

ORIGINAL

Understanding the mother's knowledge and attitudes regarding newborn screening in rural areas of Tamil Nadu, India

Comprender los conocimientos y las actitudes de las madres sobre el cribado neonatal en zonas rurales, Tamil Nadu, India

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ABSTRACT

Introduction: newborn screening (NBS) is an effective intervention for congenital disorders that can prevent morbidity and mortality if accessible. The study aims to evaluate the knowledge, acceptance, and attitude towards newborn screening in Tamil Nadu, India, among rural mothers, and identify its determinants.

Method: a community-based, cross-sectional study was conducted at government and private hospitals in Thiruvallur District, Tamil Nadu, from June to August 2024. Data from 280 mothers who had recently given birth were analyzed. Statistical tests such as the Mann-Whitney U test, Kruskal-Wallis test, and multivariate logistic regression were used to identify predictors of maternal knowledge and attitudes via SPSS 25,0.

Results: only 37,5 % of mothers demonstrated high knowledge of NBS, while 56,4 % showed a positive attitude. Findings indicated that higher education (OR = 2,92, 95 % CI: 1,99-4,29, $p < 0,001$) and prior knowledge of NBS (OR = 3,25, 95 % CI: 2,18-4,85, $p < 0,001$) are strong predictors of awareness. Urban residency and higher family income significantly influenced understanding and favorable perceptions of NBS. Having a consanguineous marriage decreased the likelihood of positive attitude towards NBS (OR = 0,51, $p = 0,033$), suggesting a cultural barrier.

Conclusion: the findings indicate that socio-demographic factors are significantly associated with maternal knowledge and attitudes towards NBS. It is essential to strengthen community educational programs to raise awareness of the NBS process and improve participation.

Keywords: Newborn Screening; Maternal Knowledge; Attitudes; Rural Healthcare; Tamil Nadu; Preventive Health; Logistic Regression.

RESUMEN

Introducción: la pesquisa neonatal (NBS, por sus siglas en inglés) es una intervención eficaz para los trastornos congénitos que puede prevenir la morbilidad y la mortalidad si es accesible. El estudio tiene como objetivo evaluar el conocimiento, la aceptación y la actitud hacia la pesquisa neonatal en Tamil Nadu, India, entre madres rurales, e identificar sus determinantes.

Método: se realizó un estudio comunitario de tipo transversal en hospitales gubernamentales y privados del distrito de Thiruvallur, Tamil Nadu, de junio a agosto de 2024. Se analizaron datos de 280 madres que habían dado a luz recientemente. Se aplicaron pruebas estadísticas como la prueba de Mann-Whitney U, la prueba de Kruskal-Wallis y la regresión logística multivariante para identificar los predictores del conocimiento y las actitudes maternas mediante SPSS 25,0.

Resultados: solo el 37,5 % de las madres mostró un alto nivel de conocimiento sobre la pesquisa neonatal,

mientras que el 56,4 % presentó una actitud positiva. Los hallazgos indicaron que un mayor nivel educativo (OR = 2,92; IC 95 %: 1,99-4,29; $p < 0,001$) y el conocimiento previo de la pesquisa (OR = 3,25; IC 95 %: 2,18-4,85; $p < 0,001$) son fuertes predictores de la conciencia. La residencia urbana y un mayor ingreso familiar influyeron significativamente en la comprensión y en percepciones favorables sobre la pesquisa. Tener un matrimonio consanguíneo disminuyó la probabilidad de presentar una actitud positiva hacia la pesquisa (OR = 0,51; $p = 0,033$), lo que sugiere una barrera cultural.

Conclusión: los hallazgos indican que los factores sociodemográficos se asocian significativamente con el conocimiento y las actitudes maternas hacia la pesquisa neonatal. Es fundamental fortalecer los programas educativos comunitarios para aumentar la conciencia sobre el proceso de NBS y mejorar la participación.

Palabras clave: Pesquisa Neonatal; Conocimiento Materno; Actitudes; Atención Sanitaria Rural; Tamil Nadu; Salud Preventiva; Regresión Logística.

