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SURGERY IN LOW AND MIDDLE INCOME COUNTRIES

Waiting Too Long: The Contribution of Delayed Surgical Access to Pediatric Disease Burden in Somaliland

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Abstract

Background Delayed access to surgical care for congenital conditions in low- and middle-income countries is associated with increased risk of death and life-long disabilities, although the actual burden of delayed access to care is unknown. Our goal was to quantify the burden of disease related to delays to surgical care for children with congenital surgical conditions in Somaliland.

Methods We collected data from medical records on all children (n = 280) receiving surgery for a proxy set of congenital conditions over a 12-month time period across all 15 surgically equipped hospitals in Somaliland. We defined delay to surgical care for each condition as the difference between the ideal and the actual ages at the time of surgery. Disability-adjusted life years (DALYs) attributable to these delays were calculated and compared by the type of condition, travel distance to care, and demographic characteristics.

Results We found long delays in surgical care for these 280 children with congenital conditions, translating to a total of 2970 attributable delayed DALYs, or 8.4 avertable delayed DALYs per child, with the greatest burden among children with neurosurgical and anorectal conditions. Over half of the families seeking surgical care had to travel over 2 h to a surgically equipped hospital in the capital city of Hargeisa.

Conclusions Children with congenital conditions in Somaliland experience substantial delays to surgical care and travel long distances to obtain care. Estimating the burden of delayed surgical care with avertable delayed DALYs offers a powerful tool for estimating the costs and benefits of interventions to improve the quality of surgical care.

Introduction

Timely surgical care is essential for the provision of high-quality health care, and delays in care may lead to needless suffering as well as poor outcomes from surgical procedures. Within low- and middle-income countries (LMICs), the need for surgical care among children is great, as more than 50% of the population are children, many of whom have significant surgical needs [1–3]. Congenital conditions affect an estimated 150 million children around the world, with 92% of the congenital conditions occurring in LMICs [4, 5]. Moreover, an estimated 17–43% of infant mortality is attributed to congenital anomalies. [6]

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The preferred metric for measuring the global burden of disease is the disability-adjusted life year (DALY), which estimates the gap between current and ideal health statuses, and accounts for both the mortality and morbidity of a health state [7]. The Global Burden of Disease (GBD) study has been indispensable in informing policy and resource allocation by providing detailed measures of disease burden across populations using the DALY metric [7]. In the case of surgical conditions, DALYs should reflect both the patient statuses before and after surgical treatment, as well as account for the timeliness of receiving care and hence the *burden of waiting* [8, 9]. Burden of disease assessment can distinguish between *met* need measured in *averted* DALYs following provision of surgical care, *unmet* need measured in *avertable* DALYs if surgical care is possible but is not provided, and *unavertable* need resulting from unavoidable health consequences regardless of any surgical intervention [9]. Finally, *delayed* DALYs can quantify the "lost" suffering of patients who had lived for years with their disabling surgical condition before surgical care was eventually provided [10].

Targeted interventions to reduce the burden of unmet surgical care can inform strategic allocation of health resources. However, few studies have quantified the contribution of delayed access to care to the unmet surgical burden of disease, particularly for surgical conditions in children. In this study, we measured delays to surgical care for children with congenital surgical conditions in LMICs, specifically quantifying the met, unmet, and delayed burden of surgical conditions using the DALY metric. This study is an extension of our previous work exploring surgical care for children in Somaliland, in which we have demonstrated a high prevalence of surgical conditions in children across the country [11].

Materials and methods

We performed a nationwide analysis using secondary data collected from medical records across all 15 surgically equipped hospitals in Somaliland. We collected data on all children receiving surgery for a proxy set of congenital conditions over a 12-month time period. The ideal age of surgery for each condition was derived using current clinical practice guidelines across both high-income countries and LMICs for all conditions. We defined delays to surgical care for each condition as the difference between the ideal and the actual ages at the time of surgery. DALYs attributable to the delays were then calculated as detailed below. Delays in care were compared by surgical specialty, distance to definitive care, and demographic characteristics.

