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SPECIAL TOPIC

Craniofacial/Pediatric

An Unoperated Crouzon Family Treated with Monobloc Distraction: Challenges and Lessons

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Background: Crouzon syndrome (CS) is a rare form of craniosynostosis characterized by bicoronal craniosynostosis and facial features including severe midface hypoplasia, exophthalmos, and hypertelorism. Most patients are diagnosed and treated in early childhood; however, there are a few reports of Crouzon patients treated as adults with monobloc facial advancement. To our knowledge, this is the first report of a family affected by CS treated sequentially with monobloc facial advancement using combined internal and external distraction osteogenesis (rigid external distraction).
Methods: We present a family from Jamaica (mother 47 years old, older daughter 17, and younger daughter 9) who were brought to our craniofacial clinic with stigmata of CS and no previous surgical intervention. Patients had bicoronal craniosynostosis and exorbitism, with varying severity, sequelae, and comorbidities. Here, we delineate our technique of monobloc distraction osteogenesis with advancement osteotomies using dual "push–pull" method, elevation of a split anteriorly based tunneled pericranial flap to seal off nasal cavity, and internal and external distraction.
Results: Our patients had favorable outcomes after reconstruction to reduce ocular symptoms and improve midface hypoplasia and aesthetic appearance. No intracranial injury, hardware/soft-tissue infection, hardware failure, or (new) loss of vision were encountered in 10 months follow-up.
Conclusions: Dual "push–pull" monobloc distraction is safe and effective for a range of ages in CS; it allows good vector control, accommodates patient compliance, and allows early rigid external distraction device removal with sufficient time for consolidation. This surgery can be performed with highly satisfactory results.
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INTRODUCTION

Crouzon syndrome (CS) affects 1.6 in 100,000 births per year and represents up to 4.8% of those born with craniosynostosis.[1,2] Most are diagnosed, treated, and followed through early childhood. CS is associated with synostosis of coronal sutures and facial features including exophthalmos, severe midface hypoplasia, and hypertelorism.[3–5] The fusion of the sutures is caused by autosomal-dominant heterozygous mutations in the fibroblast growth factor receptor 2 gene.[2] Surgical intervention is performed to correct intracranial pressure, reduce ocular symptoms, and improve midface hypoplasia and aesthetic appearance. The techniques involve LeFort III osteotomy with midface advancement or the use of monobloc advancement, with or without distraction osteogenesis.[6] Monobloc frontofacial advancement is commonly performed in childhood with distraction osteogenesis, with timing and technique institutionally dependent.[7] Unfortunately, early intervention is not always possible, due to misdiagnosis, limited healthcare, or cultural factors.

We present a family from Jamaica with stigmata of CS and no previous surgical intervention; they were misdiagnosed with Graves disease and had suffered from ostracism, poverty, and isolation. Each family member had bicoronal craniosynostosis and exorbitism, with varying severity, sequelae, and comorbidities. To date, there have been very few cases of monobloc distraction documented in adults over 40, and each prior case was affected by complications.[8] For this family in Jamaica, we sought safe, efficient, and durable surgical correction for their CS and associated symptoms. Here, we delineate our method of monobloc distraction osteogenesis using dual "push–pull"

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method in an adult, an adolescent, and a child, performed in relatively quick succession.

METHODS

Through the assistance of multiple nonprofit agencies, the family of three was brought to our clinic. This 3-year process was initiated by a velo-cardio-facial support group in Jamaica that raised donations for travel to the United States. This was done in conjunction with Craniofacial Clinic Fund, which was founded by the senior author and is funded by hospital physicians and staff for donation time and provides resources, facility fees, medication and other costs associated with care of the patients. There was also help from other nonprofit organizations, like the Ronald McDonald House of Detroit, which provided housing for their stay.

