A critical review of the prevalence of cleft lip and cleft palate in Arab countries

Iman Bugaighis[1,2]

[1]Department of Orthodontics, Egas Moniz School of Health and Science, Campus Universitário, Quinta da Granja Monte de Caparica, Portugal (Correspondence to Iman Bugaighis: isbugaighis@yahoo.com). [2]Libyan Authority for Scientific Research, Tripoli, Libya.

Abstract

Background: Orofacial cleft can occur as an isolated birth defect, a nonsyndromic abnormality, or as part of a syndrome with multiple congenital anomalies, and its prevalence can vary by ethnicity, sex and geographic location.

Aim: To review literature on the prevalence of orofacial cleft in Arab countries.

Methods: A search of relevant publications, in English, on the prevalence of orofacial cleft in Arab countries was performed on Web of Science, PubMed, Google Scholar and Scopus using several keywords, including the name of each Arab country.

Results: Our findings show an average prevalence of orofacial cleft of 1.1 per 1000 livebirths, with a range of 0.3–2.6 per 1000 livebirths in the Arab countries. There were inconsistencies in reporting for the different countries and in the methodologies used. Various publications from the same countries reported different prevalence figures.

Conclusions: The inconsistency in the findings from this study indicate an urgent need for Arab countries to establish comprehensive national birth defect surveillance systems or expand existing systems to provide reliable and up-to-date evidence for policy, practice and interventions.

Keywords: cleft lip, cleft palate, orofacial cleft, craniofacial anomaly, birth defect, Arabic countries

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Introduction

Cleft lip (CL), cleft palate (CP) and cleft lip and palate (CLP) are common congenital anomalies affecting the oral cavity and lips. These defects present as complete and/or partial disruption of the lip or palatal tissues. Cleft severity varies from a trace of notching to complete nonfusion of the upper lip, primary palate or secondary palate. These anomalies arise from the disruption of normal medial growth and fusion of the facial primordia during the first 9 weeks of intrauterine life (*1*, *2*).

Orofacial cleft (OFC) is the second most common congenital deformity after club foot, comprising almost two-thirds of craniofacial anomalies. This malformation may be categorized as an isolated birth defect, a nonsyndromic cleft or part of a syndrome with multiple congenital anomalies (*3*). Many factors may contribute to this variability in classification, such as bias caused by the exclusion and inclusion criteria used in each study, the data source, categorization of the cleft types and whether stillbirths and pregnancy terminations are included (*3*).

There are profound clinical and psychological consequences of OFCs on facial morphology, breathing, hearing, swallowing, mastication, osculation and speech (*4*, *5*). Intraorally, children with OFC experience compromised oral health with increased dental caries, collapsed asymmetric maxillary arch, altered occlusion, hypoplastic teeth and tooth agenesis, which affect dental aesthetics and function, as well as quality of life (*6*).

OFCs are ideally cared for by a multidisciplinary health care team involving a plastic/oral and maxillo-facial surgeon, orthodontist, psychologist, speech and language therapist, specialist nurse and a paedodontist. Cooperation with various other specialists, such as an ear, nose and throat consultant or cardiologist, where appropriate, should be coordinated by a specialist nurse (*4*). This complexity means that evaluating the prevalence of OFC is a critical element in planning and managing the delivery of cleft care. It is also essential in determining the individual and social burden of the anomaly. Preventive medicine is becoming increasingly central to health care; therefore, it is crucial to accurately assess the efficacy of the measures taken to reduce aetiological risk factors, where possible, and to provide planned management of OFC (*7*,*8*).

Methods

This search was performed on published articles presenting the prevalence of OFC in one or more Arab countries, including surveys, original articles and systematic reviews, with no age or date of publication limit. Opinion articles and case reports were excluded. We searched the Web of Science, PubMed, Google Scholar, Scopus and grey literature, as well as personal communications, up to August 2024. Several combinations of keywords and related terms were included in the search, such as incidence, prevalence,

orofacial cleft, cleft lip and palate, craniofacial anomalies, and Arab countries. A Boolean operator AND/OR was used to exclude or combine keywords. Subsequently, separate searches were carried out using the name of each Arab country individually. All publications surveyed were in the English language.

