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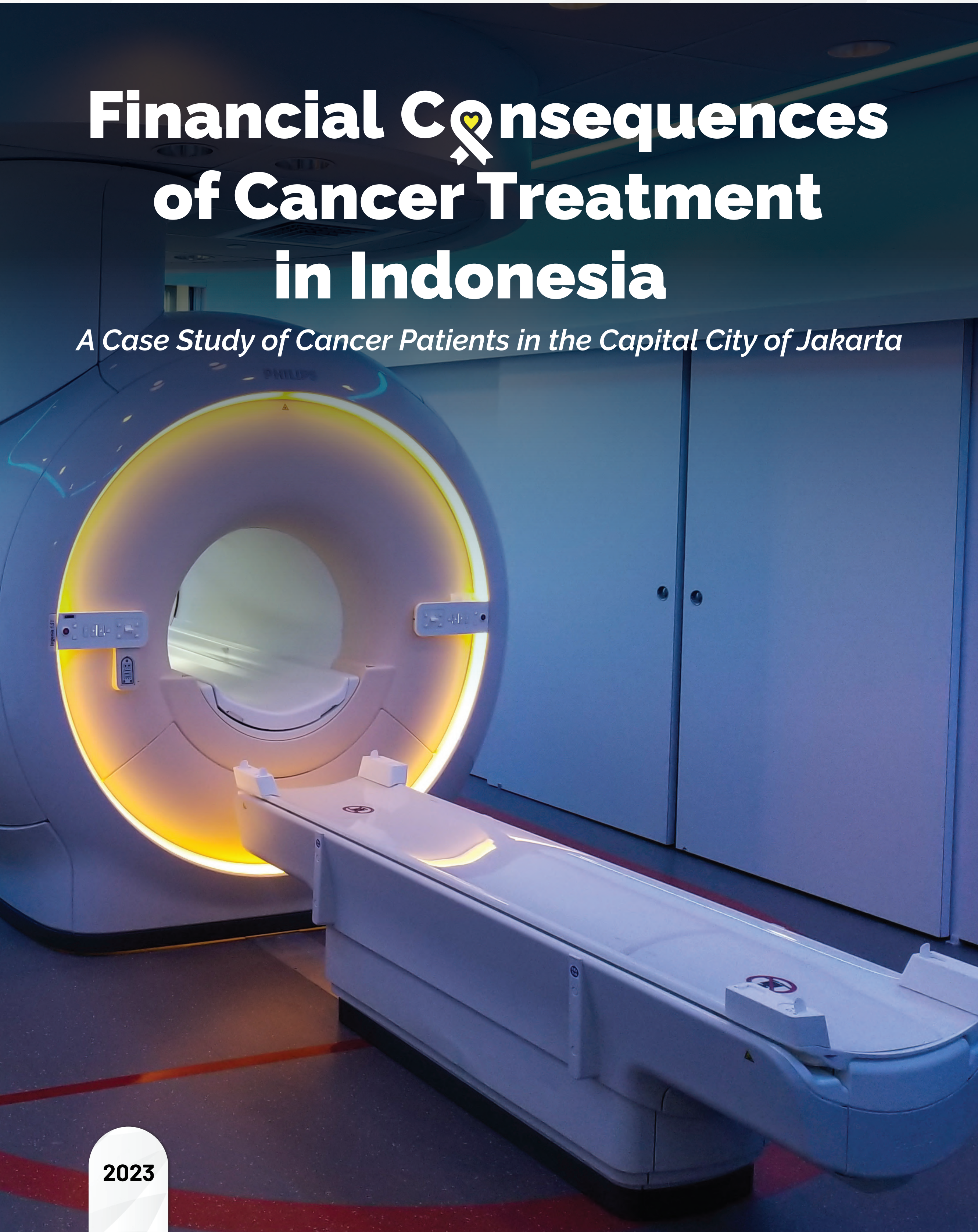
Financial Consequences of Cancer Treatment in Indonesia

A Case Study of Cancer Patients in the Capital City of Jakarta



2023

The Financial Consequences of Cancer Treatment in Indonesia: A Case Study of Cancer Patients in the Capital City of Jakarta

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LIST OF ABBREVIATIONS

AIDS	:	Acquired Immunodeficiency Syndrome
HIV	:	Human Immunodeficiency Virus
AHF	:	AIDS Healthcare Foundation
TBC	:	Trajectory of Breast Cancer
OOP	:	Out Of Pocket
BPJS	:	Badan Penyelenggara Jaminan Sosial
RS	:	Rumah Sakit
DKI	:	Daerah Khusus Ibukota
GBD	:	Global Burden of Disease
JKN	:	Jaminan Kesehatan Nasional
WHO	:	World Health Organization
G20	:	Group of Twenty
C20	:	Civil 20
LMIC	:	Low Middle-Income Countries
UHC	:	Universal Health Coverage
PTM	:	Penyakit Tidak Menular
POSBINDU	:	Pos Binaan Terpadu
PANDU	:	Pelayanan Terpadu
GERMAS	:	Gerakan Masyarakat Hidup Sehat
PROLANIS	:	Program Pengelolaan Penyakit Kronis
SISRUTE	:	Sistem Rujukan Terintegrasi
KTR	:	Kawasan Tanpa Rokok
KIE	:	Komunikasi, Informasi, dan Edukasi
PHBS	:	Perilaku Hidup Bersih Sehat
GENTAS	:	Gerakan Nusantara Tekan Angka Obesitas
UBM	:	Upaya Berhenti Merokok
SADANIS	:	Pemeriksaan Payudara Klinis
IVA	:	Inspeksi Visual Asam Asetat
PNPK	:	Pedoman Nasional Pelayanan Kedokteran
SADARI	:	Periksa Payudara Sendiri
P2PTM	:	Pencegahan dan Pengendalian Penyakit Tidak Menular
FKTP	:	Fasilitas Kesehatan Tingkat Pertama
IMT	:	Indeks Masa Tubuh
GDP	:	Gula Daerah Puasa
GDPP	:	Gula Daerah 2 jam Postprandial
PTK	:	Penilaian Teknologi Kesehatan
DNA	:	Deoxyribo Nucleic Acid
APBN	:	Anggaran Pendapatan Belanja Negara
APBD	:	Anggaran Pendapatan Belanja Daerah
RSUD	:	Rumah Sakit Umum Daerah
Babel	:	Bangka Belitung
HCP	:	Hospital Cash Plan
STC	:	Systematic Text Condensation
Menkes	:	Menteri Kesehatan
SDM	:	Sumber Daya Manusia
RI	:	Republik Indonesia

USG : Ultrasonografi
UGD : Unit Gawat Darurat
Kemenkes : Kementerian Kesehatan
KMK : Keputusan Menteri Kesehatan
ACS : American Cancer Society
BAB : Buang Air Besar
U.S. : United States
KTP : Kartu Tanda Penduduk
KK : Kartu Keluarga
UK : United Kingdom
IFR : Individual Funding Request
NHS : National Health Service
CDF : Cancer Drugs Fund
NICE : National Institute for Health Care Excellence
HPV : Human papillomavirus
CoB : Coordination of Benefit
Riskesdas : Riset Kesehatan Dasar
FKRTL : Fasilitas Kesehatan Rujukan tingkat Lanjut
INA-CBGs : Indonesian Case Base Groups
KIS : Kartu Indonesia Sehat
Faskes : Fasilitas Kesehatan

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> “There is a ‘Can’ in Cancer because we CAN beat it!

FOREWORD

When PRAKARSA staff submitted their research proposal on cancer, at first, I was not too enthusiastic. It was because this kind of research usually only portrayed curative-rehabilitative, drug-centric and other medical aspects of cancer treatment, something that the public do not have expertise or interest to digest. After the research team finished the research protocol draft, I changed my mind and enthusiastically welcomed the research plan “Financial Consequences of Cancer Treatment in Indonesia”.

What comes to our mind when we hear the word “cancer”? We usually have our own answers. Personally, my answer will be: i) cancer means a very deadly disease, ii) cancer refers to apprehensive socio-economic conditions, once you get cancer, everyone around, individuals and household alike, will experience crumbling financial conditions . Patients who have cancer will suffer both catastrophic burdens, of health and of economic simultaneously. Cancer treatment usually take months and even years. The long duration of this treatment results in the large costs that must be incurred by cancer patients. Even though cancer patients have health insurance, both the National Health Insurance – BPJS Health and private health insurance, patients and their families still bear significant costs, especially those related to other costs outside medical services (direct non-medical), for example transport costs from their residence to health facilities, purchase of meals for accompanying families, temporary housing rents and so on. On the other hand, patients and their families may also lose potential income (indirect non-medical costs) because they must undergo long duration of treatment.

With other costs incurred outside medical services, they increased expenses by patients and their families (out-of-pocket/OOP). If a cancer patient lives outside Java Island and her doctor referred her to undergo treatment at a referral hospital in Jakarta, she must rent a temporary residence and bears high transport costs for different modes of transportation ships, airplanes and cars). OOP costs will soar and creating heavy financial burdens for patients and their families (financial toxicity). Patients and their families who come from middle to lower economic groups, usually have to sell their assets or borrow money from extended families or moneylenders. As a result, it is not uncommon for them to experience debt in the medium to long term.

PRAKARSA as a public policy research and advocacy institution is very open to collaborate with various parties to promote better policy to improve people's welfare and wellbeing. We hope this research report will be of benefit and can be used as a reference for health policy formulation in Indonesia. We propose policy recommendations in this report for alternative policies at both the national and regional levels. These recommendations aim to encourage the government to improve access to healthcare services for cancer patients and to reduce the OOP for cancer patients and their families. The National Health Insurance – BPJS Kesehatan does not yet cover direct non-medical costs, so we all need to think about how cancer patients and their families are able to survive medically and non-medically while undergoing treatment.

Highest appreciation to the research team: Darmawan Prasetya, Aqilatul Layyinah, Septiara Putri, Eva Rosita and Adella Indah Nurjanah. Thanks also to the research support team, especially the review team: Victoria Fanggidae, Herni Ramdlaningrum, Eka Afrina Djamhari. Thanks to the AIDS Healthcare Foundation (AHF) for their financial support to PRAKARSA to finalize the research "Financial Consequences of Cancer Treatment in Indonesia: Case Studies of Cancer Patients in the Capital City of Jakarta" d.

Again, we hope that this research can spark discussions to find solutions to the complex non-medical problems experienced by cancer patients and their families, especially OOP aspects in the treatment process.

Jakarta, Februari 2023
Ah Maftuchan
Executive Director of The PRAKARSA

More than 22 million people in the world are predicted to be diagnosed with cancer in 2030. In Indonesia alone, in 2020 the number of new cases of cancer reached 396,914 cases and 234,511 patients were reported dead

(Sung et al., 2021).

EXECUTIVE SUMMARY

There are three types of cancer in Indonesia that have experienced the highest increase in 2020, namely: breast cancer (16.6%), cervical cancer (9.2%), and lung cancer (8.8%) (GLOBOCAN, 2020). Cancer causes an increase in the economic burden for health care providers, patients and their families. Household expenses are also affected after a patient is diagnosed with cancer, because OOP costs incurred to support treatment/therapy have not been fully covered by the National Health Insurance. Direct non-medical costs and non-medical indirect costs that are borne by patients and families greatly affect the economic situation of the family.

This research was conducted with the aim of understanding the experiences of cancer patients and their families while experiencing the progress of the cancer disease in depth; know the factors that contribute to the process of patient care and treatment; know the estimated direct medical and non-medical costs as well as indirect costs that become OOP; as well as providing evidence-based recommendations to support government interventions on the issue of providing cancer patient care. This study uses the illness trajectory model in analyzing field findings, so that the focus is the course of the disease experienced by patients and their families. The use of an illness trajectory can represent the cumulative effect of a disease that affects physical symptoms, changes in the patient's individual and social functioning, and specifically examines each stage experienced by the patient from the time he was diagnosed to experiencing further symptoms (Smit et al., 2019).

Furthermore, this study also uses the concept of OOP costs in health in order to describe the economic burden experienced by households or individuals due to loss of economic resources and opportunities due to the occurrence of a disease (Pisu et al, 2010). Compliance and willingness to continue undergoing treatment will also depend heavily on the patient's resilience in the progression of the disease they are experiencing. The concept of resilience or resilience becomes relevant and can be used to analyze the factors that contribute to the course of cancer from research informants.

> Based on field findings, during the pre-diagnosis phase, most cancer patients ignore the initial symptoms they feel. This is caused by the lack of health literacy, so that before their condition gets worse, they choose not to go to a health facility.

In addition, experience, motivation, and knowledge also influence the actions taken by cancer patients in this early phase. Then in the check-up phase at health facility, this study found obstacles experienced by cancer patients, including inadequate hospital services, minimum transparency of the stages of treatment delivered by doctors, and limited information regarding the referral stages provided by medical personnel to patients.

The factors that influence the process of care and treatment of cancer patients found are support from caregivers, extended family support, support from the community, information from third parties, and the patient's internal motivation to recover. The forms of support provided range from psychological support, mentoring, financial support, material support, support in seeking various information related to treatment, support for selecting health facilities, and arranging sources of funds for financing during treatment.

Findings related to direct non-medical costs include several substantial expenditures such as: transportation costs, accommodation (lodging), meals (other than hospital nutrition services), additional vitamins, alternative medicine, diapers, and costs for temporary childcare when patients go out for treatment. city. Transportation costs include land travel costs (including tolls or drivers), aircraft, motorcycle taxi and ship costs. As for the non-medical indirect costs found in this study, the loss of productivity of patients or their families. Loss of productivity such as salary cuts caused by absenteeism from work, prioritizing caring for cancer patients over work, or reducing work frequency due to accompanying patients undergoing treatment.

This study also conducted an analysis regarding the implications of field findings for cancer control policies in Indonesia.

01. **It relates to the factors that contribute to policy proposals based on the results of a qualitative analysis of field findings, namely:** the long duration of treatment for cancer patients with high intensity has implications for direct non-medical expenses of patients and their families. The current policy is still focused on programs to prevent and improve case management for the prevention of Non-Communicable Diseases (NCD). So that attention to curative policies for the care and treatment of cancer patients has not been maximized.

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02. **Regarding direct medical expenses which include:** treatment/supplement, technology, targeted therapy, referral system, equal distribution of health facilities, and an increase in the number of oncology specialists. One of the policies in terms of cost efficiency is increasing the capacity of Health Technology Assessment (PTK). Health Technology Assessment in the National Health Insurance program (PTK-JKN) is a policy analysis that is carried out systematically with a multidisciplinary approach to assess the impact of using health technology. However, this policy is still focused on increasing the efficiency of financing from BPJS Kesehatan and health facilities, has not yet accommodated increasing the efficiency of patient/household spending on health.

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03. **Regarding direct non-medical expenses including:** palliative care costs (homecare), transportation costs, food costs, accommodation costs, and other expenses that are not included in the benefits package of the national health insurance. Policies related to palliative care in Indonesia are currently still focused on care in health facilities. Then for other direct non-medical expenditures it is also not included in the national health insurance benefits package.

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04. **The relation to indirect costs that must be incurred by patients and their families, namely:** the risk of losing a job due to caring for a family member diagnosed with cancer, salary cuts, not getting incentives at work, reduced income, decreased productivity, mental health conditions also decreased. Currently there is no policy capable of encouraging psychoeducational treatment of patients and caregivers in the same health facility.

Policy and technical recommendations based on the segregation of duties and authorities of stakeholders (Ministry of Health, BPJS Health, Provincial Governments, District/City Governments and Hospitals) are as follows:

1. The Ministry of Health, Provincial Governments, Regency/City Governments and Hospitals need to take steps to improve oncology facilities and the quality of oncology services and transform the referral process, strengthen the cancer care hospital network, encourage the expansion of hospital accreditation and provision of hospitals specifically for cancer that can be reached easily and inexpensively by patients in all regions in Indonesia
2. 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 facilities are the key to cancer cure
3. The Ministry of Health needs to develop a policy of providing support to informal caregivers of cancer patients from psychosocial, health and work aspects
4. 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 diagnostically as there are no intervention options that can help patient)
5. The Central Government, Provincial Governments and Regency/City Governments need to provide assistance with direct non-medical costs and non-medical indirect costs (transportation, halfway houses, lodging and others) so that cancer patients, cancer sufferers and their families can undergo the treatment process good and complete healing
6. The government needs to increase socialization and literacy massively to the public about the importance of cancer prevention and early detection of cancer by involving all parties including community organizations and the mass media and making optimal use of information technology (digital).

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Chapter 1

Treatment of Cancer and Its Problems in Indonesia

Chapter 1

Treatment of Cancer and Its Problems in Indonesia

1.1 Background

Cancer is a public health issue that has a significant impact on morbidity and mortality (Sung et al., 2021; GBD, 2022). Morbidity and mortality are indicators that describe the degree of public health in an area (Hernandez, J. B., & P. Kim, 2022) Globally, it is predicted that more than 22 million individuals will be diagnosed with cancer by 2030. In Indonesia, cancer is one of the non-communicable diseases with the highest mortality rate. In 2020 the Global Burden of Cancer Study (GLOBOCAN) reported that the number of new cases of cancer in Indonesia reached 396,914 cases, of which 234,511 cancer patient's mortalities were reported (Sung et al., 2021). Based on the type of cancer, the highest number of new cases was breast cancer (16.6%), cervical cancer (9.2%), and lung cancer (8.8%) (GLOBOCAN, 2020).

Factors that can trigger a high risk of cancer and affect mortality are due to lifestyle, high prevalence of smoking, and an increase in the elderly population (Bray et al., 2012; Popat et al., 2013; GBD, 2022). Cancer poses a significant economic burden, both for patients and their families. Most cancer patients have low survival rates and potentially worsening quality of life (American Cancer Society, 2010; Bloom et al., 2015). Therefore, after being diagnosed with cancer, the financial impact is felt by patients and their families, especially in the treatment process. Referring to research findings by the ACTION Study Group (2015), households can experience catastrophic financial problems after being diagnosed with cancer, with out-of-pocket (OOP) medical expenses exceeding 30% of the household's annual income.

Through the National Health Insurance (JKN) program launched in 2014, the Indonesian government seeks to provide financial protection to all JKN participants, including cancer patients in Indonesia. BPJS Kesehatan provides packages of healthcare benefits for JKN participants who are diagnosed with cancer. The Ministry of Health reports that funding managed by BPJS Kesehatan to treat cancer reaches around 7.6 trillion for 2019-2020 (Ministry of Health, 2020). With the benefit package provided to the community, it is hoped that it can reduce OOP's burden on medical costs borne by cancer patients and their families. In 2019, the percentage of OOP in Indonesia has shown a decrease since JKN was available at 34.76% of the previous total health expenditure of 56.43 T rupiah in 2014. It's just that this figure still does not meet WHO standards with a maximum percentage of 20% (World Bank, 2020).

