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Assessing newborn screening practices in Bangladesh: Perspectives of healthcare professionals and implications for improved infant health

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ABSTRACT

Newborn screening (NBS) plays a crucial role in identifying and managing congenital disorders, ultimately leading to improved infant health outcomes. This study aims to assess the current practices of newborn screening in Bangladesh, focusing on the perspectives of healthcare professionals, and identifying potential implications for enhancing infant health. A quantitative research design was employed, utilizing in-depth interviews and focus group discussions with healthcare professionals involved in newborn care across various healthcare settings. Findings indicate that newborn screening practices in Bangladesh face several challenges, including limited awareness among healthcare professionals, inadequate infrastructure and resources, and the absence of a comprehensive national screening program. Furthermore, financial constraints, cultural beliefs, and social barriers contribute to the low utilization of screening services by families. The perspectives of healthcare professionals shed light on potential strategies to address these challenges and improve newborn screening practices in Bangladesh. These strategies include enhancing healthcare professionals' knowledge and skills through training programs, increasing public awareness about the importance of newborn screening, strengthening healthcare infrastructure and accessibility, and implementing a comprehensive national screening program. The implications of improving newborn screening practices are significant. Early detection of congenital disorders through NBS enables timely interventions, leading to reduced morbidity, mortality, and long-term disabilities in infants. Enhanced screening practices can also contribute to reducing the burden on healthcare systems by preventing complications associated with undiagnosed conditions and enabling more cost-effective management. This study highlights the need for comprehensive efforts to address the challenges faced in newborn screening practices in Bangladesh. By incorporating the perspectives of healthcare professionals, policymakers can develop targeted interventions to enhance newborn screening programs, thereby improving infant health outcomes and ensuring a healthier future for Bangladesh's newborn population.

INTRODUCTION

Newborn screening (NBS) is a simple test that can be used to identify healthy babies shortly after they are born. NBS enables healthcare professionals to detect and treat certain diseases before they cause a newborn to get sick. The goal of NBS is to find potentially fatal or disabling abnormalities in infants as soon as possible, usually before the baby shows any signs or symptoms of the disease or condition. Because of early detection, treatment can begin immediately away, reducing or even eliminating the repercussions of the disorder. Many of the disorders found during newborn screening can cause lifelong nervous system damage, intellectual, developmental, and physical

problems, as well as death if left untreated. NBS is a well-established program in developed countries as well as several Asian countries for the early detection of numerous avoidable diseases. With the control of contagious and communicable diseases under control, the Bangladesh government is now focusing more on health prevention [1]. In Bangladesh, newborn screening began in 1999. The initiative began as part of an International Atomic Energy Agency (IAEA) regional project to screen for congenital hypothyroidism (CH). The IAEA initially provided equipment, filter papers, reagents, training, and expert services to the country. Two pilot initiatives to test babies for CH have been performed since 1999. 30,000 babies were screened as part of these projects, and 16 were found to have hypothyroidism [2]. In July 2006, the Bangladesh government approved a national campaign to screen infants for CH in a few designated districts of the country. 200,000 infants will be screened as part of the program, and laboratory facilities for NBS will be expanded. Bangladesh has a population of 140 million people. Every year, over 2 million new babies are born at the current birth rate. The country's socioeconomic position is also distinctive. The country's per capita income is among the lowest in the world. Approximately 85% of babies are still born at home [3]. As a result, Bangladesh faces a significant problem in terms of neonatal screening. However, the country should make every effort to overcome these obstacles [4]. Many cross-sectional studies have already been conducted in several different countries throughout the world to study the attitudes of the public concerning the circumstances for which NBS is available, including in North America [5-12], Europe [13], the Middle East and North Africa [14-18], Asia Pacific [19-23] and India [24]. Few activities have already been conducted in the Department of Genetic Engineering and Biotechnology at Shahjalal University of Science and Technology, Sylhet, Bangladesh considering the detection and mutation patterns of sickle cell anemia, thalassemia, hemophilia, and chromosomal disorders in the lab condition [25-30]. However, newborn screening awareness has not progressed in terms of socio-economic aspects. Many surveys have already been conducted in different parts of the world to demonstrate parental or health professional participation, knowledge, attitude, consent time, cost, consent format, and perception of NBS [31]. Therefore, this study aimed to investigate health professionals' knowledge, practices, and attitudes concerning newborn screening in different parts of Bangladesh.

