

# BMJ Open Impact of out-of-pocket expenses for surgical care on households in rural Haiti: a mixed-methods study

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## ABSTRACT

**Objectives** This study aimed to report household catastrophic spending on surgery and the experiences of patients and families seeking surgical care in rural Haiti. **Design** The study used an explanatory, sequential mixed-methods approach. We collected both quantitative and qualitative data from the participants through interviews. **Setting** A rural tertiary hospital (St. Boniface Hospital) in southern Haiti. **Participants** There were 200 adult Haitian surgical patients who entered the study. Of these, 41 were excluded due to missing variables or health expenditure outliers. The final sample included 159 participants. **Primary and secondary outcome measures** The primary outcomes were (1) direct and indirect payments for surgical care; (2) the rate of catastrophic health expenditure (CHE) (as defined by the Sustainable Development Goals (10% of total household expenditure) and WHO (10%, 20%, 30% and 40% of household capacity to pay)) due to surgical care; and (3) common themes across the lived experiences of households of surgical patients seeking care.

**Results** The median household expenditure on surgery-related expenses was US\$385.6, slightly more than half of per capita gross domestic product in Haiti (US\$729.3). Up to 86% of households experienced CHE, as defined by the Sustainable Development Goals, due to receiving surgical care. Patients commonly paid for surgical costs through loans and donations (69.8%). The qualitative analysis revealed prominent themes related to barriers to care including the burden of initiating care-seeking, care-seeking journeys and social suffering.

**Conclusions** CHE is common for Haitian surgical patients, and the associated care-seeking experiences are often arduous. These findings suggest that low, flat fees in non-profit hospital settings may not be sufficient to mitigate the costs of surgical care or the resulting challenges that patients experience.

## INTRODUCTION

Haiti has seen significant improvements over the past three decades in key health indicators like under-5 mortality<sup>1</sup> and maternal mortality,<sup>2</sup> but its health system remains limited in its ability to provide accessible, high-quality healthcare.<sup>3,4</sup> To improve healthcare delivery and outcomes, the government

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The use of a sensitivity analysis and both the WHO and Sustainable Development Goal definitions for catastrophic health expenditure allows for a comprehensive evaluation of surgery-related costs.
- ⇒ The use of a convenience sample and prioritisation of patients from the lowest economic stratum limit generalisability.
- ⇒ Healthcare costs were recorded for a 1-month period prior to surgery, and it is possible that not all healthcare visits in this month were related to surgical care.
- ⇒ Some patients may have incurred surgery-related costs over a period greater than 1 month.
- ⇒ Lost earnings could be underestimated because average household expenditure was used as a proxy for lost earnings.

of Haiti adopted universal health coverage (UHC) as a primary policy objective.<sup>3,5</sup> UHC is meant to ensure that all people can access the full spectrum of health services that they need.<sup>6</sup> As it incorporates the tenant that individuals should not suffer financial hardship when seeking healthcare, financial risk protection must be integrated in health systems to achieve UHC.<sup>6</sup>

Surgical care is an essential component of UHC,<sup>7,8</sup> and it is needed to address the estimated 28%–32% of the overall global burden of disease.<sup>9</sup> The costs of accessing surgery are substantial in countries and regions which have limited surgical capacity, like Haiti.<sup>10</sup> Compared with the target set by the 2015 Lancet Commission on Global Surgery,<sup>11</sup> Haiti has been shown to have an insufficient volume of surgical providers for its population of over 11 million.<sup>12</sup> It is estimated that, in 2015, there were only six surgical, anaesthetic or obstetric providers per 100 000 people, which is far short of the recommended 20 per 100 000 people.<sup>13</sup> The geographical distribution of providers presents a further challenge to accessing care as healthcare providers are



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concentrated in urban areas, while approximately half of the population lives in rural areas.<sup>14</sup> The financial costs to overcome barriers to healthcare are an important consideration, given that Haiti's gross domestic product (GDP) per capita was US\$1176.76 in 2019, the 192nd-ranked GDP per capita in the world.<sup>15</sup> This provides context as to why Haiti's limited financial risk protection mechanisms have led to significant financial vulnerability to healthcare costs, a vulnerability that disproportionately affects poor Haitians.<sup>3</sup>