Even though the management of cancer treatment is included in the JKN financing scheme, there are still various costs incurred by patients that come from their own finances outside of the cost of medical services or are called direct non-medical costs. Direct non-medical costs include costs for transportation to health facilities, meals and drink for patient's companion , medicines that are not covered by JKN, and temporary housing costs, for those live far from referral health facilities, due to uneven distribution of such facilities in Indonesia. In addition, there are indirect costs, such as lost productivity due to cancer. Loss of productivity, among others, because patients are unable to work due to clinical symptoms they experienced, the time they must spend for treatment process and the debilitating side effects of medicines and treatment. Loss of productivity can also affect the overall economic situation of the patient's family. The ACTION Study Group (2015) reported that after one year of being diagnosed with cancer, 48% of patients experienced a catastrophic financial burden, or a condition of high medical expenses.

Based on the background review above, PRAKARSA sees the need to conduct in-depth research on the experience of cancer patients during and after treatment and the risks of OOP health costs incurred by cancer patients which include direct medical & non-medical costs as well as indirect costs. This study focuses on patients with breast, cervical and lung cancer, according to the justification for cancer with the highest prevalence in Indonesia. This study was conducted in Jakarta where cancer treatment facilities are available.

This study represents PRAKARSA's commitment to support the strengthening of the health system in Indonesia. We expect this research to contribute to a better understanding of the complexity of responses, perceptions, causes or contributions to OOP for cancer patients and their families. By having better understanding of these conditions, we hope to make better policy recommendations aiming to improve access to healthcare services and to strengthen Indonesia's health system.

1.2 Research Gaps

Several previous studies have shown that the economic burden of cancer in Indonesia is quite significant. A systematic study by Iragorri et al., (2021) reports that OOP costs excluding medical costs are quite high, especially in the LMICs (Low Middle-Income Countries), even though these countries have started implementing the UHC principles. Almost all studies conducted on LMICs reported estimates of non-medical expenses exceeding 30%, the average non-medical expenses being around 42% of annual income.

The economic burden related to cancer due to OOP spending is quite high and has an impact on the household economy which is described as financial toxicity. A systematic review study and meta-analysis by Donkor et al., (2022) reported that the financial burden for cancer patients, especially in LMIC, is quite significant. From this study, it was concluded that cancer patients, especially those with low income, more often use their own savings, sell assets, pass bills and even borrow money as a result of suffering from cancer, to incur direct medical and non-medical costs.

Pangestu & Karnadi (2018) also conducted research on the link between financial toxicity due to cancer treatment and risk-taking behavior. This research was conducted using a survey data collection method for 194 people with cancer and found that the financial burden experienced by all cancer patients. This study also found that the higher the stage of the cancer, the more courageous cancer patients are to pay, or the higher the level of costs to be incurred.

In terms of productivity loss, a study by Kristina et al., (2022) shows that the burden of cervical cancer in Indonesia has a value of lost productivity costs of 23.2 trillion Indonesian Rupiahs in 2018, with the largest portion in the age group range of 35 to 64 years. Furthermore, a study on the economic burden of lung cancer in Makassar resulted in an estimated average direct non-medical cost of around 5 million Indonesian Rupiahs during the duration of treatment (Palu et al., 2013).

Another study by Susilowati & Afiyanti (2021) examined in more detail socio-demographic factors and their effect on the financial burden of 109 female breast cancer survivors. This study found that all families and breast cancer survivors experience a high financial burden, especially for transportation costs, family accommodation, and child sick expenses. Women who are the backbone of the family, have children and earn less than five million per month experience the greatest financial burden. Women with low incomes also tend to be disobedient in the healing process because there are no costs for transportation and accommodation for waiting families.

Some of the justifications above provide information about the problems faced by patients, especially in financial terms, such as the large portion of direct non-medical costs and indirect costs of the overall expenditure on cancer medical care. These studies have explained how much it costs to carry out treatment after being diagnosed with cancer.

However, information related to a comprehensive explanation and deeper understanding from the experiences and perspectives of patients and families is still important for further exploration. First, to find out the challenges faced by patients with several types of cancer in obtaining treatment services. In addition, it is necessary to examine what are the opportunities for improving health programs in Indonesia, starting from the policy level to health services for non-medical costs and high indirect costs for families and patients with several types of cancer.

This study was conducted by applying a qualitative approach and analyzed based on illness trajectory so that deeper information, perceptions and understanding can be extracted to help strengthen health policy proposals (both national and regional), especially in dealing with financial problems caused by cancer.

1.3 Research Questions

Based on the background explanation above, this research has the following research questions:

1. What are the responses and perceptions of patients and families during the progression of the cancer course?
2. What are the factors that contribute to the care and treatment of cancer patients?
3. How and how much are the estimated direct non-medical, medical and indirect costs borne by patients and their family while undergoing cancer treatment?
4. What interventions are possible for the government to address issues related to OOP costs beyond the medical costs faced by patients and their families?

1.4 Benefits of research

1. Providing understanding to the public and policy makers regarding the experience of patients and families based on the treatment process of cancer disease
2. Provide recommendations to policy stakeholders (central government, provincial government, local government, health insurance providers and CSOs) regarding the OOP cost in three types of cancer with the highest prevalence in Indonesia based on the experiences of patients and their families

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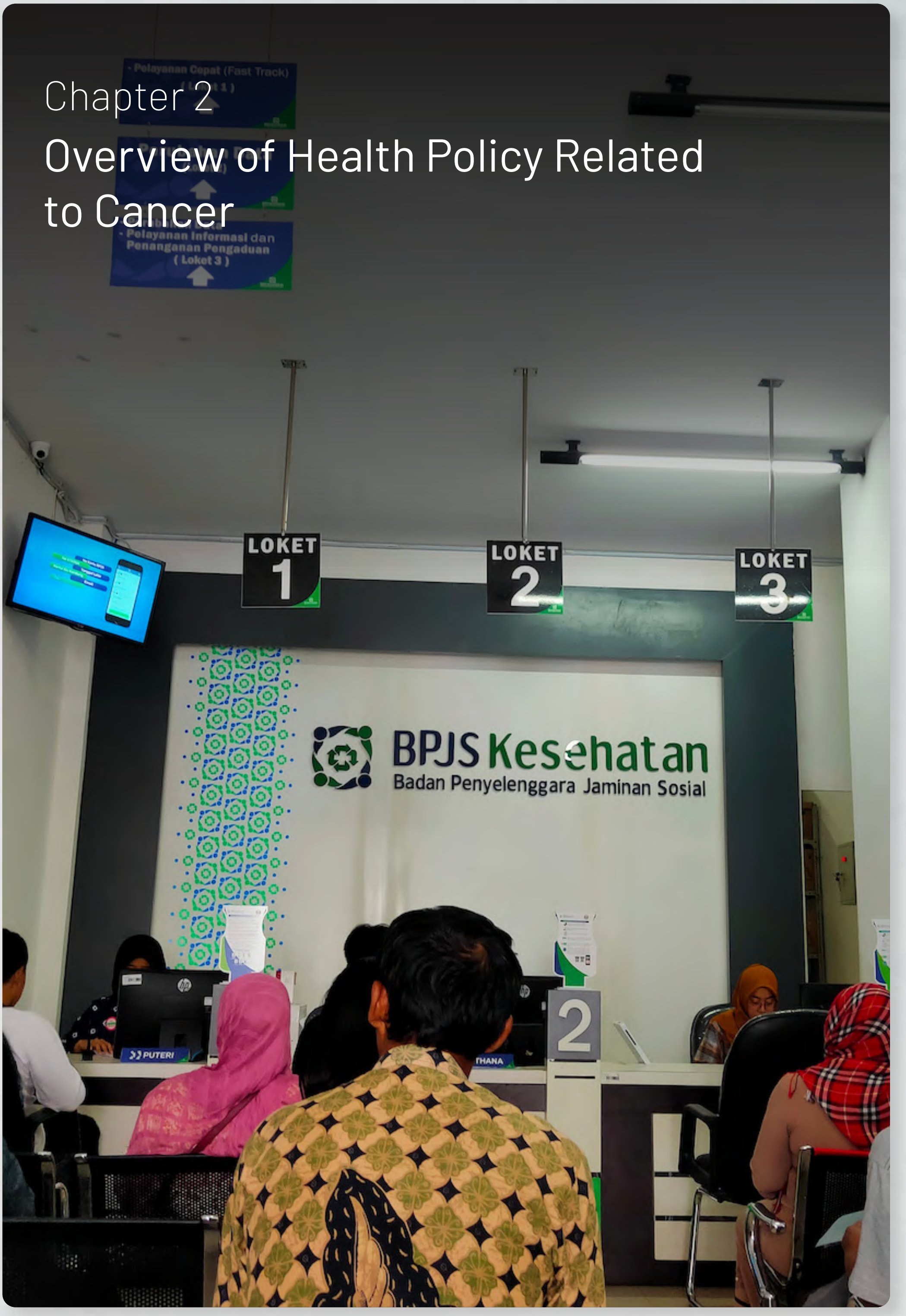
Chapter 2

Overview of Health Policy Related to Cancer



Chapter 2

Overview of Health Policy Related to Cancer

As explained in the introduction, breast, cervical and lung cancers occupy the top ranks in the number of cancer cases in Indonesia. The government already has several national policies to deal with cancer in society. The policy emphasizes preventive efforts such as health promotion, early detection and case management efforts. In general, the government already has programs and policies related to the management of Non-Communicable Diseases (PTM) including cancer. This policy focuses on prevention programs and improving case management. The policies in question include:

a. Integrated Development Post (POSBINDU) for non-communicable diseases (PTM) as an effort to detect early disease for residents aged 15 years and over, through community empowerment. Accompanied by Integrated Services for Non-Communicable Diseases (PANDU PTM) as an effort to prevent and control PTM through increasing the capacity of officers in providing early detection services, monitoring and management of PTM. At POSBINDU, main activities are carried out, such as: (1) early detection of risk factors and monitoring (for non-communicable diseases including cancer prevention); (2) Counselling and referrals; (3) Joint activities (e.g. sports and physical activity).

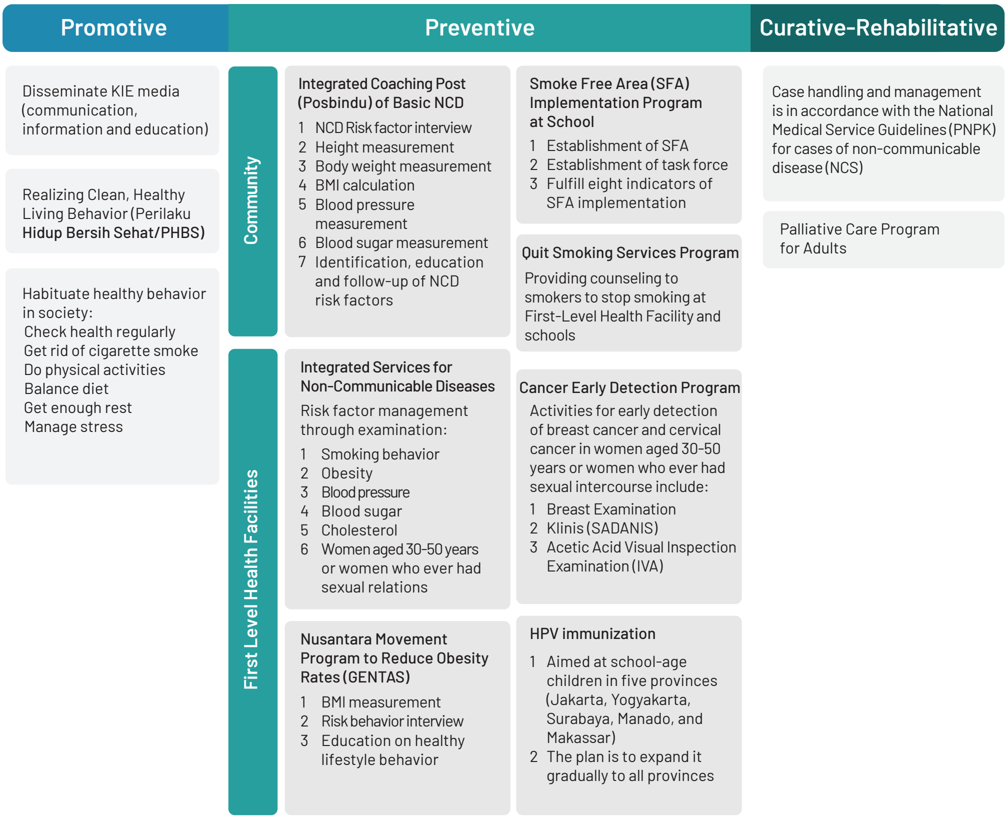
b. The Healthy Living Community Movement (GERMAS) is regulated in Presidential Instruction No. 1 of 2017. The program encourages people to adopt a culture of healthy living and abandon unhealthy habits and behaviours. The focus of this program is to build access to meet drinking water needs, public health installations and the construction of liveable settlements. There are guidelines for living a healthy lifestyle for the community which are also included in this program.

c. Chronic Disease Management Program (PROLANIS) and health history screening at the health facility level through BPJS Kesehatan Regulation Number 2 of 2019. PROLANIS aims to support people with chronic diseases to achieve optimal quality of life, encourage patients to get first level health facilities, and increase knowledge about health and prevention in patients with type 2 diabetes mellitus and hypertension.

d. Integrated Referral System (SISRUTE), a form of cooperation between BPJS Kesehatan and government and private hospitals to improve the quality of care.

In addition to the promotive policies above, further mapping of the national government's promotive, preventive and curative-rehabilitative programs can be seen in the following figure:

Figure 1. Ministry of Health Program in Non-Communicable Disease Management



Promotive

Disseminate KIE media (communication, information and education)

Realizing Clean, Healthy Living Behavior (Perilaku **Hidup Bersih Sehat/PHBS)**

Habituate healthy behavior in society:
Check health regularly
Get rid of cigarette smoke
Do physical activities
Balance diet
Get enough rest
Manage stress

Preventive

Community

Integrated Coaching Post (Posbindu) of Basic NCD
1 NCD Risk factor interview
2 Height measurement
3 Body weight measurement
4 BMI calculation
5 Blood pressure measurement
6 Blood sugar measurement
7 Identification, education and follow-up of NCD risk factors

Smoke Free Area (SFA) Implementation Program at School
1 Establishment of SFA
2 Establishment of task force
3 Fulfill eight indicators of SFA implementation

Quit Smoking Services Program
Providing counseling to smokers to stop smoking at First-Level Health Facility and schools

First Level Health Facilities

Integrated Services for Non-Communicable Diseases
Risk factor management through examination:
1 Smoking behavior
2 Obesity
3 Blood pressure
4 Blood sugar
5 Cholesterol
6 Women aged 30-50 years or women who ever had sexual relations

Cancer Early Detection Program
Activities for early detection of breast cancer and cervical cancer in women aged 30-50 years or women who ever had sexual intercourse include:
1 Breast Examination
2 Klinis (SADANIS)
3 Acetic Acid Visual Inspection Examination (IVA)

Nusantara Movement Program to Reduce Obesity Rates (GENTAS)
1 BMI measurement
2 Risk behavior interview
3 Education on healthy lifestyle behavior

HPV immunization
1 Aimed at school-age children in five provinces (Jakarta, Yogyakarta, Surabaya, Manado, and Makassar)
2 The plan is to expand it gradually to all provinces

Curative-Rehabilitative

Case handling and management is in accordance with the National Medical Service Guidelines (PNPK) for cases of non-communicable disease (NCS)

Palliative Care Program for Adults

Source : (Indonesian Ministry of Health, 2019)

Furthermore, Regulation of the Minister of Health of the Republic of Indonesia No. 13 of 2022 concerning the Strategic Plan of the Ministry of Health for 2020-2024, provides general guidelines in the management of cancer in Indonesia, including promotive-preventive and curative-rehabilitative efforts. More specifically based on Regulation of the Minister of Health Number 27 of 2019 concerning Management of Breast Cancer and Cervical Cancer. Early detection of breast and cervical cancer is carried out through breast examination and Visual Inspection Test with Acetic Acid (IVA). Breast cancer prevention is carried out with education on self-breast examination (BSE) and Clinical Breast Examination (SADANIS). Furthermore, efforts to prevent lung cancer that are carried out are health education related to the dangers of smoking and increasing a healthy lifestyle, especially on the possibility of lung disease starting from the community level, primary, secondary and tertiary health services.

In the context of tackling cancer, it is targeted that the number of districts/ cities that carry out early detection of cancer reaches ≥ 80% in the population aged 18-50 years by the end of 2024 (P2PTM Action Plan, 2020).

In the JKN program, coverage of moderate and severe JKN participants also receive health screening services, based on age at 14 screening services from BPJS Health, this includes breast, cervical and lung cancer. BPJS Health has programs such as screening (primary prevention) through self-assessment of the health of participants and their families as well as consumption patterns of nutritious food. Medical history screening is also carried out through anamnesis and physical examination by the First Level Health Facility (FKTP) (examination of body mass index (BMI) and abdominal circumference). The purpose of this activity is to determine the risk of diabetes mellitus, hypertension, chronic kidney disease, and coronary heart disease. Next is health screening or screening (secondary prevention), such as diabetes mellitus screening through GDP and GDPP examinations; cervical cancer screening through IVA examination, pap smear and cryotherapy as a follow-up to positive IVA; and breast cancer screening through clinical breast examination (SADANIS).

At the curative and rehabilitative levels, the government has strategies related to improving case management according to the National Guidelines for Medical Services (PNPK) according to the type of cancer, efforts to increase efforts and integrate palliative care, improve the referral system. On the other hand, related financing, in recent years the government has had several action plans related to cancer management such as (Directorate General of Disease Prevention and Control, 2020):

- Innovative financing sources such as the policy of increasing premiums for JKN participants;
- Cost sharing plans with private insurance, donors, patients, industry or other sources of financing;
- Re-allocation of tobacco excise funds;
- Assessment of health technology, to pay attention to cost-effectiveness principles in prioritizing programs and treatment;
- Use of biosimilars/generics in the JKN program at a lower cost than the originator.

One of the policies in terms of cost efficiency is through increasing the capacity of Health Technology Assessment (PTK). Health Technology Assessment in the National Health Insurance program (PTK-JKN) is a policy analysis that is carried out systematically with a multidisciplinary approach to assess the impact of using health technology. This policy is supported by Regulation of the Minister of Health of the Republic of Indonesia Number 51 of 2017 concerning Guidelines for PTK in JKN. The purpose of conducting a study of health technology is to obtain scientific evidence that helps policies related to benefit packages in the JKN system, both preventive ones such as screening and early detection, as well as medicines in the JKN benefit package. The existence of PTK aims to support the improvement of quality control and cost control for health interventions or technology in the JKN era.

