Establishing of National Birth Defects Registry in Thailand

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Background: *Deaths attributed to birth defects are a major cause of infant and under-five mortality as well as lifetime disabilities among those who survive. In Thailand, birth defects contribute to 21% of neonatal deaths. There is currently no systematic registry for congenital anomalies in Thailand. Queen Sirikit National Institute of Child Health has initiated a Thailand Birth Defects Registry to capture birth defects among newborn infants.*

Objective: *To establish the national birth defects registry in order to determine the burden of birth defects in Thailand.*

Material and Method: *The birth defects data come from four main sources: National Birth Registry Database; National Health Security Office's reimbursement database; Online Birth Defect Registry Database designed to capture new cases that were detected later; and birth defects data from 20 participated hospitals. All data are linked by unique 13-digit national identification number and International Classification of Diseases (ICD)-10 codes. This registry includes 19 common structural birth defects conditions and pilots in 20 hospitals. The registry is hospital-based, hybrid reporting system, including only live births whose information was collected up to 1 year of age.*

Results: *3,696 infants out of 67,813 live births (8.28% of total live births in Thailand) were diagnosed with congenital anomalies. The prevalence rate of major anomalies was 26.12 per 1,000 live births. The five most common birth defects were congenital heart defects, limb anomalies, cleft lip/cleft palate, Down syndrome, and congenital hydrocephalus respectively.*

Conclusion: *The present study established the Birth Defects Registry by collecting data from four databases in Thailand. Information obtained from this registry and surveillance is essential in the planning for effective intervention programs for birth defects. The authors suggest that this program should be integrated in the existing public health system to ensure sustainability.*

Keywords: *Birth defects, Registry, Thailand*

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Birth defects are defined as structural and functional abnormalities present at the time of birth. Currently, more than 7,000 different birth defects have been identified[1]. Birth defects are a major cause of perinatal, neonatal and childhood mortality and disability[2-5]. Furthermore, birth defects have increasingly become a major cause of neonatal deaths worldwide, contributing to 21% of the deaths[7-9].

In May 2010, the World Health Assembly (WHA) adopted Resolution WHA 63.17, urged member countries to set priorities concerning birth defects as a cause of childhood morbidity and mortality[10]. Members are encouraged to generate epidemiological data regarding birth defects, with emphasis to developing and strengthening registration and surveillance of birth defects[11,12]. In the past, hospital-based surveys were the only sources of information on birth defects in Thailand. As a response to Resolution WHA 63.17, Queen Sirikit National Institute of Child Health established the Thailand Birth Defects Registry in October 2012 to capture birth defects among newborn infants.

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Material and Method

The Thailand Birth Defects Registry was established as a joint project between the Queen Sirikit National Institute of Child Health, Department of Medical Services, Ministry of Public Health and the National Health Security Office (NHSO). Previously, in 2010, the Online Birth Registry was developed in

Thailand by the Bureau of Registration Administration, Department of Provincial Administration, Ministry of Interior, NHSO and Ministry of Public Health and funded by the United Nations Children's Fund (UNICEF). In October 2012, the Birth Defects Registry program was integrated into the Online Birth Registry. The single window concept was used by merging the birth defects database of the NHSO and Birth Registry database of the Ministry of Interior, and combining them with the new birth defects cases reported in the online Birth Defects Registry Program. These databases are updated by new additional data from multiple sources.

The Thailand Birth Defects Registry was hospital-based and utilized the hybrid reporting system to include only live births whose information were collected up to one year of age. Data were collected between July 1, 2012 and June 30, 2013, from 20 participating hospitals in 16 provinces throughout Thailand (Fig. 1). Birth defects data came from four sources: Online National Birth Registry database; National Health Security office's reimbursement database; Online Birth Defect Registry database; and birth defects data from 20 participated hospitals. All data were linked by the unique13-digit national identification number and International Classification of Diseases (ICD) 10 codes[13]. This registry includes 19 common structural birth defects conditions. Exclusion criteria for this registry were metabolic and functional anomalies, babies born outside participating hospitals, stillbirths and fetal deaths.

Statistical analysis

Birth defects were calculated in prevalence rate that is cited as per 1,000 live births.