METHODS AND MATERIALS

Participants

A cross-sectional internet survey was conducted, and a convenience sampling technique was used to draw the sample from a different region of Bangladesh. This online engagement was held to collect information from participants to avoid alienation during COVID-19. Individuals are required to be health professionals from all around Bangladesh, according to the participants' requirements. After obtaining informed consent, 281 health professionals were interviewed, and their data was analyzed. Participants were informed about the procedure and purpose of the study and the confidentiality of the information provided. Every participant consented willingly to be a part of the study during the interview period.

Ethical consent

All procedures of the present study were carried out following the principle of human investigation (i.e., the Helsinki Declaration). Furthermore, the study was conducted

under the ethical guidelines of the Institutional research ethics committee. Formal ethics approval of this research protocol [Reference Number: IEC-101(1)003] was granted by the institutional Ethical Review Board (ERB) of Shahjalal University of Science and Technology, Sylhet-3114, Bangladesh. Participants were informed about the procedure and purpose of the study and the confidentiality of the information provided. Every participant consented willingly to be a part of the study during the interview period.

Measures

The questionnaire contained informed consent along with three sections i.e., Participants' characterization, knowledge, and attitude were utilized to collect data during the interview period.

Survey utensils

In this study, the respondent was categorized by their gender (male/female), their occupation (Doctor/Medical student/Nurse/Medical Science related people/others), and their working institution type (Government/Non-Government). Participants' knowledge, attitude, and hospital facilities toward the NBS were measured using a total of 15 items structured questions (including the accessibility, and economic feasibility of this process) based on other prior studies conducted in Bangladesh as well as other countries. A pilot study was conducted before the inauguration of the final data collection. The knowledge section consisted of 8-item option-based questions concerning the present condition of NBS in Bangladesh (hospital facilities) and health professional perspectives towards NBS. The attitudes section included 5-item questions about NBS (e.g., "What do you think about the parents' act towards Newborn Screening?" etc.). The economic feasibility section questions concerning cost-effectiveness and cost estimation were also included there (e.g., "What do you think about the cost-effectiveness of NBS in Bangladesh?). All options of those answers were coded by a number (i.e., "Yes was coded as 1", "No was coded as 2", and "Maybe was coded as 3").

Statistical analysis

All data were coded and analyzed using two statistical software packages (Microsoft Excel 2019, and IBM SPSS Statistics version 25). Microsoft Excel was used to perform data cleaning, coding, editing, and sorting. An Excel file including all variables was imported into SPSS software. Descriptive statistics (e.g., frequencies, percentages, etc.) and some first-order analysis by Cross tab (e.g., Chi-square tests, Fisher's Exact test) were performed using SPSS software. Those tests were performed to examine the significant relationship between categorical variables and estimate their significance level. In addition, multiple response analysis was performed to define "multiple response sets" which show the facilities of the hospital toward NBS.

RESULTS

General characteristics of participants

A total of 281 participants were included in the final analysis among them 59% were male and 41% were female (Table 1). Of all participants, 29.9% were doctors, 55.9%

were medical students, 7.8% were nurses, 3.6% were medical science-related department students and 2.8% were other health professionals. Among male participants, 63 people were working in government institutions and 83 people were working in non-government (private) institutions. Of Female participants, 52 people were working in government institutions and 83 people were working in non-government (private) institutions (Figure 1) In total, 48% were government medical working health professionals and 52% are non-government medical working health professionals (Table 1).

Table 1. Associations between knowledge level and gender, occupation, and working institution.

		Response		Total	Df	P-Value
		Yes	No			
Gender	Male	91	24	115		
		79.1%	20.9%	100.0%		
	Female	129	37	166	1	.777
		77.7%	22.3%	100.0%		
Total		220	61	281		
		78.3%	21.7%	100.0%		
Your present occupation	Doctor	74	10	84		
		88.1%	11.9%	100.0%		
	Medical Student	117	40	157		
		74.5%	25.5%	100.0%		
	Nurse	19	3	22		
		86.4%	13.6%	100.0%		
	Medical science-related department student	6	4	10	4	.013
		60.0%	40.0%	100.0%		
	Others	4	4	8		
		50.0%	50.0%	100.0%		
Total		220	61	281		
		78.3%	21.7%	100.0%		
Medicals where currently working	Government	113	33	146		
		77.4%	22.6%	100.0%		
	Private	107	28	135		
		79.3%	20.7%	100.0%	1	.705
Total		220	61	281		
		78.3%	21.7%	100.0%		