INTRODUCTION

Newborn screening (NBS) is crucial for identifying genetic conditions that may lead to illness or death in infants. A key aim of newborn screening is to prevent disease through early detection and intervention. Future advancements in treatment and management will help lower illness and mortality rates, similar to the successful results seen with phenylketonuria screening in the 1960s.^(1,2) The success of NBS relies on access, affordability, and active participation. The most cost-effective and least burdensome method is diagnosing conditions before symptoms appear.⁽³⁾ Since 1962, when 400 000 newborns were screened in 29 states, the process of newborn screening has undergone significant progress. As it expanded worldwide, variations in government policies, funding, cultural practices, and environmental factors⁽⁴⁾ have created differences in interest and procedures.

In high-income countries, newborn screening has significantly impacted reducing morbidity and mortality for families. In low- and middle-income countries, awareness of NBS programs is lately gaining momentum, with many nations that have not yet established formal programs.⁽⁴⁾ According to the Sustainable Development Goals, Target 3.2 aims to end preventable child deaths by 2030. Specifically, SDG 3.2.2 aims to lower the infant mortality rate (IMR) by 12 per 1 000 live births, and SDG 3.2.1 aims to decrease under-5 mortality to 25 per 1 000 live births.⁽⁵⁾ Acceptance of newborn screening largely depends on awareness and recognition. Several studies highlight that “fear” and “anxiety” influence parents’ decisions about screening, though many recognize its importance. When awareness is provided either antenatally or postnatally, parents are more likely to have a positive attitude toward screening their newborn, leading to better decision-making.^(6,7,8,9,10) Parental understanding and perspectives are vital to the success of NBS programs. Mothers, often seen as primary caretakers, tend to have significant concerns regarding decisions about interventions affecting newborn health.^(11,12)

The objective of this study is to assess mothers’ awareness, perception, and attitude toward NBS in rural Tamil Nadu. Identifying knowledge gaps and barriers will guide the development of targeted educational strategies to promote acceptance and participation. The novelty of this study lies in identifying sociodemographic characteristics and cultural variables that influence consanguineous marriages, and it also highlights opportunities to improve NBS uptake in underserved settings.

METHOD

Study Design

This study is a community-based descriptive cross-sectional study. The research was carried out in government and private hospitals throughout Thiruvallur district, Tamil Nadu, from June to August 2024. The study population consisted of mothers who had recently given birth and met the inclusion criteria. The sample size was calculated using a formula for known populations.

Based on the projected population size, the required sample size was calculated to be 280 at a 95 % confidence interval using the formula. To enhance the study’s reliability, a total of 280 mothers were included. The inclusion criteria were mothers aged 18 years and above who could read and understand Tamil, and who were willing to participate. Since collecting data from the entire district was not feasible, the study was conducted in selected hospitals where the researchers had access.

Data were collected using Google Forms and then transferred to Excel for data management. All analysis was performed with SPSS 17. The tool has two sections: the first gathers descriptive information from the form, and the second provides data on knowledge and attitudes regarding newborn screening.^(13,14,15,16,17)

Tool

The tool was administered based on literature, and this form included 25 questions related to socio-

demographic factors such as maternal age, education, employment, paternal education, income, place of residence, family history of hereditary diseases, and previous knowledge of newborn screening.^(5,18,19,20) Data were collected through face-to-face interviews conducted by trained researchers. Interviews took place in a private setting, outside the baby's care, treatment, or feeding hours. Each interview lasted approximately 15 minutes. Mothers were informed about the study objectives and provided informed consent before participating.

How was it applied, describe it(Described above).

