

Statistical Data On Cleft Lip And Palate In Karakalpakstan

Makhkamov Mokhir Ergashevich¹, Isomov Miraskad Maksudovich², Makhkamov Abdulkhak Mokhirovich³, Fattayeva Dilorom Rustamovna⁴, Zaynutdinov Murodullo Omonillayevich⁵, Bukharova Fotimakhon Khasanovna⁶, Djakhangirova Diloram Abdulkhayevna⁷

¹Professor, Department of Maxillofacial Surgery, Tashkent state medical university, Uzbekistan.

Email: mokhir@yandex.ru, ORCID - <https://orcid.org/0000-0001-6167-6977>

²PhD, Associate professor, Department of Maxillofacial Surgery, Tashkent state medical university, Uzbekistan.

Email: isomov030@gmail.com, <https://orcid.org/0009-0009-4500-3882>

³PhD researcher, Deputy Head of the “General Medicine” and “Dentistry” Departments at Kimyo International University in Tashkent, Uzbekistan. Email: abdulkhak.mahkamov@gmail.com, <https://orcid.org/0009-0002-9129-8086>

⁴Associate professor, Department of Maxillofacial Surgery, Tashkent state medical university, Uzbekistan. Email: rustamovna.m.s.z@gmail.com

⁵PhD, Senior lecturer, Department of Maxillofacial Surgery, Tashkent state medical university, Uzbekistan. Email: dr.zaynutdinov@gmail.com, <https://orcid.org/0000-0001-7856-4007>

⁶Assistant, Department of Maxillofacial Surgery, Tashkent state medical university, Uzbekistan. Email: Fotik1209@gmail.com,

⁷Assistant, Department of Maxillofacial Surgery, Tashkent state medical university, Uzbekistan. Email:

djhangirovad@gmail.com

ABSTRACT

Objective: This study aimed to investigate the prevalence and regional distribution of congenital cleft lip and palate (CCLP) in the Republic of Karakalpakstan, Uzbekistan, from 2017 to 2021, and to substantiate the need for establishing a specialized rehabilitation center for affected children.

Methods: A retrospective analysis of medical-statistical data was conducted for the five-year period, encompassing 190,558 live births. The frequency of CCLP and its subtypes (unilateral/bilateral clefts, isolated cleft lip, isolated cleft palate, and atypical clefts) was calculated. Data were stratified by administrative district to assess geographic variation and potential environmental risk factors.

Results: During the study period, 254 children were born with maxillofacial pathology, yielding an overall CCLP birth frequency of 1:750 (approximately 1.33 per 1000 live births). Significant regional variation was observed. Districts with minimal industrial activity, such as Khojayli (0.76/1000), Amudarya, and Kegeyli (both 0.8/1000), had the lowest rates. In contrast, the highest frequencies were recorded in Muynak (2.82/1000), Buzatau (2.5/1000), and Takhtakupir (2.28/1000), areas notably impacted by environmental factors associated with the Aral Sea region.

Conclusion: The prevalence of CCLP in Karakalpakstan remains high and unevenly distributed, with a strong indication of environmental influence in regions with heightened industrial or ecological burden. The absence of a unified treatment protocol and a specialized care center hinders effective, standardized rehabilitation. The study underscores the urgent necessity to create a dedicated multidisciplinary center equipped with modern diagnostic and surgical capabilities, supported by an integrated computer-based information system for patient management, data analysis, and outcome comparison, to improve the quality of life for children with CCLP.

KEYWORDS: Congenital cleft lip and palate, CCLP, epidemiology, birth prevalence, Karakalpakstan, maxillofacial anomalies.

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INTRODUCTION

Congenital cleft lip and palate (CCLP) represents one of the most prevalent and complex craniofacial anomalies, posing significant medical, functional, psychological, and social challenges to affected individuals and their families [1,2]. As a multifactorial condition, its etiology involves a complex interplay of genetic predispositions and environmental exposures, including maternal nutrition, toxins, and industrial pollutants, which can substantially influence its prevalence across different geographic regions [3,4].

In Uzbekistan, and particularly within the Republic of Karakalpakstan—a region significantly impacted by the environmental legacy of the Aral Sea ecological crisis—there has been a documented rise in congenital malformations over recent decades [5,6]. Historical data indicate that the birth frequency of children with CCLP in Karakalpakstan was reported as 1 in 700-850 live births, a rate higher than the national average, suggesting a potential link to regional environmental stressors [5,7]. Despite this apparent burden, systematic epidemiological surveillance and standardized, specialized care for these patients remain underdeveloped.

