The Road Less Traveled: The Marham National Health Institute's Journey on Cleft Lip and Palate Surgery Missions

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ABSTRACT

Congenital cleft lip and palate represent the prevailing craniofacial birth anomalies on a global scale. Notably, a substantial proportion of patients within remote regions of Iran defer corrective surgery until later stages of life, often in childhood or adulthood, primarily due to intricate financial and cultural constraints. In response to this pressing healthcare challenge, a dedicated collective of volunteer plastic surgeons was established in 2009 with the explicit aim of providing medical care to these underserved patients. Over the subsequent years, this compassionate team embarked on 31 meticulously planned missions to underprivileged areas scattered across the country. Through these organized endeavors, a remarkable total of 20,579 medical visits were conducted, coupled with the performance of 2,303 essential surgeries, thus offering a lifeline of healthcare to these disadvantaged individuals.

KEYWORDS

Cleft lip; Cleft palate; Craniofacial birth defects; Plastic surgery; Pediatric surgery; Underprivileged areas

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INTRODUCTION

Congenital cleft lip and palate are the most common craniofacial birth defects worldwide ¹⁻⁵. In addition to aesthetic and psychological consequences, they markedly affect articulation, breathing, eating, drinking, and even hinder the ability to find a suitable profession ⁶⁻⁹. Children born with cleft lip and/or palate should undergo surgical repair as soon as possible to prevent long-term sequelae such as language delay, hypernasality, communication problems, frequent respiratory infections, and psychologic problems ¹⁰⁻¹². In underprivileged areas of the world, including remote regions of Iran, many patients do not undergo surgical repair until late in childhood or even adulthood due to financial deprivation. Their families sometimes neglect them due

to their unpleasant physical appearance. Many of these children do not start or even leave school due to embarrassment and fear of humiliation by their peers. As a result, they fail to receive adequate education and achieve academic performance despite having normal intellectual functioning. Moreover, affected patients inevitably experience psychological problems such as poor self-esteem, anxiety, and depression. Many of them also struggle with proper eating and drinking habits, further affecting their quality of life. However, if these patients could develop normal speech, receive adequate education, and attain a standard quality of life

Therefore, in 2009, a small group of volunteer plastic surgeons, under the supervision of the first author, started helping poor patients who had been neglected for many years due to financial difficulties and/or cultural limitations. This group has been making periodic trips to underprivileged areas throughout the country to visit and perform surgeries on impoverished patients. In this paper, the authors would like to describe the results of this expedition and provide recommendations for other groups elsewhere who would like to follow this path.

Initial steps

In 2009, a small group of plastic surgeons initiated periodic missions to underprivileged areas of Iran, providing visits and surgeries for patients with cleft lip, palate, and other congenital craniofacial malformations who had not received appropriate medical and surgical treatment. Over the next decade, the group experienced significant growth, both in terms of the number of volunteer plastic surgeons and the quality of the care provided. It is now one of the largest national health institutes in Iran, known as "Marham National Health Institute".

SYSTEMATIC METHODS IN EACH MISSION

Group members

During each mission, Marham National Health Institute assembles a multidisciplinary team comprising of the following professionals:

- 1. Board-certified plastic surgeon
- 2. Pediatric anesthesiologist
- 3. General anesthesiologist

- 4. Plastic surgery fellow
- 5. ENT surgeon
- 6. Neurosurgeon
- 7. General physician
- 8. Clinical psychologist
- 9. Surgical technologist
- 10. Nurse anesthetist
- 11. Nurse
- 12. Speech therapist
- 13. Social worker
- 14. Medical photographer
- 15. IT specialist

Other specialists have also participated in some missions. A comprehensive list of participants is provided in Table 1.

All members work on a volunteer basis, without payment. Their academic backgrounds range from full professors and associate/ assistant professors to general practitioners. Figure 1 depicts our medical team.

Patient selection

Before each mission, patients were informed through posters, billboards, flyers, social media, and other means of announcement several weeks or months in advance. During the initial hours or days of the trip, eligible patients for surgery were selected after an initial visit.