Setting

With a gross domestic product per capita of $347 (PPP), Somaliland is the fourth poorest country in the world and is classified as a low-income country by World Health Income group [12]. Pediatric health metrics in Somaliland are some of the lowest globally, with infant and under-5 mortality rates over double the sub-Saharan African average [13].

Data collection

We collected data from all hospitals in Somaliland having surgical capacity for children, with hospitals identified by Somaliland medical officials and local medical leadership, as summarized in the parent study [11]. In brief, all hospital surgical records for cases at 15 hospitals in Somaliland between August 2016 and July 2017 were reviewed. We chose to include only congenital conditions, since the date of onset of the condition is uniformly known as the date of birth, facilitating the calculation of attributable DALYs. We collected data on patient age, gender, village and region of residence, surgical procedure performed, date of surgery, and functional outcome (if available).

Proxy set of congenital conditions

We identified all children with congenital conditions between August 2016 and July 2017 at the 15 selected hospitals ($n = 285$). Of the 285 children, 5 had an unspecified congenital condition indicated as a birth defect and were eliminated from the final study sample, resulting in 280 children (Table 1). We classified these children into specialty categories, including neurosurgery (hydrocephalus, spina bifida, and encephalocele), plastic surgery (cleft lip and/or cleft palate), orthopedic surgery (clubfoot), general surgery (anorectal malformations and inguinal hernia), and urology (hypospadias).

Travel distances

Patients' self-reported villages of residence were located through Google Maps and confirmed with local collaborators for accuracy. In cases where villages could not be located on Google Maps, the location was identified through consensus by Somaliland hospital staff, Ministry of Health officials, and professional drivers, and then given approximate GPS coordinates. To estimate travel time to surgical care, we chose to measure travel time (in hours) for each child to the capital city of Hargeisa, since 86% of children with congenital anomalies in our study received care in Hargeisa. Travel time was defined as the time it takes in hours for a driver with a vehicle to travel to

Table 1 Number of procedures, by gender and residence region

		Gender		Region where surgery was received		Travel distance to receive surgery in Hargeisa			
	Total (n = 280)	Male (n = 168)	Female (n = 112)	Maroodi Jeex (n = 249)	Other regions (n = 31)	Within 2 h (n = 139)	2.1–6 h (n = 61)	6.1–10 h (n = 19)	Greater than 10 h (n = 61)
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Neurosurgery	141 (50.4)	74 (44.0)	67 (59.8)	135 (54.2)	6 (19.4)	46 (33.1)	36 (59.0)	14 (73.7)	45 (73.8)
Hydrocephalus	95 (67.3)	56 (75.7)	39 (58.2)	93 (68.9)	2 (33.3)	23 (50.0)	29 (80.6)	8 (57.1)	35 (77.8)
Spina Bifida	39 (27.8)	18 (24.3)	21 (31.3)	35 (25.9)	4 (66.7)	19 (41.3)	5 (13.9)	5 (35.7)	10 (22.2)
Encephalocele	7 (4.9)	0 (0.0)	7 (10.5)	7 (5.2)	0 (0.0)	4 (8.7)	2 (5.5)	1 (7.1)	0 (0.0)
Plastic Surgery	81 (29.3)	54 (32.1)	27 (24.1)	63 (25.3)	18 (58.1)	62 (44.6)	12 (19.7)	2 (10.5)	5 (8.2)
Cleft Lip	49 (60.5)	33 (61.1)	16 (59.3)	41 (65.1)	8 (44.4)	36 (58.1)	9 (75.0)	0 (0.0)	4 (80.0)
Cleft Palate (with/ without CL)	32 (39.5)	21 (38.9)	11 (40.7)	22 (34.9)	10 (55.6)	26 (41.9)	3 (25.0)	2 (100.0	1 (20.0)
Orthopedics	24 (8.6)	14 (8.3)	10 (8.9)	24 (9.6)	0 (0.0)	10 (7.2)	5 (8.2)	2 (10.5)	7 (11.5)
Clubfoot	24 (100.0)	14 (100.0)	10 (100.0)	24 (100.0)	0 (0.0)	10 (100.0)	5 (100.0)	2 (100.0)	7 (100.0)
General Surgery	23 (8.2)	15 (8.9)	8 (7.1)	18 (7.2)	5 (16.1)	12 (8.6)	7 (11.5)	1 (5.3)	3 (4.9)
ARM	13 (56.5)	6 (60.0)	7 (87.5)	13 (72.2)	0 (0.0)	8 (66.7)	2 (28.6)	1 (100.0)	2 (66.7)
Inguinal Hernia	10 (43.5)	9 (40.0)	1 (12.5)	5 (27.8)	5 (100.0)	4 (33.3)	5 (71.4)	0 (0.0)	1 (33.3)
Urology	11 (3.9)	11 (6.6)	0 (0.0)	9 (3.6)	2 (6.5)	9 (6.5)	1 (1.6)	0 (0.0)	1 (1.6)
Hypospadias	11 (100.0)	11 (100.0)	0 (0.0)	9 (100.0)	2 (100.0)	9 (100.0)	1 (100.0)	0 (0.0)	1 (100.0)

