



ORIGINAL ARTICLE

Establishing Baseline Compliance with Multidisciplinary Cleft Care: A Retrospective Study from Bahrain (Part 1)

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Abstract

Background: Cleft lip and/or palate (CL/P) requires timely, multidisciplinary care to optimize health outcomes. In Bahrain, no prior data describe access to such services. This study aimed to establish a hospital-based registry and assess baseline patterns of attendance across specialty clinics at Bahrain Defense Force - Royal Medical Services before the implementation of a national cleft care pathway.

Methods: In this retrospective cohort study, all patients with CL/P who attended cleft-related clinics between June 2017 and September 2020 were identified. Electronic records were reviewed to collect demographics, cleft type, and age at first visit to Pediatrics, Ear, Nose, and Throat (ENT), Speech and Language Therapy (SLT), Pedodontics, Orthodontics, and Psychology.

Results: Among 51 children (57% female, 43% male), cleft palate alone was most common (37.3%), followed by unilateral cleft lip ± palate (UCLP, 35.3%), cleft lip (17.7%), and bilateral cleft lip ± palate (BCLP, 3.9%). The mean age at first visit was 29 days for Pediatrics, 5.5 months for ENT, and 7.5 years for Orthodontics. Substantial delays were observed for SLT (mean: 8.3 years) and Pedodontics (2.2 years), and no patient had attended a Psychology clinic.

Conclusion: Timely access to core services such as Pediatrics, ENT, and Orthodontics was observed. However, substantial delays in Speech and Language Therapy, Pedodontics, and Psychology highlight gaps in referral pathways, coordination of care, and caregiver awareness. This hospital-based registry offers essential baseline data to guide and measure future improvements in Bahrain's national multidisciplinary cleft care program.

Keywords: Cleft lip, Cleft palate, Multidisciplinary care, Healthcare access, Bahrain

Introduction

Reliable data on congenital disabilities in developing countries remain limited, and the incidence of facial clefts in the Middle East is not well documented.¹ Even so, a handful of regional studies offer some insight. In Saudi Arabia, for instance, reported incidence rates range from 0.3 to 2.19 per 1,000 live

births, depending on the region.² Oman has reported a rate of 1.5 per 1,000 live births,³ while figures from Sudan and Iran stand at 0.9 and 1.03 per 1,000 live births, respectively.^{4,5} Currently, Bahrain does not have a national registry or centralized reporting system for congenital anomalies. This lack of population-level data underscores the importance of

institutional registries, such as the one developed in this study.

Individuals born with cleft lip and/or palate (CL/P) and their families face a lifelong series of challenges that often begin before birth and may continue well into adulthood. These conditions extend far beyond appearance, encompassing a range of medical and developmental concerns, including difficulties with speech, hearing impairments, recurrent ear infections, dental and palatal anomalies, and significant psychosocial impacts.⁶

Effective management of cleft conditions requires more than surgical repair. Children with CL/P often need ongoing care that supports their physical health, developmental progress, and psychological well-being.⁶⁻⁸ In response to this complexity, the multidisciplinary team (MDT) model has become the standard approach, uniting specialists across medical, dental, and allied health fields to deliver comprehensive and well-coordinated treatment.⁷

In 2013, the United Kingdom's National Health Service (NHS) introduced national standards for CL/P services, providing a structured framework for integrated care.⁸ This model connects patients with the appropriate specialists at key developmental stages to support their health, growth, and long-term well-being. Inspired by this approach, the Bahrain Defense Force - Royal Medical Services (BDF-RMS) adopted a similar multidisciplinary pathway in 2021. The NHS framework was selected for its proven effectiveness in standardizing cleft care and its suitability for Bahrain's healthcare system, which also features centralized coordination and publicly funded services.⁹

Nevertheless, even within a fully subsidized and structured healthcare system, the role of families remains critical. Parents and caregivers are often responsible for coordinating appointments, tracking treatment milestones, and advocating for timely interventions. This level of involvement, while essential, can be overwhelming. Such demands may contribute to delays in accessing specialized treatment, raising questions about whether the availability of services consistently ensures effective utilization.^{10,11}

Given the limited data on CL/P in Bahrain and the complex needs of affected individuals, this study aimed to establish baseline epidemiological data and examine the cleft care provided before the implementation of a structured multidisciplinary pathway. A follow-up study is currently underway to analyze post-implementation data and evaluate its impact and long-term effectiveness.

