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Financial struggles and coping with the aftermath of breast cancer care: An ethnographic study in Vietnam

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ABSTRACT

Breast cancer, the most common cancer diagnosed among women, disproportionately affects low- and middle-income countries (LMICs). Based on an ethnographic study conducted in Central Vietnam in 2019, including observation and interviews with 33 women patients, we investigate how women and their families managed the financial burden of breast cancer care. Our findings suggest that in a context where health-related risk protection is poorly organised and out-of-pocket expenses are burdensome, despite the presence of universal health coverage, patients must rely heavily on informal arrangements to finance their treatment. They proactively researched available information and undertook extensive and ramified work to prove their deservingness for some types of assistance, including strategically disclosing their cancer status or using tactics to accelerate the process of applying for state welfare. Affected families must make hard calculations to prioritise the pressing health need of a member diagnosed with cancer and in many circumstances, forfeited the education of their young children. We offer theoretical understanding of 'patient work' beyond the routine management of the biological aspects of an illness. In addition, we demonstrate how engaging in those various coping practices can reinforce one's vulnerability to a vicious cycle of illness and poverty and amplify socio-economic inequalities among the affected community and the larger society. We argue this situation, if not tackled urgently and appropriately, can impede the progress towards achieving Sustainable Development Goal 3 (Good Health and Wellbeing) and Goal 10 (Reduced Inequalities) in LMICs amidst the non-communicable disease epidemic.

1. Introduction

Cancer now disproportionately affects low- and middle-income countries (LMICs) where three-quarters of all cancer-related deaths are projected to occur by 2030 (IARC, 2021). In the next 50 years, LMICs will continue to bear a greater cancer burden as compared to high-income countries (HICs), driven by demographic shifts, urbanisation, and lifestyle changes (Pramesh et al., 2022). Despite this, the existing literature on the experience of cancer is largely skewed towards HICs and there is a paucity of research in LMICs (Pramesh et al., 2022), challenging the development of effective policies and practices to address the problems specifically experienced in those settings. In addition, on the topic of cancer-related financial burdens, the majority of studies have adopted quantitative methodologies (Abrams et al., 2021; Carrera et al., 2018) with limited attention to understanding the wider context of personal circumstances across the cancer continuum. Drawing upon an ethnographic study in Vietnam, this paper focuses on the various means of coping deployed to manage cancer care and how these measures could translate to immediate and longer-term outcomes for affected people in a lower middle-income setting in Asia.

1.1. Background

Of all cancer types, breast cancer is the most prevalent malignancy worldwide and the leading cause of cancer-related death in 12 of 20 regions of the world (Ferlay et al., 2021). Women in countries with low or medium Human Development Index face substantial disparities in accessing breast screening services and treatment: they are more likely to be diagnosed at a later stage and die earlier from breast cancer (Lima et al., 2021; Sung et al., 2021). Breast cancer survivors in LMICs also experience greater, longer-term after-effects of cancer treatment, including lymphedema, chest pain, impaired fertility, premature menopause, or extreme fatigue due to the unavailability of less invasive treatments and psychological care (Ganz et al., 2013).

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Breast cancer has become a major focus of social science inquiries in the last few decades, which have sought to document its long-lasting, disruptive effects across different socio-economic contexts (Kerr et al., 2018; Do, 2023). Anthropological studies in particular have adopted a biosocial lens to explore the development and experience of cancer. The 'syndemic approach' has influenced much of this work to recognise a complex web of social, structural, and cultural factors in shaping health-seeking practices and outcomes (Singer, 2009). In resource-poor countries with the double burden of communicable and non-communicable diseases (NCDs), structural constraints like overcrowded healthcare, inadequate infrastructure, low income, poor nutrition, unstable employment, and limited social networks increase people's vulnerability for developing a chronic, non-communicable condition and inhibit treatment seeking (Lora-Wainwright, 2013; Manderson and Warren, 2016; Singer, 2009). For instance, Fifita (2016) illustrates in her ethnography in Tonga that women were forced to sell their family's properties or borrow money at exorbitant interest rates to pay for cancer care due to the country's poverty and under-funded universal health coverage (UHC). Meanwhile, in Botswana where cancer has emerged as an epidemic, Livingston (2012) documents the effects and consequences of care, and shows how cancer care is a deeply social experience that always entails arduous labour in the face of political and economic pressures. Cancer patients often move eclectically across health sectors to look for alternative therapies to complement biomedical treatment (Mulemi, 2017) or travel extensively to metropolitan cities or overseas to access oncology care (Greco, 2019; Stalford, 2019). These combined factors amplify their experiences of chronicity and vulnerability to financial precarity and social marginalisation (Manderson and Warren, 2016).

In this paper, we examine how affected people manage the financial burden of cancer care in Vietnam. As this study shows, without a well-funded public healthcare and a robust social security system, women patients must pay exorbitant costs for breast cancer treatment out-of-pocket. Therefore, financial concerns dominate their everyday lives from diagnosis to survivorship, in combination with fears over the clinical risks of recurrence or metastasis. Our study illustrates the economic realities and the multigenerational, long-lasting consequences of coping on women patients and their families. Such knowledge is critical for addressing inequities in women's cancers, but has not gained traction in the current research agenda (Ginsburg et al., 2017). Our study also contributes to identifying the populations at the greatest risk for cancer-induced poverty. By doing so, our findings enrich the empirical understanding of the interrelation between chronic ill health and daily life circumstances (Livingston, 2012; Manderson and Warren, 2016), and more broadly the social structures accountable for disparate cancer outcomes.

