THE IMPACTS OF CATASTROPHIC DISEASES IN INDONESIA : AN ANALYSIS OF GLOBAL BURDEN OF DISEASE 2021

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ABSTRACT

Catastrophic diseases are medical conditions that require ongoing care, potentially life-threatening, and incur considerable expenses, experiencing growth predominantly in developing countries and representing substantial burdens to health and economic sectors. Consequently, the objective of this study is to highlight the impacts of catastrophic diseases in Indonesia, while identifying the risk factors, and potentially offering valuable strategies for family physicians aiming to mitigate these challenges. The disease burdens, such as prevalence, death, DALYs, ASDR and associated risk factors, were collected from Global Burden of Disease (GBD) 2021 during June to 5th July 2024. Furthermore, information on the financial implications was extracted from the Indonesian Social Security Agency for Health. The Indonesian majority of DALYs were contributed by cardiovascular disease while except for cancers, the other diseases exhibited higher mortality rate compared to the global ASDR. Additionally, there were notable increases in diseases prevalence between 2010 and 2021, hence majority of catastrophic diseases securing the third position worldwide in terms of DALYs. There has been a consistent rise in the caseloads and healthcare costs since 2018 till 2022. Moreover, several risk factors have been identified such as elevated BP, FPG, and smoking underscoring the necessity for intervention including smoking ban, promoting healthy dietary and lifestyle. In recent decade, catastrophic diseases have led to significant health and economic burdens across Indonesia. As a result, it is imperative to implement preventive measures to mitigate these challenges which create opportunities for family doctors to address these gaps in healthcare system.

Keywords: *catastrophic disease, disease burden, healthcare cost, risk factor, Indonesia*

1. INTRODUCTION

Catastrophic diseases are medical conditions that necessitate prolonged care, and alongside additional complications may have the potential to be life-threatening, leading to a significant demand for resources while also incurring outrageous expenditures.[1–3] These diseases are usually chronic and progressive due to their rarely noticeable symptoms, which could have emerged over time, and required lifetime managements that likely to worsen with aging.[4] Furthermore, they also lead to disabilities and deaths in younger individuals, negatively impacting their overall well-being.[3]

Globally, catastrophic diseases represent one of the most significant burdens of health issues which have undergone recent transition leading to an acceleration in their burden predominantly in developing countries.[3] For instance, cardiovascular disease (CVD) constitutes as a main contributor of mortality accountable for approximately 17.9 million deaths in 2019, and major impairment, hence reduction of quality of life proportionately larger in low- and middle-income countries. [5] Moreover, GBD 2021 study forecasted that the non-communicable diseases burden led by ischemic heart disease, stroke and diabetes will continue to escalate in 2050.[6] Hence, exorbitant cost of healthcare will perpetuate poverty while individuals with catastrophic diseases are the most susceptible stemming from extended and consistent treatment.[7] Furthermore, as a consequence of medical costs, approximately 150 million individuals suffer catastrophic health expenditure (CHE) annually that increased

at eleven percent per annum based on World Health Organization (WHO) discovery.[7]

Similarly, Indonesian social security agency for health or *BPJS-Kesehatan* (*Badan Penyelenggara Jaminan Sosial Kesehatan)* indicates that the prevalence of catastrophic disease has steadily increased and doubled in number over the period of 2014-2017.[1] In addition, according to 2018 report, the costs for treatment accounted for 22% of the entire healthcare expenses or around 14.5 trillion rupiahs where majority went for heart diseases, cancer and stroke treatment.[3,8] Meanwhile, in 2019, there were a total of nearly 20 million cases with total expenditures reaching as high as over 20 trillion Indonesian Rupiah, where half of it due to cardiac disease.[9]

Diseases that are considered high cost, high volume, and high risk are of concern to health insurance providers as they worry about the rising costs of these diseases.[1] For example, since the initiation of Indonesian National Health Insurance Program or *Jaminan Kesehatan Nasional* (*JKN*) in 2014, it has been encountered with economic shortfall amounting to 9.7 trillion, 9.75 trillion and 10.98 trillion IDR over the period 2016-2018 which projected to persist in forthcoming years.[10] *BPJS-Kesehatan* has identified eight catastrophic diseases namely cardiovascular disease (CVD), chronic kidney disease (CKD), cancer, stroke, liver cirrhosis, thalassemia, leukemia, and hemophilia as the major contributors to these deficits.[1,2,4,9,11] Furthermore, both the health and economic worldwide including Indonesia were constrained by the COVID-19 pandemic in 2020 through damaging transportation, tourism, trade, and healthcare sectors.[8,12] Consequently, the financing demand for *JKN* are projected to escalate due to a multitude of factors, such as heightened health awareness, human migration, population expansion and naturally the rise of catastrophic diseases with devastating financial implications;[1] thus, highlighting the need for comprehensive healthcare reformations specifically in prevention of catastrophic diseases by enhancing primary care system and enhancing health screening tools.[8,10]

Expedient, comprehensive, and thorough disease burden evaluations which elucidated the root causes of disability and mortality at the population level, serve as a crucial tool to fully comprehend and address the intricate impacts of catastrophic diseases throughout various periods. Moreover, these reports enable policymakers, public health researchers, and other professionals to implement strategies for disease reduction more effectively.[12] Nonetheless, it is imperative that the primary focus should be on the prevention of the catastrophic diseases particularly in primary care setting feasibly by involving family doctors to mitigate their upcoming burdens. Therefore, the purpose of this article is to highlight the impacts of catastrophic diseases particularly in Indonesia, identify the contributing risk factors and potentially offer valuable insights for family physicians to strengthen primary care services aiming to alleviate these difficulties.