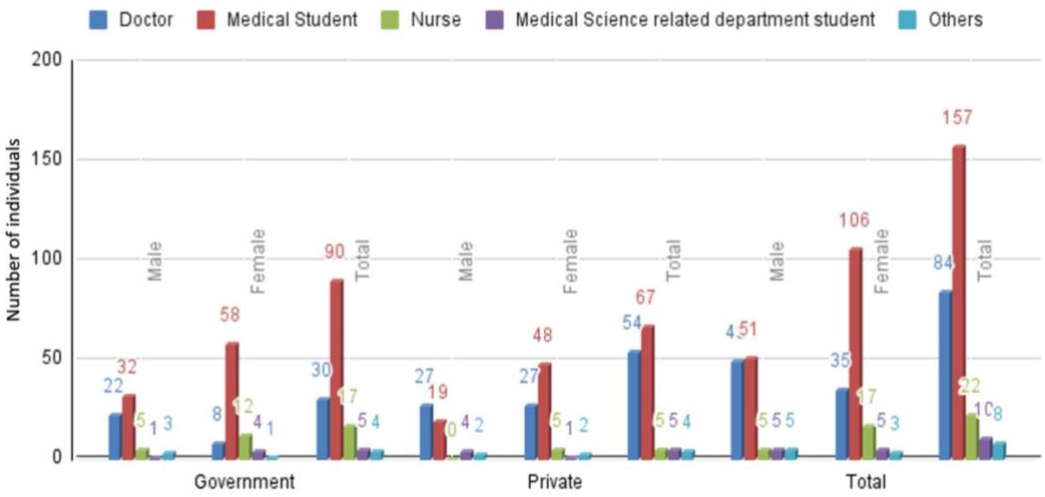

Figure 1. Distribution of participants by gender and workplace type. This figure illustrates the distribution of participants in the study based on their gender and workplace type.

Knowledge about NBS in Bangladesh among participants

The knowledge level of Health Professionals on NBS was mainly categorized into three groups that are good knowledge, and poor knowledge whilst few people would simply give a response to these survey questions by "may-be" when they are confused about their answer or not sure. In general, 78% of participants had heard of newborn screening earlier, whereas 22% had never heard of it before (Figure 2).

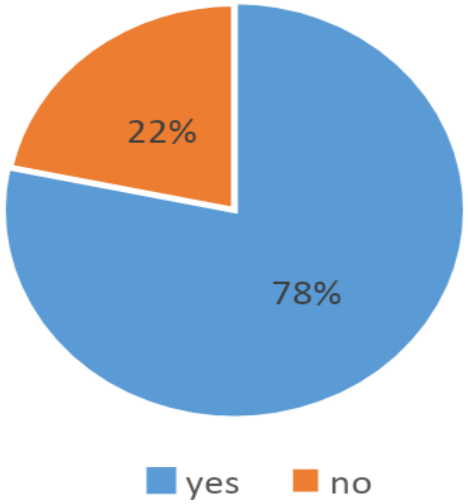

Figure 2. Knowledge level of health professionals on newborn screening (NBS). This figure presents the distribution of knowledge levels among health professionals surveyed regarding NBS.

Different knowledge levels were observed in association with Gender, occupation, and working institution (Table 2). In regard to gender, the knowledge level of Newborn screening was better among males than females (79.1% for male participants and 77.7% for female participants). On the other hand, by comparing the medical sector (both Government and Private), we found that private medical working health professionals have better knowledge (79.3%) than government medical working health professionals (77.4%). But this relationship was not significant. The Present occupation had a significant relationship with knowledge ($p<0.05$). By this, we can say that there is an association between Occupation and Knowledge about NBS. The knowledge level was better among the participants who are Doctors (88.1%) than others (Table 3). We found the P-value by doing Chi-square analysis.

Table 2. Screening availability of newborns utilizing characteristics of the respondents at hospitals in Bangladesh.

Variables	Newborn screening available in hospital (n, %)			Total
	Yes	No	May be	
Male	58, 50.4	27, 23.5	30, 26.1	115, 100.0
Female	81, 48.8	21, 12.7	64, 38.6	166, 100.0
Total	139, 49.5	48, 17.1	94, 33.5	281, 100.0
Doctor	40, 47.6	28, 33.3	16, 19.0	84, 100.0
Medical Student	79, 50.3	11, 7.0	67, 42.7	157, 100.0
Nurse	16, 72.7	3, 13.6	3, 13.6	22, 100.0
Medical science-related department student	3, 30.0	3, 30.0	4, 40.0	10, 100.0
Others	1, 12.5	3, 37.5	4, 50.0	8, 100.0
Total	139, 49.5	48, 17.1	94, 33.5	281, 100.0

There were 44.5% of Government medical records of Newborn Screening which was higher than Private medical 39.3%. Chi-square analysis was done to assess the significant relationship between the types of medical you are currently working on and if your medical keeps a record of Newborn screening. The P-value is .029 which is >0.05.

