

Exploring Hidden Costs and Experienced Financial Protection Among Insured Cancer Patients: A Cross-Sectional Study in Indonesia

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ABSTRACT

Health economics and healthcare financing increasingly emphasize financial protection as a core goal of equitable health systems. In cancer care, national health insurance can reduce direct medical payments, yet patients may still face hidden costs, including transport, accommodation, income loss, caregiver-related expenses, and uncertainty about uncovered services. However, little is known about how insured cancer patients experience these hidden costs during treatment. This study examines how hidden costs create a gap between formal insurance coverage and actual financial protection, leaving patients financially vulnerable despite insurance enrolment. Using an interpretative phenomenological approach combined with patient-centered hidden cost mapping, this study explored the lived experiences of cancer patients enrolled in national health insurance. The analysis identified five central themes: formal coverage without full financial reassurance, hidden nonmedical costs as an everyday burden, loss of income and disrupted household stability, family-based coping as both support and moral pressure, and treatment decisions shaped by hope, affordability, and uncertainty. These findings indicate that financial toxicity is not only an economic burden, but also a relational, temporal, and emotional experience that shapes how patients understand treatment continuity and family dependence. The study advances health financing scholarship by reframing financial protection as a lived sense of security, not merely as insurance status, and suggests that future research should examine how hidden costs evolve across illness trajectories and healthcare systems.



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INTRODUCTION

Cancer care has become one of the most important concerns in health economics and healthcare financing because it requires long-term, complex, and often repeated interaction with the health system (Zhou et al., 2025). Diagnosis, treatment, follow-up care, medication use, supportive therapy, and travel to specialized facilities may place patients and households under considerable financial pressure. In many health systems, the expansion of national health insurance has been designed to reduce this pressure by protecting patients from direct medical payments and improving access to essential treatment. However, formal insurance coverage does not necessarily guarantee that patients feel financially secure throughout the course of illness.

Financial hardship in healthcare is commonly discussed through concepts such as out-of-pocket expenditure, catastrophic health spending, financial risk protection, and universal health coverage. These concepts are important because they show how health payments may reduce a household's ability to meet other basic needs (Zahrebelna et al., 2024; Zhao et al., 2024). In the context of cancer, the issue becomes more complex because the burden of illness is not limited to hospital bills or medical procedures. Patients may also face transportation expenses, accommodation costs, food costs during hospital visits, income loss, caregiver-related expenses, and emotional distress caused by uncertainty about future treatment needs. These costs may be less visible in formal financing arrangements, yet they can strongly shape the patient's experience of care.

The phenomenon of financial toxicity reflects this broader burden. It describes the economic strain associated with illness and treatment, as well as its consequences for quality of life, emotional

well-being, family relationships, and treatment decisions (Yuniawan et al., 2025a; Yusuf et al., 2022). For cancer patients, financial toxicity may appear even when treatment is partially or formally covered by insurance. The lived experience of financial burden often emerges through repeated calculations, difficult household trade-offs, dependence on family support, and anxiety about whether treatment can be continued. Therefore, financial toxicity should not be understood only as a measurable economic outcome, but also as an experience that affects how patients interpret illness, care, protection, and vulnerability.

This issue is particularly relevant in social contexts where households play a central role in sustaining treatment access. When formal health financing does not fully absorb the cost of care, families often become informal sources of financial protection (Yu et al., 2024; Yuniawan et al., 2025b). They provide money, transport, food, time, emotional support, and assistance with administrative processes. However, this support may also create moral pressure for patients, especially when they feel that their illness has become a burden for others. In this sense, hidden costs do not only affect the individual patient; they reshape household roles, family responsibilities, and the emotional meaning of treatment.

Current understanding of health financing has provided valuable evidence on insurance coverage, out-of-pocket expenditure, and catastrophic health spending. Nevertheless, these indicators do not fully explain how patients experience the gap between being formally insured and feeling genuinely protected (Yang et al., 2025). A patient may hold an insurance card and still feel financially unsafe if treatment requires repeated travel, loss of income, uncovered medicines, or continuous family sacrifice. This gap between formal protection and lived protection requires deeper exploration because it reflects the subjective dimension of healthcare financing.

A phenomenological perspective is therefore highly relevant for understanding this phenomenon. Phenomenology allows financial toxicity to be examined not merely as a cost category, but as a lived experience that carries meaning for patients and families (Urdaneta-Montiel & Zambrano Morales, 2024; Waliszewski & Niedziółka, 2025). Through this approach, attention can be directed toward how patients understand hidden costs, how they make sense of insurance coverage, how they negotiate treatment decisions, and how they preserve dignity while facing economic vulnerability. Such understanding is essential for developing a more patient-centered view of healthcare financing, particularly in cancer care.

Although national health insurance is intended to strengthen financial protection, cancer patients may continue to experience hidden and indirect costs throughout the treatment trajectory. These costs often arise outside the formal boundaries of insurance benefits (Tran & Winters, 2025; Tripathi et al., 2021). Transportation to referral hospitals, accommodation near treatment centers, meals during repeated visits, communication expenses, income loss, and caregiver time may not be fully reflected in administrative assessments of healthcare financing. Yet, from the patient's perspective, these costs are part of the real price of accessing care.

Previous qualitative and phenomenological studies have begun to show that financial toxicity is experienced as a multidimensional phenomenon. It includes economic strain, emotional distress, employment disruption, family dependence, and uncertainty about future care. In the Indonesian context, interpretative phenomenological evidence has shown that insured cancer patients may still experience financial toxicity due to underinsurance, out-of-pocket non-healthcare cancer-related costs, and income disruption. This indicates that the presence of health insurance may reduce some medical expenses but may not eliminate the lived burden of cancer treatment.

