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Burden of Surgically Correctable Disabilities Among Children in the Dadaab Refugee Camp

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Abstract

Background Surgery is increasingly recognized as a means to reduce the morbidity and mortality of disabling impairments in resource-limited environments. We sought to estimate the burden of surgically correctable disabling impairments and the cost-effectiveness of their treatment among children in a large refugee camp.

Methods This is a chart review of all patients aged 0–18 years from Dadaab Refugee Camp (Kenya) treated at a facility primarily responsible for providing pediatric surgical care in the region. Total disability-adjusted life years (DALYs) averted were calculated using life expectancy tables and established or estimated disability weights. A sensitivity analysis was performed using various life expectancy tables. Delayed averted DALYs caused by delay in care were also estimated. Inpatient costs were collected to perform a cost-effectiveness analysis.

Results Between 2005 and 2011 a total of 640 procedures were performed on 341 patients. The median age at surgery was 4.6 years, and 33 % of the children treated were female. Only 13.5 % of surgeries estimated as required for common congenital surgical conditions were actually performed. The total number of DALYs averted ranged from 4,136 to 9,529 (6.4–14.8 per patient), depending on the calculation method used. Cost-effectiveness analysis resulted in values of $40–$88 per DALY.

Conclusions The burden of pediatric surgical disabling impairments in refugee camps is substantial. Surgical intervention to address this burden is both feasible and cost-effective. Such intervention can significantly decrease the burden of disability among children affected by armed conflicts.

Introduction

Childhood disability is a significant cause of morbidity, especially in low- and middle-income countries (LMICs). The World Health Organization (WHO) estimates that 150 million children suffer from some type of disability globally, most of whom reside in LMICs with limited access to medical care [1]. Multiple studies have shown that children with functional disabilities have substantially decreased quality of life (QOL) when compared to nondisabled children [2–4]. Some of this decrease in QOL in LMICs results from marginalization and stigma, both in the home and in the community [5, 6]. Evidence exists that childhood disability is a major risk factor for limitations in daily activities into adulthood [7].

Dadaab refugee camp

Shortly after the outbreak of the civil war in Somalia, the Dadaab camp was opened in 1992 in northeastern Kenya. Originally built for fewer than 90,000 inhabitants, it is currently home to more than 460,000 predominantly Somali refugees, with other refugees originating in other unstable neighboring countries [8, 9]. Health care in the camp is provided by several humanitarian organizations under the umbrella of the United Nations High Commission for Refugees (UNHCR). As a result of the ongoing

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conflict in the horn of Africa, the already limited health care resources in the camp are continuously stretched by increasing numbers of refugees (typically more than 1,000 new arrivals daily). Disabilities among the refugees are frequent and significant [10] because of the larger proportion of vulnerable persons seeking refuge and the extremely limited health care provision for the past two decades in Somalia. This results in a significant backlog of care, with patients of all ages frequently presenting with untreated chronic surgical conditions and disabilities, both congenital and acquired.

Burden of surgical disease

Surgery plays an important role in reducing the burden of disabilities in LMICs. Congenital abnormalities represent an important cause of pediatric disability, and approximately half of such abnormalities require surgical intervention [11]. Moreover, trauma is frequently the commonest cause for children's surgery in LMICs [12], and when injuries are left untreated or are improperly treated chronic disability often ensues [7, 13]. Finally, it is estimated that only 3.5 % of all surgical procedures are performed in the poorest third of the world despite a burden of disease (BoD) greater than in the rest of the world [14].

Disability-adjusted life years (DALYs)—a health gap measure combining the morbidity and mortality associated with a disease—have become a standard metric to quantify BoD [15]. DALYs often highlight diseases with a chronic component: although only 3 % of all pediatric deaths are attributable to congenital malformations, they account for a staggering 24 million DALYs worldwide [15]. Within global surgery, BoD has been divided into the *met need* (surgical care already provided, or DALYs averted), *unmet need* (potentially avoidable/treatable disability and death due to surgical conditions, or DALYs avertable), and *unmeetable need* (disability and premature death that is unavoidable, even with the best surgical care) [16, 17].

