



Mothers' knowledge and attitudes about newborn screening in Jordan

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Abstract

Newborn screening is an important public health program that helps save the lives of many infants worldwide. The aim of this cross-sectional descriptive study was to examine the knowledge and attitudes of mothers regarding the newborn screening test in Jordan. A convenient sample of 301 mothers of newborns was interviewed to collect data, using structured questionnaires about their knowledge and attitudes regarding the newborn screening. Most mothers exhibited positive attitudes toward the newborn screening. However, their knowledge about it was only moderate; their knowledge levels contributed positively to their attitudes to the test. The mothers' source of information about the test was a significant predictor for both their level of knowledge and attitudes toward the newborn screening. The healthcare providers, particularly nurses, were identified as the main source of mothers' information in Jordan. The educative role of the health professionals is key and should be better activated to optimize the outcomes of early newborn screening. Changes in current practices regarding mothers' education about NS is recommended to increase the knowledge and enhance attitude about NS among the mothers.

Keywords Newborns · Neonatal · Screening test · Postpartum mothers · Knowledge and attitudes · Jordan

Introduction

Newborn screening (NS) is a public health program designed to identify and provide early treatment to infants with critical and genetic health problems that are not obvious at birth (Bailey and Zimmerman 2019; Powell 2019). NS programs consist of various internationally recognized tests capable of detecting several disabling and fatal disorders including inborn errors of metabolism, genetic syndromes, hemoglobinopathies, congenital hypothyroidism, congenital adrenal hyperplasia,

cystic fibrosis, and severe combined immunodeficiency (Powell 2019). These disorders share the commonality of being rare—their clinical diagnosis is often extremely difficult and requires urgent treatment to prevent serious health problems, disabilities, and death (Bailey and Zimmerman 2019).

Typically, most NS tests utilize a blood spot taken from a heel prick, collected and dried on filter paper cards, and are often performed at the point of care during the first few hours or days after birth (Powell 2019; Therrell et al. 2015). This procedure is often referred to as the heel-prick screening test (HPST). The results of point-of-care NS tests are often inconclusive; therefore, positive newborn screening needs confirmatory testing (IJzebrink et al. 2021; Powell 2019). More recently, NS programs in a few countries have expanded beyond the HPST to include the bedside detection of hearing loss and congenital heart conditions (Powell 2019; Therrell et al. 2015). Through the early identification and treatment of these conditions, the program has the potential to reduce the rate, severity, and costs related to serious health problems and their consequences in children that may include irreversible disabilities or death (Powell 2019; Therrell et al. 2015).

To optimize the outcomes of the screening program, healthcare professionals should recognize their practical, informative, and educative roles toward parents with

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respect to HPST. Parents should receive timely, complete, and direct-to-the-point information on NS and its benefits, as well as the possibility and importance of returning promptly for repeat testing if the initial results are abnormal (Powell 2019). However, scientific evidence indicates that the present state of parents' education and their knowledge of NS is far from ideal.

Parents' level of knowledge about the NS test was consistently reported to be below average across cultures (Alfayez et al. 2018; Arduini et al. 2017; Fitzpatrick et al. 2019; Silva et al. 2017; Twfeeq and Abed 2016). 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 NS program (Blom et al. 2020; Franková et al. 2019; Guimarães et al. 2019). Even among those who received information from healthcare providers, awareness about the specific aspects of NS was insufficient (Franková et al. 2019). Misconceptions regarding the NS test were commonly documented. Screened conditions (Alfayez et al. 2018; Arduini et al. 2017; Fitzpatrick et al. 2019; Guimarães et al. 2019; Silva et al. 2017), the correct time to perform the test (Alfayez et al. 2018; Silva et al. 2017), and the possibility of false-positive results (Franková et al. 2019) are just a few examples depicting the common areas of inaccurate information that are prevalent among mothers about NS.

It is important for mothers to have adequate understanding and awareness of newborn screening. Current studies showed that mothers who expressed increased awareness and higher levels of knowledge about NS were more committed to having the tests performed for their newborns (Blom et al. 2020; Silva et al. 2017). The mothers' level of information and awareness about NS may vary based on several factors. Among them are the sources of information that the mothers were referred to (Franková et al. 2019), their education level (Alfayez et al. 2018; Arduini et al. 2017; Twfeeq and Abed 2016), and the number and health status of their children (Alfayez et al. 2018; Franková et al. 2019; Silva et al. 2017), etc. Having adequate figures on mothers' information needs and their contributing factors is vital in facilitating the health promotion role of healthcare providers and in optimizing the education outcomes regarding NS.