The present study is situated within this gap. It focuses on the experience of cancer patients enrolled in national health insurance who continue to face hidden costs during treatment. The central concern is not only whether patients are insured, but how they experience insurance protection in everyday treatment realities. This includes how they interpret covered and uncovered costs, how they respond to nonmedical expenses, how income disruption affects household stability, and how family support becomes both a coping mechanism and an emotional burden.

This focus is important because healthcare financing policies often evaluate protection through coverage status, benefit packages, and expenditure indicators. While these measures are necessary, they may overlook the subjective experience of patients who must repeatedly mobilize financial, social, and emotional resources to continue treatment (Swardhana & Monteiro, 2023; Tandiawan et al., 2025). A phenomenological exploration can reveal dimensions of financial protection that remain hidden in conventional economic measurement. It can show how patients experience the difference between administrative entitlement and actual financial security.

By examining the lived experience of hidden costs among insured cancer patients, this study aims to contribute to a more nuanced understanding of financial protection in cancer care. The study positions financial toxicity as a phenomenon that is not only economic, but also relational, temporal, and existential. It is relational because the burden is shared within families; temporal because costs accumulate across the treatment journey; and existential because financial uncertainty affects how patients understand illness, hope, dependence, and dignity. This perspective provides a foundation for developing the concept of experienced financial protection, which refers to the extent to which patients feel genuinely protected in the lived reality of treatment, beyond formal insurance membership.

Existing responses to financial hardship in cancer care commonly rely on practical and policy-oriented approaches, such as expanding insurance coverage, reducing out-of-pocket payments, improving benefit packages, and providing financial assistance. These approaches are essential because they address visible and measurable forms of economic burden (Sonni, 2025a; Sugianto & Tokuyama, 2025). They also support broader goals of financial risk protection and universal health coverage by seeking to reduce the direct cost of accessing healthcare. In the context of cancer treatment, such approaches can lower the burden of medical bills and improve formal access to services.

However, these practical approaches do not fully explain how patients experience financial protection in the everyday reality of treatment. Insurance coverage may reduce some direct medical costs, yet patients may still encounter transportation expenses, accommodation needs, food costs during hospital visits, loss of income, caregiver-related costs, and uncertainty about uncovered services. These hidden and indirect costs are often difficult to capture through standard financial indicators alone. As a result, the current understanding of financial protection may remain incomplete when it focuses primarily on whether patients are insured or whether particular medical services are covered.

The literature has increasingly recognized financial toxicity as a multidimensional problem that affects emotional well-being, family relationships, employment, treatment continuity, and quality of life. Previous qualitative studies have shown that cancer patients may continue to experience financial burden even when insurance or financial assistance is available. For example, studies on financial toxicity have highlighted the persistence of nonmedical expenses, income disruption, financial coping behaviours, and family involvement in sustaining treatment. Nevertheless, much of the existing knowledge still leaves an important question unanswered: how do insured cancer patients make sense of hidden costs when formal coverage does not fully translate into felt financial security?

This gap is particularly important in healthcare systems where families play a central role in absorbing the remaining burden of illness. When insurance does not cover the full practical cost of accessing treatment, patients often depend on relatives for transport, money, time, and emotional support (Solehudin et al., 2024; Sonni, 2025b). This dependence may allow treatment to continue, but it may also create guilt, anxiety, and a sense of becoming a burden. Such experiences cannot be adequately understood through expenditure categories alone. They require attention to the meanings patients attach to protection, vulnerability, dependence, hope, and treatment continuity.

A further limitation in current understanding is the tendency to treat financial protection as an administrative or economic condition rather than as a lived experience. From a policy perspective, a patient may be categorized as insured. From the patient's perspective, however, protection may still feel incomplete if each hospital visit requires repeated financial calculation, family negotiation, or borrowing money. This distinction between formal insurance status and experienced financial protection has not been sufficiently explored, especially among cancer patients who remain financially vulnerable despite being enrolled in national health insurance.

Therefore, an alternative approach is needed to explore the essence of this phenomenon in a deeper and more holistic way. A phenomenological approach offers such a pathway because it focuses on the lived experience and subjective meaning of financial toxicity. Instead of asking only how much patients pay, a phenomenological inquiry asks how patients experience, interpret, and negotiate hidden costs throughout the treatment trajectory. It allows the study to examine how financial burden is felt in everyday life, how it shapes treatment decisions, and how it transforms the meaning of insurance, family support, and hope for recovery.

Based on this gap, the present study is motivated by the following central question: how do cancer patients enrolled in national health insurance experience and make meaning of hidden costs during the course of treatment? This question emerges directly from the tension between what is formally provided by health financing systems and what is actually lived by patients and families. Addressing this question can enrich current knowledge by shifting attention from financial protection as coverage status to financial protection as experienced security in the lived reality of cancer care.

Previous studies have shown that financial toxicity in cancer care is not limited to medical bills. Pangestu et al. highlighted that insured cancer patients in Indonesia may still face financial toxicity through underinsurance, nonmedical cancer-related expenses, and income disruption. Panattoni et al. showed that financial toxicity also affects work, family life, emotional well-being, and quality of life. Waters et al. further demonstrated that patients often rely on financial assistance, insurance navigation, and coping strategies to continue treatment. These studies provide an important foundation, but they leave room for a deeper understanding of how insured patients interpret hidden costs as part of their lived treatment experience.

