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Newborn Screening In The Philippines And India: Its Status And Problems Encountered In The Program

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Abstract: This study being a collaborative research dealt with the program on Newborn Screening in the Philippines and India, its status and the glitches encountered in the program. It also aimed to determine the profile of the newborn screening program in both countries. The descriptive-comparative research design was utilized. The data from the Philippines regarding the status of newborn screening were gathered from records of the Provincial Health Office, Ilocos Sur. While the data from the state of Gujarat, India were derived from health providers, through records review and from previous research studies. A comparison on the status of the Newborn Screening in Ilocos Sur, Philippines and in Gujarat, India along legal mandate, cost of testing, specimen used, diseases screened, consent required, funding agencies and the availability of screening centers was done. The disorders screened in both the countries may not be totally the same due to the racial differences. In the Philippines, the screening includes seven metabolic and genetic diseases. In India, the screening services are more than the services the Philippines is offering. The problems encountered in the program in the Philippines and India were also identified.

Keywords: Hemolysis, Hemoglobin, Cyanmethemoglobin.

1. Introduction

Newborn screening (NBS) is a public health strategy that enables early detection and intervention of the identified genetic/metabolic disorders. Early identification and timely treatment can assure the newborn's safety and live to the fullest without threats of the disabilities brought about by genetic diseases. This Newborn Screening (NBS) in the Philippines started in June 1996 and was integrated into the public health delivery system with the enactment of the Newborn Screening Act of 2004 which is Republic Act 9288 (DOH Manual of Operation, 2004).

Potts (2003) as cited by Tadena, stated that the health screening provides the opportunity to assess and detect any problems the infants may have. Health screening actually begins immediately after birth with the first Apgar scoring and physical examination.

Neonatal Screening is one of the most essential preventive community health program of the 21 st century. It is already well established in many of the developed countries, which most of the developing countries are starting to become aware and to implement it. In India, this program is still in its neonatal stage and yet to evolve into childhood. Currently, there is no government funded neonatal screening program for the masses.

Kamath, (2015) explained that India is going through a progressive transitional transformation in their efforts to reduce infant mortality and morbidity due to diseases, and the emergence of inherited metabolic disorders. The World Health Organization (WHO) has recommended to many countries for the implementation of programs geared towards the reduction of infant mortality rate. India having an infant mortality rate of 40 should be introducing newborn screening and genetic services. The Indian Academy of Pediatrics strongly campaigns that NBS to become a public health policy, and assured of its support in terms of the technical and logistic assistance to the Government of India for initiating this program.

The study aimed to determine the status of the Newborn Screening Test in the Province of Ilocos Sur, Philippines and in the State of Gujarat, India for Calendar Year 2015-2017. It tried to compare the status of the Newborn Screening Program in the Philippines and in India along the following: Legal Mandate, Cost of the testing, Test Specimen, Diseases screened, Consent required, Funding Agencies,

and Availability of screening facilities for the procedure. The study also described the profile of the Newborn Screening Program in both countries in terms of the following: population, number of live births, and the number of screened babies for the past 3 years, and compared the problems encountered in the newborn screening program in both countries.

This study may serve as a baseline data on cases of congenital abnormalities detected through Newborn Screening Test in the Philippines, in India and other countries. It is hoped that the results may help health administrators and political leaders to facilitate the decentralization of facilities, technical and professional resources and to make it available for rural people. In the areas of medicine, nursing and other allied disciplines, this investigation will contribute to the pool of knowledge in health education as it provides a local blueprint of the status of congenital abnormalities in the locality.

To the mothers, this would provide them knowledge on what the newborn screening is all about and the benefits derived, therefore giving them the ability to decide whenever a situation comes that they need to decide whether or not to let their child undergo screening test. To the health facilities, this research is seen to contribute in the assessment of cases of congenital abnormalities in their area of responsibility. This would assist the health providers in mapping up projects and programs to help families deal with cases associated with congenital abnormalities. To the medical and nursing students, this study would serve as a reference material in their pursuit for other related researchers and more knowledge and understanding on the newborn screening procedures, which they can apply during their duties when giving health teachings. Further, for the researchers from the Philippines and India, this endeavor is seen as doorstep towards a borderless exposure into health related investigatory ventures which undeniably would help them appreciate more the significance of their chosen field of career for the advancement of the welfare of humanity.

2. Research Methodology

2.1. Research Design

This study employed the descriptive –comparative research design to gather data about the status of the newborn screening in the Philippines as represented by the Province of Ilocos Sur, Philippines, and India as represented by the State of Gujarat. Records review and data from previous researches were also utilized..