The patients underwent preoperative evaluation during multidisciplinary craniofacial clinic and by multiple subspecialties including internists, pediatric intensivists, ophthalmology, interventional radiology, and neurosurgery. Base line laboratory values and preoperative computerized tomography (CT) imaging were performed for assessment and surgical planning. None of the patients had serious comorbidities precluding them from undergoing the planned surgery. The patients were provided preoperative nutritional supplementation and laboratory values were reassessed before surgery.

Takeaways

Question: Is dual distraction after monobloc advancement an effective treatment for Crouzon Syndrome within a range of ages?

Findings: Each patient underwent monobloc advancement with combined internal and external distraction. There were favorable outcomes after reconstruction, including reduced ocular symptoms and improved midface hypoplasia, occlusion, and aesthetic appearance.

Meaning: Dual "push-pull" Monobloc distraction is safe and effective for a range of ages in treatment for unoperated Crouzon Syndrome, allows for good vector control, and accommodates patient compliance. This surgery can be performed with highly satisfactory results.

Patient-specific Preoperative Characteristics

Case 1

The mother, age 47, was evaluated for ophthalmologic, dental, cognitive, psychological, nutritional, and infectious disease pathologies. She was malnourished and had severe exophthalmos, and vision loss in her left eye due to exposure keratopathy, requiring a corneal transplant. She had normal affect and no cognitive delay, but required assistance due to keratopathy. She had severe class III malocclusion with negative overjet of 18 mm and multiple dental caries. CT scan showed a crowded foramen magnum, indentations and thinning of the inner table, "kissing carotids," a decreased clivus angle, and a suprasellar lesion. Magnetic resonance imaging and arteriogram revealed a 2 cm internal carotid artery paraclinoid aneurysm; after consultation with interventional radiology and neurosurgery, the decision was made to observe the lesion and proceed with surgery (Fig. 1).

Case 2

The younger daughter, age 9, exhibited exophthalmos, a mild vertical dystopia, and class III malocclusion with negative overjet of 10 mm. She had normal psychomotor

Fig. 1. Case 1. A, Preoperative frontal, lateral, and worm's eye views of the 47-year-old mother who had clinical features of advanced Crouzon syndrome with left-sided blindness secondary to exposure keratopathy and severe class III malocclusion. B, Postoperative results at 10 months after monobloc advancement, removal of internal and external distraction devices, bilateral lateral canthoplasty, and corneal transplant with dramatic improvement of exorbitism, monobloc advancement with overall excellent aesthetic appearance, and improved vision.

Fig. 2. Case 2. A, Preoperative frontal, lateral, and worm's eye views of the 9-year-old daughter with Crouzon syndrome who exhibited exophthalmos, mild vertical dystopia, and class III malocclusion. B, Postoperative results at 10 months after monobloc advancement and bilateral lateral canthoplasty. Dramatic improvement of facial features was achieved after restoring balance of craniofacial structures.

status without any evidence of cognitive or developmental delay. On imaging, her inner table was similar to the mother's. The posterior fontanel was open as well as a small portion of the superomedial lambdoid sutures; however, all other sutures were fused. She also exhibited kissing carotids, a decreased clivus angle, partial agenesis of the corpus callosum, and flattened pituitary gland. None of the imaging findings prohibited the planned procedures (Fig. 2).

Case 3

The older daughter, age 17, had similar physical symptoms but also known cognitive delay. She performed all functional tasks but did have difficulty with group participation. She had class III malocclusion with a negative overjet of 10 mm, a high arched palate, and supernumerary teeth in the hard palate. Imaging showed a crowded foramen magnum, kissing carotids, decreased clivus angle, partial agenesis of the corpus callosum, and no frontal sinus;