DALYs lend themselves to cost-effectiveness analysis (CEA) by estimating the cost required to offset one DALY through any given health care intervention. Interestingly, surgical treatment has been shown to cost not more—and in fact often less—in $/DALY than proven medical interventions such as anti-retroviral therapy [18–20].

Whereas health care services to displaced people have been emphasized by the global health community [21, 22], surgical services are rarely mentioned. Moreover, the BoD stemming from conflict-related population migration has never been estimated to our knowledge—neither globally nor locally. The objective of this study was to calculate the burden of surgically averted disease among children in the world's largest refugee camp and estimate the cost-effectiveness of surgical intervention in this group. Such

information, especially when extended to populations, will be important for resources advocacy in the care of these vulnerable groups.

Methods

We reviewed the hospital records of all patients aged 0–18 years residing in the Dadaab Refugee Camp and treated at BethanyKids at Kijabe Hospital, the primary pediatric surgical provider for the camp. BethanyKids is an international faith-based organization dedicated to the holistic care of children with surgical conditions. The BethanyKids unit in Kijabe, Kenya has 65 beds, 2 operating rooms, and a full surgical and rehabilitation staff. Based on a long-lasting relationship with the UNHCR, BethanyKids surgeons have visited the refugee camp for patient screening and follow-up every 2 months since 2004.

Patient records were abstracted for sex, birth date, diagnosis, and surgical interventions. Outpatient records were excluded. The mean age of refugee patients undergoing common congenital procedures was compared to that of nonrefugee patients in the BethanyKids database during the same time period (8642 patients).

Estimates of the number of children in the camp with several common congenital conditions were derived as the sum of the yearly number of new cases expected in the camp for each condition (calculated using average global incidence rates per 1,000 and yearly birth estimates in the camp) plus the yearly number of refugee children expected to enter the camp with each condition. The latter value assumes (based on consistent observations over the study period) that no child born with the index conditions received adequate care before reaching the camp. An example of such a calculation follows.

No. of cleft lip cases expected in 2010 = 300,000 (average camp population in 2010 [23]) * 43/1,000 (Somalia birth rate) * 1/1,000 (average cleft lip incidence in Africa) + 13,000 (new refugees arrived in Dadaab in 2010) * 0.62 (percentage of children in Dadaab [23]) * 1/1,000 (average cleft lip prevalence) = 21.

DALY calculation

The BoD estimates were calculated using previously established methods and country-specific life tables provided by the Global Burden of Disease Study [24]. DALYs were calculated as the product of the years lived with the disability (YLD) and the disability weight. Both universal and specific life expectancy tables for the sampled

population (Somali) were used [25, 26]. Years of life lost (YLL) were estimated for each patient based on his or her life expectancy at time of treatment. Age weighting and future discounting [24, 25] are common methods in global burden of disease studies, but they remain somewhat controversial, especially when applied to children [27–29]. A sensitivity analysis was therefore performed on the life expectancy tables using both "plain" values without any age weighting or discounting [i.e., YLL (0.0)] and standard tables [YLL (3.1), denoting 3 % discounting of future years and applied age weighting] [26].

Averted DALYs (representing *met* need) were defined as the number of DALYs potentially gained through each surgical procedure by averting death (YLL) and decreasing morbidity from the condition for the rest of the child's expected life (YLD) [16]. The YLD estimate includes the disability weight (DW), the potentially less than unitary risk of permanent disability without surgery (RPD), and the less than unitary probability of a fully successful surgery (PST). The latter factor aims to account for both the possibility of postoperative complications and the need for further procedures. Although DWs already existed for a few pediatric surgical conditions [15], for the remaining conditions they were estimated by the authors using the functional scale provided by Murray [25]. Averted DALYs are thus calculated as previously described [20, 30] using the formula:

YLL * DW * RPD * PST,

where the last three terms are constrained between 0 and 1.

Averted DALY values can be calculated either per patient, or as a cohort/population total. For instance, a 6-year-old boy with hydrocephalus treated by ventriculoperitoneal shunt insertion would have 71.05 (YLL) * 0.4 (DW) * 1 (RPD > 95 %) * 0.7 (PST of 50–95 %) = 19.9 DALYs averted.

