International Egyptian Journal of Nursing Sciences and Research (IEJNSR)

Original Article

Received 08/06/2022
Accepted 11/06/2022
Published 01/07/2022

Effectiveness of a Screening Toolkit on Empowering Mothers about Neonatal Screening Tests for Metabolic Disorders and Hearing Defects

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ABSTRACT

Background: Genetic blood screening of newborns to detect inborn metabolic disorders has been recognized as a valuable component of neonatal care for decades. Early detection of these conditions has proven to be an effective way to implement interventions that reduce morbidity, death, and related impairments. **Aim**: To evaluate the effectiveness of a screening toolkit on empowering mothers about neonatal screening tests for metabolic disorders and hearing defects. **Design:** A quasi-experimental design with pre and post-test was used. **Sample:** A convenience sample of 152 mothers was included**. Instruments:** (1): A structured interviewing questionnaire; it includes two parts: (a) Mothers' demographic data. (b) Mothers' awareness about the newborn screening program. (2): Mothers' attitude toward newborn screening program. (3): Mothers' knowledge about metabolic disorders and hearing defects. **Results:** Mothers had a higher mean score of awareness about newborn screening program, knowledge about metabolic disorders, and hearing defects post-intervention compared to pre-intervention. There was a positive correlation between the total score of mothers' awareness about the newborn screening program, metabolic disorders, and their attitudes about the newborn screening program at the 0.01 level of significance. **Conclusion:** The study concluded that implementation of a screening toolkit improved mothers' awareness of newborn screening program, and increased knowledge about metabolic disorders and hearing defects. Also, mothers showed a positive attitude toward the newborn screening program. **Recommendations:** Periodical educational training program for mothers at the maternal and child health centers regarding neonatal screening program, metabolic disorders and hearing defects.

Keywords: Screening Toolkit, Mothers, Neonatal Screening Tests, Metabolic Disorders, Hearing Defects

Introduction

The neonatal period represents a crucial time for a child's survival rate, According to the World Health Organization estimates, about 303,000 newborns die annually within the first four weeks of birth mainly due to congenital anomalies **(World Health Organization, 2017).** Newborn

screening (NBS) is a state-funded healthcare initiative that includes infant screening; parental education, appropriate follow-up, diagnostic testing, disease management, and ongoing evaluation are all part of the service. The newborn screen is a series of laboratory tests and point-of-care examinations performed on newborn infants to identify clinically occult but potentially serious disorders that require immediate intervention. **(McCandless &Wright ,2020).**

NBS completed by testing asymptomatic newborns so that problems can be identified and treated before they occur. It is offered to all newborns and is performed shortly after birth, with the best age for the test being 72 hours to five days after delivery, and those who had not been screened up to two months of age seek to distinguish a certain uncommon, but serious genetic, congenital, and metabolic disorder that may be life-threatening **(IJzebrink et al., 2021).**

With about 100,388 million people and 2.6 million births per year, Egypt has the largest and fastest-growing population in the Arab world (**United Nations, Department of Economic and Social Affairs, Population Division, 2019).** The Egyptian neonatal screening program for congenital hypothyroidism began in April 2000, while the phenylketonuria test began in November 2015. However, additional neonatal screening for genetic and metabolic illnesses in Egypt is still underdeveloped and is just as small studies for researches purpose **(PerkinElmer, 2014).** NA national program for early detection and intervention of hearing impairment was included in the presidential initiative for early detection of hearing problems in May 2019. A total of one million and 151, 284 newborn children have had their hearing tested across the country **(Egypt today, 2020)**.

The disorders targeted by NBS are typically those that would result in significant morbidity, mortality, or intellectual disability if left untreated. However, the disorders chosen for screening have been and continue to be influenced by technological capability, screening efficiency and cost-effectiveness, therapeutic intervention potential, and other political and ethical considerations. **(Bailey & Zimmerman, 2019)**.

Mothers need to be informed about the nature and purpose of NBS. Providing adequate information about NBS to mothers before testing aid in reducing parental distress in the event of a positive or false-positive screening result **(Franková et al., 2019)**. Despite the availability of parental information, a lack of parental knowledge about newborn screening is one of the most common challenges in newborn screening **(Franková et al., 2021)**. Several studies have discovered a link between a lack of parental knowledge and the distress caused by false-positive test results. This emphasizes the importance of mothers gaining and retaining information about newborn screening **(Ulph et al., 2017)**.

Primary care providers such as pediatricians, family medicine physicians, nurse practitioners, and residents play a crucial role in

the NBS process from obtaining newborn screening after delivery to diagnosis and treatment **(American College of Obstetricians and Gynecologists, 2015).** Nurses play an important role in the newborn screening program, and their contributions are critical to expanding newborn screening coverage. In a primary care setting or a health facility, nurses are frequently the first point of contact for mothers allowing them to advocate for and educate mothers about newborn screening **(Abad et al., 2019).**

Significance of the study

Only a small number of MENA countries, accounting for 12.2 percent of regional births, have widespread neonatal screening for multiple disorders, according to published data. In the majority of the region, screening is limited to a few conditions in a subset of the population. Because of limited access, the prevalence of heritable diseases in the MENA region is likely to be underestimated **(Alkhazrajy & Hassan, 2015).**

Congenital hypothyroidism affects approximately one in every 1,400 babies in the Middle East. In Egypt, where there are 2.6 million births per year, an estimated 1,857 children are born with congenital hypothyroidism (**PerkinElmer, 2014)**. Because of the prevalence and impact of sickle cell disease throughout Sub-Saharan Africa, this group of disorders is the most crucial for NBS in a large portion of the continent. Every year, approximately 400,000 babies are born with sickle cell disease around the world, with Sub-Saharan Africa accounting for more than 75% of these births **(Therrell et al., 2015).**

Extrapolations of phenylketonuria prevalence and incidence statistics by countries and regions in 2015, which only provide a general indication of the actual incidence of phenylketonuria in each region, revealed that in the Middle East region, extrapolated incidence to a population estimated used was 14 % in Iraq; 11 % in Libya; and 10 % in Egypt **(Statistics by Country for Phenylketonuria, 2015)**. One of the most common global health concerns is hearing loss. According to the World Health Organization, 466 million people worldwide suffer from hearing loss. Children account for 34 million of this total. More than 900 million people will have disabling hearing loss by 2050, according to projections **(Elbeltagy et al., 2019).**

Unfortunately, the culture and awareness of newborn screening are still lacking among both targeted mothers and health care providers. Adherence of the health care providers to the Ministry of Health and Population guidelines of proper neonatal care and screening is considered also an important debate [17]. **Therefore;** the study aims to evaluate the effectiveness of a screening toolkit on empowering mothers about neonatal screening tests for metabolic disorders and hearing defects. **(Therrell et al., 2015).**

Operational definition of screening toolkit:

In this study, a screening toolkit is defined as printed guidelines and educational sessions developed to improve mother's knowledge about

neonatal screening tests for metabolic disorders and hearing defects.

