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Monitoring of Congenital Anomalies in Developing Countries: A Pilot Model in Iran

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Abstract. Aims: This is an ongoing project aiming to establish a monitoring system of congenital anomalies in the Northwest of Iran, and to implement control and preventive tasks in the region. Methods: Our program covers about 15 000 births (average per year) in a defined area with about 350 cases (average per year) of congenital anomalies born in the region. The definition of the congenital anomalies is based on the standard coding system of the International Classification of Diseases according to the primary diagnosis of anomaly. Results: The program examines the rates and patterns of various types of congenital anomalies and looks for possible local causes and influencing factors in the population. This monitoring program provides a pilot model into the epidemiology and potential for prevention and control of congenital anomalies in the community level. Evaluation procedures are essential part of our program to monitor the effects of preventive services for congenital anomalies in order to identify and correct shortcomings. Conclusion: Our program provides some essential data as an epidemiological tool for local investigators, information for health service planners, clinicians and for genetic counselors. It may also help to identify regional interventions that could help to prevent and control congenital anomalies in the study population and similar areas.

Keywords. congenital anomalies, prevention, epidemiology, health information, control

Introduction

Occurrence of congenital anomalies varies between different countries ranging from 2 to 10 percent of births. Congenital anomalies are now making a proportionally greater contribution to ill health in childhood. They are a leading cause of perinatal mortality and childhood morbidity and disability in many countries [1-16]. The financial cost of treating children (mainly surgical correction) with birth defects, and the emotional effects and disruption of normal family life associated with deaths caused by

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congenital anomalies are also enormous for people in both developed and less developed countries.

The etiology of these disorders is still largely unknown. However, the prevention of these disorders is available in 60 percent of cases [17-18]. Genetic counseling and educational programs for high risk population are essential for success of any control program at the community level so that they can understand and accept the tenets of the preventive programs and be able to utilize it appropriately and to their advantage. Preventive strategies in developed countries have been shown as one of the contributing factors to the declining prevalence of congenital anomalies in the last few decades [19-20]. Such interventional programs should be considered by government and non-government organizations (including patient/parent support groups) in developing countries too.

Until recent years, there were no data available about the prevalence, etiology, and preventive strategies of congenital anomalies in the Northwest of Iran. Beginning from 2000, we carried out a research project on the epidemiology of congenital anomalies aiming to document the epidemiologic features of congenital anomalies in the Northwest of Iran as the baseline information to set up a regional population-based registry of birth defects [14, 21]. Our program was also presented and accepted in the 2006 annual meeting of International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) in Sweden, as a member of countries having an established registry for birth defects [21-22]. The program is now called Tabriz Registry of Congenital Anomalies (TRoCA).

1. Aims

The principal aims of our program are to establish a monitoring system of congenital anomalies in the Northwest of Iran, and to implement control and preventive tasks in the region. The TRoCA program examines the rates and patterns of various types of congenital anomalies and looks for possible local causes and influencing factors in infants diagnosed in maternity hospitals, children hospitals or genetic clinics. Application of this monitoring and surveillance program may provide a pilot model and insights into the epidemiology and potential for prevention and control of congenital anomalies in the whole region and in similar areas.

2. Design, Study Population, and Analysis

The TRoCA program was initiated in 2000. It is a hospital-based registry (located in the Alzahra University Hospital of Tabriz University of Medical Sciences) covering all births and children in the city of Tabriz. This city is one of the three major cities in the country and is the centre of East Azarbaijan Province. Infants diagnosed in three public maternity/children medical centers (Alzahra, Taleghani and Children hospitals) as having birth defects are covered in this program. These hospitals provide obstetric and gynecological services in the study population. The program covers 15 000 births (average per year) in the defined area with about 300 cases (average per year) of congenital anomalies born with one of the anomalies in this population.

The definition of the congenital anomalies for the purposes of the program is based on the standard coding system of the International Classification of Diseases (ICD) and British Pediatric Association [23]. Thus, the subjects comprised all births registered and notified to those hospitals and medical centers with a primary diagnosis under one of the following headings: nervous system anomalies, genito-urinary tract and kidney defects, anomalies of limb, chromosomal anomalies, cleft lip with/without palate, congenital heart disease, musculoskeletal and connective tissue anomalies, digestive system anomalies, eye and ear anomalies and other anomalies.

All infants are routinely examined by a gynecologist, obstetrician or neonatologist at birth and hospital discharge. The examinations include assessment of general health, maturity and congenital anomalies. General epidemiological data and basic characteristic information are collected for all births. Information is also gathered for mothers of all malformed infants. Other women giving births in those hospitals with normal newborns might be, in case, considered as matched control groups for research purposes.

Information is collected using the standard data form of European Registration of Congenital Anomalies (EUROCAT) for congenital anomalies [16]. This form is routinely used in all European countries participating in the EUROCAT surveillance program of congenital anomalies. The parents or accompanying adults are asked to provide basic information required on the form. Technical information is filled on the form using diagnostic records of each subject. Data are anonymised at source of data collection to keep personal information private. More details of the organization and performance of the TRoCA can be found elsewhere [24].

3. Epidemiological Findings

Total prevalence of congenital anomalies was 1.7 per 100 births between 2000 and 2008. Genito-urinary tract and kidney defects, anomalies of nervous system, and limb anomalies accounted proportionally for more than 68% of anomalies in the region. There was an increasing trend in the prevalence of congenital anomalies in the study area from 2000 (1.05 per 100 births) to 2008 (2.45 per 100 births).