Starting from the 22nd mission, a virtual visiting system was introduced using electronic platforms. Several weeks before each trip, patients uploaded their photos on a website. The head plastic surgeon (AK) conducted the initial screening and selected eligible patients. If additional data was required, patients were contacted by phone. This approach helped identify and schedule the majority of patients who could undergo surgery several weeks before the trip. Consequently, it enabled the team to allocate the initial hours of the trip to performing surgeries rather than visiting and screening patients, resulting in an increased number of operations during each mission.

Ethical considerations

As a qualitative review, an institutional review board (IRB) approval was not needed. A written consent form was obtained from all patients or their legal guardians for using their data for research

Table 1: Comprehensive data on 31 trips

No. of trip	City, Province	Date of trip	Duration of trip	No. of plastic Surgeons	Other group members	No. of Visits/electronic visits (if applicable)	No. of Surgeries	No. of operating rooms
1	Ramhormoz,	November	3	5	1 Nurse	300	25	2
1	Khouzestan	2009	3	3	1 Medical Photographer	300	23	2
2	Ramhormoz, Khouzestan	March 2010	3	3	1 Nurse 1 Medical Photographe0072	500	52	2
3	Mahmoud Abad, Mazandaran	November 2010	2	6	1 Medical Photographer	35	0	0
4	Ramhormoz, Khouzestan	January 2011	4	6	1 Medical Photographer	1200	105	3
5	Gavdaneh, Kohkilooye-o-	July 2011	5	9	1 General Practitioner 1 Nurse	1260	7	1
	Boyer Ahmad				2 Medical Photographer			
6	Tabriz, East Azerbayjan	August 2011	4	6	1 Nurse 1 Medical Photographer	150	10	2
	D 1				1 Pediatric Neurosurgeon			
7	Baneh, Kordestan	May 2012	5	6	2 Medical Photographer 1 Nurse	1000	30	3
	D 1	0 . 1			2 General practitioner			
8	Ramhormoz, Khouzestan	October 2012	4	6	1 Nurse 1 Medical Photographer	1600	64	3
9	Bandarabas, Hormozgan	January 2013	4	6	1 Murse 1 Medical Photographer	500	82	4
10	Ramhormoz,	September			2 General Practitioner			
	Khouzestan	2013	3	6	1 Nurse	1000	65	3
					Medical Photographer Pediatric anesthesiologist			
	Boushehr,	January		8	3 General Practitioner			
11	Boushehr	2014	5	O	1 Nurse	700	87	7
					1 Medical Photographer			
	D 11	0 . 1			2 General Practitioner			
12	Boushehr, Boushehr	September 2014	4	8	2 Nurse	200	35	4
	Dousnelli	2014			1 Medical Photographer			
					1 Orthopedic Surgeon			
13	Ramhormoz,	January	4	9	1 General Practitioner	1200	68	3
	Khouzestan	2015			3 Nurse			
					1 Medical Photographer1 Pediatric Anesthesiologist			
14	Zahedan, Sistan-	January			1 General Practitioner			
	o-Baloochestan		6	6	2 Nurse	1000	120	4
					1 Medical Photographer			
					1 Orthodontist			
15	Bijar, Kordestan	April 2016	4	4	1 General Practitioner	300	38	3
13	Dijar, Kordestan	71p111 2010	1	1	2 Nurse	300	30	3
					2 Medical Photographer			
					1 Pediatric Anesthesiologist			
	D l	N		11	2 General Practitioner			
16	Ramhormoz, Khouzestan	November 2016	5	1 general	4 Nurse 1 Nurse Anesthetist	1080	108	4
	Miouzestan	2010		surgeon	2 Social Worker			
					1 Medical Photographer			
					1 Orthopedic Surgeon			
					1 General Practitioner			
17	Zabol, Sistan-o-	January	E	7	1 ENT Specialist	600	63	2
17	Baloochestan	2017	5	7	2 Nurse	600	62	3
					1 Nurse Anesthetist			
					1 Medical Photographer			