2. METHOD

The impacts of catastrophic diseases encompass both the health and economic aspects, hence to offer a more precise representation of disease burdens, distinct metrics such as prevalence, death, disability-adjusted life year (DALYs), and age-standardized death rate (ASDR) were collected from the standardized Global Burden of Disease (GBD) 2021 study during June- 5th July 2024. Their associated risk factors were also sourced from GBD to offer potential strategies to mitigate the challenges of catastrophic diseases particularly in Indonesia. In addition, GBD Input Source Tools and GBD Compare were utilized to view the data.[5] Moreover, the following causes namely leukemia, thalassemia, stroke, cardiovascular diseases, total cancers or neoplasms,

chronic kidney disease and cirrhosis were utilized for catastrophic diseases whereas hemophilia was not included from categories of catastrophic disease for burden analysis since no data was available from GBD 2021 study. Unless stated, all of the measurements reported were in terms of all-ages number. Furthermore, data for financial implications compromising number of cases and healthcare expenditures were extracted from Indonesian Social Security Agency for Health (*BPJS-Kesehatan*). No other software and tools were utilized in data extraction, processing and analysis in this article.

Data Sources

The Global Burden of Disease (GBD) study, initiated in 1991 by the World Bank and the World Health Organization (WHO), represents a collaborative, multinational research constituting a significant milestone in the quantification of the prevalence and impact of various diseases, and their associated risk factors, thereby enhancing our comprehension of the fundamental descriptive epidemiology of global population health.[5,11] The success of the GBD study has positioned the burden of disease technique as primarily synonymous with the GBD approach, which utilizes the disability-adjusted life year (DALY) metric for its methodology, a metric that is now universally accepted.[11]

The impacts of catastrophic diseases was evaluated using various measures such as prevalence and death cases, disability-adjusted life years (DALYs), and the age-standardized death rates determined by adjusting for age using a mean without considering weights, based on the age-specific proportions of the GBD year's data for countries with populations over 5 million, to revise the global population age standard.[13] The calculation of DALYs for the GBD 2021 was constructed from an extensive array of data sources, with a total of 100,987 sources being utilized in which 19,189 were newly added and 75,459 focused on non-fatal causes of disease,

36,916 provided data on incidence rates, 22,236 contained information on prevalence rates, and 45 sources offered data on other epidemiological indicators, including remission rates.[12]

The computation of disability-adjusted life years (DALYs) involves the summation of Years Lived with Disability (YLDs) and Years Lived Lost (YLLs) from premature mortality. One DALY equivalent to one year of healthy life lost. Concurrently, YLDs are calculated by multiplying disease prevalence of associated outcome specific to the cause, age, sex, location, and year, by the relevant disability weights whereas YLLs represent the total number of years lost due to premature death calculated by subtracting the age of death from the highest potential lifespan an individual might attain at that specific age.[5,12,14] 95% uncertainty intervals (UIs), which encompassed the 25th and 95th percentile values from 500 hypothetical draws, were generated to represent the uncertainty associated with the estimation methodology. Detailed explanations of GBD analytical methods have been reported in previous literature.[5,12]

GBD 2021 measures, which encompass both all-age numbers and age-specific rates per 100,000 individuals, along with rates standardized per 100,000 individuals, were determined by GBD standard population framework. The dataset also includes percentage variations across specified time intervals (e.g. 2010-2021), along with annualized rates of change. These rates of change are ascertained by subtracting the initial value from the final value of the time interval, and subsequently dividing the quotient by the duration of the interval in years.[12]

3. RESULT
3.1. Health Burdens of Catastrophic Diseases

Exaggerated across various health determinants, the total burden of Disease Adjusted Life Years (DALYs) escalated from approximately 2.63 billion in 2010 to

2.88 billion in 2021 when COVID-19 emerged as the leading contributor to the global disease burden followed by ischemic heart diseases, neonatal disorders, and strokes accounting for an unprecedented 212 million, 188 million, 186 million, and 160 million DALYs respectively.[12] This substantial increase in 2020 and 2021, marking the first reversal in thirty years of progress which can be attributed to three primary factors namely (1) the direct health impacts of COVID-19; (2) the indirect health consequences of the pandemic, including its influence on mental health, and (3) the adverse effects stemming from overwhelmed healthcare systems and fragmented policy responses to the pandemic.[12]