2.2. Population and Sample

The Province of Ilocos Sur, Philippines was represented by the government Hospitals namely; Ilocos Sur District Hospital- Sinait, Ilocos Sur District Hospital- Magsingal, Ilocos Sur District Hospital - Sta Lucia, and the Ilocos Sur Provincial Hospital- Gabriela Silang, after getting permission from the Chief of the Provincial Health Office. In India, the data taken were supplied by the Indian medical practitioners and other researchers who conducted research studies on Newborn Screening. Further, the records, journal reports and previous research studies were reviewed and analyzed as sources of data

2.3 Ethical Considerations

The following ethical principles were considered:

Conflict of Interest: The researchers declared that there was no conflict of interest as they are public health providers concerned with the well-being of babies, mothers and the community as a whole. There are no personal gains derived except for the information which they can use for their health education activities. Privacy and Confidentiality: This is not much of a problem considering that the data gathered were of public in nature as they had been published in journals and the Health reports. However, to maintain the privacy of the hospitals, Code numbers were assigned to each hospital. Informed Consent: The informed consent was taken from the Provincial Health Office Administrators after which the permission was granted to utilize the data from the reports submitted by the health workers from the government hospitals three (3) of which are District Hospitals and one which is the Ilocos Sur Provincial Hospital-Gabriela Silang. Benefits: The benefits derived from the study were discussed to the Chief Provincial Health Officer and the other administrators in- charge of the Newborn Screening Program. And with this, pertinent reports from the different health facilities covered by the provincial health office were given for the ready reference of the researchers. This process was also done with the Health Administrators of the locale under study in Gujarat, India. Risks: The study is of minimal or even no risk considering that the data gathered did not violate the

ethical guidelines particularly on confidentiality of data and the privacy to the identity of the mothers and their babies. The data gathered are of public health information on the newborn screening program. Output Dissemination: The results of the study may be disseminated to both the health authorities representing the stakeholders of the Philippines and in India of the need to increase the awareness of mothers on the benefits of the screening program, as well as the health authorities for policy formulation.

2.4 Statistical Treatment of Data.

The statistical tools that were used to analyze the data gathered are the following: Frequency and percentage in determining the total births and number of Screened babies. Comparative analysis was done on the status of the NBS of the two countries. For the past three years.

3. Result and Discussion

The salient points are presented in table and textual forms.

Table 1. Comparative Analysis on the Status of the Newborn Screening Program in the Philippines and India.

Assessment Points	Philippines	India
a. Legal Mandate.	Rep. Act 9288- 2004	No National Policy
b. Cost or Fee	Php 550.00	Rs 2,500 -6,000 Php euiv is php 1,923.00 to 4,615.00
c. Test Specimen	Blood specimen	Blood Specimen
d. Diseases Screened	Congenital Hyperthyriodism (CH), Congenital Adrenal Hyperplasia (CAH) Galactosemia, G6PD, PKU Maple Urine Syrup disease, And Biotinase	Congenital Hyperthyriodism (CH), Congenital Adrenal Hyperplasia (CAH) Galactosemia, G6PD, PKU Maple Urine Syrup disease, Biotinase alcaptonuria *B*-Thalassemia Syndrome, Cystic Fibrosis, Sickle Cell Disease. Dehydrogenase deficiency Tyrosinenia and fatty acid Oxidation defects.
Consent Form Required	Written Consent	Verbal Consent;/ Written Consent
Funding Agencies	Coverage- Phil. Health Insurance Inc.	Not funded by the federal government
Availability of Screening Centers	4 NBS centers and 3000 health facilities	Very few Centers, most are private hospitals

This table shows the status of the Program as pointed out in the assessment points: On Policy and Guidelines of the NBS. In the Philippines, the legal mandate is the Republic Act No. 9288 or the Newborn Screening Act of 2004, the specimen taken is the blood sample, and a Health Insurance covers the Newborn Testing for the members. While in India, there is no policy or Guidelines pertaining to this program, the blood specimen is collected, the diseases screened are more in India than the Philippines, there is no fund assistance from the government, and there are only a few testing centers which are only in several private hospitals.

In 2010, there were four Newborn Screening Centers (NSCs) established in the Philippines to perform the testing all over the country: NSDC- National Institutes of Health in Manila; NSC- Visayas in Iloilo City; NSC- Mindanao in Davao City; and NSC- Central Luzon in Angeles City. The four provide laboratory and follow up services for more than 3000 health facilities (Department of Health Report 2010).