In several regions around the world, NS programs have been long established, have expanded to include several tests, and are extensively implemented on national levels (Edison et al. 2016; Powell 2019; Therrell et al. 2015). While there is a plethora of studies describing mothers' knowledge, attitudes, practices, and the uptake of NS in countries with well-established NS programs (Coupal et al. 2020; Fitzpatrick et al. 2019; Sieren et al. 2016), the evidence from Middle Eastern countries is still limited in scope and number (Alfayez et al. 2018; Twfeeq and Abed 2016). Such evidence is required the most in countries

where ongoing NS projects are currently expanding, as well as in countries where consanguineous marriage prevails and contributes to increasing rates of inherited newborn disorders. All of this is applicable to the case in Jordan (Islam et al. 2018; Therrell et al. 2015).

Jordan is a Middle Eastern country with an average of 2.7 births per woman (World Bank, 2019). NS in Jordan, operated by the Ministry of Health, is relatively recent. Starting in 2004, the program was limited to screening for phenylketonuria and congenital hypothyroidism. Over the years, the National Newborn Screening Project of Jordan has expanded to include 29 conditions. These include 20 inborn errors of metabolism, three hemoglobinopathies (including the most recently added sickle cell disease), two endocrine disorders, one hearing loss disease, and three other metabolic disorders. The screening tests in Jordan are performed primarily through the HPST (Princess Haya Biotechnology Center, 2016), while the implementation of non-HPST, such as bedside newborn screening of hearing loss, is being considered and is progressing on trial bases in Jordan (Zaitoun and Nuseir 2020; Zaitoun et al. 2020).

The national NS program in Jordan is comprehensive; it is performed at all governmental health centers in Jordan (Malkawi 2020) and includes all citizens, residents, refugees, and diplomatic missions free of charge (Al Kiswani 2021). NS tests are also available at several private laboratories in Jordan. NS receives a high priority in Jordan; when the COVID-19 pandemic forced many health sectors to shift services or shut down, NS has been among the few services that were encouraged and continued during the pandemic (Al Kiswani 2021; Malkawi 2020). In 2020 in Jordan, NS tests were performed for 92% of nearly 190,000 births for Jordanians and foreigners (Al Kiswani 2021). The vast majority of NS tests are performed during the first health visit after the birth to the primary healthcare centers in Jordan, though they may also be performed in private laboratories or in hospitals for healthy and sick newborns.

Printed awareness brochures about NS are regularly available in almost all of the healthcare settings where the NS tests are performed. Frequently, the professionals who perform the test, who are usually nurses, inform the attending parents, usually the mother, that the test is being performed. The NS tests in Jordan are done as an "ordinary practice." There are no specific formal consenting procedures to perform NS or about its storage policies. Participation is a matter of "compulsory choice"; parents are free to choose not to let their newborns undergo NS. Ideally, client education is an expected ethical duty by healthcare professionals. However, there are no explicit policies or research information specifying what or when to educate mothers of newborns about NS. Similarly, there is no information about how consistently the educative role is performed by the healthcare providers obtaining NS tests or the type of information provided.

This study is sought to bridge the information gap regarding mothers' knowledge and attitudes regarding NS in Jordan. This study was performed with the long-term goal of providing research data that would be utilized to optimize the outcomes of NS and facilitating the educative and informative role of healthcare providers by highlighting mothers' level of comprehension and information needs about the test and its contributing factors. The aims of this study are given below:

1. determine the level of knowledge among mothers of newborns about the HPST in Jordan;
2. determine the attitudes toward the HPST among mothers in Jordan;
3. examine how mother's knowledge is linked to their attitudes toward the HPST;
4. identify contributing characteristics regarding the variability in the level of knowledge and attitudes among mothers of newborns toward the HPST in Jordan.

Materials and methods

Design

A cross-sectional descriptive correlational design was applied. The reporting of this paper adhered to strengthening the reporting of observational studies in epidemiology (STROBE) statement (Von Elm et al. 2007).

Sample and setting

All Jordanian mothers, ages ranging from 18 to 40 years, who gave birth to a living newborn and registered with a health service provider were eligible to participate in this study. The mothers were enrolled by convenience from the postpartum maternity wards of two major referral hospitals, one university-affiliated and one public, located in two cities in the North of Jordan. It was not feasible to collect data from the entire country.

Patients' health information is protected by ethical policies at the data collection sites. Only healthcare professionals who are in direct contact with the patients may view their charts. Therefore, one of the researchers collaborated with the nurses, who have ethical access to the medical charts at each hospital, to identify potential participants who met the eligibility criteria, and to ask their permission to meet the researcher. The study was explained to the mothers who agreed to meet the researcher. Accordingly, those interested to participate were interviewed to complete the study questionnaire. A minimum sample size of 153 participants were required to achieve a fully powered multiple regression analysis

given 0.8 power value, 0.05 significance level, and 0.15 effect size by convention, using G* Power 3.0.10 program (Franz Faul et al. 2007b, a; F Faul et al. 2007b, a).