ARM anorectal malformation, *CL* cleft lip

Hargeisa given current road conditions and was defined for each child through consensus by Somaliland hospital staff, Ministry of Health officials, and professional drivers. Travel time was stratified as 0–2 h, 2.1–6 h, 6.1–10 h, or more than 10 h. In cases where the village of residence was outside of Somaliland (i.e., Somalia or Ethiopia), travel times were considered 24 h due to the large number of variables which can affect travel.

DALY calculations

The DALY metric measures overall disease burden by incorporating years of life lost to poor health, disability, or early death [14]. We calculated DALYs attributable to delays in surgical care (*delayed* DALYs) as the burden resulting from the difference between the optimal and actual dates of surgery (Fig. 1). The optimal age of surgery, for each condition, was incorporated in the DALY metric according to established recommended ages for intervention, while the actual age of surgery was collected from the surgical record review [15–22]. The disability weights (DW) for each condition both before and after surgical interventions were obtained from published values [23] or, for conditions without available DWs, estimated by combining expected disabilities associated with the condition based on Salomon's classification [24, 25]. Conditional

Fig. 1 Calculation of DALYs attributable to delayed care

Without discounting:

$$DALY_a = \left(\sum_{t=0}^{DOS_{act}} dw_u + \sum_{t=DOS_{act}}^{LE_{DOS}} dw_t \right) - \left(\sum_{t=0}^{DOS_{opt}} dw_u + \sum_{t=DOS_{opt}}^{LE_{DOS}} dw_t \right)$$

With discounting

$$DALY_a = \left(\sum_{t=0}^{DOS_{act}} \frac{dw_u}{(1+r)^t} + \sum_{t=DOS_{act}}^{LE_{DOS}} \frac{dw_t}{(1+r)^t} \right) - \left(\sum_{t=0}^{DOS_{opt}} \frac{dw_u}{(1+r)^t} + \sum_{t=DOS_{opt}}^{LE_{DOS}} \frac{dw_t}{(1+r)^t} \right)$$

where r = discount rate, DOS_{opt} and DOS_{act} are the optimal and actual dates of surgery, and LE_{DOS} is the conditional life expectancy *given* that the patient has survived to the date of their surgery (ie, not LE at birth).

country-specific life expectancies in 2016 for males and females were calculated from the age of the child at the date of their surgery. The life expectancy at birth was used for children less than 1 year (53.7 years for males, 57.3 years for males). After 1 year of age, the following conditional life expectancies were used: 57.9 years for males and 61.1 years for females between the ages of 1 to 4 years; 57.2 years for males, 60.6 years for females between 5 and 9 years; 53.3 years for males and 56.7 years for females between 10 and 14 years; and 48.7 years for males and 52.1 years for females older than 15 years. A 3% discount rate was used for future DALYs [26].