Views of hospital facilities in Bangladesh for NBS

We also analyzed the Hospital conditions in Bangladesh (how the tests are done, how the samples are collected, which diseases are screened, etc.). But for this, firstly we need to examine the condition of hospitals in Bangladesh. Is NBS available or not in these particular hospitals, these hospitals keep records of NBS or not.

Multiple response analysis was done to know about the hospital facilities toward NBS and to exhibit the rate of what kind of tests were done for NBS and which diseases were screened by NBS (Table 3, Table 4). Blood tests were mostly done for NBS in the Hospital of Bangladesh (31.6%) and also many other tests were performed (Table 3). We can identify that Congenital Hypothyroidism disease was mostly screened by NBS (18.7%) also many other diseases were screened by NBS (Table 4).

Table 3. The table presents frequencies of tests performed in Newborn screening programs.

Types of tests are conducted for NBS	Responses		Percent of cases
	Number	Percent	
Hearing test	79	18.5%	28.1%
Pulse oximetry	83	19.4%	29.5%
Blood test	135	31.6%	48.0%
No idea	120	28.1%	42.7%
Others	10	2.3%	3.6%
Total	427	100.0%	152.0%

The programs are offering an overview of testing practices. It outlines the specific tests conducted during NBS and their corresponding frequencies, providing insights into the frequency of each test.

Table 4. The table displays frequencies of diseases screened in newborn screening.

Diseases screened by NBS	Responses		Percent of cases
	Number	Percent	
Congenital hypothyroidism	136	18.7%	48.4%
Phenylketonuria	67	9.2%	23.8%
Galactosemia	59	8.1%	21.0%
Hemoglobinopathies	105	14.4%	37.4%
Hemophilia	123	16.9%	43.8%
Severe Combined Immunodeficiency	46	6.3%	16.4%
Cystic Fibrosis	27	3.7%	9.6%
Hearing loss	72	9.9%	25.6%
Others	13	1.8%	4.6%
No idea	81	11.1%	28.8%
Total	729	100.0%	259.4%

It is offering valuable information on disease prevalence and screening practices. It assists in assessing the extent and coverage of newborn screening programs.

From the perspective of occupation and working institutions, we observed different types of tests that are done for NBS. These percentages and total are based on our responses (e.g., Doctors who were working in the Government hospital thought that 34.7% of Blood tests, 24.5% for Pulse Oximetry tests, 18.4% for Hearing tests, 8.2% of other tests are done for NBS in their hospital and 14.3% doctors have no idea what kind of tests are done in their hospital). From the perspective of a working institution, different types of diseases are screened by NBS. These percentages and total are also based on our responses (e.g., Congenital Hypothyroidism was screened in Government hospitals at 18.8% and in Private hospitals at 18.5%)

Cost analysis for NBS in Bangladesh

Cost is a great factor in establishing NBS for Bangladesh like poverty experienced in a developing country. The attitude toward the cost-effectiveness of Newborn screening was observed in association with the present occupation. Different thoughts about cost-effectiveness are shown in Figure 3. Among all the participants, medical students thought it was more cost-effective. Also, Occupation had a significant relationship with the cost-effectiveness of Newborn screening ($p<0.05$).

