Birth defects surveillance in China

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Background: Birth defects are a global public health problem because of their large contribution to infant mortalities and disabilities. It is estimated that 4%-6% of Chinese newborns are affected by birth defects every year. Surveillance is a basic approach to understanding the occurrence and associated factors of birth defects. The Ministry of Health of China initiated a national hospital-based birth defects monitoring system 20 years ago. Nearly every province in this country has established its own surveillance system in the past. The authors reviewed the result of the monitoring system at different administrative levels in China.

Data sources: Available publications on the surveillance of birth defects and data from national and provincial birth defects surveillance systems were reviewed to evaluate the effectiveness of the surveillance systems.

Results: According to the 2009 data, the national hospital-based birth defects surveillance system monitored over 1.3 million births, which accounted for more than 8% of births in China. In addition, 30 provincial hospital-based surveillance programs covered a birth population of more than 3.6 million (22% of births in China). Great achievements have been made in terms of case ascertainment, data quality control, and online reporting. But the surveillance systems in China still have some limitations. A short ascertainment period may miss some internal anomalies, inherited metabolic diseases, and malformed fetus aborted before the 28th gestational week. Discrepancies in antenatal or postnatal diagnosis of birth defects between surveillance institutes may affect the detection rate and introduce biases. Absence of baseline data and lack of integrated database systems limit the application of surveillance data to etiological studies and affect the process of decision-making.

Conclusions: The surveillance system for birth defects is prerequisite to propose, conduct and assess any interventions for the disease. To meet the need of study and prevention of birth defects, measures should be taken to improve the national and provincial birth defects surveillance systems in China.

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Introduction

Birth defects are the main causes of fetal death, early miscarriage, perinatal death, infant death, and child disabilities and have been a global public health issue. According to a report of the March of Dimes Foundation,[1] there are about 7.9 million infants affected by birth defects, which account for 6% of live births worldwide every year. Among these cases, 3.3 million cannot live to the age of 5 and 3.2 million survive with lifelong disabilities.

The prevalence of overall birth defects in China, especially in rural areas and western areas, is higher than the world average. The estimated prevalence in China is around 4% to 6%.[1,2] Nearly a quarter of perinatal deaths are associated with birth defects either directly or indirectly.[3] In developed countries, birth defects are the primary causes of neonate and infant death[4-6] and this tendency is growing in China, particularly in coastal areas.[3,7] The subsequent problems such as death, disabilities and poverty further impair the quality of life. Surveillance plays a crucial role in identifying the prevalence, time trends and risk factors of birth defects.[8-10] It provides the basis to propose, conduct and assess preventive measures.

Most of the birth defects surveillance systems began after the Thalidomide tragedy.[11-15] From 1958 to 1959, more than 10 000 children in 46 countries including the Great Britain, Germany, Sweden, the United States of America, Australia, and Brazil were born with multiple anomalies, most of which were limb

reductions (phocomelia) as a consequence of mothers' thalidomide use during pregnancy. In 1964, several countries including the Great Britain, Israel and Finland started birth defects surveillance. Regional, national, or international birth defects surveillance systems were set up in many countries and districts during the years followed.

Congenital anomalies surveillance systems in China started in the mid 1980s.[16-19] After 20-year effort, national, provincial and regional surveillance systems in China have been established. Currently, there are three types of birth defects surveillance systems in China that are financed by the central or provincial government in China: national hospital-based, national population-based and provincial hospital-based systems. In addition, a regional population-based system was established and maintained by Beijing University in collaboration with the Centers for Disease Control and Prevention (CDC) of the United States of America.[20-23] This regional population-based system is a member of the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR).[9,21] This article reviews the history, progress and perspectives of the birth defects surveillance systems in China, particularly focusing on the national and provincial systems.