We also estimated the *delayed* averted BoD caused by the observed delays in provision of care (backlog) by multiplying the DW with the delay in care (age of actual operation minus the ideal age of operation). In the above example, the delayed averted surgical burden was (6.0−0.2) * 0.4 (DW) = 2.3 DALYs. Because of inherent challenges in attaining accurate histories of acquired conditions, this measurement was restricted to congenital malformations.

Cost-effectiveness analysis

Inpatient costs associated with surgical procedures were extracted from the patient database. They included actual patient bills for the operating room, hospital stay, medications and supplies, staff salaries, and administrative charges. Staff salaries were included in the hospital bill, but the surgeons volunteered their time and some surgical supplies were donated. The cost-effectiveness ratio was derived from the aggregate cost of all surgical admissions divided by the total DALYs averted through the procedures performed.

The Research Ethics Committee of BethanyKids at Kijabe Hospital approved this study.

Results

Between March 2005 and June 2011, 640 surgical procedures were performed at BethanyKids of Kijabe Hospital, Kenya on 341 children (under 18 years) from the Dadaab Refugee Camp. The median age of the children was 4.6 years, and 66 % were male. In all, 43 % of the procedures were performed for congenital anomalies and 57 % for acquired conditions.

The commonest congenital and acquired procedures performed are listed in Table 1, with the median age at operation. Figure 1 compares the age at surgery for the commonest congenital procedures on refugee children with that for a similar sample of nondisplaced patients during the same time period. Cleft lip repair and burn contracture release were the commonest major procedures performed for congenital and acquired conditions, respectively.

Figure 2 compares the expected cases of the five commonest congenital conditions over the study period with the actual number of procedures performed for those conditions. The overall ratio of surgeries performed over those expected was 13 % (range 10–30 %).

The estimated total and per-procedure averted DALYs are presented in Figs. 3 and 4, respectively. The delayed averted DALYs are shown in Fig. 5. Sensitivity analysis resulted in a total of 4,136–9,529 DALYs averted over the study period (corresponding to 6.4–14.8 DALYs per patient), evenly distributed between congenital (totaling 2,065–4,911 DALYs, or 7.4–17.6 DALYs per patient) and acquired conditions (totaling 2,071–4,618 DALYs, or 5.7–12.7 DALYs per patient). The total delayed averted surgical BoD for congenital malformations in this study cohort was estimated at 300 DALYs over the study period, representing 1.1 DALYs per patient.

The number of surgical procedures by specialty is compared to the respective averted BoD in Fig. 6. Plastic and general surgical procedures accounted for the most *total* attributable DALYs averted, and general and neurosurgical procedures resulted in the largest number of averted DALYs *per patient*. General surgery was also associated with the highest proportion of *delayed* averted DALYs (93.8).

Table 1 Most common congenital and acquired surgical procedures with their median age

| Procedure	No.	Median age at surgery (years)
Congenital		
Posterior medial release for club foot[a]	34	4.4
VP shunt insertion	31	1.3
Cleft lip repair	40	6.2
Hypospadias repair	26	5.8
PSARP for imperforate anus	17	1.6
Colostomy	15	2.0
Colostomy closure	14	2.2
Acquired		
Dressing change	111	3.7
Contracture release	66	5.9
Débridement	20	2.2
Cast change	14	8.6
Biopsy	12	8.1

VP ventriculoperitoneal, *PSARP* posterior sagittal anorectoplasty

[a] Club foot was treated surgically rather than with serial casting because of the advanced age of the patients
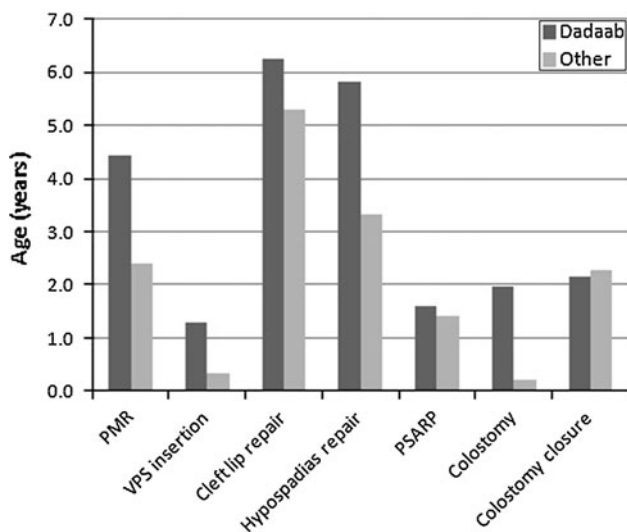
Fig. 1 Median age of patients undergoing various surgical procedures: refugee versus nonrefugee patients. *PMR* posterior median release, *VPS* ventriculoperitoneal shunt, *PSARP* posterior sagittal anorectoplasty

