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Perception and Practice of Newborn Screening among Mothers and Health Care Providers at Primary Health Care Settings in Giza Governorate, Egypt

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Abstract: Congenital hypothyroidism is one of the most common endocrine disorders in childhood, moreover it is considered as a major preventable cause of mental retardation. The perception and practice of neonatal screening for congenital hypothyroidism should be well developed among both mothers and health care providers. This study aimed to identify the perception of mothers as well as the attitude and practice of health care providers towards neonatal screening at the primary health care level. A cross sectional study design was used for the current study. The study was carried out at four Egyptian primary health care facilities at Giza governorate (two urban and two rural centers), using a structured questionnaire for the interviewed mothers and a structured interview questionnaire and an observation checklist for health care providers which providing neonatal screening services. Only 14.5% of mothers reported that they know the purpose of the heel test. Regarding the source of knowledge, approximatly 45% of mothers reported that they knew about the heel test from their relatives. More than 50% of nurses claimed that the shortage of supplies was one of the main obstacles facing neonatal screening services. All health care providers mentioned that there was no routine neonatal examination performed to newborns coming for heel test. The study concluded that there is a lack of awareness among mothers about the purpose of newborn screening test. Additionally there are several obstacles facing newborn screening services from the health care providers perspectives which should be addressed by program planners and decision makers.

Key words: Neonatal screening · Health care providers · Primary health care · Mothers

INTRODUCTION

The neonatal period represents a crucial time for a child's survival rate[1]. 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 [2]. The prevalence of major congenital anomalies was reported to be 2 - 2.5% in the Middle East countries [3]. In Egypt, a study conducted in a tertiary hospital showed that the incidence of congenital anomalies was nearly 2.5% [4].

Importance of Newborn Screening (NBS) refers to the identification of conditions that can impact an infant's long-term health or surviving [5]. Screening for such conditions soon after birth can prevent many serious disorders, such as organ damage, intellectual disability or even death [6].

There is an international consensus that each contact with the health system is not only an opportunity to provide preventive, promotional or curative services, but also to maximize the impact of the subsequent contact [7]. In this context, health care providers at the primary health care level have a number of opportunities to screen, diagnose, manage, or refer neonatal health problems including congenital abnormalities and hypothyroidism. Newborn examination is an essential component of newborn care during the routine thyroid screening and BCG vaccination in the first few days after birth [8].

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Unfortunately, till now, the culture and perception of neonatal screening is not yet well-developed among both health care providers and the targeted mothers. 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 [9]. Therefore; the main aim of the current study was to improve the quality of neonatal care services provided at the primary health care level through determining the attitudes and practices of health care providers towards NBS and identification of mother's perceptions of NBS.

MATERIALS AND METHODS

Study Design and Setting: An observational analytical cross sectional study design was used. The study was conducted at four Egyptian primary health care facilities at Giza governorate; two urban centers (Giza 1 and El Talbia) and two rural centers (Shabramant and Nazla Al-ashtar).

Sample Type and Subjects of the Study: The four primary health care facilities were conveniently chosen. The study included a convenient sample of fifty mothers and their newborn infants (0 to 7 days) from each PHC facility coming for neonatal screening services. Regarding the Health care providers, participants were selected via purposive sampling technique. The participants included 26 nurses and 24 physicians working in the four PHC facilities. Inclusion criteria for Health care providers included nurses responsible for providing the neonatal screening service (Heel test) in the selected centers and physicians who were available at the study time and accepted to participate.

Data Collection: A pre-tested structured interview questionnaire was used for the interviewed mothers. It included 18 items in three domains including: mothers' Sociodemographic characteristics, assessment of knowledge of the mother regarding neonatal screening and assessment of practice of the mother towards neonatal screening regarding the previous child. For the health care providers an observation checklist form was developed with reference to the Egyptian Family Physician Guidelines. Additionally, a structured interview questionnaire form was used including closed-ended and open-ended questions covering the following domains: sociodemographic characteristics; neonatal care guideline; courses that have been taken regarding neonatal care.

Data Analysis: "Statistical Package of Social Science Software program" SPSS, version 21 was used for the statistical analysis. The data were presented using descriptive statistics: mean and standard deviation for quantitative data, numbers and percentages were used for qualitative data. Statistical differences were tested using Chi Square test or Fishers Exact test in case of qualitative variables. Additionally, P- Values were considered statistically significant if equal to or less than 0.05. The performance checklist was scored and manually analyzed.

