

## Assessment of Mothers' Knowledge and Practices toward Care of their Children with Down Syndrome

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### Abstract

**Background:** Down syndrome is a chromosomal defect causing intellectual impairment and physical abnormalities. A healthy child is born with 46 chromosomes, whereas a child with Down syndrome has an extra copy of chromosome 21. **Aim of the study:** This study aimed to assess mothers' knowledge and practices toward care of their children with Down syndrome. **Research design:** A descriptive research design was used. **Research setting:** The study was conducted in Pediatric Outpatient Genetic Clinic at Specialized Pediatric Hospital which is affiliated to Secretariat of Specialized Medical Center at Benha City. **Study subjects:** A purposive sample of 55 mothers accompanying their children. **Tools of data collection:** Two tools were used; **Tool I:** A structured interview questionnaire sheet: It consisted of five parts; **Part 1:** Personal characteristics of the studied mothers, **Part 2:** Characteristics of the studied children, **Part 3:** Medical history of the studied children, **Part 4:** Previous obstetric history of the studied mothers, **Part 5:** Mothers' knowledge about Down syndrome. **Tool II:** Mothers' reported practices toward care of their children with Down syndrome. **Results:** The majority of the studied mothers had unsatisfactory level of knowledge regarding Down syndrome, meanwhile more than two thirds of them had inadequate level of total reported practices regarding caring of their children with down syndrome. **Conclusion:** There was a highly statistical positive correlation between total level of the mothers' knowledge and their total reported practices level toward care of their children with Down syndrome. **Recommendations:** Designing and implementing an educational program for mothers to improve their knowledge and practices about care for their children with Down syndrome.

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**Keywords:** Children, Down syndrome, Mothers' Knowledge and Practices.

### Introduction:

Down Syndrome (DS) is a chromosomal defect causing intellectual impairment and physical abnormalities. A healthy child is born with 46 chromosomes, whereas a child with Down syndrome has an extra copy of chromosome 21. Also, It is called (Trisomy 21), the medical term referred for having an extra copy of chromosome 21. Down syndrome is the result of an error in cell division called non-disjunction which results in the two chromosome 21 copies

failure to separate. Once the egg is fertilized, the zygote is left with three copies of chromosome 21 resulting in the development of Down syndrome (**Center for Disease Control and Prevention, 2023**).

Down syndrome causes physical, cognitive and behavioral symptoms. Not all children with Down syndrome have all of these symptoms; clinical features are different from child to child. Physical signs of down syndrome are usually present at birth and become more apparent as the newborn grows.

These signs include a flat nose bridge, slanted eyes that point upward, a short neck, small ears, hands and feet, weak muscle tone at birth, small pinky finger that points inward towards the thumb, one crease in the palm of their hand (palmar crease) and shorter-than-average height (**Channell et al., 2021**).

Down syndrome varies in severity among children causing lifelong intellectual disability and developmental delays. It is the most common genetic chromosomal disorder and cause of learning disabilities in children. Besides deficits in cognitive and social areas, children with DS often have other comorbid chronic health conditions such as; congenital heart defects, gastrointestinal disease, hypothyroidism, respiratory disorders, ophthalmologic problems, and hearing problems (**Stylianios et al., 2020**).

Children with DS have a number of medical complications, some of these complications are more serious than others, but most of them can be treated. The most serious complications of DS include; heart defects, blood disorders that include leukemia (cancer of the blood), hormonal disorders, skeletal problems and immune system problems (**Yamato et al., 2021**).

Caring for children with DS and meeting their needs is essential to help them overcome these challenges and live as normal a life as possible. Children with DS need greater care and support than normal other, as they suffer from some delays in learning to crawl, walk and speak. Children require meeting their basic needs, including helping them carryout daily tasks, paying attention to health and education (**National Institute of Health, 2023**).

Mothers play an indispensable and multifaceted role in the care and upbringing of children with DS. This role encompasses various dimensions including; providing emotional support, managing health care

needs, advocating for educational opportunities, fostering social inclusion and ensuring overall well-being. The journey of raising a child with DS can be both rewarding and challenging, requiring mothers to be resilient, resourceful and unwavering in their commitment (**Antonarakis et al., 2020**).