Research hypotheses:

1. Mothers who will receive a screening toolkit will have improved awareness about the newborn screening tests.
2. Mothers who will receive a screening toolkit will have a positive attitude toward newborn screening tests.
3. Mothers who will receive a screening toolkit will have increased knowledge about metabolic disorders and hearing defects.

Methods

The purpose of the study: evaluate the effectiveness of a screening toolkit on empowering mothers about neonatal screening tests for metabolic disorders and hearing defects.

Research Design:

A quasi-experimental design with (pre and post-test) was utilized.

Research setting:

The study was carried out at the maternal and child health center a multi-stage random selection of 2 districts in the Menoufia Governorate was done. The researchers randomly selected and conducted this study at maternal and child health center in Berket El Sabae district and El Iraqia rural health unit from El -Shohada district, Menoufia governorate, Egypt.

Subjects: A convenience sample of 152 mothers who attended the previously chosen settings.

Inclusion criteria

a) Aged between 20-40 years old
b) Pregnant mothers attending maternal and child health center for antenatal care
c) Mothers had children aged between 3 days and 2 months
d) Agree to participate in the research study.

Exclusion criteria:

a) The researchers excluded mothers working in the medical field

Sample size:

The sample size was calculated using the Epi Info 7.2 program. Based on a past review of the literature **(Mendes et al.2017)** reported that the knowledge of mothers of babies who were born in public maternity hospitals about the heel prick test was 70%. With α error=5% and a study power of 80%, the sample size was calculated to be 138. We added another 14 (10%) to the sample to compensate for non-responders: therefore, the total sample size was 152.

The instruments of data collection:

Three instruments were used to collect data for the study.

Instrument one: A structured interviewing questionnaire was developed by the researcher, guided by **(Franková et al., 2019)** after reviewing related literature. It was designed to collect data about mothers' awareness of neonatal screening tests. It was consisting of two parts.

i. **Part one:** Socio-demographic characteristics of studied mothers such as age, educational level, occupation, residence, number of pregnancies, duration of current pregnancy, care provided during pregnancy, family history for metabolic disorders, and source of information about NBS.

ii. **Part two:** Mothers' awareness about the newborn screening test questionnaire. It consisted of 6 questions including the definition of a newborn screening test, the purpose of NBS, the timing of the sample, screened diseases, results of NBS, and how to deal with the results. Scores of each statement ranged from zero for don't know & incorrect responses to 1 for correct response. The total score of the questionnaire ranged from 0-to 6 points. A higher score of 4 indicates sufficient awareness (> 60 %) whiles a score less than 4 indicates insufficient awareness (≤ 60%). The reliability of the scale was tested using test-retest reliability with a two-week interval. The internal consistency Cronbach Alpha Coefficient of the total scale was r = 0.81.

Instrument two: Mothers' knowledge about metabolic disorders and hearing defects questionnaire. It was developed by the researchers guided by **(Michael, 2019)** after reviewing the related literature. It was developed to assess the mothers' knowledge about metabolic disorders (congenital hypothyroidism, phenylketonuria, sickle cell disease) and hearing defects. It consisted of 24 items; each metabolic disorder included 6items (definition, causes, sing and symptoms, diagnosis, treatment, and complication) and 6 items for hearing defects. Scores of each statement ranged from zero for don't know & incorrect responses to 1 for correct response. The total score of the questionnaire ranged from 0-to 24; a score from 15 indicates satisfactory knowledge (> 60 %) and a score less than 15 indicates unsatisfactory knowledge (≤ 60%). The reliability of the scale was tested using test-retest reliability with a two-week interval. The internal consistency Cronbach Alpha Coefficient of the total scale was r = 0.87

Instrument three: Mothers' attitude toward newborn screening tests questionnaire. It is a three-point Likert scale that included 9 items to assess the mothers' attitude toward the newborn screening program. It was adopted from **(Abed & Twfeeq, 2016).** It ranged from disagreeing to agreeing. The total scores of the questionnaire ranged from 0-18: a score from 10 indicates a positive attitude (> 50 %) and a score from 0-9 indicates a negative attitude (≤ 50%). The reliability of the scale was tested using test-retest reliability with a two-week interval. The internal consistency Cronbach Alpha Coefficient of the total scale was r = 0.84.

Validity and Reliability: Tools were developed by the researcher for data collection after a review of past and current literature, and local and international related literature using books, articles, periodicals, and magazines. Then, the tools were submitted to a panel of three pediatric nursing experts for validity purposes. Tools' reliability was tested by Cronbach's Coefficient Alpha.

Ethical consideration

An official Approval was obtained from the Research and Ethics Committee of the Faculty of. Also, official permission for data collection was obtained from the dean of faculty of nursing, Menoufia university to the directors of maternal and child health centers. Written consent was obtained from mothers related to their acceptance to share in the study after an initial interview was done to inform the mothers about the purpose and methods of data collection to gain their cooperation. They were assured that the information collected would be treated confidentially and that it would be used only for research. They informed that their participation in the study was strictly voluntary, though they were free to withdraw at any time.

Pilot study

Before beginning data collection after the instruments were developed, a pilot study was carried out on 10 % of the total sample (15 mothers) to test the applicability, consistency, practicability, clarity, and feasibility of the study instruments and to estimate the needed time to fill the instruments. The researchers did not modify the tools. All mothers involved in the pilot study were excluded from the study sample.

Data collection procedure

Data collection started on August 15, 2021 to February 20, 2022.

- The researcher introduced herself to the mothers who participated in the study and explained the purpose of the study and methods of data collection.

I. **Phase I (assessment phase):**

- The researchers interviewed every mother and asked her to fill the structured interviewing questionnaire about socio-demographic characteristics; mothers' awareness of newborn screening program, knowledge about metabolic disorders (congenital hypothyroidism, phenylketonuria & sickle cell disease); hearing defects, and their attitude toward newborn screening test within 20 minutes (pretest).