In terms of cancer treatment, a PTK study was conducted to assess whether prevention programs such as screening (for example: cervical cancer screening with a DNA test, VIA or other procedures can be categorized as cost-effective). In addition, the study of oncology drugs significantly influenced the cost burden in the JKN era, so this study helps to see a value for money perspective in cost efficiency in the JKN scheme. This process helps to increase the efficiency and allocation of funds in the health system. In practice, PTK examines not only the costs incurred from health services but the perspective of the patient (societal) so that this study can provide policies related to health technology in Indonesia, in this case including cancer.

Some of the above policies provide an overview of the government's efforts in dealing with cancer, as well as efforts to increase the efficiency of both payers (BPJS Kesehatan) and health facilities so that optimal health services can be achieved and the financial burden can be handled, especially for health resources for health service providers.

The current national policy focus is on increasing appropriate and effective interventions, as well as increasing efficiency in the health system as well as rational allocation of financing. The existence of the JKN program has a significant impact on reducing medical costs incurred by patients/households. However, policy options are still needed that provide room for patients to reduce costs, especially related to OOP for access to health services, such as reducing non-medical OOP costs and evaluating lost productivity due to cancer. So that if there are policy options related to this matter, it can trigger an increase in attendance and adherence to treatment due to better access and equity, and in the long term will affect the improvement of the quality of life of cancer patients.

Currently, the Indonesian Ministry of Health also has a flagship program for equitable access to cancer services, especially in remote areas. This equity is carried out in collaboration between the government, the National Cancer Center Hospital, and The University of Texas MD Anderson Cancer Center. In the regulation of the Minister of Health of the Republic of Indonesia No. 13 of 2022 concerning amendments to the Minister of Health Regulation No. 21 of 2020 concerning the Ministry of Health's strategic plan for 2020-2024 the referral system arrangement that is currently being carried out is to develop a network of national, provincial and regional referral hospitals. Development of 7 standardized national referral hospitals; 2 provincial referral hospitals, and 19 regional referral hospitals will cover the distribution of priority services for 9 types of deadly diseases (heart, cancer, diabetes mellitus, kidney, liver, stroke/brain, MCH, TB, infectious diseases). The target of this policy is 42 national referral hospitals which are projected to become centers of excellence in administering the 9 types of diseases above. Through this effort, it is hoped that each region will form a superior service network for 9 priority types of diseases supported by the type and competence of human resources, as well as the availability of infrastructure and tools according to the stratification/level of service set.

In addition to policies at the national level, policies at the regional level are also needed to reduce the prevalence of cancer and assist patients in undergoing treatment. One of the local government policies that can be used as best practice can be seen in Fifty Cities District in West Sumatra Province. The local government has issued Regent Regulation No. 23 of 2019 concerning the prevention of breast cancer and cervical cancer. This Regent Regulation is made with the aim; expanding the scope of mass screening in the community in accordance with the regulations of the minister of health, guaranteeing the sustainability of the program through obtaining data and information on status, public health status and improving the quality of the delivery of public and individual health services for breast cancer and cervical cancer. The interventions carried out involved the role of the community, central government, and local government. However, it has not involved the role of BPJS Health directly as a strategic partner. This policy also contains a monitoring and evaluation strategy carried out by the district government, namely by forming a committee of experts on breast cancer and cervical cancer management. This expert committee will coordinate with the national cancer management committee. In terms of funding, the budget for implementing this program will come from the APBN, APBD, private sector, health insurance and/or other sources.

Other provinces in the Sumatra region that also have policies to support cancer management are Central Bangka Regency, Bangka Belitung Islands Province. Central Bangka Regent's policy number 14 of 2022 regarding the schedule for the retention of substantive archives for the people's welfare sector within the Central Bangka Regency government. The policy was issued because it saw a fairly high number of cancer patients in the region. In 2019, there were many cancer patients in this province who did not seek treatment at health facilities. So the governor issued a policy to add health facilities in the form of a pratama hospital in Central Bangka Regency. However, until 2022 the Provincial Government of the Bangka Belitung Islands is still trying to accelerate the construction of the radiotherapy building and trying to complete health facilities at the Hospital so that they can provide services and treat cancer patients.

The two regional policies above focus on preventive, curative and rehabilitative actions for cancer patients. This is in line with the three pillars recommended by the Indonesian Cancer Foundation in the management of breast cancer namely, health promotion for early detection, diagnosis of breast cancer, and comprehensive management of breast cancer. In addition to the existing policies above, until now there has been no policy related to vaccination of cancer patients and financial support during treatment if it has to be done outside the island. This is important considering that cancer patients who are referred outside the area due to limited infrastructure can increase their OOP. As an example; when the accommodation policy has been covered, but transportation costs from the place/ halfhouse to the hospital still require money.

Based on Basic Health Research (Riskesdas) data (2018) detection of breast cancer and cervical cancer in the following three provinces has increased from 2019-2022, the provinces of Bangka Belitung Islands by 30.24%, South Sumatra 25.16%, and West Nusa Tenggara 23.22%.

These three provinces are the most significant in increasing promotive and preventive efforts for breast cancer. This increase can be caused by various factors, this study seeks to deepen information related to the factors that support the treatment of cancer patients seen from the experiences of patients and the actors around them. In addition, this research also wants to get a sharper picture of the direct non-medical expenses that are still a burden to the families of cancer patients while they are undergoing a series of treatments.

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Chapter 3

Theoretical Framework

Chapter 3

Theoretical Framework

3.1 'Illness Trajectory' Model

The concept of 'trajectory' refers to a situational analysis of individual or patient experiences regarding the illness they suffer, about the use of health services, and the role of the health and social care organizations involved in their surroundings. This concept was first introduced by Strauss et al., (1976) which provides a framework to help explore narratively the experiences of patients and the actors around them when suffering from illness. The 'illness trajectory' framework has been used for approximately 30 years as part of research and observational practice to describe the experience of chronic illness, this concept continues to evolve today (1976 Straus, n.d.; Burton, 2000; Reed & Corner, 2015).

This approach centers to the course of the disease. For the patient, the course of the disease represents the cumulative effect of the disease on physical symptoms, changes in the individual's social world, and influences and perceptions of one's own identity. In this process, the 'illness trajectory' model can be applied to assess the specific phases of the disease experienced by the patient and the surrounding actors/individuals/organizations, starting from the initial identification and discovery of clinical symptoms or at the next, more severe level.

One of the most powerful forms of expression in expressing suffering due to illness is narrative. Hyden et al., (1997) explained that tracing and exposing a narrative approach to disease sufferers (for example, cancer patients) can provide an opportunity for a deeper and stronger presentation of experiences and suffering, outside of biomedical action. An approach using narrative is important, especially in terms of gathering information and understanding the circumstances in which the illness will affect the daily life of the patient (Bury, 2001; Hydén, 1997).

Several studies have been conducted using the basic illness trajectory approach from Strauss et al., (1984) and Corbin and Strauss (1992), especially for chronic diseases. Furthermore, new frameworks were developed as part of the analysis of cancer patients, one of which was the Trajectory of Breast Cancer (TBC) model published by Smit et al., (2019). There are 8 core stages built on the developed model, which include:

Pre-diagnosis

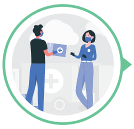
Diagnosis

Between diagnosis and treatment

Treatment

Post treatment

Advanced stage disease (advanced)



Survival (remission)

Relapse

Specifically, these eight core stages are illustrated in Figure 2.

Figure 2. TBC Model by Smit et al. (2019)

Pre-diagnosis	• Symptom appraisal is not worrisome • Delay in help-seeking • Self-blame • Fear in anticipation of results • Difficult to wait for outcome
Diagnosis	• Shock/disbelief; fear and trauma/devastation upon receiving diagnosis • Thoughts of death • Shattered feelings of indestructibility • Rely on knowledge from others' experiences; religion

Between diagnosis & treatment	• Fearful about treatment • Trust in HCP abilities; active involvement with decisions • Get all the information • Lack of information from HCP • Support and kindness from HP; satisfaction with HCP experience
Treatment	• Toxicity of treatment and side-effects; fatigue; functional limitations • Support from friends; spouse/partner; HCP • Difficulty with hair loss • Financial constraints • Keep positive mindset
Post-treatment	• Greater appreciation of life; positive personal growth • Acceptance of post-treatment body; embracing new look • Difficulty with loss of breasts; alienation from body • Support from spouse/partner; group/network; HCP • Functional limitations; physical pain • Satisfaction with HCP experience
Advanced disease	• Must continuously monitor condition • Avoid/denial of condition • Death becomes a reality • Not afraid of dying • Resistance to the disease • Rely on relationship with God
Survivorship	• Uncertainty/fear about recurrence/future • Disease happened for a purpose; desire to help other women; identity connection with being a survivor • Support from group/network; positive personal growth • Acceptance of body; embracing new look; difficulty with loss of breasts • Rely on religion and positive mindset
Recurrence	• Anger; shock/disbelief; sadness; acceptance; disappointment; fear • Trying not to mistrust information • Life if turned upside down

Based on the model built by (Smith et al., 2019), this study used 5 main stages, from pre-diagnosis to post-treatment. Each stage represents information related to personal and caregiver attitudes towards the disease experienced, strategies for seeking help and information on treatment, the role and assistance of people around, services at the hospital, the treatment process and motivation after treatment. Thus, this search is not only useful to see the treatment cycle in cancer patients, but also to understand which organizations or actors are involved and to what extent these roles can affect the healing process in cancer patients. Not only that, with this tracing, this research can understand the extent to which the factors influence the treatment process, especially the costs while undergoing treatment (direct non-medical costs and indirect costs). The stages in the model adapted in this study are limited to the post-treatment stage, according to the information to be explored and studied. The information to be studied in general is presented in Table 1.

Table 1. Illness Trajectory and Information Identification

Illness Trajectory	**Information Identification**
Pre-diagnosis	1. Initial examination due to unknown symptoms
Diagnosis	1. Patient response to cancer diagnosis 2. Response and role of the family/support system at the time of diagnosis
Between diagnosis and treatment	1. The role of the family/support system 2. Health facility information 3. Resources related to cancer treatment (before going to a health facility)
Treatment	1. Resources related to cancer treatment 2. Experience during treatment 3. The role of the family/support system
Post-treatment	Patients's post treatment motivation

Source: Generate by researchers

**The information that will be identified will be developed into a qualitative question instrument that will be given to cancer patients and their families/caregivers.*

Cancer has several levels of progression (speed of evolvement) that affect the level of risk and attitude of courage in taking risks (Pangestu & Karnadi, 2018). The severity of the cancer suffered has implications for the level of risk of financial burden that must be incurred by cancer patients and their families. In addition, the level of severity (the part that must be passed) also has an impact on the attitude of both patients and their families to pay for treatment. Thus, this study tries to answer research questions by referring to the severity of cancer, what treatment needs are needed, and to what extent the role of the surrounding actors has significance in the healing process. For this reason, the study adopted the Illness trajectory model as a research theoretical framework.

3.2 Out-of-Pocket Costs in Health Care

Out-of-pocket costs (OOP) describe the economic burden as the loss of economic resources and opportunities associated with the occurrence of a disease (Brown and Yabroff, 2006, in Pisu et al, 2010). Besides, OOP spending can also indicate an increase in the utilization of health services in a community (Bayati et al, 2019). However, increased spending on OOP costs for treatment, especially for the poor and vulnerable groups, can lead to impoverished treatment. In the Indonesian context, an increase in OOP costs can cause a household to sell several assets, issue savings, and go into debt, coupled with the vulnerability of the labor market which is still dominated by the informal sector which leaves employees without minimal access to social security. Thus, even though OOP shows an increase in the utilization of health services, there is a problem of justice if those who have to issue this OOP are socio-economically poor and vulnerable groups.

OOP costs are divided into three categories namely: psychosocial costs, indirect costs (risk of loss of productivity), and direct costs (idem). More specifically, direct costs can be divided into medical and non-medical costs which are paid either by third party payers (such as public/private insurers), or by patients using their own financial resources.

01. **Direct costs.** This fee is incurred since the patient received a medical diagnosis of cancer. These direct costs include doctor fees, hospital treatment costs, control, and drug shopping. These costs can be borne by the insurer as well as by the patient and family directly. Meanwhile, direct non-medical costs are costs such as transportation costs, lodging, parking, to social costs such as the cost of providing food to people who take patients to the hospital.

02. **Indirect Cost.** These costs arise such as lost time for work or other productivity due to having to take medication. These costs in the long term can affect income and decisions to work for patients and caregivers of cancer patients so that the impact is not only on the income and financial condition of the patient but also on the patient's household.

03. **Psychosocial Cost.** Pisu et al (2010) explain it as a loss of quality of life with the emergence of several features such as: anxiety, depression, cancer burden, marital discord, negative changes in social and family relationships, and future uncertainty.

The elaboration of the concept of OOP costs can help this study to analyze what direct non-medical costs are incurred by patients and their families. In addition, this concept also helps to review more deeply how much direct non-medical costs are incurred. This is alligned with the research findings by The Economist (2020) which found that there is a centralization of health services in Indonesia which results in cancer patients having to pay for non-medical expenses. In order to deepen the results of the research findings, the OOP concept was used in this study.

3.3 Resistance in Cancer Patients

The concept of resilience was first developed by Antonovsky (1979) in Luo et al., 2020) as a "general resource of resistance". This concept refers to resources that help a person to effectively avoid or deal with psychosocial stress. Recently, the concept of resilience has been developed in studies of chronic diseases, including cancer. Specifically Luo et al (2020), define resilience as the capacity and process of individual dynamic recalibration to change the level of psychological stress and the performance of individual functions. Dynamic here is defined as an ever-changing process that causes a person to continue to adapt not only to himself but also to his environment during a difficult period due to cancer.

Several studies have found that resilience in a person is characterized by emotional stability, defense mechanisms in managing situations, self-efficacy, self-regulation, even to the point of the emergence of self-confidence, self-esteem, and curiosity and understanding of the difficulties being faced (Beardslee, 1989; Masten, 1999; Rutter, 1987, in Luo et al, 2020). Rutter (1987) also found that these traits play a positive role in a person when facing stress or difficulties. Thus, the existence of resilience in a person will be a protection for the difficulties faced (Sun and Stewart, 2007).

In the context of cancer patients, Luo et al (2020) explained that there are three interrelated factors that cause a person to have resilience. The first is the existence of antecedents or in this context the difficulties that arise because of cancer. The second is the characteristics of resilience, namely the emergence of ego resilience, recalibration, and the process of interaction with the surrounding environment. And the third is a consequence that includes the level of stress and a person's ability to function individually and socially.

Cancer patients often need assistance from family, close friends, or neighbors. In this context, the concept of resilience does not only play an important role for cancer patients but also for their caregivers. Saria et al (2017) found several characteristics of resilience in caregivers such as acceptance of the conditions faced by patients, planning, positive meaning of difficulties encountered, time sharing and playing a positive role in the level of care for cancer patients. This confirms the importance of a palliative care approach to include patients and families to optimize services. Palliative care services improve caregiver health in terms of quality of life and satisfaction with care (Røen et al, 2018).

The concept of resilience in this study is to analyze the willingness and ability of patients and caregivers to navigate difficulties caused by cancer. Having a positive attitude on both sides can contribute to a willingness to continue learning to understand the cancer healing process, a willingness to comply with treatment, and the resources used to encourage this resilience. By analyzing these matters, this research can provide an understanding of the enablers that policy makers can take to reduce the financial impact of cancer in Indonesia.

Chapter 4

Research Methods

Chapter 4

Research Methods

4.1 Research Approach and Design

The approach used in this study is a qualitative approach. The focus of qualitative research lies in the depth of the information extracted, the capture of more specific information, and the meaning of the informants' experiences slowly (Chowdhury and Chandra, 2021). The method used in this research is a case study. This study will explore individual experiences as patients based on the 3 types of cancer with the highest prevalence in Indonesia. The case study method was chosen by the research team to identify holistically and provide meaning to the life experiences of informants in a study (Baxter and Jack, 2008). The type of case study in this research is a descriptive case study, where the results of this research will be used to provide an overview of an intervention or phenomenon and life experiences that are experienced by informants (Baxter and Jack, 2008).

4.2 Selection of Informants

Participants who served as informants in this study were determined using the purposive method (O'Reilly, 2009) and the stratified random sampling method (Omona, 2013). The purposive method was used to sort candidate informants according to the research criteria, namely only cancer patients who were undergoing treatment at the final level or were already in the recovery stage. The purposive method is not concerned with the size of the number of representative informants (population) to be interviewed because qualitative research cannot be generalized. Selection of informants using the purposive method means finding informants who can provide as much information as possible on matters relating to research problems and research objectives in depth.

As for the stratified random sampling method (Omona, 2013), the research team tried to divide the cancer patient population into several sub-populations. So that members of each sub-population are relatively homogeneous to one or more characteristics and relatively heterogeneous from members of other sub-groups. This was taken because the researchers considered three variations of the most prevalent types of cancer in Indonesia. In this method, a variable framework is needed to sort out informants according to the research objectives. This variable framework includes the type of cancer, region of origin, age, gender, cancer stage, education and work of the patient and family. It aims to capture the complexity of the OOP problem and its resilience to cancer patients across different types. In more detail, the informant variable framework is divided in the table below:

Table 2. List of Research Informant Criteria

No	Informant	Province	Age	Gender	Cancer Stadium	Total Informant
1	Breast cancer patients and caregivers	Jabodetabek	30-40	P	2-3	2
2	Breast cancer patients and caregivers	Jabodetabek	41-60	P	2-3	2
3	Cervical cancer patients and caregivers	Outside Java	35-45	P	2-3	2
4	Cervical cancer patients and caregivers	Outside Java	46-60	P	2-3	2
5	Lung cancer patient and caregiver	Sumatra and/ or Eastern Indonesia	20-30	L	2-3	2
6	Lung cancer patient and caregiver	Sumatra and/ or Eastern Indonesia	40-50	L	2-3	2
Total Informants						**12 people**

4.3 Data Collection Methods

Data collection was carried out from November to December 2022. To obtain the necessary data and information according to the research context, several data collection techniques were used through:

1. **Study of literature.** This is done by studying and reading various literature related to research discussions on socio-economic problems in families and cancer patients, national and regional health policies, and health services in Indonesia. Literature comes from various policy documents, journals and previous research results.
2. **Deep interview.** Conducted face to face with informants who fit the criteria to obtain in-depth data and information in accordance with the research discussion. In-depth interviews with informants were carried out by asking questions according to interview guidelines designed in a semi-structured manner and in-depth probing so that the interviews were directed (Mason, 2018). For in-depth interviews, the research team used a direct approach to cancer patients and their families. Before conducting the interviews, the research team first explained the aims and objectives of the research to potential informants, and after that the research team provided informed consent as written evidence of willingness and granting permission for information during the interviews to be used in research. The interview was recorded by the researcher with the permission of the informant and then transcribed. The researcher also presented the results of the field notes as material to be conveyed during internal team meetings to inform the analysis process and monitor data saturation. To maintain the confidentiality of the informants, this study uses the informant's code followed by the serial number of the informant in each direct interview excerpt.