Table 1 Prevalence and DALYs of Catastrophic Diseases in Indonesia (2021)[15]

Catastrophic Diseases	AAPN* [10³] Numbers	(95% UI)	DALYs** [10³] Years	(95% UI)
Cardiovascular Disease	14,476.46	(13,434.08–5,485.85)	20,308.89	(17,200.21 – 3,640.72)
Stroke	3,942.16	(3,639.49–4,286.19)	10,624.06	(8,956.51 – 12,309.26)
Total Cancers	1,238.01	(999.38–1,511.77)	6,995.53	(5,535.34 – 8,469.26)
Cirrhosis	67,900.32	(62,832.3 – 73,241.09)	3,276.15	(2,692.81 – 4,050.98)
Chronic Kidney Disease	29,413.90	(26,931.32 – 32,010.16)	1,990.50	(1,655.07 – 2,360.24)
Leukemia	25.51	(20.28 - 37.55)	489.50	(394.71 - 623.19)
Thalassemia	65.38	(54.6 - 78.13)	69.81	(50.09 - 88.35)

* All Ages Prevalence Number   **Disability-Adjusted Life Years

Cardiovascular diseases, including stroke and ischemic heart disease, emerged as the fifth-highest group of primary causes of death-related illnesses across 190 countries and territories in 2021.[12] Correspondingly based on GBD 2021, cardiovascular disease was also the main contributor to DALYs in Indonesia, yet the most common catastrophic diseases were cirrhosis followed by chronic kidney disease. In addition, the prevalence and disability-adjusted life years (DALYs) of catastrophic diseases in Indonesia during 2021 are shown in table 1.

From the year 2017 to 2019, cancer was being the second most significant cause of Years Lived Lost (YLLs), Disease Adjusted Life Years (DALYs), and fatalities worldwide, ranking second only to cardiovascular disease.[16,17] In fact, the probability of developing cancer during a person's lifetime, ranging from 0 to 79 years, is 1 in 4 for women and 1 in 3 for men across the globe whilst only 3% of the disease-adjusted life years (DALYs) attributed to cancer was derived from the duration spent in a state of disability, whereas the majority of DALYs, 97%, were attributed to years of life lost.[16] In nearly a decade (2010-2019), there was a notable increase in the global incidence of new cancer cases, as well as in the mortality rates associated with cancer, with a respective 26.3% and 20.9%. Furthermore, according to GBD 2019 predictions, the global cancer burden is also expected to increase over the next two decades, with cancer accounting for a significant portion of all diseases worldwide.[16] Excluding non-melanoma skin cancer, the global statistics for 2020 reveal a staggering number of new cancer cases and deaths. A total of 19.3 million new cancer cases were reported, accompanied by 10.2 million cancer-

related fatalities, resulting in a mortality rate of 51.81%.[18]

Table 2 ASDR Comparison of Indonesia and Global Catastrophic Diseases 2021[15]

Catastrophic Diseases	ASDR* (per 10^5 populations) (95% UI)	
	Indonesia	Global
Cardiovascular Disease	409.87 (343.65 - 459.43)	235.18 (214.64 - 250.52)
Stroke	217.69 (182.04 - 245.43)	87.45 (78.92 - 94.14)
Total Cancers	98.16 (76.18 - 116.72)	115.81 (106.66 - 123.96)
Cirrhosis	44.78 (36.49 - 52.51)	16.64 (15.28 - 18.26)
Chronic Kidney Disease	22.98 (18.83 - 29.04)	18.5 (16.72 - 19.85)
Leukemia	4.65 (3.78 - 6.14)	3.89 (3.34 - 4.25)
Thalassemia	0.39 (0.28 - 0.49)	0.15 (0.11 - 0.19)

*Age-standardized Death Rate

Table 2 provides the information about the comparison of age-standardized death rate (ASDR) between global and Indonesia where majority of catastrophic diseases had higher mortality rate than the world average except for cancers. This was probably due to the fact that low socio-economic index (SDI) country was less likely to develop cancer than high SDI quintile: (1 in 7) versus (1 in 2) respectively.[16] Information from the 2020 Global Cancer Observatory (GLOBOCAN) delineates that Indonesia experienced 396,914 new cancer diagnoses, with 59.08% of these cases leading to mortalities.[18] Meanwhile, a total of 213,546 new cancer cases reported in Indonesia, with 183,368 of these cases affecting women whereas the prevalence of cancer among women was found to be 57.3%, in contrast to 42.7% among men.[18] Additionally the leading causes of death were leukemia, accounting for 219 cases (12.7%), followed by colorectal (8.5%), and breast (11.4%) cancer.[18] Notably, there were no reported deaths related to cancers of the peripheral and autonomic nervous systems.[18]