Current literature highlights considerable variability in CCLP statistics across the Aral Sea region, attributed to differences in

data collection methodologies, infant mortality rates, socio-economic conditions, and access to healthcare [8,9]. Furthermore, there is a recognized gap in the establishment of modern, integrated rehabilitation protocols and dedicated treatment centers in Karakalpakstan, which are essential for coordinating the multi-stage surgical, orthodontic, and speech therapies required for optimal patient outcomes [10,11].

Therefore, this study aims to address this critical gap by analyzing the contemporary prevalence and geographical distribution of CCLP in Karakalpakstan from 2017 to 2021. By identifying high-risk districts and evaluating associated factors, this research seeks to provide an evidence-based rationale for the urgent establishment of a specialized, multidisciplinary rehabilitation center. Such a center is envisaged to standardize care, employ advanced information systems for patient management, and ultimately improve the quality of life for children born with this condition in the region.

PURPOSE OF THE RESEARCH

The primary purpose of this research is to conduct a comprehensive epidemiological analysis of congenital cleft lip and palate (CCLP) within the Republic of Karakalpakstan for the period 2017–2021. This includes quantifying its prevalence, identifying spatial and temporal trends, and assessing potential environmental and regional risk factors contributing to the observed distribution.

Furthermore, this study aims to scientifically substantiate the critical need for establishing a specialized, multidisciplinary medical and rehabilitation center in Karakalpakstan dedicated to the care of children with CCLP. By highlighting the current gaps in standardized diagnostics, staged treatment protocols, and long-term follow-up, the research underscores the necessity of implementing a centralized, high-tech healthcare model. The ultimate goal is to provide an evidence-based framework for improving clinical outcomes, enabling systematic patient management, and enhancing the overall quality of specialized care for this vulnerable patient population in the region.

MATERIALS AND METHODS

This study employed a retrospective, descriptive-analytical design based on a systematic review of medical-statistical records across the Republic of Karakalpakstan for the five-year period from 2017 to 2021. The primary data source was the official regional birth registry and clinical documentation from maternity hospitals and pediatric surgical departments, which recorded all live births and diagnosed cases of congenital malformations of the maxillofacial region. The total population under study comprised 190,558 live births. From this cohort, all cases of congenital cleft lip and palate (CCLP) and related facial clefts were identified and categorized according to clinical type: unilateral complete cleft lip and palate, bilateral complete cleft lip and palate, isolated cleft lip, isolated cleft palate, and atypical facial clefts. Data extraction included the year of birth, administrative district of residence, and specific cleft subtype. Statistical analysis involved calculating absolute frequencies, prevalence rates per 1,000 live births, and proportional distribution across districts. Comparative analysis was performed to identify regions with significantly higher or lower prevalence rates. The methodological approach also included a qualitative review of existing literature and institutional reports to contextualize the local healthcare infrastructure and identify gaps in specialized service provision, thereby supporting the argument for a dedicated rehabilitation center.

RESULTS

To study the frequency and assess the risk factors for the birth of children with congenital cleft lip and palate in the territory of the Republic of Karakalpakstan.

According to statistics for the years under study (2017-2021), 190558 children were born in Karakalpakstan. Of these, 254 people with congenital pathology of the maxillofacial region, including:

- 66 - unilateral through cleft lip and palate
- 22 - bilateral through cleft lip and palate
- 100 - isolated cleft lip (IG)
- 64 - isolated cleft palate (IP)
- 2 - atypical cleft face (AF)

Table 1

Dynamics of the frequency of birth of children with pathology of the maxillofacial region and with congenital cleft lip and palate CCLP since 2017 to 2021

Year	Total children born alive	Number of children with HPLP	Number of children with CCLP				
			IG	IP	unilateral	bilateral	AF
2017	38352	46	15	18	11	4	
2018	38386	49	18	12	13	4	1
2019	38306	47	26	9	11	4	1
2020	38158	61	21	13	16	5	
2021	37356	51	20	12	15	5	
Total	190558	254	100	64	66	22	2

The lowest rate was registered in 2017, in 2020. The rate of birth of children with congenital cleft lip and palate per 1000

newborns for the study years (2017-2021) varied from 0.76 ± 0.5 in 2017 to 2.82 ± 0.23 in 2021 ($p < 0.001$). The frequency of facial clefts during the analyzed period averaged 1:750. The results of the distribution of districts of Karakalpakstan by the frequency of birth of children with congenital pathology of the maxillofacial region are presented in Table 2.