Statistical analysis

Demographic characteristics of the children, including gender, region where the surgery was received, and travel distance to the capital city of Hargeisa were compared between surgical specialties and within each specialty by specific condition. The delayed DALYs were compared by surgical specialty, condition, gender, age, region where surgery was received, and travel time to Hargeisa using the Wilcoxon Chi-squared test statistic between median values for each group.

Ethical considerations

Institutional review board (IRB) approval was granted from Duke University. Since Somaliland does not have a national IRB, a letter of approval was granted from the Somaliland Ministry of Health. Participants in the community survey offered verbal consent for study participation. A parent or guardian provided consent for all children younger than 15 years old, and children between the ages of 12 and 15 provided assent. For the majority of children enrolled, parents answered all questions in the survey. Patients or public members were not involved in the development, design, or recruitment of the study. Results will be disseminated to the patients and relevant communities through the collaboration with the in-country partners at the Edna Adan University Hospital.

Results

We found long delays in presentation to surgical care for children with congenital conditions, translating to a total of 2362 DALYs attributable to delays in care for the 280 children—or an average of 8.4 avertable delayed DALYs per child, a value similar to other public health interventions in resource-limited settings. The greatest delayed burden was due to children with anorectal malformations and hypospadias, which had nearly three times the average number of delayed DALYs for 280 children.

Over a 12-month period, 280 children received a surgical procedure for congenital conditions. Most children (60%) were male, and 249 (89%) were from the urban region of Maroodi Jeex (Table 1). Stratified by surgical specialty, 141 (50%) received neurosurgical procedures, 81 (29%) plastic surgical procedures, 9% orthopedic procedures, and the remaining children underwent general surgical or urologic procedures. Among the 280 children, 139 travelled less than 2 h, 61 2.1 to 6 h, 19 children 6.1 to 10 h, and 61 children more than 10 h (Fig. 2).

The median age at surgery ranged from less than 1 month (interquartile range IQR: 0.69, 7.0) for children with encephaloceles to 120 months (IQR: 60.0, 132.0) for children with hypospadias, resulting in median delays ranging from 1 month (IQR: 0.69, 7.0) for encephaloceles to 108 months (IQR: 48.0, 120.0) for hypospadias (Table 2). A total of 2362.2 DALYs were associated with delayed presentation to surgical care. Avertable DALYs associated with delayed presentation to surgical care ranged from less than 290 for urologic and orthopedic conditions to over 700 for neurosurgical conditions.

Delayed avertable DALYs were higher among males compared to females (1538.0 versus 823.3 DALYs, respectively) (Fig. 3). When stratified by age, older children had more delayed avertable DALYs than children younger than 4 years of age. Delayed DALYs equaled 2223.0 in the Maroodi Jeex region, compared to 139.2 in the other regions. Children who lived within 2 h of Hargeisa had the highest number of delayed DALYs, followed by children who lived over 10 h away.

Discussion

In LMICs, timely receipt of surgical care for children with congenital conditions is critical, as congenital conditions are associated with life-long disabilities or mortality if not promptly treated [6, 27–29]. We found substantial delays to surgical care for children with congenital conditions in Somaliland. Assessing the burden of delayed unmet surgical care provides an opportunity to quantify the impact of delays on overall disease burden and gives us a powerful tool to estimate the costs and benefits of interventions to reduce delays in care.

The DALYs metric is the most common health metric used in global disease burden computations, cost-effectiveness studies, and analyses of allocation of resources [30]. Although estimating the cost-effectiveness and financial impact of pediatric surgical conditions is challenging in LMICs [31, 32], it is essential to quantify the impact of delayed care to understand the economic impact