II. **Planning Phase:** This phase includes analysis of the assessment phase (pre-test) findings and the researcher's identification of the actual needs of the studied mothers. The researchers designed a screening toolkit for the screening test and metabolic disorders (congenital hypothyroidism, phenylketonuria & sickle cell disease) and hearing defects. Each topic contains a background document that provides information and data on the epidemiology of specific conditions (such as risk factors, the burden of morbidity, and mortality), with an emphasis on public health approaches. We have also attempted to provide some information on the effectiveness and cost-effectiveness of performing NBS and early detection of metabolic disorders. As part of the Toolkit, we provide a range of demographic, health services, and epidemiological data that are relevant at global, regional, and national levels. It consisted of educational and training sessions for mothers that were developed based on identified areas of weakness in

mothers' knowledge and awareness; it included the number of sessions, content and teaching methods. The objectives for a screening toolkit were set as follows.

III. General objective

1. To provide mothers knowledge about newborn screening tests & metabolic disorders & hearing defects and encourage positive attitudes toward neonatal screening test and caring for children with metabolic disorders.

Specific objectives

By the end of the educational sessions, mothers would be able to:

1. Identify purposes of the neonatal screening test.
2. Identify the proper time for the neonatal screening test.
3. Identify the epidemiology of specific metabolic disorders
4. List the causes and risk factors for metabolic disorders.
5. Categorize signs and symptoms of different metabolic disorders.
6. Classify proper treatment of different metabolic disorders.
7. Explain how to prevent complications of different metabolic disorders.
8. Utilize healthy eating & planning of healthy meals for managing metabolic disorders such as (Phenylketonuria).
9. Follow the steps for the prevention of sickle cell crisis.
10. Demonstrate a positive attitude toward the importance of periodic checkups for children.
11. Demonstrate a positive attitude toward long-term care for children with metabolic disorders.

- **Implementation Phase:** The neonatal screening toolkit was implemented in the training unit at the maternal and child health centers of the selected settings. The program was implemented in five intervention sessions. Two sessions were held each week. Each session lasted between 30 and 45 minutes. Each session had ten mothers. The researchers used teaching strategies such as think-pair-share, workshop, discussion, debate, storytelling, role-playing, PowerPoint presentations, demonstration, videos, and brochures were also used. The researcher obtained oral feedback from the mothers at the end of each session by asking questions and allowing free comments. All precautionary measures against the COVID-19 pandemic were implemented, including (Wearing masks - spacing distances - using hand sanitizers - reducing the number of groups to 10 participants within the group). The first session contained theoretical knowledge about the neonatal screening test and its appropriate time of performance. Also, how blood samples are obtained, the importance of neonatal screening test, the interpretation of results,

and the referral place for a positive result of the screening test.

- The second session included health education about congenital hypothyroidism definition, risk factors, and causes, the clinical manifestation of an infant presented with congenital hypothyroidism, diagnostic tests, management and treatment of the disease, long term effects of the disease, and how to prevent the complications.
- The third session was applied to address all issues concerned with Phenylketonuria disease. The researcher explained to the participants' definition, risk factors, and causes, the clinical manifestation, diagnostic tests, diet management and treatment of the disease, long-term effects of the disease, and how to prevent the complications.
- The fourth session was applied to address all issues concerned with sickle cell disease. The researcher explained to the participants' definition, risk factors, and causes, the clinical manifestation, diagnostic tests, management and treatment of the disease, long-term effects of the disease, and how to prevent the occurrence of sickle cell crisis.
- The fifth session was applied to address all issues concerned with hearing defects, problems of hearing defects, management and treatment of hearing defects, assistive aids used, and how to use them as hearing aids, social support was provided including (peer & family interaction). A revision and summary were performed on the neonatal screening program, congenital hypothyroidism, Phenylketonuria, sickle cell disease, and hearing defects.

IV. Evaluation Phase:

Post-test was done immediately following the implementation of a screening toolkit to assess mother's awareness about the newborn screening tests (instrument 1) , mothers knowledge about metabolic disorders and hearing defects (instrument 2) and mothers attitude toward newborn screening tests (instrument 3).

Statistical analysis

Data were collected, tabulated, and statistically analyzed by an IBM-compatible personal computer with SPSS statistical package version 22. The descriptive statistics were expressed as mean and standard deviation for continuous data while categorical variables were expressed as counts and percentages. Chi-square ($\chi 2$) test was used to study the association between categorical variables. Wilcoxon signed-rank test (nonparametric test) was used for comparison between two related groups having not normally distributed quantitative variables. Pearson correlation test (r) was used to measure the association between two quantitative variables. A statistical significance was considered at a P-value ≤ 0.05.

Results

Tables (1) showed that nearly half of the studied mothers (48% & 44.1%) were between 25 and 29 years old and completed their education at the university. Regarding the occupation, approximately half of them were housewives (53.9%). Of residents, about 59.21% of them lived in rural areas. About the total number of pregnancies, about 56.6% of the studied mothers had between 3-5 pregnancies, and the duration of the current pregnancies were between 24 and 36 weeks for 67.97% of the studied mothers. About the family history of metabolic disorders, about 71.1 % of them had no previous history of metabolic disorders. About 28.9 % of the studied mothers had a family history of metabolic disorder, 13.8 % of them had congenital hypothyroidism, 10.5% had a hearing defect and 4.6% had sickle cell anemia.

Figure (1) represented the distribution of information received at antenatal care among studied mothers. 40% of mothers received information regarding the importance of using multivitamins and about a quarter of the studied mothers received about the importance of eating nutritious food.

Figure (2) represented the distribution of sources of information received at antenatal care among studied mothers. Three-quarters of mothers received their antenatal information from the gynecologist.

Table (2) showed that most mothers (91.4 %) have sufficient awareness of newborn screening tests post-intervention compared to pre-intervention (8.6%). In addition, the mean score increased from 2.72±2.46 pre-intervention to 5.51±1.17 post-intervention. Therefore, there were highly statistically significant differences between mothers' awareness of newborn screening test after the intervention at a 1 % level of statistical significance.

Table (3) illustrated that mothers had a higher mean score of knowledge about metabolic disorders (Congenital hypothyroidism, Phenylketonuria & Sickle cell disease) post-intervention compared to pre-intervention (5.28±1.61, 4.96±2.03, 5.11±1.74 & 1.95±2.59, 1.95±2.59, 1.21±2.14). Therefore, there were highly statistically significant differences between mothers' knowledge about metabolic disorders at a 1% level of statistical significance.

Table (4) showed that the mean score of mothers' knowledge about metabolic disorders increased from 1.76±2.16 pre-intervention to 15.35±5.05 post-intervention. Also, the mean score of the mother's knowledge of hearing defects increased from 1.76±2.16 pre-intervention to 4.46±1.45 post-intervention. Therefore, there were highly statistically significant differences between mothers' knowledge regarding metabolic disorders and hearing defects after the intervention at a 1 % level of statistical significance.