Accurate hospital bills were available for 289 surgical admissions (45 % of total). The total costs incurred for the surgical treatment of these children was $141,675. This figure yielded cost-effectiveness ratios between $40 and $88 per DALY. Cost-effectiveness ratios for each specialty are presented in Fig. 7, showing neurosurgical procedures to have the lowest cost per DALY ($26–$65).
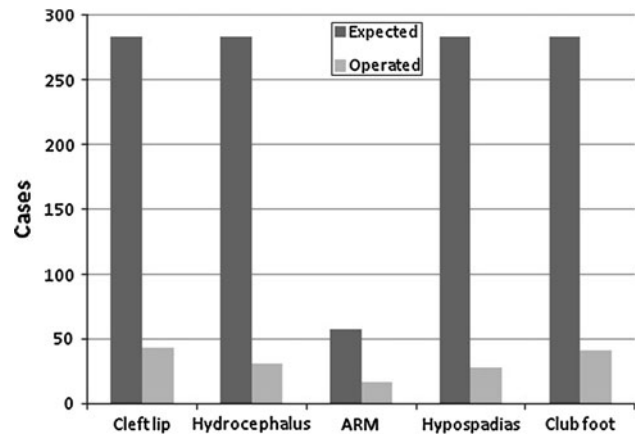

Fig. 2 Number of children with the five most common congenital conditions operated on in Dadaab versus estimated cases over the study period. *ARM* anorectal malformation

Discussion

Displaced persons are a significant vulnerable group globally, and children are among the most vulnerable in most limited-resource settings—yet the surgical needs of children in refugee camp settings have been ignored in the literature. This is the first study to quantify the burden of surgically correctable disabilities among children in a large refugee camp. Although the burden of surgical disease is generally neglected across sub-Saharan Africa [31], we found this burden to be highly significant in Dadaab. With the increasing backlog of persons seeking refugee registration in the camp, there is a compelling case to highlight the magnitude of the surgical work already performed, as well as still required, in this setting.