1.2. *Theoretical background*

We draw upon the concept of 'patient work' to understand the various immediate and longer-term strategies that patients and their families deploy to manage the social and economic burdens caused by breast cancer. Strauss (1998) first introduced the concept of 'patient work' when writing about the strategies or an organisation of efforts that people develop to handle the problems caused by their chronic illness, which involves resources, healthcare interactions, and social skills. Mattingly et al. (2011) later introduced the concept of 'chronic homework' to emphasise the strenuous efforts related to self-care management of chronic medical conditions when the health system shifted rehabilitation activities into the home, leading to a form of a borderland practice.

Previous analyses have drawn upon this 'work' concept to shed light on the everyday labour required to attend to chronic conditions within wider social settings (Gammeltoft et al., 2022; Rogvi et al., 2021; Rotheram et al., 2021). For instance, in the UK, Rotheram et al. (2021) showed how health inequalities were manifested in the 'work' taken to clean and prevent the spread of gastrointestinal infections between households living in contrasting socio-economic contexts. This concept has also informed Weaver's study (2016) which describes how the everyday 'illness work' to manage chronic comorbidities appeared less burdensome and disruptive for families with economic privileges than those living in financial disadvantages in India. Our study expands the concept of 'patient work' beyond the everyday management of health-related aspects of an illness. We describe the different types of labour that patients and their families engage in to ensure the economic survival of their families, ranging from managing social relationships to manoeuvring through the welfare system. In doing so, we show how the 'work' concept is relevant in unpacking the burden of managing an acute, chronic illness and how socio-economic inequalities could develop from the 'work' demanded of patients and their families to access and finance cancer treatment.

Research into cancer experiences has highlighted uncertainty as fundamental across the cancer care continuum (Jain, 2013), largely due to unpredictable treatment outcomes, especially in the case of advanced cancer or the use of novel treatmens (Broom et al., 2022; Greco, 2021). Theoretical underpinnings related to risk individualisation (Beck, 2002) are also useful to inform research on the strategies used to manage the survivorship uncertainties in Vietnam. Within a context of rapid privatisation of healthcare services, our ethnographic study shows how the burden of cancer is pushed to the domestic setting, despite the presence of UHC. Our study demonstrates how patients are forced to engage in the invisible 'work' of individualised cancer care with limited involvement of the welfare state. Their pursuit of cancer care is indeed informed by individualised risk management and cancer outcomes therefore must be self-determined.

1.3. *The Vietnamese context*

Viet Nam's public health system is divided into national, provincial, district, and commune levels. National general hospitals, university and college hospitals, and national research and institutes are the highest points of referral. The health system has undergone profound changes since 1986 when the country transitioned from a subsidised to a market-based economy with socialist orientation, most notably, with the greater autonomy of public hospitals, deregulation of the pharmaceutical industry and retail drug sales, and legalisation to enable private hospitals (London, 2013; Stalford, 2019). While those reforms have expanded consumers' choices, they have increased healthcare costs for the public. Out-of-pocket expenses remain high (Dao, 2023), estimated at around 39.6% of total health expenditures in Vietnam, which was more than double the global average in 2020 (Cai, 2023). The situation has led to stratification of the system and exacerbated health access inequity across different population groups and regions (Lincoln, 2014; London, 2013).

Due to a rapidly ageing population and recent success in controlling communicable diseases, Vietnam's burden of disease is now dominated by NCDs with cancer becoming the leading cause of morbidity and mortality (Teo et al., 2019; World Health Organization, 2018). The health system is however under-prepared to tackle the challenges emerging with the epidemiological shift to NCDs. Oncology infrastructure and services mostly concentrate in urban cities and disparities regarding diagnostic and treatment capability are prevalent across regions and between national and lower-level health facilities. This renders travel to obtain oncology services inevitable and laborious for the least advantaged patients residing in rural, remote areas and often leads to the overcrowding of urban public hospitals (Stalford, 2019).

Breast cancer is the most frequent cancer among women in Vietnam, with over 24,500 new cases (nearly 30% of all new cases) detected every year (GLOBOCAN, 2022). Women receive a cancer diagnosis at relatively younger ages compared to those in Western countries, with a median age at primary diagnosis of 50 years in Vietnam (Pham et al., 2021; Stapleton et al., 2018). A national breast screening program is non-existent in Vietnam, and breast screening and mammography are not covered under the existing public health insurance (Jenkins et al., 2020). This partly explains a high prevalence of late stage presentation among cancer patients in Vietnam: 49.5% of women are diagnosed at stage III or IV (Tran et al., 2016). The 5-year survival rate of women diagnosed with breast cancer in Vietnam is estimated at 80.6% (Vu Hong et al., 2019), which is noticeably lower than the corresponding rates recorded among women living in HICs (Giaquinto et al., 2022).