Continued Table 1: Comprehensive data on 31 trips

No. of trip	City, Province	Date of trip	Duration of trip	No. of plastic Surgeons	Other group members	No. of Visits/electronic visits (if applicable)	No. of Surgeries	No. of operating rooms
18	Ahwaz, Khouzestan	February 2017	3	12	1 Nurse 1 Medical Photographer	300	64	3
					1 Orthopedic Surgeon 1 Pediatric Anesthesiologist			
					1 Anesthesiologist		155	
19	Kermanshah,	June 2017	6	7	1 ENT Specialist 1 Orthodontist	1200	155 (40 in one	11
19	Kermanshah	Julie 2017	Ü	/	1 Speech Therapist	1200	day)	11
					1 Surgical Technologist		uay)	
					1 Nurse			
					1 Medical Photographer			
					2 Pediatric Anesthesiologist			
					1 ENT Specialist			
					1 Neurosurgeon			
	Ramhormoz,	November			1 General Physician			
20	Khouzestan	2017	5	9	1 Clinical Psychologist	1130	87	4
					2 Surgical Technologist			
					1 Nurse Anesthetist			
					1 Medical Photographer			
					1 Orthopedic Surgeon			
	Gachsaran,	T			1 Pediatric Anesthesiologist			
21	Kohkilooye-o-	January	5	8	3 Surgical Technologist	1235	75	4
	Boyer Ahmad	2018			1 Nurse Anesthetist			
					1 Medical Photographer			
					1 Pediatric Anesthesiologist			
					1 Anesthesiologist			
					1 Orthopedic Surgeon			
					1 Clinical Psychologist		136	
22	Birjand, North	June 2018	6	9	1 Psychologist	1137/ 887	(50 in one	8
	Khorasan	, 4110 2010	Ü		1 General physician	11077 007	day)	
					4 Surgical Technologist		uu,,,	
					3 Nurse Anesthetist			
					1 Speech Therapist			
					1 Medical Photographer			
					1 Pediatric Anesthesiologist			
					Ophthalmologist General Practitioner			
		Marramhan				2621	157 (62 in	
23	Ilam, Ilam	November	5	16	1 Speech Therapist	362/	157 (62 in	6
		2018			4 Surgical Technologist 6 Nurse Anesthetist	570	one day)	
					1 Nurse			
					1 Medical Photographer			
					1 Pediatric Anesthesiologist			
					1 Anesthesiologist			
					3 General Practitioner			
					1 Clinical psychologist			
24	Dezfoul,	January	4	8	6 Surgical Technologist	250/	125 (65 in	4
	Khouzestan	2019	-	-	1 Nurse Anesthetist	600	one day)	•
					1 Nurse			
					1 Speech therapist			
					1 Medical Photographer			
					1 Pediatric Anesthesiologist			
	NT - 1 - 1				2 Anesthesiologist			
25	Neishabour,	1 2010		1.0	2 General Practitioner	2007.500	100	
25	Khorasan-e-	June 2019	4	16	1 Clinical psychologist	300/ 600	120	6
	Razavi				10 Surgical Technologist			
					4 Nurse Anesthetist			

Continued Table 1: Comprehensive data on 31 trips

No. of trip	City, Province	Date of trip	Duration of trip	No. of plastic Surgeons	Other group members	No. of Visits/electronic visits (if applicable)	No. of Surgeries	No. of operating rooms
26	Kermanshah, Kermanshah	November 2019	4	20	1 Nurse 1 Speech therapist 1 Medical Photographer 1 Social worker 1 Pediatric Anesthesiologist 2 Anesthesiologist 2 General Practitioner 1 Clinical psychologist 16 Surgical Technologist 8 Nurse Anesthetist 1 Nurse 1 Speech therapist	1200/250	208 (75 in one day)	13
27	Tehran, Tehran	June 2021	1	9	1 Medical Photographer 1 Social worker 4 Anesthesiologist 2 General Practitioner 1 Clinical psychologist 17 Surgical Technologist 9 Nurse Anesthetist 2 Nurse 1 Medical Photographer	60/200	31	5
28	Tehran, Tehran	March 2022	1	7	2 Social worker 2 Anesthesiologist 2 General Practitioner 1 Clinical psychologist 17 Surgical Technologist 9 Nurse Anesthetist 2 Nurse 1 Medical Photographer 2 Social worker	200/210	40	5
29	Tehran, Tehran	July 2022	1	15	6 Anesthesiologist 2 General Practitioner 1 Clinical psychologist 18 Surgical Technologist 8 Nurse Anesthetist 2 Nurse 1 Medical Photographer 2 Social worker	150/235	46	6
30	Ramhormoz, Khuzestan	March 2023	4	10	3 Anesthesiologist 2 General Practitioner 1 Clinical psychologist 8 Surgical Technologist 3 Nurse Anesthetist 1 Nurse 2 Medical Photographer 1 Social worker 4 Anesthesiologist	300	67	5
31	Tehran, Iran	March 2023	1	15	2 General Practitioner 1 Clinical psychologist 14 Surgical Technologist 6 Nurse Anesthetist 1 Nurse 2 Medical Photographer 1 Social worker	130/180	34	5