3.2. Indonesian Catastrophic Diseases Trend and Rank

Subsequently, table 3 displayed the total percentage changes in the last decade (2010-2021) of both prevalence and death case caused by catastrophic diseases, which reported that the prevalence numbers of catastrophic diseases in Indonesia experienced higher percentage change compared to the global average. From the year 2013 to 2018, there has been a notable increase in the national prevalence of stroke in Indonesia, rising from 0.7% to 1.09%. This escalation in prevalence has led to a corresponding rise in the number of outpatient and inpatient treatments, as well as the financial burden that the government is tasked with managing through the National Health Insurance (JKN) Program.[19]

Similarly, the percentage changes in total death shown positive value in both Indonesia and worldwide except for thalassemia shown decline in numbers. Moreover, the figure in thalassemia remains markedly below the official projection, which is presumed to be significantly underrepresentative of the true magnitude of the situation steming from various factors, including a dearth of diagnostic resources, leaving a substantial number of affected individuals undiagnosed, particularly those residing in peripheral areas. Furthermore, the country continues to be devoid of an official, fully functional national reporting mechanism.[20] Meanwhile, chronic kidney disease recorded a lower mortality number than the global percentage. Nonetheless, considering the notorious challenges associated with CKD screening, it is possible that these results underestimate the actual prevalence of CKD patients by a significant margin.[21]

Table 3 Total Percentage Change of Catastrophic Diseases in (2010-2021)[15]

Catastrophic Diseases	Total Prevalence Change 2010-2021 (%)		Total Death Change 2010-2021 (%)	
	Global	Indonesia	Global	Indonesia
Cardiovascular Diseases	33.46 %	42.03 %	18.51 %	29.64 %
Cancers	31.38 %	54.69 %	23.44 %	39.81 %
Stroke	28.39 %	33.99 %	14.30 %	23.60 %
Chronic Kidney Diseases	27.33 %	32.76 %	44.29 %	38.67 %
Cirrhosis	22.00 %	27.00 %	7.00 %	11.00 %
Leukemia	12.65 %	17.61 %	11.00 %	12.74 %
Thalassemia	-3.51 %	8.09 %	-15.14 %	-18.07 %

Based on table 4, excluding leukemia and neoplasm, Indonesia occupy the third position in term of highest total number of DALYs attributed to catastrophic disease in 2021, in which cardiovascular disease and chronic kidney disease newly risen over the decade. Meanwhile, Indonesia is marked by a considerable prevalence of catastrophic diseases, evidenced by the overall proportion observed within the top ten largest and substantial mortality rates, which positioned the country within the third in most cases except for neoplasm and chronic kidney disease.

Table 4 Indonesia World Rank (2021) and Rank Change (From 2010)[22]

Catastrophic Disease	Prevalence (Change)	Death (Change)	DALYs (Change)	Top 3 Leading Countries (DALYs-based)
Cardiovascular Disease	7th (Δ 9th)	5th (-)	3rd (Δ 4th)	China, India, Indonesia
Stroke	4th (Δ 5th)	3rd (Δ 4th)	3rd (-)	China, India, Indonesia
Chronic Kidney Disease	4th (-)	6th (-)	3rd (Δ 5th)	India, China, United States
Thalassemia	3rd (Δ 4th)	3rd (-)	3rd (-)	Pakistan, China, Indonesia
Cirrhosis	3rd (-)	3rd (-)	3rd (-)	India, China, Indonesia
Leukemia	12th (-)	4th (-)	4th (-)	China, India, United States
Neoplasms	7th (Δ 9th)	8th (Δ 11th)	7th (-)	China, India, United States

Furthermore, within Southeast Asia region, Indonesia occupy the second position regarding total number of DALYs, prevalence, death associated with all catastrophic disease, ranking just below China in the year 2021 and thereby reflecting particular health challenges.[22] In fact, approximately 60% of the global population resides in Asia experience the highest incidence rate of strokes and it is noteworthy that the mortality rate associated with strokes is notably higher in Asia compared to North America, Western Europe, and Australasia, a situation that mirrors that observed in Eastern Europe.[19]

3.3. Economic Impacts of Catastrophic Diseases

The economic ramification of catastrophic disease such as cardiovascular disease (CVD) can be depicted through macro-perspectives where it manifests as the diminution of productive life expectancy within the population which may significantly impede Indonesia's economic trajectory when left disregarded. Simultaneously on smaller scale, the impact is observed in the form of catastrophic health expenditure (CHE) for individuals afflicted by CVD which may even extends to the household level.[5] For example, a Malaysian survey indicated that nearly 3% households were suffering from CHE while disease-caused poverty accounts for over 40%, affecting approximately 20 million people and more than a third is suffering from catastrophic diseases.[7] The cost of living remains significantly burdensome for individuals afflicted with severe illnesses with a notable lack of improvement from medical aid.[7] In Korea, approximately 20% of the population encounters severe financial distress whereas in China the incidence of Catastrophic Health Expenditures (CHE) around 13% resulted in major poverty.[7]

Table 5 Case Number and Cost of Catastrophic Diseases in Indonesia[23–25]