History

There are few publications on birth defects in China before 1980. Only some cytogenetic research and case reports on inherited diseases and congenital malformations can be found. In 1981, the first investigation on birth defects began in Chengdu, Sichuan Province by Dr. Xiao Kun-Ze and her team. The team launched birth defects surveillance involving 7 hospitals in Chengdu in 1982. In 1985, the birth defects surveillance system of Sichuan Province which involved 100 hospitals was established.[24-26] It became a member of the ICBDSR in 1987. In 1983, Dr. Lian Zhi-Hao initiated several national hospital-based birth defects surveillance systems in selected areas in Beijing and provinces of Gansu, Anhui, Liaoning and Jiangxi.[16]

Because the surveillance programs in different areas vary by purpose, scope, methodology and disease classification standards, it is difficult to integrate and analyze the data and evaluate the prevalence of birth defects at the national level. The first nationwide birth defects investigation can be traced back to October 1986 to September 1987, when the Ministry of Health of China (MOH) launched the program called Perinatal Birth Defects Surveillance and Etiology of High-Risk and High-Incidence Birth Defects. This program was led by the National Center for Birth Defects Monitoring of China (NCBDMC) in the former West China University of Medical Sciences.[17,18] This program covered over 1.2 million perinatal births in 945 hospitals across 29 provinces, cities or municipalities, identified malformations with high prevalence and their geographic distributions in China and published the *Atlas of Birth Defects in China*.[27] In 1988, the MOH established the Chinese Birth Defects Monitoring Network (CBDMN) in order to identify long-term trends and geographic distributions of birth defects and provide evidence for etiological study and prevention and treatment of birth defects. The routine tasks of the network were conducted by the NCBDMC.[14] The CBDMN became a member of the ICBDSR in replacement of the surveillance program of Sichuan Province, and started to report to the ICBDSR on birth defects monitoring data of 20 provinces in China.[9]

In 1994, the *Law of the People's Republic of China on Maternal and Infant Health Care* was issued.[28] The 23rd article of the Law states: "Medical and health institutions and midwives engaged in home delivery shall, as prescribed by the administrative department of public health under the State Council, issue uniformly prepared medical certificates for childbirths, and report to the administrative department of public health if a lying-in woman or an infant dies or a defective baby is born". The 39th article of the *Implementation Measures for the Law of the PRC on Maternal and Infant Health Care* issued in 2001 states: "The state shall build policies for surveillance and report on maternal or infant death and neonatal birth defects".[29] The main purpose of national-level birth defects surveillance is to acquire detailed information of birth defects in China and their long-term trends in order to serve etiological research and health policy-making.[14]

In 1996, the MOH combined the three surveillance systems for birth defects, maternal mortality, and child death under 5 years of age by integrating surveillance areas (cities and counties) and covered populations.[14] The National Office for Maternal and Child Health Surveillance (NOMCHS) was set up in 1998 to prove guidance for surveillance. In 2003, the NOMCHS launched a pilot population-based surveillance program in Tianjin, Beining County of Liaoning Province, Jian'ou City of Fujian Province, Gongyi City of Henan Province and Luotian County of Hubei Province to test the feasibility of establishing national population-based surveillance. In 2006, more than 300 hospitals were added to the CBDMN by MOH and thus, the sample size was increased dramatically. Meanwhile, population-based surveillance systems had been established in 64 districts and counties. The traditional manual, paper-based data reporting method was replaced by a new electronic, web-based reporting system developed by the NOMCHS in 2006.[30] In 2007,

the data began to be added into the information system of the State Statistical Bureau of China.

From the late 1980s to the early 1990s, hospital-based provincial birth defects surveillance systems had been established in many provinces nationwide (Table 1). Thirty provincial systems have been built by 2004. Several population-based surveillances were initiated in Beijing, Liaoning Province and other provinces after the national population-based surveillance was launched in 2006.

Currently, the Department of Maternal and Child Health Care and Community Health of MOH is authorized to lead the national-level birth defects surveillance programs in China. Local health bureaus oversee the surveillance activities. The National Office for Maternal and Children Health Surveillance is in charge of implementation of surveillance programs

including plan revision, staff training, quality control, data processing and analysis, information dissemination and technical support.[14,30] Maternal and child healthcare institutes of all levels are involved in the technical guidance and management for local surveillance implementations.

The national hospital-based system
Subjects and coverage
The CBDMN has developed hospital-based surveillance systems nationwide over the past 20 years. The surveillance areas, population (annual births) covered, and the number of hospitals involved increased significantly from 1988 to 2009 (Table 2). The birth population includes fetus or neonates with 28 gestation weeks or more who are born in hospitals within the surveillance system including live births, stillbirths and legal pregnancy termination. Any major birth defects, especially, any of the 23 types of congenital structural malformations,[14,30-33] identified within 7 days after birth are included. Presently, the CBDMN monitors approximately 1.38 million births annually (Table 2), which account for 8.51% of the annual live births in China.[34]

Data collection
CBDMN procedures in different periods have been described previously.[14,30-33] From the start, a three-level (hospital or county, province, and nation) network and corresponding working groups were established to conduct routine data collection, reporting and data quality management. In 2006, a multilevel surveillance network including government departments and health care institutes has been established since the health bureaus and women and children hospitals at municipal level involved in the routine surveillance work (Fig.).