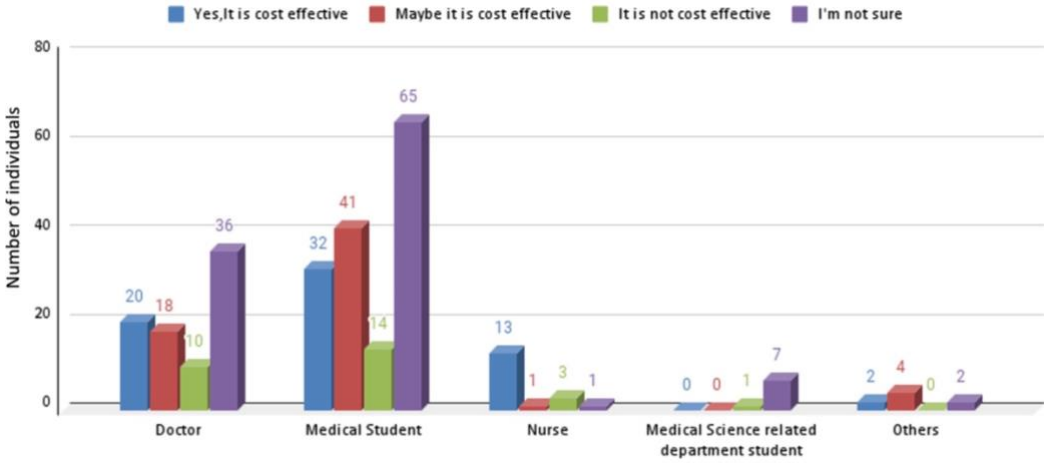

Figure 3. Attitudes towards cost-effectiveness of newborn screening by present occupation. The figure represents the distribution of attitudes towards the cost-effectiveness of Newborn screening among participants based on their present occupation. The data indicates that medical students exhibited a higher belief in the cost-effectiveness of Newborn screening compared to participants with other occupations. The significance of the relationship between occupation and the perception of cost-effectiveness was determined to be statistically significant ($p<0.05$).

DISCUSSION

The purpose of this study was to get a better understanding of newborn screening procedures and to provide information regarding newborn screening knowledge, views, and access among Bangladeshi health professionals. This study's contribution, we believe, will be not only in determining what health professionals know and don't know about newborn screening, how the tests are performed, which diseases are screened by NBS, and the importance of NBS, but also in understanding why some of them don't know about these issues and the possibility of developing an approach to enhance education and awareness among health professionals and expand the hospital's facilities for prophylactic screening.

Several countries have taken different tactics, and the situation varies widely around the world. In North America, each state has its screening process, including a minimum IEM. However, there is no agreement in the European Union concerning which IEMs should be screened [32]. For the past 50 years, Australia has had an effective newborn screening program. Phenylketonuria, hypothyroidism, galactosemia, and cystic fibrosis were initially screened for, with even more recently expanded screening for fatty acid oxidation disorders, amino acid disorders, as well as organic acidemias'. All Australasian laboratories currently screen for more than 25 disorders [33]. Screening for seven genetic abnormalities, including four IEM, was made mandatory in the Spanish National Health System in 2013. PKU (phenylketonuria), MCADD (medium-chain acyl-CoA dehydrogenase deficiency), LCHADD (long-chain 3-hydroxy acyl-CoA dehydrogenase deficiency), and GA-1 (glutaric aciduria type 1). Yet, in practice, NBS is dictated by regional regulations, therefore there is a lack of consistency in testing for

abnormalities at birth across the country. In 2011, the Community of Madrid launched an extended NBS (ENBS) with MS/MS, which included 17 metabolic disorders [34]. In this study, our participants responded by mentioning which diseases are currently being screened in Bangladesh. Congenital hypothyroidism, Phenylketonuria, Galactosemia, Hemoglobinopathies, Hemophilia, Severe Combined Immunodeficiency Syndrome, Cystic Fibrosis, hearing loss, Congenital heart disease, Microcephaly, Hydrocephalus, Down syndrome, Neonatal jaundice, LBW, Congenital Heart Diseases, and others are among the diseases on the list. Congenital Hypothyroidism (18.7%), Hemophilia (16.9%), Hemoglobinopathies (14.4%), Hearing Loss (9.9%), Phenylketonuria (9.2%), Galactosemia (8.1%) are among the most frequently tested disorders, according to our participants.