Since the early 1990s, the government of Vietnam has implemented universal or social health insurance which has reached over 90% of the total population by 2020 (Cai, 2023). Vietnam's health insurance comprises *compulsory* and *voluntary* schemes. The compulsory scheme includes public servants and formal sector employees who are enrolled as contributing groups and non-contributory social beneficiary groups (such as pensioners, war veterans, and poor households), children under 6 years old and elderly people aged 80 years and over who receive state subsidies to participate in the scheme (Le et al., 2020). Workers employed in the informal sector and agriculture are uninsured by default and if they want to be covered, they must purchase insurance as a voluntary contributor. Unlike the compulsory scheme where the government can enforce the participation and contributions of formal sector employers, there is no direct penalty for not participating in the voluntary scheme (Dao, 2020).

By the time of writing, holders of public health insurance card are covered for 80% of treatment and hospital costs at a designated hospital (or a higher-level one with an approval of transfer). Higher coverage is applied to patients with state-funded insurance cards, including those from poor-households (100% coverage), near-poor households (95%), and people with certain disability levels (Government of Vietnam, 2018). In addition to insurance-related benefits, social protection beneficiaries also receive a monthly cash transfer starting from 405,000 VND (~US$17.76) and school tuition fee exemption. While formal public assistance is available, as we illustrate later, access to such support is erratic and subject to numerous constraints and factors largely beyond a patient's control.

While most forms of cancer treatment, including surgery, chemotherapy, and radiation therapy are included within the public insurance scheme, the coverage rates for certain medications to treat breast cancer are remarkably lower. The co-payment rate for certain types of medications, such as Trastuzumab (Herceptin), a targeted cancer drug prescribed to curb HER2 - a growth-promoting protein detected among 15%–20% of primary breast cancers (Wolff et al., 2013) - is set at 40% at the time of writing. This means for insured patients, the targeted therapy costs around 649,000,000 VND (~US$28,465), regardless of their public insurance coverage (Tran et al., 2022).

2. Methods

This paper is based on an ethnographic study in Thua Thien Hue, a province in the Central region of Vietnam, conducted from April to December 2019. We also supplement the ethnographic data with observation of the social media of a breast cancer peer network from 2019 to 2022. The fieldwork combined multiple data collection techniques (observation, interviews and focus groups) and involved different stakeholder groups, which we describe in detail elsewhere (Do and Whittaker, 2020). The data presented in this paper are primarily drawn upon the interviews and observation with breast cancer patients and their caregivers. The study received the ethics approval by Monash University Human Research Ethics Committee (Project 14130) and the Internal Review Board in Human Subject Research of the Institute for Social Development Studies (Vietnam). All names used in this paper are pseudonyms.

A significant part of the nine-month ethnographic fieldwork took place within the Oncology Centre of Hue Central Hospital where the first author observed patients and medical staff at the Consulting, Diagnostic, and In-patient divisions. Hue Central Hospital is the largest public hospital serving the Central region and one of Vietnam's three largest general hospitals. The ethnography includes observation of participants on their routine care appointments at the hospital and in daily activities in non-medical settings, for example when they went grocery shopping or met with their relatives and neighbours. We also connected with the Hue branch of a breast cancer peer support network that operates across more than 50 provinces in Vietnam. We obtained rich information through attending their monthly gatherings and activities and observing the network's public Facebook page, which continued beyond 2019 after the fieldwork had finished. By the time of writing, this Facebook page attracted over 20,000 members who can post questions and receive responses from the administrators and peers. Members of this page can choose to be anonymous when interacting with others on this public page.

Via hospital encounters and the peer support network, we recruited 33 women patients (mean age: 46 years; age range: 26–62) for in-depth interviews using snowball and convenience sampling (see Table 1 summarising the background characteristics of these 33 patients). These interviews were flexible and guided by opened-ended questions, inquiring women patients about their cancer history, treatment experiences, and life changes since the diagnosis of breast cancer. All interviews were conducted in Vietnamese by the first author who is a native speaker. At the first appointment, we provided potential informants with the information about the research, sought their consent, and gathered their demographic background, illness history, and contact details. An interview then followed if the informant's time allowed or was scheduled in their next hospital visit or at their home. Patients were interviewed once or multiple times, and each interview lasted from 45 to 120 min. We also conducted follow-up interviews over the course of two to five visits with 16 patients to validate the information obtained in the first interview and explore new issues emerging from other informants' interviews. In multiple occasions, those interviews were joined by family members who accompanied patients during their hospital appointments or when interviews took place at the participant's home.

Table 1
Characteristics of patient informants ($n = 33$).

	Number of participants
Age	
Below 30	2
30-39	7
40-49	12
50-59	7
60 and above	5
Education	
Primary school and lower	12
Lower secondary	7
Upper secondary	3
Vocational training	1
College/University or higher	10
Marital status	
Single (never married)	5
Married	24
Divorced/Separate/Widowed	4
Living area	
Rural	19
Urban	14
Cancer stage (when first diagnosed)	
I	7
II	15
III	3
IV	1
Unknown	7
Primary treatment (Numbers do not add up to 33, as categories are not exclusive)	
Mastectomy	30
Breast reconstruction or breast conserving surgery	5
Chemotherapy	23
Radiation	14

2.1. Data analysis

Most interviews were digitally recorded. When informants indicated their preference for not using a recorder, the first author wrote down extensive notes during and right after the interview. Recorded interviews were transcribed verbatim in Vietnamese by either the first author or an external transcriber with accuracy checks conducted by the first author.