Ethical Considerations: The study protocol was revised and approved by Research Committee in the Public Health and Community Medicine Department. All the study subjects were treated according to the Helsinki Declaration of biomedical ethics.

RESULTS

Table 1 illustrates that the majority of the interviewed mothers age lied between 18-35 years old (90%). Seven mothers attending rural centers were less than 18 years old. Concerning education, near half women in urban areas received high education (49%) compared with minority in rural areas (7%). Only 15% of mothers were working for cash; most of them (90%) were in urban areas. All of these findings showed significant difference between urban and rural centers ($p<0.005$).

Table 2 shows that more than two thirds of interviewed mothers have not been informed (72.5%) about the heel test. The percent is significantly higher in rural than urban centers. (P=0.001). Additionally, the majority of interviewed mothers who have been informed about doing heel test were in rural centers and all of them were informed during receiving Antenatal care (ANC) services (100%). About one third of mothers in urban centers knew that the purpose of doing heel test is to diagnose hereditary diseases (29.2%).While around three quarters of mothers knew that heel test is a thyroid gland test (75.9%).

Figure 1 displays that around half of interviewed mothers knew about heel test from their relatives and the percent is almost the same in urban and rural centers. Figure 2 demonstrates that the majority of mothers in rural areas did not know the purpose of doing heel test (85.5%). While, 24% of mothers in urban centers knew the purpose of the test compared to 5% in rural centers. There is statistical significant difference between urban and rural centers.

Table 1: Percent distribution of the interviewed mothers by Sociodemographic background

Sociodemographic background	PHC Settings: URBAN n=100 No	%	RURAL n=100 No	%	Total n=200 No	%	P_Value
Current Age							
< 18 years	0	0	7	7	7	3.5	0.002
18-35 years	90	90	90	90	180	90	
>35years	10	10	3	3	13	6.5	
Mean age ± SD (years)	28.5±4.92		24.7±5.71		26.6±5.66		
Education							
Illiterate	4	4	33	33	37	18.5	0.001
Basic education	9	9	35	35	44	22	
Secondary	38	38	25	25	63	31.5	
Higher	49	49	7	7	56	28	
Working Or Not							
Working for cash	27	27	3	3	30	15	
Not working for cash	73	73	97	97	170	85	0.001

Table 2: Percent of the interviewed mothers who have been informed about doing heel test for their children

	PHC Settings: URBAN n=100 No	%	RURAL n=100 No	%	Total n=200 No	%	P_Value
Have you been informed in PHC about heel test?							
Yes	12	12	43	43	55	27.5	0.001
No	88	88	57	57	145	72.5	
	N=12		N=43		N=55		
When?							
During ANC	3	25	43	100	46	83.6	0.001
Not during ANC	9	75	0	0	9	16.4	
What is the purpose of heel test?							
Diagnosis hereditary diseases	7	29.2	0	0	7	24.1	0.296
Thyroid gland test	17	70.8	5	100	22	75.9	

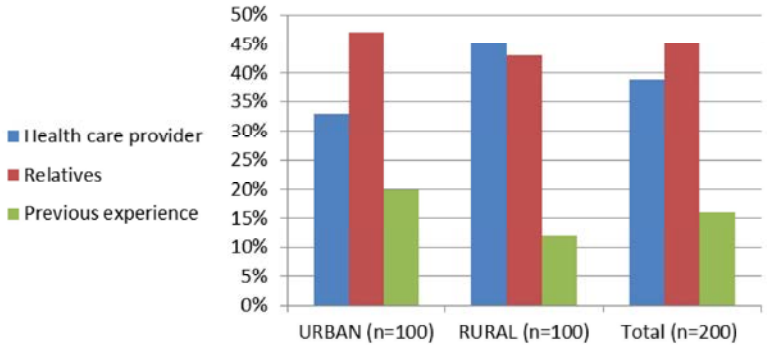

Fig. 1: Percent distribution of the interviewed mothers by their source of information about heel test. (P-value=0.134)

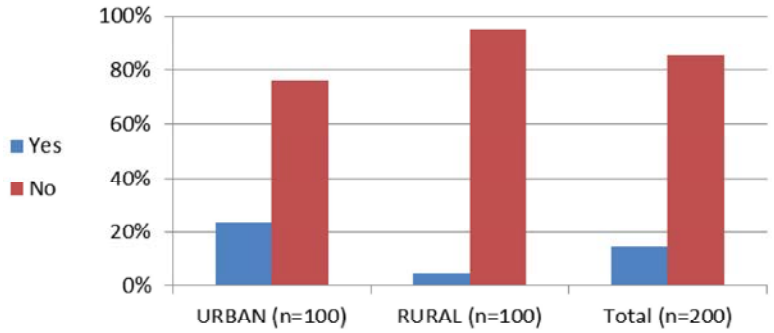

Fig. 2: Percent of the interviewed mothers according to their knowledge about the purpose of heel test. (P-value=0.001)

