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Patient-Reported Outcomes

Financial Toxicity Experiences of Patients With Cancer in Indonesia: An Interpretive Phenomenological Analysis



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ABSTRACT

Objectives: Financial toxicity (FT) is an important adverse effect of cancer. Recent systematic reviews have shown that FT may lead to treatment nonadherence and impaired health-related quality of life, both of which may adversely influence the survival rates of patients. However, less is known about how patients endure FT, particularly in low- and middle-income countries. The purpose of this study was to explore how patients with cancer experience and cope with FT in Indonesia.

Methods: Semistructured in-depth interviews were conducted to explore the experiences of Indonesian patients with cancer. Qualitative data were analyzed using interpretive phenomenological analysis approach. We purposefully recruited 8 patients undergoing active treatment (aged 27–69 years) who had been diagnosed of cancer over 5 years before and possessed health insurance at the time of diagnosis.

Results: We identified 2 main themes: (1) the experienced financial burden, with subthemes underinsurance, out-of-pocket nonhealthcare cancer-related costs, and negative income effect from employment disruption, and (2) the financial coping strategies, with subthemes reallocating household budget, seeking family support, rationalizing treatment decisions, and topping up insurance for family members.

Conclusions: This is the first interpretive phenomenological study on FT in the literature and the first qualitative FT study in Indonesia. Our findings provide insight into the occurrence of FT and coping strategies used by Indonesian patients with cancer. The subjective experiences of patients may be considered to further improve oncology care, support the need for measurement of FT, and provide mitigation programs for patients.

Keywords: cancer, financial toxicity, interpretive phenomenological analysis, phenomenology, qualitative.

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Introduction

Financial burden is an important problem experienced by patients with cancer. The oncological care needed for survival may cause catastrophic out-of-pocket health spending to patients, which is referred to as “financial toxicity” (FT).¹ FT arises from objective financial burden (eg, out-of-pocket medical costs) and subjective financial distress (ie, the perceived level of distress reported by the patients).^{2,3} FT impedes individuals of achieving financial wellbeing, where one can sustain an adequate standard of living and financial freedom.⁴

Recent systematic reviews have shown that FT may lead to treatment nonadherence and the impairment of health-related quality of life,^{5,6} an important construct that may even be associated with the survival rate of patients.⁷ The issue of FT has been reported by patients with health coverage from both developed and developing countries,^{8,9} even in those with universal health coverage (UHC).¹⁰ This is attributable to the unanticipated

proportion of medical expenses that were not covered by the health plan providers.

The lack of awareness and readiness in facing FT, which could affect the physical, psychological, and socioeconomic wellbeing of patients with cancer, was highlighted in a meta-synthesis of 14 qualitative studies.¹¹ Therefore, patients may be forced to adapt both financially and emotionally. A key psychological strategy that mediates between FT and health outcomes is coping.^{12–16} However, very few qualitative studies focusing on coping mechanisms for FT have been conducted: a German study performing content analysis, a US study using constructivist grounded theory approach, and an Australian study conducting thematic analysis, all of which conducted semistructured interviews.^{9,12,17} So far, FT studies have mostly been performed in high-income and English-speaking countries, for example, United States, United Kingdom, and Australia.^{5,18} Investigations in middle- and low-income countries are needed to enable the proper understanding of FT cases^{11,18,19} and to enable the development of valid measures and

mitigation strategies according to cultural specificity and socio-demographic context.

In Indonesia, a middle-income country,²⁰ cancer is the second highest cause of mortality after cardiovascular disease.²¹ Its prevalence was 1.49% in 2018 and estimated to rise in the future.²² Cancer is also the second most costly chronic disease financed by the public healthcare system, the *Jaminan Kesehatan Nasional* (National Health Insurance or JKN) program administered by the BPJS Kesehatan (The Health Social Security Agency).²³ The JKN was introduced in 2014 to ensure social health security for Indonesians and achieve UHC. The inception of this single-payer insurance program is relatively recent, and approximately 90% of the population have been enrolled as members.^{23,24} Even though JKN members with any type of cancer can seek treatment (eg, surgery, chemotherapy, and radiotherapy) at the designated healthcare facilities, there is still a wide gap in the distribution of general practitioners, specialist physicians, and medical devices across the country.²³ This signifies that even the insured population may not be impervious to FT given that they potentially need to incur more costs to obtain the necessary care. In essence, the proportion of uninsured population and the inequality of health delivery quality suggest the relevance of FT in Indonesian patients with cancer.