Study Objectives

In light of these challenges, this study aimed to:

1. Describe the pattern of CL/P cases at Bahrain Defence Force - Royal Medical Services.
2. Assess attendance patterns across cleft care clinics before implementing the BDF-RMS multidisciplinary care pathway.

Materials and Methods

Study Design and Participants

This retrospective cohort study reviewed all individuals diagnosed with CL/P who visited any cleft care clinics at BDF-RMS between June 2017 and September 2020. These clinics included Pediatrics, ENT (Ear, Nose, and Throat), Speech and Language Therapy (SLT), Psychology, Pedodontics, and Orthodontics. All patients seen during this period were included, with no predefined sample size or age restrictions, as the goal was to establish a comprehensive baseline registry. Patients seen solely in private clinics within the hospital or those with incomplete medical documents were omitted.

Data Collection

An institutional cleft registry was established to gather relevant patient information, including sex, national identity, cleft type, and the presence of additional congenital malformations or syndromes. Cleft types were classified according to the descriptive classification system of the American Cleft and Craniofacial Association.¹² The age at first visit to each clinic (Pediatrics, ENT, SLT, Psychology, Pedodontics, and Orthodontics) was extracted from medical records to assess compliance. In this study, compliance was defined as attending each clinic within the recommended age window as specified in the BDF-RMS cleft care pathway.

Statistical Analysis

Data were analyzed using Microsoft Excel and SPSS version 27. Descriptive statistics were calculated as appropriate, including means, medians, percentages, ranges, and ratios.

Ethical Approval

This study was conducted in accordance with the principles of the World Medical Association Declaration of Helsinki. Ethical approval was obtained from the Research and Research Ethics Committee of the Bahrain Defence Force - Royal Medical Services, Military Hospital, Kingdom of Bahrain.

Results

A total of 51 children diagnosed with CL/P were recorded in the institutional registry. Of these, 45 (88.2%) were Bahraini and 6 (11.8%) were non-Bahraini. Among all cases, 3.9% ($n = 2$) were diagnosed with a recognized syndrome, and 17% ($n = 9$) had one or more additional congenital anomalies (Table I).

Regarding cleft type, cleft palate (CP) was the most frequently observed, accounting for 37.3% ($n = 19$) of cases. This was followed by unilateral cleft lip and palate (UCLP), representing 35.3% ($n = 18$), and cleft lip (CL), which accounted for 17.7% ($n = 9$). Bilateral cleft lip and palate (BCLP) was the least common, with only two cases (3.9%) reported.

Table II presents the distribution of CL/P types by gender. Overall, CL/P was slightly more prevalent in females ($n = 29$) than in males ($n = 22$), yielding a female-to-male ratio of 1.3:1. When stratified by cleft type, CP and UCLP were more common in females, with female-to-male ratios of 2.2:1 and 1.25:1, respectively. In contrast, CL was more frequently observed in males, with a male-to-female ratio of 1.3:1. BCLP was evenly distributed between the sexes (1:1).

To assess compliance with the multidisciplinary care pathway, the age at first visit to each clinic-paediatrics, ENT, SLT, Psychology, Pedodontics, and Orthodontics-was extracted from medical records (Table III). Following hospital discharge, the initial follow-up visit was with the Paediatrician,

occurring at a mean age of 29 days ($SD = 21$), ranging from 7 to 65 days.