There is a growing understanding of the cost burden that patients experience when accessing surgical care in low-income and middle-income countries. This has been enriched by analyses of catastrophic health expenditure (CHE), an indicator for financial risk protection that quantifies financial hardship due to payments for healthcare.<sup>16</sup> CHE has been defined as 'health expenditures exceeding a share of either total expenditure, non-food expenditure, or expenditure net of basic food needs'.<sup>16</sup> CHE can be calculated using thresholds that traditionally range between 10% and 40% of the chosen denominator.<sup>17</sup>

Despite the role of financial risk protection in achieving UHC, the CHE literature pertinent to Haiti has relied on modelled estimates, and there have been no studies analysing primary data on direct and indirect payments for surgical care in Haiti. Furthermore, there is little understanding of how these costs shape patients' care-seeking journeys and inform the lived experiences of their households. To answer these questions, we conducted an exploratory, mixed-methods study to (1) report direct and indirect payments for surgical care and estimate the percentage of households that incur CHE; (2) describe patient care-seeking journeys to access surgical care, including a narrative depiction and cost analysis of care-seeking efforts; and (3) describe the effects of payments for surgical care on patients and their families.

## METHODS

### Study setting

This study is set at St. Boniface Hospital (SBH) on Haiti's southern peninsula. An estimated 58.5% of Haitians live under the poverty line, and this is reflected in the socio-economic characteristics of the southern peninsula. It is notable that prior to this study in 2016, southern Haiti was struck by category 4 Hurricane Matthew, which greatly affected infrastructure and agriculture, with 1.4 million people requiring immediate humanitarian assistance.<sup>1</sup>

SBH is a 130-bed facility with three operating rooms and two full-time surgeons, which is the largest full-service hospital on Haiti's southern peninsula. SBH performs approximately 3000 surgeries per year for a catchment area that spans four administrative departments (Sud, Sud-Est, Nippes and Grand'Anse) and over two million people.<sup>18</sup> Approximately 60% of SBH patients are from the southern peninsula, of which 40% are from the same administrative department as SBH (Sud). In accordance

with their mission to provide high-quality, accessible care to the poorest residents of southern Haiti, SBH seeks to avoid levying burdensome fees on its patients by charging a flat rate of US\$2.34 for all healthcare services, including surgery, and waiving fees for those unable to pay.

### Study design

This study used an explanatory sequential mixed-methods study design which included the collection and analysis of both quantitative and a qualitative data. Results from the quantitative component permitted estimation of direct and indirect payments related to surgical care and calculation of CHE rates. The qualitative component provided enriching contextual details about care-seeking journeys and the impact of payments on the lived experiences of patients and their households.

### Study procedures

#### Quantitative component

A 30 min survey was privately administered to all consenting adults (18 years and older) who came to the hospital for surgical care between 15 July 2017 and 30 August 2017. This survey was delivered on the day of discharge, and it collected information on sociodemographic characteristics and patient expenditures associated with accessing surgical care at SBH. These expenditures were collected for a 1-month period prior to the discharge day. A 1-month period of spending can be used to estimate earnings in a population without a stable monthly income,<sup>19</sup> and patients usually need to visit the hospital before the surgery to obtain the related consultations, physical check-ups and registration. Most of these visits can be done within a month. A question was also included to collect information on household food expenditure in the month prior to the interview. Clinical data about patient diagnosis and surgical procedure were obtained from patient charts. Patients were excluded from the quantitative analysis if (1) demographic or socioeconomic variables were missing or (2) their reported payments were improbable based on their reported profession.

#### Qualitative component

The sampling frame was established after initial analysis of survey and clinical data. It was limited to patients who underwent one of the five most frequent surgical procedures during the study period. Furthermore, patients with the lowest household expenditures were prioritised in recruitment to better understand how the poorest households experienced the costs of seeking surgical care. Patients who could not be reached after five to seven phone call attempts were excluded from the qualitative component of the study.