Passive case ascertainment methods are adopted by the CBDMN. In network hospitals, health professionals examine every neonate immediately after birth in order to screen for birth defects. Further diagnosis

Table 1. The number of member hospitals and births of provincial birth defects surveillance systems in China

Provincial systems	Year established	Hospitals in 2006	Births in 2006	Births in 2009
Beijing*	1997	175	63 835	89 701
Tianjin*	2001	23	36 043	51 896
Hebei	1990	38	69 437	137 423
Shanxi	1991	33	32 617	57 408
Inner Mongolia†	1999	68	49 754	64 393
Liaoning	1996	51	68 256	126 234
Jilin	1998	215	155 406	182 060
Heilongjiang	2001	58	52 955	59 104
Shanghai*	1991	89	145 604	185 670
Jiangsu	2000	2241	685 919	870 227
Zhejiang	2001	91	155 585	194 712
Anhui	1998	122	112 972	153 304
Fujian	1987	34	52 731	85 775
Jiangxi	1986	21	33 560	67 615
Shandong	1987	27	53 238	96 063
Henan	1995	75	131 322	195 601
Hubei	2001	52	54 891	79 021
Hunan	1996	41	41 559	86 929
Guangdong	1996	58	124 272	182 971
Guangxi†	1996	30	42 969	86 425
Hainan	1996	41	33 774	56 474
Sichuan	2001	84	58 590	97 067
Guizhou	1996	30	26 995	75 199
Yunnan	1996	42	32 911	48 785
Chongqing*	1999	88	67 347	97 389
Shaanxi	1996	25	21 228	48 232
Gansu	1997	31	21 349	38 930
Qinghai	1999	21	11 537	19 985
Ningxia†	1996	35	35 102	45 749
Xinjiang†	2004	53	33 038	48 544
Total	-	3992	2 504 796	3 628 886

Data were abstracted from provincial hospital-based birth defects surveillance systems. *: municipality directly under China's Central Government; †: autonomous region.

Table 2. The number of monitoring sites, member hospitals and annual births of the Chinese Birth Defects Monitoring Network in different periods

Periods	Cities/counties	Hospitals	Annual births (thousand)
1988-1993*	182-287	319-590	288-804
1996-2005†	132	460-480	420-620
2006-2009	351	783	642-1377