This time trend was not however significant using linear regression statistical analysis where the dependent variable was the prevalence of congenital anomalies and the predictor was the birth year from 2000 to 2008 ($P = 0.07$).

4. Applications

TRoCA provides some essential data and identifies local interventions that could help to prevent and control congenital anomalies in the study population. Some of these interventions may be specific to the study population and similar areas, whilst others may have more general applications.

Moreover, TRoCA may also help health care system for affected families who need, and an epidemiological tool for local investigators, information for health service planners, clinicians and for genetic counselors.

5. Monitoring and Evaluation

Evaluation procedures are essential part of our program to monitor effects of preventive services for congenital anomalies in order to identify and correct shortcomings. Fortunately, using our current registry of congenital anomalies, we can monitor the number of new cases in the coverage area. Patients can then be followed up to assess the extent to which the educational interventions have been taken into account and to evaluate the amount and quality of the prevention information provided to other family members. Using the registry data, prenatal diagnosis services can also be assessed by birth prevalence rate of affected individuals, the choices that couples (at risk) make with respect to using prenatal diagnosis, the rate of prenatal diagnosis performed, the rate of births of children with avoidable conditions, and the rate of medical termination of pregnancies due to fatal defects.

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References

[1] C.M. Druschel, J.P. Hughes, C. Olsen, Mortality among infants with congenital malformations, New York State, 1983 to 1988, *Pub Health Rep* **111** (1996), 359–365.
[2] E. Powell-Griner, A. Woolbright, Trends in infant deaths from congenital anomalies: results from England and Wales, Scotland, Sweden and the United States, *Int J Epidemio* **19** (1990), 391–398.
[3] M. Gatt, A*nnual Congenital Anomalies Report in Malta*, Department of Health Information, Guardamangia, Malta, 2002.
[4] M.M. Thein, D. Koh, K.L. Tan, H.P. Lee, Y.Y. Yip, C.Y. Tye, W.O. Phoon, Descriptive profile of birth defects among live births in Singapore, *Teratology* **46** (1992), 277–284.
[5] L.I. Al-Gazali, R. Alwash, Y.M. Abdulrazzaq, United Arab Emirates: Communities and community genetics, *Comm Gen* **8** (2005), 186–196.
[6] K. C. Johnson, J. Rouleau, Temporal trends in Canadian birth defects birth prevalence, 1979–1993, *Can J Public Health* **88** (1997), 169–176.
[7] International Clearinghouse for Birth Defects Monitoring Systems, *Annual Report 2005: with data for 2003*, International Clearinghouse for Birth Defects Monitoring Systems (ICBDSR), Roma, Italy, 2005.
[8] P. A. Baird, Prenatal screening and the reduction of birth defects in populations, *Comm Gen* **2** (1999), 9–17.
[9] J. Mulinare, L.Y. Wong, H.Q. Gu, J.D. Erickson, A population-based birth defects surveillance system in the People's Republic of China, *Paed Peri Epid* **17** (2003), 287–293.
[10] R.E. Stevenson, W.P. Allen, G.S. Pai, R. Best, L.H. Seaver, J. Dean, S. Thompson, Decline in prevalence of neural tube defects in a high risk region of the United States, *Paed* **106** (2000), 677–683.
[11] H. Hamamy, A. Alwan, Hereditary disorders in the Eastern Mediterranean Region, *Bull World Health Org* **72** (1994), 145–154.
[12] S. Dastgiri, D.H. Stone, C. Le-Ha, W.H. Gilmour, Prevalence and secular trend of congenital anomalies in Glasgow, U.K, *Arch Dis Childhood* **86** (2002), 257-263.

[13] C. Bower, E. Rudy, A. Ryan, Cosgrove P., *Report of the Birth Defects Registry of Western Australia*, King Edward Memorial, Hospital Women's and Children's Health Service, Subiaco, Australia, 2004.
[14] S. Dastgiri, S. Imani, L. Kalankesh, M. Barzeghar, M. Heidarzadeh, Congenital anomalies in Iran: A cross-sectional study on 1574 cases in the north-west of country, *Child: Care, Health and Development* **33** (2007), 257–261.
[15] C. Bower, S. Eades, J. Payne, H. D'Antoine, F.J. Stanley, Trends in neural tube defects in Western Australia in indigenous and non-indigenous populations, *Paed Peri Epidemio* **18** (2004), 277–280.
[16] EUROCAT Working Group, available at: <http://www.ihe.be/eurocat>, 2007.
[17] A.E. Czeizel, Prevention of congenital anomalies by periconceptional multivitamin supplementation, *BMJ* **306** (1993), 1645–1648.
[18] A.E. Czeizel, Z. Intody, B. Modell, What proportion of congenital anomalies can be prevented? *BMJ* **306** (1993), 499-503.
[19] World Health Organization, *Community Approaches to the Control of Hereditary Diseases*, Report of a WHO advisory group, World Health Organization, Geneva, Switzerland, 1985.
[20] World Health Organization, *Control of Hereditary Diseases*, Report of a WHO scientific group, World Health Organization, Geneva, Switzerland, 1996.
[21] Tabriz Registry of Congenital Anomalies, available at: <http://www.tbzmed.ac.ir/troca>, 2007.
[22] International Clearinghouse for Birth Defects Surveillance and Research, available: <http://www.icbdsr.org>, 2007.
[23] British Paediatric Association, *British Paediatric Association Classification of Disease*, 1979.
[24] S. Dastgiri, L. Kalankesh, M. Heidarzadehe, A. Tajahmade, E. Rezaiane, A new registry of congenital anomalies in Iran, *J Reg Manage* **37** (2010), 9–27.