On Profile of the Newborn Screening Program in the Philippines and in India for the past three years in terms of the population, number of births, and year Birth rate from 2015- 2017

Table 2. Distribution of Population and Live births for the Past 3 Years in Ilocos Sur, Philippines and in Gujarat, India

Ilocos Sur Year	**Population**	**Total Number of Births**	**Birthrate per 1000 Population**
2017	703,174	3,101	0.44
2016	696,421	2,992	0.42
2015	689,668	3,124	0.45

Gujarat , India Year	**Population**	**Total Number of Births**	**Birthrate per 1000 Population**
2017	67,141,736	13,898,339	20.69
2016	66,032,362	13,272,504	20.39
2015	64,919,427	13,243,563	20.39

This table shows the number of live births in the four (4) government hospitals in Ilocos Sur and the number of babies who underwent the newborn Screening. It further shows that in all the hospitals, almost all babies were subjected to this screening procedure. This is in compliance to the Newborn Screening Act of the Department of Health.

Further, it also shows the population, number of births and the birth rate for the past three years in Gujarat India in which the total births is increasing every year. It can be noted that the population of India is more than the Philippines considering the land area of India. This would show the number of newborns who should have undergone the Newborn Screening Test.

On Diseases Screened In Ilocos Sur, Philippines and in Gujarat, India The table shows the diseases screened in Ilocos Sur, Philippines and in Gujarat, India.

Table 3. Diseases Screened for the Newborn Screening Test in Ilocos Sur, Philippines and Gujarat, India

Diseases Screened Among Newborns Ilocos Sur	Total Number Screened	Total number of diseased babies	Percent
G6PD	9174	733	7.9%
CAH	9174	4	.04%
Congenital Hypothyriodism	9174	5	.05%
PKU	9174	1	01%

Diseases Screened Among Newborns In Gujarat *	Total Number Screened	Total number of diseased babies	Percent
Sickle cell	2827	2083	73.6%
G6PD,IRT	3456	562	16.3%
Congenital Hypothyriodism	18573	143	0.8%

It can be noted that in the Ilocos Sur, Philippines, among the diseases screened, G6PD has the highest percentage (7.9%) that has affected the newborn children, while the other diseases bear insignificant number. Moreover, it can be gleaned from the table that in India there were cases screened for Sickle Cell Disease and the number of those affected newborns in 2014 was 73.6%, followed by G6PD with 16.3 cases affected.

A periodic quarterly review was carried out for each facility in coordination. The screening panel included CH, G6PD, IRT, Amino acids and tests for Galactosemia. A total of 18573 selected newborns had been screened for congenital hypothyroidism with 143 (0.8%) testing positive. The expanded panel (except CH) had been done in 3456 selected newborns with a positive yield of 16.3% (total 562 In year the 2014-15. NEWBORN SCREENING from: (https://www.researchgate.net/publication/323534983_NEWBORN_SCREENING) [accessed Dec 25 2018].

It was found out in this study that in India, which is a country known for its diversified cultures and genetic make-ups, the studies and pertinent data from one of its state may not be necessarily relate to another region. An example would be the incidence of Congenital Adrenal Hypoplasia which is noted to be higher in Southern India; whereas the occurrence of G6PD is highest in Punjab and Gujarat, while B Thalassemia takes the lead in Gujarat. (R Kishore Kumar, 2014)

According to the DOH Philippines (2012), the coverage of NBS in December2010 was at 35% which a decrease was noted in 2012. The six disorders included in the National Comprehensive Newborn Screening System with the ratios noted are Congenital Hypothyroidism (CH) – (1:3,004), Congenital Adrenal Hyperplasia (CAH) – (1: 10,046), Phenylketonuria (PKU) – (1: 388,367), Galactosemia (Gal) – (1: 310,694), Glucose-6-Phosphate Dehydrogenase Deficiency (G6PD) – (1:

50), and Maple Syrup Urine Disease (MSUD). Maple Syrup Urine Disease was combined to the screening panel in the last quarter of 2012. (http://www.doh.gov.ph/newborn-screening).

While in India, there is scarcity of printed studies on normal newborn assessment. In a pilot project which involved 125,000 newborns, it was found out that homocysteinemia, hyperglycinemia, MSUD, Phenylketonuria, hypothyroidism and G6PD are the common errors of metabolism (Devi AR, Rao NA, Bittles AH, 1988).