*: The data of 1994 and 1995 were not included due to poor quality; †: The number of hospitals changed because some of them were replaced by other hospitals due to the reorganization of their medical service.
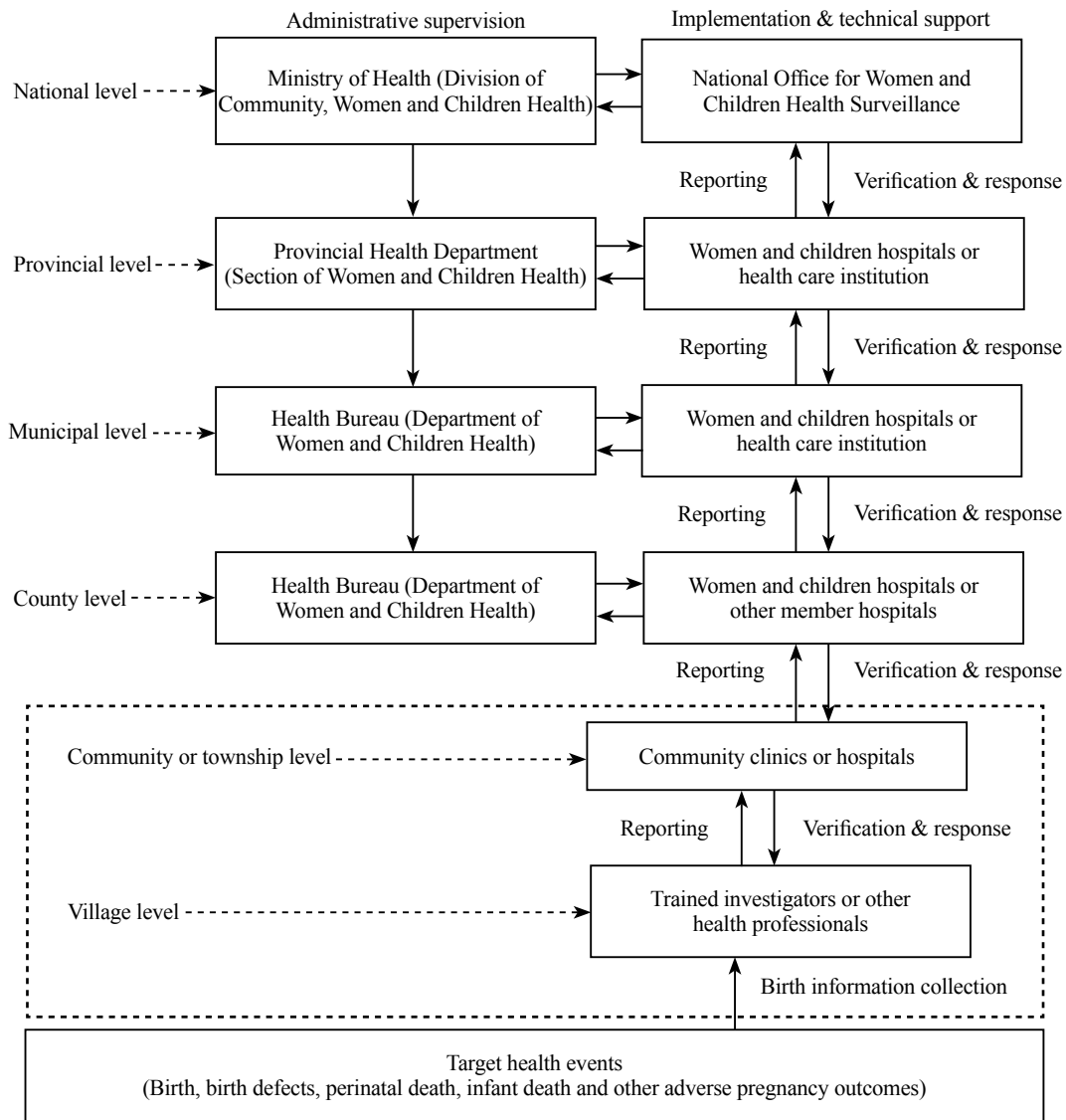
Fig. The framework of the national birth defects surveillance system.

and verification must be completed within 7 days after birth. For those affected by birth defects, an in-person interview with the mother and medical records review were conducted to gather information on routine obstetric factors, exposure to harmful factors during the first trimester of pregnancy, and clinical features of the affected children. The information is collected using a standard Birth Defects Register Form. The data about deliveries, perinatal deaths and other information including the number of perinatals, the age of maternal women, residency (urban and rural) and gender of neonates are collected using the Seasonal Report Form. The forms are checked by senior professionals in the hospital who are responsible for the quality of the data. Any forms with errors should be returned for verification. The county-level

staff submits case reports using the web-based data reporting system implemented in 2006. The collected data are submitted quarterly to the upper level of the system. Data quality checks should be conducted at every level of the system. A national-level workgroup comprises clinicians, statisticians, epidemiologists, and information technicians responsible for the final confirmation of the diagnosis, data checking, encoding and reporting. All surveillance work at each level should be completed within the timeline described in the program manual.

Data quality management
To keep data in high-quality, a set of measures or indicators have been used for quality control. The core three-level (hospital/county, provincial/municipal,

and national) quality control systems have been developed. The NCBDMC has developed a series of standard operating procedures for data collection, data abstraction, data evaluation, disease coding, etc. Surveillance staff at each level implement diagnosis verification, data checking and medical records review according to the standards established by the program. By comparing with related data from other systems like Birth Certification, Perinatal Death Registry, etc., the information on reported cases or births are checked for accuracy and completeness. In addition, the surveillance staff conduct annual surveys to identify and correct errors and inaccuracies in the collected data for annual data analysis. At the hospital/county level, the survey must cover all data reported in the previous year. At the provincial and national level, cluster sampling surveys should cover one third and 10% of member hospitals, respectively. It is required that the under-reporting rate of live births or malformations should be no more than 1%, errors or missings on the report form no more than 1%. At each level, a panel of senior health professionals is committing to evaluate the completeness, accuracy and timeliness of data. A formal annual report on data quality should be sent to the upper level within a specified timeline.

