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Maternal Awareness and Attitude about Neonatal Screening Program in the Eastern Region of the Kingdom of Saudi Arabia

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ABSTRACT

Background: despite the worldwide recognition of the importance of pre-screening education of parents, the current body of evidence suggests that parents often receive little information about neonatal screening (NS) and may even be unaware about the screening of their baby.

Aim of the work: this study aimed to assess the attitudes and knowledge of the Saudi women towards the NS program and their psychological impact.

Methods: we performed a cross-sectional study on mothers in the Eastern Region of the Kingdom of Saudi Arabia. A modified version of the Maternal Attitudes and Knowledge about Newborn Screening Survey was used to assess the attitudes and knowledge of the women towards the NS program.

Results: we retrieved 388 surveys. Twenty-five percent of the women acquired their knowledge about NS programs from the internet. Eighty-two percent of the women had healthy children and 42% of them think that the best time to know about NS programs is at the time of screening itself. Our analysis showed a significant association between the educational level and knowledge about the best time to learn about neonatal screening (p=0.0001). Almost half of the women who had one child stated that the screening should take place 2-3 months before the baby is born (p=0.018). The child health status was also associated with the knowledge that if the baby's newborn test is abnormal I might have something wrong with my DNA (p=0.015). It was also associated with knowing that NS will test for common diseases that run in families like diabetes, asthma and heart disease (p=0.02). **Conclusion:** Saudi women had a positive attitude, but with little knowledge towards the NS program. Further studies are needed to assess the predictors of different levels of knowledge.

Keywords: neonates; knowledge; attitude; public health awareness.

INTRODUCTION

Neonatal screening is defined as the mass blood-spot screening that aims at early detection of rare congenital disorders. This early detection and the following immediate treatment may improve the prognosis of such rare, but treatable conditions[(1)]. Over the past decades, NS has been recognized as a valuable component of neonatal care in many developed countries around the world[(2)]. Both national and international efforts are currently conducted to implement it as a major public health program, which requires a proper pre-screening education for parents[(3)].

Informing parents about the benefits and process of screening is associated with more positive response to the requests of additional testing[(4)]. In addition, proper knowledge about the possibility of errors in the initial NS has been proposed to be linked with less psychological harms associated with false-positive results[(5)].

Despite the worldwide recognition of the importance of pre-screening education of parents, the current body of evidence suggested that parents often receive little information about NS and may even be unaware about the screening of their baby[(1)].Regarding the Middle East, NS programs have been recently implemented. A study from Iraq reported that mother's awareness towards NS was low, but their attitudes towards NS tests were positive[(6)]. In Saudi Arabia, NS programs were offered for 16 known biochemical and endocrine genetic disorders since 2005. According to a recent report, Saudi women had a positive attitude towards the NS program. However, they had several concerns to improve the availability of medication and formulas, education materials and awareness[(7)]. However, **Al-Sulaiman*et al.*** [(7)] remained the only study that assessed NS awareness among the Saudi

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parents. Therefore, we conducted this observational cross-sectional study to assess the attitudes and knowledge of the Saudi women towards the NS program and their psychological impacts.

METHODS

Ethical consideration

The study participants were given full information about the study objectives and methodology. Confidentiality of the collected data and participant's privacy were assured and data were used only for research purpose. The act of completing and submitting the survey implied consent.

Study design

We conducted an observational cross-sectional study to determine attitudes and knowledge of the Saudi women towards the NS program and their psychological impact.
The study was conducted on mothers in the Eastern Region of the Kingdom of Saudi Arabia during September 2017.

Data collection instrument

We used a modified version of the Maternal Attitudes and Knowledge about Newborn Screening Survey. The modified questionnaire included two parts: 1: sample baseline characteristics and 2: awareness and attitude of mothers about neonatal screening program, which was measured by 22 five-point Likert-type scale questions. It was an online survey, distributed through the social media.

Data entry and statistical analysis

An Excel spreadsheet was established for entry of the data. The analyses were carried out with SPSS software (Statistical Package for the Social Sciences, version 24, SSPS Inc, Chicago, IL, USA). Frequency tables with percentages were used. Either Student-t or Mann-Whitney tests were used to compare quantitative variables, while Pearson's Chi-square test was used to analyze categorical variables. A p-value < 0.05 is considered statistically significant.

