Congenital malformations in Albania for the period 2011-2015

Dorina Toçi[1,2], Alba Merdani[1,2], Ervin Toçi[1,3], Eugena Tomini[1], Enver Roshi[1,3], Genc Burazeri[1,3]

[1]Institute of Public Health, Tirana, Albania;
[2]Mediterranean Programme for Intervention Epidemiology Training (MediPIET), Ministry of Health, Albania;
[3]Faculty of Medicine, University of Medicine, Tirana, Albania.

Corresponding author: Dorina Toçi, MD, MPH, PhD
Address: Str. "Aleksander Moisiu", No. 80, Tirana, Albania;
Telephone: 00355699944546, E-mail: doricanaku@gmail.com

Abstract

Aim: Congenital malformations (CMs) are considered a challenging public health problem worldwide. The national Congenital Malformation Surveillance System (NCMSS) was established in 2009. Our aim was to assess the prevalence of CMs in Albania during 2011-2015.

Methods: This report is based on NCMSS data for the period 2011-2015. NCMSS collects CMs data from the public sector. In addition, the reporting form enables the retrieving of basic socio-demographic characteristics for the baby and the mother and birth-related information. The prevalence of CMs (per 1000 live births) by year, type, gender, residence and mother's age were calculated based on the World Health Organization and Centers for Disease Control and Prevention guidelines.

Results: The prevalence of CMs in Albania varied from 15.2/1000 live births in 2011 (95%CI=13.92-16.54) to 16.9/1000 live births in 2015 (95%CI=15.45-18.42; P=0.094).The most frequent CMs were those affecting the cardiovascular, muscular-skeletal, genital and oral cavity/digestive system. There are regional differences in the prevalence of CMs in all years. Regions of Tirana and Gjirokastra had a considerable higher CM prevalence over the years. The male/female ratio of CMs was 1.45. In each year, the prevalence of CMs was highest among older mothers (age $\geq$30 years).

Conclusion: There are important variations in the prevalence of CMs by year of notification, regions and basic socio-demographic variables. Further research is needed to identify possible risk factors, in order to evaluate and improve antenatal control programs.

Keywords: Albania, congenital malformations, prevalence, surveillance.

Introduction

Congenital malformations (CMs) represent a significant health problem worldwide. The prevalence of specific CMs is different in different populations and its assessment depends on the health care system, the use and coverage of preventive services, access to screening, diagnosis and termination of pregnancy in severe cases (1-3). The prevalence of CMs varies from 10 to 60 cases per 1000 live births and this figure increases significantly if the CMs detected later in life (one year old to 5 years old) are included. Based on the report of the World Health Organization (WHO), approximately three million fetuses and infants are born each year with major congenital malformation (3). CMs can be isolated abnormalities or part of a syndrome and continue to be an important cause of morbidity and neonatal and infant mortality (4). Different large population-based studies report the prevalence of major malformations about 2-3% of all live births, whereas among stillbirths the prevalence of major CMs is even higher (5-9). Scientific reports consistently suggest a higher prevalence of CMs among males and colored children (10,11). Moreover, CMs contribute to about 500,000 deaths worldwide each year. Congenital malformations constitute a very sharp economic problem also. In USA about 15-30% of pediatric hospital admissions are due to CMs and every year about $8 billion are spent for medical and rehabilitative care for children with CMs (12).

In Albania prior to 2009, among all diagnosed CMs only spina bifida and congenital luxation of hip were officially reported. In 2009, the Institute of Public Health (IPH) in collaboration with the Ministry of Health and the United Nations Population Fund (UNFPA) office in Tirana began implementing the NCMSS as a first step towards identifying major CMs in Albania and exploring potential genetic, socio-demographic, environment and nutrition factors that increase the risk for CMs (13). Every diagnosed congenital malformation should be reported by an official individual form (files 4/1 / ID-SH) (13). In our country, in the context of implementation and establishment of NCMSS all obstetricians-gynecologists, neonatologists and pediatricians were trained for reporting of CMs, and also all reporting health institutions/health centers in the country already have the registry of congenital malformations. Institute of Public Health is the final center where all the reporting forms are collected, analyzed and used to generate reports and recommendations (13). The NCMSS is the only, most accurate and complete source for analyzing the epidemiological situation of CMs in Albania.

