

Mothers' Knowledge and Practice regarding Care of their Children with Congenital Hypothyroidism

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Abstract

Background: Thyroid hormone deficiency at birth is most commonly caused by a problem with thyroid gland development. **Aim of the study:** Was to assess mothers' knowledge and practice regarding care of their children with congenital hypothyroidism. **Research design:** A descriptive research design was used to carry out the study. **Setting:** The study was conducted at Outpatient Clinics, in Specialized Pediatric Hospital at Benha City affiliated to Benha University Hospital **Sample:** A convenience sampling of 150 mothers and their children with congenital hyperthyroidism. **Tools:** Two tools were used: **Tool 1- A structured interviewing questionnaire:** This tool consisted of three parts: **I:** Personal characteristics of the studied mothers. **II:** Personal characteristics of children. **III:** Mothers' knowledge regarding congenital hypothyroidism. **Tool 2:** Mothers' reported practice sheet. **Results:** Almost three quarters of mothers had unsatisfactory knowledge about congenital hypothyroidism, while almost two thirds of studied mothers had adequate reported practice regarding care of their children with congenital hypothyroidism. **Conclusion:** There was a highly statistically significant relation between total knowledge and practice of mothers and their personal characteristics. Moreover, there was a positive statistically significant correlation between total knowledge and total practice about congenital hypothyroidism. **Recommendations:** Health educational program for raising awareness of mothers through health education regarding care for hypothyroidism child can contribute to well-being of children.

Keywords: Children, Congenital hypothyroidism, Mother`s knowledge, Practice

Introduction

Congenital Hypothyroidism (CH) is one of the most prevalent endocrine and metabolic disorders in children that can affect their quality of life. If, it is left untreated, it can become a serious threat to a child's health and physical growth and mental development. CH occurs when there is a reduction of production of thyroid hormones. They function as regulators of metabolism and are essential for the development of the central nervous system. Worldwide, congenital hypothyroidism has an incidence of 1: 3,000 to 4,000 live births and is the most common

cause of preventable intellectual disability. Early detection of congenital hypothyroidism is accomplished through newborn screening tests (Venugopalan et al., 2021).

Pediatric nurse play an important role in teaching mothers about the importance of proper medication administration and the doctor will see the child regularly to make sure that the medicine is working and change the dose as the child grows. Be sure to go to all follow-up doctor visits. Monitor thyroid hormone levels frequently, because thyroid hormone is crucial for brain development. Children with congenital hypothyroidism can

sometimes develop hearing problems. If you have any concerns about child's hearing or speech development, talk to the doctor. Psychomotor development and school progression should be monitored (**Santos et al., 2021**).

Significance of the study:

In Egypt, the overall incidence of (CH) was 1:2,020 live births in 2005. The Egyptian Ministry of Health and Population started to implement the screening program for Congenital hypothyroidism in 2000 in 5 governorates, and by the end of 2003; all 27 Governorates were covered (**Abdelmuktader, 2013**). During the period from January 2003 to December 2011, 731743 neonates were screened. 568 newborns were detected to have high TSH levels in the first and second dry samples (**Ramadan et al., 2014**). So that, the current study will be carried out to assess mothers' knowledge and practice regarding care of their children with congenital hypothyroidism.

Aim of the study:

The aim of this study was to assess mothers' knowledge and practice regarding care of their children with congenital hypothyroidism.

Research Questions:

- What is the level of mothers' knowledge and practice regarding care of their children with congenital hypothyroidism?
- Is there relation between mothers' characteristics and their knowledge and practice regarding care of their children with congenital hypothyroidism?

Subject and methods:

Research design:

A descriptive research design was used to carry out this study.

Research setting:

The current study was conducted at outpatient clinics which located on the ground

floor and consists of three rooms, in Specialized Pediatric Hospital at Benha city affiliated to Benha University Hospital.

Research Sampling:

A convenience sample composed of 150 mothers and their children with congenital hypothyroidism were recruited from the previously mentioned setting during the period of data collection were included in the study.