Statistical analysis and data dissemination

The main indicator to be analyzed is the prevalence of birth defects, which is the number of birth defect cases per 10 000 perinatals. The pregnancy outcomes, socioeconomic, demographic factors, and outcomes of the birth defects are also analyzed. Bimonthly newsletters, annual reports and special analytic reports on prevalence for selected major birth defects are published by MOH.

Prevalence of major birth defects

Data from the CBDMN showed an upward trend in the prevalence of overall birth defects during 1996-2009 (Table 3). Congenital heart diseases, neural tube defects, cleft lip with or without cleft palate, polydactyly and congenital hydrocephalus were the top five birth defects in China. These malformations accounted for more than 50% of overall birth defects (Table 4).

The national population-based system
Subjects and coverage

The national population-based system was established in October 2006. A pilot program had been carried out

Table 3. The prevalence of overall birth defects identified through the Chinese Birth Defects Monitoring Network from 1996 to 2009

Year	Births	Birth defects			
		Cases	Prevalence (1/10 000)	Prevalence in urban areas (1/10 000)	Prevalence in rural areas (1/10 000)
1996	422 486	3704	87.67	80.98	101.74
1997	418 904	3707	88.49	82.44	102.59
1998	429 577	4105	95.56	88.22	112.10
1999	446 583	4524	101.30	94.55	115.78
2000	501 066	5501	109.79	102.46	127.09
2001	482 908	5064	104.86	102.23	109.69
2002	526 132	5849	111.17	109.71	113.84
2003	440 237	5714	129.79	127.43	133.69
2004	614 643	7891	128.38	126.94	130.59
2005	608 936	8462	138.96	139.27	137.53
2006	641 789	9338	145.50	146.67	140.85
2007	775 333	11 470	147.94	148.30	147.19
2008	1 305 697	17 619	134.94	149.60	117.76
2009	1 377 231	20 029	145.43	166.40	123.86

Table 4. The prevalence of top five birth defects identified through the Chinese Birth Defects Monitoring Network during 1996-2009 (1/10 000)

Rank	1996			2000			2005			2006			2009		
	Birth defect	n	Prevalence	Birth defect	n	Prevalence	Birth defect	n	Prevalence	Birth defect	n	Prevalence	Birth defect	n	Prevalence
1	CL/P	611	14.46	CL/P	703	14.03	CHDs	1459	23.96	CHDs	1642	25.58	CHDs	3969	28.82
2	NTDs	574	13.59	PD	624	12.45	PD	893	14.66	PD	1016	15.83	PD	2191	15.91
3	PD	385	9.11	NTDs	599	11.95	CL/P	836	13.73	CL/P	914	14.24	CL/P	1814	13.17
4	CHC	271	6.41	CHDs	573	11.44	NTDs	538	8.84	NTDs	525	8.18	NTDs	892	6.48
5	CHDs	259	6.13	CHC	355	7.08	CHC	458	7.52	CHC	465	7.25	CHC	827	6.00

The number of births for calculating rates are presented in Table 3. CL/P: cleft lip with or without cleft palate; CHDs: congenital heart defects; NTDs: neural tube defects; PD: polydactyly; CHC: congenital hydrocephaly.

to identify critical issues such as birth defects to be included, criteria of stillbirth, most importantly, the population and geographic areas to be covered and other important issues. Sixty-four counties and districts in thirty provinces, municipalities or municipal districts (excluding Tibet) directly under the central government were chosen as the population-based birth defects surveillance areas. All these counties or districts were selected from the monitoring sites of the CBDMN. Fetus and neonates with 28 gestation weeks or more (birth weight no less than 1000 g can be included if gestation weeks cannot be identified) born to women living in the surveillance areas for at least one year (including immigrants from other provinces or districts) were recruited and followed. The time period of identifying birth defects was from 28 gestation weeks to 42 days after birth, during which major birth defects diagnosed for the first time were required to report. Birth defects including external malformations and chromosomal aberrations were coded according to the *International Classification of Diseases* (10th edition).[35]

Data collection

As shown in the Fig., the population-based and hospital-based surveillance systems share the same structure for the above county level programs. Surveillance staffs at the community, township, or village levels were responsible for birth information collection, verification and follow-up. A birth defect registration form was used to collect information about diagnosis and exposure of mothers during pregnancy for newborns with birth defects. For birth and infant follow-up, a separate form was used to collect information on neonates and their health outcomes.