In Albania there is no description of the distribution and characteristics of CMs on national level for the period 2011-2015. In this context this study aims to describe the prevalence of CMs during 2011-2015 and monitor their time trends in order to help evaluate antenatal programs and strengthen preventive measures.

Methods

Type of study, data collection and procedures

This is a surveillance descriptive report on CMs in Albania during 2011-2015. The sources of information are all CMs reported to NCMSS and all live births reported to the Ministry of Health during the respective study years. NCMSS covers all the districts and regions of Albania. This is a mandatory passive surveillance reporting, and the reporting form is paper-based.

We used the following case definition: any CM diagnosed among live births, stillbirths, induced abortions, perinatal deaths (early neonatal deaths) and children up to 2 years of age who are born and/or residents of Albania. Blood disorders of parental origin (such as Thalassemia) which are part of other chapters of ICD-9 coding system, will not be included in CMSS (exclusion criteria).

NCMSS code the narrative diagnostic report of congenital malformations using the ninth revision of the International Classification of Diseases Coding Manual [ICD-9-CM (Congenital Anomalies 740-759)].

Albania has 36 districts and 12 regions. Each district has a maternity hospital (obstetric-gynecologic services) and a general hospital (pediatric services). Tirana (the capital of Albania)

has two university maternity hospitals, one university general hospital and two private hospitals that offer pediatric and obstetric-gynecologic services. Maternity hospitals/wards, general hospitals and primary health care centers (PHCC) are the reporting centers for CMSS in Albania. All obstetrician-gynecologists, neonatologists and pediatricians working in these hospitals and PHCC are required to fill in the CMs reporting form for every case diagnosed with CMs. Every district has a Public Health District Directory (PHDD) and the reproductive health inspector (RHI) is the responsible person for reporting diagnosed CMs from district to IPH. RHI of each PHDD is responsible for managing the surveillance system within each district.

Statistical analysis

We calculated the prevalence of CMs (per 1000 live births) using the number of CMs and the number of live births accordingly. The prevalence rates were calculated by year, type of CMs, gender, residence (urban/rural and region) and mother's age-specific groups. The prevalence of CMs was assessed according to WHO and Centers for Disease Control and Prevention (CDC) guidelines (14).

Results

During 2011-2015 in Albania there were 2384 CMs reported to NCMSS, and 166093 live births. The total prevalence of CMs for this period was 14.4 per 1000 live births. The rate of CMs per 1000 live births increased during this period from 15.2 in 2011 to 16.9 in 2015 (approximately 11% increase), mainly due to a reduction in the number of live births. In 2014 a sharp decrease can be noted. However, there is no clear trend regarding the prevalence of CMs during these years and the fluctuations are not significant (P-value for linear trend = 0.970) (Figure 1).

Figure 1. Prevalence of congenital malformations in Albania by year of notification during 2011-2015