Table 2

Distribution of newborns with maxillofacial pathology in the regions of Karakalpakstan for 2017 - 2021

Districts	Total live births					Number of children with HPLP					
	2017	2018	2019	2020	2021	2017	2018	2019	2020	2021	
Nukus	2983	2910	2905	2896	2796	3	4	3	4	3	1,18/1000
Nukus district	2964	2656	2651	2642	2542	3	4	3	4	3	1,3/1000
Amudarya	2745	2612	2607	2598	2498	2	2	2	3	2	0,8/1000
Beruniy	2654	2664	2659	2648	2602	3	2	3	4	4	1,2/1000
Buzatau	1623	1543	1538	1529	1509	3	3	5	5	3	2,5/1000
Kegeyli	2586	2592	2587	2578	2508	2	2	2	2	2	0,8/1000
Karauzyak	2154	2170	2165	2156	2126	3	3	3	4	3	1,5/1000
Kungrad	2658	2589	2584	2575	2529	5	4	4	5	6	1,9/1000
Kanlikul	1688	1602	1597	1588	1562	1	3	2	2	2	1,24/1000
Muynak	1257	1212	1207	1198	1156	2	2	4	5	4	2,82/1000
Takhtakupir	2259	2189	2184	2175	2129	4	5	5	6	5	2,28/1000
Turtkul	2673	2584	2579	2570	2535	3	3	2	3	1	0,92/1000
Khodjeyli	2896	2574	2569	2560	2518	2	3	1	2	2	0,76/1000
Takhiatash	2987	2542	2537	2528	2486	2	2	2	3	3	0,91/1000
Chimbay	2359	2018	2013	2011	2114	2	2	2	3	3	1,14/1000
Shumanay	2562	2047	2042	2026	2036	3	3	2	3	3	1,3/1000
Ellikkala	2297	1882	1877	1880	1710	3	2	2	3	3	1,4/1000
Total	38352	38386	38306	38158	37356	46	49	47	61	51	1/750

The administrative districts with the lowest birth rate of children with congenital pathology of the maxillofacial region included the Khojayli district (0.76 per 1000 newborns), in the Amudarya and Kegeyli districts (0.8 per 1000 newborns). These areas belonged to typical rural areas, where there is minimal industrial pollution.

The administrative regions with a high frequency of birth of children with congenital pathology included: Muynak (2.82/1000), Buzatau (2.5/1000), Kungrad (1.9/1000), where the figures significantly exceeded the average for the republic.

The severity of the malformation of the face is determined not only by external disfigurement, pronounced functional disorders, the child's social inferiority in preschool and school groups, conflict tension and a negative psychological background in the family, but also by the fact that the presence of a cleft causes a number of somatic disorders that lead to impaired growth and development child's body.

The problem of rehabilitation of children with congenital cleft palate is multifaceted and complex. The ultimate goal of rehabilitation measures is to restore the function of the articulatory apparatus and the formation of correct speech in children.

The main method of treating such children is the surgical removal of the palate defect - uranoplasty. However, in most cases, surgical treatment, restoring the integrity of the palatopharyngeal closure, does not always ensure its sufficient functioning, which causes difficulty in normal nutrition and various speech defects.

The severity of this pathology in children, the unsatisfactory quality of life, the difficulty of full-fledged rehabilitation of patients with congenital cleft lip and palate justifies the need for scientific research aimed at improving the methods of prevention and rehabilitation of children with congenital cleft lip and palate.

The development of specialized care for children with congenital pathology to their families at all stages of the development of society, in the most difficult socio-economic conditions, should remain the most important task of national health care. The only correct approach is an integrated approach to their treatment in the conditions of specialized centers in the dispensary regulations, using all high-tech methods of examination and reconstructive surgical treatment.

The main task of the center is to provide systematic step-by-step treatment of patients with congenital cleft lip and palate for the entire period of dispensary observation.

