REVIEW ARTICLE

Birth Defects in India: Magnitude, Public Health Impact and Prevention

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Abstract:

Birth defects refer to a group of diverse congenital conditions, which are responsible for stillbirths, neonatal deaths, chronic medical conditions and disability. Due to their low prevalence and high mortality, birth defects are not considered to be a significant health problem in India. Various data however identify that India may harbour a significant burden of birth defects, and that these conditions may be responsible for a considerable proportion of neonatal deaths in India. Although it is widely assumed that survival of patients with birth defects is low, data suggests that in 2002, there were nearly six million Indians living with impairments arising at birth. These data urge the need for implementation of a national birth defects programme in India, with a strong component of prevention. The need for significant research investments to understand the epidemiology and public health impact of birth defects in India is identified. Translation research, transcending the disciplines of medicine, public health and genetics is required to develop a low cost birth defects service as a component of the existing maternal and child health programme.

Keywords: Birth defects, India, Prevalence, Programme

Introduction:

Although birth defects are difficult to classify [1], clinical and etiologic classifications identify three broad groups of conditions, *viz*., congenital anomalies, conditions arising due to chromosomal abnormalities and genetic disorders [2]. Birth defects arise either due to a wholly genetic etiology, or due to gene-environmental interactions, where the fetal genetic susceptibility interacts with the maternal physiological environment to result in the abnormality. The etiology of nearly 50% of birth defects is unknown. Birth defects are significant contributors to stillbirths and early neonatal mortality, and are responsible for disability present since birth. Persons With Birth Defects (PWBD) survive with cognitive, locomotor, hearing, speech, visual or multiple impairments. Patients with genetic disorders survive with life-long medical conditions. With the exception of neonatal deaths, none of the other three categories of health problems, (that is stillbirths, disability or genetic disorders) are public health priorities in developing countries. As such, there are few public health or social programmes to address the needs of PWBD. Lack of access to affordable care is a norm, resulting in premature mortality and complications arising from suboptimal treatment. Lack of psychosocial support services for parents and patients, supportive services for children with disabilities, and lack of education on home management of patients affects the quality of life of patients, parents and family members.

Birth defects are considered to be insignificant health problems in India and other developing countries as they are rare, and are a proportionately lower contributor to child morbidity and mortality (Fig.1). Due to their severity, patient survival is low. The genetic risk component ensures that several types of birth defects are restricted to families, and ethnic groups. These characteristics imply that birth defects are unlikely to achieve significant population prevalence to become a public health challenge. Some additional realities contribute to the lower prioritization of these conditions by developing country health services. Providing care for children born with birth defects is resource intensive, and patient management requires a platform of clinical