Results

A total of 67,813 live births were registered in the Birth Defects Registry (8.28% of total live births in Thailand). They can be divided into 8,275 babies born in 3 hospitals from Bangkok (7.67% of total birth in Bangkok) and 59,538 babies born in 15 provinces in 17 hospitals (47.2% of total birth in 15 provinces). A total of 3,696 infants were diagnosed as having congenital anomalies, 1,772 cases with major anomalies and 1,924 cases with minor anomaly (ankyloglossia).

The number of each birth defect was shown in Table 1. The five most common birth defects were: congenital heart defects, limb anomalies, cleft lip/cleft palate, Down syndrome, and congenital hydrocephalus, (Fig. 2). The prevalence rates per 1,000 live births of each birth defect in 20 hospitals were demonstrated in Table 2. The prevalence rate of major anomalies was 26.12 per 1,000 live births.

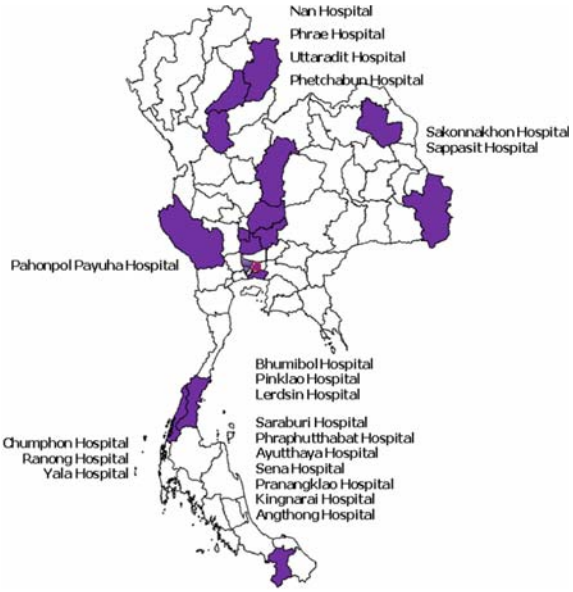

Fig. 1 Thailand birth defects project sites, 20 hospitals in 16 provinces.

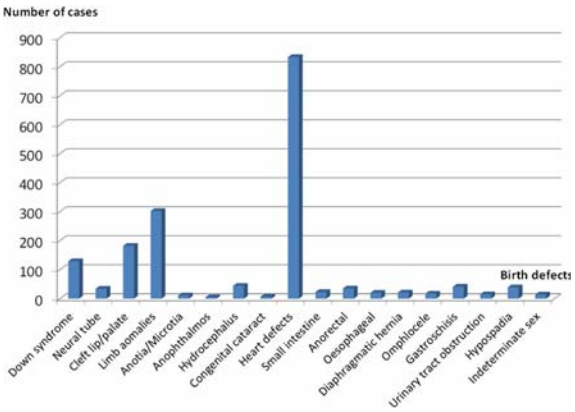

Fig. 2 The numbers of birth defects in 20 hospitals.

Discussion

Results from this study showed that the prevalence of 19 anomalies (26.12 per 1,000 live births) was higher than the prevalence of overall birth defects of the European surveillance of congenital anomalies (EUROCAT)'s registry (20.87 per 1,000 births)[14,15]. In the present study, the five most common birth defects were congenital heart defects, limb anomalies, cleft lip/cleft palate, Down syndrome, and congenital hydrocephalus. The first three common birth defects are congenital heart defects, limb defects, cleft lip/cleft

