

Research Article

Global surgical collaboration to treat bladder exstrophy-epispadias in India led to a larger geographical catchment area

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Background

A gap of care exists in low- and middle-income countries (LMICs) for patients with complex urogenital abnormalities, such as bladder exstrophy-epispadias complex (BEEC). A successful primary surgical repair is critical for optimal long-term outcomes for BEEC, but the availability of such a complex procedure is limited by the expertise needed to deliver a successful initial repair. We hypothesize that a long-term, multi-institutional collaboration based at a tertiary institution in a LMIC may improve outcomes for BEEC by encouraging earlier referrals for the first repair, rather than after failed repairs, and also increase the geographical catchment area by encouraging more distant referrals, once the availability of care becomes widely known.

Methods

A long-term collaboration between two US academic research centers and the Civil Hospital in Ahmedabad, Gujarat, India was formed in 2009. This collaboration expanded later to include another US and one Middle Eastern hospital system. The entire post-operative cohort of the collaboration was recalled in 2019 and 2020, when epidemiology and demographic surveys were obtained from 82 patients.

Results

Since 2009, the collaboration has grown overall. The geographical catchment area for referrals and distance traveled by patients to reach the collaboration site has increased to include nine states in India and surrounding countries in Southeast Asia ($P = 0.044$). Patients traveling from farther distances tended to be of higher socioeconomic status than local referrals ($P = 0.041$).

Conclusions

The success of the International Bladder Exstrophy Consortium to improve the care for BEEC patients in India and Southeast Asia is visible from its changing demographics. Patients, some even from families of a higher socioeconomic status, are traveling farther to receive care at a government-funded tertiary hospital. While not all positive benefits of a global surgery collaboration regarding earlier and primary referrals have been achieved, the collaboration is seeing benefits that align with a staged process of referrals. The continued commitment to creating a center of excellence is a model for sustained success for global surgery collaborations.

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The bladder exstrophy-epispadias complex (BEEC) is a congenital anomaly that requires specialized surgical and clinical care to achieve anatomical and functional integrity and future quality of life. While the incidence of BEEC is rare, estimated at 1 in 50 000 live births, a large majority of the burden lies in low- and middle-income countries (LMICs).¹ This burden is exacerbated by a lack of prenatal care, including early identification through ultrasound and the possibility of early termination. According to the World Health Organization (WHO), 94% of complex congenital anomalies occur in LMICs, creating a large gap in care for these children who are resource-constrained and have limited access to specialized care.²

A sustainable, long-term, and mutually beneficial surgical collaboration is a viable option for closing the gap in care.³ The development and continued investment in a collaboration between academic research centers (ARCs) from high-income countries (HICs) and a well-equipped tertiary hospital in the host country can provide training for local surgeons, increase the exposure of a rare condition for collaborating physicians, and deliver world-class care to patients. Important elements of a successful collaboration include a host center with the appropriate capacity for long-term follow-up for patients, a long-standing commitment to collaboration, and support from policymakers and officials that control funds relevant for the government-funded host institution.⁴ Global surgery collaborations require a greater degree of commitment than simply performing the initial procedure, and this model provides a sustainable way to improve care for patients while also providing a mutually beneficial experience for all stakeholders.^{5,6} Specifically, these types of collaborations require a team committed to returning to the host location for subsequent visits to complete follow-ups with patients and assist in developing the surgical capacity and capability of the host institution. The long-term commitment from the visiting surgical team requires that they serve not as itinerant surgeons, but instead as dedicated members of a team focused on long-term outcomes.

This model of ARC's collaborating with a large public hospital providing free-of-cost care to economically marginalized populations in India has been implemented in the International Bladder Exstrophy Consortium. Over the last 13 years, the consortium has developed into a "center of excellence" approved by a peer review process.⁷ Initially, the collaboration saw mostly patients presenting after failed initial repairs from outside centers and older patients presenting for initial closure of the exstrophy defect. While the timing and type of closure for BEEC remain debated among pediatric urologists,⁸ there is definitive evidence that initial rather than re-do closures are associated with better long-term continence outcomes and decreased need for multiple follow-up surgeries.⁹ We hypothesize that the formation of and continued dedication to a collaboration between ARCs and a public hospital in India will lead to earlier and primary referrals of children requiring BEEC repair and a shift in demographics of referrals from farther distances and varied socioeconomic categories.