The effectiveness of the medical examination center can only be assessed if there is a clear program of therapeutic measures, based on the conditions of a particular region.

The preparation by each center of a clear program of assistance to sick children requires a multi-stage treatment by specialists, a different sequence and timing of their implementation.

Information and computer technologies in health care will serve as the basis for the formation of new approaches to work. It is shown that the information computer space is a new technology for medical, psychological, pedagogical and social rehabilitation of patients with congenital pathology of the maxillofacial region.

According to most experts, it is currently necessary to create and implement automated information systems, which will allow the user to have complete data about the patient. At the same time, analytical and statistical work is greatly simplified, new opportunities for comparing data, making forecasts, and modeling activities in order to find optimal solutions appear.

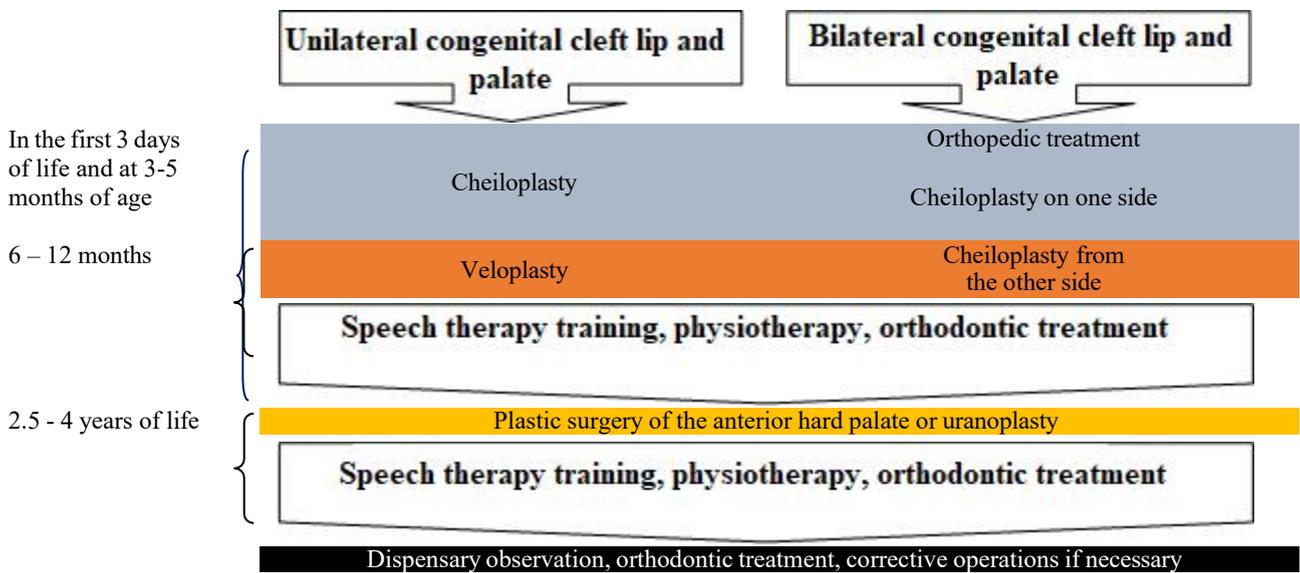


Fig. 1. Algorithm for the rehabilitation of children with congenital cleft lip and palate in Karakalpakstan.

In Karakalpakstan, unified criteria and methods for evaluating the results of treatment have not been developed, and no work has been done to compare the results of the rehabilitation of children with this pathology. The introduction of a unified system for evaluating the results, which opens up the possibility of integration into the Pan-European system for standardizing the results of treatment, is a very urgent task of pediatric maxillofacial surgery.

One of the priority areas of domestic medicine at present is also informatization (computerization) of the country's health care at all levels.

Until now, in our country there were no computer software systems for the Centers for the Rehabilitation of Children with Congenital Facial Cleft and stationary institutions where assistance is provided to children with malformations of the maxillofacial region. There are also no accounting and reporting documents developed and mandatory for rehabilitation centers that allow comparing the results of rehabilitation of patients between the Centers.