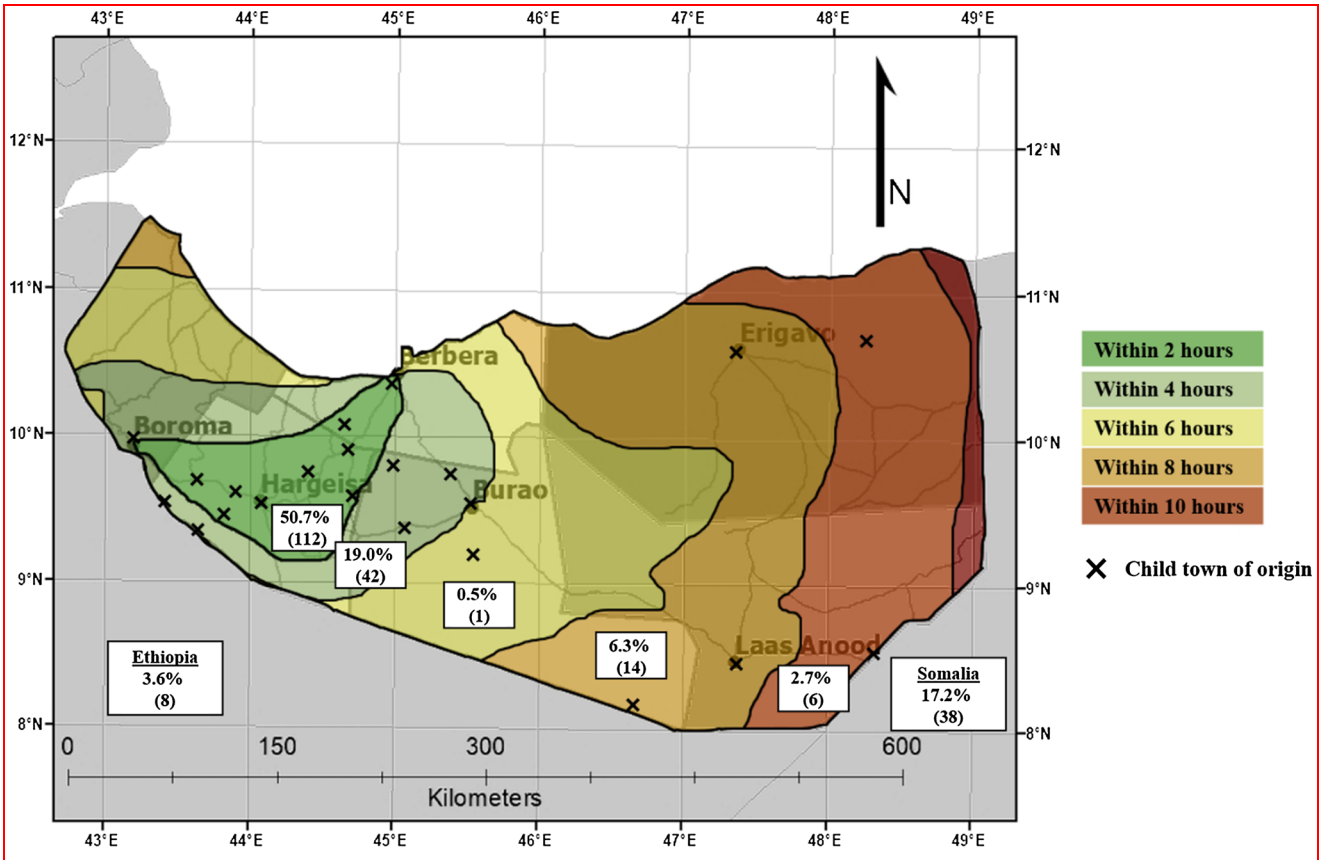

Fig. 2 Travel distances to receive surgical care for congenital conditions at hospitals in Hargeisa (n = 221)*. *includes children seen at hospitals in Hargeisa who identified their village of residence

of these conditions. Delays in the provision of surgical care in children result not only in needless suffering, but can also increase the economic impact on a child and community. Although congenital conditions are not always life-threatening, severe disability can occur if not treated promptly. For example, untreated or delays in treatment for cleft lip and/or palate can result in breastfeeding and eating hardships, resulting in malnutrition or stunting, and stigma or social discrimination [33, 34]. Delayed care to definitive treatment of anorectal malformations can result in substantial morbidity, stigmatization, and barriers to attending school [35]. In addition, delayed presentation to care increases the likelihood of having a comorbidity of chronic constipation, anemia, malnutrition, and fecal impaction, thereby influencing the efficacy of surgical intervention if sought.