Table 3: The percent of health care providers according to their knowledge and practice regarding neonatal care services

	Physicians n=24		Nurses n=26	
	No	%	No	%
Do you have neonatal care guidelines?				
Yes	21	87.5	26	100
No	0	0	0	0
Don't Know	3	12.5	0	0
Have you been informed about these guidelines?				
Yes	24	100	26	100
No	0	0	0	0
Source of these guidelines				
MOHP* guideline	24	100	26	100
Do you follow these guidelines?				
Yes	24	100	26	100
No	0	0	0	0
Training courses taken				
Yes	19	79.2	26	100
No	5	20.8	0	0
How many?				
Once	10	52.6	3	11.5
Twice	4	21.1	4	15.4
More than twice	5	26.3	19	73.1
Do you inform pregnant females about neonatal screening?				
Yes	24	100	26	100
No	0	0	0	0
Do you perform routine neonatal examination to all neonates coming for heel test?				
Yes	0	0	0	0
No	24	100	26	100

MOHP: - Ministry of health and population

As shown in Table 3, 12.5% of physicians don't know if there are neonatal care guidelines in their facility or not. All health care providers mentioned the MOHP guidelines as their source for neonatal care guidelines. The majority of health care providers have received training courses before. About three quarters of nurses have received courses related to neonatal care more than twice. On the other hand, no routine neonatal examination was performed to all neonates coming for heel test.

The mean score for neonatal screening services Mean (± Standard deviation) provided by nurses was better in rural 4.5 (±0.5) out of 10 than in urban centers 8 (±2.01) out of 10. There is statistical significant difference between urban and rural centers. (P=0.001)

Perspectives of Health Care Providers Towards Their Performance in Neonatal Care Services: Around 75% of all health care providers (nurses and physicians) mentioned vaccinations as an important component of

neonatal care. The other 25% mentioned other important components such as growth monitoring, neonatal examination and referral services if needed as in case of neonatal jaundice or congenital anomalies. More than 50% of nurses mentioned that the lack of supplies was the major obstacle facing neonatal screening services and as a result more than 50% of them mentioned the same reason as a solution they suggest for service improvement. More than 60% of physicians mentioned that availability of supplies and well trained staffs were the first two major obstacles facing neonatal care services and consequently more than 60% of them mentioned the same reasons as solutions. Only 3 physicians mentioned the importance of adding hearing screening test to neonatal screening program as suggestion to improve neonatal screening service.

DISCUSSION

Newborn screening (NBS) is considered one of the most successful screening programs worldwide. The main goal of NBS is to prevent fatal and serious complications for the newborn by providing timely management for early onset conditions [10]. The aim of this study was to improve the quality of newborn care services at the primary health care level through outlining the attitude and practice of health care providers towards NBS and identifying the perception of mothers towards NBS.

The current study revealed that the knowledge and understanding of neonatal screening among the participating mothers were found to be low. It was found that only 14.5% had some background about the purpose of the test and only 24.1% of them mentioned that the test is done to detect hereditary diseases. 75.9% of the interviewed mothers mentioned that heel test is a thyroid gland test. The current study findings were not matching the findings of a similar study conducted in Saudi Arabia, where only 22.6% of Saudi mothers had some background about the nature of the test [11]. This could be justified by the different socio cultural characteristics between Egyptian and Saudi mothers.

Results of this study highlighted that only 27.5% of mothers (n=200) have been informed in the PHC about heel test. Regarding the timing of receiving such important information about doing heel test, most of the information was received during ANC visits (83.6%). When the researcher asked the interviewed mother (n=200) "Who told you to do heel test for your baby?" forty five percent have known from their relatives and 39% were told by health care providers (physician or nurse). This discrepancy in the data may reflect the indifferences of the mothers about this issue or defective memory and illiteracy.

Regarding the performance of health care providers towards neonatal screening, the present study proved that quality of the neonatal screening services was better in rural than urban centers. This observation was proved previously by another study in Benisueif governorate, Egypt wheeas, the client satisfaction affected in 63% of the cases by good quality of service [12].