A grounded theory approach (Charmaz, 2014) guided the analysis of this study to build a nuanced understanding of the qualitative materials and generate new insights for theory and practice. We began analysing data simultaneously during the data collection phase to identify patterns and themes that we needed to further validate. Data collection continued until theoretical saturation (Charmaz, 2006) was reached, that was when no further significant insights were discovered.

Throughout the fieldwork, the first author wrote a memo to describe their first impression with the data and noted recurrent and emergent themes and concepts. This memo, along with three transcripts, were translated into English during the fieldwork and discussed with the co-authors to expand the data collection. The first author initially applied open coding on a subset of interviews with ten patients, which were selected to ensure variability in patient's age, living region (rural and urban), and cancer stage. Emergent codes (e.g 'disclosing' or 'researching' suggesting patient actions) derived from the open-coding stage were refined through constant comparison within and between transcripts, and later organised into broader codes (e.g., 'applying for social welfare'). These broader codes with selected samples of quotes were again translated into English for the whole team to develop a consistent code structure and agreed on a codebook. Upon the codebook's completion, the first author conducted focused coding (Charmaz, 2006) on the entire dataset while remaining open to unexpected insights that emerged from this stage by moving across transcripts and comparing data to data, and data to identified codes. Categories were then developed out of the focused codes and the relationships between them were eventually identified. The review of 'patient work' literature and theories was deferred until data analysis had completed.

For this paper, we begin a case study of Hồng to exemplify the long periods of time that breast cancer care involved and the financial burden patients incurred during and beyond hospital-based treatment. Following the presentation of this case study, we illustrate the consistencies of Hồng's experience with the perspectives from other patients to show how the women are socialised into their cancer patienthood after breast cancer diagnosis, thereby demonstrating how the 'work' required to finance breast cancer treatment is produced and intensified by the operation of the social structures of cancer care.

3. Findings

The case of Hồng

Hồng is a 51-year-old woman from a rural district of Ha Tinh province, which is more than a 6-h train or bus ride from our fieldwork site. When she was diagnosed with breast cancer at Hue Central Hospital in late 2018, Hồng immediately went back to her hometown to sort out an administrative application for her insurance policy (which she had previously purchased for the whole family via the state's voluntary contribution scheme) so that she would be eligible for a full coverage when receiving treatment in Hue. At the first attempt, her application was rejected at a provincial agency in charge of health insurance, as they insisted that Hồng should be treated at a local oncology ward. Having mistrust with the expertise at the provincial hospital, Hồng refused to take their recommendation. But without a referral, she would not be able to receive any treatment at Hue Central Hospital - her preferred point of care because she could not afford to pay 70% of medical costs out-of-pocket as a bypassing patient. Feeling desperate, she returned to the insurance office, paid a bribe of 4,000,000 VND (~US$175.44) and her application was accepted.

Simultaneously, Hồng's husband contacted the village head and commune authorities to inquire about applying for official poor household status to receive a monthly cash transfer from the government. However, their request was rejected. As her hometown was recently awarded with the title "New Rural Commune" – awarded by the government to communes in recognition of their success in improving the local infrastructure and standards of living, they instead directed her to apply for the state allowance as a person with a disability. Her disability allowance application was approved and with that Hồng was granted a government-funded insurance with a 100% coverage. Even with the 100% insurance coverage she was entitled to, she was held liable for paying various expenses during each hospital visit:

> Going to hospital is really costly … Every time I need someone to go with me, so the transportation costs alone are 1,000,000 VND (~US $43.86) … With the insurance, they place a cap on hospitalisation of 20,000,000 VND (~US$877.19), which meant that if I am required to stay longer, I must pay out-of-pocket. And for each stay, sometimes the doctors prescribed me some medication that was not available here [at the hospital's pharmacy], and I had to purchase them from the private pharmacies [out-of-pocket].

3.1. Immediate coping measures: negotiating the continuity of care and borrowing money from "any possible sources"

In every conversation during our ethnography, Hồng frantically spoke about the possibility of opting out of radiotherapy because she could not envisage a viable source of finance for another five-week stay at the hospital for herself and the caregivers. While complete opt-out of biomedical treatment was not a practice reported among the informants, which was largely due to our hospital-based recruitment method, we met many women who had decided to discontinue after undergoing some forms of treatment. This was particularly so when a patient's treatment regimen involved targeted treatment which came with tremendous cost and low reimbursement. Only few patients enrolled in targeted treatment but even in such cases, many could not complete the recommended regimen. For example, 55-year-old Bông from Hue City had requested that her oncologist halve the prescribed dosage from 12 to 6 months, as the whole course of treatment was beyond her ability to pay.