Managing the health care needs of a child with DS is another critical aspect of a mother's role. Children with DS are prone to certain medical conditions such as; congenital heart defects, respiratory issues and thyroid problems, which require regular monitoring and treatment. Mothers often coordinate medical appointments, track health records, administer medications and ensure that their children receive the necessary therapies, such as speech, occupational and physical therapy. They work closely with pediatricians and specialists to develop and follow through with comprehensive health care plans tailored to their child's specific needs (**Embregts et al., 2021**).

Pediatric nurses play a critical role in the care of children with DS, offering specialized attention and support tailored to the unique needs of these patients. Children with Down syndrome often face a range of health challenges and developmental delays that require ongoing medical, emotional and developmental support. Pediatric nurses are on the frontline of delivering this care, ensuring that each child receives comprehensive and individualized attention (**Bull et al., 2022**).

#### **Significance of the study:**

Down syndrome is the most common genetic pediatric disorder; the incidence of Down syndrome is between 1 in 1,000 to 1 in 1,100 live births worldwide annually, 3000 to 5000 children across the world are born with DS (**Bartz-Kurycki et al., 2018**). Down syndrome remains the most common chromosomal condition diagnosed in the

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United States. Each year, about 6,000 babies born in the United States have Down syndrome. This means that Down syndrome occurs in about 1 in every 700 infant (**Center for Disease Control and Prevention, 2023**). The incidence of Down syndrome (DS) in Egypt varies between 1:555 and 1:770 (**Abou- Yossef et al., 2014**).

### **Aim of this study:**

This study aimed to assess mothers' knowledge and practices toward care of their children with down syndrome.

### **Research Questions:**

What is the level of mothers' knowledge and practices toward care of their children with down syndrome?

### **Subjects and Method:**

#### **Research design:**

A descriptive design was used to accomplish this study.

#### **Research setting:**

The current study was conducted in Pediatric Outpatient Genetic Clinic at Specialized Pediatric Hospital which is affiliated to Secretariat of Specialized Medical Center at Benha City. It is found in ground floor and contain one room.

#### **Subjects:**

A purposive sample consisted of 55 of mothers accompanying their children attending the previously mentioned setting was involved in the current study according to the following inclusion criteria:

1. Mothers of children diagnosed with down syndrome.
2. Mothers of children aged from birth to 5 years.
3. Mothers who are willing to participate in the study.

#### **Data Collection Tools:**

The data for this study was collected by using two tools:

#### **Tool I: A structured interviewing questionnaire sheet:**

It was developed and prepared in Arabic language by researchers after reviewing the related literatures. It was consisted of five parts:

**Part 1: Personal characteristics of the studied mothers including;** age, educational level, occupation, marital status & residence.

**Part 2: Characteristics of the studied children as;** age, gender and birth order.

**Part 3: Medical history of the studied children including** children medical history during and after birth.

**Part 4: Previous obstetric history of the studied mothers, including** maternal age during pregnancy, mother complains during pregnancy, medical history and family history.

**Part 5: Mothers' knowledge about Down syndrome.**

It was adapted from **Jan et al., (2017)** to assess mothers' knowledge about down syndrome which included: definition, causes, risk factors, complications, diagnosis, clinical features, treatment and follow up including (8 question multiple choice).

#### **Scoring system of mothers' knowledge:**

It composed of 8 questions (optimal score 16) each question's answer scored as follow: Complete correct answer= (2), incomplete correct answer (1), unknown answer = (0). The total scores of mothers' knowledge were categorized as the following: Satisfactory level knowledge  $\geq$  60% while Unsatisfactory level knowledge  $<$  60 %.

#### **Tool (II): Mothers' reported practices toward care of their children with Down syndrome.**

This tool was adapted from **AboEL-Enen et al., (2022)**, in order to assess mothers' reported practices toward their children with Down syndrome. It was translated into Arabic language. It was consisted of: Feeding (13 items), personal

hygiene (6 items), follow up (4 items), self-reliance skills (4 items), social skills (6 items), cognitive skills (8 items) and sleeping pattern (2 items).