METHODS

Beginning in 2009, surgeons from two ARCs from the United States joined with the Department of Pediatric Surgery at the Civil Hospital and BJ Medical College in Ahmedabad, Gujarat, India to form a multi-institutional collaboration. Since then, the partnership has grown to include the Children's Hospital of Philadelphia, Cincinnati Children's Hospital, Seattle Children's Hospital, surgeons from Sidra Medical Center in Doha, Qatar, and a paediatric anaesthesiologist specialized in paediatric pain management. The Civil Hospital, a government-financed public hospital offering free medical care to a primary catchment area of 60 million people, serves as the host institution. The collaboration includes at least one annual visit from the same team of surgeons, during which new patients are evaluated and care plans are made, while all previous patients are recalled for long-term follow-up. Patients undergo yearly urodynamic evaluation, cystogram, ultrasound, DMSA scan, and bloodwork. The collaboration also evolved towards a more holistic approach to care, including mental health screenings, educational sessions with family members, and community-building activities for the entire cohort. In 2019 and 2020, we recalled the entire post-operative cohort for thorough examinations and data collection. We obtained epidemiology and demographic surveys from 82 patients. We calculated the distance travelled to Civil Hospital by patients based on their current Postal Index Number (PIN) and their socioeconomic status based on the possession or lack of a Below the Poverty Line (BPL) ration card which is provided to families in India that live below the state-set poverty line.

We reported continuous variables as medians and interquartile ranges (IQRs) and categorical and binary variables as counts and percentages. We used Wilcoxon rank-sum and Fischer's exact tests to compare continuous and categorical variables between the groups, setting the statistical significance at $P < 0.05$.

We performed univariate and multivariate logistic regression analysis to evaluate the role of socioeconomic status and the year that patients presented at Civil Hospital on the distance they travelled to receive care, age at time of repair, and whether it was a primary (first-time) or secondary repair. We did this to better understand how the age at complete primary repair of exstrophy (CPRE), type of repair, and the distance patients have travelled have changed over the course of this collaboration. We used the Stata/SE 17.0 (Stata 17. version 17. StataCorp; 2021) statistical software to perform all statistical analyses.

RESULTS

Between 2009 and 2020, the collaboration performed a total of 167 BEEC surgical reconstructions. Of those that returned from the 2019-2020 study period, 81 (49%) completed a demographic questionnaire. Within this cohort, 60 (74%) were primary repairs who presented to Civil Hospital for initial closure of BEEC, and 21 (26%) were redo repairs of patients who presented to Civil Hospital with a failed