In the final appointment with Hồng, she told us because her oncologist recommended that she should have oral hormone therapy for the next five years, she came up with what Dao (2023) describes as 'a calculative practice' to navigate regular hospital visits by weighing up different care routes to select the more economical option. Hồng decided to buy her medications (anastrozole) from a local pharmacy at her own expense without visiting the Central Hospital to get the insured dose, "because the train tickets cost me more." She planned to go back for her quarterly follow-up appointments only if she could borrow the money from her relatives. These coping measures were similarly adopted by other women interviewed in our study who were diagnosed with positive hormone receptor status – which is found in approximately 80% of breast cancer patients (Giaquinto et al., 2022). Due to existing drug dispensing policies, insured patients like Hồng were only entitled to receive a thirty-day dose of their medications in each hospital visit. Some medications for advanced-stage breast cancer, such as Aromasin (chemical name: exemestane), and Afinitor (chemical name: everolimus)[1] for postmenopausal women could only be dispensed on a ten-day dose, and hence patients needed three visits to the hospital every month to fully adhere to their prescription. Considering the substantial costs, when patients could not travel to obtain them from the hospital, in

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[1] Afinitor is prescribed to be taken once a day and each tablet costs 1,400,000 VND (~US$61.40).

most cases, they would miss a recommended dose completely. In Hồng's case, she adopted individualised responsibility to maintain her treatment compliance rather than depend on the health system to provide the insured medications, and simultaneously controlled the financial risks associated with a long trip to the hospital. Her story exemplifies how fate is turned into problem of the self-management of calculable risks (Beck, 2002; Beck et al., 1992). Hồng took her own actions to reduce the uncertainty of her illness when she was inadequately insured, but also her self-management practices became invisible to the welfare system.

Hồng confided in us that to pay for medical and non-medical expenses such as transportation and meals she had to seek loans from "any possible sources," as her family's savings had depleted. These included zero-interest loans from her siblings and relatives and a credit from a local post office at an interest rate of 15% per annum. Simultaneously, Hồng took another loan worth 50,000,000 VND (~US$2193) from a commercial bank using her family's land use right certificate as collateral. This, however, meant that her family would not be able to borrow more money from any formal financial institutions if they wanted to expand their farming activities or in case of other shocks. Borrowing money as a coping measure was especially common among patients from limited-income households who had already spent a significant proportion of their resources on financing burdensome treatment costs. While participants mentioned relying on their social network for help with managing medical and day-to-day expenses during treatment, it usually did not suffice given that those people were likely to have similar levels of wealth to that of the patients. Therefore, cancer patients' families resorted to loans from credit institutions or the underground market. For instance, 46-year-old Xuân, a street vendor and single mother from Khanh Hoa, sought an underground loan which charged her a usurious interest rate of 10%/month to pay for diagnostic tests, surgical costs, and inpatient stays because she had no insurance by the time of her diagnosis. Xuân however could not afford chemotherapy and radiotherapy and left after the mastectomy was finished.

3.2. *Seeking formal support*

3.2.1. *Cancer disclosure as a strategy*

Disclosing one's cancer status was a common practice among the informants who expressed no hesitation in speaking about their illness with people in their kinship group and the community. Specifically, participants mentioned the importance of assistance from people beyond their immediate family after their illness status was revealed. For instance, 56-year-old Trà, a farmer from Quang Tri, mentioned about the support, including in-kind (such as food and clothes) and cash from people in her village: "A neighbour in my village, he lent me that money. Many others living nearby heard my story, and they came to gift me 50,000 VND (~US$2.20) or 100,000 VND (~US$4.39)."

Trà described the tactic of making her cancer status known to people in the community, similarly to other women we met during our fieldwork. Having no insurance by the time of receiving a breast cancer diagnosis in 2012 because she could not afford to enrol her family in the voluntary insurance scheme, her family took out a personal loan using their house as collateral to finance her treatment. She explained how the annual interest rate was partially repaid:

> I did not try to hide my illness from others in the neighbourhood, because when I told them I had cancer, they came to visit me. They also helped give me some money. I could use the money to pay back the interest rate.

Cancer patients also chose to disclose their health condition on social media, such as Facebook, to mobilise support from the wider peer network. This was usually observed during the periods when they could not travel to metropolitan hospitals to obtain the insured medications due to financial constraints, travel restrictions during the COVID-19 pandemic, occurrence of extreme weather events, or medication stockouts at the hospital they registered with their insurance. Reports of medication stockouts were rampant during the 2022–2023 period following allegations and arrest of ministerial and public hospital leaders due to procurement wrongdoings (Le, 2022). In those circumstances, the Facebook page of the peer network became a place for patients to post photos of their histopathology reports and scripts and ask for donation or repurchase of spare pills from their fellow patients. In other cases, patients asked for peer recommendations for a local pharmacy with available stocks of the medications they were searching for and their prices. Based on the comments they received, patients could re-organise their upcoming hospital appointments or shop around for a place to purchase cheaper medications.

More importantly, disclosure carried further benefits for patients because it could influence the process of applying for state welfare for a poor household or disability support. This official recognition may provide them with longer-term entitlements, most notably, a concessional insurance card and monthly cash transfer. According to existing regulations on poverty administration, a household might apply for social welfare themselves by submitting an application form to the local authorities. This process will be accelerated when a household is nominated by other villagers, especially the village head who has a determining role in identifying potential beneficiaries and assists with the application process (Groce et al., 2017). As Trà explained: "Other villagers also cared about me because in my family, the mom was sick, the son was also sick. They nominated me to get the poor household status."