Results and discussion

Prevalence data for OFC in Arab countries are sparse. A total of 14 out of 25 articles fulfilled the inclusion criteria. Table 1 shows OFC prevalence data from the most recent publications reporting the prevalence of OFC in their designated Arab countries (14 publications). The prevalence of OFC in the included studies ranged from 0.3 to 2.6/1000 live births, with an average prevalence of 1.1/1000 live births. Most figures were based on data extracted from one or more hospitals in one or more cities within each Arab country, which was not a true representation of the overall population. The reported data mainly presented the prevalence of OFC in one or more hospitals without excluding the syndromic cases and the non-nationals. The reported occurrence of OFC was partially based on surveys lacking statistical power, mostly from countries with limited or no birth defect surveillance programmes. Findings from this review are discussed within the context of the global prevalence of OFC.

The incidence of OFC varies according to ethnicity, geographic location and socioeconomic status (*1*). In 2003, WHO estimated the global occurrence rate of OFC to be ≈1/700 newborn babies, which equates to 15 000 newborns worldwide/hour, such that a baby with a cleft is born approximately every 2 minutes (*1*). However, these figures were partially based on data lacking statistical power; mostly from countries with limited or no birth defect surveillance programme, which compromised the ability of the investigators to undertake a structured epidemiological survey.

A birth defect surveillance programme is described as continuous systematic collection, analysis and interpretation of birth defect records for public health purposes, and the timely dissemination of public health information for assessment and response to reduce morbidity and mortality (*1*, *7*). A more comprehensive analysis of the prevalence of OFC up to the end of the 20th Century was performed in 2002 (*1*, *9*). This result was similar to the WHO survey outcome, revealing an overall occurrence of OFC of around 1/700 live births, with significant geographic and ethnic differences.

Data collected from 57 registries in Europe between 1993 and 1998 show a 7-fold variation across the continent in the prevalence of OFC (ranging from 3.4 to 22.9/10 000 live births). This was even more marked for CP (ranging from 1.3 to 25.3/10 000 births) (*9*, *10*). In European countries, the prevalence of OFC ranges from approximately 2/1000 individuals in Northern Europe to 1/1000 cases in Italy, giving a mean of 1.36/1000. It is believed that these disparities are genuine because of the consistent methodology and rigorous data collection measures adopted by the European Network for the Epidemiological Surveillance of Congenital Anomalies (*9*).

Regions such as Latin America and Asia (including China and Japan) have elevated rates of OFC compared with the prevalence reported by WHO, while lower

Table 1. Published prevalence of orofacial cleft in 14 Arab countries

Author	Country	Period	Setting	Sample size	Prevalence per 1000	Birth defects	Included data
Alswairki et al *(17)*	Egypt	2013	Local registries (3 cities)	237 783	0.4	All	Livebirth, nationals
Aqrabawi et al *(15)*	Jordan	2000–2005	2 hospitals	1 548 106	1.39	All	Livebirth, nationals
Alghamdi et al *(18)*	Saudi Arabia	2020–2021	10 hospitals	124 286	1.47	Nonsyndromic	Livebirth, mixed nationalities
Suleiman et al *(19)*	Sudan	1997–2000	3 hospitals	15 890	0.9	All	Livebirth, nationals
Alkharafi et al *(20)*	Kuwait	1985–1987	National registry	1385	1.65	All	Livebirth, nationals
Nouri and Shihab *(21)*	Iraq	2008	2 hospitals	22 387	0.58	All	Livebirth
Borno et al *(22)*	Palestine	1986–1995	1 hospital	33 969	1.05	All	Live and stillbirth
Al Arrayed *(23)*	Bahrain	1980–1990	Ministry of Health	117 498	0.5	All	Livebirth
Abdelgader et al *(24)*	Libya	2014–2017	1 hospital	29 610	0.88	All	Livebirth
Khrouf et al *(25)*	Tunisia	2013–2020	1 hospital	100	1.5	All	Live and stillbirth, nationals and residents
Esmail et al *(27)*	Yemen	2005–2011	1 centre	1110	1.5	All	Live subjects between days 1 and 40 years
Khandakji et al *(30)*	Qatar	2016–2021	1 hospital	3250	1.21	All	Livebirth
Al Balushi et al *(28)*	Oman	2010 2019	Hospital-based	–	2.6	All	Mixed nationalities, livebirth
Talabani et al *(29)*	UAE	1992–1995	National registry	24 233	0.3	All	Mixed nationalities, livebirth and stillbirth