Quality control and other issues

The population-based surveillance systems share the same data quality management methods as those used by the CBDMN. The under-reporting rate of major birth defects should be no more than 1%, the number of unreported births no more than 1%, the completeness of the report forms more than 99%, errors on report forms no more than 1%, and errors resulted from data entry no more than 1‰. The prevalence of birth defects is analyzed and the surveillance data are reported annually.

Provincial hospital-based birth defects surveillance systems

Before 1995, only 6 provincial hospital-based surveillance systems were running (Table 1). In response to the *Law on Maternal and Infant Health Care* and to facilitate birth defect prevention, provincial governments have carried out birth defects surveillance

across the country. A total of 30 provincial systems have been built by 2004. The provincial systems adopt the same methods used by the hospital-based surveillance systems of the CBDMN and include the sites in CBDMN's administrative areas. The 2009 data showed that the provincial hospital-based surveillance systems monitored about 3.63 million births, which accounted for about 22% of all births in China (Table 1).[34]

Other birth defects surveillance systems

In 1991, the former Beijing Medical University and the CDC of the United States launched a collaborative population-based surveillance project for Neural Tube Defects Prevention. This project covered 30 counties in Provinces of Hebei, Shanxi, Jiangsu and Zhejiang.[20-22] The system was based on a local, three-level healthcare network and became a member of the ICBDMS in 1997. Its geographic coverage differed from that of the CBDMN. Currently, it monitors about 150 000 births annually and collects surveillance data of fetuses or neonates who were born with congenital anomalies and had gestational age greater or equal to 20 weeks. The case ascertainment period is from childbirth to 42 days after birth.[9]

Challenges and strategies for Chinese birth defects surveillance

Surveillance models

The two national surveillance systems, hospital-based and population-based, provide important surveillance data for evaluating birth defects in China and factors associated with birth defects. The hospital-based surveillance program monitors neonates born in the network hospitals. This program is easy to implement and can usually obtain high-quality diagnoses. However, the surveillance data collected by hospital-based systems represent only the birth defects information in the selected areas because the factors such as hospital delivery rate, case selection and ascertainment period vary by individual hospitals. Population-based surveillance system covers the entire birth population over a specific area and thus, can obtain more reliable prevalence estimates of birth defects. However, it needs a large amount of resources to operate compared to the hospital-based surveillance system. The main difference between the two surveillance systems is the population coverage, that is, the denominators used for calculating the birth defects prevalence are different.

The hospital-based surveillance model can be adopted by developing countries that have limited resources. With the growth of the economy and

development of healthcare services worldwide, it is becoming a necessity to build population-based birth defects surveillance systems which are supplement to hospital-based surveillance systems. About 70% of ICBDSR members adopted the hospital-based surveillance model in the mid-1990s.[9] By 2010, 90% of the members used the population-based surveillance system. There is a growing trend of changing from the hospital-based to population-based model for birth defects surveillance. Population-based surveillance in China, which is only in its beginning stages, covers only one sixth of the counties that hospital-based surveillance does, and it monitors 260 000 births annually. Furthermore, the short ascertainment period (0-42 days after birth) makes it difficult to identify and ascertain the cases of some congenital malformations including anomalies of internal organs and congenital inherited metabolic diseases that develop symptoms several months or longer after birth.

Diagnosis and case ascertainment

Case ascertainment is the process of finding and identifying possible birth defects, collecting relevant information and verifying diagnosis for including or excluding in the surveillance system. There are two types of case ascertainment methods: active and passive. For the active method, information of children with birth defects and their mothers are collected by reviewing the clinical records from member institutes (general hospitals, obstetric hospitals, pediatric hospitals, and centers for inherited diseases). The diagnoses are reconfirmed by doctors who have gone through systematic training. Active case ascertainment helps to acquire relatively accurate and complete information. For the passive method, surveillance systems rely on case reports from hospitals and physicians or search and identify cases using available administrative databases without confirming the diagnoses. The data quality can be affected by factors such as case definition, selection criteria and diagnosis. Although both hospital-based and population-based surveillance systems collect birth defects information with standardized report forms and take strict quality control measures throughout all levels, case detection rate can be greatly affected by variations in diagnoses obtained by the passive case ascertainment method.

