
To study the Awareness level of New Born Screening amongst Health Care Professionals in India with specific reference to Nagpur City

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Abstract:- A large number of the nations in the Asia Pacific Region, especially those with discouraged and creating economies, are simply starting infant screening programs for chose metabolic and other innate issue. Infant screening exercises in the Asia Pacific Region are especially imperative since births there record for roughly 50% of the world's births. The first Workshop on Consolidating Newborn Screening Efforts in the Asia Pacific Region happened in Cebu, Philippines, on March 30–April 1, 2008, as a satellite meeting to the seventh Asia Pacific Conference on Human Genetics. The second workshop was hung on June 4–5, 2010, in Manila, Philippines. Workshop members included key approach producers, specialist co-ops, scientists, and purchaser advocates from 11 nations with half or less infant screening scope. This report surveys the mindfulness exercises and nation reports from two Workshops on Consolidating Newborn Screening Efforts in the Asia Pacific Region with accentuation on the second workshop. It likewise redesigns the writing on screening exercises and execution/extension challenges in the partaking nations.

INTRODUCTION

This chapter dealt on the background as the need is felt to protect Newborn by screening.

New born are always vulnerable to several infections & diseases. Best policy to safeguard is to take preventive measures so that new born do not suffer & grow healthy. Every country has its own national health policy under which it ensures better health of every individual more so of children & new born.

Nearly two decades ago when WHO was moving with creating awareness against Hepatitis B which was most dreaded infection, awareness level in India was extremely low & hence prevention against Hepatitis B through immunization was major task before medical fraternity.

In India , Indian Academy of Pediatrics has played vital role in adopting immunization against diseases/infections like Hepatitis – B in addition to Polio, DPT,BCG by implementation of mass immunization involving many NGO's.

Protecting New born against such common diseases was possible only by creating awareness amongst people & thereby improving Health of every individual .We could see a situation when discussions were initiated as to how awareness should be increase to protect child from Hepatitis-B infection .**In early 90's , awareness level about prevalence of Hepatitis B & its prevention was extremely low. It is the coordinated efforts from WHO to increase awareness in developed & developing countries to protect newborn from Hepatitis-B which ultimately resulted into Academy of Pediatricians from different countries accepting & promoting it to protect every single new born which subsequently resulted into healthcare policy makers, proposing into regular immunization schedule,** still there is long way to go as per as including newer vaccines into regular immunization schedule is concern .

Similar orientation is required for Newborn Screening. Detection at early stage will decide future course of action including newborn's future. This requires joint effort from organization like IAP ,NGO's working for health related issues with coordinated efforts from Central government ,being policy making body.

LITERATURE REVIEW

Comparative ethical analysis of standard newborn screening and potential expanded screening for genetic susceptibility to diabetes highlights some major differences between the two. This fact alone does not imply that such screening is automatically ethically unacceptable but does suggest that these differences should be examined in detail.

The uncertainty associated with this type of genetic information and difficulty in precisely defining who is a patient mean that several WHO criteria are not adequately fulfilled. There is significant potential for psychosocial harm, particularly when testing is performed in the newborn period and in the absence of definitive therapy. It is not currently possible to comprehend fully the significance of these potential harms as they are difficult to quantify and poorly researched but some of the negative effects may be considerable, both at the level of individual families and on a population basis.

Population of the study –

For this study, private practicing doctors from Nagpur city was taken into consideration. This study focuses not only on awareness level of newborn screening.

Research Methodology –

Data Collection –

Methodology for data collection was as under –

Primary Source - Questionnaire from Medical Practitioners of Nagpur.

Secondary Source - Books, Websites, Medical Journals.

Population - Nagpur City.

Targeted Population - Medical practitioners from Nagpur City.

Sample Size – 50

RESULTS & DISCUSSIONS

Data Presentation and Analysis

The present chapter deals with the results obtained after statistical analysis of collected data. The data collection was done by using a valid and reliable research instrument. The data was collected following survey methodology. This chapter contains data analysis and interpretation of the data obtained from medical practitioner (regarding their overall view about the neonatal screening) and other library users.

Analysis of data received from medical practitioners selected in the study.

Age wise distribution of medical practitioner

Table 5.1: Information regarding age wise distribution of medical practitioner

Age	No. of Respondents	Percent	Cumulative Percent
30-40 Years	06	12.0	12.0
41-50 years	30	60.0	72.0
51-60 Years	14	28.0	100
Total	50	100	

Table 5.1 It was apparent from the information that significantly ($P < 0.05$) high percentage of medical practitioners selected in the study belong to age group 41 to 50 years.