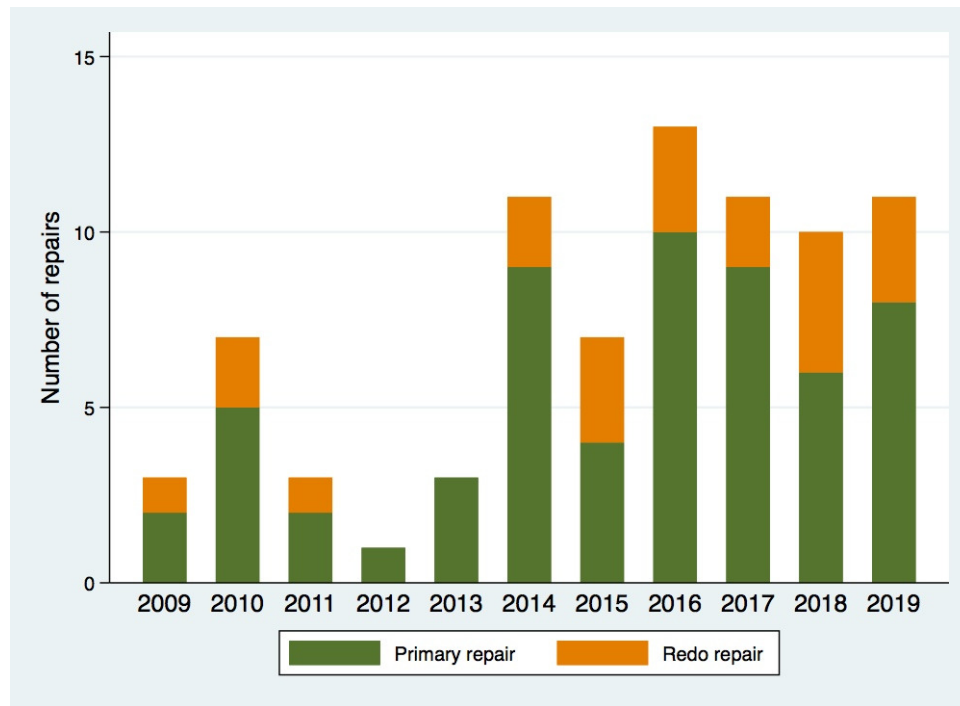


Figure 1. Increase in number of repairs over time at the international bladder exstrophy consortium.

closure completed after a primary repair had failed elsewhere.

Overall, the number of children cared for annually by the collaboration has substantially grown ([Figure 1](#)), with three closures occurring in 2009 and 11 taking place in 2019. The increase in surgical capacity has been accompanied by changing demographics within the patient cohort population. Early on, patients primarily from the state of Gujarat presented to the collaboration for care, but since then, patients from farther locations travelled for care. The geographical catchment area for referrals and distance travelled by patients and their families to reach the surgical site ([Figure 2](#)) has increased to include nine states in India and surrounding countries in Southeast Asia. Patients that underwent repair in more recent years travelled farther than those that were initially operated on at Civil Hospital earlier in the collaboration ($P = 0.044$).

The socioeconomic status of patients correlated with the distance travelled to the collaboration site; this measure increased as the International Bladder Exstrophy Consortium progressed. Compared to patients with a BPL card, families with a higher socioeconomic status travelled significantly farther to receive care ($P = 0.041$).

The number of primary vs redo repairs ($P = 0.776$; [Figure 1](#)) and age at first presentation to Civil Hospital ($P = 0.618$; [Figure 3](#)) have not changed significantly since 2009. While the volume of children and families seeking care has increased, as has that of families traveling farther to seek care, the collaboration has not yet witnessed a shift towards younger children seeking first time surgical repairs.

DISCUSSION

The changing demographics within the International Bladder Exstrophy Consortium are the result of long-term investment to create a centre of excellence at a public hospital in western India. Over the years we have seen an increase in patients traveling farther to reach the host site, the Civil Hospital-Amdavad. This is a testament to the collaboration's reach over the last 13 years. Awareness of the International Bladder Exstrophy Consortium has increased throughout a country that has 37 725 public hospitals,¹⁰ as well as to bordering nations in Southeast Asia. We believe this is a testament to the long-term nature of the collaboration, now in its 14th year. Over time, awareness of the collaboration has spread as a result of lay press articles, word-of-mouth referrals between patients and physicians, national and international medical conferences, and the efforts of the Association for the Bladder Exstrophy Community.

There is also an increasing diversity in patients, including a larger demographic cohort that typically does not seek care at a public institution. Patients of higher socioeconomic status are more likely to seek care at private institutions as opposed to government-funded hospitals in India, though they may use a greater share of public services overall since they are more likely to present for care.¹¹ The increasing preference of these patients seeking care at the collaboration's government-funded host site, the Civil Hospital-Amdavad, demonstrates a perception of localized expertise at the International Bladder Exstrophy Consortium that extends beyond the catchment area, thus breaking pre-conceived notions of what services can be obtained at a public hospital. While patients traveling from farther distances tend to be of higher socioeconomic status, indicat-