The demographics of the children cared for over the 6-year study period are not representative of any other known population group, as they reflect a multitude of forces affecting migrant populations in areas of armed conflict. Although there is no evidence that surgical disease is more common among refugees, vulnerable groups such as the young and the ill are preferentially evacuated from conflict areas, thus appearing in refugee camps more frequently than in the general population [23]. Limited data from Dadaab, however, reveals that many disabilities are not recognized. In 2009, only 2.6 % of the population were registered by the rehabilitation agencies [32]. Among these persons with disabilities, only 450 were under 18 years of age and had a physical disability. The total number of surgical procedures performed by BethanyKids over 5 years compares well with this figure, but it is obvious that 450 is a gross underestimate of pediatric physical disabilities in the camp, as many new children with surgical disabilities entered the camp during the study period. Figure 2 highlights the inadequacy of pediatric surgical
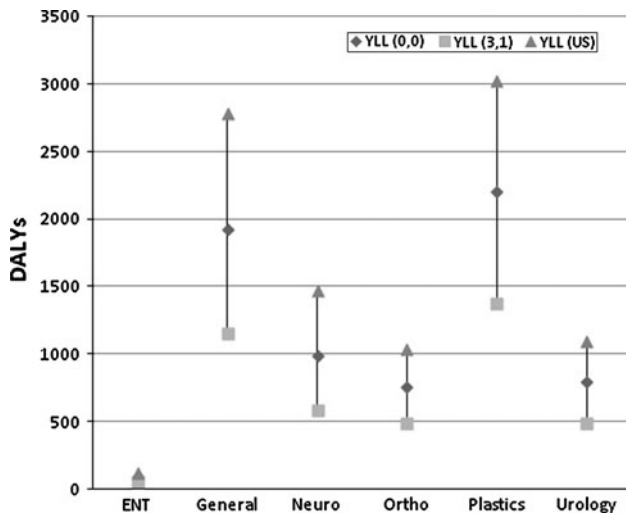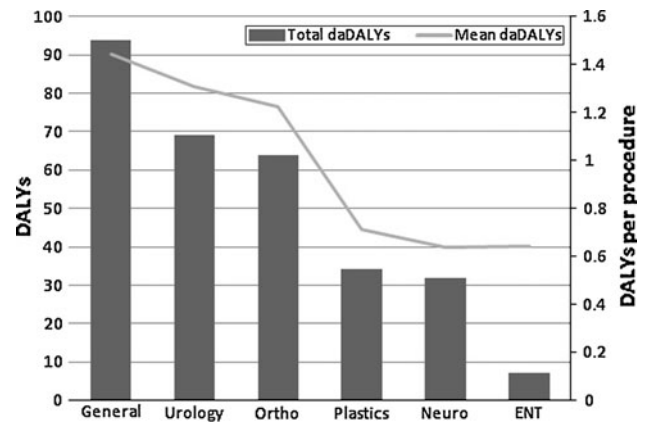
Fig. 3 Sensitivity analysis for total burden of disease (in DALYs) averted by surgical specialty. (*0.0*) DALYs using standard undiscounted Kenya life expectancy table, (*3.1*) DALYs using age-weighted and 3 % discounted Kenya life expectancy table, (*US*) DALYs using universal standard undiscounted life expectancy table. *DALYs* disability-adjusted life years, *YLL* years of life lost, *ENT* ears/nose/throat surgery, *Neuro* neurosurgery, *Ortho* orthopedic surgery, *Plastics* plastic surgery
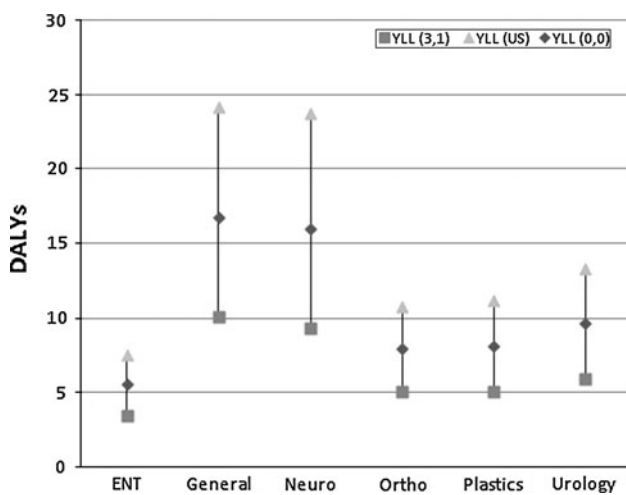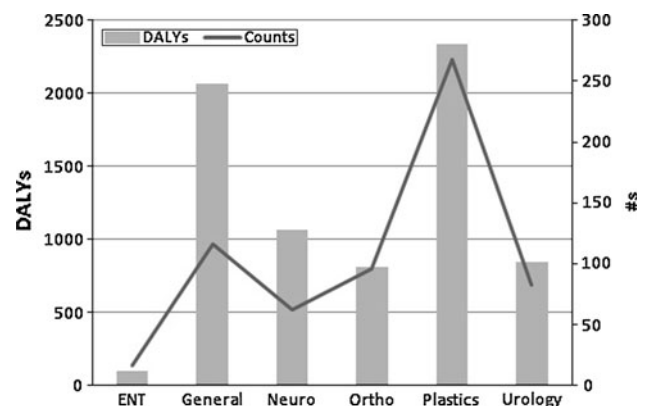

Fig. 4 Sensitivity analysis for burden of disease (in DALYs) averted per surgical procedure by surgical specialty. (*0.0*) DALYs using standard undiscounted Kenya life expectancy table, (*3.1*) DALYs using age-weighted and 3 % discounted Kenya life expectancy table, (*US*) DALYs using universal standard undiscounted life expectancy table

Fig. 5 Total and average delayed averted DALYs by surgical specialty. *daDALYs* delayed averted DALYs

Fig. 6 Number of surgical procedures and corresponding DALYs in each specialty

care in Dadaab: on average, only 13.5 % of the estimated children with congenital surgical disabilities received treatment. Although this figure is fraught with uncertainties and assumptions, it does provide a rough idea of the magnitude of the surgical need in this displaced population.