Furthermore, the FT literature in Indonesia is extremely limited.¹⁹ One study measured FT and how it affected the risk attitude of 194 patients with cancer and survivors.²⁵ Another study reported the FT of 109 patients with cancer, which was associated with household income and number of dependents.²⁶ More explorations are warranted to understand the FT dynamics in Indonesia, particularly how patients with cancer manage their lives under FT. Therefore, the purpose of this qualitative study is to comprehend how patients with cancer in Indonesia experience and cope with FT arising from cancer diagnosis and treatment.

Methods

The study design, data analysis, and reporting of findings followed the Consolidated Criteria for Reporting Qualitative Studies checklist.²⁷ The approach to the data collection and analysis was entirely inductive.

Design and Participants

Semistructured in-depth phenomenological interviews were conducted to explore the subjective experience of FT in patients with cancer. Qualitative data were analyzed using interpretive phenomenological analysis (IPA). To achieve richness of data, patient recruitment for the interviews was conducted until reaching saturation. The inclusion criteria for patients were as follows: (1) at least 23 years of age, (2) spoke Indonesian language, (3) had a diagnosis of any type of cancer, (4) diagnosed of cancer at least 5 years before the interview, (5) possessed health insurance at the time of diagnosis, (6) actively undergoing cancer treatment, and (7) signed informed consent for the study. The minimum 5-year diagnosis criterion was determined to fittingly capture the experience of cancer burden. This resulted in the minimum patient age of 23 years, that is, 5 years after the adult age of 18 years. The recruitment of patients was done through snowball sampling.

Data Collection

An in-depth phenomenological interview guide was created by S.P. and F.A.N. The interviews focused on the experience of financial burden and the influence of cancer on the financial aspects of their lives. Example questions included “How did you realize that you have cancer?”, “What burden did you experience from cancer?”, “Did your cancer disrupt your finances?”, “If the

cancer disrupted your finances, in what ways did it affect you?”, “Were there any financial adjustments that you had to make?”, and “Is there anything else that you would like to add?”.

The one-on-one in-depth video interviews were conducted between January 2022 and May 2022. Video-based qualitative interviews were chosen in response to the regulations on social restrictions during the COVID-19 pandemic. The interviews were scheduled after the patients provided an informed consent. In consideration of the potentially frail physical condition of patients who were undergoing active treatment, the interviewers offered dividing the interview into 2 sessions. Before the interview, every patient completed a brief questionnaire about their cancer history (eg, cancer type by site, year of diagnosis) and sociodemographic background (eg, age, sex, education, personal monthly net income). The interviews took place virtually on Zoom (Zoom Video Communications, Inc). All interviews were audio recorded with the patients' permission. There were 3 interviewers (E.P.H., I.H.P., and F.A.N.), all of whom had previous interviewing experience. Notes were written during and after the interview sessions. Biweekly panels were held to reflect on data collection process. After the completion of all interviews, the patients were offered an optional compensation of 200 000 Indonesian Rupiah (approximately US \$12.7) for Internet costs or mobile phone credit, which was accepted by 6 patients (75%).

IPA

The IPA was followed to analyze the qualitative data. This approach involved a detailed examination of the participants' lifeworlds and their personal lived experiences.²⁸ Therefore, we were able to understand deeply how the patients uniquely perceived and interpreted the dynamics of their FT experience.²⁹ The IPA was performed by F.A.N., E.P.H., I.H.P., and S.P. All interviews were transcribed verbatim by trained research assistants and verified by F.A.N. and S.P. First, the research team read the transcripts multiple times. To inductively derive emerging themes, exploratory notes were coded and clarified independently by E.P.H. and I.H.P. Afterward, the potential themes were refined and labeled through panel discussions. Discrepancies were resolved through a consensus process within the team led by S.P. Ultimately, all synthesized themes were central, relevant, and related to one another. Data analysis and management were performed in Microsoft Excel (Microsoft Corporation).

Ethics

All included patients were given comprehensive information about the description of the research, potential risks of triggering psychological trauma, voluntary participation, and possibility of withdrawing participation. All patients agreed to engage in the study by signing informed consent electronically. The protocol of this qualitative research was reviewed and granted ethical approval by the Research Ethics Committee of Gadjah Mada University (number KE/UGM/001/EC/2022, granted on January 11, 2022).