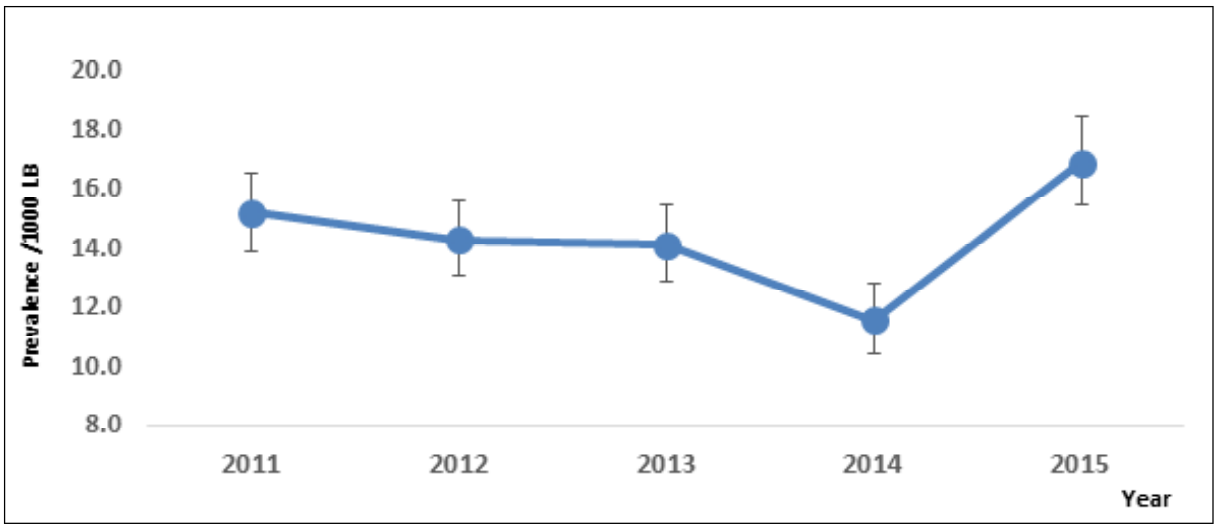


Table 1 presents information about the prevalence of congenital malformations in Albania by region of the country for the period 2011-2015. There were considerable regional variations in the prevalence of CMs during 2011-2015. Regions of Gjirokastra and Tirana had the highest rates compared to other regions during the entire study period and in each study year. During 2011-2015 the lowest prevalence rates were noted in Shkodra region. Gjirokastra had the highest rate of CMs (28.1/1000 lb), which is about 8 times higher than the rate of CMs in Shkodra (3.5/1000 lb). From

2011 to 2015, the prevalence of CMs increased by 20% in Berat region whereas in Dibra region it increased by almost 2 folds. The prevalence of CMs in Durres region increased slightly from 2011 to 2015 but in this region the highest prevalence rate was noted in 2013 (14.3 per 1000 live births), 83% more than in 2011 and 66% more than in 2015 (Table 1). In Elbasan and Fier regions the prevalence of CMs increased by 2.6 and 1.8 folds respectively, in Gjirokastra and Vlora regions it increased by 35% and 46% respectively. In other regions the prevalence of CMs decreased during 2011-2015 as in Korca and Kukes regions (a reduction of 38% and 56% respectively), in Lezha and Shkodra regions (reduction of 7% and 15% respectively) and in Tirana region it decreased by 21%. During this period the highest increase was noticed in Elbasan (plus 162%) and the highest decrease in Kukes (minus 56%) [Table 1].

Table 1. Prevalence of congenital malformations in Albania, by region and year of study

Year	Parameter	REGION											
		Berat	Diber	Durres	Elbasan	Fier	Gjirokaster	Korce	Kukes	Lezhe	Shkoder	Tirane	Vlore
2011	CMs *	24	7	29	33	43	15	23	13	13	7	282	32
	Births †	1440	1487	3741	3269	3447	547	2238	1138	1527	2178	11401	1884
	Rate §	***16.7***	*4.7*	*7.8*	*10.1*	*12.5*	***27.4***	*10.3*	*11.4*	*8.5*	*3.2*	***24.7***	***17.0***
2012	CMs	15	5	35	24	38	10	18	10	8	4	305	27
	Births	1522	1541	3468	3412	3611	511	2185	1143	1542	2368	11725	1946
	Rate	*9.9*	*3.2*	*10.1*	*7.0*	*10.5*	***19.6***	*8.2*	*8.7*	*5.2*	*1.7*	***26.0***	***13.9***
2013	CMs	11	11	48	28	47	16	12	14	10	8	262	13
	Births	1173	1382	3361	3321	3356	434	2122	1089	1615	2293	11958	1890
	Rate	*9.4*	*8.0*	***14.3***	*8.4*	***14.0***	***36.9***	*5.7*	*12.9*	*6.2*	*3.5*	***21.9***	*6.9*
2014	CMs	14	7	36	18	12	9	5	4	6	13	236	25
	Births	1177	1349	3333	3403	3426	435	2104	1024	1467	1994	11877	1685
	Rate	*11.9*	*5.2*	*10.8*	*5.3*	*3.5*	***20.7***	*2.4*	*3.9*	*4.1*	*6.5*	***19.9***	***14.8***
2015	CMs	21	11	26	75	69	17	12	3	10	5	213	37
	Births	1044	1086	3030	2829	3124	461	1877	595	1273	1839	10902	1494
	Rate	***20.1***	*10.1*	*8.6*	***26.5***	***22.1***	***36.9***	*6.4*	*5.0*	*7.9*	*2.7*	***19.5***	***24.8***
2011-2015	CMs	85	41	174	178	209	67	70	44	47	37	1298	134
	Births	6356	6845	16933	16234	16964	2388	10526	4989	7424	10672	57863	8899
	Rate	*13.4*	*6.0*	*10.3*	*11.0*	*12.3*	*28.1*	*6.7*	*8.8*	*6.3*	*3.5*	*22.4*	*15.1*