Dr Michelson Padovany, then Chief of Surgery at SBH, led the design of the interview guide and conducted all participant interviews. These 1-hour semistructured interviews were done in Haitian Creole and were held in private rooms at each participant's home or other convenient

location identified by the participant (see online supplemental appendix 1 for the interview guide). Each interview was audio recorded. The interviews were designed to explore patient care-seeking journeys, including experiences prior to presentation at SBH. The investigator inquired about modes of transportation throughout the care-seeking journey and sought to understand how direct and indirect expenditures impacted patient households.

## Analysis

### Quantitative

#### *Costs of medical services related to surgical care*

Surgical care imposes both direct and indirect costs on patients and their households. Direct payments were defined according to the WHO: 'direct payments made by individuals to health care providers at the time of service use'.<sup>20</sup> Thus, direct payments refer to costs incurred for in-hospital or out-of-hospital medical care associated with the participant's surgical condition in the month prior to the interview, including registration fees, laboratory tests, medications, surgical procedures, traditional healer fees and any other medical fee. For some conditions such as uterine fibroids, symptoms might occur long before the interview, and it would be difficult for patients to recall the exact time of onset and the related medical spending. To mitigate this recall bias, we followed the established practices of the WHO and World Bank by collecting costs for a 1-month period.<sup>21 22</sup> However, it is important to note that this limited period might not fully encompass the costs associated with a surgical condition and could lead to underestimation of CHE.

Indirect payments include costs incurred for transportation, food and housing, as well as lost earnings due to work absenteeism for patients and *accompagneurs* (caregivers, including friends or family members). The proxy for lost wages was based on self-reported household daily expenditure, family size and number of days in the hospital for both patients and *accompagneurs*. Household daily expenditure was multiplied by 30 (30 days a month) to obtain household monthly expenditure. In many low-income and middle-income countries, especially in rural areas, household expenditure is a good estimate for household effective income.<sup>17 19 23 24</sup> Lost wages were defined as the product of patient or *accompagneur* days spent at the hospital and the household daily per capita expenditure.

Direct and indirect costs were each summed to arrive at total direct and indirect payments which were then used in the CHE calculation. All costs were converted using the 2017 exchange rate (US\$1.00 to Haitian gourdes of 64.00).<sup>25</sup>

#### *Households with CHE*

There are several definitions for household CHE, but the two most commonly used are based on (1) a household's 'capacity to pay'<sup>17</sup> and (2) 'total consumption'.<sup>24 26</sup> The WHO has established the capacity to pay definition of catastrophic expenditure as 40% or more

of a household's 'effective income remaining after basic subsistence needs have been met'.<sup>19 23</sup> Subsistence needs in this case are defined as the average annual food expenditure of households whose food share is in the 45th–55th percentile of the total sample.<sup>27</sup> Meanwhile, Sustainable Development Goal (SDG) 3.8.2 uses thresholds of 10% and 25% of the total consumption, which is defined as total household expenditure. Wagstaff *et al* highlight that the 10% threshold is more relevant for the poor, considering their limited capacity to pay more and still afford necessities.<sup>28</sup>

Each approach has potential drawbacks. The WHO definition is subject to potential limitations as it relies on food expenditure as proxy of 'subsistence needs', while the proportion of food expenditure for households varies between income levels and geographical regions.<sup>29</sup> Meanwhile, the 10% threshold used by Wagstaff *et al* and the SDGs risks underestimating CHE for poor households.<sup>30 31</sup> To account for these nuances and verify the robustness of our findings, this analysis was conducted using both the WHO and SDG definitions, and then more conservative analyses were performed by adjusting the WHO threshold to 30%, 20% and 10%.

We summarised payments for surgical care and calculated rates of CHE from direct payments, indirect payments or both. In addition, we stratified the percentage of households with CHE by occupation, age, education level and health insurance status. Education level was classified as 'none or primary' and 'secondary or college'. Stata V.14.1 was used for the analysis.

### Qualitative

Interviews were conducted between 2 and 4 months after surgery to better assess the effects of surgery-related expenditure on patients and their families. After transcription and translation, a sample of the interview data was manually coded. Dedoose V.8 was used to code the remaining interviews. Key ideas and themes were identified with an inductive approach.

Grounded theory was used to identify patterns that informed hypotheses about patient experiences.<sup>32</sup> To do this, coded data were reviewed. Emerging patterns of ideas and themes were grouped into overarching concepts through an iterative process of re-evaluating interview data.