Results

A total of 9 patients with cancer history were recruited. One interview was annulled because the patient did not fulfill the minimum disease duration criterion, resulting in a final sample of 8 patients. Three patients (P1, P2, and P6) expressed their interests after receiving the patient recruitment poster on social media and were recruited through telephone. The other 5 patients (P3-P5, P7, and P8) were recruited through referrals of patients P1, P2, and P6.

None of the research team members had any previous relationship with the patients before the interviews.

The interviews were conducted in Indonesian language with an average length of 123 minutes per patient. Six patients were interviewed in a single session, whereas 2 patients completed the interview in 2 sessions with a 1-week lag in between interviews.

The included patients had a median age of 36 years (range 27-69). They were mostly female (n = 5), were part-time workers (n = 4), and had completed tertiary education (n = 6). The ethnic group of the patients were Javanese (n = 4), Chinese (n = 2), Papuan (n = 1), and Sundanese (n = 1). The cancer types were lung (n = 4), thyroid (n = 3), and throat (n = 1). The median of duration since cancer diagnosis was 6.5 years (range = 6-10 years). The characteristics of the 8 patients included in our study are presented in Table 1.

Table 1. Characteristics of included patients.

Characteristics	Description	Median (range) or n (%)
Age	(in years)	36 (27-69)
Sex	Female	5 (62.5)
	Male	3 (37.5)
Highest level of education	Bachelor's degree	4 (50)
	Master's degree	2 (25)
	Associate's degree	2 (25)
Cancer type by site	Thyroid	4 (50)
	Lung	3 (37.5)
	Throat	1 (12.5)
Disease duration	(in years)	6.5 (6-10)
Ethnicity	Javanese	4 (50)
	Chinese	2 (25)
	Papuan	1 (12.5)
	Sundanese	1 (12.5)
Province of residence	West Java	4 (50)
	East Java	1 (12.5)
	Jakarta	1 (12.5)
	Papua	1 (12.5)
	Yogyakarta	1 (12.5)
Personal monthly net income	<1 000 000 IDR	3 (37.5)
	2 000 000-4 000 000 IDR	2 (25)
	4 000 001-8 000 000 IDR	2 (25)
	>8 000 000 IDR	1 (12.5)
Marital status	Married	7 (87.5)
	Single	1 (12.5)
Occupation	Part-time worker	4 (50)
	Full-time employee	2 (25)
	Business owner	1 (12.5)
	Unemployed	1 (12.5)

Note. US \$1 = 15 731 IDR (based on the 30 December 2022 middle exchange rate).
IDR indicates Indonesian Rupiah.

The analysis resulted in 6 subthemes that were classified into 2 main themes: (1) the experienced financial burden and (2) the financial coping strategies.

The Experienced Financial Burden

Three subthemes were identified: (1) underinsurance, (2) out-of-pocket nonhealthcare cancer-related costs, and (3) negative income effect from employment disruption. These subthemes explained the factors that influence the occurrence of FT.

Underinsurance

None of the included patients were diagnosed at an early stage. All patients professed about the lengthy overall process for a definitive conclusion from the physicians. However, ultimately, all patients received the medical treatment that they needed. Even though covered by health insurance, all patients expressed their grievances about the insufficiency of their coverage, which was perceived to be the main cause of their FT. The issue of underinsurance was brought up because the policies were inadequate to cover all cancer treatment costs. One patient said:

I kept using JKN. It helped a lot even though it did not cover every medical treatment.

(P1, 62, male, lung cancer)

Therefore, all patients had to pay out of pocket for healthcare costs that included medication and diagnostic tests. Two patients said:

At that time, I could not afford a complete lab work. It was still very expensive then and it was not covered by my health insurance.

(P5, 36, female, thyroid cancer)

There were some drugs that were not covered by my insurance. For me, my most expensive medication was the nasal spray.

(P7, 27, male, throat cancer)

Furthermore, all patients expressed frustration with the costs that they may have to deal with for the rest of their lives due to the risk of relapse. Two patients mentioned:

There is nothing cheap about cancer because the treatment has no end to it.