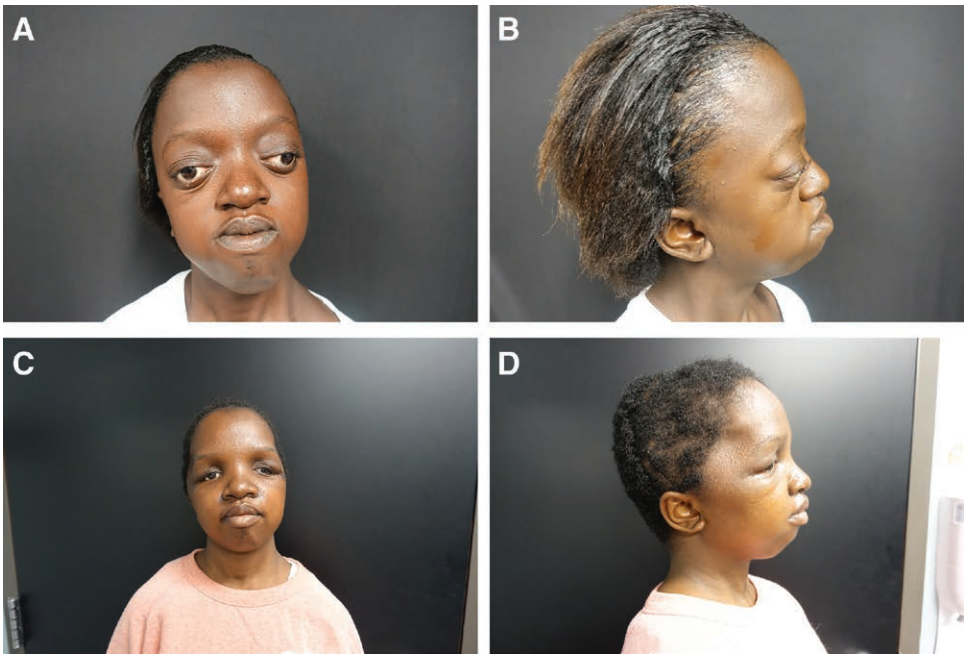

Fig. 3. Case 3. A and B, Preoperative frontal and lateral views of the 17-year-old daughter with Crouzon syndrome and cognitive impairment. C and D, Postoperative results at 10 months with excellent cosmesis and no signs of recurrence.

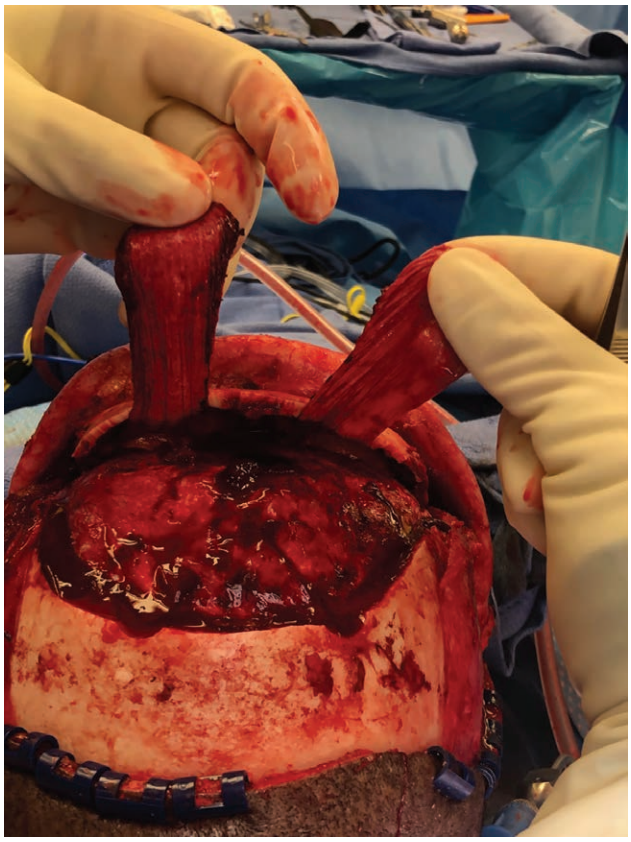

Fig. 4. Intraoperative lateral view demonstrating placement of Kawamoto internal distractor device secured anteriorly to the zygomatic arch.