Narrative analysis was used to compare and contrast these findings into stories in social context that reflected the experience of patients and their families.<sup>32 33</sup> This iterative process provided an articulate and meaningful view of lived experiences across care-seeking journeys to access surgical care and the effects of costs on patients and their families.<sup>33</sup>

### Patient and public involvement

Patients and the public were not directly involved in the design, management or dissemination of this research.

**Table 1** Sociodemographic characteristics of the study population

Characteristics	Participants (n=159)
Sex	
Female	103 (65)
Male	56 (35)
Age (years)	
Mean (SD)	40.8 (14.6)
Minimum–maximum	18–85
Education	
None or primary education	79 (50)
Secondary education and above	80 (50)
Occupation	
Street vendor	58 (36)
All others	101 (64)
Household total expenditure per month (2017 US\$)	
Mean (SD)	501.40 (444.7)
Minimum–maximum	38.50–3134.30

Figures are number (%) unless otherwise stated.

## RESULTS

### Quantitative results

#### Summary statistics of sociodemographic characteristics

Of 200 total participants, 159 remained after excluding 39 for missing demographic or socioeconomic variables and two for reporting an exceptionally large health expenditure (over US\$4000 per month) relative to their reported profession (subsistence farmers). The mean age was 40.8. There were 103 (65%) female participants, 58 (36%) participants who worked as street vendors and 79 (51%) participants who had never attended school. The mean annual total household expenditure was US\$501.4 per month (table 1).

#### Characteristics of surgical procedures and clinical course

The most frequent surgical procedures provided for study participants were Caesarean section (20%), excisional biopsy (15%), hysterectomy (11%), hernioplasty (8%), myomectomy (5%) and mastectomy (4%). Spinal or general anaesthesia was used in 131 (82%) cases, and local anaesthesia was used in 28 (18%) cases. There were 85 (53%) elective and 74 (47%) emergent cases. The mean length of stay at the hospital was 4.2 days. Postoperative complications were seen in 13 (8%) participants.

#### Direct and indirect payments

Table 2 summarises direct and indirect payments associated with seeking surgical care in the month prior to administration of the survey. Notably, 96/159 (60%) patients had their flat fee waived due to inability to pay. Median direct and indirect payments were US\$32.4 per month (range US\$0.0 to US\$1873.0) and US\$45.6 per

**Table 2** Self-reported household expenditure during the previous month for services related to the surgical condition

	Participants (n=159)
Direct expenditure	
Mean (SD)	119.3 (251)
Median	32.4
Minimum–maximum	0–1873.0
Indirect expenditure	
Mean (SD)	59.1 (52.1)
Median	45.6
Minimum–maximum	0.3–341.9
Total expenditure (direct +indirect)	
Mean (SD)	178.4 (273.4)
Median	94.4
Minimum–maximum	3.4–2021.4

Expenditures reported in 2017 US\$ using the 2017 exchange rate HTG 64.0 to US\$1.0. HTG, Haitian gourde.

month (range US\$0.3 to US\$341.9), respectively. Please see online supplemental appendix 2 for data on direct and indirect payments.

#### Percentage of households incurring catastrophic expenditure

Table 3 presents the percentage of households that experienced CHE using thresholds set by the WHO and SDGs. According to the WHO definition, 76.7% of households incurred catastrophic expenditure from the combined direct and indirect payments of seeking surgical services at SBH. A sensitivity analysis using more conservative thresholds revealed percentage increased to 82.4%, 87.4% and 93.7% when using thresholds of 30%, 20% and 10%, respectively.

According to SDG threshold of 10%, 50.3% of households incurred catastrophic expenses due to direct payments only. Likewise, 55.9% of households faced catastrophic expenses due to indirect payments only. Incorporating both direct and indirect payments, we found that 85.5% of households incurred CHE.

#### Coping strategies to meet healthcare costs

Patients reported using different coping strategies to cover healthcare costs. Of the sample, 111 (69.8%) borrowed money or solicited donations from friends and family. Next, 75 (47.1%) sold possessions and reduced spending on basic needs. Lastly, 56 (35.2%) used savings and pursued additional work.

