Hirschsprung disease: A cost analysis study of the direct, indirect costs and financial coping strategies for the surgical management in Western Uganda

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Abstract

Background: Surgical management of Hirschsprung disease (HD) in low- and middle-income countries is typically a staged procedure, necessitating multiple hospitalizations and clinic visits increasing family financial burden. Currently there is limited information on the costs borne by caretakers of children with Hirschsprung disease seeking surgical intervention. This study seeks to measure the costs and economic burden of surgical treatment for Hirschsprung Disease in western Uganda.

Methods: A cross-sectional study using cost analysis was conducted among caretakers of patients who completed surgical treatment of HD between January 2017 to December 2021 at two hospitals in western Uganda. The average direct and indirect costs incurred by caretakers presenting at a public and private hospital were computed.

Results: A total of 69 patients (M: F = 7:1) were enrolled in the study. The median age at diagnosis was 60.5 (IQR 3 - 151.25) days for children and 2- staged pull through procedure was the common surgery performed. The mean overall cost for treatment was US $960 (SD = $720), with the majority of costs coming from direct medical costs. Nearly half (48%) of participants resorted to distress financing to finance their child's surgical care. The overwhelming majority of patients (n = 64, 93%) incurred catastrophic expenditure from the total costs of surgery for HD, and 97% of participants fell below the international poverty line at the time treatment was completed.

Conclusion: Despite the availability of 'free care' from government hospital and non-profit services, this study found that surgical management of Hirschsprung disease imposed substantial cost burden on families with Hirschsprung disease patients.

Introduction

Hirschsprung disease (HD) is a common congenital condition, characterized by distal intestinal aganglionosis as a result of incomplete caudal migration of neural crest-derived cells resulting in functional intestinal obstruction.[1] HD occurs in approximately 1 in 5,000 live births, and is one of the most prevalent causes of neonatal bowel obstruction worldwide. [2, 3]. The mainstay of treatment is surgical resection of aganglionic bowel. In high-income countries (HIC), HD is typically diagnosed in the neonatal period, and managed with a single stage pull-through procedure around the time of diagnosis, decreasing costs and avoiding the morbidity of an ostomy.[4] In low- and middle-income countries (LMIC), HD typically presents in a delayed fashion and often with a complication such as complete obstruction or colon perforation.[5] In most instances, a single stage pull-through is not safe or feasible - patients are often sick or malnourished, present with severely dilated bowel (making definitive repair difficult and increasing the risk of subsequent post-operative complications) and there is often a lack of fresh-frozen biopsy to guide the extent of resection intra-operatively.[6] Ideally, patients undergoing a staged procedure would have their stomas reversed within a few months after stoma placement. However, many patients in LMIC live with stomas for 2–15 years due to a shortage of pediatric surgeons

and backlog of cases.[7, 8] A single surgical intervention can have severe financial consequences for patients and their families, especially in LMIC. Families in LMIC are up to 17 times more likely to incur catastrophic expenditure – or out-of-pocket spending of greater than 10% of annual income – should their child need surgery.[9] The staged approach and prolonged course of surgical treatment of HD in LMIC requires multiple operations, hospitalizations and outpatient visits, likely further increasing costs for children and their families. This study seeks to measure the costs and economic burden of surgical treatment for Hirschsprung Disease in Uganda

Methods

Study setting

This study was conducted at the Pediatric Surgical units, Mbarara Regional Referral Hospital (MRRH) and Holy Innocents Children's Hospital (HICH). Mbarara Regional Referral Hospital is government owned regional referral hospital located in southwestern Uganda, in Mbarara district. It serves a population of over three million people from the surrounding districts and neighboring countries like Rwanda, Democratic Republic of Congo, and Tanzania. MRRH offers healthcare services, has a small number of beds available in paediatric surgical ward, and does not provide free meals to patients and thus OOP spending is theoretically anticipated. The government distributes medical supplies through the National Medical Store, which frequently experiences shortages. Due to the lack of public access, patients are forced to buy some medications OOP from privately owned pharmacies. Furthermore, although MRRH Hospital offers basic hematologic laboratory tests, the patient's family is responsible for paying for more expensive diagnostic imaging and laboratory investigation especially during out of stock. Additionally, patients typically foot the bill for lodging, meals, and transportation. HICH is private not for profit (PNFP) pediatric general hospital in the Western region of Uganda, located 3 km west of MRRH. It receives annual outpatient visit of 20,468, and 3,922 annual admissions.