*Absolute number of congenital malformations (CMs).
†Absolute number of live births (LB).
§Rate of CMs per 1000 live births.

Table 2 presents detailed information about the prevalence rate of CMs by gender and mother's educations for each year under study. During the 2011-2015 period and in each year the CMs prevalence was higher among males than females. In 2012 and 2013, there were noticed the highest rates of CMs among males compared to females (male:female ratio 1.64 and 1.78, respectively). From 2011 to 2015, the prevalence of CMs among males increased by 6.6%, meanwhile the prevalence of CMs among females decreased by 9% (Table 2). There was a positive correlation between the prevalence of CMs and mother's age: the prevalence of CMs increased steadily with the increasing of age of the mother. For example, in 2011 the prevalence of CM babies was 6.7% among mothers aged <20 years, 11.3% among those aged 20-24 years, 14.8% among those aged 25-29 years, to a stunting 21.5% and 28.9% among those aged 30-34 years and 35 years old or older (Table 2). Such positive association with age and similar trends were noticed in each year under study as well (Table 2).

Table 2. Prevalence of congenital malformations by newborns' gender and maternal age in Albania during 2011-2015 *(total number of births as reported by INSTAT)*

Variable	Year									
	2011		2012		2013		2014		2015	
	CMs (LBs)*	Rate†	CMs (LBs)	Rate	CMs (LBs)	Rate	CMs (LBs)	Rate	CMs (LBs)	Rate
Baby's gender										
Male	298 (17849)	16.7	316 (18478)	17.1	311 (18661)	16.7	231 (18683)	12.4	304 (17103)	17.8
Female	220 (16436)	13.4	177 (16995)	10.4	160 (17089)	9.4	152 (17077)	8.9	190 (15612)	12.2
Mother's age										
<20 years	19 (2852)	6.7	20 (2818)	7.1	18 (2634)	6.8	23 (2697)	8.5	15 (2363)	6.3
20-24 years	128 (11357)	11.3	127 (12142)	10.5	120 (11757)	10.2	104 (11505)	9.0	119 (9785)	12.2
25-29 years	171 (11532)	14.8	158 (11616)	13.6	154 (12010)	12.8	131 (12039)	10.9	189 (11204)	16.9
30-34 years	128 (5953)	21.5	117 (6264)	18.7	134 (6570)	20.4	82 (6739)	12.2	115 (6720)	17.1
≥35 yearsld	75 (2592)	28.9	75 (2633)	28.5	52 (2779)	18.7	45 (2780)	16.2	61 (2643)	23.1

* Absolute number of congenital malformations (CMs) and absolute number of live births (LBs) (in parenthesis).
† Rate of CMs per 1000 live births.

The most affected systems were musculoskeletal and cardiovascular ones with the highest prevalence rates (3.3 and 3.2 CM cases per 1000 live births respectively). Congenital anomalies of the integument, respiratory and urinary systems are the less affected ones with the lowest prevalence rates (0.1, 0.1 and 0.3 CM cases per 1000 live births respectively) (Figure 2).

Figure 2. The prevalence of congenital malformations by body system affected in Albania during 2011-2015

