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Original Article

Web design software to record the characteristics of children with cleft palate/cleft lip

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ABSTRACT

Background: Cleft lip (CL) and cleft palate (CP) are among the most common birth defects in the craniofacial region affected by various environmental and genetic factors. The prevalence of these abnormalities varies in races and countries. Therefore, it is a necessity to design a website to register newborns with CL ± CP in Iran. This study aimed to design a website to record the characteristics of children with CL ± CP.

Materials and Methods: First, a website was designed to register the characteristics of children with CL ± CP. To evaluate the accuracy of the website, the characteristics of all children (n = 31) with CL ± CP were recorded and analyzed.

Results: Due to the capability of the website to print and create reports in Excel format, the data of registered patients were analyzed.

Conclusion: As CL ± CP are very common defects around the world including Iran, it is necessary to design a website to record all information about these children in Iran. Hope this website helps the public health authorities to improve program effectiveness to treat these children.

Key Words: Cleft lip, cleft palate, congenital abnormalities, records, software

INTRODUCTION

Birth defects that exhibit clinical presentations affect both families and governments. Psychological impact of these defects on families and patients during childhood and after puberty, along with the costs of treatment reveals the importance of health-care programs. In recent decades, governments have made crucial improvements in children's lives, however, much more needs to be done.[1] It is suggested that a combination of genetic (internal) and environmental (external) factors should be considered etiological factors.[2] Around 1 billion people living in developing countries are exposed to poor health, poverty, and malnutrition. These risk factors affect morbidity and mortality rates.[3] Cleft lip (CL) ± cleft palate (CP) are among the most common birth defects and infant morbidity in the craniofacial region due to various environmental and genetic factors.[4] The prevalence of these abnormalities varies across countries and racial groups. The prevalence of CL ± CP is about 1 of every 700-1000 births.[5] In Iran, the incidence has been estimated to be 1 in 1000 birth.[6] Affected children need care from birth until adulthood. Undoubtedly, orofacial clefts cause many problems for the patient, the

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family, and society. Children born with these defects need multidisciplinary care including nursing, maxillofacial surgery, orthodontics, plastic surgery, speech therapy, audiology, psychology, genetics, and dentistry. Therefore, standards of care for patients with CL ± CP continue to be a concern.[5] To provide good quality care for affected children, it is necessary to identify the possible etiological factors and record the clinical characteristics. Currently, Iran does not have a CL ± CP registration system. A registration system enables authorities to monitor newborns. The prevalence of congenital defects has an indicative value. Designing a website is the first step to collect data about the affected children. This website should have all information which helps the public health authorities to improve treatment program effectiveness globally especially, in developing countries. The overall aim of this pilot study was to design a website to register the children with craniofacial defects at the Dental School of Hamadan University with special focus on patients with CL ± CP.

MATERIALS AND METHODS

In this pilot study, first, based on the craniofacial anomalies register (CARE) committee, a website along with a questionnaire was designed;[6] hence, it matches with other similar and related websites. To evaluate the accuracy of the website, the characteristics of 31 patients with CL ± CP were recorded and analyzed. The address of the website was http://tagsan.com/lab/login/, therefore, it would be freely available to anyone in the world. This website was capable of printing and could create reports in Excel format. These capabilities, allowed us to do analysis which is needed for future health programs.

RESULTS

The results of this study can help authorities to improve oral health care across the country. For example, the data showed that 23 (74.2%) of the affected children were males. In addition, the most prevalent CP was complete cleft in both right and left sides (11 each; 35.5%), followed by complete left palate cleft + incomplete right palate cleft (n = 4; 12.9%). In 2 (6.5%) cases, the mother had a CL. There was a positive family history of CL (19.4% in maternal family members and 6.5% in paternal family members). Medications (antibiotics, anti-inflammatory, and antianxiety drugs) taken by mothers during pregnancy were reported in 12.9%. Other anomalies in the affected children were congenital eye abnormalities and congenital cardiovascular anomalies in 6.5% and 3.2% of cases, respectively. Furthermore, the collected data showed that except a single case, all registered clefts were nonsyndromic clefts. In 9 (29%) cases, the parents had a family relationship and in 6 (19.4%) cases, there was a history of CL/CP in maternal relatives.

DISCUSSION

Craniofacial clefts are the most common birth defects in the head-and-neck area. Numerous problems such as dental disorders, malocclusion, and facial deformities occur in patients with craniofacial defects. Besides, craniofacial defects have a great impact on mastication, esthetics, feeding, speech, and hearing. Importantly, the affected children and parents face psychological problems. Patient registration promotes a better understanding of CL/CP or other craniofacial anomalies and also improves patient care and health- care planning.[6]

Creating a web-based database across the country would improve the current level of knowledge on the prevalence of craniofacial anomalies and the associated geographical, ethnic, and cultural variations.

The CL/CP and CARE have benefits as follows:

1. In each health district, the number of lip and palate cleft cases is low, but collecting data from all districts can be used as an important source for research studies. Moreover, there will be a chance for clinical and molecular genetic studies which are effective for the treatment
2. Registering a sequence of cases allows for the comparison of similar cases, which can be used to evaluate the effectiveness of treatments and future standard adjustments
3. Registering the incidence rate of congenital craniofacial anomalies paves the way for planning and provision of services
4. Recording all information on craniofacial anomalies can provide information about the team and workload.[7]

In a study carried out by Anastassov *et al.* in Bulgaria in 2017, an Electronic Medical Record for Facial Anomaly was designed in general section and a private section. The general section included general instructions for website properties, registration

options, and a tutorial video demonstrating how to enter the website. Other sections included all information about facial anomalies, digital library, and the list of names and locations of specialists were accessible. The results of this study indicated that 800 of these patients were noticeably improved.[8]

National quality registries have been established in Sweden. The quality registry for CL and CP is a collaboration between the six Swedish CLP centers since 1999. The aim of the registry is to make certain that treatment is of good quality throughout the country. Furthermore, the registry allows to compare the treatment outcomes related to surgical technique, growth, speech, and dental development.[9]

In 1982, CARE has been established as a data registry for all specialties involved in cleft care in the UK. The elected members included orthodontics, plastic surgery, maxillofacial surgery, and speech and language therapies. Data collection methods have been improved since then.[7]

In 1967, a form of medical registration of births was introduced in Norway. This form included information on congenital malformations in newborns. The Medical Birth Registry found that a significant number of clefts had not been registered at birth.[10]

In the present study, valuable information was collected from this website. Although this study was a pilot study, the data obtained from this study shows that this website can be used to collect data from all patients with CL ± CP across the country.

CONCLUSION

Craniofacial anomalies have a great impact on the quality of life and health-care use and costs. The patient registry is the first step to develop a health-care planning in a country. Data collecting will help the authorities to improve the health-care quality. A web-based data collection procedure is needed to standardize the variables in the analysis. It is suggested that at early stage, the website becomes available only in one city or state. Later, it can be available in the whole country which allows getting all information about craniofacial anomalies. It is hoped that a web-based health-care system acts as an umbrella for the collection of accurate and standard CL and CP data globally.

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Conflicts of interest

The authors of this manuscript declare that they have no conflicts of interest, real or perceived, financial or nonfinancial in this article.

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