Table 1. The number of each birth defect in 20 hospitals

Hospital/birth defects	Nan	Phrae	Phet cha bun	Utta radit	Sara buri	Phra phut tha bat	Ayut thaya	Sena	King narai	Ang thong	Pra nang klao	Pa hon pol Pa yuha	Sakon nak hon	Sap pasit	Chum phon	Ra nong	Yala	Bhu mibol	Lerd sin	Pin klao	Cases of birth defects
1. Down syndrome	4	3	5	8	5	2	17	1	4	1	8	14	13	11	4	3	16	7	1	2	129
2. Neural tube defects	1		1	2		1	6				1	4	4	8		1	2	2	1		34
3. Cleft lip/Cleft palate	6	5	8	10	18	4	9	2	5	3	8	16	15	19	4	7	24	9	3	7	182
4. Limb anomalies	7	7	15	7	20	6	28	17	4	3	13	51	37	16	1	2	29	29	1	9	302
5. Anotia/Microtia		2	1		1			1	1	3	1									1	11
6. Anophthalmos/ Microphthalmos				1		3						1									5
7. Ankyloglossia	115	195	464	26	23	2	79	1	34	47	3	484	12	8		1	216	61	1	152	1,924
8. Congenital hydrocephalus	4		2	1	6		3	1	2	1	2	3	3	9	1	1	2	2		1	44
9. Congenital cataract							2				1	2				1				1	7
10. Congenital heart defects	25	29	17	29	171	33	42	8	9	4	63	68	95	128	7	1	60	24	2	18	833
11. Small intestine atresia/stenosis	2		1	2	3		2						1	3		2	5	2			23
12. Anorectal atresia/stenosis	1		3	4	5		4			1	2	3	3	2	1	1	1	2	2		35
13. Oesophageal atresia with or without TE fistula			1	1	2		2		1		1	1	1	5	2		2			1	20
14. Diaphragmatic hernia			1		1	1	3	1				2	1	4		1	3		1	2	21
15. Omphalocele			1	1	1				1	1	2	1		3	1		3	1		1	17
16. Gastroschisis	1	1		1	5	2	4	1	2		1	4	2	11		1	3	1		1	41
17. Urinary tract obstruction	2			1	3							1	1	3			1	3			15
18. Hypospadia	3			2	4		3		2		2	2	3	4			6	6	1	1	39
19. Indeterminate sex	1		1				1	1				1	2	2			1	2	2		14
Total cases of birth defects	172	242	521	96	268	54	205	34	65	64	108	658	193	236	21	22	374	151	15	197	3,696
Total live births	2,146	2,555	4,253	3,579	4,853	1,797	5,384	1,301	2,427	1,189	3,317	3,322	4,614	7,135	4,327	3,105	4,234	4,065	2,229	1,981	67,813

Table 2. The prevalence of each birth defect in 20 hospitals compared to EUROCAT study

Hospital/birth defects	Nan	Phrae	Phetchabun	Uttaradit	Saraburi	Phraphutthabat	Ayutthaya	Sena	Kingnarai	Angthong	Pranangklao	Phonpol Payuha	Sakonnakhon	Sappasit	Chumphon	Ranong	Yala	Bhumibol	Lerdsin	Pinklao	Prevalence/ 1,000 live births	EUROCAT Prevalence in/ 1,000 births
1. Down syndrome	1.86	1.17	1.17	2.23	1.03	1.11	3.15	1.64	1.64	0.84	2.41	4.21	2.81	1.54	0.92	0.96	3.77	1.72	0.44	1	1.90	1.82
2. Neural tube defects	0.46		0.23	0.55		0.55	1.11				0.3	1.2	0.86	1.12		0.32	0.47	0.49	0.44		0.50	0.52
3. Cleft lip/cleft palate	2.79	1.95	1.88	2.79	3.70	2.22	1.67	2.06	2.06	2.52	2.41	4.81	3.25	2.66	0.92	2.25	5.66	2.21	1.34	3.53	2.68	1.33
4. Limb anomalies	3.26	2.73	3.52	1.95	4.12	3.33	5.20	1.64	1.64	2.52	3.91	15.35	8.01	2.24	0.23	0.64	6.84	7.13	0.44	4.54	4.45	3.61
5. Anotia/microtia		0.78	0.23		0.20			0.41	0.41	2.52	0.3									0.5	0.16	0.02*
6. Anophthalmos/ Microphthalmos			0.27		1.66						0.3									0.07	0.09	
7. Ankyloglossia	53.58	76.32	109.09	7.26	4.73	1.11	14.67	14	14	39.52	0.9	145.69		2.6	1.12		0.32	51.01	15	0.44	76.72	28.37
8. Congenital hydrocephalus	1.86		0.47	0.27	1.23		0.55	0.82	0.82	0.84	0.6	0.9	0.65	1.26	0.23	0.32	0.47	0.49		0.5	0.64	0.47
9. Congenital cataract							0.37				0.3	0.6				0.32				0.5	0.10	0.09
10. Congenital heart defects	11.64	11.35	3.99	8.1	35.23	18.36	7.8	3.70	3.70	3.36	18.99	20.46	20.58	17.93	1.61	0.32	14.17	5.9	0.89	9.08	12.28	6.64
11. Small intestine atresia/stenosis	0.93		0.23	0.55	0.61		0.37						0.21	0.42		0.64	1.18	0.49			0.33	0.18
12. Anorectal atresia/stenosis	0.46		0.70	1.11	1.03		0.74			0.84	0.6	0.9	0.65	0.28	0.23	0.32	0.23	0.49	0.89		0.51	0.27
13. Oesophageal atresia with or without TE fistula			0.23	0.27	0.41		0.37	0.41	0.41		0.3	0.3	0.21	0.7	0.46		0.47			0.5	0.29	0.22
14. Diaphragmatic hernia			0.23		0.20	0.55	0.55					0.6	0.21	0.56		0.32	0.7		0.44	1	0.30	0.23
15. Omphalocele			0.23	0.27	0.20			0.41	0.41	0.84	0.6	0.3		0.42	0.23		0.7	0.24		0.5	0.25	0.25
16. Gastroschisis	0.46	0.39		0.27	1.03	1.11	0.74	0.82	0.82		0.3	1.2	0.43	1.54		0.32	0.7	0.24		0.5	0.60	0.23
17. Urinary tract obstruction	0.93			0.27	0.61							0.3	0.21	0.42			0.23	0.73			0.22	0.77
18. Hypospadia	1.39			0.55	0.82		0.55	0.82	0.82		0.6	0.6	0.65	0.56			1.41	1.47	0.44	0.5	0.57	1.45
19. Indeterminate sex	0.46		0.23				0.18					0.3	0.43	0.28			0.23	0.49	0.89		0.20	0.06