#### Qualitative results

Of 30 total eligible patients for interviews, 12 were excluded due to non-response. This section includes descriptions of themes that emerged from the semi-structured interviews. Themes include (1) the hidden cost of seeking care, (2) care-seeking journeys and (3)



**Table 3** Proportion of the study population experiencing catastrophic health expenditure according to WHO and SDG definitions

CE threshold	Proportion (95% CI) of population with CE by expenditure type		
	Total	Direct	Indirect
WHO definition			
Capacity to pay (%)*			
≥40	76.7 (70.0 to 83.3)	51.3 (43.4 to 59.2)	42.8 (34.9 to 50.5)
≥30	82.4 (76.4 to 88.4)	60.3 (52.5 to 68.0)	46.5 (38.7 to 54.4)
≥20	87.4 (82.2 to 92.6)	67.9 (60.5 to 75.3)	58.5 (50.7 to 66.2)
≥10	93.7 (89.9 to 97.5)	77.6 (70.9 to 84.2)	81.1 (74.9 to 87.3)
SDG definition			
Total household expenditure (%)			
≥10	85.5 (80.0 to 91.1)	50.3 (42.5 to 58.2)	55.9 (48.2 to 63.8)

Data are presented as % (95% CI).

\*Household capacity to pay is the effective income remaining after basic subsistence needs have been met.

CE, catastrophic expenditure; SDG, Sustainable Development Goal.

social suffering. These themes are intertwined; each elaborates the others.

#### Hidden costs of care-seeking

Patients reported several costs incurred along the care-seeking journey. These ‘hidden costs’ include the costs of transportation, ancillary fees, lost wages due to work absenteeism, and damaging arrangements necessary to borrow money or solicit donations. Arrangements are considered damaging if they are disadvantageous for patients in the long term (eg, selling property, livestock, etc). It is important to note that ‘costs’ as perceived by the patient are not limited to monetary expenses; they are often experienced as social suffering.

#### Transportation-related costs

As only 5% of the study participants are from the commune in which SBH is located, Fond des Blancs, most patients travelled to SBH from a different commune. By administrative department, 39% of patients came from the Sud department (which contains multiple communes), where SBH is located. Of the remaining patients, 40% travelled from the Ouest department (which includes the capital city of Port-au-Prince), and 17% came from the Nippes department, which is adjacent to Sud. No patients in this study travelled from any of the northern departments.

While SBH offers an ambulance service for patients in emergency situations, there is no routine patient transportation available. Thus, patients face significant barriers in accessing the surgical care that is available at SBH. Private transportation is the primary mode of transportation to the hospital. However, private transportation fees can be expensive as they are unregulated and they frequently fluctuate based on demand and conditions. During the rainy seasons, drivers increase prices due to the poor condition of the roads.

During the rainy season, it is worse. The taxi driver increases the fees for transportation. Right now, the price is double what I used to pay: 250 gourdes [HTG] instead of 100 gourdes [HTG] from my neighborhood to St. Boniface Hospital.

Where I live is far, far, far away from the hospital, but I needed the care. You can see for yourself that even motorcycles cannot get here. So, I had to walk down that narrow road to the large unpaved road to find a motorcycle to take me to the hospital.

#### Ancillary hospital fees and costs of accompaniment

Ancillary hospital fees include food, housing and laboratory tests that are not available at the hospital. SBH does provide hot meals to hospitalised patients, but it does not offer options for patients with special diets. Therefore, patients with dietary restrictions must purchase their own food. While the hospital stay is included in the registration fee for patients, this is not the case for accompagnateurs, who must support themselves. Accompagnateurs provide patients with both practical support and moral support, which are critical throughout their treatment course and often help to compensate for resource and provider shortages. However, this accompaniment may double or triple the costs of a patient stay.

I traveled on a motorcycle to the hospital. I borrowed 2500 gourdes [TG] to go. I went alone, but two people came to support me there.

I foresaw that I would need money for myself and for the person that would accompany me.