The male preponderance of the operated children mirrors the 60 % male refugee ratio found in several camp surveys [23]. Other explanations may include issues of

sex-based access to care and a higher prevalence of acquired injury-related surgical disabilities in the young male refugees.

The unique variety of surgical conditions, both congenital and acquired, presenting in the refugee camp reflects a population virtually devoid of previous access to surgical care. Thus, it is expected that most, if not all, of those with fatal conditions have died, whereas those with nonfatal conditions generally survived, first presenting for care at whichever age refugees reached the camp health care system (Table 1; Fig. 1). This extreme scenario virtually transforms urgent pediatric surgical conditions into chronic elective disabilities—as witnessed by teenagers and even adults with unrepaired open bladder exstrophy, cleft lip, or rectovestibular fistula.

This unique spectrum of diseases, quite different from that of "traditional" pediatric surgery, requires a corresponding unique skill set for any organization attempting to serve such populations. At BethanyKids, we have developed over the years such expertise and are passing it on to
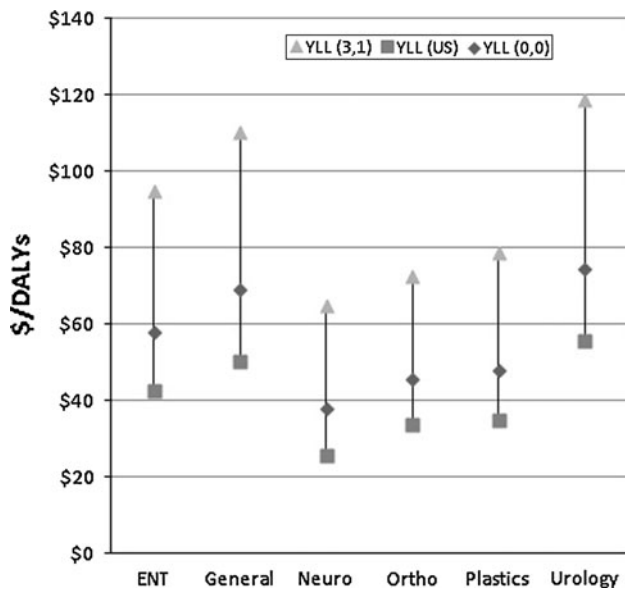
Fig. 7 Sensitivity analysis on cost per averted DALYs in each surgical specialty. (*0.0*) DALYs using standard undiscounted Kenya life expectancy table, (*3.1*) DALYs using age-weighted and 3 % discounted Kenya life expectancy table, (*US*) DALYs using universal standard undiscounted life expectancy table

national pediatric surgeons through a disability-focused accredited pediatric surgical training program.

Although DALYs may not provide the most accurate reflection of the true perception of a disease state by the individual [25], they have rapidly become the most common metric for BoD. The total BoD in any population includes met, unmet, and unmeetable components [16]. In the context of a refugee camp, the unmet need continuously fluctuates based on the demographics and health status of the incoming and outgoing refugees. However, because BethanyKids was the sole provider of pediatric surgical care in the camps over several years, we have had the unique opportunity to estimate the magnitude of the met need. This magnitude depends on the life tables used and the inherent assumptions regarding age weighting, future discounting, and use of country-specific versus universal tables (discussed earlier). Generally, the country-specific, discounted tables generated the lowest DALY values, while undiscounted, universal tables produced the highest. Although each of these options has its inherent pros and cons, it is reassuring that all DALY estimates were well within one order of magnitude.

The ability of DALYs to capture the burden of chronic disability is highlighted by the disparity between the numbers of surgical procedures in each specialty and their corresponding BoD. General surgical and neurosurgical procedures appear to be associated with the greatest BoD, likely because of the higher DW frequently characterizing congenital malformations in these specialties (e.g., imperforate anus, spina bifida).