Here, this study shows how cancer patients enrolled in national health insurance experience and make meaning of hidden costs during the treatment trajectory. The study uses an interpretative phenomenological approach to explore how patients understand financial protection, uncertainty, family dependence, and treatment continuity. This approach is appropriate because it focuses on the meaning of lived experience rather than only the amount of money spent. The analysis also applies patient-centered hidden cost mapping to clarify how direct nonmedical costs, indirect costs, caregiver-related costs, and psychosocial financial burden shape the experience of care. In response to the knowledge gap, this study shows that financial protection is not only a formal insurance status, but also a lived sense of security that may remain incomplete during cancer treatment.

The article is organized to guide the reader from the broader issue of healthcare financing to the lived experience of hidden costs (Purnomo et al., 2025; Rabie & Shebaita, 2025). The introduction explains the general and specific background, identifies the knowledge gap, and presents the rationale for a phenomenological inquiry. The method section describes the phenomenological design, participant selection, data collection process, data analysis strategy, trustworthiness procedures, and ethical considerations. The results section presents the major themes that emerged from participants' accounts, including formal coverage without full reassurance, hidden nonmedical costs, income disruption, family-based coping, and treatment decisions under uncertainty. The discussion then connects these findings with existing literature, explains their contribution to health economics and healthcare financing, and concludes with implications for policy, practice, and future research.

RESEARCH METHODS

Study Design

This study employed a qualitative phenomenological design to explore the lived experience of cancer patients enrolled in national health insurance who continued to encounter hidden costs throughout the treatment trajectory. A phenomenological approach was considered appropriate because the study aimed to understand how patients experienced, interpreted, and negotiated financial burden beyond formal insurance coverage. Rather than measuring financial toxicity solely through expenditure or catastrophic health spending indicators, the design enabled an in-depth exploration of the meanings attached to hidden nonmedical costs, income loss, caregiver-related expenses, uncertainty, and household-level coping strategies.

An interpretative phenomenological approach was used to examine how participants made sense of financial protection in the context of cancer treatment. This approach is grounded in the assumption that lived experience is shaped by personal, social, economic, and institutional contexts. In this study, the phenomenon was not limited to the existence of treatment costs, but extended to the subjective meaning of being insured while still feeling financially vulnerable. Interpretative Phenomenological Analysis (IPA) was therefore applied to capture the depth and complexity of participants' accounts, particularly the tension between formal health insurance coverage and experienced financial protection.

To strengthen the relevance of the analysis to health economics and healthcare financing, IPA was integrated with patient-centered hidden cost mapping. This combination allowed the study to retain the interpretative depth of phenomenology while systematically identifying the types of costs that shaped participants' treatment experiences, including direct medical costs, direct nonmedical costs, indirect costs, caregiver-related costs, psychosocial financial burden, and adaptive financial behaviours.

Participants and Sampling

Participants were adult cancer patients who were enrolled in national health insurance and had undergone cancer-related diagnosis, treatment, or follow-up care. Participants were selected using purposive sampling to ensure that the data reflected rich and relevant experiences of the phenomenon under investigation. The sampling strategy prioritized variation in cancer type, treatment stage, socioeconomic background, employment status, distance from treatment facilities, and duration of treatment.

The inclusion criteria were: (1) aged 18 years or older; (2) diagnosed with cancer by a healthcare professional; (3) enrolled in national health insurance during the treatment period; (4) had experience with cancer-related treatment costs, including medical, nonmedical, or indirect costs; (5) able to communicate their experiences clearly; and (6) willing to provide written informed consent. Participants were excluded if they were clinically unstable at the time of data collection, unable to participate in an interview due to severe physical or psychological distress, or had no direct experience of managing treatment-related financial burden.

Data Collection

Data were collected through in-depth semi-structured interviews. This method was selected because it allowed participants to describe their experiences in their own words while ensuring that key issues related to healthcare financing, hidden costs, and financial coping were consistently explored. The interview guide was developed based on the study aim, the research questions, and sensitizing concepts from health economics and financial toxicity literature. The guide covered participants' experiences of insurance coverage, out-of-pocket spending, nonmedical expenses, income disruption, family support, treatment decisions, and coping strategies.

The interviews began with broad questions about the participant's treatment journey, followed by more focused questions about financial experiences. Example guiding questions included: "Can you describe your experience of using national health insurance during cancer treatment?"; "What kinds of costs did you still have to manage during treatment?"; "How did treatment affect your work, income, or household expenses?"; and "How did your family respond to the financial burden of treatment?" Probing questions were used to clarify meanings, deepen descriptions, and explore emotional or relational dimensions of the experience.

All interviews were audio-recorded with participant consent and transcribed verbatim. Field notes were prepared after each interview to document contextual information, nonverbal expressions, emotional tone, and preliminary analytic reflections. Where relevant and available, supplementary contextual information such as caregiver accounts, participants' descriptions of treatment-related spending, or documents related to referral and insurance procedures was used to support contextual understanding. These supplementary materials were not treated as quantitative financial records, but as contextual aids for interpreting participants' lived experiences.

Data Analysis

Data were analyzed using Interpretative Phenomenological Analysis, supported by patient-centered hidden cost mapping. The analysis was conducted through several systematic stages designed to identify both individual meanings and shared thematic patterns across participants.

First, each transcript was read repeatedly to gain a holistic understanding of the participant's account. Initial notes were made to capture descriptive, linguistic, and conceptual features of the data. Particular attention was given to expressions that reflected uncertainty, financial vulnerability, dependence on family, treatment-related decision-making, and the perceived gap between insurance coverage and actual financial protection.