Generally speaking, there are no significant variations in diagnosis of external malformations among surveillance programs. However, diagnosis of malformations of internal organs may differ greatly because of variations in professional skills of physicians/clinicians at different institutes. Surveillance data showed that the autopsy rate among fetal and perinatal deaths and the rate of chromosomal testing for Down syndrome were low. In 2009, the CBDMN identified 4731 fetal deaths with birth defects, and only 1.14% (54) of them were examined by autopsy and 41.4% (96/232) of Down syndrome cases were confirmed by karyotype analysis. Usually, the reported cases had not enough diagnostic information for identifying subtypes of complicated malformations such as congenital heart diseases and limb reductions. Therefore, the diagnoses of the reported cases were difficult to confirm by the NOMCHC because of limited information. In order to improve the completeness of case reporting and the accuracy of the diagnosis of congenital malformations, active case ascertainment is recommended for both hospital-based and population-based surveillance. Providing institutes and the surveillance staff with more training on birth defect diagnosis and case ascertainment methodology would help to improve the quality of surveillance data.

Web-based birth defects surveillance systems

Birth defects surveillance in developed countries beginning in the 1960s has been growing from stand alone surveillance systems in individual countries to integrated systems that promote data sharing among surveillance programs because of advances of technology in computer network, database, communication and statistical analysis. The data collection method has been shifted from manual, paper-based to electronic, web-based reporting that is gradually changing to real-time reporting. Technologies such as data mining are often used in data analysis. Electronic, web-based surveillance system with functions of online data collection, processing and analysis has been widely used. For a long time, the birth defects surveillance systems in China have been using manual, paper-based data collection and reporting methods, which made data utilization inefficient. In 2006, the implementation of the Online Data Reporting System for Maternal and Child Health Surveillance in China developed by the NCBDMC made surveillance data more accurate and timely. Over the past several years, Beijing, Tianjin, Guangdong, Hubei and Jiangsu built their own provincial/regional electronic birth defects surveillance systems. Improving the electronic surveillance system is a long process that needs continuous efforts to update system's hardware and software, increase system security level, enhance abilities in data management and statistical analysis, and promote data sharing among the national and the provincial surveillance systems.

Geographic information system (GIS) has been used for data management and analysis to explore geographic characteristics of birth defects. The World Health Organization encourages the application of GIS

in epidemiological research and surveillance in order to present visually the distribution of the diseases in space and time. The application of knowledge discovery (data mining) technology would make the best use of the surveillance data and help to extract critical information from large databases, monitor trends and irregular patterns of diseases of interest, and provide evidence and supports for decision-making. This technology provides a bright future for computer-assisted diagnosis, prediction and trend analysis. Recently, the NCBDMC has utilized GIS to identify spatial distribution patterns of selected birth defects in China.[36] The application of information technologies and comprehensive analytical methods would improve the accuracy and timeliness of surveillance data.

Utilization of surveillance data

Birth defects surveillance systems are built for improving the health of the population. There are two main purposes: finding new teratogens that cause birth defects and providing the baseline data for birth defects research and prevention. An advanced surveillance system enables program staff to collect, analyze and disseminate information and provide quality data for birth defects research and prevention. Surveillance data can be used to monitor the distribution, secular trend of birth defects and identify major issues affecting the health status of the birth population. The surveillance data can also be used for epidemiological research, risk assessment and evaluation of intervention measures. The CBDMN and current population-based systems in China do not collect the exposure data for newborns except for cases of birth defects. Thus, lack of exposure data of the population limits the utilization of the surveillance data to some etiological studies. The surveillance data are necessary for public health policy-makers to gain knowledge of birth defect trends and associated factors in a population.

Summary

Surveillance plays an important role in the research and prevention of birth defects. By 2008, there were 48 members of the ICBDSR that have launched long-term surveillance programs and started international collaborations. Surveillance can provide baseline data on birth defects, which are essential for initiating and developing prevention services at local, provincial and national levels. Information on geographic and temporal changes in frequencies of specific birth defects is needed to assess the effectiveness of intervention programs. Although the surveillance systems cannot catch all birth defects in a population,

they can provide reliable prevalence estimates for some specific congenital malformations. China has set high standards for birth defects surveillance, research and prevention. The national mid-term and long-term plans on population and health for 2010-2020 have included etiologic research, prevention and treatment of birth defects. For China's birth defects surveillances, it is of paramount importance to improve the systems themselves as well as the utilization of surveillance data, especially in the field of etiologic research and policy-making in human healthcare.

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