Figure 1: Our medical team. A. At the operating room, 1st mission (Ramhormoz, November 2009), B. Prepared for initiating medical visit, 11th mission (Bushehr, January 2014), C. At the operation room, 27th mission (Tehran, June 2021)

purposes and releasing their photos, as necessary. All medical staff appearing in the photos also provided written informed consent for publication of their photos.

Surgical procedures

Before surgeries, all patients were examined under the supervision of the head plastic surgeon (AK), and a surgical plan was established for each patient. However, during surgery, the attending plastic surgeon had the discretion to make changes to the predefined plan if necessary. All surgeries took place in operating rooms (OR) at local hospitals. Due to the limited number of ORs in these small hospitals, elective surgeries by local surgeons were not scheduled during the mission period, and only emergency surgeries were performed. This strategy allowed for the maximum utilization of available ORs to perform simultaneous surgeries.

Furthermore, since these operations were conducted in small hospitals located in remote areas with limited access to specialized equipment, the team prepared all necessary equipment and brought it to the local hospitals during each mission.

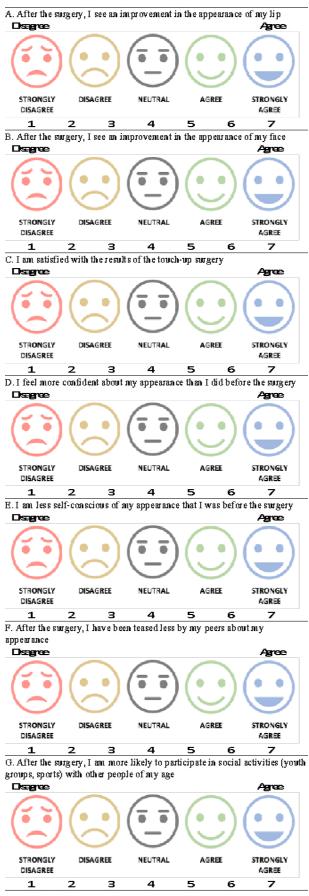


Figure 2: Patient satisfaction questionnaire

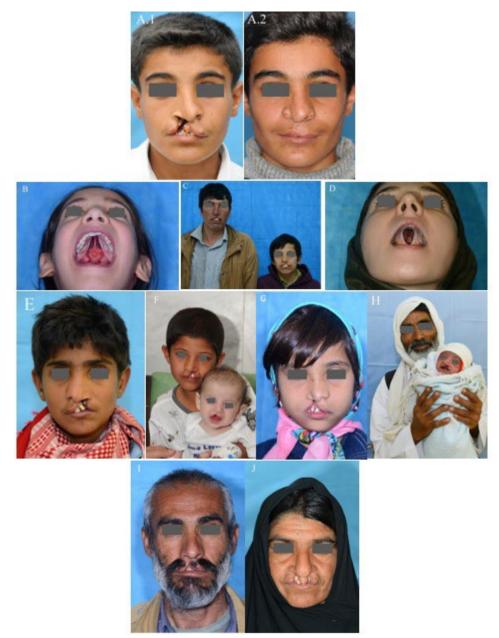


Figure 3: A few numbers of patients undergoing surgery by the Marham National Health Institute. **A.** A 12-year-old boy with primary cleft lip, the first patient undergoing surgical repair of cleft lip by the Marham National Health Institute in 2009; *A.1.* Before surgery, *A.2.* One year after surgery, **B.** A 6-year-old girl with unrepaired cleft palate, **C.** A 24-year-old man and his 13-year-old nephew with primary cleft lip, **D.** A 11-year-old girl with unrepaired cleft palate, **E.** A 12-year-old boy with primary cleft lip, **F.** Two brothers (7 years old and 5 months old) with primary cleft lip, **G.** A 7-year-old girl with primary cleft lip, **H.** A 2-month-old boy with primary cleft lip, the youngest patient undergoing surgical repair of cleft lip by the Marham National Health Institute, **I.** A 35-year-old man with primary cleft lip, **J.** A 62-year-old woman with primary bilateral cleft lip, the oldest patient undergoing surgical repair of cleft lip by the Marham National Health Institute

