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KNOWLEDGE AND ATTITUDES OF MOTHERS TOWARD NEWBORN SCREENING TEST IN BAGHDAD CITY

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ABSTRACT
The newborn Screening (NBS) program is a public importance health service. The early detection through newborn screening test facilitates transfer of affected infants for timely treatment, stop disabilities, and mental retardation save lives infants, families, and society, also it saves newborns from unnecessary invasive measures and families from economic and emotional costs of diagnostic odysseys, it is therefore important to highlight about NBS. All newborns are offered screening for phenylketonuria (PKU), galactosemia and congenital hypothyroidism (CHT). A descriptive cross-sectional study in order to determine knowledge of mothers toward Concepts Related to Genetic Testing and NBS and determine attitudes of them toward NBS. 26 primary health care centers have been chosen by multi-stage random sample stage, with simple random sample technique to cover about 20% of all PHCCs from AL-Karkh and Al-Russafa Sectors in Baghdad city. Total study sample was 566 mothers attending PHCCs who had children aged between 3 days -2 months. The data collection took place from the 15th of December, 2014 to the 7th of April, 2015. The results of the study show that all of the studied items were under cutoff point, since mean of score, and relative sufficiency values show a failure response, about knowledge of mothers toward Concepts Related to Genetic Testing and newborn screening test since their mean of score values, as well as relative sufficiency's values are recorded under cutoff point, Mother's attitudes toward newborn screening test. The results show that all items have pass assessment, since their means of score, and relative sufficiency's values recorded extremely upper cutoff point. Mother's awareness toward concepts related to genetic testing and newborn screening test was low but attitudes of them toward newborn screening test was positive,

KEY WORD: NBS, PHCCs,

INTRODUCTION

The newborn Screening (NBS) is a public health service. It is completed by testing (newborns) that are asymptomatic so that they can be recognized and treated before problems occur. NBS is offered to all newborn and is done shortly after birth, the best age of test seventy two hours to five days after delivery and those who had not screened up to two months of age aiming of test to distinguish a certain uncommon, but serious genetic, congenital and or metabolic disorder that may be life threatening[1]. In Iraq the program has been occurred in April, 2013, taking 2 provinces *i.e.* Baghdad and Karbala, as starting provinces, all newborns are offered screening for phenylketonuria (PKU), galactosemia and congenital hypothyroidism (CHT)[1]. Phenylketonuria (PKU) was in numerous countries the first disorder for which (NBS) programs were started[2]. If mothers are aware and have knowledge of the purpose, process and benefits of screening, they may be act in response to the needs of other testing after a positive (abnormal) outcomes or insufficient sample[3]. Knowledge about NBS may also help to reduce psychosocial harms; for instance, by informing mothers prior to testing, that a first positive result is a likelihood and does not signify a confirmatory diagnosis, it may be likely to decrease the risk of psychosocial harm related with getting a false positive NBS outcomes[4]. Although several factors influence mother's views about NBS, but they have been established to encourage doing the newborn screening test. Positive attitudes are not necessarily dependent upon sufficient knowledge of screening, as there is substantial facts suggesting that mothers generally have incomplete knowledge of which conditions are tested for, the special effects of the conditions and the treatments accessible[5]. The mandatory system of NBS has been necessary rooted in the individualized baby safety baby benefit form, which maintains the addition of tests to compulsory screening panels in the argument that information collected from infants is used to directly benefit infants [6].

METHODOLOGY

A descriptive cross-sectional study, 26 primary health care centers have been chosen by multi-stage random sample stage, with simple random sample technique to cover about 20% of all PHCCs from AL-Karkh and Al-Russafa sectors in Baghdad city. Total study sample was 566 mothers attending PHCCs who had children aged between 3 days -2 month. A standardized modified questionnaire was used with the Arabic translation. Modified through an intensive review of relevant literatures for phenomenon of knowledge attitude and practice on newborn screening test. It was composed of (2) major parts reliability and validity of the questionnaire was determined through a panel of experts and pilot study. The questionnaire and the structured interview technique were used as means of data collection .The data collection took place from the 15th of December, 2014 to the 7th of April, 2015. Data were analyzed through application of the descriptive data

analysis approach (frequency and percentage) (Chi square test, binomial test).