Table (5) clarified that post-intervention; the majority of mothers (84.9 %) have a positive attitude toward the newborn screening test. In addition, the mean score increased from 4.85±3.75 pre-intervention to 12.51±1.95 post-intervention.

Therefore, there were highly statistically significant differences between mothers' attitudes post-intervention at a 1 % level of statistically significant

Table (6), fig (3), and fig (4) showed a positive correlation between the total score of mothers' awareness about the newborn screening tests, metabolic disorders, and their attitude. It reflected that there was a very highly significant positive correlation between total knowledge and total attitude at 0. 001 level of statistical significance.

Table 1: Socio-demographic characteristics of the studied mothers (N = 152).

Item	No	%
Age groups (years)		
<25	40	26.31
25–29	72	48
30–34	30	19.74
>35	10	6.58
Educational level		
Primary education	35	23.0
Secondary education	50	32.9
University education	67	44.1
Residence		
Urban	62	40.78
Rural	90	59.21
Mother's occupation		
Housewife	82	53.9
working	70	46.05
Total number of pregnancies		
<2	60	39.5
3–5	86	56.6
≥6	6	3.9
Family history of metabolic disorder:		
Yes	44	28.9
No	108	71.1
If yes, mention the disorder:		
Hypothyroidism	21	13.8
Sickle cell anemia	7	4.6
Hearing defect	16	10.5

Figure (1): Distribution of information received at antenatal care among studied mothers (N=152).

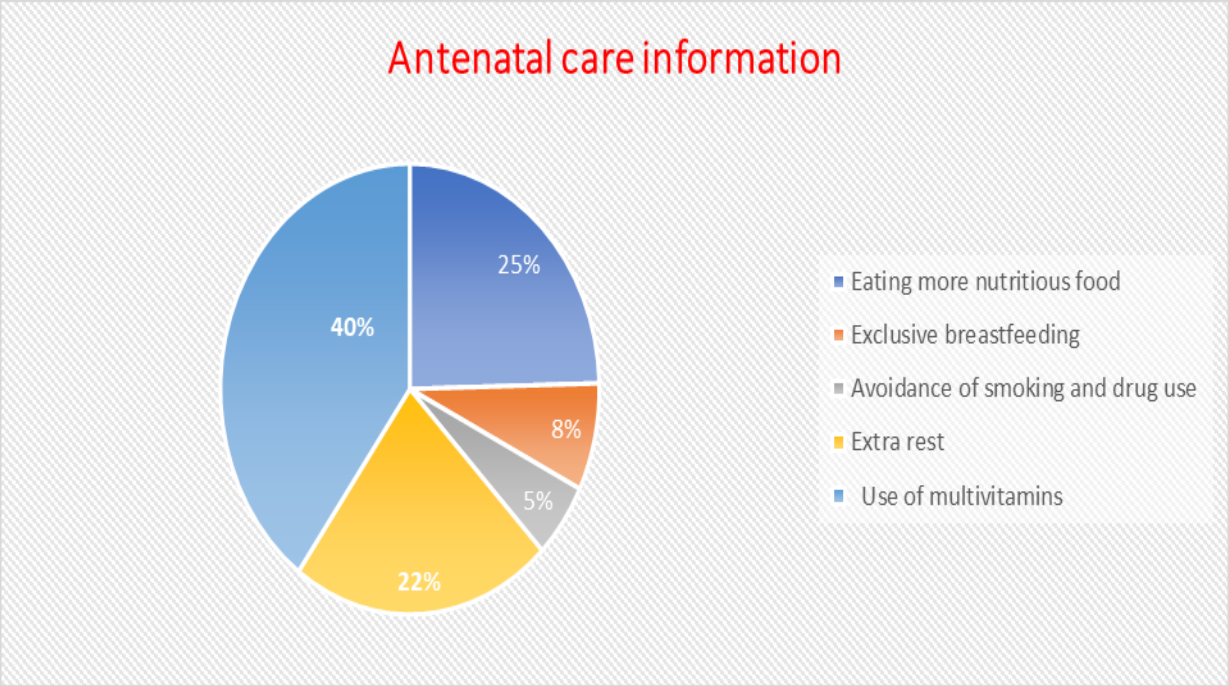


Figure (2): Distribution of mothers about antenatal care sources of information.

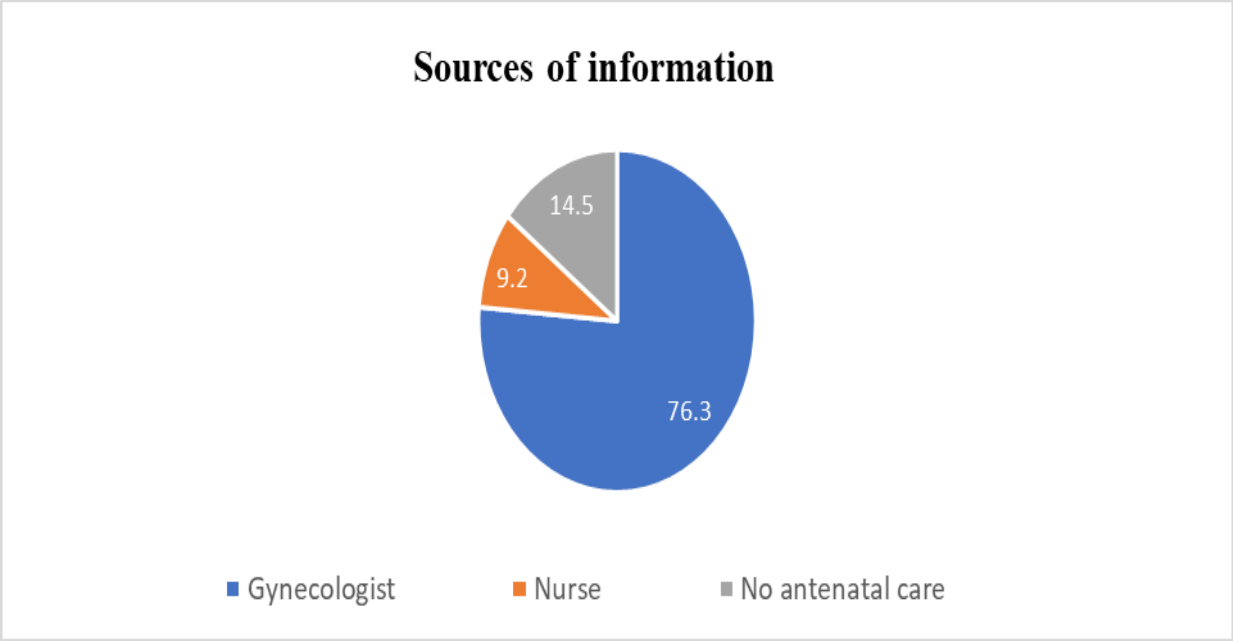


Table (2): Total mean score of mothers' awareness about newborn screening test (NBS) pre and post-intervention (N=152).