Second, emergent themes were developed from detailed notes within each transcript. These themes were grounded in participants' words and experiences, while also reflecting interpretative engagement with the meaning of financial burden. For example, statements about transportation, meals, accommodation, and repeated hospital visits were examined not only as cost categories, but also as part of the lived experience of accessing care.

Third, hidden cost mapping was applied to organize cost-related experiences into analytically meaningful categories. These categories included direct medical costs, direct nonmedical costs, indirect costs, caregiver-related costs, psychosocial financial costs, and adaptive financial behaviours. This mapping was used to strengthen the connection between phenomenological findings and healthcare financing concepts without reducing participants' experiences to numerical expenditure data.

Fourth, themes were compared across cases to identify convergence and divergence among participants. This stage allowed the analysis to move from individual accounts to broader experiential patterns. The process generated major themes related to formal coverage without full financial reassurance, hidden nonmedical costs, loss of income, family-based coping, and treatment decisions shaped by affordability and uncertainty.

Fifth, the final thematic structure was refined by examining whether each theme was sufficiently supported by participant accounts and whether the themes collectively represented the essential meaning of the phenomenon. The final interpretation focused on the concept of experienced financial protection, referring to the difference between being formally insured and feeling genuinely protected in the lived reality of cancer treatment.

RESULTS

The analysis revealed that financial protection was not experienced by participants as a fixed administrative status, but as a fragile and continuously negotiated condition throughout the treatment trajectory. Although participants were formally covered by national health insurance, their accounts showed that insurance coverage did not eliminate the financial, emotional, and relational burden of cancer treatment. The lived experience of hidden costs emerged through repeated encounters with transport expenses, accommodation needs, medicine-related uncertainty, loss of income, caregiver burden, and the moral pressure of depending on family members.

Across the interviews, participants did not describe financial toxicity merely as a matter of expenditure. Rather, they framed it as an experience of disrupted security: the sense that treatment could continue only if the household was able to mobilize money, time, labour, and emotional endurance. Five major themes were identified: (1) formal coverage without full financial reassurance; (2) hidden nonmedical costs as an everyday burden; (3) loss of income and disrupted household stability; (4) family-based coping as both support and moral pressure; and (5) treatment decisions as negotiations between hope, affordability, and uncertainty.

Formal Coverage Without Full Financial Reassurance

Participants commonly entered treatment with the expectation that national health insurance would provide substantial protection from the cost of cancer care. For many, insurance membership initially created a sense of relief because it signified that major medical procedures, consultations, or

hospital-based services would be covered. However, this sense of relief gradually became unstable as participants encountered expenses that fell outside their initial understanding of coverage.

Insurance was therefore experienced not simply as protection, but as a conditional form of security. Participants described having to learn, often through repeated visits and unexpected payments, which parts of their treatment were covered and which still required personal or family resources. This uncertainty shaped how they understood the meaning of being insured.

One participant expressed this shift from confidence to uncertainty:

“At first, I thought having insurance meant I would not have to worry about treatment costs. But after several hospital visits, I realized there were still many things we had to pay for ourselves. I felt protected, but not completely safe.”

This account illustrates the central tension in participants’ experience: formal insurance coverage reduced some forms of financial exposure, yet it did not fully remove the feeling of vulnerability. The phrase “not completely safe” captures the distinction between administrative coverage and lived financial protection. Participants did not deny the value of insurance; rather, they emphasized that the protection they experienced was partial, uneven, and dependent on circumstances surrounding each stage of treatment.

For some participants, uncertainty arose from unclear information about coverage rules. They described confusion about referral procedures, additional medicines, diagnostic tests, or supportive treatments. This confusion created a sense of dependence on hospital staff, administrative processes, and the ability of family members to ask questions or negotiate information.

Another participant stated:

“Sometimes I did not know whether a medicine was covered or not. I only found out when I was told to pay. At that moment, I could not argue because I needed the medicine.”

This experience shows how financial uncertainty was embedded in the clinical moment. Participants were often required to make payment decisions while facing fear, pain, or urgency. In such situations, the distinction between covered and uncovered services became more than a technical matter; it became part of the emotional burden of treatment.

The theme suggests that insurance was experienced as necessary but insufficient. Participants valued the existence of coverage, yet their narratives showed that financial protection must be understood from the patient’s perspective, not only from the presence of an insurance card or formal entitlement.

Hidden Nonmedical Costs as an Everyday Burden

The most frequently emphasized burden was not always direct medical payment, but the accumulation of hidden nonmedical costs. Participants repeatedly mentioned transport, meals during hospital visits, temporary accommodation, communication costs, parking fees, and other small but recurring expenses. These costs were often described as invisible to the health financing system but highly visible in household life.

For participants living far from treatment centres, the cost of reaching care became part of the illness experience itself. Hospital visits required planning, money, physical energy, and assistance from family members. Treatment was therefore not experienced only inside the hospital; it began at home, with the question of whether the patient had enough money and support to travel.

One participant explained:

“The treatment may be covered, but going to the hospital is not free. Every visit means transport, food, and sometimes staying overnight. These are the costs that slowly exhaust us.”

The expression “slowly exhaust us” reflects how hidden costs were experienced cumulatively. Participants did not necessarily frame each expense as catastrophic when viewed separately. However, repetition transformed small payments into an ongoing financial strain. The burden was intensified by

the long duration of cancer treatment, which involved repeated consultations, examinations, therapy cycles, and follow-up visits.

Participants also described how nonmedical costs affected their emotional state before and after each hospital visit. Some reported feeling anxious days before treatment because they had to calculate whether the household had enough money for travel and daily expenses. Others described postponing non-urgent needs at home to prioritize hospital-related expenses.