Catastrophic Diseases	Case Number			Costs (billions IDR)		
	2018	2019	2022	2018	2019	2022
Cardiovascular Disease	11,628,273	13,041,463	15,495,666	9,389	10,276	12,144
Total Cancers	1,990,091	2,452,749	3,147,895	2,979	3,543	4,501
Stroke	1,914,455	2,127,609	2,536,620	2,271	2,549	3,235
Chronic Kidney Disease	1,648,667	1,763,518	1,322,798	2,116	2,321	2,156
Thalassemia	174,740	224,886	305,269	431	509	615
Cirrhosis	169,603	183,531	193,989	294	311	330
Leukemia	100,955	134,271	146,162	290	361	429
Hemophilia	54,416	70,999	116,767	307	406	650
Total	17,681,200	19,999,026	23,265,166	18,076	20,276	24,059

There has been a consistent growth among all catastrophic diseases with regard to caseloads and total costs. As presented in Table 5, cardiovascular disease was the main reason of healthcare services followed by cancer, stroke and chronic kidney disease and this trend has remained since 2018. According to Indonesian National Health Insurance Report (2020), CVD incurred the highest annual healthcare expenditures while stroke-related costs were the third highest among all diseases, representing approximately IDR 9.8 trillion (655 million USD) and IDR 2.5 trillion (167 million USD) respectively.[5] Globally, stroke emerges as the leading cause of mortality and disability, imposing a substantial financial toll on post-stroke care. Presently, stroke represents nearly 34% of global healthcare expenditures and within the United States, the anticipated cost of stroke healthcare, encompassing follow-up care,

rehabilitation, and inpatient treatment, is projected to reach an average of USD 140,000 per individual.[19]

3.4. Risk Factors Associated with Catastrophic Diseases

Table 6 exhibits a comprehensive array of primary risk factors, arranged in order of their importance for the year 2021, with a specific focus on those linked to catastrophic diseases and within this framework, three fundamental categories of risk factors have been identified and consistently referenced are:

- Metabolic Risks: These encompass elevated fasting plasma glucose (FPG) levels, increased systolic blood pressure, diminished kidney function, elevated body mass index (BMI), and raised low-density lipoprotein (LDL) cholesterol.
- Behavioral Risks: This category includes behaviors such as tobacco use and excessive consumption of sodium.
- Environmental/Occupational Risks: This involves exposure to ambient particulate matter, among other potential occupational exposures (e.g. benzene and formaldehyde).

Table 6 Leading All Ages Risk Factors Associated with Catastrophic Diseases (2021)[15]

Cause	Top 5 Leading Risk Factors	Other Potentially Modified Risk Factors
Total All Cause	High Blood Pressure, Smoking, High Fasting Plasma Glucose, Kidney Dysfunction, Ambient Particulate Matter	High BMI, High LDL, High Sodium
Cardiovascular Disease	High Blood Pressure, Smoking, High LDL, Kidney Dysfunction, Ambient Particulate Matter,	High Sodium, High Fasting Plasma Glucose
Cancer	Smoking, Unsafe Sex, Low Calcium, Ambient Particulate Matter, High BMI,	High Fasting Plasma Glucose
Stroke	High Blood Pressure, Smoking, Kidney Dysfunction, Ambient Particulate Matter, High Sodium,	High LDL, High Fasting Plasma Glucose
Chronic Kidney Disease	Kidney Dysfunction, High Blood Pressure, High Fasting Plasma Glucose, High BMI, Low Vegetables	High Sodium
Thalassemia	No Available Information	
Leukemia	High BMI, Smoking, Occupational Benzene, Occupational Formaldehyde	
Liver Cirrhosis	High Alcohol Use, Drug Use	

Indonesia, ranking fourth in terms of population size, has been significantly impacted by concurrent trends of urbanization, aging populations, and changing lifestyles.[5] In addition, Indonesia is progressively adopting a chronic care management approach to combat catastrophic diseases, which are exacerbated by elevated blood pressure, nutritional factors, and tobacco consumption. Based on Global Burden of Disease (GBD) analysis, hypertension is the major contributor to cardiovascular diseases, especially stroke (36-42%) and ischemic heart disease (20-25%) whereas smoking and elevated cholesterol levels

contribute to 25% and 19% of IHD proportion respectively.[5] Moreover, it has been predominantly consistent affecting both genders, while there was a notable escalation in high Body Mass Index (BMI) which are attributed to lifestyle modifications, dietary shifts, and evolving cultures in the last three decades.[5] On the other hand, more than a third of Indonesian adults consume tobacco highlighting a pronounced gender inequality of nearly 200% in males.[5]

Both ischemic heart disease and stroke share a multitude of modifiable risk factors and therapeutic interventions. In addition to the well-established risk factors for cardiovascular diseases, such as elevated blood pressure, high cholesterol levels, increased body mass index, kidney dysfunction, exposure to both ambient and household air pollution, a lack of physical activity, and tobacco use, the escalating global prevalence of diabetes between 2010 and 2021 is recognized as an additional factor contributing to the lack of progress in reducing the cardiovascular disease burden.[12]