DISCUSSION

The findings of this study confirm that congenital cleft lip and palate (CCLP) remains a significant public health concern in Karakalpakstan, with an overall prevalence of 1:750 live births (approximately 1.33 per 1,000) during the 2017–2021 period. This rate aligns with, and even exceeds, earlier reports from the region and underscores a persistent epidemiological burden [5,7]. More importantly, the analysis reveals pronounced geographical heterogeneity, with certain districts—notably Muynak (2.82/1000), Buzatau (2.5/1000), and Takhtakupir (2.28/1000)—exhibiting prevalence rates significantly above the regional average. These areas are historically associated with the severe environmental degradation of the Aral Sea basin and intensive agricultural or industrial activity, suggesting a plausible etiological link between environmental contaminants and the increased risk of CCLP, as supported by multifactorial models of craniofacial pathogenesis [3,12,17].

Conversely, districts with minimal industrial presence, such as Khojayli (0.76/1000), Amudarya, and Kegeyli (both 0.8/1000), recorded the lowest rates. This gradient further reinforces the hypothesis that anthropogenic factors—including chemical pollution, pesticide exposure, and possibly poor water quality—may contribute to the elevated risk observed in more heavily

impacted zones [14,18]. Such an environmental association has been documented in other regions with similar ecological challenges, highlighting the need for targeted public health interventions aimed at reducing prenatal exposures in high-risk areas [4,16].

Despite the clear medical need illustrated by these statistics, the current healthcare response in Karakalpakstan remains fragmented. There is no specialized center for the coordinated, multidisciplinary management of CCLP, resulting in inconsistent treatment protocols, delayed surgical interventions, and inadequate long-term rehabilitation [10,11]. The absence of a unified follow-up system and standardized outcome measures impedes both clinical quality improvement and comparative research, a gap also noted in other settings without centralized care models [8,13].

The proposed establishment of a dedicated CCLP rehabilitation center, supported by an integrated digital health information system, represents a critical step forward. Such a center would enable the implementation of a staged treatment algorithm—from early cheiloplasty and veloplasty to later orthodontic and speech therapy—within a framework of continuous dispensary observation [9,15]. Computerized patient registries would not only streamline care coordination but also facilitate epidemiological surveillance, outcome analysis, and resource planning, thereby transforming isolated clinical actions into a systematic public health strategy [6,19].

Furthermore, the integration of such a center into a broader national or international network would allow for the adoption of pan-European treatment standards and outcome measures, enhancing the quality and comparability of care [20]. It would also serve as a focal point for professional training, community outreach, and preventive programs, addressing the condition from a holistic bio-psycho-social perspective.

In conclusion, the data presented herein not only quantify the burden of CCLP in Karakalpakstan but also highlight the urgent need for structural healthcare reform. Investing in a specialized, informatics-supported treatment center is not merely a clinical upgrade but a necessary response to an environmentally influenced public health challenge, with the potential to significantly improve the health outcomes and social integration of affected children.

CONCLUSION

This study demonstrates that congenital cleft lip and palate (CCLP) represents a significant and persistent public health challenge in Karakalpakstan, with a recorded prevalence of 1:750 live births from 2017 to 2021. The marked geographical variation in prevalence—significantly elevated in environmentally impacted districts such as Muynak, Buzatau, and Takhtakupir—strongly suggests a link between regional ecological factors, including industrial and agricultural pollution, and the risk of congenital craniofacial anomalies.

The current healthcare infrastructure lacks a centralized, multidisciplinary framework for the systematic diagnosis, treatment, and long-term rehabilitation of children with CCLP. This gap results in inconsistent care pathways, delayed interventions, and inadequate follow-up, ultimately compromising patient outcomes and quality of life.

Therefore, the findings of this research underscore an urgent need for the establishment of a specialized, multidisciplinary medical and rehabilitation center in Karakalpakstan. Such a center should implement standardized treatment protocols, integrate digital health information systems for coordinated care and outcome monitoring, and adopt evidence-based surgical, orthodontic, and speech therapies. This initiative would not only enhance clinical outcomes but also strengthen epidemiological surveillance, support professional training, and facilitate the integration of regional data into broader national and international healthcare frameworks.

Addressing the burden of CCLP in Karakalpakstan requires a proactive, systematized, and technologically supported healthcare approach—one that is responsive to both the medical needs of affected children and the environmental realities of the region.

Conflict of Interest

The authors declare that there is no conflict of interest regarding the publication of this paper. No financial, personal, or professional relationships have influenced the design, execution, analysis, or reporting of this study.

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