4.4 Scope and Research Location

The unit of analysis for this study was cancer patients based on their type and the location of this study was carried out in DKI Jakarta. Patients are currently undergoing treatment at several hospitals in DKI Jakarta and are selected based on predetermined informant criteria. The selection of this location was carried out by considering the centralization of special health services for cancer in the DKI Jakarta area. Based on research by The Economist (2020), the centralization of services, resources, and complete technology for treating cancer is a problem in the health insurance system in Indonesia. Referring to the research findings, we argue that DKI Jakarta as the national capital has more complete hospitals and enough medical personnel compared to other provinces in Indonesia and causes more patients to pile up in Jakarta.

This is also supported by the findings of PRAKARSA (2020), which shows that the UHC index in DKI Jakarta province has reached 70.

This shows that health facilities and services in DKI Jakarta are quite complete and can provide maximum services for all types of diseases including cancer.

4.5 Processing and Analysis Data

This study uses thematic analysis (Creswell, 2013) to identify, analyze, obtain patterns of information obtained, and construct themes that emerge from data collection. This research also follows the stages of thematic analysis using the systematic text condensation (STC) method by Malterud (2012). The reason for using this method is because this method provides a concise reference for getting common threads in the analysis of different cases, which is suitable for this study. STC is also a descriptive approach, emphasizing the participants' experiences as expressed by themselves, rather than exploring the possible meanings that underlie what is said. Thus, minimizing the dominance of researchers on the results of field data.

The data collected through the data collection techniques above are then analyzed through a coding or grouping and storage system so that data access is easy to use. Thematic analysis (Creswell, 2013) is a flexible method because this method does not depend on theory and epistemology so that it can be applied to a variety of theoretical and epistemological approaches. The purpose of using thematic analysis is to construct themes from a set of collected data. The thematic analysis was carried out through six stages, namely (1) familiarizing with the data; (2) compiling initial codes; (3) constructing themes; (4) examine the resulting themes; (5) define the themes; and (6) making groupings of predetermined themes (Braun, V. & Clarke, V, 2006).

Chapter 5

Field Findings: The Financial Consequences of Cancer Treatment in Indonesia

Chapter 5

Field Findings: The Financial Consequences of Cancer Treatment in Indonesia

5.1 Attitudes and Experiences of Patients and Their Families When Diagnosed with Cancer

Cancer patients have a greater chance of recovery if they are diagnosed and treated earlier. However, it is not uncommon for cancer to have no significant symptoms and encourage cancer sufferers to seek medical attention. The results of interviews with patients and caregivers on three types of cancer found that cancer is identical to a serious disease with symptoms that are also serious, and the assumption that cancer arises due to an accumulation of unhealthy lifestyles. This causes cancer patient informants and caregivers who feel they have a healthy lifestyle, do not have a lineage with a history of cancer, to be late for an earlier examination.

> *"(I was) shocked, shocked. Because I don't have it (unhealthy lifestyle), I don't smoke, there are no risk factors. There is no hereditary factor either. Yes, some of my colleagues do smoke. And if someone smokes, I like to avoid it."*
>
> *(D, lung cancer patient, Karawang).*

> *“I’m in shock. Yes, I don’t believe how come I can get it.”*
>
> *(IEW, lung cancer patient, Lampung).*

> *“Yes, what a surprise. Because according to her mother she eats healthy food, never smokes, and has a healthy lifestyle. That’s why I was shocked, I was shocked.”*
>
> *(AF, lung cancer caregiver, Karawang).*

In addition to strong self-views related to having a healthy lifestyle, the lack of knowledge about cancer also causes cancer sufferers to only perform simple treatments when the first symptoms appear. This was disclosed by the following two informants:

> *“...I used to have vaginal discharge. The leucorrhoea smelled really bad, so I only took medicine (from the store), I was working in the household at the time, right (ART), so my employer had a drugstore so I took medicine from his shop. But I continue to experience vaginal discharge, I think it’s cured. And after a while, how come after the fasting month my body feels increasingly unwell, and I experience a drastic weight loss too...”*
>
> *(V. Cervical cancer patient, Karawang).*

> *“When I (initially) got it (the lump) was still small, at that time my brother was only receiving treatment in the village first and my sister was still silent and didn’t tell anyone. it’s big, isn’t it, shut up brother, then when you’re big, you’re taken to the hospital...”*
>
> *(P, caregiver of breast cancer patient, Bangka Belitung).*

A study on breast cancer patients in Yogyakarta found that patients tended to reject early symptoms as an early indication of the appearance of cancer (Prabandari, et al. 2022). In line with the findings of this study, the interview excerpt above illustrates that cancer patients at the pre-diagnosis stage tend to reject the initial symptoms that appear as an indication of serious illness. Only when these symptoms get worse, such as the intensity of the pain that keeps recurring, changes in the shape of the lump, and pain in several parts of the body, will the cancer patient be moved to have an examination at the hospital. Denial of early symptoms is also an indication of low public health literacy in high-risk diseases such as cancer (Brand, et al. 2019).

Undergoing cancer treatment medically is not easy, it is strongly influenced by various factors, especially the experiences and motivations of the cancer patients themselves. Usually, by seeing firsthand the final events of cancer that are not treated medically, it becomes a lesson as well as an experience for cancer sufferers to continue treatment and motivate them to take medical action, according to the experience of the following respondents:

> *"...at that time the lump was like this (showing hand), then the medicine was village medicine, yes, it contained turmeric powder. I'm afraid to die, it's bad (breasts), people will run away, that's what I'm afraid of. So I was determined to have surgery, the important thing is not to come back (recover)"*
>
> *(N, breast cancer patient, Belitung).*

A person's knowledge about cancer also greatly influences the actions taken by cancer patients. Like respondent D, a lung cancer patient from Karawang who works as a doctor, he knows the process that must be followed, so he can examine himself and decide for himself according to his knowledge.

> *"Then go to the lab for an examination, why do the X-rays show these symptoms of cancer, I will immediately continue the examination. the scan results I was diagnosed with cancer. They were given the choice of (hospital) A or B (all hospitals are in Jakarta). I said (hospital) A aja (hospital in Jakarta)..."*
>
> *(IEW, lung cancer patient, Lampung).*

The quotation above is in accordance with the results of research (Yulia. 2012) that as much as 92% of patients' level of knowledge about therapeutic treatment is high in patients who have undergone chemotherapy treatment and according to the results of research by Febriyanti (2013) which shows that respondents who have low knowledge in the late group are at risk 1.86 times greater than the not too late group.

In addition to the lack of knowledge and experience that affects the patient's actions, health workers also do not provide proper guidance to patients and their families in the early stages before undergoing treatment. This was disclosed by one of the caregivers of a lung cancer patient from Lampung Province who was confused about having to go to a doctor at which health care center to seek treatment.

> *"...in July we decided to have surgery, from there we started following the steps and were examined but we didn't seem to know where to go first, first to the Oncologist or to the Lung Doctor. We were only told that my father had cancer in the lung, right? But we were directed where to go first to Ongology or to the lungs first, right? then we decided to go to the pulmonologist..."*
>
> *(R. Caregiver of lung cancer patients. Lampung).*

The interview excerpt above explains that medical personnel who do not provide treatment directions and referrals to patients and their families can have an impact on delaying further treatment. In addition, this initial emergency can also worsen the patient's condition. The results of the interview stated that only when the patient was immobile, at the initiative of the patient's family, was examined by a pulmonary doctor.

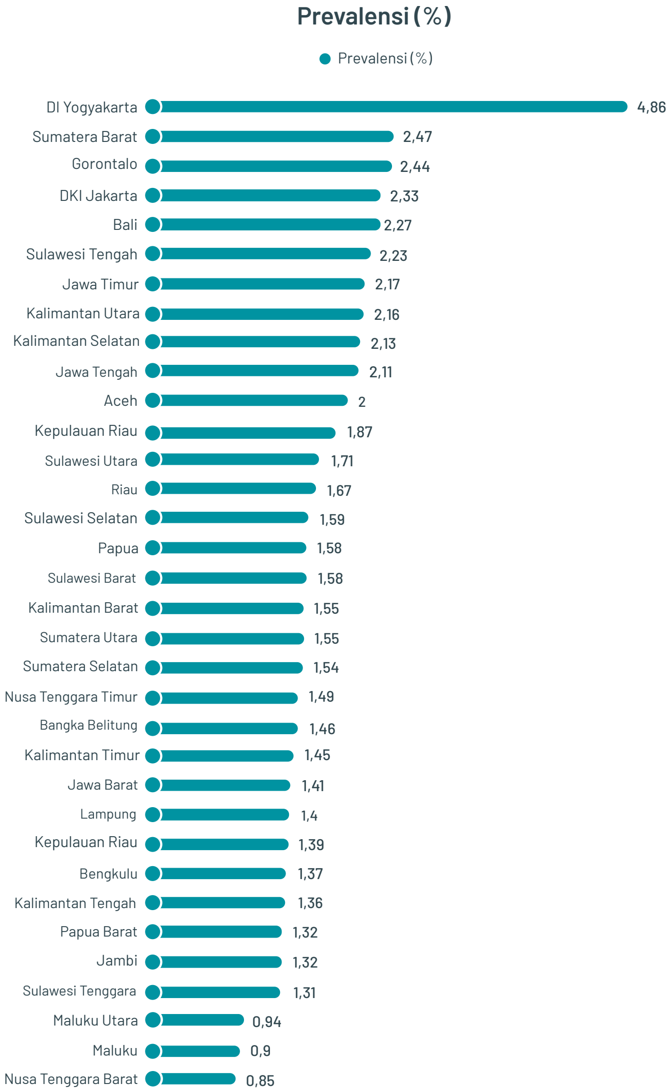
On the other hand, the completeness of equipment for detecting cancer at the regional level is also an obstacle for cancer sufferers to obtain information about their disease. One informant from Bangka Belitung Province explained that the process of waiting for one month for samples taken at a hospital in Bangka Belitung had to be sent to Jakarta first and could take as long as one month.

> *"...the results of the anabelt (results of initial sample examination) in Belitung yesterday were ordered to be sent back to Jakarta, so we are waiting for the results for more than a month..."*
>
> *(F, caregiver of breast cancer patient, Bangka Belitung).*

Delayed detection of cases of cancer patients in Bangka Belitung will continue to occur considering that cancer registration referral hospitals are still concentrated in only 14 type A hospitals in 14 provinces. Bangka Belitung is not included. In more depth, the analysis of this study also found that even though a province has a high prevalence of cancer patients, such as Gorontalo Province (see figure 3), this province does not have cancer registration referral hospitals.

The determination of the registration center hospital is contained in the Decree of the Minister of Health of the Republic of Indonesia number HK.02.02/MENKES/410/2016 concerning Cancer Registration Implementing Hospitals and National Cancer Burden Data Control Center Hospitals. The problem occurred because the hospital's scope of work was only for a number of districts and cities in each of these provinces and did not become a registration center for the surrounding provinces. So, for patients who come from outside the scope of work of the hospital, they are forced to get a medical assessment in Jakarta and it takes longer.

Figure 3. Prevalence of Cancer patients based on Doctor's Diagnosis in Population of All Ages by Province



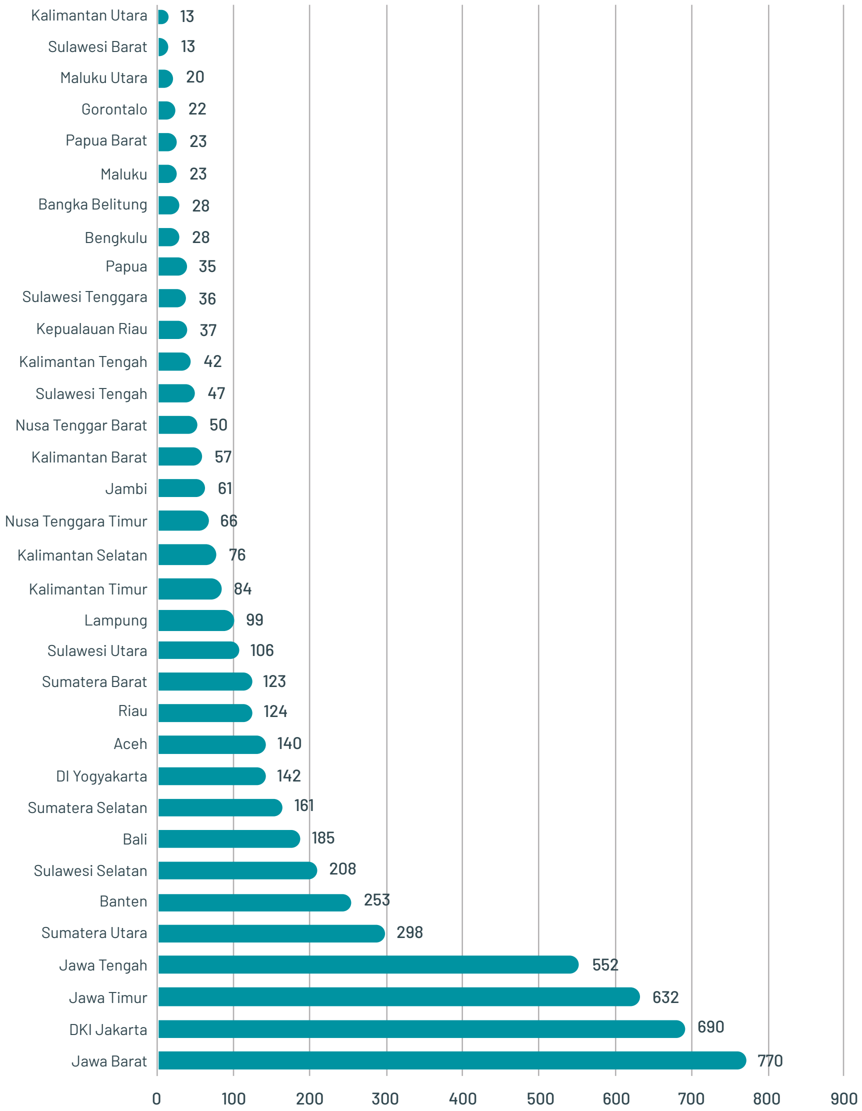
Source: Indonesia Ministry of Health Basic Health Research (2018)

The slow handling of cancer in the early stages of treatment is also due to the limited number of medical specialists at the regional level. The informant from Lampung explained that there was only one pulmonary specialist at the hospital in Lampung, who even had a retired status. The doctor also only comes in once a week which makes it difficult for cancer patients to get adequate initial treatment. This is expressed in the quote below:

> *"....we don't know that the doctor at the hospital in Lampung is only (present) one day a week because he has retired"*
>
> *(IEW, lung cancer patient, Lampung).*

The interview excerpt above is confirmed with data from the Ministry of Health in 2021 (Arlinta, 2021). The data noted that Indonesia only has 139 internal medicine specialists as hematology oncology consultants who are only spread across 17 provinces. Most internal medicine specialists are also concentrated in big cities on the island of Java (see figure 4). Meanwhile, the number of surgeons nationally is only 217 people and spread across 28 provinces. This number will be smaller according to each doctor's specialization category, which is: only 118 doctors specializing in radiation oncology, and only 80 doctors specializing in pediatric hematology and pediatric oncology consultants. This number is quite small considering that cancer cases in Indonesia in 2020 alone reached 396,914 cases (GLOBOCAN, 2020) which were not only concentrated in Java.

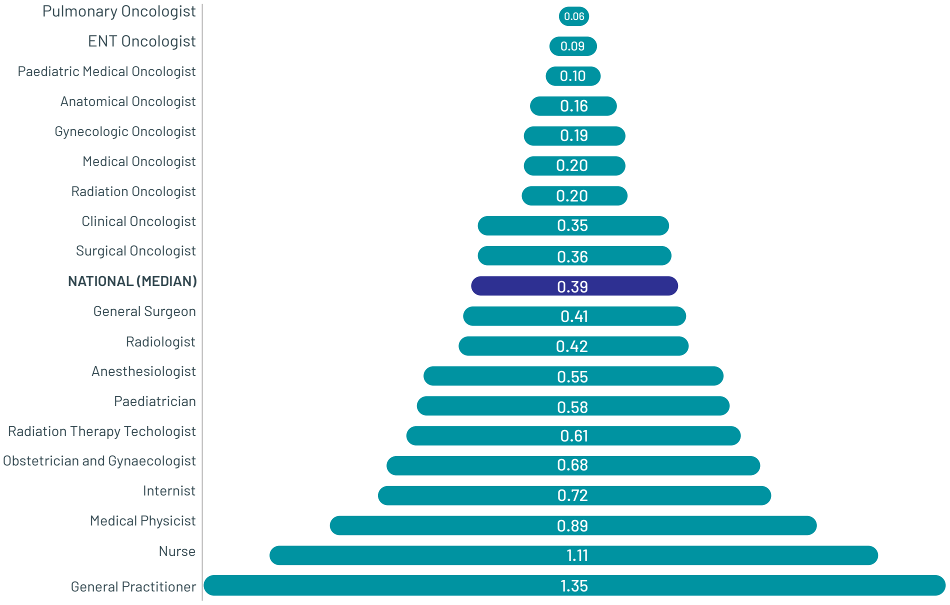
Figure 4. Number of Internal Medicine Specialists in Hospitals by Province in 2021



Source: Republic of Indonesia Health Profile 2021

In Figure 5., the staff availability ratio (Staff Availability Ratio) for oncology specialists is below 50% and some are below 39% (median in Indonesia). General practitioners, nurses and internal medicine specialists are projected to have a SAR of more than 70%. Meanwhile, the low availability ratio for oncology specialists reflects the large gap between the need for and the availability of this specialty, so this figure is considered as a high scarcity of resources.

Figure 5. Median number of oncology doctors in Indonesia (2022).