Ethical considerations

Ethical approvals were obtained by the Institutional Review Board located at a university-affiliated hospital and the Ministry of Health, which also approved data gathering at the public hospital. One of the researchers explained the study and the research subject rights to the study participants who signed written consent forms prior to the data collection.

Measurements and variables

The data was collected using a structured questionnaire composed of multiple tools to measure the following variables:

1. Mothers' background information: A data collection tool was designed by the researchers to collect information on mothers' sociodemographic information and other HPST-related questions. The sociodemographic information included the mother's age, educational level, number of children, preexisting congenital and/or genetic disease, and any significant health issues for children (Table 1).
2. Mothers' knowledge about HPST: This variable was measured using 13 items of knowledge about the HPST, which are adapted to reflect the regular practice of NS in Jordan from the previously published literature (e.g., Rosales et al. (2015), Alfayez et al. (2018), Newcomb et al. (2013)). The knowledge scale assesses mothers' knowledge on key information regarding the HPST; responses were measured as "true," "false," or "unknown." A score of 1 was used to weigh a correct answer, while a score of 0 was assigned for incorrect or "I do not know" responses, with the total knowledge score ranging from 0 to 13 and the higher scores indicating a higher knowledge level (Table 2).
3. Mothers' attitude about HPST: This variable was measured using the nine-item attitude scale of a previously published study by Quinlivan and Suriadi (2006). For this study, the response format was adapted for the attitude scale from the original "yes/don't know" format to the three-point Likert scale. The responses of the attitude scale in this study ranged from a score of 1 indicating "disagree" to a score of 3 indicating "agree," ranging the total attitude score from 9 to 27, with the higher scores indicating a more positive attitude toward the HPST (Table 3).
4. Information related to HPST: This included structured questions on sources of information about the HPST,

Table 1 Mothers of newborns sociodemographic characteristic ($n = 301$)

Characteristic	Response	<i>N</i> (%)
Age (years)	18–23	49 (16.4%)
	24–30	125 (41.3%)
	31–35	75 (24.3%)
	> 35	54 (18%)
Number of children	1–2	134 (44.5)
	3–4	118 (39.2)
	5–6	43 (14.3)
	> 6	6 (2)
Education level	No education (< 1 year)	5 (1.7%)
	Schooling level (1–12 years)	100 (33.2%)
	Mid-college diploma (14 years)	62 (20.6%)
	University Bachelor's degree (16 years)	123 (40.9%)
	Master's degree or higher (> 16 years)	11 (3.7%)
Mother's history of genetic diseases	Glucose 6 phosphate dehydrogenase (G6PD)	9 (3%)
	Phenylketonuria (PKU)	0 (0%)
	Congenital hypothyroidism (CHT)	18 (6%)
	Healthy mothers	274 (91%)
Previous children's health issues	No health issues	283 (94%)
	Carrier of congenital or heredity disease	1 (3%)
	Have congenital or heredity disease	14 (4.7%)
	Dead because of congenital or heredity disease	3 (1%)

Table 2 Mothers' knowledge about the heel-prick screening test

Knowledge statements	Mothers' response <i>F</i> (%)		
	True*	False	Unsure
1. The test is a simple procedure for the discovery of genetic and congenital diseases	187 (62.1%)	13 (4.3%)	101 (33.6%)
2. The test is important to ensure the infants' good health condition	226 (75.1%)	3 (1.0%)	72 (23.9%)
3. The test helps in detecting metabolic disorders of an infant to avoid further deterioration of the child's health status	164 (54.5%)	3 (1.0%)	134 (44.5%)
4. When diagnosed early, there is a chance of an excellent prognosis and the newborn may be spared from lifelong impairment and can enjoy a normal life	187 (62.1%)	1 (0.3%)	113 (37.5%)
5. The test aids in the early detection of common genetic and congenital diseases such as PKU, G6PD, and CHT	153 (50.8%)	33 (11.0%)	115 (38.2%)
6. The test can identify more than 25 genetic and congenital diseases	50 (16.6%)	12 (4.0%)	239 (79.4%)
7. The blood spot would help future research related to public health problems	113 (37.5%)	6 (2.0%)	182 (60.5%)
8. The program is operated by the Ministry of Health	199 (66.1%)	3 (1.0%)	99 (32.9%)
9. The test is performed by pricking the newborn's heel	241 (80.1%)	1 (0.3%)	59 (19.6%)
10. The best time to do the test for a newborn is between three to seven days	183 (60.8%)	25 (8.3%)	93 (30.9%)
11. The heel-pricking is performed by a nurse, midwife, or doctor	238 (79.1%)	2 (0.7%)	61 (20.3%)
12. The blood samples will be sent to the Newborn Screening Laboratory center and the result will be released in 7–14 working days	128 (42.5%)	16 (5.3%)	157 (52.2%)
13. If the results of the heel-prick test are abnormal, it means that the newborn has the risk of developing a genetic or congenital disorder	176 (58.5%)	5 (1.7%)	120 (39.9%)