#### Lost wages due to surgery

Reports of lost wages due to work absenteeism were common among the study population. Even minor surgery may require taking a leave of absence from work for the procedure and recovery. Often, the threat of lost

wages leads patients to delay seeking surgical care. When the patient does decide to go to the hospital, it may be at the expense of their job. Here, a patient explains:

I was a motorcycle taxi driver, but the motorcycle was not mine. Because of the surgery, I couldn't keep the motorcycle.

Notably, patients who sold non-perishable items fared better following surgery. In most cases, they could enlist help from family members to manage the business or store inventory to maintain their livelihood.

I had a business of selling **pepe** [used clothes from USA or Panama] that I estimated at 10,000 gourdes [HTG]. It was easy to go to Fond des Blancs because my children are not young and my goods will not spoil. I am still selling **pepe** [after the surgery].

### Strategies for covering costs

Patients employed various strategies to raise money to pay for surgical care. Our quantitative results revealed that most patients either (1) borrowed money or solicited donations, (2) saved money or (3) sought additional work. The qualitative results support these findings and provide additional context.

To raise money through borrowing or donations, patients often directly asked for contributions from friends of family, or they had someone ask on their behalf. A patient who had a hernia repair explained with sadness that his grandmother tried to borrow money on his behalf:

I had a hernia in my groin. I asked my grandmother for help getting it fixed. She called my uncle that lives in the Dominican Republic, but he didn't respond. To complete my treatment, my grandmother borrowed money and took me to SBH. I got [surgery] there.

Many patients also took on additional work to cover the costs of surgery. For example, farmers often attempted to till more land or work as labourers on other farms. Many of these jobs provide low wages, leading to extended delays in surgery due to the length of time it takes to accumulate sufficient funds. Further complicating this situation, patients would pursue additional work despite having an existing surgical disease in need of treatment. Conditions like groin hernias can make physical labour particularly difficult and painful.

I saved money to go. I took on additional work; when I make 50 gourdes [HTG] for a day of work, I don't use it all. I save half of it. That's how I saved money for transportation, registration, and medicines. I did that for a long time— I don't even remember how long because I stopped counting the days, weeks, or months. Taking on additional work on top of being a farmer is not easy. While I don't find additional work every time, most frequently I farm other peoples' land.

### Journey to care

The decision to seek surgical care is complex and influenced by several factors. Patients do not always seek surgical care immediately when they first realise that they have a surgical problem. This decision can be delayed due to lack of money, absence of complications or pain that is bearable, given the need to continue working. In these situations, an increasing level of acuity will often pass a threshold that prompts the patient to seek surgical care. The following quote by a taxi driver explains the beginning of one such journey:

The disease that brought me to SBH—I had it for 3 years. I decided to have surgery when it began to be painful. I noticed that it became painful with work... Then, I went to St. Therese Hospital, and I was told that I had hernia.

Patients with conditions that remained stable and produced bearable pain explained that the decision to seek care was delayed primarily by a lack of money and the burden of taking leave from work.

I knew that I needed surgery for this mass on my leg. It was ugly, but I lived with it for 5 years before finally going to St. Boniface Hospital. It took time because I lacked money, and because I couldn't take time off from work.

When seeking surgical care in Haiti, the journey itself can be overwhelming. Patients often travel to several hospitals to find a facility that can provide care, but they must also travel to have laboratory tests done or find other medical services that are needed to complete their care. This journey is rarely linear; instead, it is fragmented and a source of deprivation, suffering and pain—also known as social suffering.

First I went to Miragoane. After some laboratory tests, I was referred to Fonds des Negres—to the Salvation Army hospital—then to Fond des Blancs. But, I had gone to multiples places for the same condition (Miragoane, Fonds des Negres, Madian, 6<sup>th</sup> section, Ladimon). This was a very bad experience for me. I had to walk long distances to go to those hospitals, and I couldn't find a solution. At some point, I couldn't walk or eat anymore because I was disappointed and scared that I wouldn't find a solution to my problem. I heard that SBH provides good care, and finally I went there. They took care of me.

Further extending the care-seeking journey, patients often chose facilities that they trusted over sites that were in closer geographical proximity. Some patients reported that they chose SBH because of its good reputation or its flat fee payment structure.

I have heard about St. Boniface Hospital a lot—many good things. That's why I didn't go to the hospital in my community in Petit-Goave. It is a public hospital, but as you know, there are fees that I couldn't afford.