Table 1: Registered Syndromes and Malformations Among the Children Born with CL/P

Syndromes	
Goldenhar syndrome	1
Pierre Robin syndrome	1
Additional Congenital Malformations	
Cardiomegaly	1
Brain tumour	2
Ductus Arteriosus	2
Ureteric stenosis	1
Microphthalmia	1
Achondroplasia	1
Cleft foot	2
Nasal cleft	1

Table 2: Distribution of Cleft Deformities by Gender

Cleft Deformities	Male	Female	Total	%
Cleft Lip	6	3	9	17.7
Cleft Palate	6	13	19	37.3
CLP	9	11	20	39.2
- UCLP	8	10	18	35.3
- BCLP	1	1	2	3.9
Unspecific	1	2	3	5.9
Total	22	29	51	100.0

ENT assessments were conducted at a mean age of 5.5 months ($SD = 2.4$). However, there was considerable variability in attendance at SLT appointments, with first visits occurring between 4.5 and 11.1 years of age, and an average of 8.3 years ($SD = 2.5$). The mean age at first pedodontics appointment was 2.2 years ($SD = 1.5$), while orthodontic visits occurred at an average age of 7.5 years ($SD = 3.3$). Notably, none of the children attended the psychology clinic during the study period.

Discussion

This study marks the first hospital-based effort to establish a baseline registry for children born with CL/P in Bahrain. Documenting patterns of care and clinic attendance between 2017 and 2020

Table 3: Patient's Ages at the First Visit in Different Medical/Dental Clinics

	Mean Age (Standard Error)	Age Range		**Recommended Ages
Pediatrics Clinic	29 (21.9) Days	7 Days	65 Days	Birth – 3 Months
ENT	5.5 (2.4) Months	3.36 Months	10.8 Months	4- 18 Months
Speech and Language Therapy	8.3 (2.5) Years	4.5 Years	11.1 Years	18 Months – 5 Years
Psychology Clinic	-	-	-	18 Months – 5 Years
Pedodontics Clinic	2.2 (1.5) Years	9.7 Months	4.24 Years	Birth – 18 Months
Orthodontics Clinic	7.5 (3.3) Years	5. 60 Years	13.1 Years	6 – 10 Years

** Based on the RMS- BDF cleft lip and palate care pathway

provides essential foundational data to inform future research, clinical service development, and resource planning. A second study is currently underway, initiated after the implementation of the multidisciplinary CL/P care pathway in 2021. This follow-up aims to extend the dataset to the present day, evaluate improvements in care compliance, and assess the long-term effectiveness of the newly adopted pathway.

Cleft lip and palate cases (39.2%) were observed in our cohort more frequently than isolated CP or CL cases. This distribution is consistent with patterns reported in both regional and global literature.^{4,13-16} However, the relatively higher proportion of CP cases (37.3%) compared to CL cases (17.7%) differs from findings in Jordan, and Iran, where CL was more frequently reported.^{13, 14} In contrast, our results align more closely with Saudi Arabia, Kuwait, and Sudan studies, suggesting possible regional variation within the Middle East and North Africa.^{15, 16, 4}

When cleft types were analyzed by gender, CP was more frequently observed in females, while CL appeared more common in males. This gender distribution is consistent with findings from Jordan, Iran, Saudi Arabia, and Pakistan.^{13-15,17} However, some variation from the literature emerged when examining UCLP and BCLP. UCLP was more common in females, and BCLP showed an equal distribution between the sexes. These patterns contrast with Turkey and the Netherlands reports, where UCLP and BCLP were more commonly observed in males.^{18,19} These differences are likely influenced by the relatively small sample size of the

current study, which may have limited the ability to detect broader population trends.

The association of CL/P with other congenital anomalies is well-documented, with reported frequencies ranging from 1.5% to 63.4% in various cohorts.^{20,21} In our registry, 29.5% of patients had one or more additional anomalies, comparable to rates in Saudi Arabia (23.0%), and Pakistan (28.5%).^{15, 17} As in other studies, we counted all anomalies that required treatment or long-term follow-up.