A participant described this calculation:

“Before every control visit, I always counted the money at home. It was not only for the hospital. I had to think about transport, meals, and what my children would eat while I was away.”

This account shows that hidden costs were not isolated from broader household responsibilities. The participant’s experience of treatment was intertwined with caregiving obligations, food security, and family survival. Thus, hidden costs functioned as a bridge between health service access and household economic vulnerability.

Participants’ narratives also indicated that nonmedical costs were less visible in formal discussions of insurance coverage. While insurance reduced the burden of some medical payments, it did not address the everyday expenses required to make treatment practically accessible. For participants, this gap shaped the meaning of financial toxicity: the problem was not only whether treatment was covered, but whether they could afford the full journey of care.

Loss of Income and Disrupted Household Stability

Another major theme was the disruption of income caused by illness, treatment schedules, and physical weakness. Participants described how cancer treatment reduced their ability to work, maintain regular income, or contribute economically to the household. For those engaged in informal work or daily wage labour, missing work immediately affected household cash flow.

Loss of income was experienced not merely as a financial problem, but as a disruption of identity, responsibility, and family roles. Participants who had previously been income earners described feeling dependent, guilty, or less useful to their families. This emotional dimension made financial toxicity more than an economic burden; it became a deeply personal experience of losing control.

One participant stated:

“Before I was sick, I could work and help my family. After treatment started, my body became weak. I could not work as before, but the expenses kept coming.”

This statement captures a double burden: income decreased while treatment-related expenses continued. Participants repeatedly described this imbalance as one of the most distressing aspects of their illness journey. The household had to absorb both the loss of productive capacity and the rise of health-related expenditure.

The disruption was particularly severe for participants whose income depended on physical labour, small trade, farming, transport work, or other informal economic activities. Unlike salaried workers with sick leave or employment protection, these participants experienced illness as an immediate interruption of livelihood.

Another participant explained:

“If I do not work, there is no income. But if I force myself to work, my body cannot tolerate it. I felt trapped between needing money and needing treatment.”

The phrase “trapped between needing money and needing treatment” reflects the essence of this theme. Participants did not experience treatment decisions as purely medical choices. They were embedded in the economic realities of household survival. The need to continue therapy competed with the need to maintain income, pay for daily needs, and avoid deeper indebtedness.

Caregivers also became part of this income disruption. When family members accompanied patients to hospital visits, they often had to miss work or reduce their own economic activities. In this way, cancer-related financial toxicity spread beyond the patient and affected the household as a unit.

Participants' accounts suggest that financial protection should not be evaluated only through medical cost coverage. A patient may receive insured treatment while simultaneously experiencing income collapse, productivity loss, and household instability. These indirect costs formed a central part of the lived experience of financial burden.

Family-Based Coping as Support and Moral Pressure

Family support emerged as an important mechanism for coping with hidden costs. Participants described receiving help from spouses, children, siblings, neighbours, or extended family members. This support included money, transport, food, accompaniment to hospital visits, assistance with administrative procedures, and emotional encouragement.

However, family support was not experienced only as relief. It also carried moral pressure. Participants often felt guilty for becoming financially dependent on others or for causing family members to sacrifice their own needs. This ambivalence was central to their experience of coping.

One participant said:

"My family helped me a lot, but every time they gave money, I felt sad. I knew they also had their own needs. I felt like my illness became everyone's burden."

This quotation shows that support and distress coexisted. Family assistance enabled treatment continuity, yet it also made participants aware that their illness affected the economic well-being of others. The feeling that "my illness became everyone's burden" reflects the relational nature of financial toxicity.

Participants also described coping strategies such as borrowing money, selling household assets, reducing food expenses, delaying other family needs, using savings, or asking relatives for temporary assistance. These strategies were often framed as necessary, but emotionally painful. They allowed treatment to continue, but they also signalled the erosion of household resilience.

Another participant explained:

"We sold some things at home because I had to continue treatment. I was grateful that there was something to sell, but I also felt afraid. What if later we have nothing left?"

This account reveals that coping strategies could generate new forms of insecurity. Selling assets or borrowing money solved immediate treatment-related needs but produced anxiety about the future. Coping was therefore not a simple sign of resilience; it was also evidence of financial fragility.

Participants' narratives showed that households became informal financial protection systems. When formal insurance did not cover the full burden of treatment, families absorbed the remaining costs. Yet this family-based protection was unequal and unstable. Its effectiveness depended on the economic capacity of relatives, the strength of social networks, and the willingness of others to provide repeated support.

This theme highlights that financial toxicity is socially distributed. The patient experiences the illness, but the household carries much of the economic adjustment. For this reason, participants' accounts suggest that financial protection policies should consider not only the insured individual, but also the family system that sustains treatment access.

Treatment Decisions as Negotiations Between Hope, Affordability, and Uncertainty

Participants described treatment as a continuous negotiation between the hope for recovery and the reality of limited financial resources. While they generally wanted to follow medical recommendations, financial constraints affected how they planned hospital visits, purchased medicines, arranged transport, and responded to unexpected costs.

Some participants described delaying visits, waiting until money was available, reducing other household expenses, or depending on relatives before continuing care. These decisions were not framed as refusal of treatment, but as attempts to balance medical necessity with economic survival.

One participant explained:

“I never wanted to stop treatment. But sometimes I had to think first: do we have money to go to the hospital this week? If not, I had to wait or ask someone for help.”