After surgery, patients must undergo a period of recovery. Depending on the type of surgery, this can require weeks or months of limited mobility, which exacerbates existing challenges and costs from work absenteeism. This can place an arduous burden on the rest of the household and lead to social suffering for the patient and family members.

### Social suffering

Social suffering incorporates the collective in the suffering of an individual; the pain inflicted on an individual by political, institutional and economic forces is transmitted throughout that person's social network.<sup>15</sup> Social suffering is starkly visible in settings where Haitians are unable to access surgical care or the care-seeking journey depletes them of resources. This financial suffering is acutely felt by the individual, but it is also often passed along to the entire family. SBH patients frequently reported that they feel immense pressure as the primary wage earner to support their families. Yet, when they fall ill with surgical disease, they are limited or unable to continue earning income, and the family suffers.

All I can do is crush stone, and it takes a long time to crush enough stone to fill up a truck. We are all affected by my surgery. My children have not gone to school since my surgery. They didn't take their final exam to move up a class next year. The director of the school heard that I underwent surgery, so he kicked them out of school because he thought that I wouldn't be able to pay for them anymore. Right now, they are home with me, waiting for the next year to resume class. In the meantime, I need to find money to pay overdue bills.

After my surgery, I can't sleep at night. I get 2–3 hours of sleep—I am always awake thinking about my children and what I can do to take care of them. They are still young, and I need to provide for them, but I can't do [what I used to do] right now. To find money, I sold possessions like my chair and desk. I am currently on chemotherapy. I need to send a specimen overseas so we can learn more about the disease to get more treatments. I don't have the USD 100 to do it. Even the 25,000 gourdes [HTG] I paid for chemo drugs didn't pay off [my debt]. I talked to my husband, and we are both feeling sorry and sad. I think a lot at night and cry sometimes [the patient began crying and the interview was paused for a few minutes]. I am not ready to die. I have my children that I need to take care of.

## DISCUSSION

The costs of seeking surgical care were substantial for patients at SBH. It was estimated that up to 93.7% of study participants incurred catastrophic expenditure due to direct and indirect payments. This study illuminates the direct and indirect surgical costs as well as the

lived experiences of patients and their families. Several methods were used to cope with these costs, and the most common of these was borrowing from others and soliciting donations (69.8%). In addition to monetary cost, the lived experiences of patients revealed social suffering with tremendous impact on employment, businesses, education and food security.

Worldwide, direct payments alone result in catastrophic expenditure for 150 million people seeking healthcare annually.<sup>21</sup> For surgical care, approximately 3.7 billion people risk catastrophic expenditure due to out-of-pocket payments in the event they need surgery, and an estimated 81.3 million people actually experience catastrophic expenditure annually, of which 32.8 million are from direct costs and 48.6 million are from indirect costs.<sup>10</sup>

A 2012 study in Haiti reported rising rates of catastrophic expenditure for healthcare and found that of the poor households that did not use healthcare services, 70% cited healthcare cost as the deterring factor. Furthermore, poor households were three times less likely to consult healthcare services than rich households.<sup>3</sup> The costs of surgery undoubtedly contribute to these findings and, in fact, a previous modelling study estimated that 73.8% of Haitians were at risk of impoverishing expenditure when accessing surgical and anaesthesia care.<sup>15</sup>

A pilot study conducted in the Central Plateau of Haiti showed that the median total out-of-pocket expenditure for patients with breast cancer across a care cycle, including diagnostic visits (US\$233), chemotherapy (US\$259) and surgery (US\$38), was US\$717,<sup>34</sup> which was over 50% of the national GDP per capita (US\$1389.12 in 2015).<sup>15</sup> Alongside the findings of our study, these results suggest that financial cost is a significant barrier to and consequence of seeking care for surgical conditions in Haiti.