RESULTS

Table (1) shows distribution and initial assessment items of knowledge of mothers about concepts related to genetic testing. Results show that the item which has pass assessment is Level of consanguinity of parents' effect on the genetic disease), while leftover items were reported failure assessments, since their mean of score values, as well as relative sufficiency's values are recorded under cutoff point. Table (2) shows summary statistics and initial assessment items of Knowledge of mothers about Newborn screening test. Results show that all of the studied items were under cutoff point, since Mean of score, and relative sufficiency values show a failure response. Table (3) shows summary statistics and initial assessment items for: the sources of information. The result recorded highly significance at $P<0.01$ for all the studied items. The PHCC personal, were the highest source of information 261 (46.1%). Table (4) shows summary statistics items of mother's attitudes toward newborn screening test. The results show that all items have pass assessment, since their means of score, and relative sufficiency's values recorded extremely upper cutoff point

TABLE 1: Distribution and initial assessment items of Knowledge of mothers about Concepts Related to Genetic Testing.

Items		Resp.	No.	%	MS	SD	RS%	Ass.
Knowledge of mothers about Concepts Related to Genetic Testing	There is DNA in your baby's bloodspots	Don't know	327	57.8	0.42	0.49	42	Failure
		No	2	0.4				
		Yes	237	41.9				
	Some of the tests in the newborn screening are genetic tests	Don't know	387	68.4	0.31	0.46	31	Failure
		No	2	0.4				
		Yes	177	31.3				
	If your baby's newborn tests are abnormal you might have something wrong with your DNA	Don't know	364	64.3	0.31	0.46	31	Failure
		No	3	0.5				
		Yes	199	35.2				
	If your baby's newborn tests are abnormal, your baby's father might have something wrong with his DNA	Don't know	361	63.8	0.36	0.48	36	Failure
		No	2	0.4				
		Yes	203	35.9				
	Level of consanguinity of parents affect on the genetic disease	Don't know	238	42.0	0.58	0.49	58	Pass
		No	1	0.2				
		Yes	327	57.8				

TABLE 2: Distribution and initial assessment items of Knowledge of mothers about Newborn screening test

Items		Resp.	No.	%	MS	SD	RS	Ass.
Knowledge of mother about Newborn screening test	Do you know what newborn screening test is?	Incorrect	287	50.7	1.71	0.80	57.1	Under
		Incomplete	154	27.2				
		Complete	125	22.1				
	Do you know why the heel prick is done?	Incorrect	299	52.8	1.67	0.78	55.5	Under
		Incomplete	157	27.7				
		Complete	110	19.4				
	Do you know what are the conditions that the heel pricks done for?	Incorrect	398	70.3	1.46	0.76	48.6	Under
		Incomplete	77	13.6				
		Complete	91	16.1				
	Do you know how the conditions could affect your child?	Incorrect	355	62.0	1.54	0.76	51.4	Under
		Incomplete	123	21.7				
		Complete	92	16.3				
	Do you know how the test is done?	Incorrect	296	52.3	1.70	0.81	56.7	Under
		Incomplete	143	25.3				
		Complete	127	22.4				
	Do you know when the test is done?	Incorrect	308	54.4	1.66	0.80	55.5	Under
		Incomplete	140	24.7				
		Complete	118	20.8				
	Do you know why the test is done at the time it is?	Incorrect	355	62.7	1.53	0.75	51.0	Under
		Incomplete	122	21.6				
		Complete	89	15.7				
	Do you know what the test results mean?	Incorrect	386	68.2	1.48	0.75	49.2	Under
		Incomplete	91	16.1				
		Complete	89	15.7				
	Do you know when the results will be available?	Incorrect	387	68.4	1.49	0.77	49.6	Under
		Incomplete	81	14.3				
		Complete	98	17.3				
	Do you know how the conditions would be dealt with if found?	Incorrect	413	73.0	1.41	0.73	47.1	Under
		Incomplete	73	12.9				
		Complete	80	14.1				