* Microtia not included

palate. These have prevalence of 12.28, 4.45, 2.68 per 1,000 live births, respectively, which are higher than EUROCAT registry (6.64, 3.61, 1.33 per 1,000 births)[15].

The difference between the present study and EUROCAT might be due to the nature of the participating hospitals in the present study, secondary and tertiary care hospitals, which are referral centers. Performing a community based study may help reduce this bias. Furthermore, the present study includes only live births up to one year of age and excludes still birth and termination of pregnancy for fetal anomaly (TOPFA). Termination of pregnancy is illegal in Thailand, except in cases that will do harm to the mother, and still births are not routinely reported. These are factors that also influence the prevalence of birth defects.

In the present study the prevalence of limb anomalies was found to be significantly higher in Pahonpol Payuha Sena hospital in Kanchanaburi Province (15.35/1,000 live births). Further studies are needed to be performed to establish the criteria for the diagnosis of limb anomalies.

Orofacial clefts are usually obviously visible after birth. This should make the prevalence of cleft lip more accurate than cleft palate, which might be missed due to lack of thorough examination. The prevalence of this defect is high in Pahonpol Payuha Sena hospital and Yala hospital. Further studies are required to determine the risk factors affecting orofacial cleft in this area to prevent and reduce this birth defect. Down syndrome was shown to correlate with advance maternal age, with a prevalence of 1.9/1,000 live births which is similar to EUROCAT study (1.82). This condition can be detected by prenatal diagnosis. Prenatal screening for Down syndrome is neither obligatory nor widely available in rural areas, and patients are responsible for the costs. Neural tube defects can be categorized to anencephaly, encephalocele and spina bifida. Our data only shows live births; therefore, anencephaly was not included in the birth defects database. The prevalence of encephalocele and spina bifida is 0.5/1,000 live births which is similar to EUROCAT (0.52 per 1,000 births) and International Clearinghouse for Birth Defects Surveillance and Research (average 0.62, range 0.25-2.30, per 1,000 births) registries[15,16]. Folic acid fortification food programs are not available in Thailand, which could have prevented neural tube defects.

Ankyloglossia was the most common minor anomaly birth defect in this study; with the prevalence of 28.37/1,000 live births. The prevalence of this anomaly is very high in Phetchabun Hospital and Pahonpol Payuha Sena hospital, but there were no other cases reported from the other hospitals. The high prevalence rate could be unsuccessful breastfeeding, which has been shown to lead to ankyloglossia. The prevalence of other birth defects was not significantly different between the present study and other registries.