(P1, 62, male, lung cancer)

After I was operated and the thyroid cancer along with the glands was removed, I had to take medication for the rest of my life.

(P6, 35, female, thyroid cancer)

Out-of-pocket nonhealthcare cancer-related costs

To obtain treatment and examination, all patients also had to disburse on nonhealthcare costs, which included transportation, accommodation, and wages for domestic helper (eg, caregiver, housekeeper, nanny, and driver). P3 shared his experience:

It was 2016 and 2017. I went to Singapore every three weeks. So, in those two years, I went to Singapore probably 35 times. I spent 10 million rupiah every time I went to Singapore for flights and hotel rooms.

(P3, 62, male, lung cancer)

For all patients, transportation was highlighted to be their main nonhealthcare costs. Five patients (P2, P4, P5, P6, and P7) had to travel out of town due to the unavailability of certain medical procedures in their residence city or town. For example, P4 had to travel 400 kilometers from Malang to Yogyakarta for every round of treatment:

JKN is really good. Even poor people are covered. We don't have to think much about the treatments, but we have to think about transport, accommodation, and others. As a patient, it is really a burden. Every three months I have to prepare funds, mostly allocated for transportation and accommodation.

(P4, 36, female, thyroid cancer)

Negative income effect from employment disruption

After being diagnosed of cancer, all patients experienced disrupted livelihood and loss of income. In treating cancer, they had to make lifestyle alterations that affected their work behavior. They recognized the need to improve their work-life balance in favor of maintaining a healthy diet, fending off fatigue, and allocating time for follow-up examinations and treatments. All patients viewed cancer as a change that negatively influenced their work performance and career, such as loss of clients and potential job promotion with higher pay. One patient described:

Being a cancer survivor, <my co-workers> became sympathetic toward me. They reduced my workload and told me not to get too tired. I find this discriminatory. I was seldomly involved in decision-making process.

<At the time> I was supposed to become a permanent employee. I could have shined in that company and become a young executive. I was making <tens of millions of rupiah>.

(P2, 30, female, thyroid cancer)

Furthermore, 5 patients (P2, P4, P5, P6, and P7) felt to have inconvenienced their colleagues due to treatment scheduling that required partial or full days of leave and treatment side effects. P5 was bothered by the attitude of her colleagues:

At work, I felt that they were lacking awareness. I mean, they could not really accept that I had to take days of leave. They could not really tolerate that. It was unpleasant becoming the talk of the office, a gossip.

(P5, 36, female, thyroid cancer)

Six patients (P2, P3, P4, P5, P6, and P8) had to leave their occupations, where 4 became homemakers with part-time work, 1 started a business, and 1 became unemployed. Two patients reflected on this change:

Yes, clearly I switched jobs because of cancer. I was working in a corporation with a high workload with at least eight hours of work, and sometimes doing overtime. My body does not agree with this.

(P2, 30, female, thyroid cancer)

Praise the Lord, I had high income before I got cancer. But what can I do about it? God's plan for men is different from the plans of the men themselves.

(P7, 27, male, throat cancer)

The Financial Coping Strategies

Four subthemes were identified: (1) reallocating household budget, (2) seeking family support, (3) rationalizing treatment decisions, and (4) topping up insurance for family members. These subthemes expressed how the patients adjusted their financial conditions in coping with the experienced FT.

Reallocating household budget

Financial sacrifices were made to allow for cancer treatment. All patients expressed that cancer-related expenditures had become a fixed component of the household financial budget. Given that cancer is a life-threatening disease, healthcare budgeting became the financial priority in the family. Portions of regular monthly income and lifetime savings had to be reallocated

to finance treatment costs and supplements during post-treatment recovery. Basic living expenses (eg, housing, food, clothing, transportation) were economized and luxury wants (eg, vacation, hobbies) were either delayed or canceled. The funds saved from these cost-cutting measures were channeled to pay for the ongoing cancer treatments or in anticipation of future ones. P5 shared her experience in economizing costs:

At the end, we sacrificed the needs that were not so urgent. These were actual needs! But we had to pay for the treatment, so, it's okay, we postponed them.

I had to adjust my budget to afford the transport to the hospital. At first, my husband and I took the train and bus which cost 70.000 rupiah. Then, I told my husband that we would save money if we biked from Bogor to Jakarta and back. The fuel cost did not exceed 50.000 rupiah per trip.