Post-operative care

On the last day of the mission, cleft palate and other complex operations were not performed to prevent any immediate post-operative complications that may arise after the departure of the surgical team. Plastic surgeons and their assistant general

physicians visited patients after surgery to facilitate their discharge per the protocol and as soon as it is safe for the patients to be discharged. The rapid follow-up assessments and discharge makes more beds available for further admissions. Individual post-discharge guidance, including diet and special care instructions, were also provided to each patient.

Follow-up

Short-term post-operative follow-up, including management of possible surgical complications and suture removal, was performed by local plastic surgeons, general surgeons, pediatric surgeons, or ENT surgeons, depending on availability.

For the long-term follow-up, in the earlier missions, patients were contacted via telephone by the group's supporting staff and referred to the head plastic surgeon if necessary. Starting from the 22nd mission, an electronic follow-up system was developed by the group's IT specialists. Patients were electronically followed up using a website, regularly contacted, and requested to upload new photos into the system. This electronic follow-up system enabled the scheduling of patients requiring further surgeries for future missions.

On the 27th, 28th, 29th and 31st missions, after virtual selection, patients were referred to 15 Khordad Hospital in Tehran, Iran for surgery.

Providing accommodation for patients

For patients coming from more remote areas, temporary accommodation facilities and appropriate food supplies were provided by collaborating non-profit organizations (NGOs). In several missions, transportation of patients to the hospital was arranged through vehicles provided by other NGOs or local medical universities. Financial aid was provided by private donors during each trip, covering all associated costs.

Patient satisfaction

To assess patient satisfaction, in the last five trips, a total of 100 patients aged 15 years and older were randomly selected to complete a patient satisfaction questionnaire. Patient satisfaction towards the received treatment was measured using numerical ratings for seven questions (Figure 2). Patients were instructed to score 7 if they strongly agreed with the question and 0 if they strongly disagreed.

SUMMARY OF ACCOMPLISHMENTS

Number of trips

To date, 27 missions have been conducted in underprivileged regions of Iran thus far, with an additional 4 missions in Tehran. The missions in Tehran were primarily due to travel restrictions during the COVID-19 pandemic or when patients were residing in cities and rural areas near Tehran. Detailed characteristics of all missions are summarized in Table 1.

Number of visits

Overall, 20,579 patients with cleft lip and palate and other congenital craniofacial anomalies have been visited during 31 missions. From the 22nd to the 31st missions, 3,732 visits were performed electronically before the trips, using electronic systems. A complete list of the indications for medical visits during the trips is provided in Table 2.

Table 2: List of indications of medical visits

Cleft lip

- Unilateral vs. Bilateral
- Revision
- Complete vs incomplete (microform, miniform, microminiform)

Cleft palate

• Primary vs secondary

Alveolar Bone grafting

Alveolar fistula

Composite graft of nasal alae

Craniofacial clefts

Cleft lip-nasal deformity

Jaw deformity

AV malformation

Giant congenital nevus

Craniosynostosis

Hypertelorism

Other Craniofacial anomalies

Table 3: List of surgeries

Cleft lip

- Unilateral vs. Bilateral
- Primary repair vs. Revision surgery
- Dermis-fat graft
- Complete vs. incomplete (lesser-forms of incomplete: minor-form, microform, and mini-microform, complete)

Cleft palate

Primary vs. secondary (hard palate)

Alveolar Bone graft Closure of Alveolar fistula

Composite graft of nasal alae

Facial clefts

Table 4: Postoperative complications observed in the study population

Postoperative complication	Number of	Comment
Postoperative complication	cases	
Bleeding	4	2 patients with cleft lip (one patient underwent immediate reoperation)
bleeding		2 patients with cleft palate (one patient underwent immediate reoperation)
Dehiscence	1	$Patient\ had\ undergone\ lip\ adhesion\ for\ bil lateral\ cleft\ lip.\ He\ underwent\ reoperation\ 3\ months\ later.$
Stich abscess	3	
Irregular healing of scars	3	
Residual irregularities and	-	
asymmetry in the lip	5	

