is to offer assistance and support to individuals with chronic illnesses such as cancer. As the number of cancer patients continues to rise annually, the demand for palliative care has also increased.

An example of informal caregiver-provided palliative care is demonstrated by the partner of a cervical cancer patient in our study. The patient often experienced anxiety and reluctance to visit hospital and undergo examinations. However, the partner approached patient's reluctance by reframing the hospital visit as a trip, making it less pressing for the patient. This helped alleviating the patient's fear and anxiety associated with treatment and therapy. It is important because the patient also experienced side effects of treatment, such as stomach upset, nausea, insomnia, decreased appetite, and bleeding, leading to a desire to discontinue the treatment process. In such situations, the caregiver played a crucial role in ensuring the patient's comfort, providing positive affirmations, and encouraging the patient to continue treatment/therapy. This type of care provided by informal caregivers, falls under the umbrella of palliative care.

According to the aforementioned study, the families of cancer patients opt for home-based palliative care for several reasons. Firstly, it helps in saving treatment costs. Additionally, patients tend to be more open and receptive to care when they are in a familiar and comfortable environment, which has a positive psychological impact on them. By providing palliative care at home, the burden of non-medical costs for patients is reduced. Currently, the policy only covers palliative care costs if the doctor specifically mentions it in the hospital diagnosis.

### Conclusion and Recommendations

Out-of-pocket expenses remain a significant challenge for cancer patients in Indonesia. The need for specific medications and targeted therapies often results in high additional costs for patients and their families. Moreover, cancer patients require various forms of support, including palliative care provided by informal caregivers. These caregivers play a crucial role in supporting the overall well-being of cancer patients. However, there is currently a lack of policies and support systems in place for informal caregivers in Indonesia. This gap highlights the need for policy measures to address and recognize the important

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contributions of informal caregivers in the care of cancer patients.

Based on above conclusion, this policy briefs offer several policy recommendations as follows:

- The Ministry of Health, provincial governments, municipalities, and hospitals should undertake proactive measures to enhance oncology infrastructure and elevate the standards of oncology services. Simultaneously, efforts should be made to streamline the referral process, fortify the network of cancer care hospitals, foster the proliferation of hospital accreditation, and facilitate convenient and cost-effective accessibility of specialized cancer hospitals for patients across all regions in Indonesia.
- The Ministry of Health must improve quality and affordable cancer diagnosis services in all regions of Indonesia. Quality and easily accessible cancer diagnosis and cancer therapy services and treatment facilities are the key to treat and cure cancer.
- The national government, provincial governments, and municipalities must extend support in the form of financial aid for non-medical direct and indirect costs. These costs encompass transportation, shelters, lodging, and other related expenses. By alleviating the burden of these non-medical expenditures, individuals affected by cancer can embark on their treatment and healing journey with enhanced well-being and optimal conditions.
- The Ministry of Health needs to develop a policy of providing support to informal caregivers of cancer patients from psychosocial, health and work aspects.
- The Ministry of Health needs to develop policies/programs that integrate palliative care for all cancer patients at all levels of health facilities in Indonesia, not limited to terminal patients (the phase of care where the patient's condition has been diagnosed medically as there are no intervention options that can help the patient).
- The government must widen the outreach of socialization and increase public literacy about the importance of cancer prevention and early detection of cancer by involving all parties including community organizations and the mass media as well as making optimal use of information technology (digital).

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