The traditional use of the DALY metric does not allow for understanding of how delays in care in impact burden of disease assessment, nor does it account for variable residual disabilities postoperatively. Recent editions of the GBD study have provided postoperative (residual) disability weight values for a small group of pediatric conditions [24]. However, these values are based on the assumption that treatment was provided at the appropriate time and to a standard of surgical care, not for delayed care which may be associated with greater disease severity and increased potential for postoperative surgical complications [23]. In our study, we used the approach of incorporating delays in care directly into the DALY metric by adjusting for the age at presentation, thereby accounting for the "lost" burden suffered by children while waiting for their surgical care [36]. Although this calculation still does not account for the potentially higher residual disability after surgery when surgical care is provided at a more advanced age, incorporating delayed DALYs results in more accurate burden of disease and economic impact estimates [24, 37–40].

The delayed DALYs related to surgical procedures for children (mean of 8.4 averted DALYs/child) are comparable to other public health interventions. For example, antiretroviral therapy to prevent mother-to-child transmission of HIV averts 8.6 DALYs compared to no treatment

Table 2 Recommended age of surgery, disability weights, mean delay to surgery, and delayed averted burden, by condition

	Recommended age of surgery	Disability weight (untreated)	Disability weight (treated)	Median age at presentation (months, IQR)	Median delay to surgery (months, IQR)	Total averted DALYs	Mean averted DALYs per child
Neurosurgery				5.0 (1.5, 8.0)	4.0 (1.0, 7.0)	702.1	4.9
Hydrocephalus	1 month [15]	0.74 [48]	0.30 [49]	6.0 (2.0, 9.0)	5.0 (1.0, 8.0)	613.6	6.5
Spina Bifida	48 h of life [16]	0.605 [48]	0.221 [49]	2.0 (0.66, 5.0)	1.9 (0.59, 4.9)	79.1	2.1
Encephalocele	At birth [17]	0.60 [50]	0.221 [49]	1.0 (0.69, 7.0)	1.0 (0.69, 7.0)	9.5	1.4
Plastic Surgery					27.0 (4.5, 67.5)	634.78	7.8
Cleft Palate	6–12 months [18]	0.231 [49]	0.013 [49]	60.0 (19.5, 66.0)	51.0 (10.5, 57.0)	284.7	5.8
Cleft Lip	3–6 months [18]	0.122 [51]	0.013 [49]	24.0 (9.0, 72.0)	19.5 (4.5, 67.5)	350.1	10.9
Orthopedic				54.0 (21.0, 120.0)	47.0 (14.0, 113.0)	236.9	9.8
Clubfoot	7 months [19]	0.20 [50]	0.013 [49]	54.0 (21.0, 120.0)	47.0 (14.0, 113.0)	236.9	9.8
General Surgery				42.0 (3.0, 72.0)	35.9 (0.0, 59.0)	507.2	22.1
ARM	Within 3 days [20]	0.85 [50]	0.123 [49]	36.0 (0.0, 60.0)	35.9 (0.0, 59.9)	365.1	28.1
Inguinal hernia	3 years [21]	0.50 [52]	0.00 [49]	57.0 (24.0, 72.0)	21.0 (0.0, 36.0)	142.1	14.2
Urology				120.0 (60.0, 132.0)	108.0 (48.0, 120.0)	281.2	25.6
Hypospadias	6–18 months [22]	0.31 [48]	0.013 [49]	120.0 (60.0, 132.0)	108.0 (48.0, 120.0)	281.2	25.6
					TOTAL	2362.2	8.4

ARM anorectal malformation; IQR interquartile range; SD standard deviation

Mean ages used include: 9 months—cleft palate with or without cleft lip; 4.5 months—cleft lip; 12 months—hypospadias