RESULTS

In this cross-sectional study, we retrieved 388 surveys. Almost all of the included subjects were Saudi women and 89 % get medical care in the first 3 months of pregnancy. The majority of the included participants were more than 25 years old. Half of the participants had a college or higher degree and 25% of them acquired their knowledge about NS programs from the internet. Eighty-two percent of the women had healthy children and 42% of them think that the best time to know about NS programs is at the time of screening itself. **Table1** showed distribution and baseline characteristics of mothers about concepts related to Neonatal Screening Program. **Table 2** showed the percentage of the included women who answered the different knowledge and attitude questions. Our analysis showed a significant association between the educational level and knowledge about the best time to learn about neonatal screening (p=0.0001). Educational level was also significantly associated with the knowledge that the child should have the NS after the first day and before the third day (p=0.014). The right time for the next NS test was also linked to the same factor (p=0.025). Seventy-six percent of women with a college degree stated that neonatal screening is a simple test (p=0.001). It was also associated with knowing that NS will test for common diseases that run in families like diabetes, asthma and heart diseases (p=0.01).

Almost half of the women who had one child stated that the screening should take place 2-3 months before the baby is born (p=0.018). A number of children was also significantly associated with knowledge that baby's father might have something wrong with his DNA (p=0.021).The child health status was also associated with the knowledge that if the baby's newborn test is abnormal I might have something wrong with my DNA (p=0.015). It was also associated with knowing that newborn screening will test for common diseases that run in families like diabetes, asthma and heart disease (p=0.02).

Eighty percent of women who had an early pregnancy care said that NS is a simple test (p=0.002) and 76 % of women with a healthy child said that NS is a simple test (p=0.02). They also were more likely to know who is responsible to tell them about the test result (p=0.013). They were also more aware that newborn screening can identify babies with certain serious inherited diseases (p=0.001). Early pregnancy care was also associated with knowledge that baby's father might have something wrong with his DNA (p=0.014).

There was a significant association between the source of information and the knowledge about

the prick of the baby's heel (p=0.033). It was also associated to the knowledge that the child should have the NS after the first day and before the third day (p=0.003). The right time for the next NS test also showed a significant association with the same factor (p=0.00001).

Knowing when the baby should have another newborn screening also had the same expected association (p=0.019). And to find the baby's discomfort worthy (p=0.047). **Tables 3 & 4** showed association between the number of children and the health status of the child regarding the knowledge about NS.

Table 1: demographic and base line characteristics (n= 388)

		No.	%
Age (years)	18-24	62	16
	25-30	116	29.9
	31-35	95	24.5
	Less than 18	12	3.1
	More than 36	103	26.5
Nationality	Saudi	386	99.5
	Non-Saudi	2	0.5
Educational level	Bachelor degree	148	38.1
	Collage	79	20.4
	High school	119	30.7
	Less than high school	28	7.2
	Master or higher	14	3.6
Time you get medical care	I did not get medical care	14	3.6
	In first 3 months of pregnancy	347	89.4
	In last 3 months of pregnancy	6	1.5
	middle 3 months of pregnancy	21	5.4
Source of learning about newborn screening	My doctor or midwife	88	22.7
	my doctor's nurse in the doctor's office	15	3.9
	My baby's doctor or nurse practitioner	36	9.3
	The nurse here in the hospital	72	18.6
	A medical assistant at a doctor's office	6	1.5
	Internet	97	25
	A book, video or advertisement	28	7.2
	Friend or family member	46	11.9
Children number	1	97	25
	2	98	25.3
	3	72	18.6
	4 or more	121	31.2
Children health status	Carrier of congenital or hereditary disease	30	7.7
	Have congenital or hereditary disease	28	7.2
	Healthy	321	82.7
	Dead because of congenital or hereditary disease	9	2.3
The best time to learn about newborn screening is	2-3 months before the baby is born	135	34.8
	2-3 weeks before the baby is born	88	22.7
	When the baby has the screening	165	42.5

Table 2: knowledge about neonatal screening.