Source: Gondhowiardjo et al.,(2022)

Treatment of cancer in Indonesia is centralized in the capital city of DKI Jakarta. This study found that all cancer patients immediately received referrals to hospitals in DKI Jakarta after receiving the results of a medical assessment by a doctor. This referral was made because the health facility where the cancer sufferer received the diagnosis did not have readiness in terms of technology, human resources, and the completeness of cancer treatment facilities. This was expressed by two informants as follows:

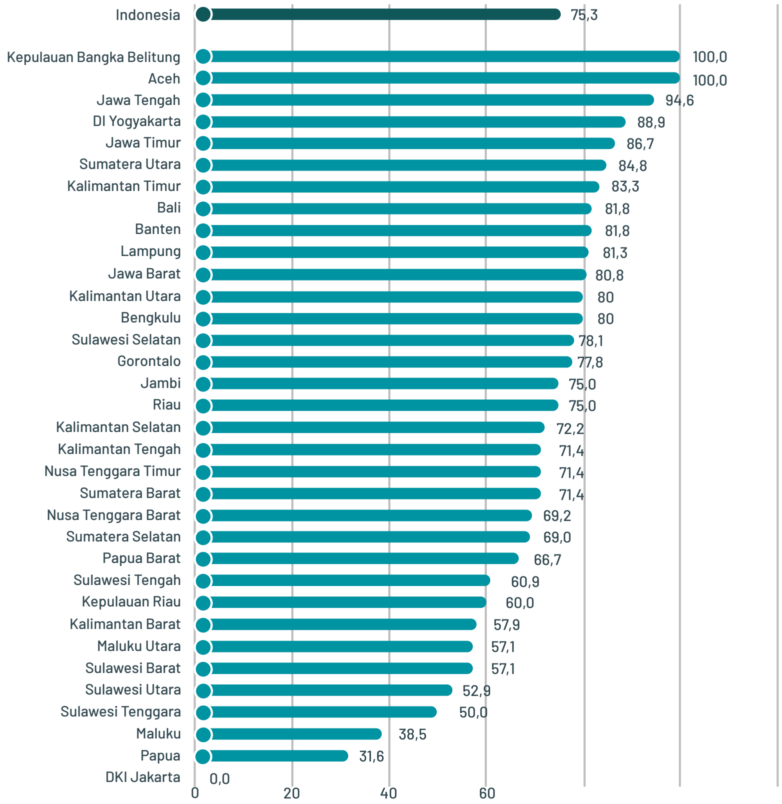
> *"Indeed, the facilities in Bangka Belitung are not complete, so the doctor referred him to a hospital in Jakarta, that's just a district hospital. Yes, we think going to Palembang is more difficult, what's really nice is going to Jakarta. The cost to Palembang is also higher. Sometimes when we go to Palembang we have to transit to Jakarta first, then to Palembang there are no flights all the time, if it's Jakarta every day, then the cost is rather cheap compared to Palembang."*
>
> *(N, breast cancer patient, Bangka Belitung).*

> *“.... to the pulmonologist we were referred to a hospital in Jakarta, at that time the covid was still exploding right, all of these hospitals have become covid referral hospitals...”*
>
> *(R, lung cancer caregiver, Lampung).*

The two interview excerpts above describe the perceptions of cancer patients and their caregivers that health human resources, medical technology, and hospital facilities in their areas of origin are inadequate. This can occur in cancer patients who come from Bangka Belitung and Lampung Provinces, because these two provinces mostly only have type C hospitals, even Bangka Belitung Province only has hospitals with the highest type being type C only.

Data from the Ministry of Health noted that there were 1,593 type C hospitals in Indonesia. This type of hospital also has the largest number compared to type D hospitals (905 hospitals), type B (437 hospitals), and only two percent of hospitals (47 hospitals) in Indonesia are in the type A category. specialist medical service centers including internal medicine, type C hospitals do not have complete treatment for cancer patients.

Figure 6. Data on the distribution of type C hospitals by province in Indonesia in 2021



Source: Republic of Indonesia Health Profile 2021 by Indonesian Ministry of Health

Referrals for treatment to DKI Jakarta are a new problem for patients and their caregivers. In addition to concerns regarding costs and time that must be spent,patients and caregivers are worried about the situation of the home when they have to seek treatment outside their home town, in Jakarta, which doesn't only take one or two days. This also contributes to increased stress, panic, and unpreparedness to face the consequences of cancer such as: long treatment processes, risks of not being able to work, even to the risk of disrupted household finances during treatment, both for patients and caregivers.

Cancer patients face a tiered referral process before getting a final treatment referral at a national cancer treatment center hospital. The referral system is indeed regulated in the RI State Gazette No. 122 of 2012 concerning the health service referral system. This regulation stipulates that the first treatment is carried out at the first level health facility, continues to the second level, and finally at the third level. At level two, patients will be referred to hospitals with types (in order of referral level) D, C, B, and A, depending on the patient's medical needs. The interview results showed that the patient, most of them go straight to the hospital or second-level health facility because the condition of the symptoms of cancer is quite acute, such as continuous bleeding or the intensity of pain that the patient continues to feel increases. Thus, patients will be referred to a certain type of hospital if they require more complex treatment. Interview results confirm that this system is already running in the field, it's just that patients have to wait several days or even weeks to get treatment at a referral hospital. This actually happened to patients who came from DKI Jakarta, as disclosed below:

> *"... it didn't stop (bleeding) I said, why didn't it stop, okay, I took it to the hospital already. Hospital (type D in Jakarta). I was treated first and needed a transfusion of four blood bags. Continued on the ultrasound, after the ultrasound I got the results that I had cancer. We were referred to (a type B hospital in Jakarta), in the end I went back and forth. It didn't take long for me to bleed a lot and the clots were big. When I sleep, oh God, it hurts, I'm being treated in bed, right? When I first entered the ER, I couldn't stop the bleeding, like blood from giving birth. It's not bad to be treated at the hospital, there are 7 days, and every 2 days you need to do that control again (outpatient). Entered the ER 4 times. In the end, the doctor suggested going to the hospital (type B in Jakarta). There wasn't much treatment, I waited 1 month and a half, so I just came here directly (type A hospital in Jakarta), so I'm here to be served until now. It was around September (2022) here."*
>
> *(P. Cervical cancer patient. Jakarta).*

The initial period of treatment in hospital causes patients to experience increased stress, fear, and pain. This study found that although medical personnel cannot provide certainty about the duration of treatment and guarantee of recovery, patients get motivation to continue treatment when there is transparency in the treatment process from doctors. In addition to increasing adherence to continue undergoing the treatment process, cancer patients also tend not to seek alternative treatments, as expressed by one of the following informants:

> *"I asked the doctor: "Sir, if I already have one person treating me, what if I use an alternative, the doctor will continue with the alternative?" (the doctor answered) "Oh don't that's called double treatment. Now I'm being treated with me, so if you believe in me, follow me, don't go anywhere in your mind, already follow me." So from there I entrusted it to the doctor, until now. Yesterday night my sister personally told (asked me to seek treatment) to move to an alternative, I said: "I can't just go to the cancer center hospital, if I don't want an alternative because it's not monitored (the progress of the disease)"*
>
> *(Z, cancer patient breast, Banten).*

In the early stages of pre-diagnosis and diagnosis in the trajectory stage of illness (Smit, et al, 2020) patients tend to ignore the initial symptoms and when the condition of the disease increases, they begin treatment. This neglect was made on the basis of the patient's strong perception of a healthy lifestyle and regards cancer as an accumulation of unhealthy lifestyles. The findings of this study are actually in line with the findings in a study of attitudes and initial responses of breast cancer patients by Prabandari, et al (2022) in Yogyakarta. However, this study found that there were obstacles when cancer patients carried out initial examinations, among others due to inadequate hospital services, low literacy on cancer symptoms and disease, and limited information regarding the referral stages provided by medical personnel to patients. Furthermore, this study also found that transparency of the stages of treatment conveyed by doctors can encourage patients to comply with medical treatment at the hospital compared to alternative treatments.

Table 3. Summary of attitudes and experiences of patients and their families when diagnosed with cancer based on illness trajectory

Stages of pain and treatment	Attitudes and obstacles
Feel the symptoms	Attitude: 1. Tend to think of the initial symptoms as a common disease because they feel they have a healthy lifestyle. 2. Carry out health checks at the hospital when the intensity of symptoms has increased. 3. Families support cancer sufferers to go to health facilities. Obstacle: 1. Health literacy about cancer is not good enough. 2. Patients do not have the habit of going to a hospital/health facility.
Check yourself into a health facility	Obstacle: 1. Health facilities do not have enough specialist doctors to examine symptoms of cancer. 2. Health facilities where patients live do not have sufficient technology to examine symptoms of cancer pain and have to delay treatment. 3. Health workers at local health facilities do not provide clear instructions to cancer patients regarding further examinations and referrals during the initial treatment process.

Source: Generate researcher

5.2 Factors Contributing to the Care and Treatment of Cancer Patients

The process of treating and treating cancer patients varies, depending on the type of cancer and the stage of diagnosis in the patient. There are external and internal factors that contribute to the process of caring for and treating cancer patients. External factors that emerged from the results of the study included: support from caregivers, extended family support, support from the community, to information from third parties. While the internal factors that influence the care and treatment of cancer patients are the patient’s internal motivation to recover.

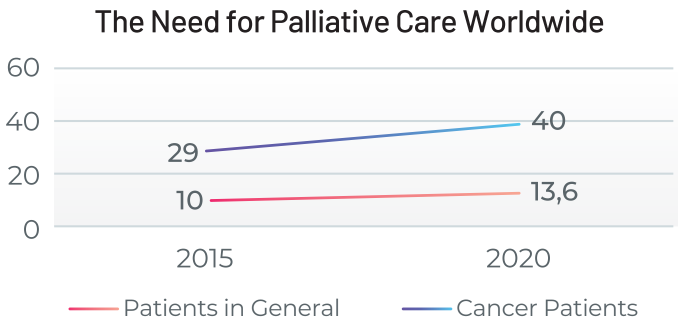
In connection with the process of caring for and treating cancer patients, there is an approach specifically developed for cancer patients, namely palliative care. Palliative care is a care approach that can improve the quality of life of patients and their families facing life-threatening disease conditions (cardiovascular disease, cancer, organ failure, etc.). The goal of palliative care itself is to prevent and alleviate suffering through early identification, thorough thorough assessment, and management of pain and other physical, psychosocial and spiritual problems (Indonesia Cancer Care Community, n.d).

WHO also provides a basic foundation for patients and their families in carrying out palliative care, namely:

1. improving the quality of life and considering death as a normal process in the life cycle ,
2. not hastening or delaying death
3. eliminating pain and other disturbing complaints,
4. maintaining psychological and spiritual balance,
5. trying to keep sufferers active until the end of their lives,
6. trying to help overcome the atmosphere of grief in the family (Indonesia Cancer Care Community, n.d).

Based on data from WHO every year around 56.8 million people in the world, including 25.7 million people who are at the end of their life years need palliative care. Of the total individuals requiring palliative care only 14% received this care. Considering the large number of individuals requiring palliative care each year, equal distribution of national policies, programs, resources and training for palliative care professionals is urgently needed (WHO Palliative Care, 2020). The following is the need for palliative care in the world in 2020.

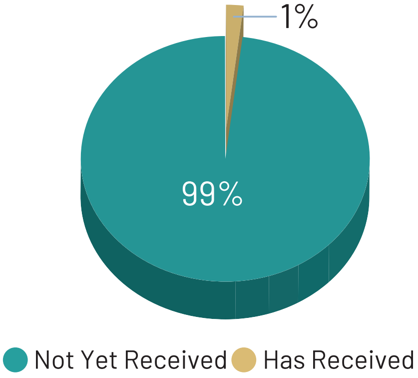
Figure 7. Palliative Care Need Worldwide from 2015-2020



Source: Hannon, 2015; WHO, 2020; Indonesia Ministry of Health 2022

Based on the graph above, palliative care in the world is constantly increasing. Even within five years, specifically for cancer, the need for palliative care has also increased. Data from the Ministry of Health in 2022 shows that the coverage of palliative care in Indonesia has only reached 1% in terminal patients, as illustrated in the following diagram:

Figure 8. Percentage of Palliative Care Coverage in Indonesia



Source: Indonesia Ministry of Health, 2022

The need for palliative care training for professionals or patient families will increase as the world's population continues to age. Moreover, countries in the Asian region are currently experiencing a demographic bonus of productive age. In ten to fifteen years the number of elderly people will increase sharply, so what needs to be watched out for is the readiness of caregivers, families and professionals in using a palliative care approach. If palliative care is carried out from the start when a cancer patient is diagnosed, it can have an effect on reducing unnecessary medical costs spent on hospitals and other health services (WHO Palliative Care, 2020).

Based on Riskesdas 2018 data, palliative care in Indonesia is still focused on cancer and HIV/AIDS because there is a significant increase in these two types of disease every year (Widowati, Dwi E.R., Indarwati, R., & Fauziningtyas, R., 2020). Until now, no data has been found on the distribution of palliative care carried out by all FKRTL in Indonesia. For example, palliative care that has been carried out by one of the national cancer referral hospitals in DKI Jakarta from 2016 (1,021 visits) to 2018 only reached (1,217 visits) (National Cancer Center for Dharmais Cancer Hospital, Ministry of Health RI, 2020). Implementation of palliative care in health facilities also cannot be identified clearly. So that this condition makes policies regarding supervision of the implementation of palliative care very necessary.

In Indonesia itself there is a special palliative care policy regulated in the Minister of Health Decree (KMK) number 812 of 2007 concerning palliative policies. However, in this policy palliative care implementers only focus on doctors, nurses, health workers and other related personnel. The family is still positioned as the target of palliative care itself. Then in this policy, implementers of palliative care must also be certified which of course will hinder the expansion of the scope of the required human resources. If the relevance of palliative care is withdrawn which is currently needed, it is necessary to comprehensively revise this policy. Given the urgency of the majority of cancer patients not receiving palliative care in

Indonesia, human resources who have received training related to palliative care are still limited, and have not been included as a national priority program in the health sector. In addition, the determination of the time for palliative care needs to be carried out by the hospital or the patient's family also needs to be regulated in this policy. Because in the theory of illness trajectory, when the patient is initially diagnosed and experiencing symptoms, then diagnosed with cancer and experiencing conditions of pain/illness, palliative care can already be carried out (Palliative care, 2020). So that palliative care goes hand in hand with medical care for the treatment of cancer patients.

One of the parties that has the most role in providing palliative care for cancer patients is the patient's companion, both from the family (informal caregiver) or professional staff (formal caregiver). Informal caregivers are family members (spouse, parents, siblings, children, close friends) who are not paid for providing care to cancer patients. They have a very large role in the care of cancer patients during and after cancer therapy is carried out. They are also part of the treatment team because they help and supervise medication administration, manage side effects, report patient problems, and provide self-care assistance and other matters (ACS, 2016; RI Ministry of Health, 2022). Whereas formal caregivers are trained professionals who come to the house on a predetermined schedule and provide care and assistance to cancer patients (ACS, 2016; RI Ministry of Health, 2022).

The role of the caregiver at the five stages in the illness trajectory model from pre-diagnosis to post-treatment is vital. This is evidenced by field findings in this study, that the family is the main figure to support and accompany cancer patients in the entire treatment process. Sociologically, the patient's companion (caregiver) has different relationship patterns including: husband-wife relationship, parent-child relationship, and sibling relationship. This relationship pattern shows the tendency for those who are willing to accompany cancer patients to be members of the nuclear family. As in the following interview excerpt:

> *"My mother and I are close, so we often confide in them. Even though not everything is said. The problem is who knows who wants to be alone. But indeed, not everyone can be open when they have this disease. So there are rarely other people close"*
>
> *(F, cervical cancer patient, Karawang).*

> *"I'm the only one who takes care of N's mother, I take care of her myself"*
>
> *(P, sister of a breast cancer patient, Bangka Belitung).*

When undergoing treatment, the role of the family as a support system for cancer patients is very important. Regardless of what type of cancer the patient has, the family plays an important role in the diagnosis and treatment phase. Proximity to caregivers as in the interview excerpt above causes cancer patients to feel they have listeners and are not alone in undergoing a series of treatments.

Family support is also very influential for the psychological condition of cancer patients during treatment. While undergoing treatment there are several physical side effects that are felt by patients such as; bleeding, stomach pain, nausea, and decreased hemoglobin levels, and others. In addition, there are also psychological side effects that are also experienced by cancer patients while undergoing treatment including: excessive anxiety, sleep disturbances, excessive worry, weakness, coughing, abdominal pain when urinating, and others. In the concept of illness trajectory, support from the family causes them to be able to support cancer patients through each stage of treatment according to the type of cancer. The treatment process is recognized as physically and psychologically burdensome for the patient and his family, as the following interview excerpt states:

> *"Right now there's no bleeding, since I've been in the light sometimes when I'm tired, I'm really tired. A short walk is still close, the stomach really hurts. If you pee it's like coughing. If you have taken the medicine, sometimes you can sleep, sometimes you can't, if your soul is calm, it's good to be able to sleep. If you're not feeling well, the weather is hot because your mind is worried, try to calm down and calm down so that the bleeding doesn't come out like that"*
>
> *(F, cervical cancer patient, Jakarta).*

> *"At most when the light runs out it's nausea, weakness, and bowel movements, appetite also decreases, that's all... That's why every time I go to the hospital I say let's go to a tourist spot. So to think about it isn't going anywhere. But going there for treatment is considered just tourism..."*
>
> *(H, husband of a cervical cancer patient, Jakarta).*

The interview excerpt above shows that the role of the family in providing assistance to cancer patients when experiencing side effects of treatment is very necessary. The family plays a role in providing encouragement to patients who can reduce their anxiety and worries while undergoing treatment. In addition, the family also plays a role in maintaining food intake while undergoing treatment. As in the following interview excerpt:

> *“If he’s not reminded to snack, to eat, he’s really lazy. That’s why I always remind him, tell him to snack. If he wants any vegetables, I will cook them according to his request”*
>
> *(R, wife of a lung cancer patient, Lampung).*

> *“Mother always reminds me to take medicine, and also reminds me to take care of my mind. I mean, you’re the head of the family, so there must be some tasks that can be delegated, so I don’t think about it myself”*
>
> *(AF, lung cancer patient, Karawang).*

In cases where patients experience limitations in doing household chores or other work, the role of family and companions becomes important, to replace the roles that are usually carried out by patients.

> *“So all the washing, everything, I’ll do it, if you just have to rest, the problem is you can’t be too tired…Yes, at night I’ll wash it in the sun tonight, in the morning I can just pull it like that”*
>
> *(H, husband of cervical cancer patient P, Jakarta).*

Both men and women have a vital role to play in providing both practical and emotional support. In traditional gender roles, women are usually responsible for all domestic work and men are more focused on increasing financial security. The results of the interview above illustrate that the patient’s husband also contributes to domestic work because his wife has limitations in doing heavy work such as washing clothes.

This study shows that family support and internal motivation of cancer patients play a role in maintaining daily food consumption. Increasing family support in reminding food and medicine, causing increased adherence to cancer patients. Then, related to the psychology of cancer patients is also greatly influenced by the support of the family. Maintaining positive thoughts while undergoing treatment is also a very important thing to pay attention to, especially because it is part of palliative care for cancer patients.