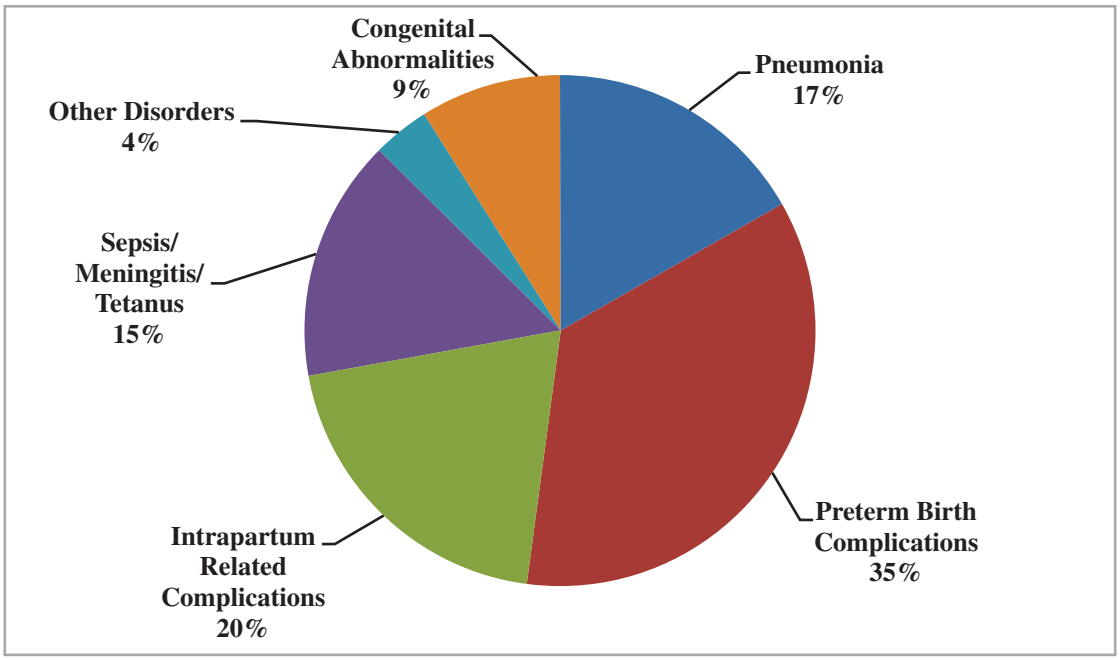

Fig.1: Causes of Neonatal Mortality in India

services which may be out of the scope of the medical services of developing countries. Children born with impairments require a range of supportive services such as speech therapy, special care for children with cognitive impairments, or special schools for visually impaired children. These latter services fall into the realm of disability support services, which are underdeveloped in low income countries. Furthermore, lack of linkages between health and social service departments results in the absence of a referral route for long-term care of children born with impairments. Another reason for a low priority of birth defects arises from a perception that birth defects services require high cost, and technology-intensive genetic services. The availability of low cost, primary prevention strategies for birth defects is significantly underplayed. Finally, there is a low awareness about birth defects within the public health system, and capacity building programmes to increase awareness about common birth defects is lacking.

In countries with low annual numbers of births, birth defects represent a minor health problem. In contrast, in countries with high numbers of births, such as India, Nigeria, China, Bangladesh and Pakistan, birth defects may be of significant magnitude, affecting several health indicators. This review focuses on birth defects in India, highlighting the various sources of data that point to India having possibly, the highest global burden of morbidity and mortality due to birth defects.

Magnitude and Impact on Neonatal Mortality:

Fig. 1 shows that birth defects, specifically congenital anomalies, are the fifth largest cause of neonatal mortality in India. There is no nationwide surveillance for birth defects in India, and the true magnitude of these defects in the country remains unknown. Estimates on the magnitude of these conditions can be made from a number of sources. Birth defects affect 2 to 3 % of births [4, 5] and as India has reported 27 million births in 2011, around 540000 to 810000 pregnancies may have been affected with major or minor congenital anomalies. That this estimate may reflect the highest global burden of birth defects is reflected in some other sources of global data [3].

Table 1: Neonatal Mortality (NM) due to all Causes and due to Congenital Anomalies (CA) in Various Regions of the World [a]

Countries	Estimated NM (2010) all causes	Estimated number of deaths due to CA (2010)	Proportion of NM due to CA to mortality due to all causes (Rank)	Proportion of NM due to CA by region to total global burden of NM due to CA (Rank)	Global burden of mortality due to congenital anomalies
Africa	1064000	60000	5.6 (6)	22 (2)	1.9
America	137000	27000	19.7 (2)	10 (5)	0.87
Eastern Mediterranean	444000	35000	7.88 (5)	13 (3)	1.13
Europe	78000	16000	20.5 (1)	6 (6)	0.52
Southeast Asia	1096000	99000	9.03 (4)	37 (1)	3.22
Western Pacific	252000	33000	13.09 (3)	12 (4)	1.07
World	3072000	270000			

[a] *Data from [3]*

Table 1 presents data on neonatal mortality due to all causes, and due to congenital anomalies. The data shows that in the developed regions of the world, congenital anomalies contributed to a significant proportion of neonatal deaths (Europe 20.5 %, Americas 19.7 %, Western Pacific 13 %). The proportionate cause of neonatal mortality due to congenital anomalies was relatively lower in developing regions (Southeast Asia 9%, Eastern Mediterranean 7.8 %, African 5.6 %). However, in terms of absolute numbers of deaths due to congenital anomalies, the developing countries of the Southeast Asia and Africa harboured 59 % of the global burden of neonatal deaths due to congenital anomalies. Of these, 37 %, that is 99 000 neonatal deaths were contributed by countries of the Southeast Asian region. Amongst these, 76662, accounting for 76 % of all neonatal deaths due to congenital anomalies occurring in the Southeast Asian countries was contributed by India. India accounted for 28 % of the global neonatal mortality burden due to congenital anomalies.