**Scoring system of mothers' reported practices:**

The mothers' reported practice was categorized into each positive statement responded by the subjects according to 3-point Likert scale (Always = 2, Sometimes = 1 and Never = 0). So, the total mothers' reported practices of 43 items (86 points) and total level of mothers' reported practices was categorized by using scoring system as:

- Adequate level of mothers' reported practices 75% - 100%
- Inadequate level of mothers' reported practices < 75%.

**Content validity:**

The data collection tools were revised by a panel of (3) experts one of them was Professor of Pediatric Nursing while two of them were Assistant Professor of Pediatric Nursing, Faculty of Nursing, Benha university to determine the extent to which the items related to each other, and test clarity, relevance, comprehensiveness, simplicity and applicability and the necessary modifications were done accordingly reliability performed to confirm validity of the study tools.

**Reliability of tools:**

Reliability of the tools was checked by testing its internal consistency using Cronbach's alpha coefficient test. It was 0.849 for mothers' knowledge and 0.960 for mothers' reported practices.

**Ethical consideration:**

The study was approved by the Scientific Research Ethical Committee at the Faculty of Nursing/ Benha University. The researchers informed all mothers about nature and expected outcomes from their inclusion in the study in order to obtain their acceptance. The studied mothers were informed that the

study is harmless, all gathered data were confidential and used for the research purpose only. They were informed that, they were optionally allowed either to participate or not in the study and they had the right to withdraw from the study at any time without giving any reason, oral consent was obtained from the studied mothers.

**Pilot study:**

A pilot study was carried out on 10% of predetermined sample of the studied mothers about (5 mothers) to test applicability of the study tools. Participants involved in the pilot study were included from the study sample. The results of pilot study helped to make modifications of the study tools.

**Field work:**

The study was carried out from beginning of October 2023 to the end of February 2024. The researchers was available in previous setting; according to the policy of the setting one day per week (Thursday) from 9 A.M to 2 P.M. to data collected from the previously mentioned setting. The researchers introduced herself to mothers, explained the purpose of the study and providing brief idea about the current study and its outcomes. The researchers interviewed 2-4 mothers per day. The researchers interviewed each mother individually, then the researchers assessed mothers' knowledge and their reported practices toward care of their children with Down syndrome. The needed time to fill questionnaire sheet (tool I) took about 20–25 minutes and mothers' reported practices toward care of their children with down syndrome (tool II) took about 30-45 minutes. The researchers assisted mothers who couldn't fill the questionnaire. The researchers asked questions in simple Arabic langue and recorded the response of mothers in the sheet.

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### Statistical analysis:

The collected data was coded and transformed into specially designed form to be suitable for computer entry process. Data was entered and analyzed by SPSS (Statistical Package of Social Science) version 22. Software graphics were done by using micro soft office excel program version 2010. Quantitative data was presented by mean and standard deviation. Qualitative data was presented in the form of frequency distribution tables, number and percentage, it was analyzed by Chi-square ( $\chi^2$ ) test. Person correlation coefficient (r) was used for correlation analysis and Level of significance was set as a highly statistical significance ( $P < 0.001$ ), No statistically significant at ( $P > 0.05$ ) and statistical significance ( $P < 0.05$ ).

### Results:

**Table (1):** Shows that, less than half (49.1%) of the studied mothers aged between 20-<30 years with mean age  $28.85 \pm 6.11$  years, all (100%) of them were married. Regarding occupation; more than two-thirds (69.1%) of them were house wife and vast majority (94.5%) of them didn't have kinship with their husband.

**Figure (1):** Clarifies that, less than half (43.6 & 41.8%) of the studied mothers had secondary education or its equivalent and high education respectively.

**Table (2):** Presents that, more than half (56.4%) of the studied children aged between 2-<4 years, with mean  $3.46 \pm 0.937$  years and majority (85.5%) of them were girls. In addition, less than two thirds (61.8%) of the studied children were diagnosed with Down syndrome when their age ranged from birth < 6 months. Regarding birth order, more than one third (36.4%) of them were the third child.

**Figure (2):** Clarifies that, less than two thirds (63.6%) of the studied children were

delivered via caesarean section and more than one third (36.4%) were delivered normally.