Study design

Parents and legal guardians of patients who had completed surgical treatment for HD at MRRH and HICH between January 2017 to December 2021 were retrospectively enrolled in the study. Demographic and clinical data were abstracted from within the existing hospital databases where appropriate. Parents/legal guardians of patients were identified and contacted by phone and invited to participate in the study. An interviewer guided questionnaire was administered in person to parents/legal guardians by research assistants knowledgeable in the local languages (Runyankole & Luganda).

Survey Design: The survey instrument was adopted from the previously validated WHO/TB patient cost survey questionnaire with some changes for cost analysis. For determination of direct and indirect costs, financial costing as opposed to economic costing was used. The survey was structured to analyze costs at three distinct time periods: before surgical intervention, during admission for surgery and during follow up. The survey assessed both direct and indirect costs. Direct costs were further subdivided into medical and non-medical costs. Medical costs included the consultation fee, admission charges, medicines, lab

tests, radiography, other procedures and other sundries. Non-medical costs included travel costs, food during health care visit or hospitalization and accommodation costs. Indirect costs included time loss for the caregiver (for example at admission, at OPD for follow up, at travelling) and loss of income from admission. Additionally, we assessed coping strategies, or mechanisms used by households to mitigate the adverse circumstances of one of their member's illnesses. The strategies captured during the assessment included use of any savings (cash or deposit) to cover cost due to illness, borrowed money, sold property, social welfare (e.g., NGO, UN or other support) and charity.

Data analysis

Monetary values were reported in the local currency of Ugandan shillings (UGX) and converted to US dollars (US $) using purchasing power parity (1 US$ [in 2021] = 1,311 UGX). Catastrophic expenditure was defined as spending greater than or equal to 10% of yearly household income. Impoverishing expenditure was defined as out-of-pocket spending that pushes a family below the international poverty line (2,838.8 UGX (2019) per day per capita). Statistical analysis was performed using Stata software (v.13, College Station, Texas, USA) and SPSS Statistics (v.28.0, Armonk, NY). Descriptive analysis performed on all survey data. Total direct and indirect costs as well as total expenditure were calculated. Continuous variables were compared using the student's t-test with equal variance and categorical variables were compared using chi-squared test where appropriate. A P value < 0.05 was considered significant.

Ethical considerations: Approvals were sought from the respective Hospital Directors of Mbarara Regional Referral Hospital and Holy Innocents Children's Hospital, Faculty Research and Ethics Committee, Institutional Ethical Review Committee of Mbarara University of Science and Technology (Ref: MUST-2022-373)

Results

Between January 2017 and December 2021, a total of 105 children began surgical treatment for HD at MRRH and HICH. Of these, 82 completed surgical treatment and 69 participants met inclusion and exclusion criteria, consented, and were enrolled into the study.

Sociodemographic characteristics of the study participants are shown in Table 1. The median age at diagnosis of the patients was 60 days (IQR of 3 -151). The majority of patients, 62 (91%) were less than 1 year and 6 (9%) were more than 1 year at presentation. Patients were predominantly male (n = 60, 87%). Most of the patients (n = 58, 84%) received their definitive treatment in MRRH and 11 (16%) were treated at HICH. Median distance travelled from residence to treatment facility was 97.1km (IQR of 64.3 to 264.8). The vast majority (n = 66, 95%), underwent a two-staged procedure. The majority of the participants (n = 43, 62.3%) were peasants or farmers, followed by 14(20.3%) who were business/professional and 12 (17.4%) were unemployed. The median estimated net monthly wage was US $114 (IQR $8 - $267). The social economic status among participants was 29(45%) with poor income, 23 (35%) had middle-income and 13 (20%) were rich. This is summarized in Table 2.

Table 1
Social demographic characteristics of the patients, N= 69

Characteristics	n (%)
Median Age at diagnosis in days (IQR)	60.5 (3–151.25)
< 1 year	62 (91.2)
> 1 year	6 (8.8)
Sex	60 (87.0)
Male	9 (13.0)
Female	
Treatment facility	58 (84.1)
MRRH	11 (15.9)
HICH	
Median distance from residence to treatment facility in KM (IQR)	97.1 (64.3-264.8)
Stage of HD treatment	1 (1.5)
Single staged	66 (95.6)
Two staged	2 (2.9)
Three staged	

Table 2
Guardian characteristics, N= 69

Characteristics	n (%)
Participant Education level	17 (24.6)
Not educated	30 (43.5)
Primary	17 (24.6)
Secondary	5 (7.3)
Tertiary	
Household Head Education level	10 (14.5)
Not educated	23 (33.3)
Primary	30 (43.5)
Secondary	6 (8.7)
University	
Occupation	12 (17.4)
Unemployed	43 (62.3)
Peasant/Farmer	14 (20.3)
Business/Professional	
Median Estimated net monthly wage in USD (IQR)	114 (8–267)
Social economic status	29 (44.6)
Poor	23 (35.4)
Middle-income	13 (20.0)
Rich	