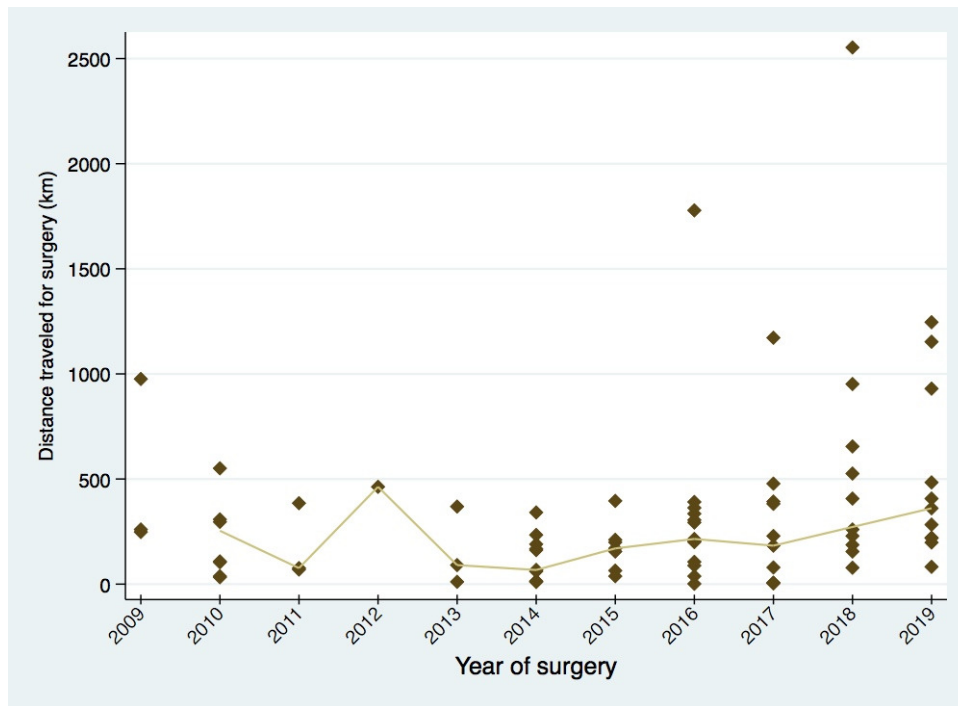


Figure 2. Increase in distance travelled by patients and families to the international bladder exstrophy consortium over time.

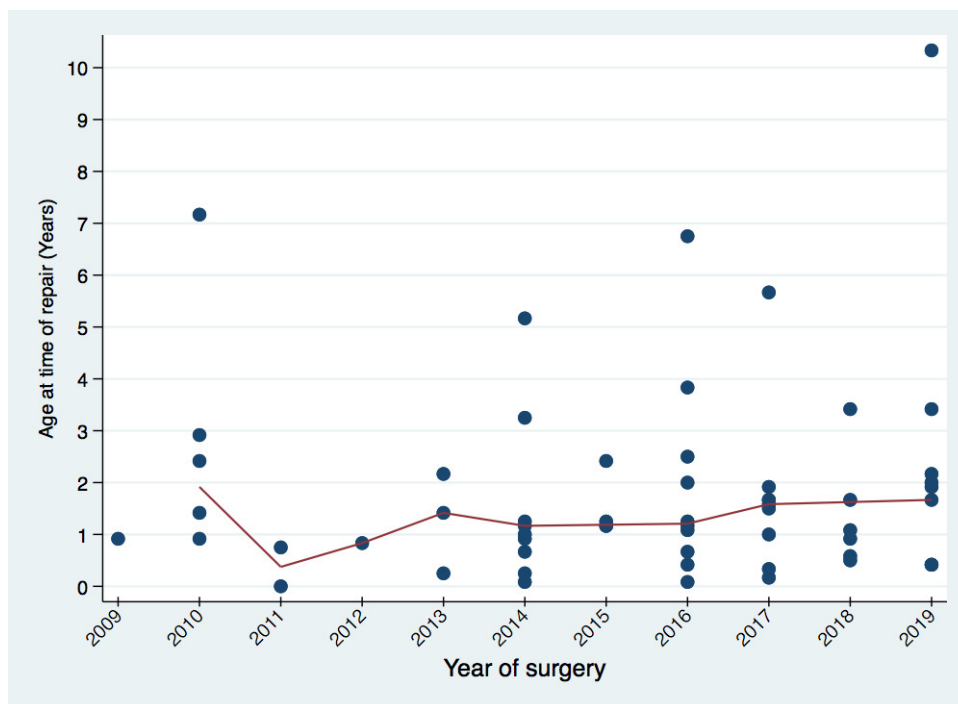


Figure 3. Age at time of first repair over time at the international bladder exstrophy consortium.