Nature of Practice

Table 5.2: Distribution of medical practitioner with respect to their nature of practice

Nature of Practice	No. of Respondents	Percent	Cumulative Percent
GP	05	10.0	10.0
Gyn	08	16.0	26.0
Ped	33	66.0	92.0
Phy	4	8.0	100.0
Total	50	100.0	

Table 5.2 It was apparent from the statistical analysis of data that significantly ($P < 0.05$) high percentage of medical practitioners selected in the study were pediatricians.

Qualification

Table 5.3: Distribution of medical practitioners with respect to their professional qualification

Qualification	No. of Respondents	Percent	Cumulative Percent
DCH DNB	2	4.0	4.0
MBBS	5	10.0	14.0
MBBS DCH	3	06.0	20.0
MBBS FCGP	1	2.0	22.0
MD(Paed)	30	60.0	82.0
MD DGO	9	18.0	100
Total	50	100	

Table 5.3 It was observed from statistical analysis of data that majority of medical practitioners selected in the study were MD (Paed) qualified.

Length of Practice

Table 5.4: Distribution of medical practitioners with respect to their length of practice

Length of Practice	No. of Respondents	Percent	Cumulative Percent
10-15 Years	07	14.0	14.0
15-20 Years	16	32.0	46.0
20-25 years	14	28.0	74.0
25-30 years	10	20.0	94.0
>30 Years	3	6.0	100
Total	50	100	

Table 5.4 It was apparent from the statistical analysis of data that majority of medical practitioners were doing medical practice from 15 to 20 years.

Support to recommendation of New born Screening by medical practitioners

Table 5.5: Information regarding support to recommendation of New born Screening by medical practitioners

Recommendation to New Born Screening	No. of Respondents	Percent
Yes	30	60
No	20	40

Table 5.5 It may be concluded from the study results that sizable number of doctors recommended new born screening.

Table 5.6: Information about views of Medical Practitioners regarding facilities & infrastructure available for Newborn Screening in India

Facilities and Infra for NBS	No. of Respondents	Percent	Cumulative Percent
Very Good	2	4.0	4.0

Good	10	20.0	24.0
Average	24	48.0	72.0
Poor	12	24.0	96.0
Not Aware	2	4.0	100.0
Total	50	100.0	

Table 5.6 It was apparent from the statistical analysis of data that according to majority of medical practitioners facilities & infrastructure available for Newborn Screening in India are of average levels.

Table 5.7: Information regarding various strategies employed to create awareness for NBS

Strategies to create awareness for NBS	No. of Respondents	Percent	Cumulative Percent
Use of WHO Report	8	16.0	16.0
Mass Awareness involving NGO's	10	20.0	36.0
Using IAP's Recommendation	28	56.0	92.0
Any Other	2	4.0	96.0
All Options	2	4.0	100.0
Total	50	100.0	

Table 5.7 It was apparent from the statistical analysis of data that according to significantly ($P < 0.05$) high percentage of medical practitioners using IAP's recommendations is the best option for creating awareness about NBS.

Table 5.8: Responses of medical practitioners regarding number of babies need to undergo NBS

Responses on No. of babies need to undergo NBS	No. of Respondents	Percent	Cumulative Percent
Every Baby	21	42.0	42.0
1 in 5	17	34.0	76.0
1 in 10 or less	12	24.0	100.0
Total	50	100	

Table 5.8 It was apparent from the statistical analysis of data that significantly ($P < 0.05$) high percentage of Medical Practitioners recommended that baby should need to undergo NBS

Table 5.9: Responses of medical practitioner regarding the statement which states that cost is major constraint for NBS

Cost is Constraint for NBS	No. of Respondents	Percent	Cumulative Percent
Strongly Agree	18	36.0	36.0
Agree	21	42.0	78.0
Just Agree/Just Disagree	9	18.0	96.0
Disagree	2	4.0	100
Total	50	100	

Table 5.09 It was evident from the statistical analysis of the data that significantly ($P < 0.05$) high percentage of medical practitioners agree that cost is major constraint for NBS.

Table 5.10: Views of medical practitioners regarding voluntariness of New Born Screening

Voluntariness of NBS	No. of Respondents	Percent	Cumulative Percent
Strongly Agree	2	4.0	4.0
Agree	8	16.0	20.0
Just Agree/Just Disagree	17	34.0	54.0
Disagree	13	26.0	80.0
Strongly disagree	10	20.0	100.0
Total	50	100.0	

Table 5.11 It was apparent from the statistical analysis of data that significantly ($P < 0.05$) high percentage of medical practitioners feel that voluntariness of new born screening should be allowed.

Hypotheses Testing

Awareness about newborn screening is low among doctor.