Patients had an average of two visits before surgical treatment. The median number of surgical admissions per patient was 3 (IQR of 2–4) with a median length of hospital stay of 11 days (IQR of 9–14). The median waiting time to receive the service was 30 minutes (IQR of 20–60) and the mean travel time to the treatment facility was 3 hours (SD = 2.2). The median number of OPD visits for follow-up was 4 (with an IQR of 3–5). There were no statistically significant differences in hospital visit characteristics between the two facilities (Table 3).

Table 3
Hospital visit characteristics, N=69

Characteristics	Overall	Stratified by treatment facility		
	Mean (SD)	MRRH Mean (SD)	HICH Mean (SD)	p value
Mean no. of visits before attending the facility	2 (0.7)	2.0 (0.7)	1.9 (0.7)	0.5878
Median no. of surgical admission	3 (2–4)	3 (2–4)	3 (2–4)	0.5985
Median length of hospital stays in days	11 (9–14)	11 (9–14)	10 (9–14)	0.3754
Median waiting time to receive service (mins)	30 (20–60)	40 (20–60)	20 (20–60)	0.8190
Mean travel time to the treatment facility (Hrs)	3 (2.2)	3 (2.3)	1.8 (1.0)	0.1409
Median no. of OPD visits for follow up	4 (3–5)	4 (3–5)	4 (3–5)	0.5159

Table 4 and Fig. 2 summarizes the costs of treatment for HD. The mean overall cost for treatment was US $960 (SD = $720). Total cost of treatment was greater for patients at HICH ($1,950 ± 929) compared with MRRH ($769 ± 461, P < 0.0001). Direct medical costs were greater for patients at HICH ($1389 ± 954) than at MRRH ($219 ± 328, P < 0.0001). There was no statistically significant difference in nonmedical and indirect costs between the two hospitals. Table 5 further stratifies direct and indirect costs.

Table 4: Direct and Indirect cost related to HD management

Type of cost expenditure	Overall, Mean (SD)	Stratified by treatment facility		
		MRRH Mean (SD)	HICH Mean (SD)	P value
Direct cost	896	712	1,869	< 0.0001
	(683)	(436)	(919)	
Medical	406	219	1,389	< 0.0001
	(640)	(328)	(954)	
Non-Medical	490	492	480	0.8998
	(284)	(244)	(460)	
Indirect cost	54	49	81	0.0660
	(53)	(46)	(76)	
Total (direct + Indirect)	960	769	1,950	< 0.0001
	(700)	(451)	(929)	

Table 5

Direct and indirect cost distribution across cost categories

Type of cost expenditure	Cost category	All Patients	Treatment facility		*P* value
		Mean (SD)	MRRH	HICH	
			Mean (SD)	Mean (SD)	
DIRECT COST					
Medical	Treatment before facility	157	164	121	0.4889
		(185)	(195)	(127)	
	Hospitalization	393	216	1329	< 0.0001
		(614)	(329)	(896)	
	Consultation at follow up	7	0	44	< 0.0001
		(29)	(0)	(62)	
	Medicine at follow up	3	2	6	0.4832
		(14)	(13)	(18)	
	Other fees at follow up	3	1	10	0.0163
		(11)	(7)	(22)	
Non-Medical	Feeding cost at admission	188	175	254	0.1295
		(157)	(122)	(278)	
	Transport cost at admission	128	133	103	0.2462
		(78)	(72)	(106)	
	Transport cost at follow up	174	184	123	0.108
		(114)	(110)	(126)	
INDIRECT COST					
	Time lost during hospitalization	17	15	26	0.0602
		(17)	(16)	(22)	
	Waiting time at hospitalization	12	11	19	0.1795
		(17)	(16)	(22)	
	Travelling time	1	1	1	0.4158

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Type of cost expenditure	Cost category	All Patients	Treatment facility		*P* value
		Mean (SD)	MRRH	HICH	
			Mean (SD)	Mean (SD)	
		(1)	(1)	(1)	
	Waiting time at OPD	25	23	36	0.1875
		(31)	(27)	(47)	
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Participants resorted to different strategies to cope with dissaving and cover costs related to surgical treatment of HD. Sixty-two (90%) of participants used savings, 33(48%) of the participants sold their property and 31(45%) borrowed money (Fig. 4). Among the participants who borrowed money, 7 (23%) took a loan from family members, 24 (77%) took a loan from the bank. Of those who sold their property 23 (70%) sold land and 6 (18%) sold livestock, 1(3%) sold a motorcycle and 3 (9%) sold farm products. Some patients (n = 10, 15%) received charitable donations from organizations such as UNHCR and UN and Bethany Kids. Three percent of patients received charity from good Samaritans and other religious institution.