Conclusion

The present study established the Birth Defects Registry by collecting data from four databases in Thailand. Information obtained from the birth defect surveillance is essential in the planning for effective intervention strategies or programs for birth defects. The authors suggest that this program as well as programs on prevention and control of birth defects should be integrated in the existing public health system.

Potential conflict of interest

None.

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การจัดตั้งระบบการจดทะเบียนความพิการแต่กำเนิดในประเทศไทย

สุทธิพงษ์ ปั้งคานนท์, ศิราภรณ์ สวัสดิวร, จุฬาลักษณ์ คุปตานนท์, อุไรวรรณ โชติเกียรติ, วารุณี วานเดอพิทท์

ภูมิหลัง: ความพิการแต่กำเนิดเป็นสาเหตุหลักของการเสียชีวิตในทารกและเด็กอายุต่ำกว่า 5 ปี ในรายที่รอดชีวิตอาจทำให้เกิดความพิการไปตลอดชีวิต ในประเทศไทยความพิการแต่กำเนิดเป็นสาเหตุการเสียชีวิตของทารกแรกเกิดคิดเป็นร้อยละ 21 สถาบันสุขภาพเด็กแห่งชาติมหาราชินี ได้เริ่มจัดทำโครงการจดทะเบียนความพิการแต่กำเนิดในเดือนตุลาคม พ.ศ. 2555 โดยได้รับทุนสนับสนุนจากกรมการแพทย์ กระทรวงสาธารณสุข

วัตถุประสงค์: เพื่อจัดตั้งระบบการจดทะเบียนความพิการแต่กำเนิดเนื่องจากยังไม่มีระบบการจดทะเบียนความพิการแต่กำเนิดในประเทศไทย

วัสดุและวิธีการ: ข้อมูลความพิการแต่กำเนิดได้มาจาก 4 แหล่ง คือ ข้อมูลความพิการแต่กำเนิดจากการออกหนังสือรับรองการเกิด ข้อมูลความพิการแต่กำเนิดจากฐานข้อมูลของสำนักงานหลักประกันสุขภาพแห่งชาติซึ่งเชื่อมโยงกับระบบการจ่ายค่าตอบแทนจากโรงพยาบาลต่างๆ ทั่วประเทศ ข้อมูลความพิการที่ได้จากการลงทะเบียนความพิการเมื่อมีการตรวจพบในภายหลัง และข้อมูลความพิการจากฐานข้อมูล ของโรงพยาบาลที่เข้าร่วมโครงการ โดยข้อมูลเหล่านี้ใช้เลขประจำตัวประชาชน 13 หลักและรหัสการวินิจฉัยโรคระบบ ICD-10 เป็นตัวเชื่อมโยง โดยได้ทำการจดทะเบียนความพิการแต่กำเนิดจำนวน 19 โรค เป็นการศึกษาข้อมูลเฉพาะภายในโรงพยาบาล การเก็บข้อมูลเป็นแบบประสมประสาน เก็บข้อมูลเฉพาะเด็กแรกคลอดมีชีพจนกระทั่งอายุ 1 ปี

ผลการศึกษา: ได้ทำการศึกษาข้อมูลใน 20 โรงพยาบาลนำร่องในพื้นที่ 16 จังหวัด มีจำนวนเด็กแรกคลอดทั้งหมด 67,813 ราย พบเด็กที่มีความพิการแต่กำเนิด 3,696 ราย มีค่าความชุกของความพิการชนิดหลักเท่ากับ 26.12 ต่อทารกแรกคลอดมีชีพ 1,000 ราย ความผิดปกติที่พบบ่อย 5 อันดับแรกได้แก่ โรคหัวใจพิการแต่กำเนิด ภาวะแขนขาพิการ ปากแหว่ง เพดานโหว่ กลุ่มอาการดาวน์และภาวะน้ำคั่งในสมองแต่กำเนิดตามลำดับ

สรุป: ข้อมูลที่ได้จากการจดทะเบียนความพิการแต่กำเนิดจำเป็นสำหรับการวางแผนป้องกันโรคอย่างมีประสิทธิภาพ ข้อเสนอแนะจากการศึกษาครั้งนี้คือควรผนวกระบบการจดทะเบียนความพิการแต่กำเนิดและการวางแผนป้องกันความพิการ เข้าเป็นส่วนหนึ่งของระบบสุขภาพเพื่อให้เกิดความยั่งยืนของโครงการ