Items:	Pre-intervention		Post-intervention		χ^2	P-value
Total mother's awareness about NBS:	**No**	**%**	**No**	**%**		
-Sufficient awareness	69	45.4	139	91.4	74.59	< 0.001
-Insufficient awareness	83	54.6	13	8.6		
Mean ±SD	2.72±2.46		5.51±1.17		**Wilcoxon test** 13.23	< 0.001

Table (3): Mean score of mother's knowledge about metabolic disorders Pre and post-intervention (N=152).

Items:	Pre-intervention	Post-intervention	Wilcoxon test	P-value
Congenital hypothyroidism	1.95±2.59	5.28±1.61	13.32	< 0.001
Phenylketonuria	1.46±2.10	4.96±2.03	14.26	< 0.001
Sickle cell disease	1.21±2.14	5.11±1.74	16.81	< 0.001

Table (4): Total mean score of mothers' knowledge about metabolic disorders and hearing defects pre and post-intervention (N=152).

Items	Pre-intervention		Post-intervention		χ^2	P-value
	No	**%**	**No**	**%**		
The total mean score of mothers' knowledge about metabolic disorders					**Wilcoxon test**	
Mean ±SD	4.63±6.08		15.35±5.05		9.48	< 0.001
The total mean score of mothers' knowledge about hearing defects					**Wilcoxon test**	
Mean ±SD	1.76±2.16		4.46±1.45		13.81	< 0.001

Table (5): Total mean score of mothers' attitudes about newborn screening test pre and post-intervention (N=152)

Items:	Pre-intervention		Post-intervention		χ^2	P-value
	No	%	No	%		
Total mother's attitude about NBS:						
-Positive attitude	65	42.8	129	84.9	58.35	
-Negative attitude	87	57.2	23	15.1		< 0.001
Mean ±SD	4.85±3.75		12.51±1.95		**Wilcoxon test** 22.26	< 0.001

Table (6): Correlation coefficient between the total scores of mothers' awareness about newborn screening test and knowledge about metabolic disorders and the total attitude score of studied mothers post-intervention (N=152).

The total score of awareness and knowledge Post-intervention	Total attitude score Post-intervention	
	R	P
- **Total awareness score about the newborn screening program**	0.85	< 0.001
- **Total knowledge score about metabolic disorders**	0.79	< 0.001

Figure (3): Correlation coefficient between total scores of mothers' awareness about newborn screening test and total scores of mothers' attitude regarding neonatal screening test (N=152).

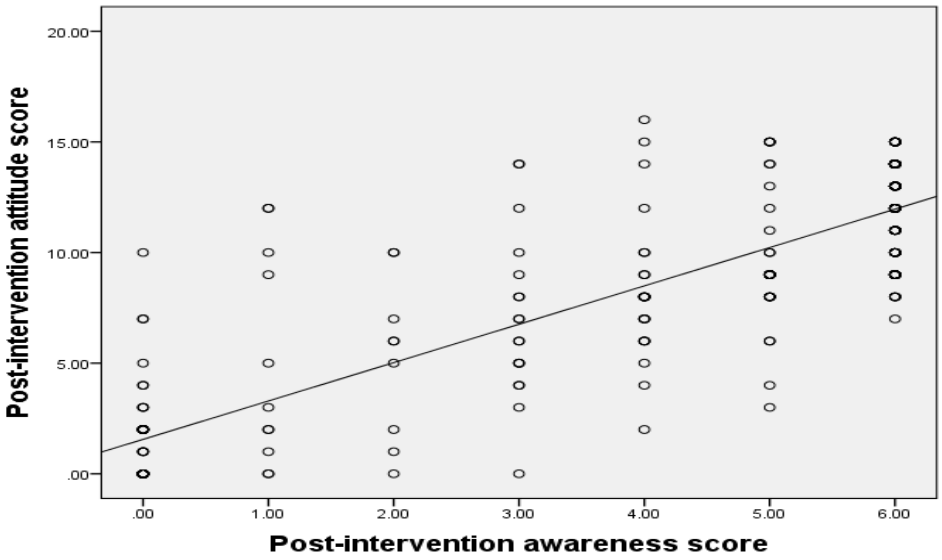
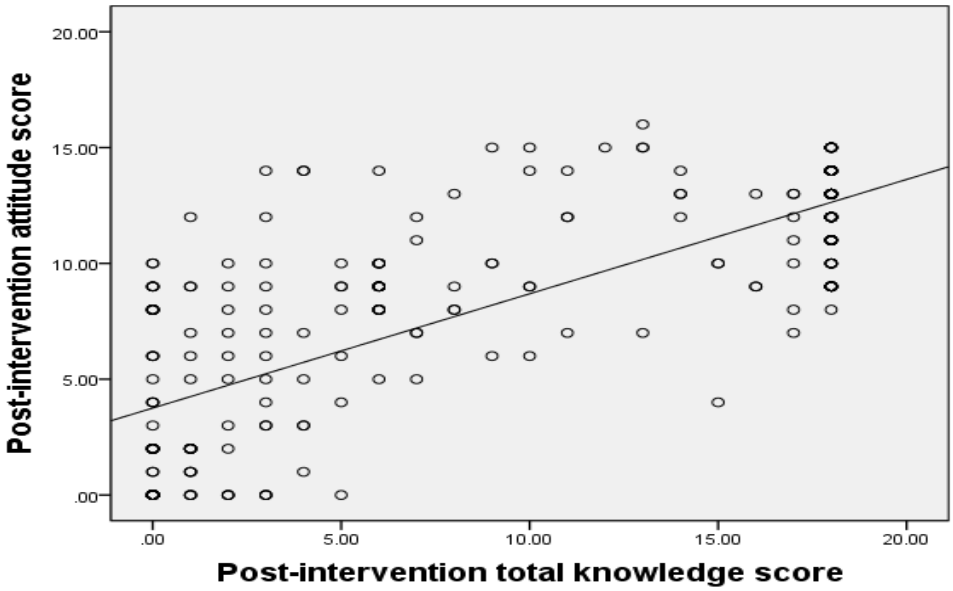


Figure (4): Correlation coefficient between total scores of mothers' knowledge about metabolic disorders and total scores of mothers' attitude regarding neonatal screening test post-intervention (N=152).