The overwhelming majority of patients (n = 64, 93%) incurred catastrophic expenditure from the total costs of surgery for HD. There was no statistical difference in the proportion of patients who incurred CHE at each hospital (Fig. 3). In our cohort, 80% of families (n = 55) were at or below the international poverty line prior to starting surgical treatment for HD. Of the 20% (n = 14) of families who were not at or below the poverty line, 12 (85%) incurred impoverishing expenditure as a result of the total costs of surgical treatment. As a result, 97% of patients below the poverty line at the time treatment was completed (Fig. 5). At MRRH, 86% of patients were at or below the poverty line at baseline, whereas 46% of patients of patients were at the poverty line at HICH (P = 0.002). seventy five percent of patients above the poverty line incurred impoverishing expenditure at MRRH, whereas 100% of patients above the poverty line treated at HICH incurred impoverishing expenditure.

Discussions

This study highlights devastating financial consequences of Hirschsprung Disease – nearly all families of children with Hirschsprung Disease in western Uganda are driven into poverty by the time the child completes surgical treatment. As alarming as these findings are, they are not exceptionally surprising- the Lancet Commission on Global Surgery estimated that that 81 million people face CHE each year accessing and paying for surgery and that the world's poorest patients are 61 times more likely to face catastrophic expenditure compared with the richest patients.[10]

We found that nonmedical costs, especially transportation, account for nearly one half of direct costs to families. It has previously been demonstrated that high costs contribute to delays in reaching care.[11, 12] Due to the severe shortage of pediatric surgeons in LMIC, most pediatric surgical care is offered in large cities, further increasing transportation and other nonmedical costs.[13] An ideal and long term solution to this is increasing pediatric surgical capacity in rural regions. In the interim, thoughtful, locally driven surgical outreach camps can decrease direct nonmedical costs to families and bring care to families.[14, 15]

Cost of medical treatment before presentation to a pediatric surgical ward accounted for over one quarter of direct medical costs. Typically, patients had two visits at another facility before presenting for definitive treatment. Misdiagnosis and inefficient referral patterns likely contribute to this delay in receiving care.[11] Training programs geared toward the education of first-line medical providers, who are the first point of contact into the medical system is one local solution that has been introduced.[16] These programs can improve these providers ability to recognize congenital conditions, and lead to more appropriate referrals[17]

We found that the direct medical costs of treatment were nearly four times greater at the private hospital (HICH) compared with the government referral hospital (MRRH). The established fee that was charged as a package during hospitalization accounted for most of this cost. At MRRH, over one half of direct medical costs were attributable to the hospitalizations. All government referral hospitals in Uganda provide healthcare free of charge – there are no doctors' fees, fees for operative services or patient beds. Multiple studies have demonstrated high medical costs at Ugandan public hospitals.[18–20] Supplies are frequently out of stock and some medications that are commonly prescribed in the pediatric surgical ward are not provided by the government. These supplies are given to families by charitable donation whenever possible – when it is not, families must purchase them at private pharmacies. This likely accounts for the high hospitalization costs, even with "free" healthcare.

Indirect costs, or self-estimates of the lost productivity, accounted for a small proportion of total costs. We feel that this is an underestimate. The majority of participants self-identified as unemployed, or a peasant or farmer. These participants do not earn a discrete for-profit income, making difficult to estimate the cost of lost productivity. A long median length of stay (11 days in our study, compared to as little as 4 days in HIC), multiple visits before surgical treatment, multiple hospitalizations and follow up visit and long travel distances are all factors that contribute to lost productivity for these families. Surgical quality improvement initiatives targeting factors such length of stay and readmission should be carefully considered and have the potential to minimize decrease productivity loss for these patients.[21] Productivity loss is further compounded by the profound social consequences of pediatric ostomy. Up to half of fathers of patients with stomas leave the family which exacerbates significant economic burden.[22] Children with stomas are often not allowed to attend school – an ostomy can even lead to an end to their schooling further compromising their own future productivity.[22, 23]

Consistent with previous findings, we found that to finance surgical treatment, a large portion of households (over 90%) of the households used their savings, approximately half (45%) of the households had to borrow money and / or resort to distress financing (the sale of physical assets).[18, 19] Only 15% of our patients received some form of charity. The largest source of charity came from the United Nations, which covered all the cost for the care received by refugees from a local camp and charitable organizations such as Bethany Kids. These practices can have unanticipated consequences - reliance on support from social connections to finance surgery can damage social networks, which are especially fragile for children with colorectal conditions.