TABLE 3: Distribution and initial assessment items of the sources of information

Items		Resp.	No.	%	MS	SD	RS	C.S. [P-value]
What are the sources of your information?	Midwives	No	535	94.5	0.06	0.23	05.5	P=0.000
		Yes	31	5.5				HS
	Friends	No	495	87.5	0.13	0.33	12.5	P=0.000
		Yes	71	12.5				HS
	Family	No	497	87.8	0.12	0.33	12.2	P=0.000
		Yes	69	12.2				HS
	PHCC personal	No	305	53.9	0.47	0.52	46.6	P=0.000
		Yes	261	46.1				HS
	Private clinic	No	532	94.0	0.06	0.24	06.0	P=0.000
		Yes	34	6.0				HS
	PHCC leaflet/book	No	513	90.6	0.09	0.29	09.4	P=0.000
		Yes	53	9.4				HS
	TV radio	No	502	88.7	0.11	0.32	11.3	P=0.000
		Yes	64	11.3				HS
	Internet	No	493	87.1	0.13	0.34	12.9	P=0.000
		Yes	73	12.9				HS
	Others	No	564	99.6	0.00	0.06	0.40	P=0.000
		Yes	2	0.4				HS

(*) HS: Highly Sig. at P<0.01, Bin. : Binomial test.

TABLE 4: Distribution and initial assessment items of Mother's Attitudes toward newborn screening test

Items		Resp.	No.	%	MS	SD	RS	Ass.
Mother's Attitudes toward newborn screening test	Do you think newborn screening: Useful if it prevent a disease	Unsure	204	36.0	2.27	0.96	75.8	Pass
		No	3	0.5				
		Yes	359	63.4				
	Do you think newborn screening: Useful if it reduces the severity of disease	Unsure	27	4.8	2.90	0.43	96.6	Pass
		No	3	0.5				
		Yes	536	94.7				
	Do you think newborn screening: Useful even if it cannot improve the disease as may help you to decide about further children (assets for future family plan)	Unsure	4	0.7	2.98	0.18	99.4	Pass
		No	2	0.4				
		Yes	560	98.9				
	Do you think newborn screening: Is beneficial to the new born	Unsure	5	0.9	2.92	0.30	97.4	Pass
		No	35	6.2				
		Yes	526	92.9				
	Do you think newborn screening: Is harmful to the newborn	**Unsure**	**512**	**90.5**	**1.18**	**0.57**	**39.4**	**Pass**
		No	**5**	**0.9**				
		Yes	**49**	**8.7**				
	Do you think newborn screening: Is morally justified	Unsure	45	8.0	2.83	0.55	94.3	Pass
		No	7	1.2				
		Yes	514	90.8				
	Do you think newborn screening: Would made your feel guilty if the baby is found to have a genetic disease	Unsure	7	1.2	2.80	0.43	93.2	Pass
		No	102	18.0				
		Yes	457	80.7				
	Do you think newborn screening: If your baby seems healthy is newborn screening still necessary	Unsure	51	9.0	2.80	0.58	93.5	Pass
		No	9	1.6				
		Yes	506	89.4				
	Do you think newborn screening: Do you think the screening test mandatory	Unsure	7	1.2	2.89	0.35	96.2	Pass
		No	50	8.8				
		Yes	509	89.9				