*Correct answer is "true" for all items

PKU, phenylketonuria; G6PD, glucose 6 phosphate dehydrogenase; CHT, congenital hypothyroidism

preferred time to learn about it, and reasons why some mothers would not allow the HPST to be performed on their children.

Adequate psychometrics were reported for both of the original questionnaires (Quinlivan and Suriadi 2006;

Table 3 Attitude of mothers toward the heel-prick screening tests

Attitude statements	F (%)		
	Agree	Neutral	Disagree
1. Useful if it prevents a disease	234 (77.7%)	61 (20.3%)	6 (2.0%)
2. Useful if it reduces the severity of a disease	233 (77.4%)	65 (21.6%)	3 (1.0%)
3. Useful even if it cannot improve the disease as it may help me decide about mothering children in the future	204 (67.8%)	84 (27.9%)	13 (4.3%)
4. Is beneficial to the newborn	264 (87.7%)	36 (12.0%)	1 (0.3%)
5. Is harmful to the newborn	5 (1.7%)	53 (17.6%)	243 (80.7%)
6. Is essential for the well-being of the newborn	248 (82.4%)	51 (16.9%)	2 (0.7%)
7. Is morally justified	239 (79.4%)	58 (19.3%)	4 (1.3%)
8. Is against my religious belief	5 (1.7%)	50 (16.6%)	246 (81.7%)
9. Would make me feel guilty if the newborn is found to have a genetic disease	123 (40.9%)	17 (5.6%)	161 (53.5%)

Rosales et al. 2015). For its use in this study, the items were translated into Jordan's official language (Arabic) following the World Health Organization's guidelines on the translation and adaptation of instruments (WHO 2021). Subsequently, the Arabic version of the questionnaires was critically reviewed by expert scholars and clinicians with variable degrees of specialty in maternal–newborn nursing and practices related to the NS program for face and content validation and terminology matching to the Jordanian culture. A pilot test was conducted to test the applicability of the study protocol, evaluate the readability and clarity of the adapted questionnaire, and estimate the approximate time required to complete it. Internal consistency reliability and content validity were adequate in this study, i.e., the Cronbach alpha coefficients were 0.712 for the attitude scale and 0.909 for the knowledge scale.

Data collection procedure

The data collection was conducted between November (2019) and February (2020). The mothers were interviewed between days 1 and 3 after birth while they were in the postpartum wards. Considering the mother's frail physical state after delivery, the mothers' responses on the structured questionnaires were gathered using face-to-face interviews with the researcher who documented their responses verbatim. At each interview, it took between 10 and 15 min to complete a questionnaire.

Data analysis

The data was coded and transferred into Excel sheets, which then were exported into the Statistical Package of Social Sciences (SPSS), version 21, for analysis. Descriptive statistics were used to present the participants' characteristics and describe the main variables. A multiple regression analysis at a 95% confidence interval was used to identify mothers'

characteristics that best predict their knowledge level and attitudes toward the HPST. Seven variables were entered into the model: mother's age, educational level, number of children, a positive history of congenital and genetic diseases including both CHT and G6PD (glucose 6 phosphate dihydrogen), children's health status, and source of information about the HPST. The bivariate correlation (two-tailed Pearson's r) was used to examine any relationship between the mothers' knowledge and their attitudes. The main source of information was further grouped into "information received by healthcare providers" and "other sources" to simplify the analysis. Then, the independent sample t -test (two-tailed) was applied to examine a difference in the means of knowledge and attitude based on the main source of information about the HPST.

Findings

Participants

Out of 320 invited mothers, 301 mothers agreed to participate (response rate = 94.1%). Most participating mothers were young, with ages ranging between 24 and 30 years for 41.3% of the sample. Approximately 84% of the mothers had between one and four children. Most of our sample population were educated, with 65% having attended at least two years of college. The majority (91%) reported no history of genetic disorders but 6% reported having CHT and 3% G6PD. The vast majority of the mothers reported having healthy children (94%). More information about the sociodemographic characteristics of the mothers is detailed in Table 1.