This account demonstrates that access to care was not determined only by formal entitlement. Even when treatment was available and partially covered, the ability to reach and continue care depended on household liquidity, mobility, and social support.

For participants, uncertainty was a constant feature of treatment. They were uncertain about future costs, treatment duration, physical recovery, income, and family capacity to continue providing support. This uncertainty shaped their emotional experience and influenced decision-making.

Another participant stated:

“The hardest part was not knowing how long this would continue. If it was only one time, maybe we could manage. But cancer treatment keeps going, and the costs keep following us.”

The phrase “the costs keep following us” expresses the temporal nature of financial toxicity. Participants did not experience financial burden as a single event. It followed them across diagnosis, treatment cycles, follow-up care, and daily life. This continuity created a sense of exhaustion and unpredictability.

Participants also described how treatment decisions were shaped by the desire not to become a burden. Some hesitated to ask for help repeatedly, even when they needed it. Others continued treatment while silently reducing household consumption or hiding their anxiety from family members.

These accounts show that treatment decisions were not purely clinical or individual. They were relational, moral, and economic. Participants negotiated care within the boundaries of what the household could endure. The experience of financial toxicity therefore shaped not only access to treatment, but also the emotional meaning of continuing treatment.

Thematic Matrix of the Lived Experience

The themes identified in this study can be understood as interconnected dimensions of one broader phenomenon: the gap between formal insurance coverage and experienced financial protection.

Major Theme	Core Experience	Illustrative Meaning
Formal coverage without full financial reassurance	Participants valued insurance but still felt financially vulnerable	Being insured did not always mean feeling financially safe
Hidden nonmedical costs as an everyday burden	Transport, meals, accommodation, and recurring expenses accumulated over time	The journey to care became part of the cost of illness
Loss of income and disrupted household stability	Illness and treatment reduced earning capacity while expenses continued	Financial toxicity emerged from both rising costs and falling income
Family-based coping as support and moral pressure	Families helped sustain treatment but also carried emotional and economic strain	Coping depended on household and social networks
Treatment decisions as negotiations between hope, affordability, and uncertainty	Participants balanced medical need with available money and family capacity	Continuing treatment required repeated financial negotiation

Essential Meaning of the Phenomenon

The essential meaning emerging from participants' experiences is that financial protection was lived as an incomplete and fragile form of security. National health insurance reduced some direct medical costs, but participants continued to face hidden nonmedical expenses, income loss, caregiver burden, and emotional distress. These burdens accumulated throughout the treatment trajectory and shaped how patients understood the meaning of being protected.

For participants, financial toxicity was not only the presence of costs, but the experience of continuously negotiating care under conditions of uncertainty. The illness disrupted household stability, altered family roles, and required repeated strategies to mobilize money and support. The experience of cancer treatment was therefore inseparable from the experience of managing hidden costs.

The findings show that the patient's sense of financial protection cannot be fully captured by insurance status alone. It is shaped by whether patients can reach care, continue treatment, maintain household stability, and preserve dignity while relying on family support. In this sense, the phenomenon can be summarized as experienced financial protection: the gap between being formally insured and feeling genuinely protected in the lived reality of illness.

DISCUSSION**Summary of the Main Findings**

This study shows that financial protection was experienced by insured cancer patients as an incomplete and fragile form of security, rather than as a condition guaranteed by formal insurance membership. In response to the central research question, the findings reveal that hidden costs shaped how patients interpreted insurance protection, negotiated treatment continuity, and managed vulnerability within the household.

Contribution of the Findings to the Research Question

The findings answer the central research question by showing that hidden costs were not experienced as separate or secondary expenses, but as an integral part of the cancer treatment journey. Participants did not describe financial toxicity only in terms of direct medical payment. They experienced it through repeated transport costs, food expenses during hospital visits, accommodation needs, income disruption, caregiver involvement, and uncertainty about uncovered services. These elements shaped the meaning of treatment because patients had to think not only about clinical recovery, but also about the financial capacity required to remain in care.

A key contribution of this study is the distinction between formal insurance coverage and experienced financial protection. The results suggest that national health insurance may reduce exposure to some direct medical costs, but it does not automatically create a lived sense of financial security. Patients may be formally insured and still feel financially unsafe when each hospital visit requires additional spending, family negotiation, or income sacrifice. This distinction is important because it shifts attention from insurance status as an administrative category to protection as an experience lived by patients and families.

The study also contributes by showing that financial toxicity is relational. The burden did not remain within the individual patient. It moved across the household through caregiving, borrowed money, reduced consumption, family support, and emotional guilt. Family members became part of the hidden financing system that sustained treatment access when formal coverage did not fully absorb the cost of care. This finding deepens the understanding of financial toxicity by showing that economic strain is also experienced as moral pressure, dependence, and concern for the well-being of others.

Another contribution lies in the temporal nature of hidden costs. Participants experienced financial burden not as a single crisis, but as a repeated and cumulative condition across diagnosis, treatment, follow-up, and daily recovery. This temporal pattern explains why small nonmedical expenses could become meaningful sources of distress over time. The cost of transport, meals, and lost working days may appear minor when viewed separately, but participants experienced these costs as exhausting because they returned with every treatment cycle and hospital visit.

The findings further show that treatment decisions were shaped by a continuous negotiation between hope, affordability, and uncertainty. Participants wanted to continue treatment, yet their ability to do so depended on available money, family support, physical capacity, and the predictability of future costs. This finding helps explain why access to care cannot be understood only through formal entitlement. Access also depends on whether patients can practically and emotionally sustain the full journey of care.