rates are found in South Africa and Southern Europe (*9*). Canada and parts of Northern Europe have a higher rate of CP, whereas regions of Latin America and South Africa have reported lower rates (*9*). Comparisons among ethnic groups in the United States of America and the United Kingdom of Great Britain and Northern Ireland (*11*) have shown that migrant groups tend to have a prevalence of OFC similar to the corresponding rates in their country of origin rather than the rates in the country to which they have relocated. This emphasizes the genetic element in the development of this anomaly.

There is a dearth of reliable data on the prevalence of OFC in developing countries (*7*, *12*). Hospital-based surveys from developing countries have shown that one of the highest rates of OFC is in Afghanistan, with 4.9/1000 live births (*13*), and one of the lowest rates is in Libya, with 0.28/1000 live births (*14*).

The prevalence of OFC in Arab countries range from 0.3 to 2.6/1000 live births, with an average prevalence of 1.1/1000 live births. However, these figures do not represent the actual OFC occurrence in each country because of the research methodology used (*17–25*, *27–30*). Most of the surveys did not differentiate between syndromic and nonsyndromic OFC, and did not include stillbirths or terminated pregnancies. Therefore, different publications from the same country presented different prevalence figures.

A recent systematic review on the prevalence of OFC in Saudi Arabia, which included babies of foreigners residing in the country, reported that 7 of 13 surveys included the prevalence of this anomaly (*31*). The time interval for all the revised studies was 15 years, and the authors reported an OFC prevalence of 0.65–1.9/1000 live births. In other Arab countries where > 1 study has been reported, the prevalence data varied similarly: Jordan, 1.39/1000 in 2004 (*16*) and 2.4/1000 in 2008 (*15*); Oman, 1.5/1000 in 2001 (*32*) and 2.6/1000 in 2022 (*28*); Libya, 0.28/1000 in 1994 (*14*) and 0.38/1000 in 2008 (*33*) and 0.88/1000 in 2020 (*24*); and Iraq, 0.58/1000 in 2009 (*21*) and 2.2/1000 in 2013 (*34*). The prevalence reported in other Arab countries was: Egypt, 0.4/1000 in 2019; Kuwait, 1.42/1000 in 2024 (*20*); United Arab Emirates, 0.58/1000 in 1998 (*29*); Bahrain, 0.35/1000 in 1995 (*23*); Palestine, 1.05/1000 in 2014 (*22*); Tunisia, 1.5/1000 in 1986 (*25*); Sudan, 0.9/1000 in 2005 (*19*); and Qatar, 1.1/1000 in 2024 (*30*). According to the Lebanese Cleft Palate–Craniofacial Program website, the frequency of OFC in Lebanon was 1/440 live births (*35*), but their cited reference was missing. OFC rates in the Syrian Arab Republic (*36*) and Morocco (*26*) were not reported. The electronically available publications from other Arab countries, such as Mauritania, Algeria and Comoros, seem to be inaccessible via academic search engines and have not been cited in OFC publications. This may be because French is the academic language in those countries, or the data were published in local scientific journals not covered by search engines.

Similarly problematic is that many investigations focused on one city in a particular country, which meant there was insufficient information to give an overview of the whole country. For example, the 3 Libyan investigations only reported the prevalence of OFC in Benghazi (*14*, *24*, *33*). Establishing national surveillance systems is required to facilitate networking within and between countries.

Proportions of cleft types

OFCs have a wide range of phenotypic variations, including CL, CLP and CP sub-phenotypes, such as CL, CL and alveolus, Simonart's band, complete/incomplete and soft, hard or submucous CP (*9*). Most OFC investigations have reported a higher occurrence of unilateral CLP, accounting for 30–35% of total nonsyndromic oral cleft cases. Isolated cases of CP and CL comprise, on average, 20–25%, while bilateral CLP is less often observed (10%) among individuals with OFC (*9*). Other cleft types, including submucous clefts, comprise 10% of the proportion of OFCs. Generally, 15% of oral clefts are syndromic (*9*). Among the 85% of oral cleft cases that are nonsyndromic, almost 50% have other milder abnormalities (*1*, *9*).