(P5, 36, female, thyroid cancer)

To increase personal cash flow and sustain their treatment, 3 patients (P1, P3, and P8) sold tangible assets. Two patients shared their experiences:

I sold <real estate> property. It was enough for the drug costs.

(P1, 62, male, lung cancer)

By chance, my husband had invested in land which was then sold. My husband then purchased <Singaporean> dollars to pay for the treatment.

(P8, 69, female, lung cancer)

After entering remission or upon improvement of health, the patients still had to allocate budget for medical tests, supplements, and dietary needs. Learning from the years of experience in undergoing treatment and the utilization of health insurance, the patients and their family were able to estimate the amount of funds needed for each round of examination and treatment. Afterward, the amount was budgeted along with the identification of the source of the funds. Household expenditures were mapped and sorted according to priority or nature of urgency. All patients increased their healthcare budget. One patient described:

I divide my income into sets of funds. When I was single, I saved money frequently. I thought if I fell sick, it would implode my finances. And turns out I was right. So, I divided my money into living, investments, zakat <Muslim charity>, and entertainment. Only now my healthcare funds have larger portion. It even goes to 40%!

(P2, 30, female, thyroid cancer)

Seeking family support

Due to high costs, not all patients were able to gather sufficient funds for treatment. In addition to cutting back on expenses and using their savings, 3 patients (P4, P5, and P7) had to seek external financial support from family members. Initially, P4's cancer treatment costs were financed by her father because she did not have a steady flow of income before getting married. After becoming a married woman, she obtained financial support from both her father and husband. Spouses, parents, and other relatives were not only materially helpful but also emotionally supportive and even had a role in healthcare decisions. The patients felt that family support enabled them to mitigate FT and focus more on undergoing treatment and recovering. In the case of P8, her husband had a central role in making treatment decisions and financing out-of-pocket costs. She regarded this as the social role and responsibility of her husband:

My husband handles every treatment. I gave <control> to him. If he says that there is no money left and this is somewhere I should get treated, then I would obey him. I am not the kind of wife who questions whether we

have money or not, even though I know how much my husband has in the bank. Money management is my husband's responsibility.

(P8, 69, female, lung cancer)

Rationalizing treatment decisions

An interplay of factors was considered by the patients when making healthcare decisions, for example, the potential risks and benefits of the treatment, how to gather the funds needed for treatment, and how the treatment choice would financially affect the family. Being constrained, the patients rationalized their decisions as a response. Faced with options recommended by the physicians, every patient selected the alternative that matched their financial capacities. When the patients perceived that a condition improvement or an increase in chances of recovery was possible, they showed their willingness to disburse more money for treatment. Four patients (P1, P3, P4, and P8) opted for costlier treatments that they assumed to be more effective. For example, in treating her thyroid cancer, P4 opted for brand name instead of generic drugs, even though certain brand name drugs were not covered by the JKN insurance scheme. P1 also selected a costlier alternative that he needed to pay out of pocket:

After discussing with my family about costs, we chose the more expensive medicine because it is said that my hair would not fall, no nausea, no tinglings, no baldness. The cheaper one they say has more side effects.

(P1, 62, male, lung cancer)

Three patients (P1, P3, and P8) opted for treatment overseas in Singapore and Malaysia, thereby incurring higher transportation and accommodation costs. They learned about the potentially better quality of healthcare overseas through the experience of others. After discussing with his family, P3 decided to participate in a clinical trial of a new cancer drug in Singapore:

The doctor in Singapore spoke with my brother. My friend suggested him to get a second opinion. I heard that some hospitals in Singapore were backed by pharmaceutical companies and if lucky, we could get free trials as part of their <research and> development.

(P3, 62, male, lung cancer)

Three patients (P1, P5, and P6) also sought for complementary alternative treatments to sustain their conditions in the forms of herbal medicine and spiritual healing. Three patients shared their experiences:

So the herbal medicine was made by boiling. A liter cost 800 thousand rupiah. Each day I had to finish a liter. I bought eight liters at a time and I stored it in the fridge.

(P1, 62, male, lung cancer)

I was referred by a pharmacology lecturer about this lotus pill. I had consumed it before I decided to get surgery. The pill was expensive, and I took 15 pills a day.