The concept of experienced financial protection offers a useful way to synthesize these findings. It refers to the degree to which patients feel genuinely protected in the lived reality of illness, not merely the degree to which they are formally covered by insurance. This concept captures the central meaning of the phenomenon identified in this study: being insured did not always mean being financially secure. By developing this interpretation, the study contributes to health economics and healthcare financing by bringing patient experience into the understanding of financial protection.

Relationship with Previous Literature and Theory

The findings are consistent with previous research showing that financial toxicity in cancer care is multidimensional. Pangestu et al. reported that Indonesian cancer patients may experience financial toxicity despite having health insurance, particularly through underinsurance, out-of-pocket nonhealthcare cancer-related costs, and income disruption. The present study supports this evidence and extends it by interpreting these burdens as part of the broader lived experience of incomplete financial protection. In this study, the most important issue was not only the presence of cost, but the meaning patients attached to cost while trying to continue treatment.

The findings also align with phenomenological research by Panattoni et al., which showed that financial toxicity affects emotions, family life, work, and quality of life. The present study similarly demonstrates that financial burden cannot be separated from emotional and relational experience. However, this study adds a stronger healthcare financing perspective by emphasizing the gap between formal insurance membership and the patient's lived sense of security. This helps connect phenomenological insight with policy-relevant concerns about financial risk protection.

The study further complements qualitative evidence from Waters et al., who found that financial burden persisted among metastatic breast cancer patients despite access to insurance and financial assistance. Their study showed that patients continued to rely on cost-coping behaviours, including debt, employment adjustments, and medication-related decisions. The present findings resonate with this pattern, but add a more explicit interpretation of how patients make meaning of these coping strategies. Coping was not experienced only as practical adaptation; it also carried anxiety, guilt, and fear of future insecurity.

The results are also relevant to the broader concept of financial protection in universal health coverage. Global health financing frameworks commonly assess financial protection through out-of-pocket spending and catastrophic health expenditure. These indicators remain essential because they show whether healthcare payments threaten household welfare. However, the findings of this study suggest that such indicators may not fully capture the lived experience of patients whose burden arises from hidden nonmedical costs, indirect costs, and repeated household trade-offs. Financial protection therefore needs to be understood not only as reduced direct payment, but also as the patient's ability to access and continue care without sustained insecurity.

From a phenomenological perspective, the findings strengthen the view that illness is experienced within a lifeworld shaped by social relations, economic conditions, and personal meaning. Cancer treatment was not experienced only as a clinical process. It was experienced as a disruption of work, family roles, financial expectations, and future planning. This interpretation supports the use of phenomenology because the central phenomenon cannot be fully understood through cost categories alone. It requires attention to how patients live through uncertainty, dependence, and the fragile hope of continuing treatment.

The findings do not contradict previous economic approaches to financial toxicity; rather, they complement them. Quantitative indicators can identify the scale of financial hardship, while phenomenological inquiry can explain how that hardship is felt, interpreted, and managed in daily life.

Together, these perspectives can provide a richer understanding of healthcare financing. The contribution of this study is therefore not to replace economic measurement, but to show why patient experience should be included when evaluating whether insurance truly protects people during serious illness.

Implications of the Findings

The findings have important implications for how financial protection is understood in cancer care. Formal insurance coverage remains essential, but the results suggest that coverage alone may not be sufficient to create a lived sense of financial security. Patients experienced financial protection through the practical ability to reach care, continue treatment, manage household needs, and avoid repeated financial distress. This means that healthcare financing should not be evaluated only through administrative enrolment or covered medical services. It should also consider whether patients can sustain the full treatment journey without hidden costs undermining their well-being.

From a health economics perspective, the findings support a broader understanding of financial toxicity. Financial toxicity was not limited to direct payment for medical treatment. It appeared through transport costs, accommodation needs, food expenses during hospital visits, income disruption, caregiver time, debt, and emotional distress. These experiences show that hidden costs can weaken the protective function of insurance even when the core treatment is formally covered. Therefore, policies that aim to improve financial protection should pay closer attention to nonmedical and indirect costs that shape access to cancer care.

The findings also have practical implications for cancer services. Hospitals and health systems may need to provide clearer information about covered and uncovered costs, referral procedures, expected treatment pathways, and available financial support. Patients in this study experienced uncertainty as part of their financial burden. This suggests that better communication and financial guidance could reduce anxiety and help patients prepare for treatment-related expenses. Such support may be especially important for patients who live far from treatment centers, depend on daily income, or require frequent caregiver accompaniment.

The relational dimension of financial toxicity also deserves attention. The findings show that families often function as informal sources of financial protection when formal coverage does not absorb the full cost of care. Family support helped patients continue treatment, but it also produced guilt, dependence, and moral pressure. This implies that cancer care should recognize the household as part of the care context. Supportive policies may need to consider caregiver costs, lost work time, and the social burden carried by families during long-term treatment.

Professionally, the findings encourage healthcare providers to view financial distress as part of the patient's lived experience of illness. Clinical conversations often focus on diagnosis, treatment options, and medical side effects. However, patients may also need space to discuss transport difficulties, lost income, fear of debt, and uncertainty about future expenses. When financial concerns are acknowledged as part of care, patients may feel less isolated and more able to express barriers that affect treatment continuity.

The findings are also relevant beyond the immediate study population. Many patients with chronic or high-cost illnesses may experience a similar gap between formal coverage and lived security. Although the present study focused on cancer patients enrolled in national health insurance, the central insight may inform broader discussions on universal health coverage, equity, and patient-centered healthcare financing. Financial protection should not only ask whether people are insured. It should also ask whether they feel able to continue care without sacrificing household stability, dignity, and emotional well-being.