Bold color items are reversed to the scoring scale assessment

DISCUSSION

Knowledge of mothers about Concepts Related to Genetic Testing

Regarding to knowledge of mothers about concepts related to genetic testing. The current Study shows the pass assessment for the question of Level of consanguinity of parents affecting on the genetic disease, while leftover questions reported failure assessments, above half of the studied sample don't know that (There is DNA in the baby's bloodspots) this agree with study of Patricia (in Texas, 2013) (32.9%)of mothers respondents were Unsure or Disagree[7]. Also 68.4% of mothers Don't know if some of the tests in the newborn screening are genetic tests, this disagrees with Patricia 2013 study that (47.9 %) of mothers were Unsure or Disagree[7]. Most of respondents don't know that abnormal NBS results might indicate abnormalities in their own or the father's DNA, this agrees with (Patricia) study that (68.2% and 71.4%, respectively) were unsure or did not agree that abnormal NBS results might indicate abnormalities in their own or the father's DNA[7]. Mothers hadn't received any information regarding genetic concepts so it is not astonishing that confusion about genetic concepts or medical procedures should be found, over third of mothers said that DNA is present in human tissue. But most mothers did not understand that abnormalities in a child's DNA could reflect abnormalities in the parent's DNA, telling that mothers do not understand the concepts about inheritance or DNA meaning. This agrees with Patricia 2013 in Texas [7]. Level of Education was significantly related to understanding that DNA is in blood, most mothers receiving information about DNA through television and movies.

Knowledge of mother about Newborn screening test

The results show that all of the studied samples had inadequate information since mean of score and relative sufficiency values shows a failure responding of mothers about NBS. Similar findings were reported by a group in an Australian study with women who had received written and oral information, only 37% known the term heel prick test or 'newborn screen'. Confirmation has repeatedly shown that most parents were uninformed or misinformed regarding NBS[8]. Some researchers[9,10] established that parents who lacked general information about NBS described higher levels of worry in response to their newborns' abnormal NBS for any disorders than the few parents who reportedly were well informed about NBS. Also, many health care providers were badly prepared with the information necessary to educate parents [10] .This unlike with Lewis *et al*.,[11] parental knowledge of condition specific information is generally found to be good, because the selected groups were parents of children either affected by one of the disorder or who were carriers of the condition [11]. A parent who has to take a child for regular treatment is more likely to have a good knowledge of the effects of the condition in comparison with an individual who has an unaffected child [11]**,** therefore more attention needs to be paid to the sample composition, the potential sample effects, and the implications for results. These studies found that there was an interaction between technical knowledge, other 'experimental knowledge' and moral beliefs, The present study shows that about half of mothers did not know what is newborn screening test. This agree with a study in Texas **[7]** where 59% of women did not know what is newborn bloodspots, this disagrees with a sample of Dutch parents known the term 'heel prick' and knew how the heel prick had been conducted, but most did so "without really knowing what are the conditions that the heel prick done for[12] that is supported by the present study as most of mothers (70, 3%) did not know what are the conditions that the heel prick done for. This agree with a study in Wisconsin [13] reported that 86.3% of mothers were unable to correctly recall a single disorder. Also half of mothers (52%) did not know why the heel prick is done this disagrees with the result of Nicholls [14] in Ontario where most of women (82%) were able to correctly identify the main purpose of NBS**.** The reason of difference in having knowledge is due to the system of program in Ontario. The test is voluntary allowing mothers to receiving information before test at the time of inform consent while in Iraq the test is (mandatory) may be not allowing mothers to receive information**.** Also in Wisconsin [13] about 21.1% did not know or incorrectly answer "What is their understanding of the purpose of newborn screening, the difference in level of knowledge because of better education and received information about NBS at any time**.** Also most of mothers (68%) did not know what the results mean and when the results will be available. This agrees with a study in Texas [7] where 91% of the women did not understand how they would receive results and in Wisconsin[13] about 61.1% of mothers did not know or incorrectly answer, when you could receive the results of your baby's test. The studies evaluating parental knowledge have done so through the recall of information. Only to assess the remembering of specific information, no assessment is made of the understanding of the information, and at best the results reflect the personals memory[15], therefore it tells us little if anything about the quality of the parental decision-making or consent. Mothers sometimes felt they had a poor knowledge, unable to remember details such as the exact names of the conditions. Several mothers suggested that severe tiredness was detrimental to their ability to remember details.