Disclosing one's cancer status only comprised the first step in the laborious process of navigating through the social security system in Vietnam. In the following section we describe other types of interpersonal, cultural 'work' involved to establish and negotiate identities and access to material support.

3.2.2. *Navigating the politics of social welfare*

To mitigate the impacts of inadequate insurance coverage and manage the tremendous expenditure demanded in cancer treatment, seeking a source of longer-term support from the government was a kind of 'work' that patients and families actively engaged in. The amount of work to make oneself eligible for some form of allowance from the government was often intensive and strenuous. Our interviews revealed that women carefully researched social security schemes applicable to breast cancer patients. For example, 36-year-old Hôm, an active member of the peer network, proudly considered herself as a key informant about social protection regulations and entitlements. She often shared her application experience with fellow patients by writing Facebook posts. Following her diagnosis of stage IIB breast cancer and treatment of a metastasis, Hôm spent months seeking information about the social benefits for people with a disability from her village leader, the local authorities, her peers, and the Internet. She vividly recollected the process which had happened more than three years prior to our interview:

> I brought my medical record and identification card to the social policy department. There was a young female officer there who reviewed my profile. She then asked me to fill in a form and to write a declaration letter. I then needed to get the village head and the commune secretary of the Communist Party to sign on that letter.

In contrast with Hôm's successful application, our interviewees illustrated the uncertainty inherent to the process of certifying social protection beneficiaries among patients residing in other jurisdictions despite their prolonged, laborious efforts. By the time of her diagnosis, Lan (56 years old, Quang Binh province) was not covered by any health insurance because of her casual job at a timber-processing plantation. Knowing a villager who also had breast cancer and had received the disability allowance, she prepared and submitted her application through the commune's Office of Social Policies. However, her application was only approved with a health insurance card for a near-poor household with 95% coverage without any cash transfer: "My family was already very poor. But later they told me I was not qualified because

I could still walk on my own and they thought I was able to continue earning money."

Lan's remarks bring to attention the issues of including a chronic disease like cancer as a criterion for recognising people with disabilities who are eligible for social protection allowance. Many patients living with breast cancer or other types of cancer may not show visible impairment even though their illness might be terminal and significantly affect their daily functioning and income-generating capacity. Therefore, it may be challenging for village and commune officials to screen for eligible applicants who are chronically ill.

To mitigate the uncertainty associated with social welfare verification, some patients resorted to paying a bribe to a government official in the hope that it could accelerate the approval process and increase their chance of success. For instance, a former childcare educator Hay from Quang Tri province had already enrolled in the compulsory insurance scheme by the time of her primary diagnosis. With this, she was covered for 80% of her treatment costs. However, when she met fellow patients at the hospital, she was told that "paying only 20% of the remaining costs was already a burden." Hay attempted to seek a "poor household" certificate by paying a bribe to a commune officer and village head. When it was successful, Hay was granted a concessional insurance card with 100% coverage with a monthly cash transfer.

Paying a bribe was a common practice when patients needed to obtain the approval letter to register their insurance at a national-tier hospital with more advanced oncology services. Like Hay, Minh had already had an insurance card as she was working as a civil servant by the time of her diagnosis. However, she still had to pay for roughly 70% of the surgical costs and all other hospitalisation expenses as a bypassing patient because the insurance transfer had not yet been cleared at the time of her mastectomy. Just before chemotherapy, she paid a bribe to a contact at the province's office dealing with health insurance in order to facilitate the procedure of having the transfer approval which allowed her to receive full insurance entitlements at the hospital of her choice. The cases of Minh and Hay exemplify how patients have become very "active" navigating state bureaucracies around health insurance and poverty administration throughout the process of seeking cancer treatment.

3.3. *Beyond survivorship: altering life trajectories*

Due to its chronicity and time commitment, pursuing breast cancer treatment causes remarkable disruptions to patients' employment and earning capacity, which appeared more pronounced for older women. Because of their age and the acuteness of their health condition that left them with limited ability to seek new opportunities, the financial consequences on those women were often more difficult to manage. 47-year-old Hay, for example, a former childcare educator whose husband suddenly passed away due to a stroke at the time of her mastectomy, had to shift to a factory job:

> My working time [at the childcare] was not flexible. Now that I still have follow-up care, for some appointments I must take leave for 2 or 3 days. I decided then that I would quit because I did not want to affect my school … But because I retired earlier, my pension was reduced a lot … I've been working in a new job in a factory, assembling bottles and cleaning … With that I have more money to raise my younger son who is now at high school.

Meanwhile, for other patients who were self-employed in the agricultural sector (like the case of Hồng) or working under a casual contract with little or no income protection, pursuing time-extensive treatment equated to a complete loss of income. These impacts continued beyond the completion of hospital-based treatment. As previous accounts illustrate, many patients were left with little choice but to become indebted while they themselves had lost the capacity to resume the same level of income they had earned in the pre-cancer period. These compounding burdens forced them into precarity, including, for instance, having their children migrate to metropolitan cities in search of alternative, higher sources of income. This strategy was particularly a solution among families residing in rural regions. In Xuân's case, for instance, a single mother to three children aged under 20, her eldest son Bảo permanently migrated to Ho Chi Minh City, 500 km from their hometown, after her cancer diagnosis. The income from her street food stall and her son's then casual job could not be sustained after she underwent a mastectomy and a lengthy inpatient stay for which she was not insured. Bảo relocated to obtain work for a paint-manufacturing business in Ho Chi Minh City and sent home a monthly remittance to help Xuân pay for her debt and support his younger sibling's education. He also obtained a two-year loan from his employer to cover their debt and pay for expenses related to Xuân's follow-up care.