The reporting of cleft categories varied among the Arab countries, where CP was the most observed anomaly in Kuwait (*37*), Egypt (*17*) and Libya (*24*). In contrast, CL or CLP formed the majority of cases in Jordan (16), Iraq (*21*), Saudi Arabia (*18*) and Qatar (*30*), while a similar proportion of CP and CLP was observed in Palestine (*22*). It is unclear whether these variations were due to genetic or environmental factors, or due to the data source, sample selection bias or study design of the investigations.

Sex predilection of OFC

The male/female discrepancy in the incidence of OFC varies geographically and ethnically (*9*). The reported average male/female ratio among Caucasians is about 2:1, and this differs according to the severity of the cleft (*38*). A Japanese population had a higher incidence of CLP among males than females, but this was not so in their CL cohort (*39*).

Currently, there is no recognized explanation for this sex discrepancy, although differences in the timing of critical craniofacial developmental stages may be a factor (*40*). Kochhar et al. suggested that female sex hormones may delay the palatal developmental process (*41*). A higher occurrence of CLP among males was reported in several Arab countries, including Egypt (*17*), Saudi Arabia (*18*), Jordan (*16*), Iraq (*21*), Libya (*24*), Kuwait (*20*), Palestine (*22*), Oman (*28*) and Qatar (*30*). A single hospital-based survey in Sudan (*19*) noted a higher occurrence of OFC among females than males (10:3), while a survey in Libya (*14*) observed a similar incidence of OFC in both sexes.

Those figures may not represent the existing incidence of OFC in those countries because of the lack of universal registry systems (*7*, *30*, *31*). CP was reported to be the most prevalent type of OFC in Kuwait (*20*, *37*) and Libya (*24*). A higher incidence of CP among females was reported in numerous populations, such as those in

Kuwait (*20*), Yemen (*27*), Saudi Arabia (*18*) and Northern Ireland (*42*). No sex bias was noted in Denmark (*43*).

In addition to genetic and environmental factors, published data on OFC prevalence could be biased due to other factors that affect their accuracy and comparability, including: the birth cohorts being investigated; period over which the survey was conducted; ascertainment procedures; inclusion and exclusion criteria; clinical categorization of the cases surveyed; and sampling variations (*9*). A comprehensive investigation into the epidemiology of OFC should also consider a range of other aspects of interest, including the sub-phenotype of clefts beyond the generally used classification of CL, CLP and CP. This would include microforms, submucous CP, Simonart's band, pregnancy terminations and stillbirth related to oral clefts in the offspring, and the severity of the observed clefts (*9*).

Cleft laterality

CLP and CL can develop unilaterally or bilaterally. According to the International Perinatal Database of Typical Orofacial Clefts working group (*2*), the rate of occurrence of bilateral cleft cases was 10.3% for CL and 30.2% for CLP; of which, 60.1% of CL and 38.9% of CLP were found on the left side regardless of sex, ethnicity or severity of the cleft (*2*, *9*). Similar findings were reported in Kuwait (*37*), Saudi Arabia (*18*) and Syrian Arab Republic (*36*), while a higher frequency of right-sided clefts was observed in Iraq (*21*). Matern et al. (*44*) hypothesized that an increased incidence of left-sided clefts may indicate the dominant role of the left side and may be caused by dysfunctional expression of the *NODAL*, *LEFTY* and *PITX2* genes. Right-sided clefts may result from inadequate suppression of genes that govern development of the right side, while bilateral clefts may arise from aberrant activation of genes unrelated to laterality. Another hypothesis proposed by Johnston and Brown (*9*, *45*) suggests that blood vessels supplying the right side of the fetal head depart the aortic arch in greater proximity to the heart, which may result in better blood supply on that side.

One of the limitations of this review was that it was undertaken only on publications in English language, because it is the formal scientific language used in the dental and medical fields in most Arab countries. We had limited access to investigations published in Arabic. However, variations in the epidemiological outcome reported in the surveyed publications highlight the requirement for Arab countries to establish national birth defect surveillance programmes or to expand existing programmes to the national level. These initiatives should be planned by experts with sufficient knowledge and proficiency and should consider existing infrastructure and human resources, as well as the priorities of each country (*12*). Arab countries should be encouraged to publish their results, including OFC surveillance data, to enhance the visibility of their birth defect surveillance programmes. Several Arabic countries have been experiencing continuous political unrest and social instability, which, despite the availability of national human and financial resources, is likely to compromise the development of such schemes.