Mothers' knowledge about the heel-prick screening test

The mean knowledge score of the mothers regarding the HPST was 7.34 (SD = 4.44). Only 40% of the mothers scored

10 or more correct answers out of 13—the total score on the knowledge scale—while only 14% of mothers had all correct answers. Regarding the procedure, most mothers knew that a blood specimen for the test is obtained by pricking the heel of the newborns (80%) and obtained by a nurse or a midwife (79%). However, only 43% of the mothers were aware that the results of the test may take between 1 and 2 weeks. Three-quarters of the mothers (75%) knew that, generally, the test is beneficial for the health of their newborns. However, merely around half of the mothers were knowledgeable about the specific benefits of the HPST in detecting metabolic disorders (55%) and the common genetic and congenital conditions (e.g., PKU, G6PD, and CHT) screened through the test (51%). Only a few participants (17%) were aware that the test was able to detect more than 25 disorders. Very few (38%) were informed that the blood specimen may be stored for subsequent research purposes. Further and more specific details of the mothers' responses on the knowledge items are presented in Table 2.

Attitude of the mothers toward the HPST

The overall attitude toward the HPST among mothers was relatively positive ($M = 18.0$, $SD = 1.69$, total possible score = 9–27). As indicated in Table 3, most mothers perceived the HPST as being beneficial (88%), contributing to the wellbeing of newborns (83%), and not being harmful (81%). However, about 41% admitted that they would feel guilty if the newborn is found to have a genetic disease. When the mothers were asked whether they would

feel stressed at the time of the HPST performance, 59% responded that they would.

Relationship between mothers' knowledge and attitude

There was a significant moderate positive relationship between the mothers' knowledge and attitudes ($r = 0.50$, $P < 0.01$).

Main sources of information, preferred time of learning, and reasons for not performing the heel-prick test

Detailed results of the mother's sources of information, the best time to receive information on the test, and reasons for not performing the test are provided in Table 4. When asked about the main source of information on the HPST, 46% of the mothers mentioned healthcare providers. Of the total who received their information from the healthcare providers ($n = 139$), 81% got their information from nurses and midwives. Only 3% of the mothers sought information from the media, internet, or printed material. On the other hand, 39% indicated no specific source of information.

As shown in Table 4, around a quarter of the mothers (72, 24%) reported that they have reasons for not having the test performed on their newborns. Almost half of those who had this perception (33 of 72, 46%) believed that having a confirmed diagnosis of genetic or congenital diseases for newborns would result in negative psychological and emotional developmental consequences for the newborns. While the rest of the mothers, who perceived that the HPST should not be performed, were split almost

Table 4 Main sources of information, preferable time of learning, and reasons for not performing the heel-prick test ($n = 301$)

Main source of information about heel prick test	F (%)
No specific source of information	117 (38.9%)
Nurse	83 (27.6%)
Family member	36 (12.0%)
Midwife	30 (10.0%)
Doctor	26 (8.6%)
Printed readings	4 (1.3%)
Internet	4 (1.3%)
Television	1 (0.3%)
Most favorable time to learn about the heel prick test	F (%)
Two to three weeks prior to giving birth	142 (47.2%)
At the time of test performance	110 (36.5%)
One to two months prior to giving birth	49 (16.3%)
Perceived reasons by the mothers for not having heel-prick screening test performed on newborns	F (%)
No perceived reasons for not having heel prick screening test performed	229 (76%)
Confirmed diagnosis of genetic disorders may affect the psychological and emotional development of the child	33 (11%)
Fear of difficulty to obtain insurance or employment in future if having a genetic and congenital disease is known	20 (6.6%)
Fear of discrimination of having a child with a genetic disease	19 (6.4%)

equally in believing that such diagnoses would lead to difficulties in obtaining health insurance (20 of 72, 28%) and to discrimination by peers or society (19 of 72, 26%).

Main source of information and association to level of knowledge and attitude

The mothers who received information from the health-care providers showed slightly increased mean scores of knowledge levels ($M = 8.76$, $SD = 3.03$) compared to the mean knowledge score ($M = 6.35$, $SD = 5.11$) of those who received information from other sources (e.g., internet, media, etc.) or had no specific sources. Similarly, the mean scores of the attitudes ($M = 18.44$, $SD = 1.52$) of mothers who received information from healthcare providers were higher than those ($M = 17.69$, $SD = 1.75$) who obtained their information from other or no specific sources. The differences of means were significant between both groups for both knowledge levels ($t(299) = 4.9$, $p = 0.00$) and attitude scores ($t(299) = 3.9$, $p = 0.00$).