The financial burden of surgical treatment of Hirschsprung Disease in our setting is especially is especially severe. The vast majority (93%) of families incurred catastrophic expenditure as a result of HD treatment, with nearly all participants (97%) incurring impoverishing expenditure. Previous studies estimated that 27% of patients seeking treatment for all pediatric surgical conditions incurred catastrophic expenditure.[18] Our study highlights the particularly high financial burden of pediatric colorectal conditions in LMIC. This study has several limitations. This study was performed at two in institutions in the same region of Uganda. These results are therefore not necessarily representative of all government or PNFP hospitals in Uganda specifically or other LMIC's in general. Cost reporting bias may have also been present due to poor recall according to illness severity and clinical outcome, which parent was interviewed (mother/father), as well as the time elapsed since the events occurred.

Conclusion

Despite the availability of ‘free care’ from government hospital and non-profit services surgical management of Hirschsprung disease imposes substantial cost burden on families. with Hirschsprung disease patients. Our findings highlight the need for targeted interventions to minimize delays in seeking, reaching and receiving care, decrease the burden of direct medical costs during hospitalization and decrease the number of hospitalizations and length of stay to minimize lost productivity.

Declarations

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Author contributions

All authors named in this manuscript have contributed substantially to this work and meet the criteria for authorship. Ahmed Hamad Binde took part in initial concept design, proposal writing, data interpretation,

manuscript writing/revision, and approval of final work. Other author also contributed towards data collection, data interpretation, revision of the manuscript, and approval of final work.

Competing interests

The authors declare that they have no competing interests

Ethical approval

This study was approved by the Mbarara University Research Ethics Committee (MUST REC).

Informed consent

We confirm that all eligible participants or their caregivers provided consent to participate in this study and that the study obtained approval from the Mbarara University Research Ethics Committee

Consent for Publication: All authors consented to have this work published.

Availability of Data: The datasets used during the current study are available from the corresponding author on reasonable request.