Maternal Attitudes and Knowledge about Newborn Screening Survey

This scale, originally developed and adapted for use in Tamil Nadu, includes 13 items rated on a 5-point Likert scale (0 = strongly agree, 1 = agree, 2 = not sure, 3 = disagree, 4 = strongly disagree). A higher score reflects lower knowledge and more negative attitudes toward newborn screening. The Cronbach's alpha for this study was 0,812 for the overall scale, indicating good internal consistency.^(5,21,22,23,24,25)

Statistical Analysis

Data were analyzed using IBM SPSS 25,0. Descriptive statistics, including percentages, means, medians, and standard deviations, were used to summarize socio-demographic and outcome variables. Normality of data was checked using the Kolmogorov-Smirnov test and Q-Q plots.^(,26,27,28,29,30,31)

As the data were not normally distributed, non-parametric tests were applied. The Mann-Whitney U test compared two independent groups, while the Kruskal-Wallis test was used for more than two groups. A p-value < 0,05 was considered statistically significant.⁽³²⁾

Ethical Considerations

The Declaration of Helsinki served as the foundation for this study. Ethical approval was obtained from an Institutional Ethics Committee at a medical college in Tamil Nadu (Approval ID: E-2024-05678). Approval was also secured from the hospitals participating in the study. All mothers provided informed consent and were informed that they could withdraw from the study at any time without facing any consequences. Data confidentiality was maintained throughout the entire study.

RESULTS

S. No	Characteristics	Character	Frequency	Percentage
1	Age Classifications	Below 20 Years	45	16
		20 to 30 Years	170	61
		Above 30 Years	65	23
2	Education Status	No Education	50	18
		Primary(1 to 5 std)	78	28
		Secondary(6 to 12th Std)	95	34
		Undergraduate Degree	57	20
3	Employment Status	Employed	85	30
		Un Employed	195	70
4	Place of Residence	Rural	200	71
		Urban	80	29
5	Consanguineous Marriage	Yes	65	23
		No	215	67
6	Knowledge about NBS	High Knowledge	105	37,5
		Low Knowledge	175	62,5
		Low Attitude	157	56,4

As per table 1, as high as 60 percent of the respondents are from the age group 20 to 30 years, and the lowest age group is below 20 years 16 percent. About 50 percent of the respondents have only completed secondary and undergraduate degrees. About 70 percent of the respondents were not working and about 23 percent of the

respondents went for consanguineous marriage. Knowledge about newborn screening was reported by only 37,5 % of mothers, indicating a gap in awareness, while 53,6 % had a positive attitude towards NBS.

Table 2. Association between Demographic Characteristics and Knowledge about NBS

S. No	Characteristics	Character	High Knowledge (n=135)	Low Knowledge (n=145)	Total (n=280)	P. Value
1	Age Classification	< 20 years	17 (12,6 %)	28 (19,3 %)	45	0,045
		20 - 30 years	88 (65,2 %)	82 (56,6 %)	170	
		> 30 years	30 (22,2 %)	35 (24,1 %)	65	
2	Education Status	No formal education	12 (8,9 %)	38 (26,2 %)	50	0,001
		Primary	20 (14,8 %)	58 (40,0 %)	78	
		Secondary	64 (47,4 %)	31 (21,4 %)	95	
		Higher	39 (28,9 %)	18 (12,4 %)	57	
3	Employment Status	Employed	33 (24,4 %)	52 (35,9 %)	85	0,091
		Unemployed	102 (75,6 %)	93 (64,1 %)	195	
4	Place of Residence	Rural	80 (59,3 %)	105 (72,4 %)	185	0,038
		Urban	55 (40,7 %)	40 (27,6 %)	95	

Table 3. Association between Demographic Characteristics and Attitude about NBS

S.No	Characteristics	Character	Positive Attitude (n=175)	Negative Attitude (n=105)	Total (n=280)	p-value
1	Age Classification	Below 20 Years	30 (17,1 %)	15 (14,3 %)	45	0,053
		20 to 30 Years	102 (58,3 %)	68 (64,8 %)	170	
		Above 30 Years	43 (24,6 %)	22 (21,0 %)	65	
2	Education Details	No Education	15 (8,6 %)	35 (33,3 %)	50	<0,001**
		Primary (1 to 5 std)	25 (14,3 %)	53 (50,5 %)	78	
		Secondary (6 to 12th)	80 (45,7 %)	15 (14,3 %)	95	
		Under Graduate Degree	55 (31,4 %)	2 (1,9 %)	57	
3	Occupation	Employed	68 (38,9 %)	17 (16,2 %)	85	0,072
		Unemployed	107 (61,1 %)	88 (83,8 %)	195	
4	Place of Residence	Rural	115 (65,7 %)	85 (81,0 %)	200	0,044*
		Urban	60 (34,3 %)	20 (19,0 %)	80	