Discussion

The newborn screening test is a vital health service for the general public. Early detection using newborn screening tests allows for the prompt transfer of affected infants for treatment, preventing impairments and mental retardation, and saving the lives of infants, families, and communities. It also protects newborns and families from unnecessary invasive measures. It is therefore important to highlight newborn screening tests **(Hui, J. 2020).**

The present study hypothesized that mothers who will receive the newborn screening toolkit will have a better awareness of the neonatal screening test. In addition, mothers who will receive a screening toolkit will have good knowledge about metabolic diseases. And finally, the mothers who will receive a screening toolkit will have good skilled knowledge about the management of metabolic diseases and hearing defects and show a positive attitude toward the newborn screening tests.

Regarding mothers' awareness about the neonatal screening test, the present study revealed that the majority of mothers had sufficient awareness about newborn screening tests post-intervention compared to pre-intervention with statistically significant differences. This result was consistent with **Davey et al., (2005)** who found that women were aware of newborn screening.

On the other hand, this result was inconsistent with **Jatto et al., (2018)** who found that 62% of participants were not aware of the neonatal screening program. Also, **(Alfayez et al. 2018; Arduini et al. 2017; Fitzpatrick et al. 2019; Silva et al. 2017; Twfeeq and Abed 2016)** reported that across cultures, parents' knowledge of the NBS test was consistently below average. Many mothers

reported not knowing what the newborn screening test was or anything about it **(Franková et al. 2019; Twfeeq and Abed 2016).** Mothers frequently conveyed receiving inadequate or no information about the NBS program **(Blom et al., 2020; Franková et al., 2019; Guimarães et al., 2019).** Even among mothers who got information from healthcare providers, there was a lack of understanding of the precise characteristics of NBS. There were a lot of misconceptions about the NBS test **(Franková et al., 2019).**

The finding of our study could be attributed to the effect of a screening toolkit and the appropriate time selected for the intervention. Previous studies appeared that the time at which screening data is given is a basic determinant of women's capacity to satisfactorily retain the data. Therefore, it may be more beneficial for health professionals to try to supply this data during the third trimester of the prenatal period. In addition, to encouraging the comprehension of the materials, presenting data at this time would empower mothers and caregivers to retain more details, and also provide an opportunity for feedback **(Kassem et al., 2022).**

Regarding mothers' knowledge about metabolic disorders (congenital hypothyroidism, phenylketonuria & sickle cell disease), the mothers' knowledge about the diseases improved post-intervention compared to pre-intervention with statistically significant differences. This result was in the same line as **Tariq et al., (2017)** who reported that their study demonstrated a remarkable improvement in knowledge, reported practice, and attitude toward congenital hypothyroidism.

Meanwhile, this result was inconsistent with **Ez Eldeen Mahgoub et al., (2022)** who mentioned that three-quarters of studied mothers had unsatisfactory total knowledge scores about congenital hypothyroidism. While about one-quarter of them had satisfactory total knowledge scores. Also, this finding was incongruent with **Neethu et al., (2020)** who found that less than one-third of mothers showed poor knowledge, more than two-thirds of them showed average knowledge, while no one of mothers showed good or excellent knowledge before counseling. The fact that public health education at antenatal clinics and the immunization centers had a significant impact on the knowledge of care seekers emphasizes the importance of health practitioners in community education. This also reflects the impact of the training course that enhance mothers' knowledge and skills required for the management of hypothyroidism to be able to make informed decisions about their newborns **(El-Enein & Nasar, 2011).**

Regarding mothers' knowledge about phenylketonuria, there were highly statistically significant differences between mothers' knowledge post-intervention compared to pre-

intervention. This result was agreed with **Vitalis et al., (2017)** who revealed that both the parents and the children knew the recommended daily formula intake levels after their intervention. In addition, **MacDonald et al., (2008)** mentioned that overall maternal knowledge of most aspects of diet was good. On the other hand, this was inconsistent with **Elsayed, et al., (2020)** who reported that nearly more than half of them have poor knowledge about PKU. Our findings reflect the effective implication of a screening toolkit, as research confirms the need for professional actions focusing on conveying practical knowledge of the PKU diet to the family. Furthermore, NBS education can be achieved among mothers by receiving information antenatally, from a healthcare professional, or through an information sheet at the time of screening **(Araia, et al., 2012).**

Concerning mothers' knowledge of sickle cell disease (SCD), there were highly statistically significant differences between mothers' knowledge post-intervention compared to pre-intervention. This result was in agreement with **Abd El-Gawad, (2017)** who reported that nearly two-thirds of the mothers had poor knowledge regarding the SCA pretest while; nearly 80 % of them had good knowledge post-test. Meanwhile, this was in disagreement with **Awd, Abdel-Sadik, & El-AAsar, (2018)** who found that approximately two-fifths of mothers had poor knowledge about sickle cell anemia. This improvement to good knowledge post-test assessment might be to mothers' engagement and education in the current study helped them to improve their knowledge and actions regarding SCA in general & specifically. In addition, most studies were performed on children having sickle cell anemia, not on neonates.

Concerning mothers' knowledge about hearing defects, the current study showed that there were highly statistically significant differences between mothers' knowledge regarding hearing defects post a screening toolkit intervention. This result was supported by **Qirjazi, et al., (2020)** who mentioned that the vast majority of mothers were aware of what their baby was being tested for, and the staff involved in hearing screening adequately and appropriately explained the details of a hearing test to mothers. Also, this finding was in agreement with **Elbeltagy, Bakry, and Waly, (2019)** who found that only half of the studied parents showed a good level of knowledge about neonatal hearing screening and hearing loss.

On the other hand, **Jatto et al., (2018)** reported that mothers lacked knowledge about hearing defects and risk factors for infant hearing loss. This could be attributed to differences in setting, demographic characteristics of participants, projects applied in some studies, and policy. Therefore, it is important to consider implementing public awareness programs to improve mothers' knowledge and attitudes about

infant deafness, as well as newborn screening and management to reduce the effects of infant deafness. This indicated that the researchers' screening toolkit intervention method resulted in an improvement and empowerment in mothers' knowledge of metabolic disorders and hearing defects.

Concerning mothers' attitude toward newborn screening tests, there were highly statistically significant differences post intervention. The mothers in this study attributed their positive attitude to the tests being important, useful and preventive, which is consistent with the findings of other studies **(Kasem et al., 2022); Blom et al., 2020; Guimares et al., 2019; Sieren et al., 2016; Twfeeq & Abed, 2016).** Meanwhile, other mothers have used the same predictive quality of NBS as a rationale for not doing the test on their newborns. The dread of receiving a positive screening test is the cause.