Several determinants, such as evolving demographic patterns of the population, enhanced diagnosing capabilities and recording cancer cases and mortality, as well as modifications in risk factors for cancer, including metabolic, behavioral, environmental, and occupational exposures, may play a role in the observed trends of increasing standardized incidence and mortality rates within lower socioeconomic development (SED) quintiles.[17] Given that a substantial portion of the population in lower SED quintiles faces challenges in accessing timely diagnosis, comprehensive treatment, and cancer prevention services, it is imperative to strengthen the infrastructure for cancer control, expand the cancer workforce, and enhance access to universal health coverage and adequate financial security.[17]

3.5. Strategies

The overall prevalence of catastrophic diseases can be mitigated through the implementation of intervention strategies aimed at addressing modifiable risk factors, particularly those with established effectiveness, such as tobacco control and strategies for lowering blood pressure and cholesterol levels. Additionally, the scope encompasses a comprehensive approach addressing biological, social, and psychological aspects, through education, self-care mechanisms (including online therapy), primary care access, and community engagement initiative programs to provide psychological therapies, pharmaceutical interventions, and specialized assistance.[12] In Indonesia, several strategies have been implemented to proactively identify individuals at risk such as POSBINDU *(Pos binaan terpadu)* and PROLANIS *(Program pengelolaan penyakit kronis)*.[5]

Aiming at individuals aged 15 and above, particularly within the productive age group, POSBINDU represents a community-driven integrated health post run by community health cadres (volunteers) overseen by primary health care (PHC) authorities. This program is structured to fortify communities by conducting screenings for non-communicable diseases (NCDs), focusing on diabetes and hypertension, alongside identifying their associated risk factors, such as obesity, dietary habits, lack of physical activity, and tobacco use.[26] However, research finding indicated that the execution of POSBINDU was not as successful as planned, with an average participation rate among the elderly of 47.51%, falling short of the target established by the Ministry of Health, which aimed for an 80% participation rate.[27] Similarly, the Indonesian National Health Insurance System (NHIS) launched the PROLANIS, an chronic disease management program in 2014 which primarily aimed at addressing type

2 diabetes and hypertension, with the objectives of managing clinical and laboratory outcomes, averting complications, and improving the overall quality of life for patients. This program is designed to be implemented within the primary care setting, encompassing both government-operated community health facilities and private practitioners, as well as primary care clinics. Unfortunately, the implementation of PROLANIS have yielded inconclusive results.[28]

Furthermore, the Indonesian Minister of Health has implemented a series of measures aimed at reducing the incidence of strokes within the country. These measures include promoting preventive actions such as advocating for routine physical examinations, encouraging the cessation of smoking, promoting regular physical activity, maintaining a nutritious diet, ensuring sufficient sleep, and enhancing stress management techniques. The subsequent step focuses on encouraging individuals to become more self-aware by conducting regular blood pressure and cholesterol checks, or by visiting health service facilities at least once annually. Then, the next phase aims to expand health services and increase the availability of human resources through curative activities and finally involves enhancing rehabilitative services to prevent disability or the recurrence of strokes.[29]

Moreover, on population-level, it is also imperative to implement regulations such as smoking ban, unhealthy food charges, while encouraging fitness training.[5] The Framework Convention on Tobacco Control has proposed the implementation of smoke-free policies (SFP), proven to be one of the most effective anti-smoking strategies. In Indonesia, the Health Act 36/2009, and Presidential Decree 109/2012, enacted by President Susilo Bambang Yudhoyono in 2009 and 2012 respectively, represent the legislative frameworks governing SFP within the country.[30] The Decree

delineates the detailed provisions, whereas the Act merely endorses the nationwide adoption of SFP across all provinces, cities, and districts. Within these designated areas, the production, distribution, marketing, promotion, and consumption of tobacco products are strictly prohibited. Furthermore, these areas, which encompass hospitals and educational institutions, are designated as smoke-free zones under the SFP.[30]

On the other hand, in alignment with national-scale strategies for cancer control mainly at breast cancer, cervical cancer, and childhood cancer, spearheaded by the World Health Organization to diminish the global cancer burden, investing in the prevention and treatment of cancer should be given top priority, primarily due the profound link between socioeconomic status and health outcomes.[17] Therefore, health policies must emphasize the importance of ensuring universal access to health coverage and safeguarding individuals against the catastrophic financial impact of cancer treatment, as well as the enduring financial repercussions for families post-diagnosis. For example, the incidence of cervical cancer which is completely preventable, thus in all socioeconomic contexts, it is crucial to implement vaccination strategies against the human papillomavirus (HPV), adopt screening protocols, and ensure accessible treatment for cervical cancer.[17]