(P6, 35, female, thyroid cancer)

I traveled to Pematang to pursue an alternative treatment. They rubbed my neck with cotton dipped in holy water. I personally do not understand these things. They prayed while rubbing my neck. Abracadabra, the cotton was suddenly drenched in blood. They said my cancer was gone.

(P2, 30, female, thyroid cancer)

Furthermore, all patients expressed their willingness to pay for certain expenses out of pocket if they could afford them to save time. They learned this from their experience in navigating claims process and doctor referrals that consumed considerable time. Two patients conveyed their stress:

Turns out some laboratories in East Java were not under the JKN scheme. They do 100% in Yogyakarta and Semarang, but, in Surabaya is not that simple. The queue is long, and the process is complex!

(P5, female, 36, thyroid cancer)

The rules are just really complicated. I mean it's convoluted in my opinion. I ended up paying more.

(P4, 36, female, thyroid cancer)

All patients highlighted the importance of earlier assessment to obtain a faster medical referral and timelier treatment to prevent the spread of cancer. The patients indicated that getting earlier assessment would have enabled them to prevent a higher level of FT. They believed that by being early, they could have been more thorough in consulting with the doctors and navigating the insurance administration flow. Two patients shared their experiences:

All this time, I have been paying for blood work with my own money. I don't use JKN for this, it's faster. It's fine because it's only every six months. But, I do use JKN for scans because they are expensive!

(P6, 35, female, thyroid cancer)

I planned to make a biopsy appointment at xxx laboratory, but I had heard that the waiting list for this was long. It would take two, even three months before one could get in. After samples are taken, the results would also take one or two months. This is way too long. They have way too many patients.

(P1, 62, male, lung cancer)

All patients also rationalized in earning the money to finance for treatments. Although every patient was aware that working while undergoing treatment might delay the recovery process, they persisted. One patient described:

I am a cancer patient who must work to pay for my treatment. Praise the Lord, I still work to support myself. It's true that my husband earns <an income>, but that is for daily needs. But for my treatment, I have to keep earning <money> to sustain it.

(P2, 30, female, thyroid cancer)

Topping up insurance for family members

All patients emphasized the importance and benefits of health insurance when accessing medical care. One patient expressed his appreciation:

I was lucky to be insured. It helped me cover my costs.

(P1, 62, male, lung cancer)

However, people with cancer history are unlikely to obtain a new private health insurance policy after diagnosis. Therefore, patients had to either use public insurance or finance the entire treatment using personal assets. Four patients (P1, P2, P3, and P6) compensated by signing up family members into health insurance programs or topping up their existing premiums to cover critical illnesses (eg, cardiovascular disease, stroke, and cancer), even though prospective insurance claims would never be channeled to the patients. This was done to enhance household financial planning and prevent possible future FT within the family members. P3, who was an insurance agent before getting cancer, expressed his regret on not being financially protected against cancer. He compensated by upgrading this family members' protection:

Now, after I got cancer, the insurance did not want to cover me. It is possible for heart diseases, but when it comes to cancer, they suddenly have all these provisions.

Even when I had insurance <in the past>, it was never 100% <covered>. For myself, I could not top up my insurance anymore because of my

<cancer> history. What I can do is to maintain my health, eat well and do enough sports, but for my young children.. I tell them to get enough exercise and I also added their insurance protection.

(P3, 62, male, lung cancer)

In addition, 2 patients (P2 and P6) who had the financial capacity financed their family members to get cancer screening, motivated by prudence and perceived unpredictability of cancer diagnosis. P6 shared her experience:

We are regulars at xxx lab and they have these cancer risk assessments. But my husband did not want to <do them>, oh well.. But for my children.. I was pregnant after I had the cancer, so this may affect them. So, we routinely did the assessments them. My doctor said that my cancer is not <a> genetic <disease>, not passable to my children, but I still do this just for my peace of mind, just to be sure.

(P6, 35, female, thyroid cancer)

Discussion

This is the first qualitative study to explore how Indonesian patients with cancer experience FT and, to the best of our knowledge, the first interpretive phenomenology study on FT in the literature. Our analysis of qualitative data resulted in 2 themes: “the experienced financial burden” and “the financial coping strategies.” The former elaborates the perceived contributing factors to the experience of FT, and the latter discusses the coping strategies implemented by the patients.