Table 5: Results of the patient satisfaction questionnaire completed by 100 patients

Question	Mean±SD
A. After the surgery, I see an improvement in the appearance of my lip	6.1±0.83
B. After the surgery, I see an improvement in the appearance of my face	6.0 ± 0.44
C. I am satisfied with the results of the touch-up surgery	6.1±0.70
D. I feel more confident about my appearance than I did before the surgery	5.3±0.54
E. I am less self-conscious of my appearance that I was before the surgery	5.3±0.78
F. After the surgery, I have been teased less by my peers about my appearance	5.1±0.49
G. After the surgery, I am more likely to participate in social activities (youth groups, sports) with other people of my age	4.0±0.46

Number of surgeries

A total of 2,303 surgeries were performed during the 31 missions. The age of patients ranged from 2 to 62 years. Figure 3 shows a subset of patients who underwent surgery. A summary of all surgeries is provided in Table 3.

The highest number of surgeries per mission were performed in Kermanshah (the 26th mission, 208 surgeries), Ilam (the 23rd mission, 157 surgeries), and Birjand (the 22nd mission, 136 surgeries). Notably, the surgical team managed to perform 75 surgeries in one day in Kermanshah (26th mission), 65 surgeries in one day in Dezful (24th mission), 62 surgeries in one day in Ilam (23rd mission), and 50 surgeries in one day in Birjand (22nd mission).

Table 4 provides a summary of postoperative complications observed in the study population, and Table 5 shows patient satisfaction levels after cleft lip surgery, assessed in 100 patients.

DISCUSSION

First introduced in 2009 as a seven-member group of plastic surgeons, the Marham National Health Institute has gradually evolved over fourteen years. It began its work by taking simple but essential steps to build the institute's foundation and achieve the highest level of efficiency. Currently recognized as a nationally-renowned NGO, the Marham National Health Institute has a well-organized structure and adheres to strict internal disciplines

in its pursuit of providing free surgical care to impoverished patients with congenital craniofacial malformations.

The Marham National Health Institute has remarkable features that distinguish it from other NGOs and charity organizations. We can categorize these distinguishing aspects of the Marham National Health Institute as follows:

Dedication of time and specialty instead of money

The Marham National Health Institute operates based on its fundamental principle of "dedication of time and specialty rather than money," unlike most NGOs that rely on monetary donations. The institute welcomes valuable time and professional support from volunteers working in related professions, such as the precious time and surgical expertise provided by plastic surgeons.

The traveling medical team (medical trips vs. standard care centers)

Due to the high costs of accommodation and transportation in large cities, as well as other obstacles that make traveling difficult for lowincome families, the medical team of the Marham National Health Institute travels to remote areas to find patients in need. Additionally, a significant proportion of patients, especially children, who suffer from highly unpleasant physical appearance have been neglected by their families for several years. Therefore, the difficulty in accessing medical services geographically makes them more likely to be deprived of necessary repair surgeries. The Marham Institute's traveling to remote areas ensures that repair surgeries are provided to these neglected patients, whose families may not be willing to travel long distances to seek the necessary surgery.

Implementing practical methods and strategies to boost the efficacy

The Marham Institute implements basic and fundamental rules to optimize its output. These strategies have been comprehensively described in the "methods" section. In summary, recruiting a multidisciplinary medical team, using the electronic visiting system for patient selection, making vigorous

efforts to maximize the number of available ORs and hospital beds, providing specialized surgical equipment, and employing a rigorous follow-up system have all contributed to achieving the goal of operating on the highest number of patients in a short period in small hospitals of underprivileged areas.

RESULTS

The Marham Institute has achieved a large number of surgeries on a nationwide scale. In addition to its charitable work, the Marham Institute is the largest center for performing cleft lip and palate surgery in Iran. By using a virtual visiting system for effective patient selection before missions and employing efficient OR and bed management strategies during missions, the plastic surgeons have been able to perform a significant number of surgeries during each trip. Remarkably, the plastic surgeons achieved even higher records in terms of the number of surgeries performed in a single day, with 50 surgeries performed in Birjand during the 22nd mission, thanks to the availability of sufficient operating rooms. This achievement was surpassed in three subsequent missions, with 62 surgeries in Ilam, 65 surgeries in Dezful, and 75 surgeries in Kermanshah, all performed in a single day.