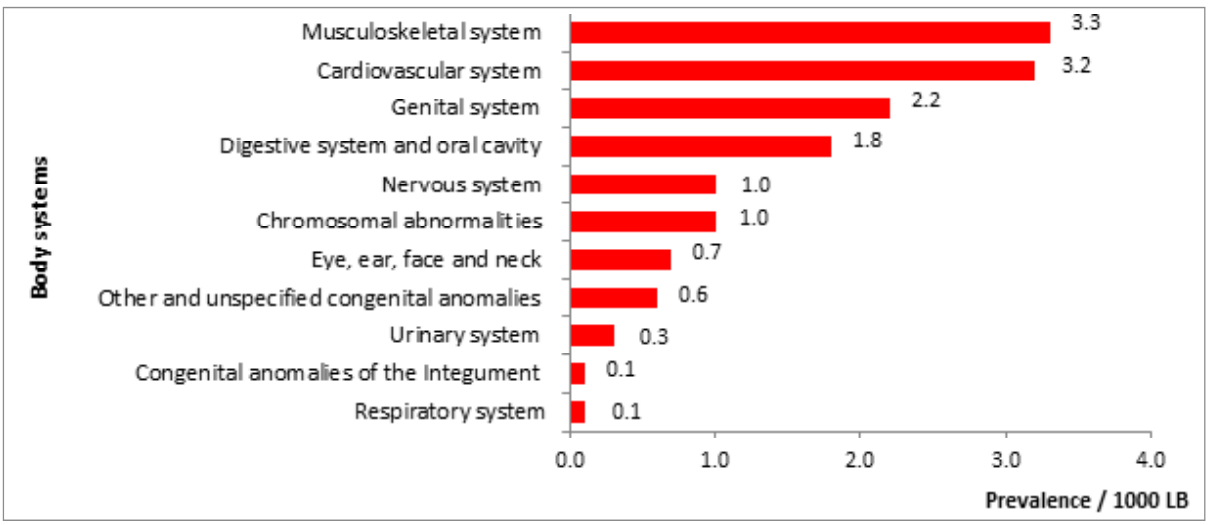
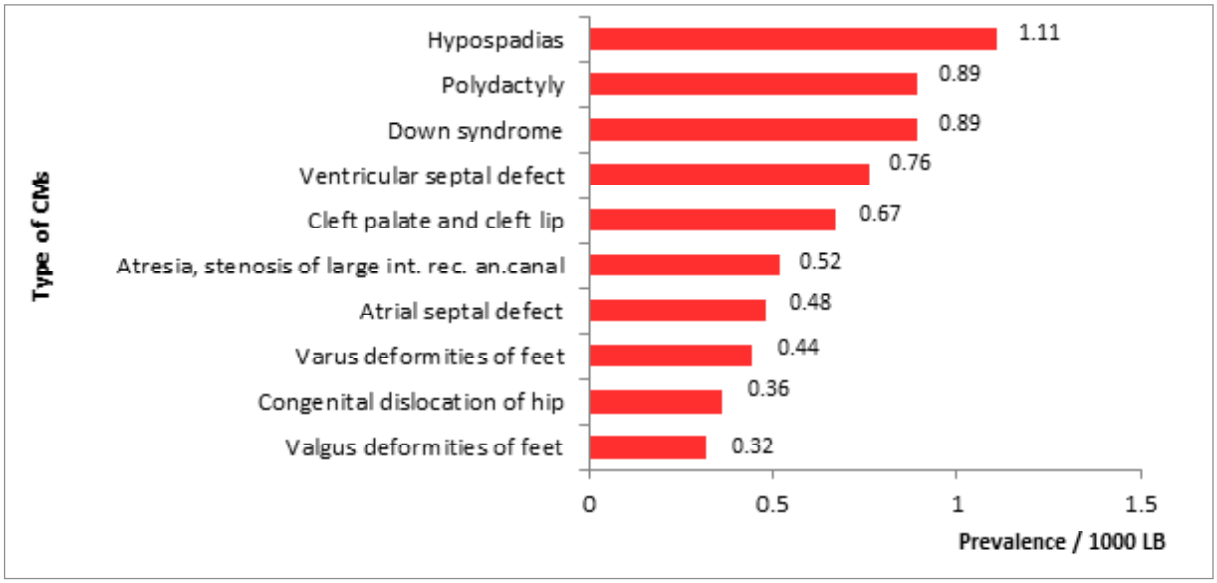