The current results revealed a very highly significant positive correlation between the total score of mothers' awareness about the newborn screening test, metabolic disorders, and their attitude. Our findings are consistent with **Ayas, & Yaseen, (2021) and Kassem et al., (2022)** who reported that there was a significant moderate positive relationship between the mothers' knowledge and attitudes. On the other hand, it was inconsistent with **Elbeltagy, Bakry & Waly, (2019)** who revealed no significant association between parents' knowledge and attitude toward hearing loss and their socio-demographic characteristics.

The current study findings indicated the great effect of a screening toolkit on empowering mothers' knowledge about the neonatal screening test, metabolic disorders and hearing defects and eventually changed their attitude. This could be explained by the fact that knowledge plays a key role in modifying behavior when caregivers are provided with the basic knowledge about their children's condition, developmental prognosis, and various treatment approaches. This will assist them in practicing new and healthy behaviors. This is based on behavior modification theory (**Ajzen and Fishbein, 1980; Fishbein et al., 2001),** which determines whether a person's attitude uses knowledge and assumes that it is often practiced increase. In short, if you don't believe or evaluate knowledge, you're less likely to act on it. (National Academies of Sciences, Engineering, and Medicine, 2016).

Conclusion:

Based on the current study's findings and the research hypothesis, it concluded that a screening toolkit improved mothers' awareness of newborn screening tests, and increased knowledge about metabolic disorders & hearing defects. Also, mothers showed a positive attitude toward newborn screening tests.

Recommendations:

Based on the finding of the current study, the following recommendations are suggested:

1- Institutional and community health care providers should have formal education on NBS to have a broader understanding of the programs
2- Periodical educational training program for mothers at maternal and child health centers regarding neonatal screening tests and metabolic disorders.
3- Primary health care providers must explain the NBS program orally or through the distribution of brochures, modules, or pamphlets during the third trimester
4- Developing a guideline booklet for mothers of children with metabolic disease or hearing defects is essential to upgrade their knowledge about the care of children.

References:

1. Abad, P. J. B., Sibulo, S. K., Sur, A. L. D., & Rnd, R.(2019) Role of the nurse in newborn screening: Integrating Genetics in Nursing Education and Practice.
2. Abd El-Gawad,s.,(2017): "Empowering Mothers to Overcome Sickle Cell Crisis in Their Children through Engagement and Education." American Journal of Nursing Research, 5(5): 182-190. DOI: 10.12691/and-5-5-4
3. Alfayez FM, Alamir MA, Alnahwi HA, Aleid DM, Alsheef HJ, Alzakari MJ (2018) Maternal awareness and attitude about neonatal screening program in the eastern region of the Kingdom of Saudi Arabia. The Egyptian Journal of Hospital Medicine 70(2):265–272
4. Alkhazrajy, A. P. D. L. A., & Hassan, A. A. (2015). Evaluation of neonatal screening program applied at primary health care centers in Baghdad/Iraq. European Journal of Biology and Medical Science Research, 3(6), 40-58.
5. American College of Obstetricians and Gynecologists. (2015). Newborn screening and the role of the obstetrician-gynecologist. Committee Opinion No. 616. Obstet Gynecol, 125, 256-260.
6. Araia, M. H., Wilson, B. J., Chakraborty, P., Gall, K., Honeywell, C., Milburn, J., ... & Potter, B. K. (2012). Factors associated with knowledge of and satisfaction with newborn screening education: a survey of mothers. *Genetics in medicine*, *14*(12), 963-970.

7. Arduini GAO, Balarin MAS, da Silva-Grecco RL, de Marqui ABT (2017) Knowledge of puerperal mothers about the Guthrie test. *Revista Paulista de Pediatria*, *35*(2), 151–157. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5496718/pdf/0103-0582-rpp-2017-35-2-00010.pdf
8. Awd, R. A. E. M., Abdel-Sadik, B. R., & El-AAsar, H. N. (2018). Mothers' knowledge and practice regarding care of their children with sickle cell anemia. *Retrieved from pull. edu. eg/eulc_*.
9. Ayas, M., & Yaseen, H. (2021). Knowledge and Attitudes of Parents towards Childhood Hearing Loss and Pediatric Hearing Services in Sharjah, United Arab Emirates. *International Journal of Environmental Research and Public Health*, *18*(12), 6188.
10. Bailey DB Jr, Zimmerman SJ. (2019) The Future of Newborn Screening: Why and How Partnerships Will Be Needed for Success. North Carolina medical journal. 2019 Jan-Feb. PubMed PMID: 30622201]
11. Blom M, Bredius RG, Jansen ME, Weijman G, Kemper EA, Vermont CL, Hollink IH, Dik WA, van Montfrans JM, van Gijn ME (2020) Parents' perspectives and societal acceptance of implementation of newborn screening for SCID in the Netherlands. J Clin Immunol 1–10
12. Davey, A., French, D., Dawkins, H., & O'Leary, P. (2005). New mothers' awareness of newborn screening, and their attitudes to the retention and use of screening samples for research purposes. *Genomics, Society and Policy*, *1*(3), 1-11.
13. Egypt today (2020)Egypt conducts hearing screening for 1.151M children as part of a presidential initiative. available at https://www.egypttoday.com/Article/1/95316/Egypt-conducts-hearing-screening-for-1-151M-children-as-part
14. Elbeltagy, R., Bakry, H. M., & Waly, E. H. (2019). Hearing loss-related knowledge and attitude toward neonatal hearing screening among Egyptian parents. *The Egyptian Journal of Otolaryngology*, *35*(2), 207-212.
15. Elbeltagy, R., Bakry, H. M., & Waly, E. H. (2019). Hearing loss-related knowledge and attitude toward neonatal hearing screening among Egyptian parents. The Egyptian Journal of Otolaryngology, 35(2), 207-212.
16. El-Enein, A., & Nasar, O. (2011). Nurses' Performance and Knowledge Regarding Newborn Screening Program for Congenital Hypothyroidism, EL-Behaira Governorate. *Journal of High Institute of Public Health*, *41*(1), 98-111.