It is evident from the study results that significantly high percentage of doctors are unaware of Newborn Screening, hence the hypothesis which states that awareness about newborn screening is low among doctor is **accepted**.

Infrastructure constraints have restricted the penetration of Newborn Screening.

It is apparent from the study results that majority of doctors are of the opinion that India have no infrastructure to treat babies diagnosed with genetic disorder. It was also evident that facilities and infrastructure available for new born screening in India are of average quality; hence the hypothesis which states that infrastructure constraints have restricted the penetration of Newborn Screening is **accepted**.

Lack of promotional efforts are responsible for low awareness about Newborn screening

It was evident from the study results that majority of doctors are not confident regarding steps taken to increase awareness about New born Screening by IAP/IMA or concern medical regulatory body in last 3 years, hence the hypothesis which states that lack of promotional efforts are responsible for low awareness about Newborn screening is **accepted**.

Cost of procedure is barrier for Newborn Screening

It was observed from the study results that according to significantly ($P < 0.05$) high percentage of doctors ,cost is a major constraint for NBS, hence the hypothesis which states that Cost of procedure is barrier for Newborn Screening is **accepted**.

Doctors do not consider newborn screening essential

It was indicated by the study results that according to significantly ($P < 0.05$) high percentage of doctors new born screening should be voluntary, hence the hypothesis which states that, doctors do not consider newborn screening essential is **accepted**.

Alternate screening methods or diagnostic methods are sufficient to detect most of common disorders.

It was evident from the study results that according to significantly ($P < 0.05$) high percentage of doctors alternate screening methods are not sufficient to detect most common disorders, hence the hypothesis which states that alternate screening methods or diagnostic methods are sufficient to detect most of common disorders is **rejected**.

CONCLUSION

Awareness level about New born Screening amongst doctors from Nagpur City is not high.

Considering the risk involved for newborn, joint initiative from Paediatrician's organization, NGO & government should launch awareness campaign amongst common people. Concern authority should ensure the availability of required infrastructure to treat such babies.

LIMITATION OF THE STUDY

Following are the limitations for the research

- 1) The study is limited to only Nagpur city.
- 2) Sample size is constraint for information.

REFERENCES

- [1] Levy HL. Lessons from the past—looking to the future. *Newborn screening*. *Pediatric Ann* 2003; 32:505–8.
- [2] Guthrie R, Susi A. A simple phenylalanine method for detecting phenylketonuria in large populations of newborn infants. *Pediatrics* 1963; 32:338–43.
- [3] Streetly A, Grant C, Pollitt RJ, et al. Survey of scope of neonatal screening in the United Kingdom. *BMJ* 1995; 311:726.
- [4] Wilson J, Jungner G. *Principles and Practice of Screening for Disease*. Geneva: WHO, 1968.
- [5] Beauchamp TL. Methods and principles in biomedical ethics. *J Med Ethics* 2003; 29:269–74.
- [6] Seymour CA, Thomason MJ, Chalmers RA, et al. Newborn screening for inborn errors of metabolism: a systematic review. *Health Technol Assess* 1997; 1: i–iv, 1–95.
- [7] Serving the family from birth to the medical home. *Newborn screening: a blueprint for the future—a call for a national agenda on state newborn screening programs*. *Pediatrics* 2000; 106 (2 Pt 2):389–422.
- [8] Fyro K, Bodegard G. Four-year follow-up of psychological reactions to false positive screening tests for congenital hypothyroidism. *Acta Pediatric Scand* 1987; 76:107–14.
- [9] Sorenson JR, Levy HL, Mangione TW, et al. Parental response to repeat testing of infants with “false-positive” results in a newborn screening program. *Pediatrics* 1984; 73:183–7.
- [10] Newborn screening fact sheets. American Academy of Pediatrics. Committee on Genetics. *Pediatrics* 1996;98(3 Pt 1):473–501
- [11] Anonymous. Proposed international guidelines on ethical issues in medical genetics and genetic services: WHO/HGN/GL/ETH/98 1; Geneva: WHO 2000.
- [12] Pollitt RJ, Green A, McCabe CJ, et al. Neonatal screening for inborn errors of metabolism: cost, yield and outcome. *Health Technol Assess* 1997; 1: i–iv, 1–202.
- [13] Baird P. *Genetics and Healthcare*. *Perspect Biol Med* 1990; 33:203–13.
- [14] Holtzman NA, Marteau TM. Will genetics revolutionize medicine? *N Engl J Med* 2000; 343:141–4.
- [15] Wilkie AOM. Genetic prediction: What are the limits? *Stud Hist Phil Biol Biomed Sci* 2001; 32:619–33.