Training and education

The Marham Institute provides a valuable training opportunity for plastic surgeons to expand their expertise by performing a considerable number of surgeries and sharing knowledge and experience with their colleagues during these missions.

Furthermore, health care providers, medical staff, and managers in local hospitals gain experience in dealing with a large number of patients during a short period, similar to what occurs during crises. These "crisis management" skills will help them prepare for unforeseen crisis situations such as floods, earthquakes, etc.

Cooperation and teamwork skills are also nurtured among all participants. Additionally, several rare congenital craniofacial malformations and familial cases have been identified during these trips ¹¹, which can be used for educational and research purposes.

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Comprehensive dataset and rigorous electronic screening and follow-up system

The Marham Institute possesses a unique dataset comprising the initial data and long-term followup results of over 13000 patients with congenital craniofacial malformations in Iran. This valuable information can be utilized for national and international educational and research projects.

Currently, the Marham Institute utilizes a virtual visiting system for screening and selecting operable patients, as well as for long-term follow-up. This electronic system has enabled surgeons to increase the number of operations during trips and easily evaluate the success of the operations and monitor the longterm aesthetic outcomes over time. Additionally, this meticulous follow-up system helps surgeons guide their patients in further care, such as selecting appropriate timing for orthodontic care or scheduling them for re-operations in upcoming trips, if needed.

Patient satisfaction

While we have not assessed patient satisfaction in all patients, we randomly selected 100 patients (15 years of age and older) to complete a patient satisfaction questionnaire. By employing this questionnaire, we aimed to gain a more nuanced and comprehensive understanding of patient satisfaction, which can help healthcare providers in improving their services and enhancing patient-centered care.

Our results indicated a high overall satisfaction rate among patients after cleft lip surgery, reflecting the success of the surgical interventions and their positive impact on self-perception and quality of life. Patients expressed appreciation for the improved appearance of their lips and face. These findings support previous studies highlighting the effectiveness of cleft lip surgery in addressing both functional and aesthetic concerns 14-16.

However, it is important to note that while patient satisfaction levels are generally high regarding treatment outcomes among patients with cleft lip, there are lingering concerns regarding the aesthetic aspects 15, 16.

Our results also revealed areas where patient satisfaction could be further improved. For instance, patients reported ongoing concerns related to selfconfidence and social interactions following the surgery. These findings underscore the need for continued psychological support and follow-up care to address such concerns and optimize long-term patient satisfaction. Another noteworthy aspect is the importance of considering both physical and psychological aspects when evaluating surgical outcomes.

LIMITATIONS TO THIS METHOD

The present report has a few limitations that need to be considered. Firstly, the study did not originally intend to assess patient satisfaction using validated questionnaires during the missionary trips, as these missions were not planned for research purposes. The decision to include this assessment was made after the 27th trip. Consequently, patient satisfaction had not been evaluated during all the trips, and we randomly selected 100 cases from the latest trips to complete the questionnaires. Secondly, the complication rate was determined based on data documented by our physicians during each mission. In the manuscript, we did not specify a predefined follow-up period because many patients had delayed their surgeries for several decades due to financial and cultural constraints, often waiting until their 30s or 40s. Thus, expecting these patients to travel long distances for routine postoperative assessments was not feasible. However, for certain patients who required multiple surgeries to address their initial malformations, we maintained regular contact and provided followup care during subsequent trips to other cities until their surgeries were completed or they were satisfied with the outcomes. This might explain any possible disagreement between the rate of common postoperative complications in our study and those reported in the previous literature.

CONCLUSION

Originating from a small group of volunteer physicians and paramedics and gradually growing into a nationally-renowned NGO, the Marham Institute operates independently. It has no affiliations with any governmental, political, ethnic or religious group. The institute's mission is to provide free surgical care for all patients with congenital craniofacial malformations, regardless of their nationality, language, ethnicity, and religious beliefs.

All medical and non-medical staff members at the Marham National Health Institute work on a voluntary basis and do not receive bonuses, pay increments, or financial incentives from their workplace in

exchange for their cooperation with the institute. The dedication, hard work, commitment, and enthusiasm of young board-certified plastic surgeons and other healthcare providers have led to 31 medical missions in underprivileged areas of Iran, resulting in 20,579 free medical visits and 2,303 repair surgeries on impoverished patients with congenital craniofacial malformations, primarily cleft lip and palate.