Table 2 and Fig. 2 illustrate the birth defects paradox in India. With the very large number of births occurring in the country each year, the number of estimated neonatal deaths due to anomalies is significantly less than mortality due to common causes, such as pneumonia, birth asphyxia, sepsis or preterm births. However, in terms of absolute numbers, the number of birth defects is extremely large and should be a matter of public health concern. This observation is supported by another source of data. The International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) publishes data from birth defects registries across the world, permitting comparison of the number of pregnancies affected with congenital anomalies [5]. Indian data is reported by the Birth Defects Registry of India (BDRI) [6], a local registry maintained by the Fetal Care Research Foundation, Chennai, which records data from several hospitals from across the country. That congenital anomalies are responsible for a larger burden of reproductive wastage as well as live births in India as compared to developed nations can be identified from the ICBDSR data [5].

Table 2: Causes of Neonatal Deaths in Southeast Asian Region Countries [a]

Countries	Pneumonias, sepsis, asphyxia	Preterm birth complications	Congenital abnormalities
Bangladesh	35917	36998	6299
Bhutan	157	158	34
DR Korea	1931	2715	978
India	445726	303689	76662
Indonesia	26117	32342	9539
Maldives	17	13	14
Myanmar	10634	12286	1630
Nepal	7502	10416	1256
Sri Lanka	1963	637	1063
Thailand	1838	2478	1579
Timor-Leste	535	362	88