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Figures

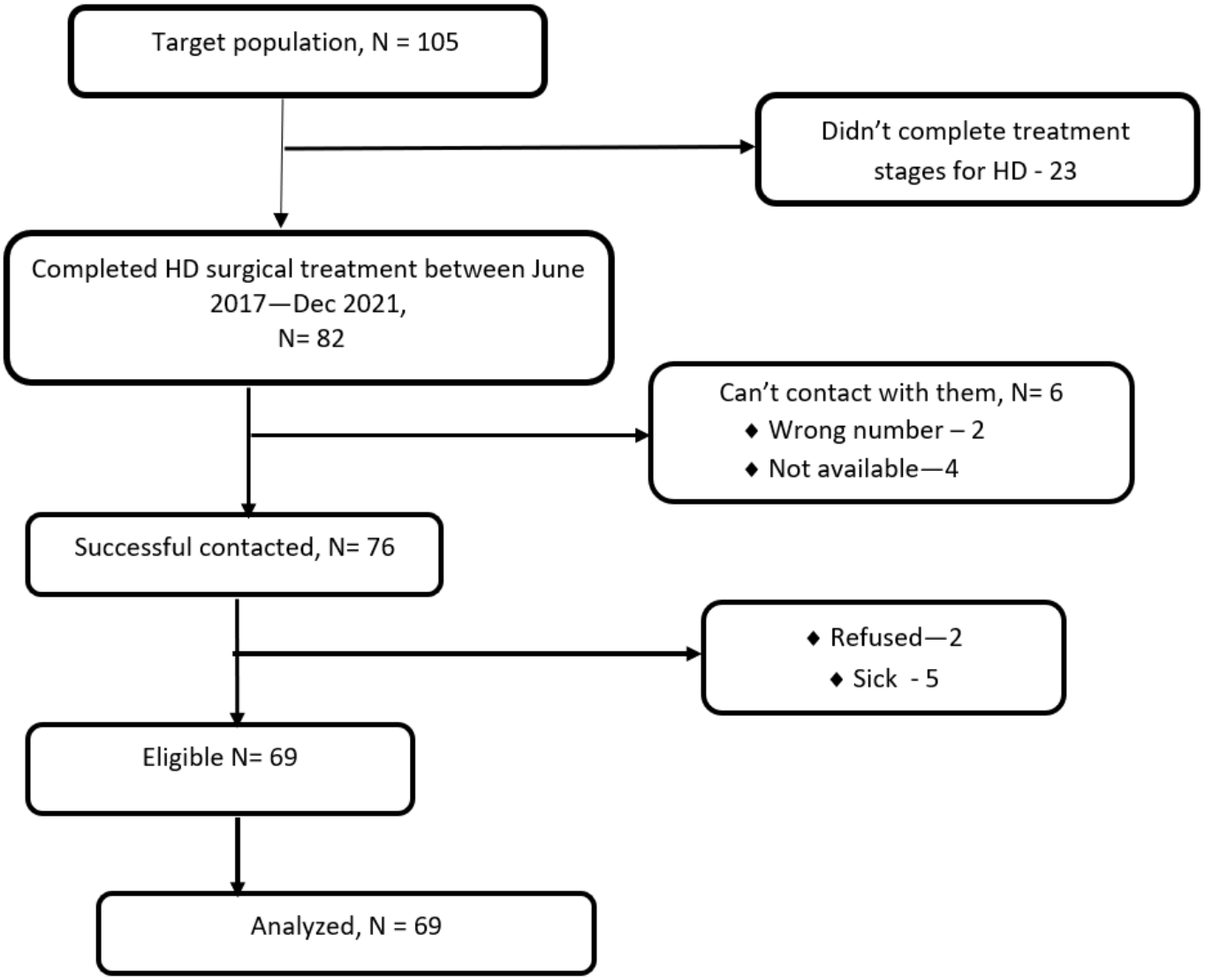

Figure 1

Flow chart of enrolled participants in the study

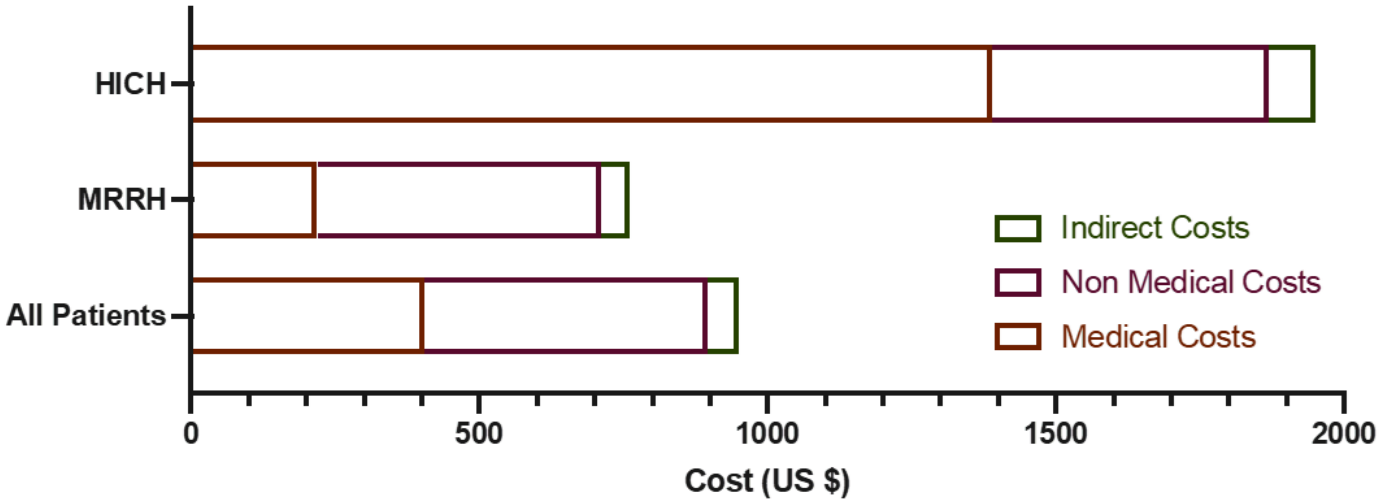

Figure 2