In the United States, all states take blood samples from newborns to conduct screening tests. These specimens or sections of them (often known as blood spots) are typically preserved for a length of time. At the moment, each state decides what happens to each blood sample after the screening tests. It is exceedingly difficult to acquire accurate national data because newborn screening regulations vary among states. Different nations' protocols differ in many ways, including specimen collection, diagnosis, organization, follow-up, and therapy. The NBS program is implemented in Spain, as it is in other European countries such as Belgium, Bosnia, Germany, Italy, and the United Kingdom. The Newborn Bloodspot Screening Working Group (NBSWG) was created by the Standing Committee on Screening in 2014 to produce a national policy framework for newborn screening in Australia [35]. National programs in New Zealand, the United States, the United Kingdom, Canada, and the Netherlands are being examined as possible precedents. The NBSWG's main task is to provide an evidence-based decision-making framework for determining whether conditions should be added to or removed from the newborn screening panel [7]. The results of the investigation indicated the current state of newborn screening in the hospital. When we examine the responses of the participants, we see that several tests were performed for newborn screening. Hearing test, Pulse oximetry test, Blood test, Karyotyping, Echo, Anomaly scan, X-Ray Arm/Leg, Blood grouping, CRP, S. Electrolytes, S. Creatinine, S. Calcium, CBC, S. Bilirubin, LXL, Portable CXR, and others are some of the tests available. The majority of individuals in this research said that blood tests are usually done for NBS (31.6%). Pulse oximetry (19.4%) and hearing tests are also conducted frequently. The majority of participants also stated that the preponderance of blood samples was acquired by heel prick (26%) and cord blood (14%) (25.3 %). As a result, we looked at the percentages of those tests and illnesses that were screened at various hospital types to determine our hospital condition for newborn screening. This survey confirms earlier research, which has consistently revealed highly positive attitudes toward NBS. NBS is seen as a regular element of the birthing process, with minimal discussion among HCPs and parents. In Bangladesh, there is currently an inadequate study on newborn screening. As a result, there is currently insufficient information available on the internet. Health professionals' Knowledge, Perspectives, Practices, and Hospital Facilities are critical in a resource-constrained nation like Bangladesh. By analyzing the data, this study contributes new information. Further research into these findings might give insight into aspects of the research that assist parents to become more conscious and make more informed decisions, as well as promote an understanding of NBS programs and save many children's lives.

Robert Guthrie, a researcher in the United States who is commonly regarded as the "father of newborn screening," pioneered newborn screening in the 1960s. Since descriptive research on how the offer of NBS is conveyed to parents is lacking, determining the experience of consent in practice is challenging. Understanding the

perspectives of people who have directly participated in the consent process may provide useful descriptive data for NBS programs and providers [36].

This study looks into how parents act differently. Its affordability can play a significant role in making it more accessible. Even parents who are not well-off are interested in having their baby checked, provided it is cost-effective. The understanding and awareness of newborn screening methods among parents and professionals were minimal. Parents preferred concise, to-the-point information about newborn screening and its advantages, as well as the possibility of retesting and the significance of returning for retesting as soon as possible if the initial reports were abnormal. Parents, providers, and newborn screening providers all agreed that a simple, easy-to-read pamphlet with contact information would be beneficial. Parents should get this information before the baby is born, ideally in the third trimester of pregnancy, according to all focus group members. Providers requested a quick summary of information and tools to help them prepare for effective parent education [37].

Bangladesh is a growing country with so many additional problems to contend with. The global newborn screening program is a huge undertaking for a nation like Bangladesh. Finding adequate funding to carry out such a program will be the most difficult challenge. Another big obstacle is the social norm, which still sees over 80% of deliveries done at home. On the other hand, the enthusiasm of medical experts and the government is a very promising indicator in the direction of developing a newborn screening program. It now requires worldwide community collaboration. For a country like Bangladesh, the worldwide newborn screening program is a huge undertaking. The most challenging task will be obtaining sufficient financing to carry out such a program. Another significant big obstacle is the social norm, which still sees over 80% of deliveries made at home. On the other hand, medical professionals and the government's enthusiasm is a very encouraging indicator that a newborn screening program will be developed. It now requires global community cooperation.

CONCLUSIONS

This research highlights the need to address the lack of knowledge, attitudes, and access to newborn screening among health workers in Bangladesh. To improve the situation, actions at the levels of medical education, clinical care, health policy, and information systems are necessary. Proposed solutions include streamlined access to screening results, low-literacy information for parents, and clear communication guidelines for healthcare providers. Community knowledge and mobilization are crucial for successful implementation. Collaboration with the media and e-health technology can help overcome challenges. A nationwide database of diagnosed cases is needed to establish a national screening mechanism, requiring the participation of physicians and Ministry of Health initiatives.

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AUTHOR CONTRIBUTIONS

This work was a collaboration among all the authors. MFM, SNS and RAIR designed outlines of the manuscript. SNS and RAIR wrote the initial draft of the manuscript. SNS, RAIR, FT, SKM collected the data. MGRM, CMOF, GCB and MFM reviewed the scientific contents described in the manuscript. All authors read and approved the final submitted version of the manuscript.

CONFLICTS OF INTEREST

There is no conflict of interest among the authors.

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