ing that they possess the resources to locate services and afford travel, the increasing diversity of patients would ideally include more patients of lower socioeconomic status from farther away. For a variety of diagnoses and conditions in diverse locations around the world, people of higher socioeconomic status tend to present earlier for diagnosis and access more rapid referral processes, largely because they have the necessary means and access to care.¹²⁻¹⁷ This has

not been specifically identified in India for other surgical collaborations, but this is a trend in other global health collaborations throughout LMICs. While we strive to ensure that access to the collaboration is democratized, equitable, and open for all, it is unsurprising that the benefits of collaboration described here have been accessed preferentially by families with more resources among those living farther away from the collaboration site.

However, it is important to acknowledge that inferring economic status solely by possession of a BPL card only distinguishes patients and families living below the poverty line, and many families treated within the collaboration have resources placing them only slightly above the BPL threshold – meaning they still experience the challenges of economic marginalization. We are committed to future philanthropic efforts within the collaboration to make care more accessible for those in the immediate catchment area who still fail to access available care. For example, the International Bladder Exstrophy Consortium is currently partnered with the Association for the Bladder Exstrophy Community to raise funds for travel, while seeking other ways to expand the collaboration's benefits to a larger, diverse patient population in the region without undermining the growth of its other centres. The International Bladder Exstrophy Consortium would encourage the creation of similar partnerships so that more people can benefit from its activities.

Additionally, we continually strive to increase the number of primary vs redo repairs and lower the age of initial closure at Civil Hospital overall. Children who receive expert primary repairs at younger ages using the complete primary repair of exstrophy historically have better outcomes as opposed to those that present at a later age and after an unsuccessful repair.³ While this benefit has not yet been achieved, we expect that patients will begin to present at younger ages and for primary repairs as the collaboration grows and continues to provide a high level of care. We hope that regular presentations of the collaboration's outcomes at national conferences, physician outreaches, and surgical teaching workshops held at Civil Hospital will gradually lead to a stage migration to earlier referrals for primary surgery.

As the staged process of referrals continues for the collaboration and the geographic catchment area grows, we expect that, while access is easier for local patients, collaborative care will be more beneficial to those who travel farther. Again, this benefit may first be realized by patients and families of higher socioeconomic status, but over time, as the collaboration works to become even more accessible, it should also benefit patients with fewer resources. It is clear that the collaboration site has become a preferred destination for the management of a difficult congenital condition, and the increase in primary referrals, rather than after failed initial repairs, may mean better long-term outcomes.

The benefits seen at the International Bladder Exstrophy Consortium are a testament to the long-term investment for creating a centre of excellence in a LMIC, as opposed to one-time or "short-term surgical missions" which are focused on increasing surgical volume over a short time-frame and do not always lead to improved surgical capacity for host institutions.¹⁸ Consequently, there is little focus on follow-up and long-term care for patients, resulting in higher complication rates that are outside of the local health system's capacity to address.¹⁹ Furthermore, when volunteer teams are not well-integrated with the local hosts, they can burden local providers, stress hospital resources, and create negative opinions of HIC volunteers.²⁰

While conceived and executed with best intentions, these global surgery programs can cause more harm than good for local populations.

Alternatively, the International Bladder Exstrophy Consortium has worked to embody the guiding principles for ethical engagement in global surgery from the American Surgical Association Working Group on Academic Global Surgery²¹ which include the following:

1. Local priority: The interests of the local partners and patients should take precedence in all decision making.
2. Resources: Programs should not hinder existing infrastructure and obtained HIC resources should be focused on the host site and partners.
3. Clinical care: HIC surgeons and staff should create a plan for complication management and long-term follow-up.
4. Capacity building: Training should be applicable to the LMIC setting in which host partners will function, focus on local as opposed to visiting surgeons, and not contribute to outmigration.
5. Research: Research should be mutually collaborative and equitably attribute authorship.
6. General: All HIC partners should practice cultural sensitivity and uphold the standards of care and practice that exist in their HIC.