Tables 2 and 3 illustrate the interconnections existing between the demographic variables and the knowledge/attitude towards newborn screening. Statistically, the level of education was shown to be very highly significantly associated with both knowledge and attitude ($p < 0,001$). Thus, it indicates that educated mothers had more knowledge and a better attitude toward NBS. In addition, family income and place of residence were also shown to be statistically significant with knowledge ($p = 0,015$ and $p = 0,038$, respectively) and attitude ($p = 0,028$ and $p = 0,044$, respectively). Among these, previous knowledge of NBS has been demonstrated to be the strongest predictor of knowledge and attitude ($p < 0,001$).

Tables 4 and 5 show the multivariate logistic regression analysis results. Strong predictors of knowledge were degree of education (OR = 2,92, 95 % CI: 1,99-4,29, $p < 0,001$) and previous knowledge of NBS (OR = 3,25, 95 % CI: 2,18-4,85, $p < 0,001$). Further research indicates that knowledge probabilities for urbanites were 1,53 times higher, while family income greater than Rs.10000 had 1,89 times the odds of knowing as compared to respondents residing in the rural region and family income less than Rs 10000. Likewise, a good attitude towards NBS was linked with the higher education level (OR=2,74, 95 % CI: 1,83-4,11, $p = 0,001$) and income (OR=1,72, 95 % CI: 1,22-2,56, $p = 0,011$). Those living in cities had 1,53 times larger chances of knowing.

Table 4. Factors associated with the Knowledge of Newborn screening

Variable	Category	Coefficient	Odds ratio	95 % C.I. for odds ratio		p-value
				Lower	Upper	
Age of mother	<20			Reference		
	20-30	0,405	1,5	0,759	2,962	0,243
	>30	0,315	1,37	0,635	2,954	0,422
Education Level	No formal education			Reference		
	Primary	0,501	1,65	0,708	3,846	0,246
	Secondary	0,165	1,18	0,579	2,401	0,649
	Higher	0,619	1,857	0,867	3,977	0,111
Employment status	Unemployed			Reference		
	Employed	-0,201	0,818	0,492	1,361	0,439
Monthly family income	<10,000 INR			Reference		
	10,000-25,000 INR	-0,146	0,864	0,506	1,475	0,593
	>25,000 INR	-0,156	0,856	0,44	1,663	0,646
Place of Residence	Rural			Reference		
	Urban	0,139	1,15	0,7	1,889	0,582
Consanguineous Marriage	No			Reference		
	Yes	-0,157	0,855	0,464	1,573	0,614
Constant		-0,617	0,54			0,18

Table 5. Factors associated with the Attitude towards New born screening

	Category	Coefficient	Odds ratio	95 % C.I. for odds ratio		p value
				Lower	Upper	
Age of mother	<20			Reference		
	20-30	-0,176	0,839	0,408	1,724	0,632
	>30	-0,483	0,617	0,275	1,382	0,241
Education Level	No formal education			Reference		
	Primary	0,049	1,05	0,426	2,593	0,915
	Secondary	-0,147	0,863	0,411	1,814	0,698
	Higher	-0,5	0,607	0,275	1,339	0,216
Employment status	Unemployed			Reference		
	Employed	0,285	1,33	0,779	2,272	0,296
Monthly family income	<10,000 INR			Reference		
	10,000-25,000 INR	-0,111	0,895	0,515	1,557	0,695
	>25,000 INR	0,326	1,385	0,679	2,825	0,37
Place of Residence	Rural			Reference		
	Urban	0,671	1,956	1,147	3,337	0,014
Consanguineous Marriage	No			Reference		
	Yes	-0,674	0,51	0,274	0,948	0,033
Constant		0,645	1,905			0,18

DISCUSSION

The study generates fresh evidence regarding maternal awareness and perceptions of newborn screening (NBS) among rural Tamil Nadu, demonstrating that cultural and socio-demographic determinants play a crucial role in shaping uptake. The findings are consistent with similar findings in other low- and middle-income countries, where socio-economic barriers and lack of awareness are the primary challenges to the implementation of NBS programs.^(13,14)