Variables	No		Uncertain		Yes	
	No.	%	No.	%	No.	%
I knew that NS is a simple test for discovery of genetic disorders	27	7	64	16.5	297	76.5
I understand everything I need to know about newborn screening	154	39.7	88	22.7	146	37.6
I know why hospital prick my baby's heels during NS	171	44.1	45	11.6	172	44.3
I knew that my child should have the NS after the first day and before the third day	96	24.7	48	12.4	244	62.9
I know the right time for the next NS test	171	44.1	81	20.9	136	35.1
I know when my baby should have another newborn screening.	170	43.8	58	14.9	160	41.2
I know it is my baby's doctor or nurse practitioner to tell me the investigation results	38	9.8	16	4.1	334	86.1
Doing the newborn screening is worth the discomfort the baby feels	22	5.7	62	16	304	78.4
There are no risks to my baby or me from genetic testing	28	7.2	57	17.4	303	78.1
Newborn screening can identify babies with certain serious inherited diseases	14	3.6	66	17	308	79.4
Newborn screening is a kind of genetic testing	27	7	157	40.5	204	52.6
Genetic testing should be soon after birth	16	4.1	65	16.8	307	79.1
If the results of the newborn screening are not normal, it means my baby has a genetic disease	30	7.7	207	53.4	151	38.9
If my baby's newborn test is abnormal my baby's father might have something wrong with his DNA	62	16	241	62.1	85	21.9
If my baby's newborn test is abnormal I might have something wrong with my DNA	69	17.8	241	62.1	78	20.1
If my baby's newborn test is abnormal my baby's father might have something wrong with his DNA	17	4.4	47	12.1	324	83.5
Newborn screening will test for common diseases that run in families like diabetes, asthma, and heart disease	64	16.5	106	27.3	218	56.2
Babies with serious illnesses may look healthy when they are born	7	1.8	20	5.2	361	93
I wish I had more information about newborn screening	7	1.8	6	1.5	375	96.6
I trust the people in the Lab to keep my baby's name and other information private	11	2.8	58	14.9	319	82.2
Doing research on public health problems is a good way to use infant bloodspots from newborn screening	4	1	15	3.9	369	95.1
It would be OK for the state to share my baby's bloodspots with researchers if my baby's name or other private information is not connected to the blood sample.	63	16.2	37	9.5	288	74.2
If future research is done on my baby's bloodspots I want to know about it	16	4.1	18	4.6	354	91.2

Table 3: number of children in relation to knowledge about neonatal screening

Variables	No. of children								P value
	1		2		3		4		
	N	%	N	%	N	%	N	%	
I knew that NS is a simple test for discovery of genetic disorders	76	78	75	76	56	77	90	74	0.69
I understand everything I need to know about newborn screening	36	37	36	36	24	33	50	41	0.96
I know why hospital prick my baby's heels during NS	37	38	40	40	32	44	63	52	0.27
I knew that my child should have the NS after the first day and before the third day	50	51	63	64	49	68	82	68	0.24
I know the right time for the next NS test	26	27	33	33	27	38	50	41	0.25
I know when my baby should have another newborn screening.	37	38	32	32	31	43	60	50	0.13
I know it is my baby’s doctor or nurse practitioner to tell me the investigation results	84	85	86	86	61	84	103	85	0.73
Doing the newborn screening is worth the discomfort the baby feels	77	78	76	76	56	78	95	78	0.69
There are no risks to my baby or me from genetic testing	72	73	77	77	59	82	95	78	0.8
Newborn screening can identify babies with certain serious inherited diseases	73	74	76	76	58	81	101	83	0.7
Newborn screening is a kind of genetic testing	52	53	50	50	38	53	64	53	0.8
Genetic testing should be soon after birth	76	77	80	80	52	74	99	82	0.15
If the results of the newborn screening are not normal, it means my baby has a genetic disease	36	37	33	33	33	46	49	40	0.15
If my baby’s newborn test is abnormal my baby’s father might have something wrong with his DNA	20	21	18	18	14	19	33	27	0.02*
If my baby’s newborn test is abnormal I might have something wrong with my DNA	19	20	17	17	13	18	29	24	0.3
If my baby’s newborn test is abnormal my baby’s father might have something wrong with his DNA	87	88	87	87	62	86	88	73	0.007*
Newborn screening will test for common diseases that run in families like diabetes, asthma, and heart disease	46	46	55	55	45	62	72	59	0.2
Babies with serious illnesses may look healthy when they are born	91	92	94	94	65	90	111	92	0.5
I wish I had more information about newborn screening	94	95	97	97	69	95	115	95	0.7
I trust the people in the Lab to keep my baby’s name and other information private	79	80	84	84	58	80	98	81	0.7
Doing research on public health problems is a good way to use infant bloodspots from newborn screening	92	93	93	93	67	93	117	97	0.6
It would be OK for the state to share my baby’s bloodspots with researchers if my baby’s name or other private information is not connected to the blood sample.	72	73	71	71	45	62	100	83	0.04*
If future research is done on my baby’s bloodspots I want to know about it	90	91	90	90	61	85	112	93	0.7

*Significant

Table 4: the relation of child health and knowledge about neonatal screening.