The choice of health facility for treatment is also influenced by their family, as in the interview below:

> *"Sir, if I already have one person, treat me, what if I go to an alternative? So apart from the doctor, I also want to try alternative medicine... (the doctor answers) oh no, that's called double treatment. Now I'm being treated with me, so if you believe in me, just follow me, don't go anywhere in your thoughts, just follow me. Yesterday evening my sister personally asked me to move to alternatively, I replied that I couldn't, I still wanted to go to Darmais, because if the alternative will not be monitored for treatment. Most ever, it's herbal medicine alternative, don't underestimate it. But if the alternative can not be seen progress every month. So, at this hospital, everything is checked, from the breast to the abdomen, down to the bones, they are also checked. The whole body is checked, so you can find out how far it has progressed"*
>
> *(Z, breast cancer patient, Banten).*

> *"As for alternative medicine, it's only occasionally, which is not covered by BPJS. Because the medicine is also expensive, just vitamins up to 500 thousand."*
>
> *(H, husband of a breast cancer patient, Jakarta).*

Not all cancer patients want to try alternative treatments, as evidenced by the patients who were research informants who preferred to go to health facilities. Although sometimes the patient's family tries to give consideration to make comparisons to alternative treatments. However, cancer patients have commitment and trust in the doctor who is treating them so that consideration of alternative treatment is avoided. Usually the family also gives consideration to using alternative medicine because the costs incurred for medical treatment are quite expensive.

When the patient accesses the hospital, there is one condition where one of the cancer drugs is not covered by BPJS Kesehatan, because it has not been included in the benefit package in the JKN scheme. In the process, Avastin for lung cancer has high costs and causes patients to have burdens related to medical expenses.

> *"He'em, the name of the medicine is Avastin, now Avastin is not covered by BPJS. That's why it's not included in the list of BPJS medicines, that's why we bought it ourselves... No, we'll buy the medicine for 14 million, mas. Every 3 weeks. Yes, that is to stop the fluid in his lungs..."*
>
> *(R. caregiver for lung cancer patient, Lampung).*

In addition, the family plays an important role in providing financial and material support to cancer patients while undergoing treatment. As in the following interview excerpt:

> *"... yes, his brother transferred to help give money to buy medicine. Even though the term is ready or not, we have to be ready financially. Thank God I'm still working..."*
>
> *(R, caregiver for lung cancer patients, Lampung).*

> *"If I have to take his father to Jakarta, I will leave my child with my brother who is in Lampung. Because coincidentally all the families are in Bandar Lampung"*
>
> *(R, caregiver for lung cancer patients, Lampung).*

The two interview excerpts show that support from the family can be provided in various forms. Even a previous study conducted by Kristanti, et al regarding improving the quality of life for cancer patients with palliative care through the family as a caregiver showed that the patient's quality of life had a close correlation with the emotional and social aspects that were intervened in the study. The interventions carried out include; training in bathing, dousing, feeding, helping patients with toilet matters, changing body positions, and maintaining oral hygiene (Kristanti, S.M., Sri, S., & Christantie, E., 2017). Maintaining oral hygiene is very important in fighting the side effects of chemotherapy and radiation such as dry mouth and reduced appetite. The results of Kristanti's research, et al, namely the basic skills of family members who become caregivers of cancer patients affect changes in several aspects of quality of life in palliative care for cancer patients.

In addition to improving basic skills to support palliative care provided to cancer patients, families and patients also need to make adjustments regarding their expenses. These expenses are not only related to treatment but expenses to support daily life and costs that are not covered by health insurance/health insurance. As in the following interview excerpt:

> *"....for daily meals I often give my nephew side dishes, because I don't spend too much, aka limiting..."*
>
> *(N, breast cancer patient, Bangka Belitung).*

> *"Yes, it's mostly from savings, sis, what we use. Home economics households are affected, let alone for treatment, just think about second household matters, the important thing is to get well first"*
>
> *(H, husband of cervical cancer patient, Jakarta).*

Household financial allocations that should be used to meet daily needs are used to support medical expenses. Even though the costs incurred do not directly pay for treatment, these costs are incurred to support during treatment such as; transportation, meals, temporary housing, additional medication, and so on. As stated by one of the following lung cancer patients:

> *"...in all respects cancer treatment, transport and other needs definitely affect the family finances, and it was not facilitated by local government"*
>
> *(D, lung cancer patient, Karawang).*

The above expenses can be categorized as out of pocket expenses which will be further discussed in the next sub-chapter.

From the various efforts that have been made to support treatment, the resilience of families and cancer patients has increased. The factors related to building resilience in the context of cancer patients and their families are; antecedents that arise due to cancer, psychosocial recalibration due to the process of interaction with the surrounding environment, and the consequences of increasing coping mechanisms to function individually and socially (Luo, et al., 2020). These resilience-forming factors are reflected in the following interview excerpts:

> *“I actually thought of looking for additional income, because the finances were exhausted but I still had to pay the boarding house. I believe that Allah will surely provide us with sustenance, but we still have to work hard to find that sustenance from where else, then we will continue to use it for what the result will be. Because life is also full of risks, yes, but in that risk we can take the lessons that exist. So there is no need to blame this and that, because surely everyone will be given their own trials”*
>
> *(AF, lung cancer patient, Karawang).*

> *“The doctor said that this cancer is actually chemotherapy not to kill, but only to cause the cancer cells to not be active… I am from 2020 until now, yes, I am definitely tired, but I am trying to give in to feeling tired”*
>
> *(R, lung cancer patient, Lampung).*

In line with the resilience theory of Luo, et al. (2020) the two interview excerpts above show the factors that form the resilience of cancer patients, one of which is lung cancer patient informants, namely the formation of resilience mechanisms that support the individual and social functioning of patients. In addition, resilience is also formed in families who are caregivers for cancer patients, as shown in the interview statement below:

> *“Yes, at least he can’t work, like at home he can’t do heavy work like washing, he has to get lots of rest. So, all the washing, whatever, I’m the one doing it, if you just have to rest, because you can’t be too tired. Usually I wash it in the sun at night, when it’s finished in the morning, I just pull it like that”*
>
> *(H, husband of cervical cancer patient, Jakarta).*

> *"... yes, when I'm taking control or going to the hospital, we invite him, let's go there for a tour, that's because I'm afraid that if I tell him to go to the hospital, I'll drop him. If you say tourism, your mind won't go anywhere."*
>
> *(H, husband of cervical cancer patient, Jakarta).*

Caregiver assistance in doing household chores can increase resilience cancer patients and also to maintain the patient's quality of life. Then the caregiver's way of communicating also helps maintain positive thoughts on the patient so they don't feel heavy while undergoing a series of treatments. Caregiver resilience of family members was also found to have implications for decision-making considerations related to wider affairs as in the following interview excerpt:

> *"Because we thought it would be really hard if we had to go to private schools, so we chose to send our children to public schools. Because the initial money for one child is 12-13 million, if you have 2 children it's 25 million. Meanwhile, we need additional medical expenses... To be honest, we are sad, but like it or not, we have to make sacrifices"*
>
> *(R, caregiver for lung cancer patients, Lampung).*

Resilience that emerges from patients and their families is of course also supported by existing social capital. Social capital that has a significant impact on the formation of patient and family resilience is support from the community.

> *"The response from our neighbors is good, because we are also kind to them. When we want to go to Jakarta for treatment, we will leave the house to be looked after. If you are saying goodbye, always pray that you will get well soon. Then when we return to Lampung, the treatment is complete, sometimes cakes, vegetables, and compote are sent. So I am grateful to have such good neighbors"*
>
> *(R, caregiver for lung cancer patients in Lampung).*

Based on the interview excerpts above, it appears that support from neighbors can also have a positive impact on caregivers. So when accompanying cancer patients for treatment even though they have to travel long distances such as from Lampung to Jakarta, they remain enthusiastic because they get support from the environment where they live. In addition, there is support that is also needed from the work environment of caregivers or patients so that the treatment process can run as it should according to the diagnosis received.

In this study, caregivers of cancer patients have quite diverse status and occupations. Among them productive workers (civil servants and informal workers) and not working. The role of a full-time caregiver when assisting cancer patients requires caregivers to compromise with the environment in which they work. A work environment that can support and understand the condition of cancer patient caregivers is one of the external factors that influence the smooth process of treatment and care for cancer patients.

> *"Well, fortunately, that's why I said earlier, fortunately I still have a boss who is still understanding, so he really understands my condition, because he has experienced it like that. When he took care of his mother, he had to go back and forth to Jakarta, he understood very well and at that time he also had a boss who understood him like that so he really understood that fortunately like that..."*
>
> *(R, caregiver for lung cancer patient, Lampung).*

The caregiver's statement above shows that, if there is support from the caregiver's work environment, then he or she can carry out multiple roles in the same period of time. The complexity of the dual roles played by caregivers—as housewives as well as workers, for example—cause caregivers often need support from the extended family to the community in which they live. As expressed by the following lung cancer patient caregivers:

> *"Yes, they (the family) support it like that, for example, yes, even though they support us, we don't just have to stand idly by, right? At most, they gave their older brother a transfer to help buy the drug Afastin. yes even though the term is not big but yes thank God it can help us right..."*
>
> *(R, caregiver for lung cancer patient, Lampung).*

Based on a study conducted by the U.S. National Cancer Institute. Department of Health and Human Services (2019) support for caregivers of cancer patients is needed because:

New roles as caregivers often increase stress.

It's normal to understand how you feel when you become a caregiver.

Caregivers often do too many things without asking others for help.

Caregiver feels that he can no longer give himself time.

Therefore, as a caregiver for cancer patients, what needs to be done is to balance all activities that are carried out every day, focus on what needs to be done, take care of yourself while caring for the patient, and take time to rest and calm down. The resilience of a caregiver will be strengthened when they can provide support for patients while undergoing treatment. The majority of caregivers will learn more about themselves during the journey of undergoing palliative care for cancer patients (National Cancer Institute, 2019).

As for other external factors that also contribute to the process of caring for and treating cancer patients, namely information from third parties (other than health workers). Patients interact and obtain information from third parties during the treatment process. The information obtained includes several things including; regarding administrative processes, health services, halfway house facilities, to education about cancer that patients experience. This information helps patients significantly in undergoing the process of care and treatment more easily. For example in the case of lung cancer patients below:

> *"There is no education for them (Nakes) for us. So far, they have never told me, madam, you can't do this. In fact, I have asked several times whether there are restrictions or not, so that's why? nothing. Just give him what food he wants, but just reduce the sugar. Reducing sugar, I know from someone in their home environment who also has cancer. There is a cousin of mine who is a nurse, she has a fellow nurse who has cancer as well… keeps reducing meat like that, it just*

> *so happens that my husband really likes meat. They (health workers) only told me because when I went to chemo my husband would definitely feel nauseous, so yesterday the doctor told me that there was dilation of the stomach or in other words, gastric dilatation"*
>
> *(R, caregiver for lung cancer patient, Lampung).*

The quote shows that health workers have not provided comprehensive information related to education for cancer patients. Information and education regarding this matter is actually found by patients and caregivers through family members and their relations. Other information that also helps patients and families undergo treatment more easily is related to the availability of shelters for them in locations close to cross-region advanced referral health facilities. As in the following interview excerpt:

> *"I know there is a halfway house from people near here, yes, not from the hospital. Local people who provide information about halfway houses for cancer patients. In the end, my sister and I went straight to the halfway house, we walked for about 5 minutes from Darmais Hospital, and it turned out that there was a house there. This halfway house is from a foundation, not owned by the government. But the conditions for living there are easy, you only need to provide your KTP, KK, sick notes from Darmais. You can enter and live there. Then at this shelter, there are not only breast cancer patients, but there are also heart patients who live here..."*
>
> *(N, breast cancer patient, Belitung).*

The mechanism for staying at the halfway house is also not limited, so patients who are undergoing treatment no longer need to worry about their accommodation as long as the halfway house quota is still available, as stated by the following breast cancer patient:

> *"...it's up to the length of stay, some are up to 5 months depending on the duration of the treatment. I am now 3 weeks old. For its capacity can be 4 to 6 patients who live here. Only 1 person per patient is allowed to accompany her..."*
>
> *(N, breast cancer patient, Belitung).*

Then regarding the facilities obtained while staying at the halfway house, conveyed through the following interview excerpt:

> *"...staying here is free, you don't have to pay for rice, detergent, bath soap, cooking oil, sugar, everything is available. So if you want to buy side dishes, just share with other patients at the shelter. So if we drink water, we save IDR 5,000 every day..."*
>
> *(N, breast cancer patient, Belitung).*

The process of caring for and treating cancer patients requires intensive days of time, causing the patient to be able to arrange accommodation and transportation, especially if the patient is from out of town or outside the island. The existence of facilities such as halfway houses helps patients to take treatment more effectively and efficiently because the location of the halfway house is close to the hospital. Of course this also reduces the financial burden of accommodation and transportation of patients, as well as being a place for connecting patients with other patients, and giving rise to initiatives to form their own community. The availability of halfway houses around the hospital is mostly supported by the private sector or NGOs.

Table 4. Summary of factors that contribute to the process of care and treatment of cancer patients

No	Stages of care & treatment	Actor	Role	Impact on cancer patients and their families
1	Early diagnosed with cancer	Family (spouse, parents, children, siblings)	Provide psychological support	• Patients feel not alone in facing a cancer diagnosis • Patients are stronger to accept their condition • Patients are better prepared to enter the stage of treatment and care according to the type of cancer • Courage in patient decision making
			Assist in finding alternative treatment (medical)	• Patients get certainty about the treatment undertaken • Patients are assisted to continue treatment to referral health facilities • Patients receive information on alternative treatments before and during treatment at health facilities

			Looking for information about treatment and medication that must be undertaken	• Patients get consideration to choose a treatment that suits their condition and needs
2	Undergo initial and advanced treatment/ therapy	Family (spouse, parents, children, siblings)	Provide financial and material support	• Sending assistance in the form of funds to help with medical expenses • Patients feel helped by the role of family members in replacing his position • Sharing roles between patients and other family members in carrying out duties as family members • Formation of resilience in managing household expenses
			Registering patients using BPJS Kesehatan	• Treatment, therapy, surgery are free and only need to incur direct non-medical costs during treatment
			Improve patient quality of life	• Patient discipline in consuming food and medicine • Patients maintain psychological and spiritual balance • The patient remains active in carrying out daily activities according to his ability • Patients have listeners who feel and are not alone during treatment • Patients may face side effects caused by medication/therapy/ surgery Patients have the motivation to undergo treatment/ therapy according to doctor's recommendations

				• Formation of resilience mechanisms that support the individual and social functioning of patients
		Community	Provide material support and affection	• The thoughts of the caregiver/ family accompanying the patient for treatment can focus and stay positive
			Provide education and information about cancer	• Caregivers/families receive education regarding patient dietary restrictions • Caregivers/families get information about shelters that are close to the location of the hospital
			Providing halfway houses	• Patients and caregivers/ families can save on direct non-medical expenses • Helping patients take medication more effectively and efficiently • Become a liaison vessel for patients with the cancer community
		Work environment	Provides flexibility in working hours	• Caregivers/family can accompany cancer patients in undergoing treatment/therapy

5.3 Direct Non-medical Costs and Indirect Costs Incurred while Undergoing Cancer Treatment

Cancer can be treated with several interventions such as: surgery, targeted therapy, radiotherapy, chemotherapy and other interventions. When a patient is undergoing treatment or medical action (for example undergoing radiotherapy or chemotherapy cycles), the patient must intensively come to the hospital, both the hospital in the area where the patient is located, and at a referral hospital in another city. Although patients can undergo medical procedures and treatment where they live, with certain clinical conditions and cases, cancer patients must be referred to a higher type of hospital/referral hospital in order to obtain more complete services and the availability of sub-specialties that are more suitable for treating cancer cases.

This causes patients and companions to incur substantial own costs (OOP), such as transportation, accommodation (lodging), and meals (besides hospital nutrition services). Transportation costs include land travel costs (including tolls or drivers), aircraft, motorcycle taxi and ship costs. Several informants explained that the transportation costs to be borne to get to the hospital were quite large, even reaching seven million rupiahs for one treatment, especially for patients who do not live in Jakarta.

> *"There are so many… I just took grab, took grab & gojek, I've almost 7 million, sis, it's going back and forth to the hospital."*
>
> *(P, cervical cancer, Jakarta).*

> *"If you go round and round, it can be almost 2 million if you go back and forth for 2 people. If you go alone, it's about 1 million, so the plane fare."*
>
> *(N, breast cancer, Bangka Belitung).*

In addition, other direct non-medical costs are when the patient and companion have to find a place to live (accommodation) because they have to come to a referral hospital in another city such as Jakarta. By renting accommodation and temporary housing, patients can access the hospital more closely and according to the treatment/care schedule.

From the results of in-depth interviews, patients undergoing radiotherapy must come to the hospital every day with a total of 29-35 arrivals. Then chemotherapy is generally done once every 3 weeks for 4 to 5 months. From the information obtained, the costs incurred for one treatment duration range from IDR 1.2 million to IDR 3 million per month depending on the duration of the treatment.

> *"It depends… in one week at most 700,000 for food."*
>
> *(R, lung cancer, Lampung).*

> *"It costs 1.2 million a month. As for (pampers), yes, I'm over 15, I just drank yesterday. 20 (perpers) sold out. Yesterday I bought 50 thousand vitamins"*
>
> *(F, cervical cancer, Jakarta).*

> *"... living at a relative's house in Ciputat for about 2-3 months, but once I also stayed behind the cancer center hospital, 150 thousand per day. If a month 3 million."*
>
> *(P, assistant to breast cancer patient N, Bangka Belitung).*

Other direct non-medical costs incurred include vitamins, alternative medicine and pampers. Even though it is not as big as the cost of accommodation, this is still a concern regarding expenses for both the patient and his companion. Furthermore, there are patients who have expenses for temporary care of children when the patient seeks treatment in Jakarta.

> *"My son, when I'm in Jakarta, I leave it with my brother. Incidentally, all the families in Bandar Lampung are just father-in-law in Metro"*
>
> *(R. Caregiver of lung cancer patient, Lampung).*

There are basically three measurement components in assessing lost productivity:

1. Premature death,
2. Permanent disability, and
3. Temporary disability.

Few studies measure overall productivity loss, or examine one or more of the cost components mentioned above (Monserrat et al., 2019). The field findings describe the loss of salary/income due to the reduced quality of life of cancer patients and the intensive treatment they are undergoing and affect productivity while undergoing work, so that the costs studied in this study focus on the impact on the income of patients and their families.

Loss of productivity experienced by patients, can be seen such as patients being advised to stop working, salary cuts related to absenteeism, or other reductions in income. For families and companions, productivity and performance are also affected because they have to accompany patients to carry out treatment. In its definition, loss of productivity is not only defined in terms of patients who are sick and then unable to continue work, the duration of working hours is limited due to medication or disability. Likewise from the side of the assistant whose activity/frequency of work is reduced due to accompanying sick patients, which in turn affects the level of income. In addition, it also affects the contribution of individuals to the economy as a whole due to morbidity and mortality due to cancer (Venkatesan, Priya 2008).

Several informants shared their experiences when suffering from cancer or being caregivers for cancer patients, some experienced salary cuts due to absenteeism, prioritized caring for cancer patients over work, or reduced work frequency due to accompanying patients undergoing treatment.