In practice, the International Bladder Exstrophy Consortium is focused on meeting the above criteria. First, there is a conscious focus on maintaining local priority. The coordinators from both the host and visiting teams frequently discuss the priorities of local partners throughout the planning process. This includes focusing on the host team's goals and adjusting the collaboration so it best serves the local patient cohort. For example, the first few years of the collaboration identified a greater need for patient education, so the collaboration added novel education initiatives that included a doll representative of a BEEC patient,²² while research endeavours focused on the patients' quality of life. Patient- and family-centred educational lectures on the condition and optimal care pathway were strengthened based on the gathered information. Second, the collaboration has focused on leveraging the existing infrastructure to provide more care to a greater number of patients. Collaboration funding is prioritized for the host institution's needs, including purchasing necessary resources for the collaboration and providing services to patients. Importantly, funds are not overwhelmingly dedicated to travel for the visiting team. Third, the clinical care plan for complication management for the collaboration was devised together with the host and visiting providers and is based on pathways produced over several years.³ The clinical care aspect of the collaboration is centred on an annual commitment of the primary surgeons from HICs to return for patient follow-up. Additionally, all interval follow-up care is completed by the host team with support from the teams from HIC through regular teleconference communication. Fourthly, all aspects of the collaboration are committed to capacity building. All repairs are performed

with at least one resident of the host institution participating in the surgery. Emphasis is placed on knowledge sharing between host and visiting stakeholders, with a focus on training local resident and attending physicians to create autonomous surgeons that have the capacity to perform the CPRE with the same outcomes as the teams from the HIC ARCs. A small number of CPREs have been successfully performed by host surgeons outside of the collaboration's time, demonstrating successful development and continued capacity building. We are currently collecting outcome data in an effort to quantitatively demonstrate the collaboration's capacity building intentions over time. Fifthly, the collaboration has produced several collaborative research studies, four of which have resulted in publications, each equitably crediting host partners with first authorship or corresponding authorship.^{3,23-25} Lastly, cultural sensitivity is of primary importance for the collaboration, so local partners lead all patient interactions and all visiting partners are educated on cultural sensitivity prior to attending the collaboration.

The International Bladder Exstrophy Consortium provides a sustainable, long-term collaboration generating positive, long-term benefits for local partners and patients. It demonstrates that surgical outcomes on par with HICs may be expected when important criteria are rigorously followed,³ while patients and families also gain several ancillary psychosocial benefits, including group support, one-on-one counselling and social resources. By focusing on surgical capacity over volume, the collaboration's scope can widen to gain earlier referrals and increase the geographic catchment area for patients.

LIMITATIONS

Our study is limited by the challenges of collecting data within a research-limited setting. Technology disparities and high work loads of resident physicians at the host institution, along with language and cultural barriers, increase the difficulty in collecting and maintaining data for such a large patient cohort population. These are challenges that the collaboration is actively working to overcome in order to accurately evaluate success and identify areas of needed improvement. Additionally, while the International Bladder Exstrophy Consortium began in 2009, it did not have the available infrastructure to do in-depth follow-up with demographic data collection until 2012, so the data are weighted towards patients that returned to the collaboration in its latter years. Specifically, this data are limited to those patients that returned in 2019 and 2020 to complete the demographic questionnaires, so information on patients that were operated on in earlier years, but did not return in 2019 or 2020, is absent.

CONCLUSION

The shift in demographics of children treated within the International Bladder Exstrophy Consortium indicates that

this sustained long-term collaboration has progressed from a local to multi-nation regional effort to close the gap of care that exists for BEEC patients in India and Southeast Asia. Patients, even from families of higher socioeconomic status, are travelling farther to receive care at a government funded tertiary hospital. While not all positive benefits of a global surgery collaboration have been realized regarding earlier and primary referrals, the collaboration is seeing benefits that align with a staged process of referrals. With continued investment in infrastructure at our host institution and expanding research efforts, we hope that the collaboration's putative benefits will be distributed more widely to ensure equity by reaching resource-challenged populations in the region. We believe that the model of collaboration between ARCs from HICs and a high capacity, well-endowed local institution such as the Civil Hospital-Ahmedabad provides a replicable model to create a centre of excellence to address a rare but devastating congenital anomaly.

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DISCLOSURE OF INTEREST

The authors completed the ICMJE Disclosure of Interest Form (available upon request from the corresponding author) and disclose no relevant interests.

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