Comparable findings have also been reported in other low-income and middle-income countries; for example, in Uganda, which provides free care at government facilities, studies have estimated that 45% of paediatric and up to 55% of adult surgical patients experience catastrophic expenditure at a regional referral hospital.<sup>26 35</sup> Meanwhile, it has been reported that 78.8%–95.1% of surgical patients in Madagascar and 94% of those in Malawi face catastrophic expenditure.<sup>36 37</sup>

The financial coping mechanisms described in this study, including borrowing, using savings and taking on additional work, correspond with those identified in other analyses.<sup>38–40</sup> In Haiti, one study in the Central Plateau found that 67% experience hardship financing (borrowing money or selling belongings) to pay for care at a dedicated non-communicable disease clinic.<sup>41</sup> In Ethiopia, when accessing care for their children and newborns, families had to use savings and borrow from others to cover costs.<sup>42</sup>

To our knowledge, there are neither previous studies on coping strategies for expenses incurred due to surgical care nor qualitative analyses of the household lived





experiences when managing the associated challenges. Here, qualitative findings like ‘To complete my treatment, my grandmother borrowed money and took me to SBH’ and ‘My children have not gone to school since my surgery’ illuminate that the livelihoods of both patients and their families are at stake when seeking surgical care.

As the first study of its kind in southern Haiti, this analysis highlights the critical need for financial risk protection in the provision of surgical care. At the hospital level, potential solutions include offering a wider array of surgical and ancillary services and collaborating with local surgical providers to offer services at reduced cost for the surgical population. These could help reduce the burden of direct payments. At the government level, the Ministry of Public Health and Population (Ministère de la Santé Publique et de la Population (MSPP)) should incorporate these findings into health policy development and implementation while further using them as an advocacy tool in healthcare debates. This study provides an opportunity to develop policy to protect citizens from catastrophic expenditure; for example, the MSPP could expand the health insurance system to include disability insurance, and it could further subsidise the indirect costs of food, transportation, etc.

At an international level, these findings support the need for health policymakers to redefine ‘catastrophic expenditure’ to include indirect payments. Like surgery was once described by Drs Paul Farmer and Jim Kim as the ‘neglected stepchild of global health’,<sup>43</sup> we believe that indirect payments are the ‘neglected stepchild of catastrophic expenditure’ as they have been similarly omitted in analyses and policymaking around healthcare expenditure.

Finally, the qualitative data presented here provide important insight into the lived experience and social suffering of patients. Damaging financial arrangements to cover healthcare costs, lost education for dependents and decreased household income are a few of the potentially devastating indirect payments of surgery. These often have long-term consequences on the economic and social livelihood of patients and their families.

## LIMITATIONS

This study was subject to several limitations. First, patients recruited to this study were the ones who were able to get to SBH and were willing to participate in the study. It is possible that catastrophic expenditure might be higher in the overall population of care-seeking patients. Additionally, reported lost earnings, as part of indirect payments, could be underestimated because we used the average household expenditure as a proxy for potential lost earnings. For some conditions such as uterine fibroids, the symptoms might have occurred long time ago, and it would be difficult for patients to recall the exact time of onset and the related medical spending. To mitigate the recall bias, we followed the previous practice and adopted a 1-month recall period in the survey.<sup>21 22</sup> However, 1-month medical spending might not fully capture the

costs related to the symptoms and therefore could lead to underestimation of catastrophic health spending.

While the 2-month time gap between surgery and patient interviews could introduce recall bias, holding interviews close to the date of surgery would, conversely, limit the study in its ability to capture the experience of CHE, which may take time to manifest. Two months was selected as an intermediate. Furthermore, the sample used in this study was conveniently collected over 6 weeks and prioritised those from the lowest economic stratum, and the estimates therefore may not be generalised and could suffer from potential bias. Lastly, time spent seeking care was not included in these calculations, again raising the likelihood of underestimating lost wages.

## CONCLUSION

Direct payments are not the only important determinant of CHE. Indirect payments can also contribute to CHE. As healthcare improves and more people receive surgical care, demands will be intensified for policymakers to reduce out-of-pocket spending on healthcare. However, without recognition of the other costs in overall healthcare expenditure, indirect payments will remain neglected and families will continue to suffer. This study shows that, in southern Haiti, indirect payments can contribute more to catastrophic expenditure than direct payments. Patients make heroic efforts to pay for healthcare. Yet, in a system that fails to provide financial risk protection and mitigate indirect payments, patients and their families will continue to suffer disastrous financial outcomes and immense social suffering.

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