> *"Yeah, that's for sure,... judging from the attendance, one of the things you can see is from the presence, right? From there, it's clear that the deduction is up to 40% if for example it's more than 5 days in a row, right?"*
>
> *(IEW, lung cancer, Lampung).*

> *"So, since my husband has been sick, his salary has been lowered, like every 3 months, eh, every 4 months, or every 3 months, 3 months, so at first the husband still received 100% full salary plus the bonus then the 2nd one - 3 months to 2 - there has been a reduction so the husband only receives 75% salary."*
>
> *(R, caregiver for lung cancer patients, Lampung).*

The above findings regarding direct non-medical costs and lost productivity are consistent with several studies. A study conducted by Susilowati and Affiyanti in Indonesia reports that indirect costs have a financial impact on breast cancer sufferers. Treatment of these costs includes transportation, lodging, lost productivity and other expenses besides medical costs. As many as 92.7% of the participants in this study indicated that more indirect costs were spent on transportation, lodging and sick expenses for children (Susilowati and Afiyanti, 2021). A study by Kristina et al., (2022) reported a total loss of productivity for deaths caused by cervical cancer in 2018 amounting to IDR 23.2 trillion, with the largest loss in the 15-64 year age group (IDR 12.2 trillion).

Based on the type of cancer condition, when compared to patients who do not experience metastases (spread of cancer to other organs), patients with metastases have a higher rate of lost productivity and indirect costs. Cong et al., (2022) reported that the loss of productivity one year after being diagnosed with cancer reached 106 working days for cancer patients with metastases and 46 working days for patients without metastases.

A study by Darba and Marsya (2019) reports on estimating productivity costs due to premature death in lung cancer patients in Spain, using several parameters (mortality, income and unemployment rate). In 2017, lung cancer contributed to 10.83% of all cancer deaths and over a 10 year period, lost productivity was estimated at 13.1 billion Euros. For breast cancer patients with metastases in the US in 2015, Trogdon et al., (2021) reported that nationally loss of work and productivity at home was valued at 67 million US dollars for young women, 246 million dollars for middle-aged women, and 66 million dollars for older women. By 2030, the total cost of cancer patients is predicted to reach 152.4 billion US dollars, 86.1 billion in direct medical costs and 66.2 billion in lost productivity costs. Productivity costs are slightly higher than medical costs in patients aged 18-44 years. (Gogate et al., 2021).

A systematic study from Kamal et al., (2017) explains that most of the literature describes that cancer treatment has an effect on patient productivity caused by the clinical effects of the treatment process. In the end, the effect of the treatment affects job loss, cognitive impairment, obstacles in lifting heavy loads and difficulties in keeping up with the speed of working with other people. From the side of the companion, factors associated with loss of productivity are due to intensive cancer treatment, travel to get treatment, costs related to treatment and changing working hours due to having to care for or accompany patients.

During the treatment period, households still spend quite a lot of money even though they are already covered by JKN. To overcome this, patients use savings as the main source of funding during the cancer treatment process.

> *"Yes, it does affect sis, because we're done for treatment. Just the second household chore, the important thing is to recover first, we use the savings"*
>
> *(H, husband of cervical cancer patient P. Jakarta).*

> *"Yes, the impact is far away, luckily there is the leftover money to come here (to the hospital). Yes, if you can't do it every month, you have a little savings. I have nothing but hope."*
>
> *(N, breast cancer patient, Bangka Belitung).*

> *"Yes, yes, ma'am, if you count it, that's it, fortunately you have savings, so you don't borrow like that."*
>
> *(V, cervical cancer, Karawang).*

The above exposure results are in line with several reported studies. Progressive worsening of the disease and the need for non-medical costs during cancer treatment causes households to use savings, seek loans or even sell assets (Bhoo-Pathy et al., 2019). The catastrophic financial burden on households also causes stricter household financial management behavior, especially in managing other expenses. This was expressed by two research informants as follows:

> *"... it's easy for me to sell it, so thank God there's something I can sell, right? You can add more and that's the rest of the savings, right?"*
>
> *(R, IEW lung cancer patient companion, Lampung).*

> *"I just don't spend too much on a daily basis, then when I eat, my nephew gives me the side dishes, my nephew gives me that."*
>
> *(N, breast cancer patient, Bangka Belitung).*

5.4 Analysis of Cost Implications for Cancer Control Policies

Treatment and treatment of cancer requires time with high intensity, so this disease has its own complexity. The findings in this study also show that direct medical and non-medical expenses for cancer patients are very high. Based on interview results, the average cancer patient spends at least IDR 5,000,000 a month for transportation costs to health facilities. The high cost is also influenced by several factors, one of which is the uneven distribution of health facilities and the lack of oncology specialists in the regions, requiring patients to pay more to go to other areas such as Jakarta. In addition, the interview results show that there are medicines and supplements that are not covered by BPJS Kesehatan, especially for patients with high stages, for example, like Avastin, requiring the patient to incur additional costs.

5.4.1. Medical direct discharge

Cancer is a disease with a high economic impact, both from the side of health service providers and sufferers. When diagnosed with cancer, patients may experience financial difficulties due to medical (medical) costs. The burden can also trigger symptoms such as anxiety and depression, which ultimately have the potential to affect the patient's quality of life. This condition is known as financial toxicity, where the patient experiences financial problems that not only affect the economic status of the household, but also their quality of life (Pangestu and Rencz, 2022).

Medical direct costs are costs that must be incurred related to medical services, for example: costs for consultations, treatment, actions, procedures and other medical services. One of the efforts to overcome the high medical costs incurred by patients is the existence of a health insurance mechanism including JKN. The burden of catastrophic costs from several diseases including cancer is borne by JKN so that JKN participants do not need to pay for the entire treatment. Treatment and procedures covered by BPJS Kesehatan in the JKN scheme are referred to as "benefit packages".

According to the BPJS Health report, in 2020 cancer is the disease with the second most cases (2.2 million cases) after heart disease, and the total cancer claims are quite large, namely 3.1 trillion rupiah. In practice, not all drugs and actions can be covered by BPJS Health, this is due to limited resources (which come from JKN participant contributions), so that in the process the benefit packages are selected on rational principles by prioritizing quality control and cost control according to Permenkes 71 year 2013 concerning Health Services at JKN. Drugs entered must comply with cost-effectiveness principles, where the costs incurred are commensurate with the clinical benefits obtained (Nadjib et al., 2020). So that the treatment in the JKN system is expected to be of good quality and also have "value for money".

> *"No, we will buy the medicine for 14 million, mas, per 3 weeks. Yes, that's to stop the fluid in his lungs. It's targeted therapy, Avastin's name. We have to take it (targeted therapy) 6 times, my husband uses the Avastin drug 6 times. But yesterday we were able to use AB product 2 times. it's empty, so we've used Avastin. Almost 7 of you."*
>
> *(R. caregivers of lung cancer patients. Lampung).*

Based on the results of the interview above, there are problems such as targeted therapy which is not guaranteed which is quite expensive, (even though the chemotherapy series is guaranteed by BPJS). Patients have to pay for Avastin (Bevacizumab) out of their own pocket because it is not guaranteed by BPJS Kesehatan. Avastin for the treatment of lung cancer is not yet included in the JKN scheme. Previously, Avastin was included in the benefit package only for indications for treating metastatic colorectal cancer. However, the clinical benefits are not significant enough and the cost is high enough that this drug is not cost-effective and has the potential to affect efficiency in the JKN system (Kristin et al., 2021). When a drug is not included in the benefit package, there are two general reasons:

1. It has not been assessed for its feasibility to be included in the benefit package, and
2. It is excluded from the benefit package because new drugs are available that are more effective, drugs are not cost-effective and funding is prioritized on disease others in the JKN system.

Regarding high medical costs, one of which is the drug Avastin, further studies are needed regarding cost-effectiveness and affordability analysis by the system. Specialist professions, patients and related stakeholders can recommend this drug for further study through a health technology assessment mechanism. If the drug being studied has value for money, it can be considered for inclusion in the benefit package as a lung cancer therapy, or through a negotiation mechanism price of the drug.

Incorporating drugs and procedures into the benefit package is not an easy thing due to the high cost of therapy and the need for proof of significant benefits to patients. Matters related to guarantees for oncology drugs are a challenge not only in Indonesia, but also in other countries, even with higher income and economic levels. As a result of the principle of clinical benefit, cost effectiveness and input from stakeholders are the priority factors in making drug guarantee decisions.

For example, in the UK there are several mechanisms where oncology drugs are not guaranteed, but doctors and patients can still strive to gain access to them through several mechanisms, such as:

- Individual Funding Request (IFR): a mechanism by which physicians submit requests for funding support when cancer drugs are not provided by the NHS. Drugs that are not available are usually due to limited evidence regarding the benefits of the drug, or because the price is very expensive and does not provide value for money for the NHS (National Health Service). IFR can be submitted if the doctor believes that the patient's clinical condition is very different from the patient's case in general, as well as the patient's response to the drug is very different (clinical benefits are very significant in these patients).
- Cancer Drugs Fund (CDF): In the UK, this mechanism is used where health technology has promising benefits but has not been decided by NICE (National Institute for Health and Care Excellence) because it still requires more time and evidence in making a decision, so there is conditional approval for use in patients who need it for short periods of time.
- Private health services: pay directly for medical treatment or private insurance. In this case if the drug is not provided by the NHS, or a new treatment exists (this must be considered whether it has passed clinical trials or not).
- Clinical trials: patients can become participants for drug clinical trials, if the drug required is in accordance with the patient's diagnosis.
- Crowdfunding: collecting money from the community (example: charity)

Cancer prevention programs have been mentioned in the previous chapter, such as changing lifestyles and lifestyles, vaccination programs, and regulations for dealing with cancer (there are guidelines for tackling uterine and breast cancer and special strategies for establishing cancer registration) (P2TM Directorate Action Plan, 2020). The strategic document does not include prevention efforts from the primordial level of prevention that affect cancer. Such efforts include increasing cigarette excise and sugar tax, or from primary prevention such as physical activity, a healthy diet, avoiding smoking, and expanding vaccination coverage (for HPV).

Based on Presidential Regulation (Perpres) No 82 of 2018 concerning Health Insurance, regional governments are required to allocate a portion of cigarette tax to BPJS Health for the implementation of JKN. 10% of the total cigarette excise is a cigarette tax that is handed over to the local government. The Ministry of Finance (2019) reports that funds of around IDR 1.34 trillion from cigarette tax proceeds have been allocated to improve BPJS Kesehatan funding.

Furthermore, on secondary prevention efforts which include screening and early detection. Screening coverage must also be strengthened because even though the program has been running in 34 provinces in Indonesia, the total number of women participating in cervical and breast cancer screening was only 9.8% or around 3.6 million of a total of 37.4 women aged 30-30 years in the 2007 period. -2018 (Wahidin et al., 2022). Efforts to strengthen the program can be increased, such as socializing prevention programs, expanding preventive services (including screening) in JKN, increasing the capacity of health workers as well as cadres in the community, and strengthening cooperation with local governments for program implementation in primary health services. With prevention and early detection, cancer can be prevented or treated early, so as to prevent long-term illness and death, besides that it can reduce the burden of medical costs both from the patient's side and health care providers. Clinical governance is also important, to provide the best service for cancer patients.

The government has also developed a National Cancer Action Plan, which focuses on increasing the number of health facilities for cancer as well as the quality of trained human resources needed to provide comprehensive cancer care and services. Strategies and policies related to promotive, preventive, curative and rehabilitative activities that have been pursued by the government can be expanded by optimizing governance, synergy, and multi-sectoral cooperation along with monitoring and evaluation processes in achieving cancer treatment targets.

Furthermore, reviewing benefit packages, improving governance, increasing the implementation of strategic purchasing, analyzing tariffs, and evaluating contributions for JKN participants are also still needed, as written by Anissa et al., 2020; Aidha, C. N., & Chrisnahutama (2020). This aims to build efficiency or enable the expansion or evaluation of existing benefit packages to improve services in JKN. The choice of financing innovations can be considered by the government, such as (Siregar et al., 2022):

1. Look for sources of funds to finance the health sector, such as the allocation of tobacco excise
2. Risk-sharing scheme (especially for cancer essential medicines) or coordination of benefits (CoB) with private insurance as an alternative financing mechanism
3. Collaboration with the pharmaceutical industry to gain special access to certain cancer therapies (Patient Access Scheme)

Some of the mechanisms and policies above can be used as learning materials to form solutions that ultimately have an impact on handling the catastrophic burden on patient households due to the high cost of medical OOP.

5.4.2. Non-medical direct expenses

The costs incurred by BPJS Kesehatan related to claims for service fees for cancer from 2015-2018 only increased in a few provinces, such as DKI Jakarta, Central Java and South Sumatra. Meanwhile, other provinces tend to experience stagnation or decline, according to the graph below.

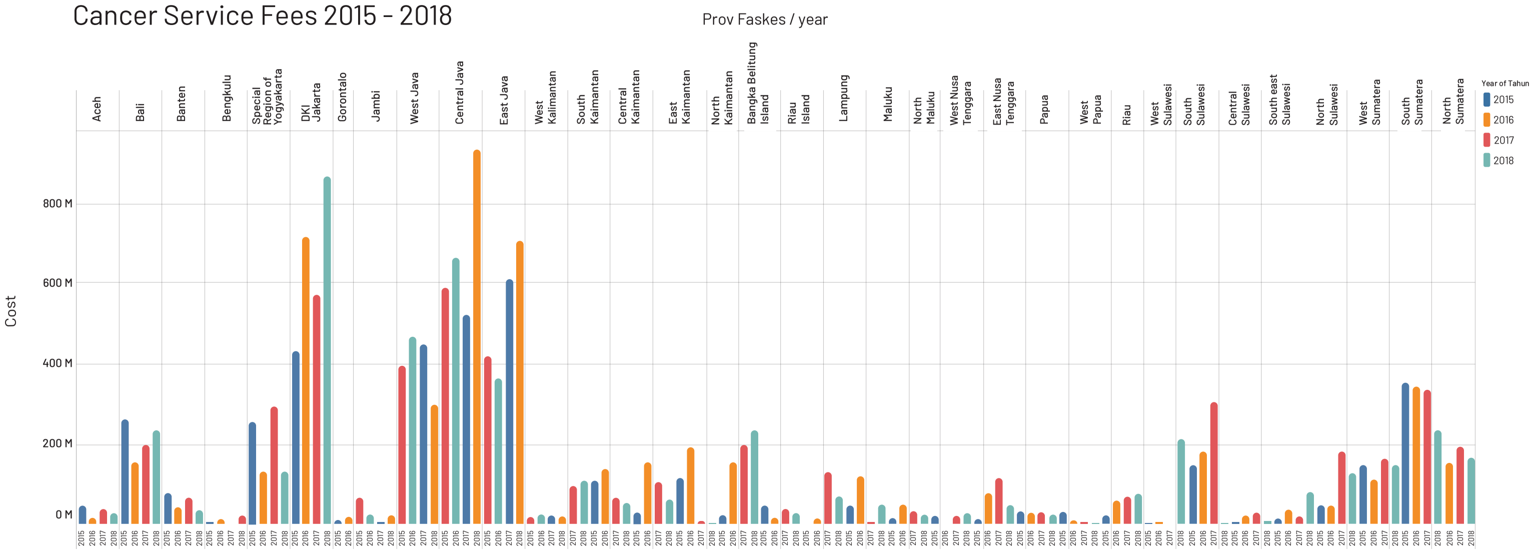
The stagnation or decrease in claims related to the cost of cancer services is of course influenced by the availability of advanced referral health facilities (FKRTL/hospitals) which fall into the class A category. The infrastructure of FKRTL that meets the criteria as a referral facility for handling cancer treatment is still centralized in several cities. big. So that claims for cancer service costs increased only in a few provinces. While other provinces that do not have FKRTL as a referral for cancer patients have decreased claims for this fee.

Regarding health services for cancer patients at FKRTL, there is a palliative care approach that can be used to improve the patient's quality of life. However, the current policy regarding palliative care covered by JKN is contained in Permenkes number 26 of 2021 concerning guidelines for Indonesian Case Base Groups (INA-CBGs) code Z51.5. The rates for palliative care in this regulation are not specifically applied to cancer, but to diseases in general. Then, palliative care in this policy is only carried out in health facilities such as hospitals. Meanwhile, costs incurred for home care (homecare basis) cannot be recognized.

Currently BPJS Kesehatan can only cover palliative care costs if the doctor specifically writes down a diagnosis of palliative care for patients who are hospitalized. In addition, the national guidebook for cancer palliative programs also still uses palliative care in health facilities only and has not been expanded on a homecare basis. Budgeting, monitoring, evaluation, and achievement targets for the national cancer palliative program have also been set for 2020. However, implementation and data from the Ministry of Health regarding the coverage of cancer palliative care (1%) is still very far from the 2020 achievement target (80%) (Ministry of Health , 2015).

Whereas in this study, it was found that the implementers of palliative care were mostly informal caregivers or the patient's own family. So when doing palliative care, homecare basis is the main choice for families of cancer patients. Besides the cost which is not too much, patients are also more open, and psychologically have a positive impact. Of course the government needs to expand the coverage of palliative care financing in the community by maximizing the role of the family (homecare basis). So that the palliative care that is carried out does not add to the non-medical direct cost burden of cancer patients while undergoing treatment/therapy/surgery.

Figure 9. Cancer service costs based on BPJS Health claims per province 2015-2018



Source: BPJS Kesehatan 2015-2018

Homecare-based palliative care must be integrated with health facilities to maintain the quality of health services and patient safety. But with a note not to move the hospital to the house to carry out palliative care.

This study also found that direct non-medical expenses increased in cancer patients due to the health system in the area of residence that did not have adequate health facilities to treat cancer in the early stages of treatment. Some of the limitations in health facilities in the patient's area of origin are: limitations of specialist doctors and limitations of technology for examining cancer symptoms.

This causes cancer patients to be referred and undergo treatment in the capital. Referrals to other provinces also cause patients and their caregivers to incur direct non-medical costs such as: transportation, lodging, consumption costs during treatment, with a high intensity of visits. However, these costs are not included in medical expenses, so they are not covered by existing health insurance. Increasing the number of referral hospitals and also developing regional special cancer hospitals can be one of the efforts to reduce this problem. In addition, improving the quality of the hospital network with special cancer services can also be strengthened to expand the scope of services.

The government can also develop policy mitigation costs outside of medical services as a form of financial protection (for example travel vouchers, cash transfers) with a conditional nature so that it not only helps patients to reduce direct non-medical costs, but also as an effort to comply (compliance) in resolving episodes. treatment (e.g. completing cycles of chemotherapy).

5.4.3. Indirect cost

Receiving a cancer diagnosis is not easy, because cancer is the second highest cause of death in the world after cardiovascular disease. In addition, the long treatment process and the side effects of the treatment cause psychological and economic burdens for cancer patients so that few of them want to stop their treatment and give up on their condition.