Direct and Indirect cost related to HD management

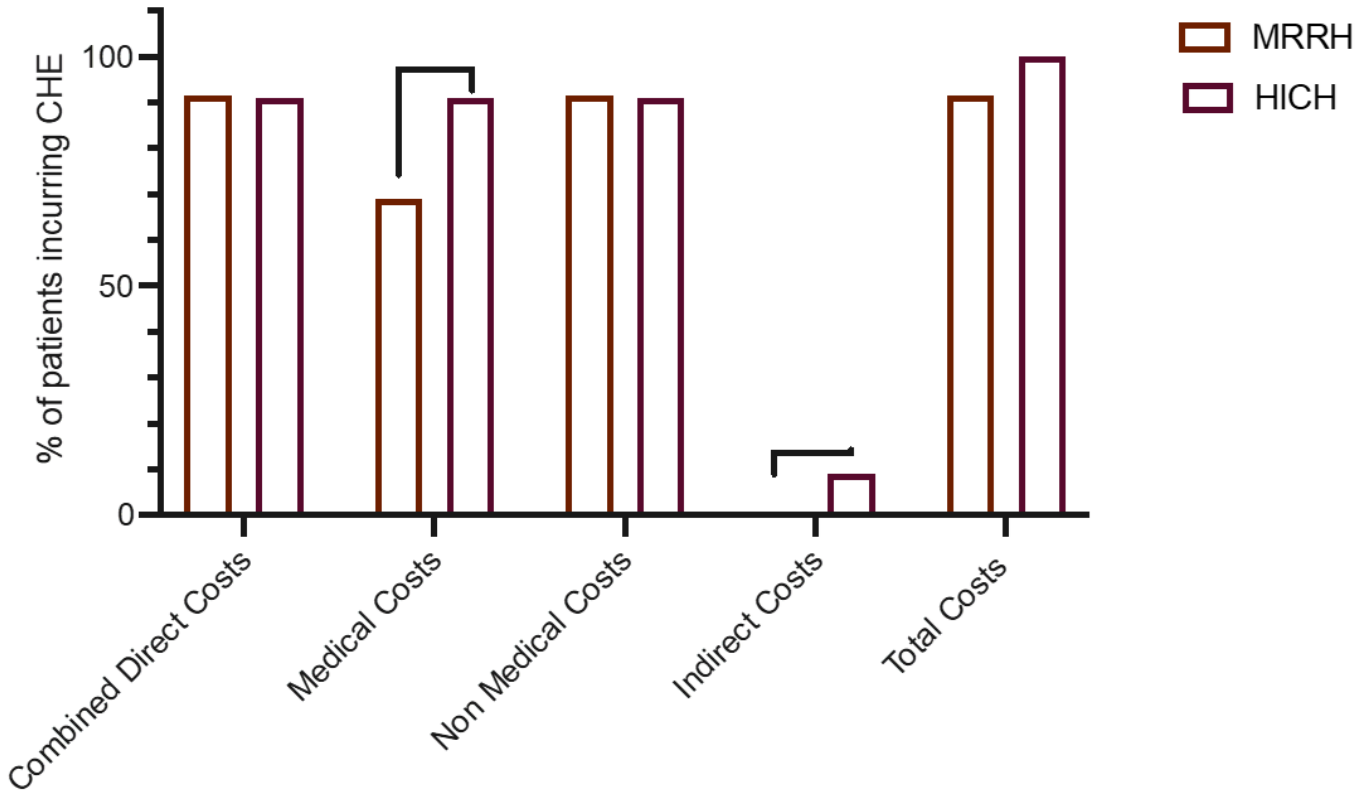

Figure 3

Bar graph comparing catastrophic expenditure for HD Surgery at MRRH and HICH. ** p<0.01, * p<0.05 (Chi-squared test)