Furthermore, compliance and adherence also play crucial roles in the management of catastrophic diseases, necessitating policy adjustments to the preventive strategies particularly employed in primary care, for instance, by extending operating hours to evenings and weekends due to accessibility challenges caused by conflicting hours between employment schedules with the operational hours.[5] Furthermore, exploring behavioral, socioeconomic, and cultural determinants of catastrophic diseases will lead to a more

comprehensive understanding of the issue.[5] These underscore the importance of conducting evaluations to improve the delivery of healthcare and enhance patient engagement in the management of chronic conditions.[5]

LIMITATIONS

A persistent challenge in the Global Burden of Disease (GBD) analysis stems from the inconsistent availability of primary epidemiology data, a key source of instability and constraint. For instance, hemophilia does not fall within the delineated categories for catastrophic diseases within the analysis of disease burden in this article, as no relevant data from the Global Burden of Disease (GBD) 2021 study was recovered. The incorporation of new data, advancements in the burden estimation pipeline, and fluctuations in datasets and methodologies, all contribute to the fluctuation in GBD estimates of health and health loss across cycles.[12] Although this method cannot wholly replace the reliability of high-quality primary data, it ensures that populations or causes, characterized by a scarcity or absence of data, are not overlooked. A recurring obstacle in the Global Burden of Disease analysis is the lack of high-quality primary data, stemming from errors in methodology and the potential underreporting of diseases.[12] It is anticipated that the ability to assess the effects of catastrophic diseases in Indonesia will improve as additional data becomes available. Future iterations will incorporate efforts to address current limitations associated with the collection of data.

4. CONCLUSION

There have been concerning increase in the prevalence of catastrophic diseases in Indonesia, which have led to significant disease burdens and economic downfall. In Indonesia, cardiovascular diseases were the main contributor to DALYs whereas majority of the catastrophic diseases had higher mortality rate than the world average. Moreover, mostly if not all catastrophic diseases have shown positive percentage changes in prevalence and death number in Indonesia over the last decade. Meanwhile, there has been a consistent growth among all catastrophic diseases in terms of caseloads and total health expenditures. As a result, it is imperative to implement preventive measures to mitigate these challenges which create opportunities for family doctors to address these gaps in healthcare.

REFERENCES

1. Margina RA, Prena G Das, Studi P, Manajemen M. UNIT COST ANALYSIS OF HAEMODIALYSIS SERVICES BY ACTIVITY BASED COSTING APPROACH AS A STRATEGY. 2024;4(06):4834–45.
2. Syiar Cakke S, Balqis, Indar, Palutturi S, Ishak H, Zulkifli A, et al. Analysis of Factors Influencing the Willingness to Pay BPJS Kesehatan Contributions of Mandiri Participants in the Working Area of Bua Health Center, Luwu District. Pharmacogn J. 2024;16(1):211–6.
3. Wartiningsih M, Silitonga HTH, Supriyanto S, Chalidyanto D. Analysis of Perception Differences of Patient Satisfaction with Catastrophic Disease on Hospital Service Before and After BPJS. 2019; Available from: http://dspace.uc.ac.id/handle/123456789/2451
4. Yogesswara GAP, Qoyyimi DT, Abdurakhman A. Managing Heart Related Disease Risks in Bpjs Kesehatan Using Collective Risk Models. Media Stat. 2023;15(2):175–85.
5. Muharram FR, Multazam CECZ, Mustofa A, Socha W, Andrianto, Martini S, et al. The 30 Years of Shifting in The Indonesian

Cardiovascular Burden—Analysis of The Global Burden of Disease Study. J Epidemiol Glob Health. 2024 Mar 1;14(1):193–212.

6. Institute for Health Metrics and Evaluation. Global Burden of Disease 2021. GBD 2021 Study. 2021.

7. Guo P, Qin Y, Wang R, Li J, Liu J, Wang K, et al. Perspectives and evaluation on the effect of financial burden relief of medical insurance for people with catastrophic diseases and its influencing factors. Front Public Heal. 2023;11(April):1–9.

8. Pudji Nugraheni W, Nuraini S, Kusuma Hartono R. The Effect of the Covid-19 Pandemic on the Utilization. 2022;13(1):9–16. Available from: https://doi.org/10.22435/hsji.v13i1.6028

9. Riza Y, Budiarto W, Haksama S, Kuntoro, Yudhastuti R, Wibowo A, et al. Health services for catastrophic patients through the national health insurance program: literature review. J Public Health Africa. 2023;14(S2).

10. Nugraheni WP, Zahroh AH, Hartono RK, Nugraha RR, Chun CB. National Health Insurance Deficit in Indonesia: Identification of Causes and Solutions for Resolution. Glob J Health Sci. 2020;12(13):58.

11. Kristina SA, Santosa KA. An estimated mortality and disability adjusted life years (Dalys) of non-communicable diseases in indonesia. Int J Pharm Res. 2020;12(2):3040–5.

12. Ferrari AJ, Santomauro DF, Aali A, Abate YH, Abbafati C, Abbastabar H, et al. Global incidence, prevalence, years lived with disability (YLDs), disability-adjusted life-years (DALYs), and healthy life expectancy (HALE) for 371 diseases and injuries in 204 countries and territories and 811 subnational locations, 1990–2021: a

systema. Lancet. 2024 May 18;403(10440):2133–61.