Figure 3 displays the prevalence of the ten most frequent congenital malformations in Albania during 2011-2015. Hypospadias had the highest prevalence rate among all congenital malformations reported in the surveillance system during 2011-2015 (1.11 per 1000 live births). Among the most prevalent CMs during 2011-2015 in Albania, Down syndrome and polydactyly are ranked in the second and third position (0.89/1000 live births respectively). Also, ventricular and atrial septal defects were the most prevalent malformations among cardiovascular defects (0.76 and 0.48 per 1000 live births respectively). Cleft palate and cleft lip, and atresia and stenosis of large intestine, rectum and anal canal were the most prevalent malformations among digestive system and oral cavity malformations (0.67 and 0.52 per 1000 live births respectively). The most prevalent malformations of musculoskeletal system

were: polydactyly, varus and valgus deformities of feet and congenital dislocation of hip (0.89, 0.44, 0.32 and 0.36 per 1000 live births respectively).

Figure 3. Prevalence of most frequent types of congenital malformations in Albania during 2011-2015



Discussion

This is the first comprehensive report detailing the birth prevalence of congenital malformations in Albania for the period 2011-2015. This report aimed to assess the burden of congenital malformations as a tool for the improvement of a congenital malformations surveillance system and monitoring of CMs.

In Albania, congenital malformations are the first cause of death among infants (15,16). The percentage of births among women over 30 years of age continues to increase with almost 10% more women in this age category giving birth from 2011 to 2015 (17). The total number of live births in Albania has decreased from 34297 in 2011 to 29554 in 2015, a 14% decrease over 5 years. Congenital malformations rates have remained relatively stable over the years, except for the year 2014 in which the rate decreased by almost 40% compared to other years under study. During 2013 and 2014 the staff in district public health directories was replaced in almost all districts of Albania which was reflected in the lack and/or inappropriateness of monitoring of the surveillance system in the respective districts contributing this way to gaps in reporting and therefore an artificially lower prevalence rate of CMs in these two years (16). Also, in mid of 2013 two private hospitals in Tirana started providing pediatric services and obstetric-gynecologic services which contributed to a lower prevalence rate of CMs in the last three years because these hospitals were not involved in the mandatory reporting scheme of the national congenital malformations surveillance system. Since 2014, private hospitals in Albania providing pediatric and obstetric-gynecologic services are included in the CMSS through the Ministerial Council's Decision on "Defining the Format, Way of Collecting and Reporting the Data from Providers of Public and Private Health Care Services". The declining trend of number of CMs in Albania and especially in Tirana more or less mimics the declining trend of number of births in our country.

For the period 2011-2015, CMSS covered all pregnancies and children up to 2 year old from the public sector. Therefore to CMSS report all maternity wards / hospitals, pediatric wards/hospitals and primary health care centers (baby's consultancy room) of all districts of Albania, making it a population based registry and not only a hospital based surveillance. In Albania virtually all births occur in maternity hospitals/wards and only 1.5% of births occur at homes with medical assistance (15). The observed differences in the prevalence among regions could be partly explained by variations in diagnostic practice (inadequate training of medical staff and infrastructure in some districts), and reporting problems in some districts due to frequent turnover of staff in public health district directories (16). The list of reported congenital malformations in Albania includes all diagnosis of congenital malformations according to International Classification of Diseases, ninth revision (ICD-9). From 2011 to 2015, the six main types of congenital malformations were hypospadias; polydactyly; down syndrome; ventricular septal defect; cleft palate and cleft lip; and atresia and stenosis of large intestine, rectum and anal canal.

Conflicts of interest: None declared.

According to WHO Health For All Database (HFA-DB), the prevalence of CMs in Albania is approximately two folds lower than the prevalence of CMs in Croatia (2011-2014), and Montenegro (2011). From 2011-2013 the prevalence of CMs in Albania is higher than the prevalence of CMs reported from Italy in the HFA-DB. The prevalence of CMs in Albania is two folds lower than the prevalence of CMs in the European Region during 2011-2013 (18).

Conclusion

There is need to improve reporting of CMs from public and private sector through trainings of PHDD and medical staff in all districts. There is need to investigate the reasons of regional differences in CM rates and to raise the public awareness about CMs in Albania, especially targeting unemployed, older and low educated mothers. There is need to develop comprehensive and systematic approaches to improve birth outcomes and reduce CM rates, by prioritizing prevention policies across disciplines and to evaluate the NCMSS according to WHO and CDC guidelines in order to improve antenatal programs.

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