As affected families made hard calculations as to whose needs should be prioritised and whose would be forfeited, in many circumstances they had to choose between the pressing health need of a member diagnosed with cancer and the educational opportunities of their young children. For example, for Ninh, a 51-year-old woman from Quang Binh province, the diagnosis of breast cancer shattered her son's educational prospects, as he faced the financial pressure from his mother's expensive treatment:

> My son only finished high school. At that time I fell sick [with breast cancer], so he did not go to university. He just went for a shorter vocational training so that he could go on to earn money soon … My life has already been tough. If I had had more money back then, I would have sent him to college. But I did not. I feel so much pity for him.

For affected young women, dropping out of school is likely to lead them to marriage at a young age given the job scarcity in rural areas and their limited capacity to migrate to urban cities in search of employment. For instance, for a year Khanh had to be accompanied by her then 17-year-old daughter to radiotherapy treatment in Danang City, a 3-h journey by bus from her hometown in Thua Thien Hue. This was during the period when her daughter was preparing for university entrance exams. Khanh's advanced cancer diagnosis prompted her daughter to abandon her university dream to remove the burden of paying for university tuition fees and instead took on a casual job. Not long after that, the daughter got married:

> When she was working at the clothes store, she met a man 5 years her senior who was a timber trader … Then she came back home one day and told me she wanted to marry him. She was only 19 years old then … So my two younger brothers called for a big family meeting on my behalf to discuss her marriage. In the end everyone agreed that she should [get married] because they were all afraid that I would die soon.

The early marriage of Khanh's daughter was considered by her whole family to be a decision that fulfilled the daughter's filial duties in light of the parent's uncertain cancer prognosis. In Vietnam, marriage has value as not only an individual's achievement, but also their family's symbolic capital (Nguyen and Hoang, 2019). Such a decision was also a strategy of securing the daughter's future and easing the financial burden for her family when the breadwinner fell seriously ill. Although the marrying decision may reduce the immediate risks to their life, it foreclosed future opportunities of higher education and job security for Khanh's daughter.

4. Discussion

Our study has offered empirical evidence for burdensome and arduous cancer care 'work' of patients and their families within a context of under-funded public healthcare and precarious formal support to sufferers of cancer. Patients' accounts emphasise the vital importance of UHC that ensures a patient's access to some form of biomedical treatment for breast cancer. In its absence, a patient is more likely to drop out or only complete part of the recommended regimen.

However, in most instances, being covered by health insurance does not entitle patients to a full reimbursement of costs. As our ethnography suggests, pursuing treatment for breast cancer involves enormous out-of-pocket costs even for insured patients. Existing literature has similarly noted the consequences of managing ill-health in Vietnam, suggesting tremendous out-of-pocket expenses associated with hospital-based treatment and the limited protective role of health insurance against the detrimental impacts of high health expenditures (Hoang et al., 2017; Nguyen, 2012). In the context of cancer, financial catastrophe is estimated to hit 64% of cancer patients in Vietnam within one year of their primary diagnosis (Bhoo-Pathy et al., 2017). In lieu of proper insurance coverage and rampant stock-outs of insured drugs, incurring debts has become a primary strategy among informants in our study to cope with spikes in medical spending.

While borrowing may serve to meet the urgent health needs of the debtors, those maladaptive coping measures may lead borrowing households to persistent indebtedness, exposing them to the risk of exploitation and leave long-tern consequences for household welfare (Mitra et al., 2016; Wagstaff and Lindelow, 2010). Being burdened with debts increases the risk of impoverishment because managing acute and chronic diseases involves persistent spending associated with repeated hospitalisations and prolonged use of medications, which possibly demands additional debts over the course of treatment while the initial ones remain unsettled. Indebtedness is also related to households' vulnerability to poverty due to cancer patients' temporary or permanent loss of earning capacity as a consequence of lengthy treatment schedules or debilitating treatment side effects.

Considering risk-mitigation strategies, some women found the need to disclose their ill health to people in their social network to make themselves qualified for some types of assistance. This finding contrasts with previous studies in other settings where cancer patients are prompted to conceal their cancer status as a means of coping due to the widespread stigma towards cancer patients and their families (Banerjee, 2020; Mulemi, 2010). Patients in our research context had few options but revealed their cancer status to open the possibilities for mobilising social capital from their informal network, which is vital for households to recover from adverse life events (Nguyen-Trung et al., 2020). Disclosing one's cancer status to relatives and people in their community can be seen in this case as an act with an element of intentionality and deliberation, as it asks something of those who receive the information (Davis and Manderson, 2014). In choosing to disclose their illness and forgo any possibility of medical confidentiality, patients may incur some risks, for instance, social and cultural stigmatisation. Social stigma associated with breast cancer was infrequently noted throughout our ethnography, which was largely due to a common belief that cancer was caused by structural forces, including the inequalities resulting from a new rapacious market economy, poverty, or the long-lasting consequences of war, rather than individual behaviours (Do and Whittaker, 2020). However, research conducted elsewhere in Vietnam has observed that stigma is a notable challenge facing women when seeking oncology services (Jenkins et al., 2020), resonating with other countries' settings where social stigma strongly impacts how women with breast cancer are treated by their families and the wider community (Bosire et al., 2020). For the women in our study, the financial benefits outweighed the associated costs and potential risks: people in the communities who learned about cancer were obliged to offer help to disadvantaged families due to the social norms of Vietnamese kin and sociality. Speaking with others about cancer also constituted a strategy for patients to deal with the intricacies of the disability and poverty administration systems when needy individuals are required to present and prove their deservingness in order to obtain state entitlements (Lincoln, 2023).