Tools for data collection:

Three tools were utilized for data collection:

Tool I: A structured Interviewing Questionnaire Sheet: It was designed by the researcher under supervision of the supervisor after reviewing the literature national and internationally it was written in an Arabic language and composed of three parts as following

Part (I): Personal data of the studied mothers including: age, educational level, job, income, occupation and residence.

Part (2): Personal data of the studied children including: Age, gender, order among the brothers, hypothyroidism in one of the parents and years the child suffering from hypothyroidism.

Part (3): Mothers' knowledge about congenital hypothyroidism: it was adapted from **Ramadan et al., (2014)** to assess knowledge related to congenital hypothyroidism, it included 5 items.

Tool II: Mothers' reported practice about care of their children with congenital hypothyroidism: it was adapted from **Ramadan et al., (2014)**: To assess their reported practices regarding their children with congenital hypothyroidism such as nutrition which consisted of 4 questions, follow-up which consisted of 8 questions, and physical activity which include 4 questions.

Tools validity:

Tools were submitted to a jury of three experts (one professor in pediatric nursing faculty of nursing at Benha University and two assistant professors in (pediatric nursing). All required modifications were done.

Tools Reliability:

Internal consistency of the tools was evaluated by using Cronbach's coefficient alpha test. Reliability of knowledge equal 0.83, reliability for practice equal 0.87.

Ethical considerations:

A permission of the Dean of Faculty of Nursing at Benha university Ethical research committee was obtained. Oral consent was taken from the mothers. Methods of data collection were explained to mothers. Each mother was assured of the confidentiality of her data and data of children.

Pilot study:

It was carried on a sample of 10% of the expected sample size (15) of mothers and their children with congenital hypothyroidism to evaluate the reliability and applicability of the tools and estimate the time required for answering the questionnaire. The tools were modified according to the results of the pilot study and experts' opinions. This phase took one week in December, 2020.

Field work:

The process of data collection started from the beginning of December (2020) to the end of May (2021), covering a long period of 6 months. The data was collected from the previously mentioned setting. The researcher was available at each study setting 1 day weekly (morning shifts) this day was Saturday to collect data using the previous tools.

Statistical analysis:

The collected data was organized, coded, categorized, analyzed and tabulated using Statistical Package for Social Science (SPSS) version 20. Graphics were done using Excel

program. Quantitative data was expressed as mean and standard deviation, while Qualitative data was expressed as percentage. Statistical test such as chi-square (χ^2) was used for determining number and percentage distribution. Pearson correlation coefficient (r) was used for correlation analysis. A statistical significant difference was considered if p-value $P < 0.05$, a highly statistical significant difference was considered if p-value $P < 0.001$ and no statistical significant difference was considered if p-value > 0.05 .

Results

Table (1): Illustrates distribution of the studied mothers according to their personal data. Less than two thirds (60.7%) of studied mothers aged 25 - 35 years with mean age of 32.54 ± 9.71 years. Regarding the mothers' education, less than half (45.3%) of them had middle education. Moreover, less than half of studied mothers (49.3%) had not enough income.

Table (2): Shows distribution of the studied children according to their personal data. It was observed that less than half (41.3%) of studied children aged from 1 - 3 years with a mean age of 2.82 ± 2.19 . More than one third (34%) of them were the second child in the family. The majority (89.3%) of the studied children didn't have hypothyroidism in one of the parents, while only (10.7%) of studied children has hypothyroidism in one of the parents, the majority of children who have hypothyroidism in one of the parents (81.3%) the mother who have the disease. More than two thirds (69.3%) of studied children suffering from hypothyroidism from more than year.

Figure (1): Displays that, about three quarters (75.0 %) of studied mothers had unsatisfactory total score knowledge. While, it was revealed that, about one quarter (25.0

%) of studied mothers had satisfactory total score knowledge regarding caring of their children with congenital hypothyroidism.

Figure (2): Displays that, more than two thirds (66%) of studied mothers had adequate total practice score, and more than one third (34%) of them have inadequate total practice score.