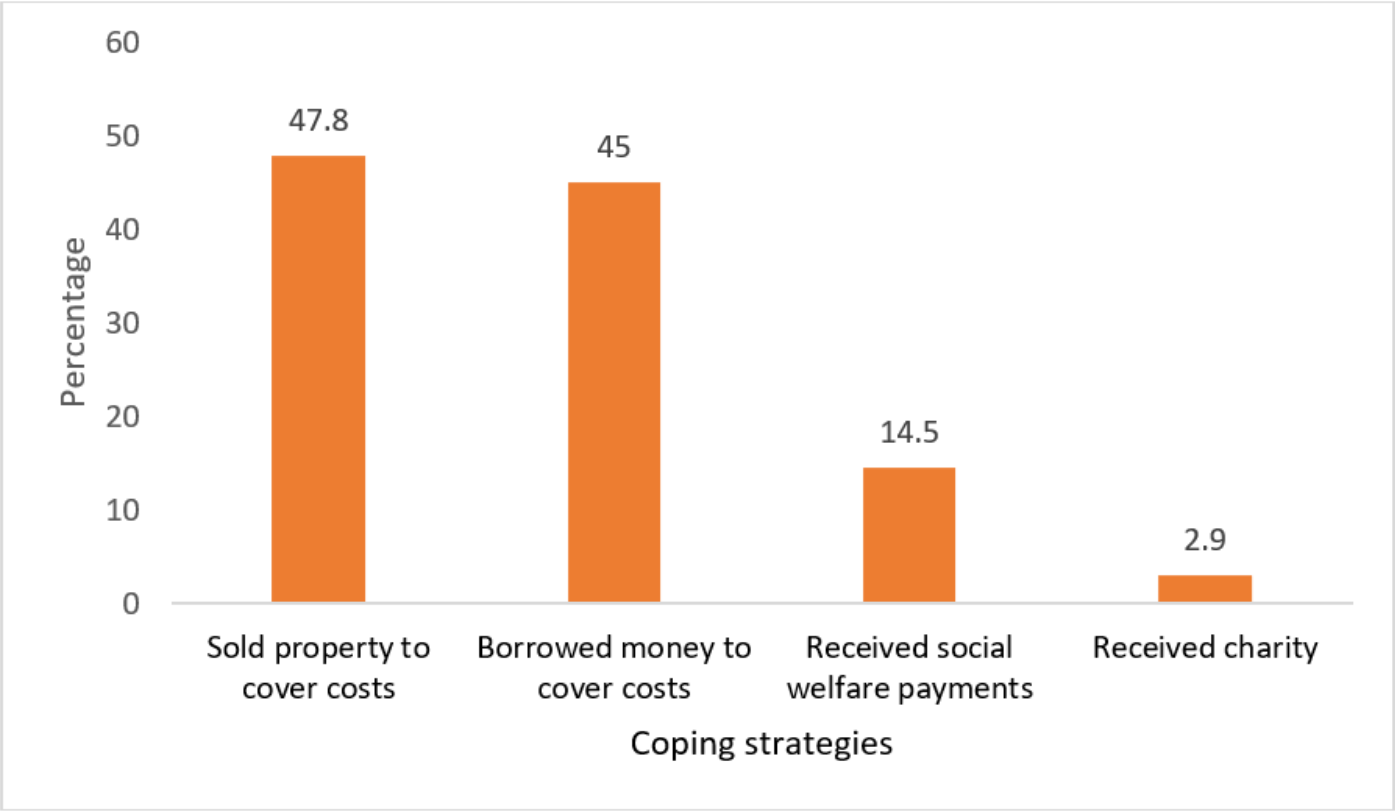

Figure 4

Coping Strategies related to surgical management of HD

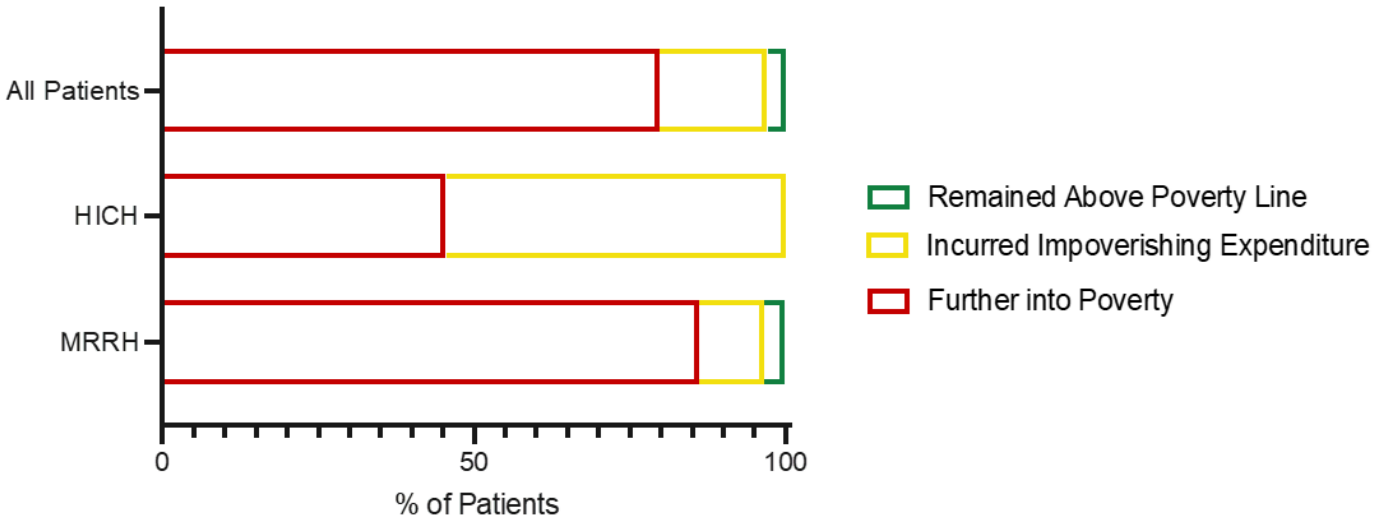

Figure 5

Impoverishing Expenditure for HD Surgery