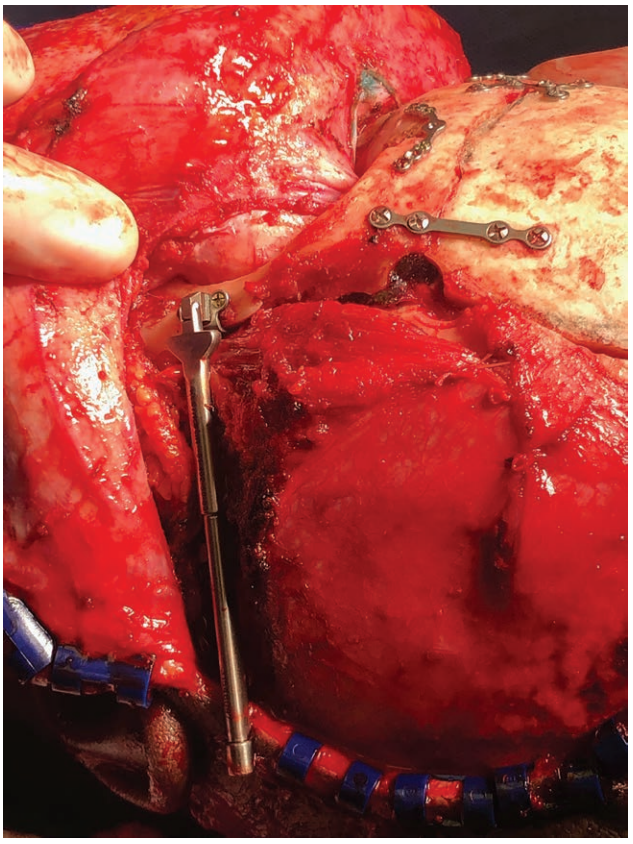

Fig. 5. Intraoperative image demonstrating the frontal sinus dead space and the split pericranial flap passed under the superior orbital rim to seal the nasal cavity.

additionally, it revealed a midline submucous cleft of the alveolus. This patient may have benefited from facial bipartition but was deemed unnecessarily high risk (Fig. 3).

Surgical Technique

Our surgical technique starts with a coronal incision and elevation of the scalp in the subgaleal plane followed by development of a large pericranial flap. After exposure to the zygomatic arches, the periorbita and temporalis muscles are elevated, protecting the facial nerve. In conjunction with neurosurgery, traditional monobloc osteotomies are performed using powered drills/saws and manual osteotomes. Once the frontofacial skeleton is downfractured and mobilized, the pericranial flap is divided and passed under the superior orbital rims to seal off the nasal cavity (Fig. 4). Adherus dural sealant is applied. The frontal bone is plated to the facial skeleton using titanium miniplates. Kawamoto-type internal distractors are placed on the calvarium above the level of the external auditory canal, and above the zygomatic arch (Fig. 5). Anchoring footplates for percutaneous pins are placed on the superior orbital rims and maxilla along the pyriform aperture. The percutaneous pins are placed as the skin is redraped and closed over a Jackson–Pratt drain. A rigid external distraction (RED) device is secured to the scalp with hand-tightened pins. The percutaneous pins are wired to the RED, creating external four points of control. Frost sutures left in place for several days for protection (Fig. 6).

After a latency of 5–6 days, distraction is performed in synchronicity with external and internal distractors at 1 mm per day until correction in exophthalmos and slightly overcorrected occlusion. The Jackson–Pratt drain is removed when output is less than 30 ml per day. After completion of distraction, the external device is removed. After consolidation for at least 6 weeks, the internal distractors are removed in the operating room. Preoperative CT imaging and surveillance x-ray films are used to plan, monitor, and evaluate progress.

RESULTS

The mother (case 1) underwent surgery first. Distraction began on post-operative day (POD) 5. In total, she was distracted 18 mm at the apex, 27 mm at the zygomatic arch, and overjet was 14 mm (Fig. 7). The RED was removed 2 months after surgery; 3 months later, percutaneous pins and the internal hardware were removed and she underwent bilateral lateral canthal reconstruction. Two weeks later, she underwent corneal transplant to the left eye with ophthalmology. At her final visit, 10 months postoperatively, there were no signs of relapse and she had gained appropriate weight, was physically active and socially interactive, felt more confident, and had improved vision (Fig. 1).