Table (3): Clarifies that there is a highly statistical significant relation between studied mothers' total knowledge score and age, educational qualification, occupation as well as residence ($P < 0.001$). Meanwhile, there was no statistically significant relation between studied mothers' total knowledge score and monthly income ($P > 0.05$).

Table (4): Clarifies that, there is a highly statistical significant relation between studied mothers' total knowledge score and educational qualification, occupation, residence as well as monthly income ($P < 0.001$). Meanwhile, there is no statistical significant relation between studied mothers' total knowledge scores and their age ($P > 0.05$).

Table (1): Distribution of the studied mothers according to their personal data (n=150).

Items	No	%
Age (years)		
< 25 year	22	14.7
25 - < 35 year	91	60.7
≥ 35 year	37	24.6
Mean ±SD	32.54±9.71years	
Educational qualification		
Illiterate	11	7.3
Read or write	25	16.7
Middle education	68	45.3
University education	46	30.7
Monthly income		
Not enough	74	49.3
Enough	62	41.4
Enough and save	14	9.3

Table (2): Distribution of the studied children according to their personal data (n=150).

Items	No	%
Age (years)		
<1 year	31	20.7
1 - > 3 years	62	41.3
3 - > 5 years	34	22.7
≥ 5 years	23	15.3
Mean ±SD	2.82±2.19 years	
Child's Ranking		
First	28	18.7
Second	51	34.0
Third	39	26.0
The last	32	21.3
Family history of the disease		
Yes	16	10.7
No	134	89.3
yes (n=16)		
The father	3	18.7
The mother	13	81.3
Onset of the disease		
Less than year	46	30.7
More than year	104	69.3

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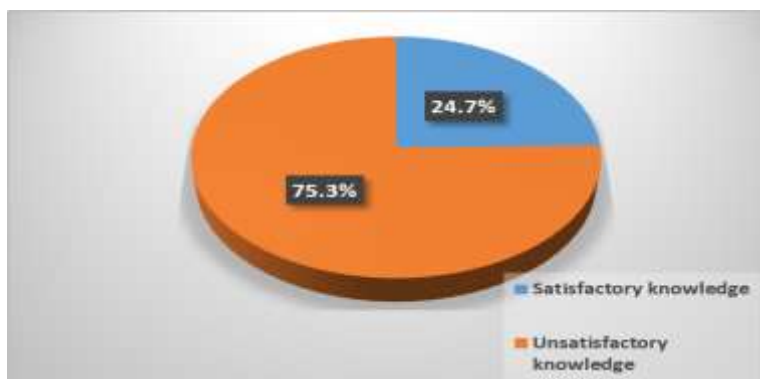


Figure (1): Distribution of studied total mothers' knowledge about congenital hypothyroidism

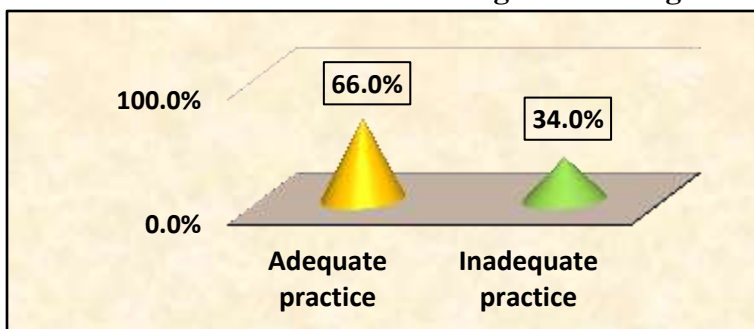


Figure (2): Distribution of studied total mothers' practice about congenital hypothyroidism

Table (3): Relation between mothers' total knowledge score and their personal data (n=150)

