# Economic Burden of Spinal Muscular Atrophy (SMA) in Singapore: Direct Medical Costs Amidst Absence of Disease-Modifying Treatments and other Patient-Borne Costs

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## INTRODUCTION

Spinal Muscular Atrophy (SMA) is a debilitating, progressive neuromuscular disease affecting 1 in 10,000 births and is considered a rare disease[1]. SMA treatment costs are high and its effects on government healthcare financing sustainability, and financial burden on patients are concerning and warrants examination[2]. By quantifying the financial burden imposed by SMA on individuals, families, healthcare system and society, it informs healthcare financing policies and resource allocation.

## OBJECTIVE

This pioneering study aimed to evaluate direct medical costs of SMA in Singapore's multi-payer healthcare system from the government's and patients' perspective. Information from this study serves to inform policy supporting SMA families, particularly in Singapore where reimbursement decisions prioritize the healthcare system perspective.

## METHODS

| | | | |
|---|---|---|---|
| **Study Design** | Retrospective cohort study | | |
| **Data Source** | Electronic medical records from National University Hospital (NUH) and KK Women's and Children's Hospital (KKH) | | |
| **Patient Population** | Children and young adults with SMA | | |
| **Identification of SMA Patients** | • ICD-10 code G12.0 for cases from 2011 onwards<br>• ICD-9 code 335.0 for cases before 2011 | • Additional outpatient cases identified using SNOMED codes | |
| **Data availability** | Inpatient admission data | 2014 to 2018 for NUH | 2014 to 2019 for KKH |
| | Outpatient data | 2004 to 2019 for NUH | 2015 to 2019 for KKH |
| **Data analysis** | Data within the common period of data availability (2014-2018 inpatient data and 2015-2019 outpatient data) was analyzed. The analysis examined the types of healthcare services consumed, government subsidies, and patient out-of-pocket payments. Costs were adjusted to 2022 Singapore dollars (SGD) with the healthcare specific consumer price index in Singapore. *Currency conversion: 1 USD = 1.35 SGD* | | |

## RESULTS

***Patient population*** • Number of patients: 61 • Mean age: 14.9 years old • Mean follow-up duration: 3.5 years

***Inpatient healthcare utilization***

**No. of admissions:** 49 admissions
- 53.0% day-admissions for polysomnography

**Patient composition:**
- Private patients: 14.2%
- Subsidized patients: 85.7%

**Average duration of non-elective hospitalizations:** 14.4 days

**Gross cost per day before taxes and subsidies:** USD1,134.88

**Government subsidies:**
- Decrease out-of-pocket bill for subsidized patients by ~USD347.52 per admission day compared to private patients.

**Top cost per patient year:** • Ward charges • Respiratory support • Diagnostic tests

**Top out-of-pocket costs:** • Scoliosis rod implants • Respiratory support

***Outpatient healthcare utilization***

**Service utilization:**
- Average no. visits: ~ 4 times annually.
- Annual outpatient cost per patient: USD641.39 per year.

**Government subsidies:**
- Reduced financial burden by USD589.43 per year for subsidized class patients compared to private class patients

**Top cost per patient year**
- Medicine
- Rehabilitation

***Overall direct medical costs***

**Annual average direct medical cost per capita**
- SMA: ~ USD3,306.65 per patient
- Chronic Disease*[4]: ~ USD2,810.59 per patient

*Hypertension, heart disease, stroke, transient ischemic attacks, diabetes, depression, arthritis, chronic obstructive pulmonary disease, asthma, and cancer.

Table 1. Average inpatient cost and utilization, mean (SD) (2014-2018)

| Billing Class | Gross cost per day (USD) | Subsidy per day (USD) | Bill payable per day (USD) | Length of stay (days) |
|---|---|---|---|---|
| ALL | 1,134.88 (672.57) | 614.15 (447.40) | 531.24 (382.21) | 6.22 (10.89) |
| Ward A, B1 (Private) | 800.04 (282.04) | 28.87 (49.12) | 827.16 (336.20) | 9.86 (21.69) |
| Ward B2, C (Subsidized) | 1,200.34 (643.77) | 723.69 (382.03) | 479.64 (355.67) | 5.73 (8.89) |

Table 2. Average outpatient cost and utilization, mean (SD) (2015-2019)

| Billing Class | Gross cost per year (USD) | Subsidy per year (USD) | Bill payable per year (USD) | No. of visits per year |
|---|---|---|---|---|
| ALL | 641.39 (730.72) | 163.99 (247.60) | 450.92 (575.11) | 4.06 (4.9) |
| Private | 730.89 (1,066.48) | 0 (0) | 835.18 (1,141.13) | 4.28 (3.66) |
| Subsidized | 519.62 (621.36) | 213.65 (238.07) | 243.46 (402.81) | 2.95 (5.22) |

## DISCUSSION

This study highlights significant direct medical costs of SMA for patients and the healthcare system. SMA's impact on respiratory, swallowing, and musculoskeletal functions leads to higher average costs compared to other chronic diseases. Government subsidies are helpful in containing costs for many families, but direct medical costs alone do not capture economic burden, which include significant private healthcare costs, non-medical expenses, caregiver burden, and intangible effects such as quality of life for the patient and family[3]. Disease-modifying treatments could reduce direct medical costs if the need for interventions like scoliosis surgery or respiratory support is reduced. While medication costs may rise, there could be offsetting reductions in other expenses. Targeted measures are urgently needed to ease the financial burden on patients and ensure sustainable healthcare financing.

## DECLARATION

Ethics approval: National Healthcare Group Domain Specific Review Board (NHG DSRB 2020/01428)
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