Limitations of the Study

This study has several limitations that should be considered when interpreting the findings. First, the phenomenological design aimed to generate a deep understanding of lived experience rather than statistically generalizable conclusions. The findings therefore should not be treated as representing all cancer patients enrolled in national health insurance. Instead, they provide rich insight into how

hidden costs may be experienced and interpreted within a specific treatment and healthcare financing context.

Second, participant experiences may have been shaped by local health system arrangements, referral pathways, hospital access, socioeconomic conditions, and family structures. Patients in other regions, insurance schemes, or cancer care settings may experience hidden costs differently. For example, patients living closer to treatment centers may face less transport burden, while those in remote areas may experience greater nonmedical costs. These contextual differences limit broad generalization but strengthen the need for careful interpretation within the setting of the study.

Third, the study relied primarily on participants' accounts of their financial experiences. Such accounts are valuable because they reveal meaning, emotion, and perception, but they may not fully capture the exact financial amount spent by patients and households. The purpose of the study was not to calculate expenditure, but to understand how financial burden was lived and interpreted. Future studies may combine phenomenological interviews with household expenditure documentation to deepen understanding without reducing the phenomenon to numerical measurement.

Fourth, the use of retrospective narratives may have influenced how participants described their experiences. Participants may have emphasized events that were emotionally significant, financially difficult, or closely connected to treatment decisions. This does not reduce the value of the findings, because phenomenology is concerned with meaningful experience. However, it suggests that the findings should be read as interpretations of lived experience rather than as chronological records of every cost encountered during treatment.

Fifth, caregiver perspectives were considered only as contextual information where available. Because financial toxicity often affects the household, a fuller understanding may require direct exploration of caregiver experiences. Caregivers may interpret financial burden differently from patients because they often manage transport, income disruption, emotional support, and administrative processes. Including caregiver voices more systematically may strengthen future analysis of the relational burden of hidden treatment costs.

Finally, the study focused on hidden costs among insured cancer patients. It did not compare insured and uninsured patients, different cancer types, or different stages of treatment in a systematic way. These comparisons may reveal important differences in how financial protection is experienced. Nevertheless, the focus on insured patients was appropriate for addressing the central question of this study: why formal coverage does not always translate into experienced financial security.

Prospective Statement for Future Research

Future research can extend these findings by examining experienced financial protection across different patient groups, disease categories, and health system contexts. Cancer care provides a powerful setting for studying hidden costs because treatment is often long, repeated, and emotionally demanding. However, similar experiences may occur among patients with other chronic or high-cost conditions, such as kidney failure, cardiovascular disease, diabetes complications, or rare diseases. Comparative phenomenological studies could clarify whether the meaning of financial protection differs across illness trajectories.

Further research should also explore the household dimension of financial toxicity in greater depth. The present findings show that families often absorb hidden costs and help sustain treatment continuity. Future studies could include patients and caregivers as connected participants to understand how financial burden is shared, negotiated, or silently carried within households. This direction would help explain how illness reshapes family roles, economic responsibilities, and emotional relationships.

Another important direction is to examine the temporal experience of hidden costs. Financial burden may change from diagnosis to active treatment, follow-up care, recurrence, or palliative care. Longitudinal qualitative research could show how patients' meanings of protection, vulnerability, and coping evolve over time. This would provide a more dynamic understanding of financial toxicity as a continuing experience rather than a single event.

Future studies may also integrate phenomenological findings with health economics indicators. Such integration could help connect lived experience with policy measurement. For example, qualitative themes on hidden costs, income disruption, and family coping could inform the development of patient-centered measures of financial protection. This would allow future research to bridge the gap between economic evaluation and patient experience.

Policy-oriented research should examine how health systems can respond to hidden costs without reducing them to narrow financial categories. Possible areas include transport support, accommodation assistance, caregiver support, financial counselling, clearer insurance communication, and early identification of patients at risk of financial distress. These interventions should be evaluated not only by their economic outcomes, but also by whether they improve patients' lived sense of security during treatment.

Overall, this study opens a broader question for healthcare financing research: how can health systems move from formal coverage toward protection that patients genuinely experience in daily life? Answering this question requires continued attention to both economic structures and human experience. By placing patient meaning at the center of analysis, future research can contribute to more equitable, responsive, and humane models of financial protection in cancer care and other high-cost health conditions.

CONCLUSION

This study explored the lived experience of hidden costs among cancer patients enrolled in national health insurance, with a focus on how they understood financial protection during treatment. The findings show that insurance coverage reduced some direct medical burdens, but it did not fully protect patients from transportation costs, income loss, caregiver-related expenses, uncertainty, and household-level financial strain. These experiences reveal a gap between formal insurance coverage and experienced financial protection, where patients remain vulnerable despite being administratively insured. By using a phenomenological approach, this study extends previous research by explaining not only what costs patients face, but also how those costs shape their sense of security, dependence, dignity, and treatment continuity. The study contributes to health economics and healthcare financing by placing patient meaning at the center of financial protection analysis. Future research can develop this insight through comparative or longitudinal studies that examine how hidden costs and experienced financial protection evolve across different illnesses, regions, and health financing systems.

CONFLICT OF INTEREST

The Authors Declare That There Is No Conflict Of Interest Related To This Study. The Sponsor Had No Role In The Study Design, Data Collection, Data Analysis, Interpretation Of Findings, Manuscript Preparation, Or The Decision To Submit The Article For Publication. All Authors Remain Fully Responsible For The Content, Analysis, And Conclusions Presented In This Manuscript.

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