Personal data	Satisfactory knowledge (n=37)		Unsatisfactory knowledge (n=113)		X ²	P-value
	No	%	No	%		
Age (years)						
< 25 year	2	5.4	20	17.7	92.5	0.000
25 - <35 year	4	10.8	87	77.0		
≥ 35 year	31	83.8	6	5.3		
Educational qualification						
Illiterate	1	2.7	10	8.8	58.8	0.000
Read or write	1	2.7	24	21.2		
Middle education	5	13.5	63	55.8		
University education	30	81.1	16	14.2		
Occupation						
Working	33	89.2	16	14.2	71.3	0.000
House wife	4	10.8	97	85.8		
Residence						
Rural	6	16.2	93	82.3	54.2	0.000
Urban	31	83.8	20	17.7		
Monthly income						
Not enough	15	40.5	59	52.2	5.6	0.06
Enough	15	40.5	47	41.6		
Enough and save	7	18.9	7	6.2		

Table (4): Relation between total reported practices score of the studied mothers and their personal data (n=150)

Personal data	Adequate practice (n=99)		Inadequate practice (n=51)		X ²	P-value
	No	%	No	%		
Age (years)						
< 25 year	16	16.2	6	11.8	3.24	0.19
25 - <35 year	55	55.6	36	70.6		
≥ 35 year	28	28.3	9	17.6		
Educational qualification						
Illiterate	0	0.0	11	21.6	64.5	0.000
Read or write	4	4.0	21	41.2		
Middle education	56	56.6	12	23.5		
University education	39	39.4	7	13.7		
Occupation						
Working	48	48.5	1	2.0	33.1	0.000
House wife	51	51.5	50	98.0		
Residence						
Rural	51	51.5	48	94.1	27.2	0.000
Urban	48	48.5	3	5.9		
Monthly income						
Not enough	27	28.1	47	87.0	49.0	0.000
Enough	58	60.4	4	7.4		
Enough and save	11	11.5	3	5.6		

*A Statistical significant P< 0.05

**A Highly Statistical significant P< 0.001

Discussion

Congenital hypothyroidism is defined as thyroid hormone deficiency present at birth. CH must be diagnosed promptly because delay in treatment can lead to irreversible neurological deficits. Before the newborn screening program, CH was one of the most common preventable causes of intellectual disability. Newborn screening programs have led to earlier

diagnosis and treatment of CH, resulting in improved neurodevelopmental outcomes (Kollati et al., 2020).

Regarding personal data of studied mothers, the present study showed that less than two thirds of studied mothers aged ranged (25 - <35 year) with a mean age of 32.54±9.71 years. This result consistent with Dei-Tutu et al., (2020) who conducted a study about "Correlating

Maternal Iodine Status with Neonatal Thyroid Function in Two Hospital Populations in Ghana: A multicenter Cross-Sectional Pilot Study " who found that the maternal age was (25–33) years old with mean 29.3 years. Meanwhile, result disagreed with **Tariq et al., (2018)** who conducted a study about "Assessment of knowledge, Attitudes and Practices towards Newborn Screening for Congenital Hypothyroidism before and after Health Education Intervention in Pregnant Women in a Hospital Setting in Pakistan" who found that less than two thirds of studied mothers were less than 25 years of age. This may be due to differences in study sample and site for the study conducted.

Concerning mothers' educational qualification, the present study showed that less than half of studied mothers had middle education. This finding is congruent with **Nagarathnamma et al., (2018)** who conducted a study about " Effectiveness of Structured Teaching Programme Regarding Knowledge on Importance of Iodine Rich Food among Prenatal Mothers at Selected PHC, Ramanagara district" and found that less than half of mothers had completed secondary school education. This could be attributed to living in rural areas. Meanwhile, disagreed with **Poornima & Padmaja, (2018)** who conducted a study about "A Study to Assess the Effectiveness of Structured Teaching Programme on Knowledge Regarding Prevention of Iodine Deficiency Disorder Among Mother's Under Five Children At Selected Anganwadi Center, Tirupati" and found that majority of mothers having primary education.

Regarding personal data of studied children, the present study showed that less than half of

studied children (41.3%) aged from 1 - 3 years with a mean age of 2.82 ± 2.19 . This result disagreed with **Ahmed et al., (2019)** who conducted a study about " Developmental Outcomes in Early-Treated Congenital Hypothyroidism: Specific Concern in Tc99m Thyroid Scan Role " who found that the majority of studied children was in the ages ranged between 3-7 years with a mean age of (4.6 ± 1.9) years).