The stories documented in our study suggest that cancer care is largely about managing the health and social security systems. When their life was struck by cancer, women proactively researched available information about state welfare and undertook extensive work to prove their deservingness. This type of 'work' sometimes required the use of tactics such as paying a bribe to accelerate the application process and can be understood as a form of everyday resistance. They are ways for women to object to the marketisation of the health sector along with the state's abolishment of a socialist planned economy that has led to increasing health inequities (London, 2013). However, we do not argue that political consciousness underpins their practices; rather, they should be seen as pragmatic actions for economic survival to resume control over a precarious life and mitigate the exorbitant costs that cancer patients cannot afford. For those in our study, being officially poor or recognised as a person with a severe disability has become a statuary resource for families in the advent of serious illnesses, resonating with the accounts illustrated in Lincoln's ethnographic study of urban poverty in Vietnam (2023). When these strategies were successful, however, they could only obviate a modest fraction of their cancer care problems. While social protection for cancer patients exists, the access depends on numerous factors beyond the control of individuals even when they experience economic deprivations or possess an eligible form of disability. A key factor is the incentive to report reduced poverty to authorities where poverty alleviation is capped within the local budgetary limits or at the direction of higher-level government officials (Chaudhry, 2016).

The 'work' demanded to finance breast cancer treatment is more intensive for families who have already been resource poor prior to cancer diagnosis, reside in remote rural areas where oncology services are limited, or are single woman-headed households. To bear the tremendous costs and/or repay their outstanding debts involves their loved ones, including school-aged children, to engage in income-generating activities. This often comes with the cost of the children's education and has deleterious effects on the welfare of the individuals and their household over the long run. Being deprived of opportunities to pursue higher education limits pathways out of poverty through a high-status job in a society like Vietnam that has a long history of valorising university degrees (Tran, 2014). The burden brought about by cancer care, in such ways, further aggravates the already vulnerable situations of those families, throwing them into a cycle of indebtedness and poverty.

The circumstances of patients in the present study bring to attention what Manderson and Warren (2016) describe as "recursive cascades" in their study of patients living with co-occurrent chronic conditions, such as high blood cholesterol levels, breast cancer, arthritis, obesity, and disabilities in Australia. They introduce the idea of "cascade" to capture the interrelationship between chronic ill health and social conditions such as social exclusion and poverty even within a high-come setting with universal health care. Our study has shown how the responses to an acute, chronic condition produce a cancer/poverty recursive cascade: for people affected by cancer, the priority on cancer treatment has been made to the detriment of their families' future income and welfare. Understanding this recursivity is important to acknowledge the burden of living with cancer beyond individual patients to consider the inter-generational impacts, as well as the economically harmful ramifications for the wider community and the society at large, given the vast changes in Vietnam's epidemiological transition to NCDs. If not tackled urgently and appropriately, the economic burden caused by cancers would impose unprecedented pressure on the social welfare system and inevitably affect the country's remarkable but fragile progress recently achieved in economic growth and poverty reduction. It is imperative that stronger measures to control cancer are implemented to reform the public insurance scheme and roll out a national breast cancer screening program to allow early diagnosis and hence reduce the high costs associated with treating advanced-stage cancers.

5. Conclusion

This study sheds light on the various forms of labour that patients and their families engage in to self-manage the financial risks and burden of breast cancer. Much of their 'work' remains invisible to the health and social welfare systems in a context similar to many LMICs where health-related risk protection is poorly organised and out-of-pocket expenses are burdensome. Our study expands the 'patient work' concept by showing its relevance in attending to households' re-prioritisation of resources, strategic interaction with their social network, and calculative dealing with the social security system to cope with the tremendous costs of breast cancer treatment. We offer theoretical understanding of how these types of 'work' can reinforce one's vulnerability to a vicious cycle of illness and poverty, and intensify socio-economic inequalities among the community and the larger society in the long term. This knowledge is important to inform health and social policies that seek to support the most vulnerable populations and address the growing burden of cancer that is threatening LMICs' progress towards achieving Sustainable Development Goal 3 (Good Health and Well-being) and Goal 10 (Reduced Inequalities).

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CRediT authorship contribution statement

Trang T. Do: Writing – review & editing, Writing – original draft, Validation, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Andrea Whittaker:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Formal analysis, Data curation, Conceptualization. **Mark DM. Davis:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Conceptualization.

Data availability

The data that has been used is confidential.

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