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CONFLICT OF INTEREST

None declared.

FINANCIAL DISCLOSURE

None.

REFERENCES

- Calzolari E, Bianchi F, Rubini M, Ritvanen A, Neville AJ; EUROCAT Working Group. Epidemiology of cleft palate in Europe: implications for genetic research. *Cleft Palate Craniofac J* 2004;41(3):244-249. doi:10.1597/02-074.1
- Kancherla V, Oakley GP Jr, Brent RL. Urgent global opportunities to prevent birth defects. Semin Fetal Neonatal Med 2014;19(3):153-160. doi:10.1016/j. siny.2013.11.008

- 3. Derijcke A, Eerens A, Carels C. The incidence of oral clefts: a review. *Br J Oral Maxillofac Surg* 1996;**34**(6):488-494. doi:10.1016/s0266-4356(96)902 42-9
- 4. Butali A, Mossey PA. Epidemiology of Orofacial clefts in Africa: Methodological challenges in ascertainment. *Pan Afr Med J* 2009;**2**:5. doi:10.4314/pamj.v2i1.51705
- IPDTOC Working Group. Prevalence at birth of cleft lip with or without cleft palate: data from the International Perinatal Database of Typical Oral Clefts (IPDTOC). Cleft Palate Craniofac J 2011;48(1):66-81. doi:10.1597/09-217
- 6. Al-Namankany A, Alhubaishi A. Effects of cleft lip and palate on children's psychological health: A systematic review. *J Taibah Univ Med Sci* 2018;**13**(4):311-318. doi:10.1016/j.jtumed.2018.04.007
- 7. Lohmander A, Persson C. A longitudinal study of speech production in Swedish children with unilateral cleft lip and palate and two-stage palatal repair. *Cleft Palate Craniofac J* 2008;**45**(1):32-41. doi:10.1597/06-123.1
- 8. Arosarena OA. Cleft lip and palate. *Otolaryngol Clin North Am* 2007;**40**(1):27-vi. doi:10.1016/j. otc.2006.10.011
- Ardouin K, Davis S, Stock NM. Physical health in adults born with cleft lip and/or palate: a whole of life survey in the United Kingdom. *Cleft Palate Craniofac J* 2021;58(2):153-162. doi:10.1177/1055665620944758
- 10. Kummer AW. Communication disorders related to cleft palate, craniofacial anomalies, and velopharyngeal dysfunction. *Semin Speech Lang* 2011;**32**(2):81-82. doi:10.1055/s-0031-1277711
- 11. Miller CK. Feeding issues and interventions in infants and children with clefts and craniofacial syndromes. *Semin Speech Lang* 2011;**32**(2):115-126. doi:10.1055/s-0031-1277714
- 12. Farronato G, Cannalire P, Martinelli G, et al. Cleft lip and/or palate: review. *Minerva Stomatol* 2014;**63**(4):111-126.
- 13. Kalantar-Hormozi A, Abbaszadeh-Kasbi A, Shalbaf S, Davai NR. Introducing a family with tens of rare craniofacial clefts. *J Craniofac Surg* 2019;**30**(5):e395-e397. doi:10.1097/SCS.000000000005269
- 14. Landsberger P, Proff P, Dietze S, et al. Evaluation of patient satisfaction after therapy of unilateral clefts of lip, alveolus and palate. *J Craniomaxillofac Surg* 2006;**34**(Suppl 2):31-33. doi:10.1016/S1010-5182(06)60008-5
- 15. Oosterkamp BC, Dijkstra PU, Remmelink HJ, et al. Satisfaction with treatment outcome in bilateral cleft lip and palate patients. *Int J Oral Maxillofac Surg* 2007;**36**(10):890-895. doi:10.1016/j.ijom.2007.07.008
- 16. Bhat M, Shetty S, Shetty P, Khan FA, Husain A, Ragher M. Evaluation of Patient and Parent Satisfaction After Orthodontic Treatment/Orthognathic Surgery for Cleft Lip and Palate Deformity. J Pharm Bioallied Sci 2019;11(Suppl 2):S184-S187. doi:10.4103/JPBS. JPBS 289 18