[a] *Data from [3]*

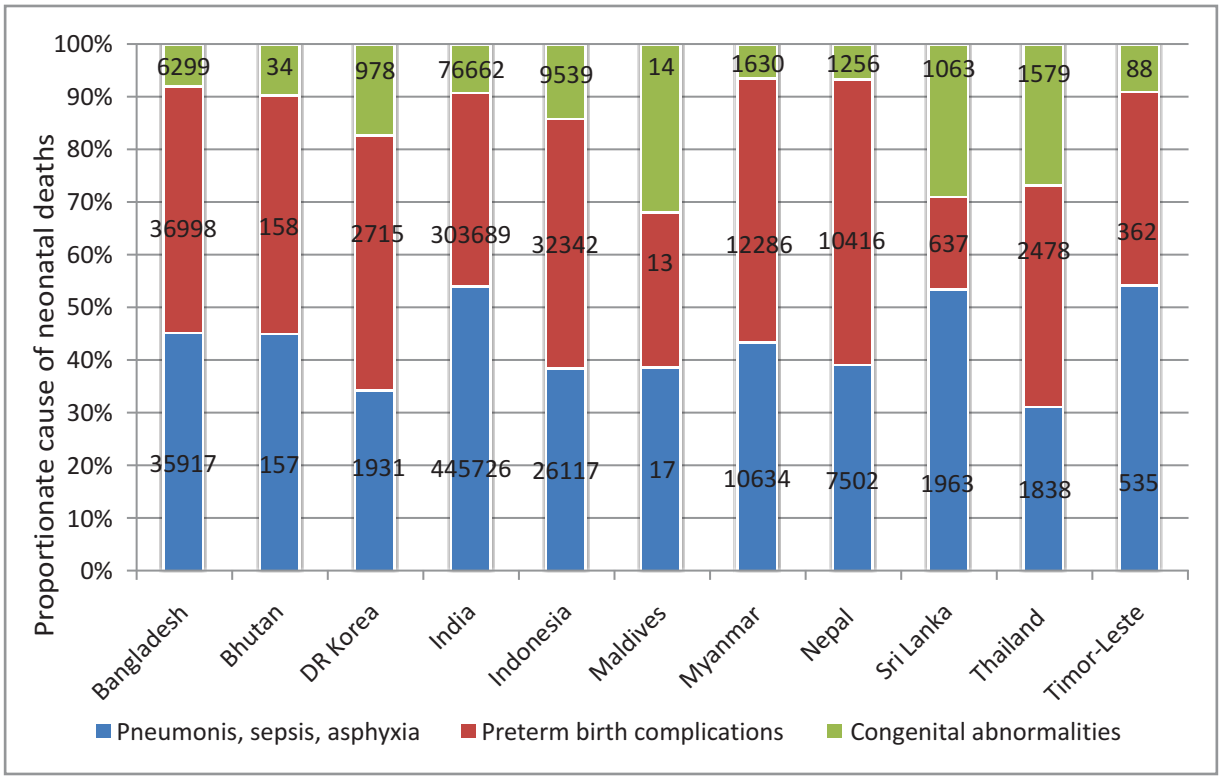

Fig. 2: Neonatal Mortality by Cause in Countries of the Southeast Asian Region

Taking spina bifida as an example, Table 3 shows that out of 170 581 pregnancies reported by the Hungarian, Paris and Utah registries, there were 23 live births (0.01%), no stillbirths, and 32 pregnancy terminations (0.01%) due to spina bifida. In contrast, the Indian registry reported 63 livebirths, 76 stillbirths and 86 pregnancy terminations (0.04% each) out of 205 285 births. The data hints at the reproductive wastage due to anomalies, utilization of health services for termination of pregnancies due to anomalies, and the birth of children who are likely to survive with disability caused by the birth defects. These disparate pieces of evidence urge the need to establish surveillance for birth defects in the country.

This is illustrated in the data from a nation-wide disability survey conducted in by the National Sample Survey Organization in 2002 [7]. This survey reported that 32 % of the 17.43 million disabled individuals, amounting to nearly five and a half million individuals reported disability since birth (Table 4). Some of the defects may have originated due to other causes such as birth trauma. However, the magnitude of birth defects is reflected in the data that over 7.8 million individuals with mental retardation, 1.6 million individuals with speech impairments, over one million with hearing impairment, over 2.75 million with impaired locomotion and over 360 000 with visual impairments were estimated to have been born with these impairments. These data therefore

Table 3: Absolute Number of Birth Defects Reported from Selected Registries from Developed Nations and the Indian Registry [a]

Countries	Total births	Anencephaly	Spina bifida	Encephalocoele
	(LB+SB +ToP)[b]	Number of cases LB/SB/ToP (Rate per 10 000)		
Hungary	90 722 (90 335 + 387 +440)	1 + 0+ 7	13 + 0 + 17	2 + 0 + 7
USA Utah UBDN[c]	52 459 (52 164 +295+32)	2 + 4+ 9	8 + 0 + 4	4 + 0 + 0
France Paris	27 400 (27 044 + 356 +299)	0 + 1 + 11	2 + 0 + 11	2 + 0 + 5
India	205 285 (199 687 +5 598 +494)	14 + 83 + 119	63 + 76 + 86	6 + 9 + 17

[a]Data from reference [5]; the data is for the year 2010, Registries have been selected at random as illustrative examples, [b]LB, SB, ToP indicate livebirths, stillbirths and termination of pregnancy respectively, [c]Utah Birth Defects Network

Population Prevalence:

Due to the significant mortality associated with birth defects, it is erroneously assumed that the population prevalence of these conditions is likely to be low [7]. Some birth defects are not lethal, so that children survive till later ages. As such, the high birth prevalence is likely to be translated into high population prevalence for some conditions, especially with the accrual of patients over time. warn that India possibly has the highest global load of birth defects, which may be contributing to a considerable number of neonatal deaths. Accrual of surviving patients over time is possibly responsible for a high prevalence of patients surviving with the morbidity and disability associated with birth defects, and no subsidized government health care.

Table 4: Estimated Numbers of Individuals Reporting Disability at Birth and Some Illustrative Causes of Congenital Impairment[a]