Regarding to gender of studied children, the finding of the current study revealed that more than half of studied children were male, while less than half of the studied children were female. This result was congruent with **Flávia et al., (2017)** who conducted a study about " Neonatal Screening: 9% of Children with Filter Paper Thyroid-Stimulating Hormone Levels between 5 and 10 μ IU/mL have Congenital Hypothyroidism" who found that the majority of children were males. While disagreed with **Saeidinejat et al., (2020)** who conducted a study entitled " Assessment of Intelligence Quotient Score in Children at The Age of Six with Suspected Congenital Hypothyroidism: A retrospective Cohort Study " who found that the distribution of gender was approximately equal.

Regarding to presence of family history of the disease among the parents, the current study showed that the majority of the studied children have no family history of hypothyroidism. This finding was in the same line with the study done by **Keshavarzian et al., (2016)** who conducted a study entitled "The Incidence of Congenital Hypothyroidism and its Determinants from 2012 to 2014 in Shadegan, Iran: a Case-Control Study" who found that the majority of children have negative history of maternal congenital hypothyroidism. While this finding disagreed

with **Doustmohamadian et al., (2020)** who conducted a study about " Congenital Hypothyroidism and its Related Factors in an Iranian Population: A Retrospective Study in Semnan (2011–2016)" who found that the majority of children have a history of thyroid disease in at least one parent.

Concerning to the onset of the disease among the studied children, the current study showed that more than two thirds of studied children suffering from hypothyroidism from more than year. This may be due to the early investigation and follow up. This finding is congruent with **Santos et al., (2021)** who conducted a study about" Adhesion to Treatment by Children with Congenital Hypothyroidism: Knowledge of Caregivers in Bahia State, Brazil "and found that the duration of the disease was about 3 years. While, this finding disagreed with **Flávia et al., (2017)** who found that the majority of the cases were diagnosed in the first three months of life.

Concerning to total level of mothers' knowledge about congenital hypothyroidism, the current study reported that about three quarters of studied mothers had unsatisfactory total knowledge score. While, about one quarter of them had satisfactory total knowledge score. This finding agreed that was of **Neethu et al., (2020)** who conducted a study about " Assessment of Risk Factors of Congenital Hypothyroidism and Impact of Patient Counseling On Improving Knowledge, Attitude and Practice of the Disease In Post Natal Mothers-A Pilot Study " who found that less than one third of mothers shown poor knowledge, more than two thirds of them shown average knowledge, while no one of mothers shown good or excellent knowledge before counseling.

Also, this finding is supported by **Poornima & Padmaja, (2018)** who found that in pre-test more than one third of mothers had inadequate knowledge, more than one third of them had moderate knowledge and less than one third of mothers had adequate knowledge. While, this result disagreed with **Bragaa et al., (2020)** who conducted a study entitled "Congenital Hypothyroidism as A risk Factor for Hearing and Parents' Knowledge about its Impact on Hearing" who found that less than half of parents/guardians of children with CH had minimal knowledge about the disease.

Concerning total level scores of mothers' reported practices regarding care of their children with congenital hypothyroidism, the current study shows that, less than two thirds of studied mothers have adequate total practice score, and more than one third of them had inadequate total practice score. This finding is consistent with **Poornima & Padmaja, (2018)** who found that less than one third of mothers had inadequate on practices, more than one third of them had moderate on practices and more than one third had adequate on practices. While this finding disagreed with **Neethu et al., (2020)** who found that more than two thirds of mothers shown poor practice, while more than one third of mothers shown good practice.