13. Guo X, Li J, Yin X, Zhang Z, Zhong Q, Zhu F. Trends in deaths and disability-adjusted life-years of stroke attributable to high body-mass index worldwide, 1990–2019. Front Neurol. 2023;14.

14. Institute for Health Metrics and Evaluation. GBD 2019 Data and Tools Overview. 2020;(May). Available from: https://www.healthdata.org/sites/default/files/files/Projects/GBD/IHME_GBD_2019_1_DATA_TOOLS_GUIDE_Y2020M10D15.PDF

15. Institute for Health Metrics and Evaluation. Seattle, United States: Institute for Health Metrics and Evaluation (IHME),. 2021. Global Burden of Disease Study 2021 (GBD 2021). Available from: https://vizhub.healthdata.org/gbd-results/.%0A

16. Fitzmaurice C, Abate D, Abbasi N, Abbastabar H, Abd-Allah F, Abdel-Rahman O, et al. Global, regional, and national cancer incidence, mortality, years of life lost, years lived with disability, and disability-Adjusted life-years for 29 cancer groups, 1990 to 2017: A systematic analysis for the global burden of disease study. JAMA Oncol. 2019 Dec 1;5(12):1749–68.

17. Kocarnik JM, Compton K, Dean FE, Fu W, Gaw BL, Harvey JD, et al. Cancer Incidence, Mortality, Years of Life Lost, Years Lived With Disability, and Disability-Adjusted Life Years for 29 Cancer Groups From 2010 to 2019 A Systematic Analysis for the Global Burden of Disease Study 2019. JAMA Oncol. 2022;8(3):420–44.

18. Prihantono, Rusli R, Christeven R, Faruk M. Cancer Incidence and Mortality in a Tertiary Hospital in Indonesia: An 18-Year Data Review. Ethiop J Health Sci.

2023;33(3):515–22.

19. Rochmah TN, Rahmawati IT, Dahlui M, Budiarto W, Bilqis N. Economic burden of stroke disease: A systematic review. Int J Environ Res Public Health. 2021;18(14).

20. Wahidiyat PA, Sari TT, Rahmartani LD, Iskandar SD, Pratanata AM, Yapiy I, et al. Thalassemia in Indonesia. Hemoglobin [Internet]. 2022;46(1):39–44. Available from: https://doi.org/10.1080/03630269.2021.2023565

21. Hustrini NM, Susalit E, Rotmans JI. Prevalence and risk factors for chronic kidney disease in Indonesia: An analysis of the National Basic Health Survey 2018. J Glob Health [Internet]. 2022 Oct 14;12:04074. Available from: https://jogh.org/2022/jogh-12-04074

22. Institute for Health Metrics and Evaluation. Seattle, United States: Institute for Health Metrics and Evaluation (IHME),. 2021. GBD Compare Visualizations. Available from: https://vizhub.healthdata.org/gbd-compare/

23. BPJS Kesehatan. Laporan Pengelolaan Program Tahun 2019 dan Laporan Keuangan Tahun 2019. 2020. p. 1.

24. BPJS. Laporan Pengelolaan Program dan Keuangan BPJS Kesehatan Tahun 2022 [Internet]. Bpjs Kesehatan. 2022. Available from: https://www.bpjs-kesehatan.go.id/bpjs/arsip/detail/2169

25. Badan Penyelenggara Jaminan Sosial. Laporan Pengelolaan Program dan Laporan Keuangan Penyelenggaraan Kesehatan Nasional 2018. 2018;(1):170.

26. Widyaningsih V, Febrinasari RP, Pamungkasari EP, Mashuri YA, Sumardiyono S, Balgis B, et al. Missed opportunities in hypertension risk factors screening in Indonesia: A mixed-methods evaluation of integrated health post (POSBINDU) implementation. BMJ Open. 2022;12(2):1–11.

27. Sari CWM, Khoeriyah VN, Lukman M. Factors Related to The Utilization of Integration Health Program (Posbindu) Among Older Adults in Indonesia: A Scoping Review. Clin Interv Aging. 2024;19:1361–70.

28. Alkaff FF, Illavi F, Salamah S, Setiyawati W, Ramadhani R, Purwantini E, et al. The Impact of the Indonesian Chronic Disease Management Program (PROLANIS) on Metabolic Control and Renal Function of Type 2 Diabetes Mellitus Patients in Primary Care Setting. J Prim Care Community Heal. 2021;12.

29. Venketasubramanian N, Yudiarto FL, Tugasworo D. Stroke Burden and Stroke Services in Indonesia. Cerebrovasc Dis Extra. 2022;12(1):53–7.

30. Yunarman S, Zarkani A, Walid A, Ahsan A, Kusuma D. Compliance with smoke-free policy and challenges in implementation: Evidence from bengkulu, Indonesia. Asian Pacific J Cancer Prev. 2020;21(9):2647–51.