Fig. 6. Postoperative image demonstrating the RED device.

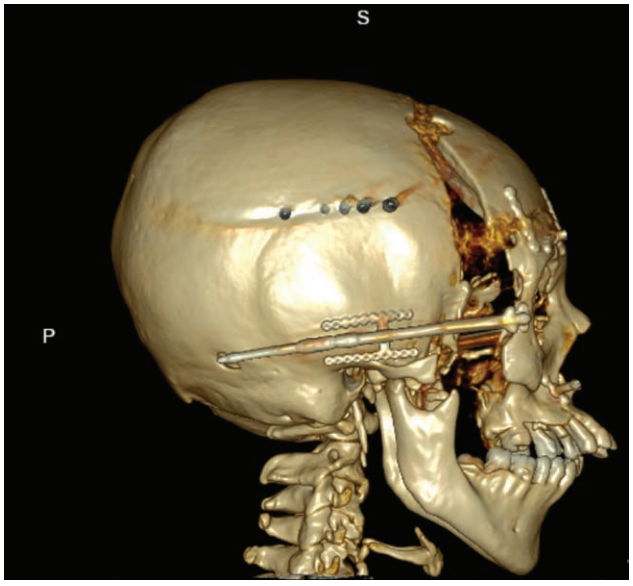

Fig. 7. Postoperative right lateral 3D CT image demonstrating distraction of midface with improvement of zygomatic arch position, occlusion and placement of distractors.

The younger daughter (case 2) underwent monobloc surgery after the mother. Distraction began POD 6. Distraction was completed at three weeks and the RED was removed 1 month postoperatively. Total distraction was 15 mm at the apex, 18 mm at the arch, allowing overcorrection of her malocclusion with overjet of 6 mm. She consolidated for 8 weeks and underwent hardware removal and bilateral canthal reconstructions. Before returning to Jamaica, she was showing off her new look on social media, singing and dancing, and happy with her appearance and function (Fig. 2).

The older daughter (case 3) underwent monobloc surgery 6 weeks after her younger sister. Extubation was delayed until POD 9 due to agitation and secretions, distraction was initiated at POD 6. At completion of distraction, the apex was advanced 17 mm, the arch 28 mm with overjet of 7 mm. Three months after surgery, the hardware removal and canthal reconstructions were performed. At the time of her return home, she showed no relapse and was highly satisfied with her postoperative appearance (Fig. 3).

All of patients underwent monobloc advancement without complication and uneventful postoperative and ICU stay. None of our patients experienced serious complications, intracranial injury, hardware or soft-tissue infection, hardware failure, or (new) loss of vision.

DISCUSSION

CS is characterized by bicoronal craniosynostosis and facial features including severe midface hypoplasia, exophthalmos, and hypertelorism.[3] There are very few reports of Crouzon patients treated as adults with monobloc facial advancement,[8] and one additional report includes a Crouzon family treated with different modifications of the monobloc facial advancement over generations of treatment.[2] To our knowledge, this is the first report of a family affected by CS treated sequentially with monobloc facial advancement using combined internal and external distraction osteogenesis.

Treatment of CS is based on the surgical history of the patient and can include LeFort III osteotomy with staged fronto-orbital advancement or single-staged monobloc frontofacial advancement. The LeFort III osteotomy provides adequate midface advancement and improvement of airway management. However, one-step LeFort III advancement has a lesser effect on intracranial hypertension and cosmesis compared to monobloc when not combined with staged fronto-orbital advancement.[9] Additionally, advancement is limited by the soft tissues and entails potentially increased risk and morbidity associated with the harvesting of bone grafts.[10] Orbital correction and airway improvement are achievable with both techniques, but there is greater lateral orbital rim advancement following monobloc distraction compared to the LeFort III technique.[11] The monobloc procedure is advantageous because the surgery can be completed in a single stage with advancement of the frontal bone, orbits, and midface as a single unit, but it has been shown to have higher morbidity and serious complications including meningitis and cerebrospinal fluid leak.[6,8,9,12] These risks of infection, particularly in older patients, are thought to be due to increased or persistent nasofrontal dead space after advancement due to the limited ability of the brain to fill the space after advancement[13] and exposure to the nasal cavity and ethmoid sinuses.[6]