Predictors of mother's knowledge about HPST

The results of the regression analysis indicated that the seven predictors (Table 5) explained 25% of the variance in the mothers' knowledge level about the HPST ($R^2 = 0.252$, $F(7, 300) = 14.08$, $p < 0.01$). It was found that sources of information significantly predicted their level of knowledge ($B = 0.172$, $P = 0.001$), as did the health status of other children ($B = 0.27$, $P = 0.001$) and the number of children a mother has ($B = 0.163$, $P = 0.03$). The remaining demographic and professional variables did not show a significant predictive relationship ($p > 0.05$).

Predictors of mothers' attitudes toward the heel-prick screening test

The results of the regression analysis indicated that the seven predictors (Table 6) explained 10% of the variance in the mothers' attitudes toward the HPST ($F(7, 300) = 4.545$, $p < 0.01$). It was found that the information sources significantly predicted their attitudes ($B = -0.118$, $P = 0.001$). Mothers who received information from nurses and physicians displayed more positive attitudes toward the test. The remaining demographic and professional variables did not show significant predictive relationships ($p > 0.05$).

Discussion

The NS is a public health program adopted globally for improving the health and survival of neonates, and promoting the welfare of children and families. This study was driven by the notion that: increasing the parents' knowledge, positive attitude, and uptake of NS will help optimize and improve the health promotion goals of NS. Therefore, mothers of newborns have to be fully informed and aware of the test. Exploring aspects related to mothers' understanding of the HPST would supplement the success of the national efforts regarding the NS program and support drawing internationally applicable conclusions driven from comparing the research evidence across countries. To the best of our knowledge, this is the first study addressing mothers' level of knowledge, attitudes, perceptions, and contributing factors regarding the HPST among mothers in Jordan.

Based on our findings, it is safe to say that the mothers' knowledge regarding HPST in Jordan is only partial and insufficient. Our findings are in accordance with the research findings of other comparable studies regarding mothers' knowledge about the HPST (Arduini et al. 2017; Fitzpatrick

Table 5 Predictors of knowledge about heel-prick screening tests among the mothers

Predictors	Unstandardized coefficients <i>B</i>	Standardized coefficients		<i>t</i> -value	<i>P</i>	95% confidence interval
		Standard error	Beta			
(Constant)	6.626	1.508		4.395	0.000	3.658–9.593
Age (years)	0.047	0.055	0.060	0.854	0.394	−0.062–0.157
Educational level	0.386	0.244	0.087	1.585	0.114	−0.093–0.866
Mother having G6PD	1.362	1.354	0.052	1.006	0.315	−1.302–4.026
Mother having CHT	0.074	0.958	0.004	0.078	0.938	−1.812–1.961
Number of children	0.461	0.212	0.163	2.171	0.031	0.043–0.879
Previous children's health status	−0.698	0.167	−0.270	−4.182	0.000	−1.026–−0.369
Source of information about the heel-prick test	−0.243	0.074	−0.172	−3.276	0.001	−0.389–−0.097

G6PD, glucose 6 phosphate dehydrogenase; CHT, congenital hypothyroidism

Table 6 Predictors of attitude toward the heel-prick screening tests among the mothers

Predictors	Unstandardized coefficients	Standardized coefficients		<i>t</i> -value	<i>P</i>	95% confidence interval
	<i>B</i>	Standard error	Beta			
(Constant)	18.470	0.629		29.348	0.000	17.231–19.708
Age (years)	0.000	0.023	–0.001	–0.019	0.985	–0.046–0.045
Educational level	0.143	0.102	0.085	1.404	0.161	–0.057–0.343
Mother having G6PD	–0.064	0.565	–0.007	–0.114	0.909	–1.177–1.048
Mother having CHT	–0.195	0.400	–0.027	–0.488	0.626	–0.982–0.592
Number of children	0.064	0.089	0.060	0.724	0.470	–0.110–0.239
Previous children’s health status	–0.121	0.070	–0.123	–1.737	0.084	–0.258–0.016
Source of information about the heel-prick test	–0.118	0.031	–0.218	–3.797	0.000	–0.179––0.057

G6PD, glucose 6 phosphate dehydrogenase; *CHT*, congenital hypothyroidism

et al. 2019; Franková et al. 2019). The overall knowledge of the mothers in our study was merely average regarding the test. The analysis of the knowledge items indicated that the mothers of newborns in Jordan lacked fundamental information about the HPST.