Conclusion

Published literature on the prevalence of OFC in most developed countries reflect the actual occurrence at the community level based on established epidemiological surveillance networks. Reported data on the prevalence of OFC in Arab countries and other developing countries are partially based on surveys that lack statistical power, mostly from countries with limited or no birth defect surveillance programmes. Therefore, there is an urgent need to develop national birth defect surveillance programmes or to expand existing surveillance systems nationwide in in those countries. Arab countries should be encouraged to publish their results, including OFC surveillance information, to enhance the visibility of their birth defect surveillance programme data.

Examen critique de la prévalence des fentes labiales et palatines dans les pays arabes

Résumé

Contexte : La fente orofaciale peut se manifester comme malformation congénitale isolée, comme anomalie non syndromique ou comme syndrome comportant de multiples anomalies congénitales, et sa prévalence peut varier en fonction de l'origine ethnique, du sexe et de la localisation géographique.

Objectif : Examiner la littérature sur la prévalence des fentes orofaciales dans les pays arabes.

Méthodes : Une recherche des publications pertinentes, en anglais, sur la prévalence des fentes orofaciales dans les pays arabes a été effectuée sur Web of Science, PubMed, Google Scholar et Scopus à l'aide de plusieurs mots-clés, y compris le nom de chaque pays arabe.

Résultats : Nos résultats montrent une prévalence moyenne des fentes orofaciales de 1,1 pour 1000 naissances vivantes, avec une fourchette de 0,3 à 2,6 pour 1000 naissances vivantes dans les pays arabes. Il y a eu des incohérences dans l'établissement des rapports des différents pays ainsi que dans les méthodologies utilisées. Plusieurs publications provenant des mêmes pays ont fait état de chiffres de prévalence différents.

Conclusion : Du fait de l'incohérence des résultats de la présente étude, il est urgent que les pays arabes mettent en place des systèmes nationaux complets pour la surveillance des malformations congénitales ou étendent les systèmes existants afin de fournir des données fiables et actualisées sur les politiques, les pratiques et les interventions y afférentes.

استعراض نقدي بشأن انتشار الشفة المشقوقة وفلح الحنك في البلدان العربية

إيمان بوقعيقيص

الخلاصة

الخلفية: يمكن أن يحدث الشق الفَمَويّ الوَجْهي بوصفه عيبًا ولاديًّا منعزلاً، أو شذوذًا غير متلازم، أو جزءًا من متلازمة مع تشوهات خِلقية متعددة، ويمكن أن يختلف معدل انتشَاره حسبَ العِرق والجنس والموقع الجغرافي.

الأهداف: هدفت هذه الدراسة الى استعراض مؤلفات تدور حول انتشار الشق الفَمَوي الوَجْهي في البلدان العربية.

طرق البحث: أُجري بحث في المنشورات ذات الصلة، باللغة الإنجليزية، عن معدل انتشار الشق الفَمَوي الوَجْهي في البلدان العربية، على كلٍّ من Web of Science، PubMed، Google Scholar، Scopus، وذلك بعدة كلمات مفتاحية، منها اسمَ كل بلد عَربي.

النتائج: تشير النتائج التي توصلنا إليها إلى أن متوسط انتشار الشق الفَمَوي الوَجْهي 1.1 لكل 1000 ولادة حية، بمعدل يتراوح بين 0.3–2.6 لكل 1000 ولادة حية في البلدان العربية. وكانت هناك تباينات في التبليغ عَلى مستوَى مختلف البلدان وفي المنهجيات المستخدمة. وأظهرت منشورات مختلفة من البلدان نفسها أرقامًا مختلفة لمعدلات الانتشار.

الاستنتاجات: يشير التباين في نتائج هذه الدراسة إلى حاجة البلدان العربية الماسة لإنشاء نُظُم وطنية شاملة لترصُّد العيوب الولادية، أو توسيع نطاق النُظُم القائمة لتوفير دلائل موثوقة ومُحدثة للسياسات والممارسات والتدخلات.

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