All nurses did know that they have neonatal care guidelines in their PHC facility. Overall, 12.5% of physicians didn't know that they have neonatal care guidelines in their PHC facility which may be due the shorter the mean duration of work at the current PHC facility among physicians and the high turnover among physicians as most of them consider working at the PHC as transient period waiting for their residencies at other facilities so they are not interested.

In the current study there is controversy, as 100% of HCPs mentioned that the Ministry of Health and Population (MOHP) guidelines are their source of neonatal care guidelines and 100% of them have been informed about these guidelines while 12.5% of physicians don't know about neonatal care guidelines and on the other hand, 41.7% of physicians consider MOHP guidelines as their source of information about neonatal care.

All health care providers mentioned that there was no routine neonatal examination performed to all neonates coming for heel test. Neonatal examination was done for cases of neonatal jaundice and congenital anomalies upon mothers request for examination and referral services were done for those cases. These results don't match the results of a study conducted in the United Arab Emirates, where screening of newborn infants includes systematic examination with a checklist of all live births to detect any abnormalities [13]. Many Arab countries have established national registries for congenital abnormalities [14]. Despite the high percent of health care providers who received training courses about neonatal care, none of them perform neonatal examination as an essential screening tool for early detection of neonatal health problems beside the dry blood spot test (heel test).

CONCLUSIONS

The current study concluded that despite the low knowledge and understanding of NBS among the participating mothers, high acceptance of NBS was found

among them, in addition to the lack of awareness among primary health care providers and mothers about the importance of NBS. Raising maternal and health care providers awareness about neonatal screening through health education is highly recommended.

REFERENCES

1. World Health Organization, 2016. Congenital anomalies Factsheet. Website:http:// www.who.int/ mediacentre/ factsheets/ fs370/ en/. Accessed in August, 2018.
2. World Health Organization, 2017. Neonatal mortality. Website:http://www.who.int/gho/child_health/mortality/neonatal/en/. Accessed on Septembaer, 2018.
3. Mashuda, F., A. Zuechner, P.L. Chalya, B.R. Kidenya and M. Manyama, 2014. Pattern and factors associated with congenital anomalies among young infants admitted at Bugando medical centre, Mwanza, Tanzania. BMC Research Notes, 7(1):195.
4. El Koumi, M.A., E.A. Al Banna and I. Lebda, 2013. Pattern of congenital anomalies in newborn: a hospital-based study. Pediatric Reports, 5: 5(1).
5. Centers for Disease Control and Prevention, 2015. Understanding the Causes of Major Birth Defects: Steps to Prevention Website:https:// www.cdc.gov/ cdcgrandrounds/ pdf/archives/2015/january2015.pdf. Accessed in September, 2018.
6. Bekhit, O.E. and R.M. Yousef, 2013. Permanent and transient congenital hypothyroidism in Fayoum, Egypt: a descriptive retrospective study. PloS one, 8(6): e68048.
7. Hinton, C.F., C.J. Homer, A.A. Thompson, A. Williams, K.L. Hassell, L. Feuchtbaum, S.A. Berry, A.M. Comeau, B.L. Therrell, A. Brower and K.B. Harris, 2016. A framework for assessing outcomes from newborn screening: on the road to measuring its promise. Molecular Genetics and Metabolism, 118(4): 221-229.
8. Ministry of Health and Population, 2008. Practice guidelines for family physicians.
9. 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: InSeminars in Perinatology, 39: 171-187.
10. Jansen, M.E., K.J. Lister, H.J. van Kranen and M.C. Cornel, 2017. Policy making in newborn screening needs a structured and transparent approach. Frontiers in Public Health, 21: 53.
11. Al-Sulaiman, A., A.A. Kondkar, M.Y. Saeedi, A. Saadallah, A. Al-Odaib and K.K. Abu-Amero, 2015. Assessment of the knowledge and attitudes of Saudi mothers towards newborn screening. BioMed Research International, doi: 10.1155/2015/718674.
12. Walid, A.A., M.R. Elrafie, N.A. Afifi and E. Elshabrawy, 2009. Quality of care and under utilization of antenatal care in Benisueif PHC. M. S. thesis, Cairo University, Egypt.
13. Al-Gazali, L., H. Hamamy and S. Al-Arrayad, 2006. Genetic disorders in the Arab world. Bmj, 333(7573): 831-834.
14. Hamamy, H.A. and N.A. Al-Allawi, 2013. Epidemiological profile of common haemoglobinopathies in Arab countries. Journal of Community Genetics, 4(2): 147-167.