While attendance at some clinics was on schedule, others were affected by significant delays. Timely access to cleft care was observed across the Paediatrics, Orthodontics, and ENT clinics. Although a slight variation was noted in the age at first paediatric follow-up, this was likely due to the admission of some infants to the neonatal intensive care unit, which naturally delayed their outpatient visits.²² Orthodontic appointments, however, were generally attended on time. The visibility of dental issues, particularly in the anterior teeth, and their potential impact on self-esteem and social confidence in children with CL/P²³ may influence patients or caregivers to prioritize timely orthodontic care. Similarly, ENT visits occurred within the recommended timeframe.

Attendance at the pedodontics clinic was notably delayed in our sample, with the average first visit occurring at approximately 2.2 years of age. According to the American Academy of Pediatric Dentistry (AAPD), the first dental visit should occur within six months of the first tooth's eruption and no later than the child's first birthday.²⁴ Missing this critical window for early dental care may contribute

to poor oral hygiene and increased periodontal issues, often observed among individuals with CL/P.²⁵

In our study, individuals with CL/P accessed SLT much later than recommended, with an average age of 7.8 years at their first appointment. The Royal College of Speech and Language Therapists recommends an initial assessment by 18-24 months and a second review around age three, allowing for timely intervention if needed.²⁶ The aim is to ensure children develop clear, intelligible speech before starting school. Since speech plays a crucial role in a child's social and academic development,²⁷ such delays are concerning and may have lasting effects.

The observed delays in accessing certain services can be attributed to a combination of structural, logistical, and caregiver-related factors. For instance, limited specialist availability and high caseloads can result in extended waiting times.¹¹ Additionally, referral processes that lack standardized follow-up protocols may cause unintended postponements.¹⁰ Moreover, caregiver-related challenges, such as difficulty managing multiple appointments or limited awareness of recommended intervention timelines, have also been identified as contributors to delays in cleft care.²⁸ These challenges are gradually being addressed through Bahrain's multidisciplinary cleft care pathway, which aims to ensure more timely access to all essential services.

A notable finding in our study was that none of the patients had attended psychological services. This absence does not necessarily indicate a lack of need but may reflect barriers such as limited awareness, fear, stigma, or distrust of mental health care.²⁹ In 2019, a study in Bahrain found that even primary healthcare providers held stigmatizing attitudes toward mental illness, which may contribute to families' reluctance to seek psychological support, despite its potential benefits.³⁰

Building on the findings of this initial study, a second phase of research is underway to evaluate cleft care patterns following the implementation of a structured MDT pathway in 2021. By comparing pre and post-implementation data, this study aims to assess improvements in clinic attendance, intervention timeliness, and overall service compliance.

In parallel, qualitative studies involving individuals with CL/P, caregivers, and healthcare providers are recommended. These may reveal deeper, context-specific barriers to accessing care that are not captured through quantitative data alone, offering further guidance for refining national cleft care strategies.

Conclusion

This study established the first hospital-based CL/P registry in Bahrain, providing foundational data on patient demographics and service utilization. Cleft palate was the most common type (37.3%), followed by unilateral cleft lip and palate (35.3%), with a higher prevalence among females for CP and UCLP. Nearly one-third of patients presented with associated anomalies, including 3.9% with a recognized syndrome.

Clinic attendance patterns revealed timely follow-up in Pediatrics, ENT, and Orthodontics. However, significant delays were observed in Pedodontics, Speech and Language Therapy, and Psychology, highlighting gaps in service coordination that may impact long-term outcomes.

This registry provides a valuable platform for ongoing evaluation and inter-hospital collaboration to enhance cleft care nationwide. The findings establish a strong foundation for future research, policy development, and pathway optimization within Bahrain's healthcare system. They also provide actionable insights to guide enhancements in multi-disciplinary care and add meaningful regional data to the global literature on cleft service delivery and compliance.

Funding

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Conflict of Interest

None declared.

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