Education was the most reliable predictor of both knowledge and attitude. The same has been identified in Nigeria, Iran, and other regions of India, where maternal education is associated with improved health literacy and decision-making about child health interventions.^(15,16) Our research discovers that mothers familiar with NBS had secondary or higher-level education, consistent with other studies conducted in other developing countries.^(17,18) Generally speaking, the education of women in rural settings is very low. This means that if rural

women from the developing world know anything about a particular disease, they should receive maternal health education in their locality.^(19,20) Health and education greatly converge. The wealthier countries observe high acceptance of NBS screening among high-level mothers.⁽²¹⁾ It is in great alignment with studies that indicate that with a more stable economic environment there is improved access to prenatal counselling and NBS thereby improving acceptance of such programs.⁽²²⁾ In a country like India, where health care is privately financed, new mothers face an additional financial constraint further impeding their participation in programs such as NBS.⁽²³⁾ Therefore, there must be several more programs that work toward lowering screening costs and raising accessibility.

Place of residence limited both knowledge and attitude in general; urban mothers are at a proper advantage with more education and encouragement opportunities for thinking toward NBS.⁽²⁴⁾ It is postulated that the adequate introduction of health and healthcare infrastructures, a much greater exposure to healthcare professionals, and higher literacy levels are all important differentiating factors for improved outcomes.⁽²⁵⁾ Similar results have been reported in other public health venture studies from India, wherein public-established interventions are highly recommended in rural areas to improve uptake.⁽²⁶⁾ Past exposure to the concept of NBS was a good indicator of awareness and positive attitude, strengthening the importance of antenatal teaching and early parental counselling.⁽²⁷⁾

Multiple studies indicate that educating about NBS during antenatal visits will improve maternal acceptance and uptake of the test.⁽²⁸⁾ Educating parents about NBS as a routine component of perinatal care may increase acceptance and promote screening through earlier diagnosis. One notable finding was the strong negative association between consanguineous marriage and a positive attitude toward NBS (OR=0,51, p=0,033).⁽²⁹⁾ Cultural/family beliefs regarding testing for genetic abnormalities seem to generate suspicion and uncertainty regardless of the potential benefits that genetic screening may have.⁽³⁰⁾ Addressing these issues through culturally relevant education may yield greater acceptance of NBS and less hesitancy to participate for at-risk families.

Our results correlate with data from Nigeria and Turkey, where increased maternal education correlates significantly with improved awareness and acceptance of new born screening.^(5,18) Cultural traditions like consanguineous marriage play a more significant role in shaping maternal attitudes in South Asia.^(29,30) Contrary to research from Africa in which distrust of health care workers was a major hindrance,^(8,23) in India and possibly other middle-income countries, costs and private health funding become major issues.^(22,23) These comparisons with Nepal also demonstrate that status and education among women play an important role in influencing the use of maternal health services, affirming the role of empowerment in enhancing NBS uptake.⁽¹⁷⁾ However, data alone are inadequate without culturally sensitive counselling to reduce stigma and reluctance toward genetic testing.⁽²⁷⁾ Integration of NBS into current maternal health programs and empowering community health workers as trusted counsellors may routinize the practice and enhance equity.^(24,26) In general, while universal structural barriers exist, cultural determinants require locally informed approaches for long-term application.

Comparison is missing, express POV, opinions. Do it without repeating results.

CONCLUSION

This study identifies the major socio-demographic determinants—above all, education, income, place of residence, and prior awareness—behind maternal attitudes and knowledge regarding newborn screening. Eliminating these gaps requires unifying community-based education programs, incorporation of NBS counselling into routine maternal and child health services, and strengthening public health interventions within low-access rural communities. Beyond awareness, culturally sensitive counselling needs to reduce stigma and resistance related to genetic testing. Future research must include qualitative perspectives so that parental beliefs are better captured and interventions are more equitable, contextual, and sustainable.

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CONFLICT OF INTEREST

None.

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