Disabilities	All Disabled	Disability Arising at Birth	%	Illustrative Causes of Congenital Impairment
Any disability	17 428 100	5 599 300	32	
Impaired locomotion				
Locomotor	10 010 600	2 756 900	28	Folate deficiency causing neural tube defects, developmental deformities such as developmental dysplasia of the hip, congenital limb deformity
Impaired speech				
Speech	2 027 400	1 652 400	82	Genetic syndromes, chromosomal syndromes, rubella infection, maternal alcohol intake
Impaired hearing				
Hearing	2 886 700	1 069 300	37	Genetic syndromes, single gene disorders, aminoglycosides during pregnancy, rubella infection, prematurity, maternal diabetes, toxemia, anoxia
Impaired cognition				
Mental retardation	934 800	785 700	84	Trisomy 21, preterm birth, maternal iodine deficiency, several single gene disorders
Mental illness	1 037 800	237 500	23	
Visual impairment				
Blindness	1 904 000	295 700	16	Congenital cataract, retinopathy of prematurity, congenital syphilis, developmental disorders
Low vision	770 100	67 000	9	

[a] *Numbers reported from[7]*

Genetic Disorders:

The data presented above refer specifically to congenital anomalies that are evident at birth. Genetic disorders are diagnosed later in life and are therefore not captured through pregnancy outcome data. Other than the haemoglobinopathies, genetic disorders are largely ignored by health services of developing countries, as these conditions are severely debilitating and have limited for achieving high population prevalance. That patients with genetic disorders can also achieve significant numbers is reflected in the data on haemophilia, a bleeding disorder, and the only genetic disorder for which there is a nation-wide registry in India [8]. Patient data is collected from 76 centres across the country and the data from this national registry is reported to a global survey conducted by the World Federation of Hemophilia

Table 5: Estimates of Genetic Disorders: Birth Prevalence and Population Prevalence after Five Years Assuming 100 % Survival

Disorders	Incidence per 10000 births	Estimated number of annual births [d]	Estimated number of patients after five years considering 100% survival
Sickle cell disease	2.8[a]	7587	37935
Thalassemia	0.7[a]	1897	9485
Hemophilia	1[b]	2768	13840
Duchene Muscular Dystrophy	3[c]	8129	40645
Total		20381	101905

[a]Incidence rate from [27], [b] Incidence rate from [28], [c] Incidence rate from [29], [d] using 27 million annual births as the denominator

[9]. This global survey permits comparison of data on number of haemophilia patients in different countries. The data shows that India reports the second highest number of patients with haemophilia A (11 586) in the world, ranking next only to the USA which reports 13 276 patients. As only one fourth of Indian patients with haemophilia are diagnosed, India may in reality harbour over 50 000 patients with haemophilia A [8]. The economic implications of providing care for patients is illustrated by the fact that the annual basic cost of treatment for a single patient may be as high as $5000. Table 5 estimates that if children born with four common disorders were to survive for a period of five years in India, the total numbers of affected would accrue to over 100 000 patients. All these data indicate the immediate need to introduce prevention for birth defects, and to establish birth defects surveillance in India, so that the magnitude of patients and their health care needs can be anticipated.

Global Developments in the Field of Birth Defects:

The suffering of patients and families due to lack of subsidized services was first brought to global attention through a report published by the March of Dimes [10]. This report described birth defects as the "hidden toll of dying and disabled children in low-income countries", and identified several low-cost preventive interventions that could reduce birth defects in these countries. Despite the emphasis on low cost interventions, birth defects did not become a global agenda, as developing countries were unconvinced about the magnitude of these conditions, about the feasibility of addressing birth defects in resource constrained settings and their ability to address a new agenda in the background of the Millennium Development Goal targets. The need to address birth defects in developing countries re-emerged as a global agenda with the 63rd World Health Assembly declaration [1], followed by the development of guidelines for prevention and control of birth defects in the Southeast Asian countries by the Southeast Asian Regional Office (SEARO) of the World Health Organization (WHO) [11], and the development of birth defects surveillance guidelines, jointly authored by the WHO, Centers for Disease Control and Prevention (CDC) and the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) [12]. In its 2013 report, the United Nations Children's Fund (UNICEF) drew attention to the issue of childhood disability [13].

Birth Defects Services in India:

Despite these global initiatives, developing countries including India have been slow to initiate a birth defects service. In 2013, India launched a service for screening and referral of children with nine specific types of birth defects (neural tube defects, Down syndrome, orofacial clefts, talipes, developmental dysplasia of the hip, congenital cataract, congenital deafness, congenital heart diseases and retinopathy of prematurity) as a component of the national child health programme (Rashtriya Bal Swasthya Karyakram, RBSK) [13]. Independent of the RBSK, several states have programmes for prevention and control of sickle cell disease [14, 15]. As a result of advocacy by non-governmental organizations (NGOs), free clotting factor concentrate is provided to patients with haemophilia [16]. The National AIDS Control Organization has mandated free transfusion services for patients with thalassemia and haemophilia [17]. All these services represent components of a disconnected and fragmentary birth defects programme, with a focus on providing medical care rather than prevention.