Generally, the mothers in our study needed informative support on all areas related to the HPST included in this study. However, the mothers require focused education specifically regarding (a) genetic and congenital conditions screened by HPST, (b) timing of the results release and the need for follow up, (c) the meaning of the abnormal findings, and (d) the storage of the dried blood spots for future research purposes. Our findings about the specific areas of knowledge inadequacy strongly resonated with the research findings of other studies that identified similar areas of knowledge inadequacy and misconceptions regarding the HPST (Arduini et al. 2017; Fitzpatrick et al. 2019; Franková et al. 2019; Mendes et al. 2017; Rosales et al. 2015; Silva et al. 2017; Twfeeq and Abed 2016). Collectively, the results of these research studies, when added to our findings, should be utilized by healthcare providers, and be integrated into the primary health care practices, in order to improve the information provided to mothers of newborns.

In our study, most mothers demonstrated adequate knowledge about the HPST procedure being executed by a nurse or a midwife through pricking the heel of newborns. It is plausible to argue that these findings themselves may not indicate that the mothers were provided with adequate information regarding the test per se; rather, they may be explained by the mothers’ preexisting knowledge that nurses and midwives are typically the professionals who collect blood specimens from neonates in Jordan. Additionally, in a past study (Hasegawa et al. 2011), it was reported that most mothers could not recall being informed about NS, its implications, or that it was performed on newborns. However, the mothers remembered noticing a bandage on their

newborns’ heels. Through such concrete images, the mothers elicited information associated with the HPST procedure (Hasegawa et al. 2011). Further research is required to explore how mothers build their perceptions and knowledge about the HPST. Moreover, it would be helpful to the field of science to explore the perspectives and practices of the healthcare providers who are involved in informing parents about their educative practices about HPST procedures with the mothers.

On another note, our findings further indicated a relative degree of uncertainty about the test among respondents who were not fully informed. Careful observation of the knowledge responses by the mothers, who did not select the correct answers, indicates that most mothers were more uncertain of their knowledge, rather than possessing the wrong information, i.e., more mothers perceived the information “unknown” to them compared to those who indicated a “false” response to the knowledge items. These findings deserve thoughtful attention and lead to the potential conclusion that the mothers may be underprovided with information support about the test.

Although the mothers’ knowledge was inadequate, their general attitude was positive toward the test. The positive attitude was specifically attributed, by the mothers in this study, for the tests being important, beneficial, and preventive—which is in harmony with the findings of studies located in other countries (Blom et al. 2020; Guimarães et al. 2019; Sieren et al. 2016; Twfeeq and Abed 2016). On the other hand, the same predictive quality of the NS was also an identified reason for some mothers to avoid performing the HPST on the newborns. The reason is the fear of obtaining positive results by screening tests.

The mothers feared the possibility of knowing in advance that a newborn may have developed a disability or fatal health condition. Their concerns were based on several negative psychological, emotional, social, and financial

consequences of the screened condition on the children and the families. As some mothers described it in a past study, the information would prove to be “psychologically taxing” and “burdensome” (Hasegawa et al. 2011). In a more recent study, the inconclusive NS results led to a heightened sense of uncertainty among parents, while inconclusive and positive NS results lead to a heightened sense of anxiety and increased fear of the children’s vulnerability among parents (Hayeems et al. 2017). All of which calls for parent-professional communication to be based on the understanding of these concerns. Healthcare providers need to create a delicate balance between being informative, sympathetic, and supportive to the mothers regarding the HPST procedure. Our findings on the reciprocal association of the mothers’ knowledge to their attitudes toward the test are in support of this call. However, this finding requires further examination and confirmation from future studies.

Similar to our findings, several studies exhibited an association between the number of children and their health status with the mothers’ knowledge about NS (Alfayez et al. 2018; Franková et al. 2019). However, the source of information appeared to be a prominent predictor for both the mothers’ knowledge level and attitudes, which was in line with the findings of Alfayez et al. (2018). The healthcare providers, particularly nurses, were identified as the main source of mothers’ information in Jordan. In the previously published literature, healthcare providers were often the main (Arduini et al. 2017; Blom et al. 2020; Franková et al. 2019) and best rated (Blom et al. 2020) source of information. Other sources such as the internet and education materials were also cited sources of information in other studies (Alfayez et al. 2018; Franková et al. 2019); however, they were not prominent in the current study. These findings highlight the informative and supportive role of healthcare providers, nurses in particular, and the vitality of their roles in improving the mothers’ knowledge and attitudes regarding HPST in Jordan.

The findings of our study have several implications to improve primary healthcare practice by healthcare providers and newborn screening services, both in Jordan and worldwide. In order to optimize the health promotion outcomes of the HPST and design structured health education interventions, healthcare providers need to bridge the gaps in knowledge, perceptions, and unique needs exhibited by mothers. Well-designed HPST education programs demonstrate promising results of increased knowledge and awareness and maximize uptake of NS among mothers (Mendes et al. 2017; Tariq et al. 2018).