Source of information

Mothers reported receiving information about NBS through a variety of methods and sources that ranged in reliability and potential accuracy from a discussion with a health care provider to watching a television program. Some mothers actively sought out information, for example, reading books, while others learned about NBS incidentally as part of their circumstances, for example abnormal test results. (Nurses, physicians, laboratory technicians), and internet, friends, family, TV radio ,PHCC leaflet (books, magazines, brochures), Private clinic and Midwives. PHCC personal, were reported the highest source of information (46.1%). This agrees with a current survey of information for newborn screening found that 53% of the programs that responded provided information by providing information via pediatrician, nurse or midwife[16]. Other studies support this result [17-19].

This unlike with Tluczek *et al*., they found only 13% of parents recalled receiving information from a health professional prenatally, 4% recalled receiving written literature, and about 6% were not informed or did not remember receiving any information about NBS[20]**.** The present study shows that only (5.5%) of mothers receiving information from midwife, this disagrees with results obtained by Detmar *et al*., [12] who noting the role played by the midwife. Some mothers said that they had read about the test in a brochure or seen something on television. The internet was not a great primary source of information for mothers about NBS. They had seen little or no information .Despite not receiving information through medical sources, participants in all of the groups thought that the PHCCs personal played a key role in the provision of information. This may suggest that the reference to (official) sources relates to written information. Leaflet was rare source of information just (9, 4%) this agrees with a study done by Hargreaves who showed that written information, while being received, is rarely cited as a primary source, with some studies suggesting that instead it plays a greater role as a reference material as opposed to influencing the initial decision-making [21, 25].

Attitudes towards newborn screening

In Iraq the test is related to the BCG vaccine in which no one will obtain the vaccine unless he do the test (this will highlight another issue weather it is right to do this or not in which there is some people refuse to do the test mostly because of their ignorance about screening test and its benefits and this might lead to lose the test and even the BCG vaccine and this should never be done. Overall, most mothers had a positive attitude towards newborn screening. Respondents supported screening primarily for its ability to reduce the severity of a disease, or prevent long-term complications of a disease. Interestingly similar notes have been reported with respect to parental attitudes toward genetic testing for pediatric deafness where (96%) of the respondents displayed a positive attitude, despite having poor understanding of genetics and deafness [22]. Numerous studies had also reported that generally the public have positive attitudes toward genetic testing [22, 23].

A majority of the women felt that screening of the newborn was useful if it could prevent or reduce the severity of a disease (63.4%) (94.7%) this agrees with a study done by (JULIE) 2005 in Australia where the majority of the women felt that screening of the newborn was useful if it could prevent or reduce the severity of a disease (85–86.5%)[24]. Only (1.3%) of mothers don't think or unsure regarding the question, If newborn screening could not improve the health of their child and its role was principally to help them to decide future genetic risk, this agrees with a study (JULIE) 2005 in Australia nearly one in three women expressed reservation[24]. The majority of the mothers (92.9%) felt that newborn screening was beneficial, (only 8%) did feel that it had the potential for harm. This agrees with Jule *et al*.,[24] in Australia the majority of the mothers (72.5%) felt that newborn screening was beneficial and 6% of did feel that it had the potential for harm**.** Regarding (Do you think newborn screening is morally justified**)** most of the mothers 90% answered yes this agree with Jule *et al*.,[24] where 63% of the mothers answered yes about the moral justification of newborn screening. Regarding (Do you think newborn screening would made your feel guilty if the baby is found to have a genetic disease) the majority of mothers answered yes (80%) this disagrees with Jule *et al*.,[24] where (33%) of mothers may feel guilty if their baby was found to have a genetic disease**.** The majority of respondents (89.9%) supported mandatory testing because of concerns that some mothers may refuse out of ignorance This is supported by a research which has noted that parents practice the heel prick as routine[21,25]. Such 'routinisation' is found international.

CONCLUSION

Mother's awareness toward concepts related to genetic testing and newborn screening test was low (Failure assessment**)** But attitudes of them toward newborn screening test was positive, (pass assessment)**.**

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