Prevention of Birth Defects:

The data on the magnitude of birth defects in India suggests the need to establish a full-fledged birth defects programme, with components of surveillance, prevention, treatment and management of patients, competency development, ethical and regulatory overview, research and advocacy. One of the major concerns about allocation of health resources for birth defects is that only 50 % of defects can be prevented, and amongst preventable defects, available interventions implemented over a period of time can prevent another 50 % of defects [18]. Several preventive interventions during the pre-conception period and the antenatal period (such as pregnancy education, micronutrient supplementation, screening and management of high-risk pregnancies, ultrasonography during the antenatal period with option of pregnancy termination) can not only prevent congenital anomalies and some chromosomal conditions, but also improve birth outcome [19-24]. Evidence indicates that preconception correction of undernutrition [23] and anemia [24] results in a significant improvement of birth weight. Thus, expansion of the existing maternal health services to include interventions in the preconception period, can not only prevent birth defects, but also be an added incentive to maternal and child health programmes in terms of improved birth outcomes.

Genetic testing followed by pregnancy termination is the other method for prevention and control of genetic disorders and certain types of chromosomal abnormalities. Unlike preconception and antenatal interventions that can be targeted towards all women, genetic testing services will need to be limited to a smaller group of women who may report a family history of a disorder. India has the biotechnological capacity for genetic testing, and private sector services are widely available. Genetic testing has not yet been translated into the public health system, and the process of referral of prospective parents for genetic counselling has not yet been established.

Beyond prevention, nearly all other components of a birth defects programme are already in place, or the expertise is available. The existing maternal and child health information system in India, the Mother Child Tracking System [25], for example, can be used for collection of nationwide data on congenital anomalies occurring at government health facilities. Provision of care is a difficult challenge that confronts developing nations. India's child health programme, the RBSK has established a district level service platform (the District Early Intervention Centre) for the diagnosis and referral of children with birth defects. The NGO sector, made up of parents and patients, are likely to be willing partners with public health services, especially in providing education and psychosocial support. Extensive capacity building

exercises will be needed as health service staff members have limited familiarity with the birth defects.

The Role of Research:

Although a significant amount of information on the genetics of birth defects is available, there are few systematic studies on the epidemiology of birth defects in India. Data is needed on the burden of the prevalent birth defects, their public health impact in terms of numbers of affected pregnancies as well as the burden and trends of genetic disorders and births due to chromosomal anomalies. Studies to measure the prevalence of risk factors for birth defects amongst adolescent girls and women of reproductive age, or amongst specific ethnic groups are needed. Needs assessment of affected families is essential to determine the quality of life of affected patients and families. Studies on the prevalence of morbidity, out of pocket expenditure and psychosocial and other support needs of families are warranted. Health system studies are required to determine the opportunities and challenges for implementation of a birth defects prevention programme. Evidenced models to determine the impact of pre and peri-conception services on pregnancy outcome would identify the utility of such interventions in prevention of birth defects. Contextual education and counseling material, development of referral pathways for genetic counseling, development of ethical and regulatory guidelines, research to develop low cost psychosocial and other support services in the public health system and exploring the role of parent-patient organizations for delivery of services for birth defects are needed.

The Way Forward: The trauma of birth defects in developing countries [26] extends beyond the suffering of patients and families, and affects health care providers, as they are unequipped to offer support and referral for patients and their families. The evidence presented in this review indicates that in the Indian context, neglecting birth defects does not result in reducing the problem. Rather, the numbers of affected accumulate and the patient surge has the potential to overwhelm public health resources. Majority of the components for a birth defects programme are already in place in India, and several NGOs have established models for providing medical services, prevention, surveillance, education and psychosocial support. Trans-disciplinary research is needed to develop models by which available components of a birth defects programme can be brought together to address the suffering of the affected.

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