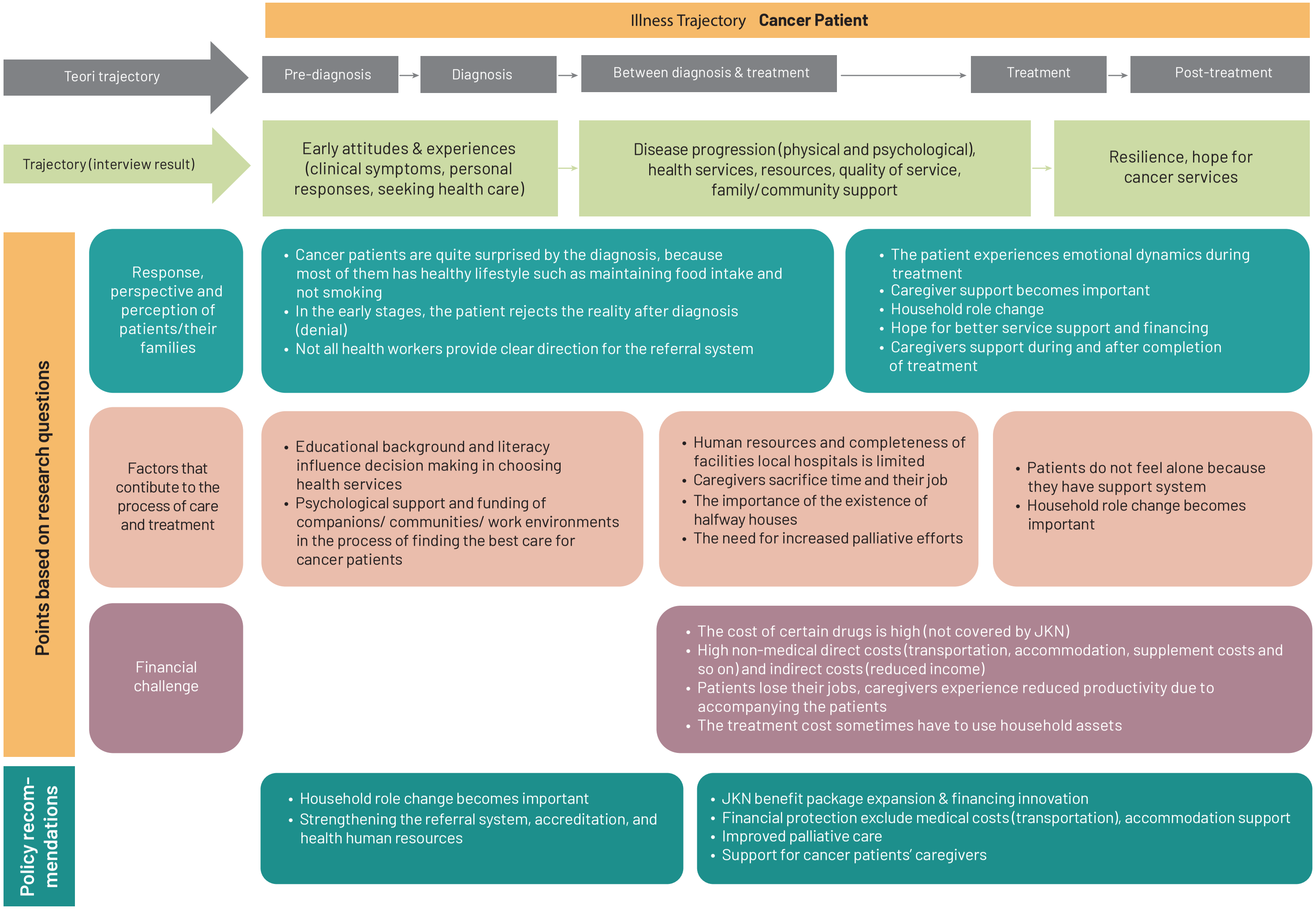
By being diagnosed with cancer, patients have lost days due to having to be hospitalized, receiving treatment and medication or side effects that affect productivity, in this case reduced income, salary, and lost productive work days. (Pangestu & Karnadi, 2018) From a caregiver perspective, cancer also has an impact on productivity and psychological aspects. Caregivers who are still productive must be willing to put aside their work in order to care for their families who are cancer patients, so they have to postpone work, have their wages cut, do not get incentives at work, or have reduced income. (Cong etc., 2022) Not only in terms of decreased productivity, conditions mental health can also be disrupted, one of the findings in the study was acknowledged by caregivers who felt a little hopeless because they did not recover from their family's treatment, they were also afraid in the future if they lost their partner who is a cancer patient.

Excessive anxiety from patients and caregivers will exacerbate and reduce self-efficacy in cancer treatment. Self-efficacy is very important in minimizing cancer cell metastases. Self-efficacy is the patient's belief in his own ability to deal with certain situations, in this case the cancer he is suffering from. Therefore there is a need for psychological and educational support (psychoeducation) as a support system to help provide information in solving problems experienced by patients and caregivers, such as reducing stress levels, managing symptoms, developing relaxation techniques and adaptive abilities that can restore emotional instability. and can be a source of social support for caregivers and cancer patients.

For cancer patients in the Regulation of the Minister of Health Number 34 of 2015, palliative services are provided for cancer patients since the diagnosis is established and treatment is integrated with a psychosocial approach. For caregivers, the need for psychological assistance can already be obtained by caregivers who are participants in the National Health Insurance-Indonesian Health Card (JKN_KIS), in Presidential Regulation Number 82 of 2018 concerning Health Insurance, that JKN_KIS participants can benefit from health care and protection in meeting basic needs. good health promotive, preventive, curative and rehabilitative services. To get psychological assistance for JKN-KIS participants, first consult their complaints at the First Level Health Facility (FKTP) then if further treatment is needed the doctor will provide a referral to the Advanced Health Facility (Faskes).

However, it is still difficult for caregivers to consult directly with the FKTP because sometimes caregivers do not have free time to consult other health facilities and do not realize that their condition requires consultation and psychiatric help. This encourages the need for psychoeducational treatment of patients and caregivers in the same health facility.

Figure 10. Illness Trajectory results of field data analysis



Illness Trajectory **Cancer Patient**

Teori trajectory

Pre-diagnosis → Diagnosis → Between diagnosis & treatment → Treatment → Post-treatment

Trajectory (interview result)

Early attitudes & experiences (clinical symptoms, personal responses, seeking health care) → Disease progression (physical and psychological), health services, resources, quality of service, family/community support → Resilience, hope for cancer services

Points based on research questions

Response, perspective and perception of patients/their families

- Cancer patients are quite surprised by the diagnosis, because most of them has healthy lifestyle such as maintaining food intake and not smoking
- In the early stages, the patient rejects the reality after diagnosis (denial)
- Not all health workers provide clear direction for the referral system

- The patient experiences emotional dynamics during treatment
- Caregiver support becomes important
- Household role change
- Hope for better service support and financing
- Caregivers support during and after completion of treatment

Factors that contibute to the process of care and treatment

- Educational background and literacy influence decision making in choosing health services
- Psychological support and funding of companions/ communities/ work environments in the process of finding the best care for cancer patients

- Human resources and completeness of facilities local hospitals is limited
- Caregivers sacrifice time and their job
- The importance of the existence of halfway houses
- The need for increased palliative efforts

- Patients do not feel alone because they have support system
- Household role change becomes important

Financial challenge

- The cost of certain drugs is high (not covered by JKN)
- High non-medical direct costs (transportation, accommodation, supplement costs and so on) and indirect costs (reduced income)
- Patients lose their jobs, caregivers experience reduced productivity due to accompanying the patients
- The treatment cost sometimes have to use household assets

Policy recom-mendations

- Household role change becomes important
- Strengthening the referral system, accreditation, and health human resources

- JKN benefit package expansion & financing innovation
- Financial protection exclude medical costs (transportation), accommodation support
- Improved palliative care
- Support for cancer patients' caregivers

Chapter 6

Conclusion and Recommendation

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Conclusion and Recommendation

6.1 Conclusion

Ignoring early symptoms is common for cancer patients in the pre-diagnosis condition. This neglect has an impact on delays in the initial treatment of cancer because it is only when the pain increases in intensity that new cancer sufferers have the initiative to carry out medical examinations at the hospital. The neglect carried out by cancer patients in the early stages is more due to the patient's perception of a lifestyle that is quite healthy and the strong assumption in patients that cancer is synonymous with an accumulation of unhealthy lifestyles.

The delay in this examination also had an impact on the patient's treatment pattern, which went directly to the first advanced health facility or hospital, and not to the Puskesmas/ FKTP first. Some patients, especially those who live in areas without type A and B hospitals, experience difficulties in obtaining examination results. This study found that in the early stages of experiencing symptoms, patients and their families had limited knowledge about cancer symptoms and disease, were constrained in obtaining initial examination results, and limited information on treatment referrals by medical personnel to patients. Furthermore, the study found that these limitations could delay patients' treatment by one month. The initial stage of diagnosis is also a difficult situation for patients because patients are stressed, panicked, and afraid because the cancer treatment process is quite long and expensive. Transparency of the stages of treatment by doctors encourages patients to comply with treatment at the hospital compared to alternative medicine.

Family and caregiver support as well as the internal encouragement of cancer patients play an important role. The results of this study found the role and support of caregivers, extended families, and the community of cancer patients and cancer survivors. In addition, internal encouragement and motivation are factors driving patients to continue the treatment process. The caregiver status of cancer patients is quite diverse, namely: husband or wife, children, or the patient's siblings. The relationship pattern between patients and caregivers shows that the role of the nuclear family is very important in supporting the treatment process of cancer patients in Indonesia.

The role and support of the family and caregivers are the supporting factors for the emergence of resilience in cancer patients. The treatment process not only has an impact on the emergence of side effects such as loss of appetite, metabolic disorders, and insomnia in patients, but also increases anxiety in cancer patients. Family support for patients can make patients easily adapt to the treatment process, accept and experience the side effects they suffer, and strengthen cancer patients psychologically. Besides being able to strengthen cancer patients, this also encourages patients to want to undergo the treatment process with all its consequences.

However, the role modalities and family support are not integrated in the palliative care system. The results of the analysis of this study found that the practice of treating cancer patients by their families and caregivers was carried out at home (home-based care). However, several health policies related to palliative care are general to all types of catastrophic diseases and have not been disaggregated by type of disease. This policy also only targets palliative care in hospitals and does not involve the patient's family and caregivers. In addition, the coverage of palliative care is still below 10% for cancer patients. Thus, the role modalities and family support for patients are not integrated in the palliative care scheme carried out by the hospital.

All patients are already using BPJS Health which causes direct expenditure for basic medical needs at the hospital is no longer needed. It's just that the patient and family have to pay their own expenses (OOP) for transportation costs, consumption during treatment, purchase of vitamins and supplements, accommodation (lodging), and the cost of paying for driver services. This is due to patient referrals to hospitals outside their area of residence to obtain a more adequate treatment package. Some patients actually have to fly to other islands in Indonesia for treatment. The findings of this study found that the costs for direct non-medical expenses are quite large, and the costs are even greater because the treatment process must be quite intense. This accumulation has caused him and his family to make several adjustments to managing household finances such as moving children's schools, minimizing household daily consumption, using existing savings, and in some cases having to borrow from relatives or colleagues.

Patients and caregivers also experience the impact of indirect costs such as loss of productivity to termination of employment. The process of cancer treatment causes patients to experience obstacles at work which causes them to experience salary cuts due to frequent absences until they are advised to stop working. Likewise from the side of the assistant whose activity/frequency of work is reduced due to accompanying sick patients, which in turn affects the income level of the patient's and caregiver's household.

This research further found that not all drugs and cancer treatment measures can be covered by BPJS Kesehatan. This study found that lung cancer patients need to pay quite expensive costs related to Avastin (Bevacizumab) from their personal pockets because it is not guaranteed by BPJS Kesehatan. Avastin for the treatment of lung cancer is not yet included in the JKN scheme. Previously, Avastin was included in the benefit package only for indications for treating metastatic colorectal cancer. This type of treatment is included in targeted therapy or special treatment and not for all lung cancer patients. Targeted therapy is indeed not included in BPJS Kesehatan funding because it has been criticized by many for not fulfilling the cost-effective principle, where the costs incurred should be commensurate with the clinical benefits obtained. However, this study found that further studies are needed to determine whether this treatment needs to be included in the BPJS Health financing scheme because the costs incurred by patients for this treatment reach tens of millions with a high intensity of care.

6.2. Recommendation

Based on the results of the analysis of research findings, there are several policy recommendations and technical improvements as follows:

1. **The Ministry of Health, Provincial Governments, Regency/City Governments and Hospitals need to take steps to improve oncology facilities and the quality of oncology services and transform the referral process, strengthen the cancer care hospital network, encourage the expansion of hospital accreditation and provision of hospitals specifically for cancer that can be reached easily and inexpensively by patients in all regions in Indonesia.** The central and regional governments need to provide facilities and infrastructure capable of supporting minimum health services for cancer patients in the regions. Facilities with adequate technology or equipment, one of which is radiotherapy. The government also needs to strengthen health facilities considering that several provinces only have hospitals with C accreditation. The Ministry of Health needs to make referral hospitals networked among the nearest provinces. Capacity building and provision of human resources are of course also needed to support services. In addition, strengthening the monitoring scheme for promotive and preventive services is also needed so that the public can get better information, especially at the early stages of pre-diagnosis.

2. **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 facilities are the key to cancer cure.** Prevention efforts can be made by tightening the consumption of products that are harmful to health, such as increasing taxes on artificially sweetened drinks and increasing cigarette excise. Other prevention efforts that need to be carried out by the Ministry of Health are strengthening vaccination schemes and establishing integrated screening and registration in every province in Indonesia. This study found that although there are already 13 cancer registration centers in Indonesia, the scope of work of these hospitals is limited to districts and cities in one province. So that a cancer registration center hospital is needed in several other provinces more evenly.
3. **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 role of the caregiver is very important in increasing patient adherence to treatment and the quality of life of cancer patients. So that innovation is needed to provide psychological services such as through telemedicine to expand services that can be accessed by caregivers at the FKTP level.
4. **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 diagnostically as there are no intervention options that can help patient).** This integration can be carried out by integrating home-based care and medical palliative care in hospitals. In addition to being able to involve caregivers in the treatment process, this scheme can also provide education to caregivers in supporting the improvement of the quality of life of cancer patients.
5. **The Central Government, Provincial Governments and Regency/City Governments need to provide assistance with direct non-medical costs and non-medical indirect costs (transportation, halfway houses, lodging and others) so that cancer patients, cancer sufferers and their families can undergo the treatment process good and complete healing.** The government can cooperate with civil society organizations in the form of shelters with a quota scheme, especially in the DKI Jakarta area as the region with the most national cancer treatment referral hospitals. This effort is of course short-term in nature and has an immediate impact on patients and their families.
6. **The government needs to increase socialization and literacy massively to the public about the importance of cancer prevention and early detection of cancer by involving all parties including community organizations and the mass media and making optimal use of information technology (digital).** This is necessary considering that

many community organizations contribute to supporting cancer healing in patients such as good practices in providing shelter support, medical services, and providing assistance with vehicles for treatment. Socialization through the media also needs to be done to encourage the expansion of socialization and continuous strengthening of healthy living campaigns.

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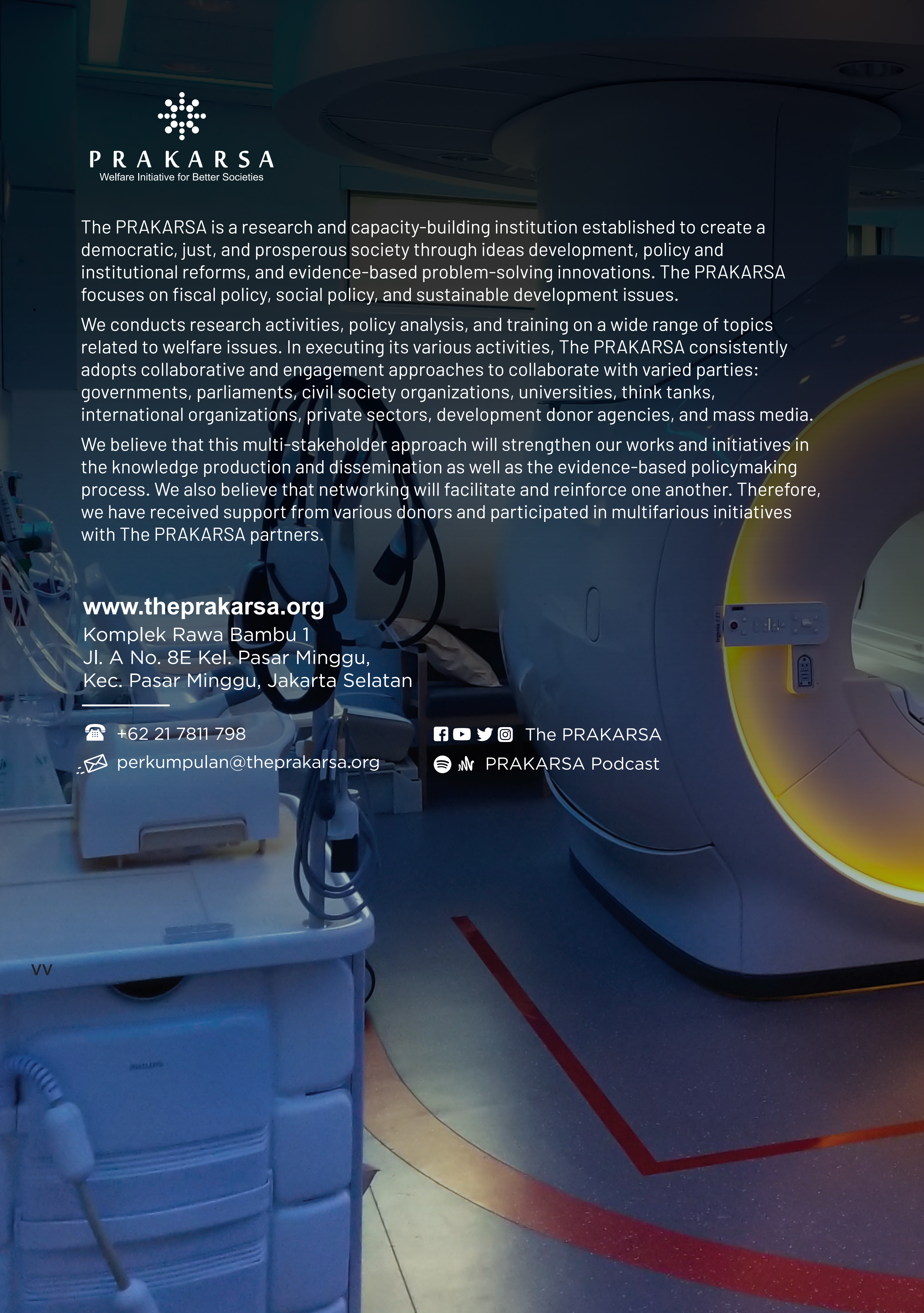

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