17. Elsayed, A.K., AlRafay, S.S., Khalifa, O.A., and Mohamed, I.A . (2020). Assessment of Mothers' Care toward their Children having Phenylketonuria. *Egyptian Journal of Health Care*, *11*(2), 241-254.
18. Ez Eldeen Mahgoub, Z., Mohammed Adly, R., Rabie Abd Elsadik, B., & Mohammed Abd Elazez, S. (2022). Mothers' Knowledge and Practice regarding Care of their Children with Congenital Hypothyroidism. *Journal of Nursing Science Benha University*, *3*(1), 432-444.
19. Fitzpatrick P, Fitzgerald C, Somerville R, Linnane B (2019) Parental awareness of newborn bloodspot screening in Ireland. Ir J Med Sci 188(3):921–923. https://doi.org/10.1007/s11845-018-1949-0
20. Franková, V., Dohnalová, A., Pešková, K., Hermánková, R., O'Driscoll, R., Ješina, P., & Kožich, V. (2019). Factors influencing parental awareness about newborn screening. *International journal of neonatal screening*, *5*(3), 35.
21. Franková, V., Driscoll, R. O., Jansen, M. E., Loeber, J. G., Kožich, V., Bonham, J., ... & Zeyda, M. (2021). Regulatory landscape of providing information on newborn screening to parents across Europe. European Journal of Human Genetics, 29(1), 67-78.
22. Guimarães MF, Rabelo FA, Figueiredo I (2019) Knowledge about neonatal screening among postpartum women and complexity level of birthing facilities. International Journal of Neonatal Screening 5(1),
8. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7510197/pdf/IJNS-05-00008.pdf
23. Hui, J. (2020). Implementation of Newborn Screening Programme for Inborn Errors of Metabolism in Hong Kong-Progress and Challenges. *HK J Paediatr (new series)*, *25*(1), 1-2.
24. IJzebrink, A., van Dijk, T., Franková, V., Loeber, G., Kožich, V., Henneman, L., & Jansen, M. (2021). Informing Parents about Newborn Screening: A European Comparison Study. International journal of neonatal screening, 7(1), 13.
25. Jatto, M. E., Ogunkeyede, S. A., Adeyemo, A. A., Adeagbo, K., & Saiki, O. (2018). Mothers' perspectives of newborn hearing screening programme. *Ghana Medical Journal*, *52*(3), 158-162.
26. Kasem, A., Razeq, N. M. A., Abuhammad, S., & Alkhazali, H. (2022). Mothers' knowledge and attitudes about newborn screening in Jordan. *Journal of Community Genetics*, 1-11.

27. MacDonald, A., Davies, P., Daly, A., Hopkins, V., Hall, S. K., Asplin, D., ... & Chakrapani, A. (2008). Does maternal knowledge and parent education affect blood phenylalanine control in phenylketonuria?. *Journal of human nutrition and dietetics*, *21*(4), 351-358.
28. McCandless SE,Wright EJ. (2020) Mandatory newborn screening in the United States: History, current status, and existential challenges. Birth defects research. 2020 Mar 1 [PubMed PMID: 32115905]
29. Mendes, C. A., Guigen, A. P., Anastácio-Pessan, F. D. L., Dutka, J. D. C. R., & Lamônica, D. A. C. (2017). Knowledge of parents regarding newborn screening test, after accessing the website "Babies' Portal"-Heel prick test. *Revista CEFAC*, *19*, 475-483.
30. Michael F. Cellucci, MD (2019) Newborn Screening Tests (for parents), numerous children's health, kids health parents available at https://kidshealth.org › parents › newb...
31. National Academies of Sciences, Engineering, and Medicine. (2016). Parenting matters: Supporting parents of children ages 0-8
32. Neethu, J., Anwar, F., Alex, A., Reshma, R., Rajan, R., & Prasobh, G. R. (2020). Assessment of Risk Factors of Congenital Hypothyroidism and Impact of Patient Counselling On Improving Knowledge, Attitude and Practice of the Disease In Post Natal Mothers-A Pilot Study. *American Journal of Pharmacy & Health Research;8*(05) ISSN: 2321-3647
33. Qirjazi, B., Toçi, E., Tushe, E., Burazeri, G., & Roshi, E. (2020). Mothers' perceptions of universal newborn hearing screening in transitional Albania. *PloS one*, *15*(8), e0237815.
34. PerkinElmer, (2014) Egypt, PerkinElmer Build World's Largest Neonatal Screening Laboratory. Available at https://www.perkinelmer.com › stories
35. Sieren S, Grow M, GoodSmith M, Spicer G, Deline J, Zhao Q, Lindstrom M, Harris A, Rohan A, Seroogy C (2016) Cross-sectional survey on newborn screening in Wisconsin Amish and Mennonite communities. J Community Health 41(2):282–288. https://doi.org/10.1007/s10900-015-0094-1
36. Silva MPC, Contim D, Ferreira LA, de Marqui ABT (2017) Guthrie test: pregnant women's perception during prenatal care. Revista Brasileira De Saúde Materno Infantil 17(2):291–298

37. Statistics by Country for Phenylketonuria – Right Diagnosis.com (2015) ,Last updated on April 17, 2015. Available at: http://www.rightdiagnosis.com/p/phenylketonuria/stats-country.htm
38. Tariq, B., Ahmed, A., Habib, A., Turab, A., Ali, N., Soofi, S. B., ... & Ariff, S. (2018). Assessment of knowledge, attitudes, and practices towards newborn screening for congenital hypothyroidism before and after a health education intervention in pregnant women in a hospital setting in Pakistan. *International Health*, *10*(2), 100-107.
39. Therrell, B.L., C.D. Padilla, J.G. Loeber, I. Kneisser, A. Saadallah, G.J. Borrajo and J. Adams. (2015) Current status of newborn screening worldwide: In Seminars in Perinatology, 39: 171-187.
40. Tawfeeq WF, Abed LM (2016) Knowledge and attitudes of mothers toward newborn screening test in Baghdad City. Diyala Journal of Medicine 10(1):66–74171-176 ISSN.
41. Ulph, F.; Wright, S.; Dharni, N.; Payne, K.; Bennett, R.; A Roberts, S.; Walshe, K.; Lavender, T. (2017) Provision of information about newborn screening antenatally: A sequential exploratory mixed-methods project. Health Technol. Assess. 2017, 21, 1–240.
42. United Nations, Department of Economic and Social Affairs, Population Division (2019). World Population Prospects 2019: Data Booklet (ST/ESA/SER.A/424). Available at: https://population.un.org/wpp/Publications/Files/WPP2019_DataBooklet.pdf (accessed Dec. 1, 2019)
43. Witalis, E., Mikoluc, B., Motkowski, R., Sawicka-Powierza, J., Chrobot, A., Didycz, B., ... & Car, H. (2017). Phenylketonuria patients' and their parents' knowledge and attitudes to the daily diet-multi-centre study. *Nutrition & metabolism*, *14*(1), 1-9.