Variables	Health Status of children								P value
	Carrier of congenital or hereditary disorders		Had a congenital or hereditary disorders		Healthy		Dead because of congenital or hereditary disease		
	N	%	N	%	N	%	N	%	
I knew that NS is a simple test for discovery of genetic disorders	26	87	18	64	244	76	9	100	0.02*
I understand everything I need to know about newborn screening	14	47	11	39	119	37	2	22	0.6
I know why hospital prick my baby's heels during NS	13	43	9	32	146	45	4	44	0.7
I knew that my child should have the NS after the first day and before the third day	22	73	13	46	203	63	6	66	0.1
I know the right time for the next NS test	12	40	5	17	115	35	4	44	0.4
I know when my baby should have another newborn screening.	14	47	10	36	132	41	4	44	0.17
I know it is my baby’s doctor or nurse practitioner to tell me the investigation results	26	87	24	86	275	86	9	100	0.6
Doing the newborn screening is worth the discomfort the baby feels	23	77	25	89	249	77.5	7	78	0.8
There are no risks to my baby or me from genetic testing	25	83	25	89	245	76	8	88	0.5
Newborn screening can identify babies with certain serious inherited diseases	26	87	18	64	257	80	7	78	0.1
Newborn screening is a kind of genetic testing	15	50	8	28	176	54	5	65	0.001*
Genetic testing should be soon after birth	22	73	22	78	257	80	6	66	0.7

*Significant

DISCUSSION

The present study assessed mother's awareness and attitude towards NS programs. It was not surprising that most of our participants heard about neonatal screening as 89 % of them had a medical care in the first three months of pregnancy. This was similar to results of another research where 93 % of mothers have heard about NS before[8], while another study showed lower levels of awareness[1]. A recent study on Saudi citizens also showed low knowledge among the participants[7]. Interestingly, the source of information was very variable. The first ranked source was the internet (25 %) than a medical care provider (22%). This low presentation of a valid source of information should catch our attention. In another study on a French population 34 % of the women got their information from midwives, GPs and obstetricians respectively[8]. Our results suggested that mothers are aware of NS, but do not feel well informed about it. Only 56 % agreed that NS will test for common diseases that run in families like diabetes, asthma and heart disease. Only 37 % understand what they need to know about the NS tests. This showed the limited awareness of the purpose of NS and the diseases being tested[9,10]. Half of the women were not sure or disagreed that genetic testing is a part of the neonatal screening. While, 78% of them did not know that if the baby's newborn test is abnormal might mean that something is wrong with baby's father DNA. Eighty percent of the women did not know that if the baby's newborn test is abnormal might mean that something is wrong with baby's mother DNA. That was echoed by other studies[6,11].

Another surprising result was that 44 % did not know why the hospitals prick their baby's heel. This was explained in another study by performing this test away from the mother in order to avoid any unnecessary anxiety[3]. It may be more applicable to inform and educate the mother during prenatal care[12,13]. Doctors should not avoid informing the mothers about the tests especially that 78% said that the screening worth the baby's discomfort. Seventy-eight percent saw no risk of the genetic testing the baby. This showed a general acceptance and understanding to do what is necessary for the benefit of their babies. Other studies actually suggested that educating mothers about benefits and the process of screening is associated with improvement of follow up rates[4,14]. Almost all women wished to know more information about NS and 91 % of our sample wanted to be informed if any future tests are done on their babies. Similarly, mothers in another studies also wished to be informed[1]. Mothers find it very important to be informed to make sure to achieve the benefits, minimize any harm and build a trust with their doctors[15]. Our sample had a positive attitude toward research on such a public health problem as 95 % said it is a good thing to use bloodspot to solve such a problem. But only 70 % accepted to share bloodspots with researchers even if names or any other private information were connected to the sample. Further studies are needed to discuss the reasons and the concerns of mothers.

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