Overall, our subtheme findings correspond with previous FT studies. We found 3 contributing factors in the occurrence of FT: out-of-pocket healthcare and nonhealthcare cancer-related expenditures,¹¹ being underinsured,³⁰ and employment disruption that caused negative income effects.^{31,32} In coping with FT, 4 financial adjustment strategies were identified: expenditure reduction and budget reallocation,^{12,33} seeking financial support,^{12,33} rationalizing treatment,³⁴ and topping up insurance.¹¹ Interestingly, none of our included patients applied for formal loans to pay for their treatment, which was a coping strategy found in German patients with cancer.¹² This indicates Indonesian patients' preference for interpersonal over institutional support from corporations or financial institutions. In Indonesia, family may have a considerable influence in health decisions.^{35,36} We found that family members (eg, spouse, parent, and sibling of a parent) had a nuanced role, which was even framed as a responsibility. Not only did they provide financial and emotional support, but also, for some, family members determined healthcare decisions for the patient. This is a cultural distinction illustrated by collectivistic behavior.

Indonesia is making meaningful progress toward achieving UHC.³⁷ However, the patients' experiences of hardship in obtaining cancer care (ie, from diagnosis to treatment) indicated inequalities in access to healthcare. The results of this study challenge the way we look at “FT,” which has been defined as the consequence of cancer treatment. It may be possible that patients with cancer have experienced subjective FT even before undergoing treatment due to a lack of healthcare access and quality. Therefore, Indonesia must accelerate their efforts in advancing the necessary infrastructure and facilities, including but not limited to skilled health professionals. Furthermore, in adherence to the World Health Organization, the goal of UHC is to ensure every person has access to health services without financial hardship.³⁸ Presently, the issue of FT has received little to no attention in Indonesia. There are initiatives that may be considered to tackle this issue. First, communicating to patients about FT. Patients can be educated by health professionals about the financial and other

psychosocial consequences of treatment, even under insurance coverage. Second, properly detecting subjective FT in patients using a valid and reliable scale. Concurrently, mitigation programs can be provided to patients to prevent and combat FT. Interventions such as nonhealthcare cost coverages (eg, transportation and accommodation related to treatment) and provision of financial navigation programs have been shown to ameliorate FT.³⁹ To anticipate the negative income effects of cancer, employment reintegration programs may also be provided. Future investigations may be directed toward the measurement of FT and the development of mitigation programs that may alleviate FT for the Indonesian population.

This study has limitations. First, we focused on the subjective experience of the patients through IPA. The use of this approach enables researchers to interpret the unique and subjective lived experience of the participants, instead of making empirical generalizations. Therefore, applying the findings of this study in other contexts calls for a more careful judgment. Second, although the relatively small sample size may be a potential limitation of the present study, data saturation was reached as no important new themes emerged by the fourth interview. All our patients had survived their cancer for at least 6 years and half of them were patients with thyroid cancer. We believe this attained sufficient richness in shared perspective upon the phenomenon of FT to derive representative conclusions. Third, the levels of FT in patients were not objectively assessed before the interview. This was chosen because we wanted to explore the phenomenon of FT in an entirely inductive approach. To be more resource efficient, future studies may consider using a validated scale (eg, the Comprehensive Score for Financial Toxicity) to screen patients with FT. Fourth, our inclusion criteria did not allow us from capturing the FT experiences of patients who were in end-of-life care, specifically from being unable to afford cancer treatment. This perspective has yet to be explored and may be considered for future FT studies. Fifth, conducting virtual interviews might have excluded prospective patients who did not possess the technological access. However, the use of videos was essential to capturing facial expressions and body language cues.

Conclusion

We provided an insight into the experience of FT and coping strategies used in patients with cancer in Indonesia. Our IPA revealed the perceived factors contributing to the experience of FT: underinsurance, out-of-pocket nonhealthcare cancer-related costs, and negative income effect from employment disruption. In response, financial coping strategies were implemented through household budget reallocation, family support obtainment, treatment rationalization, and the purchase of health insurance for family members. We expect that the findings of this qualitative study may help policymakers in healthcare in Indonesia and other countries with similar characteristics.

Author Disclosures

Links to the individual disclosure forms provided by the authors are available [here](#).

Supplemental Material

Supplementary data associated with this article can be found in the online version at <https://doi.org/10.1016/j.vhri.2023.11.007>.

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