In a systematic review by Knackstedt et al,[14] they showed a 33.7% incidence of major complications with monobloc

distraction versus 17.6% incidence for LeFort III distraction. In a review series by Arnaud, there was a 28% complication rate after monobloc advancement which included 20% cerebrospinal fluid leak rate.[3,11] Witherow et al[15] showed in a retrospective review that complications after monobloc advancement included persistent cerebrospinal fluid leak in eight of 20 patients, cranial bone loss and acquired hypernasality in 25% secondary to the distraction process. In their patient series, Fearon and Whitaker[16] reported 29 patients ages 3–26 years old with various craniosynostosis who underwent LeFort III and 10 who had monobloc advancement. He found that the aesthetic appearance was improved more substantially in older patients; however, there was no significant aesthetic difference based on the surgical technique. There were fewer complications with the LeFort III procedure compared to monobloc advancement which had significantly increased risk of infection (5% versus 50%).[16]

Although our current case series was small, there were no postoperative infections. As part of our monobloc technique, we utilized anteriorly based split pericranial flap to fill the dead space,[17] thereby decreasing the collection of fluid and risk for infection. Likewise, the comparison study by Fearon showed no difference in infection rate if a "galeofrontalis flap" was used to separate the nasal cavity and ethmoid sinuses.[6,16] In the presented series, there was no evidence of soft-tissue infection in any of the patients due to external pin sites. Our low rate of postoperative complications may be due to number of patients, multidisciplinary preoperative optimization, use of tunneled pericranial flaps with dural sealant, prophylactic antibiotics and close postoperative management and observation.

DISTRACTION

The use of distraction permits greater midfacial advancement without the need for bone grafting and allows for soft-tissue stretching.[4] The different methods of distraction osteogenesis include internal and external distraction. The use of distraction osteogenesis with monobloc advancement may allow for at least partial remucosalization of the nasofrontal area before advancement, which may decrease the risk of complications.[6] External distraction helps control advancement of the midface, and control of different vectors of the midface and maxilla.[2] Some of the disadvantages of an external distraction devices are patient discomfort, susceptibility to external forces, possibility of pin dislodgement or intracranial advancement of distraction screws associated with trauma.[7,10,18,19] By their own initiative, our patients wore thick scarves over distractors for discretion, cushioning and warmth. Another drawback is potential for scarring of midface incisions; our patients did not experience keloids or hypertrophic scarring. There have also been reports of a 23% relapse rate with use of external distraction for hypoplastic midface, and greater anterior overcorrection of the hypoplastic maxilla is needed in growing children compared to adults, to compensate for a partial relapse and growth deficit.[20] In a study performed by Way et al[21] assessing orbital volumes and globe protrusion in young patients with Crouzon–Pfeiffer syndrome, showed stable orbital volume at 1 year postoperatively with clinical regression back to syndromic form around 12 years of age.