In Hyderabad, City of India, there was another study in 2000 on the "Expanded Newborn Screening" which tested 18,300 babies for amino acid disorders such as CH, (CAH), G6PD deficiency, biotinidase deficiency, galactosemia and cystic fibrosis. The testing resulted to a high prevalence of CH with one case in 1700 babies, followed by CAH and G6PD deficiency. Further, aminoacidopathies came out as the next most common disorder. It was also worthy to note that there was a very high prevalence of inborn errors of metabolism having one (1) in every thousand newborns.. (Devi AR and Naushad SM, 2004)

Dr. Shah of Gujarat also presented 12 programme mode in a conference entitled "Implementing NBS Programme: The Gujarat Experience." This would lead to the creation of epidemiological data for IEMS and select gene disorders and would be a first in India (https://www.researchgate.net/publication/323534983_NEWBORN_SCREENING [accessed Dec 25 2018]. On Problems Encountered in the NBS Program in the Philippines and India

A. In the Philippines, the problems encountered in the NBS Program include the following:

1. There are still mothers who do not understand the importance of NBS; there are still those who resist the procedure especially in remote areas;
2. There are mothers who do not submit their children for the confirmatory test because of the fees they may pay and the cost of treatment, and may not understand the nature of the disease;
3. There are only few designated centers to do the screening; and that the results may be delayed.

In 2010, there were four Newborn Screening Centers (NSCs) established in the Philippines to perform the testing all over the country: NSDC- National Institutes of Health in Manila; NSC- Visayas in Iloilo City; NSC- Mindanao in Davao City; and NSC- Central Luzon in Angeles City. The four provide laboratory and follow up services for more than 3000 health facilities (http://www.doh.gov.ph/newborn-screening).

B. India. In India, the problems encountered in the program include the following:

1. Many neonatologists performed genetic screening for the babies born under their care without any national guidelines to follow;
2. With the large number of children born with the disorders and paucity of centers carrying out newborn screening;
3. The procedure is expensive and accessible only in few centers; and only a few qualified geneticists are available.
4. The screening program in India is currently not funded by the Federal Government
5. There is limited awareness among the medical fraternity and research teams in some government hospitals and there is resistance from the in-house staff. (Kumar, 2014).

4. Conclusion

Based on the findings of the study, the following conclusions were drawn:

In the Philippines, for the past three years, there are only few newborn babies born in the government hospitals who were not subjected to the newborn screening; while in India, there were only few newborn babies screened in government hospitals. Out of the seven (7) diseases screened, G6PD is the most common metabolic disorder topping the number of cases in the Philippines While in India, with the big population, where there is diversified cultures and genetic make-ups, the incidence of B - Thalassemia takes the lead in Gujarat and G6PD followed.

As to the profile of the NBS Program in the Philippines and India lies on the following: the National Policy on Newborn Screening in the Philippines, while in India, the NBS program has no standards or any national guidelines followed. The cost of the testing is more expensive in India; there are more metabolic and genetic disorders screened in India; the Philippine Health Insurance covering

the program, while in India, there is no federal support, mostly Private Hospitals in India perform the NBS.

The problems encountered in the NBS Program include the following: resistance of some mothers to the NBS testing which may be due to their low awareness level; the resistance of mothers for the confirmatory testing because of the high cost of treatment; and there are few Testing Centers and that the release of results may be delayed.

Recommendations

Based on the findings of the study, the Philippines having different problems from that of India, the following are recommended:

In the Philippines:

Doctors and staff nurses, especially those assigned at the Obstetrical/ Delivery ward must fully discuss RA 9288 known as "Newborn Screening Act" as part of their discharge plan to the mothers. This may increase the level of knowledge of mothers on the said law and will improve their compliance level to the program. Community Health Workers should form part of their functions to conduct health education classes to discuss the newborn screening especially on the importance, the disorders screened, the process of the screening, the benefits of screening and the consequences of not subjecting to newborn screening procedure. The cost of the procedure should be subsidized by the Government, especially for those families which cannot afford it.

In India:

In as much as there is no national guidelines, the Indian government should create a standard Newborn Screening policy to regulate the program. The Government should establish more regional centers which can offer conclusive diagnosis to high risk neonates and strengthen them with procedural capability to undertake this responsibility. Such regional centers identified as reference centers for confirmatory diagnosis and therapy should be funded by the government. A public-private partnership should be established in order to offer a low cost package of newborn screening. Screening Centers should be made available strategically in many hospitals. Mass education and media propagation should be conducted by the medical communities to increase the knowledge of all parents and would-be parents. Lastly, more research activities need to be conducted on the compliance of mothers to this program, the status of implementation by health facilities, as well as the benefits and impact to the community.

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