The mothers in this study identified a need to receive the HPST information two to three weeks prior to giving birth and at the time of obtaining the blood sample, which is comparable to suggestions in other studies (Alfayez et al. 2018; Franková et al. 2019). In a large-scale survey study

from Canada, knowledge of NS was higher among mothers who had higher levels of education, received an information sheet at the time of NS, and received information about how to interpret the results. The study also revealed that promoting satisfaction with NS education among mothers may be achieved by receiving information antenatal, from a healthcare professional, or from an information sheet, at the time of screening (Araia et al. 2012).

Therefore, we recommend that the information about NS be provided as soon as possible during pregnancy. However, based on our findings of the mothers’ preference, the healthcare providers, nurses, in particular, should emphasize the information two to three weeks prior to the mother’s giving birth; i.e., at least around the 36 weeks of gestation. The mothers of newborns in Jordan will benefit from structured educational interventions about NS that should be integrated regularly into antenatal programs. Primary healthcare policies should facilitate the educative role of the healthcare professional in the clinical practice in antenatal and post-natal settings.

To conclude our findings, we provide the following recommendations for a health education program about HPST aimed at mothers:

- Build the education about NS on mothers’ baseline knowledge about it and focus on their information needs, specifically those needed information areas that have been identified in our study and international literature.
- The education should be provided mainly by healthcare providers and supplemented by educational material (online and/or printed).
- Specifically, target expectant mothers after 36 weeks of gestation as well as at the time of performing the test.
- Consider the unique need for knowledge among mothers who have several children or children with health issues as well as mothers who have limited access to newborn care by health professionals.
- Adding a type of consistent professional documentation of the provided education about NS to the mothers is recommended to activate and sustain the educative role of the healthcare providers.

Our findings and the above suggestions pave the way for significant changes in current practices regarding mothers’ education about NS; specifically that practice by nurses who are the main informers about NS in Jordan, as indicated by our findings. An interventional study is recommended to assess the feasibility of implementing such changes and to determine how these changes may contribute to an increase in knowledge and an enhanced attitude about NS among the mothers.

It is additionally recommended that this study be replicated with more thorough questions. This would facilitate

the investigation of more knowledge aspects related to parents making an informed decision regarding NS in Jordan as well as in other countries. IJzebrink et al. (2021) evaluated the knowledge contents of 26 European parental information products and compared their findings to 8 knowledge aspects that were identified earlier as standard for parents' informed decision-making about NS by the General Medical Council (GMC)-UK (Michie et al. 2003). These 8 aspects are as follows: the purpose of screening, the likelihood of positive and negative findings, the possibility of false-positive and false-negative findings, uncertainties and risks attached to the screening process, medical implications of screening, social implications of screening, financial implications of screening, follow-up plans including the availability of counseling and support services (Michie et al. 2003). In addition to these aspects, IJzebrink et al. (2021) recommended adding knowledge related to storage of NS material, consent of parents, privacy, and confidentiality regarding the results, performing the heel prick, and stakeholders involved in order to optimize the parents' knowledge about NS and be used as a reference to evaluate or develop information products about NS (IJzebrink et al. 2021).

Limitations

Despite our maximum efforts to enhance the quality of our study, there are a few limitations that must be acknowledged. Among them are the inherent limitations of cross-sectional studies using self-reported questionnaires from a convenience sample (Polit and Beck 2017). Nevertheless, correlational nonexperimental studies, such as this one, are efficient for describing a problem of interest and are often necessary when experimental research designs are not feasible (Polit and Beck 2020).

Collecting data from the mothers using face-to-face interviews facilitated data collection considering their frail physical state after labor. However, participants may have felt uncomfortable answering questions in front of a researcher. It is possible that social desirability, the Hawthorne effect, and experimenter effects affected the mothers' direct responses and views. Nevertheless, this study provided an initial understanding of Jordanian mothers' knowledge gaps, attitudes, and views toward the HPST. These findings, if integrated with the current body of knowledge about the topic, could be utilized by healthcare providers and decision-makers to improve the practices and policies of primary care of infants and their parents, which could be the subject of future research studies.

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Declarations

Ethics approval Ethical approvals were obtained by the Institutional Review Board located at the university-affiliated hospital King's Abdullah Hospital (Irbid-Jordan) and the Ministry of Health (Amman-Jordan), which also approved data gathering at the public hospital. One of the researchers explained the study and the research subject rights to the study participants who signed written consent forms prior to the data collection.

Conflict of interest The authors declare no competing interests.

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