In contrast, internal distraction devices are buried and designed to push the midface complex forward.[10] These are secured at the temporal bone and lateral orbital rim for advancement. These devices have the advantage of being more stable and covered by soft tissue, which can decrease the external pin site infections, but have a higher likelihood of subcutaneous infections.[7] They can be less awkward for the patient, improving patient compliance and acceptance, thus leading to greater stability and a longer consolidation period compared to the external device.[6] However, they are not without their limitations. One of the main disadvantages of internal distraction for midface profile is asymmetric movement or inadequate advancement of the midface due to limited vector control.[10,22] The lateral placement of the internal devices can increase force and possible fracture of lateral orbit while amplifying midface concavity.[7,10,22] Although the internal distraction device has a lower profile, there can be a higher propensity to have an infection in the subcutaneous tissue due to location of device.[7] Another review found that patients who underwent external distraction had higher rates of displacement and 7.3% needed reoperation; patients with internal distraction had higher rate of infections with eight patients versus three patients with external distraction.[23]

In our series, all three patients underwent placement of internal and external distraction devices using a "push–pull" method. According to Schulten et al,[10] the use of this technique allows for differential movement of superior and inferior facial levels while advancing the midface with symmetrical movement laterally at the zygomaticomaxillary complex (ZMC). Hariri et al[22] demonstrated the use of combined distraction in two pediatric patients with Crouzon syndrome with adequate advancement of midface allowing for tracheostomy decannulation with good aesthetics with no reported changes at 18 months. We chose this combined distraction technique for several reasons. We valued the differential vector control of external distraction, which was shown in previous studies[10,22] but also intended to remove the RED as soon as possible for patient comfort and convenience, and due to limited treatment time. Although there is limited distraction in side-to-side vector due to the lateral vector set by the internal distractors, in the senior author's experience, the dual distraction still allows for rotation in the anterior-posterior plane, which was used in our series for rotational advancement of the maxilla to correct the occlusion. The RED was also utilized to control the lateral wall advancement during the distraction process and stabilization of the midface. Internal distractors provided longer-term stability and additional support for the advancement. The mother had a longer latency period to provide increased time of healing and bone formation after distraction due to her age.

Our patients underwent distraction until there was correction of exorbitism, adequate advancement of the orbital apex, and midface advancement with improved occlusion. They all exhibited improved aesthetic outcomes. Although the psychosocial aspects were not measured objectively, each patient demonstrated improved

self-esteem and confidence after completing the distraction process and was pleased with their aesthetic outcome, which they displayed through multiple social media and regional news updates before returning to Jamaica.

Previous studies on treatment of CS and facial advancement have shown the importance of long-term follow-up for evaluation of the distraction and advancements.[20] Our study is limited by the short-term follow-up period of 6–10 months and the family's return to Jamaica, but we will continue to follow their progress in the future. Further long-term follow-up will be needed to fully assess the impact of our procedures. A larger number of patients would allow further comparisons of this technique with other described methods.

This case series presented a unique opportunity to provide the correction of CS with monobloc advancement to three family members. This brought its own challenges and lessons throughout the treatment period. One challenge included the logistics of establishing and providing care for the patients preoperatively to assure medical stability and surgical optimization. Multiple nonprofit organizations provided funding for travel and medical care and the patients received charitable donations for appropriate clothing during the winter and housing. This was also met with the philanthropy of multiple medical specialists, which included providing left corneal transplant for the mother before returning home to Jamaica.

The patients also faced emotional challenges; not only were they undergoing a life changing procedure in an unfamiliar environment, but they had to observe their family while waiting to undergo the surgery. This caused anxiety and apprehension, but this was anticipated. Our team met with the family multiple times to review the surgical and anticipated postoperative courses and provided tours of the hospital units for a better transition. They also had a liaison to assist with the language barrier and coordinate with specialty care teams to provide support while staying in temporary living arrangements.

We were able to show that monobloc facial advancement with use of combined distraction can be completed safely with a high degree of improvement of exorbitsm with good cosmetic results in adults. The importance of preoperative planning and multimodal team approach while utilizing the same surgical team improves surgical efficiency, which improved the operative outcome and recovery for our patients.

CONCLUSIONS

Dual "push–pull" monobloc distraction is safe and effective for a range of ages in CS; it allows good vector control, accommodates patient compliance, and allows early RED device removal with sufficient time for consolidation. This surgery can be performed with highly satisfactory results.

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PATIENT CONSENT STATEMENT

Patients provided written consent for the use of their images.

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