Concerning to relation between total scores of mothers' knowledge and their personal data, the current study reported that there was a highly statistical significant relation between total scores of mothers' knowledge and age, educational qualification, occupation as well as residence ($P < 0.001$). Meanwhile, there was no statistically significant relation between total scores of mothers' knowledge and monthly income ($P > 0.05$). This finding agreed with **Farahat et al., (2017)** who conducted a study

about" Socioeconomic Determinants Affecting Compliance to therapy in Patients with Congenital Hypothyroidism in Sharkia Governorate" and found that compliance to therapy was affected by the occupational and educational levels of the parents as well as residence, income, social class of the parents and presence of symptoms and associated congenital anomalies. Also, this finding disagreed with **Bragaa et al., (2020)** who found that there was no correlation between socioeconomic class and level of information about congenital hypothyroidism.

Concerning to relation between total scores of mothers' reported practice and their personal characteristics clarifies that, there is a highly statistical significant relation between total scores of mothers' reported practice and educational qualification, occupation, residence as well as monthly income ($P < 0.001$). Meanwhile, there was no statistical significant relation between studied mothers' total reported practice score and age ($P > 0.05$). This finding disagreed with **Machado et al., (2019)** who conducted a study entitled " Influence of Socioeconomic Factors on The Perception of Cochlear-Vestibular Symptoms and Adherence to The Treatment of Congenital Hypothyroidism" who found that socioeconomic factors did not influence treatment adherence or perceived cochlear-vestibular symptoms by caregivers of children with congenital hypothyroidism.

Conclusion

Almost three quarters of the studied mothers had unsatisfactory knowledge about congenital hypothyroidism, while almost two thirds of the studied mothers had adequate reported practice. There was a positive statistically significant correlation between total

knowledge and total practice about congenital hypothyroidism in children.

Recommendation

- 1-Periodical educational training program for mothers at the hospital regarding care of their children with congenital hypothyroidism.
- 2-Developing of a guideline booklet for mothers of children with congenital hypothyroidism is essential to upgrade their knowledge about the care of children with congenital hypothyroidism.
- 3-Reinforce the importance of Pre-marriage examination, minimizing the phenomenon of marriage of relatives and prenatal examination.

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معلومات وممارسات الأمهات تجاه رعاية أطفالهن المصابين بنقص افراز الغدة الدرقية الخلقي

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يعرف قصور الغدة الدرقية الخلقي بأنه نقص حاد في هرمون الغدة الدرقية عند الأطفال حديثي الولادة والذي يتسبب في ضعف الوظيفة العصبية وتوقف النمو والتشوهات الجسدية لدى الأطفال. لذلك هدفت الدراسة إلي تقييم معلومات وممارسات الأمهات فيما يتعلق برعاية أطفالهن المصابين بقصور الغدة الدرقية الخلقي. وقد أجريت هذه الدراسة في العيادات الخارجية بمستشفى الأطفال التخصصي بمدينة بنها التابعة لمستشفى بنها الجامعي. علي ١٥٠ أم وأطفالهن المصابين بنقص افراز الغدة الدرقية الخلقي. حيث كشفت النتائج عن أن هناك ما يقرب من ثلاثة أرباع الأمهات لديهن معلومات غير مرضية عن قصور الغدة الدرقية الخلقي ، في حين أن ما يقرب من ثلثي الأمهات الخاضعات للدراسة لديهن تقارير كافية عن رعاية أطفالهن المصابين بقصور الغدة الدرقية الخلقي. كانت هناك علاقة توجد علاقة ارتباطية ذات دلالة إحصائية ايجابية بين المعلومات الكلية للأمهات وممارستهن الكلية. وأوصت الدراسة بأن هناك حاجة إلي تنفيذ برنامج تدريبي تثقيفي دوري للأمهات في المستشفى بخصوص رعاية أطفالهن المصابين بقصور الغدة الدرقية الخلقي، وضع نشرة إرشادية للأمهات الأطفال المصابين بقصور الغدة الدرقية الخلقي أمرًا ضروريًا لرفع مستوى معرفتهم حول رعاية الأطفال المصابين بقصور الغدة الدرقية الخلقي وكذلك التأكيد على أهمية فحص ما قبل الزواج والتقليل من ظاهرة زواج الأقارب وفحص ما قبل الولادة.