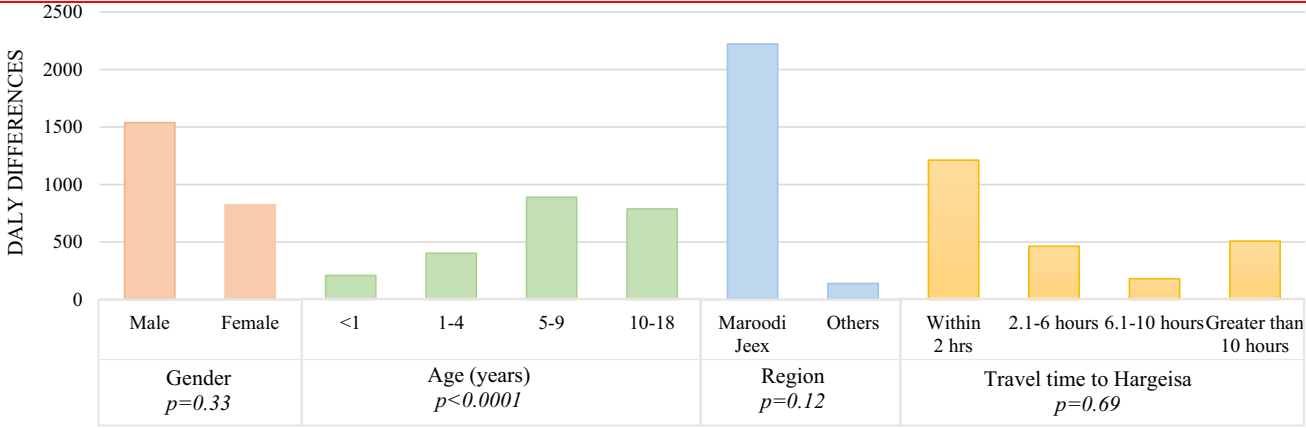

Fig. 3 Delayed DALY differences by gender, age, region, and travel time

[41]. Investment in surgical care is a cost-effective public health measure [42]. We found a similar large number of delayed averted DALYs for patients with hypospadias and anorectal malformations [43].

The provision of high-quality surgical care is multi-dimensional and requires prompt care as well as adequately trained workforce, supplies, and other resources [44–46]. Our data provide evidence of the large impact of delays in surgical care among children with congenital anomalies in low-income settings. The inability to receive surgical care depends on many barriers, including patient, institutional, and structural factors [2, 47–52]. At a patient level, the delay in receiving surgical care often occurs because of financial restrictions or travel barriers if a health facility is

too far away. In Somaliland, 29% of people live in urban areas such as Maroodi Jeex, and 38% of those living in rural areas are classified as living in poverty [53]. In addition, families with a child with a surgical need are more likely to become impoverished and remain in poverty due to the expenses around the procedure and other non-medical costs [54]. Interestingly, the highest number of delayed DALYs occurred among children from that same area, indicating that even families living close to the country's highest level hospitals experience long delays in care.

Our study has several limitations: First, although the surgical logbooks contained information on the children's age, procedure, and residence location, we were not able to assess elements which could influence delays in care, such as manpower or infrastructure limitations, or associated comorbidities. Second, our calculations for delays in care rely on published recommended ages at which children in high-income countries (HIC) typically undergo surgical care. Although these ages have been used in similar analyses of surgical care in LMICs [55], such recommendations may not be transposable to the context of care in Somaliland—where, for instance, safe pediatric anesthesia considerations may delay the ideal surgical time. Third, the institution-based design of our study would exclude children with similar conditions who never reached a hospital, suggesting a potential survivor bias. Thus, the DALY estimates may underestimate the true burden of disease for congenital conditions. Future studies would ideally include community-derived data in order to account for the hidden burden of children who die before reaching hospital care [56].

In summary, our study demonstrates a significant and quantifiable burden of delayed surgical care for children with congenital conditions in Somaliland. Moving forward, quantifying further the impact of delays in care may be helpful for accurately assessing the burden of conditions requiring surgery in LMICs [57]. Further research on the causes of delays in care may help identify specific geographic regions or populations to target for health care expansion and inform the future configuration of services. Our findings further support the growing body of evidence that scaling up pediatric surgery in LMICs can markedly improve the quality and outcomes of health care of children.

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