Besides the *met* surgical need attributable to surgical interventions, our data allow calculation of the *delayed* averted burden caused by the years lived with disability preceding the surgical treatment. This previously unidentified factor is likely a sub-component of the *unmet* need, although its irrecoverable nature makes it behave more like an *unmeetable* need. Not only is past suffering not recoverable, but in the case of many pediatric surgical conditions, delay in care may be associated with more challenging surgical procedures and a higher likelihood of complications. A 20-year-old patient with an unoperated cleft palate will not only have suffered for 20 years from the sequelae of her condition, but her surgery will be more challenging than in a 1-year-old, and her speech deficits are likely irreversible. The advanced age at surgery for congenital malformations in the displaced children compared to nondisplaced ones (Fig. 1) highlights an even greater surgical backlog in the refugee camps than in the surrounding, already severely resource-limited, LMICs. Also there is a higher delayed averted burden in this most vulnerable population. The tremendous challenge caused by armed conflict and population displacement is further increased by the inadequacy of the current pediatric surgical care provided (evidenced by fewer than 25 % of children with congenital surgical conditions receiving treatment). Ongoing efforts by the UNHCR and its implementing partner agencies to improve health care in the camps are hindered by the constant increase in refugee numbers and the security concerns of the ongoing armed conflict in the region [8].

Our study draws upon previously established CEA methods for surgical interventions [19, 20, 28]. The current cost-effectiveness ratios of $40–$88 per DALY compare favorably with other studies that have shown surgical intervention to be a cost-effective method for decreasing BoD. Debas et al. [11] estimated a cost per surgically averted DALY in LMICs at between $33 and $94. Gosselin et al. [30] arrived at CEA values of $172 per DALY in a Nigerian hospital and $223 per DALY in Haiti. Our cost per DALY may have been artificially decreased by the exclusion of "fixed" costs such as the depreciation of hospital equipment and the reliance on donated surgeon time and equipment. More likely however, even highly specialized surgical procedures on children are likely to be cost-effective because of the long life expectancy following the procedure and hence the many years of disability averted. This favorable CEA supports the inclusion of pediatric surgical care in the package of services offered to displaced populations.

The most cost-effective procedures proved to be neurosurgical ones (due likely to the impact of relatively simple procedures such as ventriculoperitoneal shunts on high-DW conditions). Urologic operations were the most

expensive (the majority being hypospadias repairs, with a relatively low DW).

Limitations

Our study has several limitations. Despite the apparently comprehensive nature of the surgical care provided by the BethanyKids facility, the type of procedures performed reflected in part the type of surgical expertise available during that time. Moreover, with waiting times of up to 1 year for most procedures, our data cannot be used to estimate the true BoD in the camp over a given period of time. This estimation remains a task for future studies.

We have attempted to capture the uncertainty factor intrinsic to the various life tables [33] in the sensitivity analysis, but the three estimated YLL modifiers (DW, RPD, PST) each carry significant additional uncertainty. As most DWs for the conditions included in the study were not available in the literature, the study needed to rely on much coarser estimates using published methods. As for the RPD and PST, they are not only crude but very context-dependent: for many surgical conditions, delay in treatment can increase the risk of permanent disability (e.g., speech problems with a cleft palate) and lower the probability of successful treatment (e.g., urinary continence after bladder exstrophy closure). Moreover, the PST depends significantly on the quality of the surgical facilities, equipment, and expertise available and on a multitude of other patient-related factors (e.g., nutritional status, anemia, other co-morbid conditions) that are difficult to quantify.

Finally, all CEAs are inherently associated with multiple assumptions and a large degree of uncertainty [28]. Although some limitations were evident in our case (surgeons' salaries, donated equipment, fixed costs), dollar values associated with surgical work remain difficult to assign with any certainty.

Conclusions

This first estimate of burden of surgical disease averted in the Dadaab Refugee Camp highlights the significant impact that surgical intervention can have in such a setting and its cost-effectiveness. Given the magnitude of the number of persons displaced by armed conflicts across the globe, such data can inform appropriate resource allocation for the health care needs of these vulnerable populations.

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