**Table (3):** Shows that, less than half (49.1%) of mother aged during pregnancy  $20 < 30$  years, with mean age  $28.25 \pm 5.38$  years and 70.9% of them medically followed up for pregnancy. Also; less than two thirds (65.5%) didn't have any problems during pregnancy and the majority (85.5% & 94.5%) of the them not taking any medications during pregnancy without consulting a doctor and didn't exposed to any radiation during pregnancy respectively.

**Table (4):** Demonstrates that, less than two thirds (63.6%) of the studied mothers didn't have chronic diseases and the majority (80%) chronic diseases was blood pressure. And all (100%) of studied mothers didn't have other children with Down syndrome. On the same line; the majority (85.5%) didn't have a history of Down syndrome or genetic disorders in the family.

**Figure (3):** Shows that, the majority (85.5%) of the studied mothers had unsatisfactory level of knowledge regarding Down syndrome, while minority (14.5%) of them had satisfactory level of knowledge regarding Down syndrome.

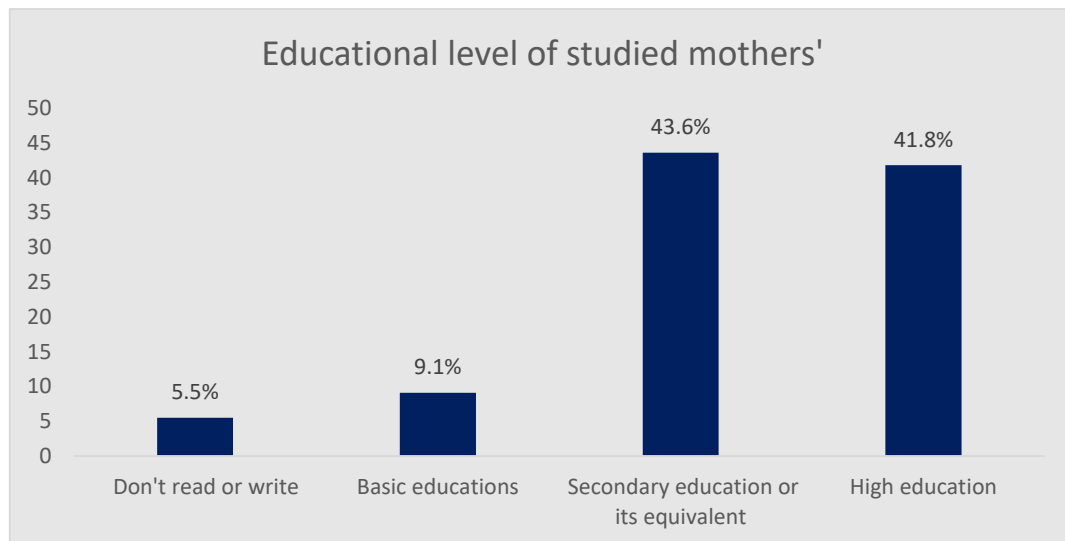
**Figure (4):** Shows that, more than two thirds (69.1%) of the studied mothers had inadequate level of total reported practices regarding caring of their children with Down syndrome. While less than one third (30.9%) of them had adequate level of total reported practices regarding caring of their children with Down syndrome.

**Table (5):** Clarifies that, there was highly statistical positive correlation between total level of the mothers' knowledge and their total reported practices level toward care of their children with Down syndrome ( $P = < 0.001$ ).



**Table (1): Distribution of the studied mothers regarding their personal characteristics (n=55)**

Mothers personal characteristics	No.	%
<b>Age in years</b>		
Less than 20 years	3	5.5
20 < 30	27	<b>49.1</b>
30 < 40	20	36.4
≥ 40	5	9.1
<b>Mean ±SD</b>		<b>28.85±6.11years</b>
<b>Marital status</b>		
Married	55	<b>100.0</b>
<b>Occupation</b>		
House wife	38	<b>69.1</b>
Working	17	30.9
<b>Presence of degree of kinship between parents</b>		
Yes	3	5.5
No	52	<b>94.5</b>
<b>Degree of kinship (n=3)</b>		
First degree of kinship	3	100.0

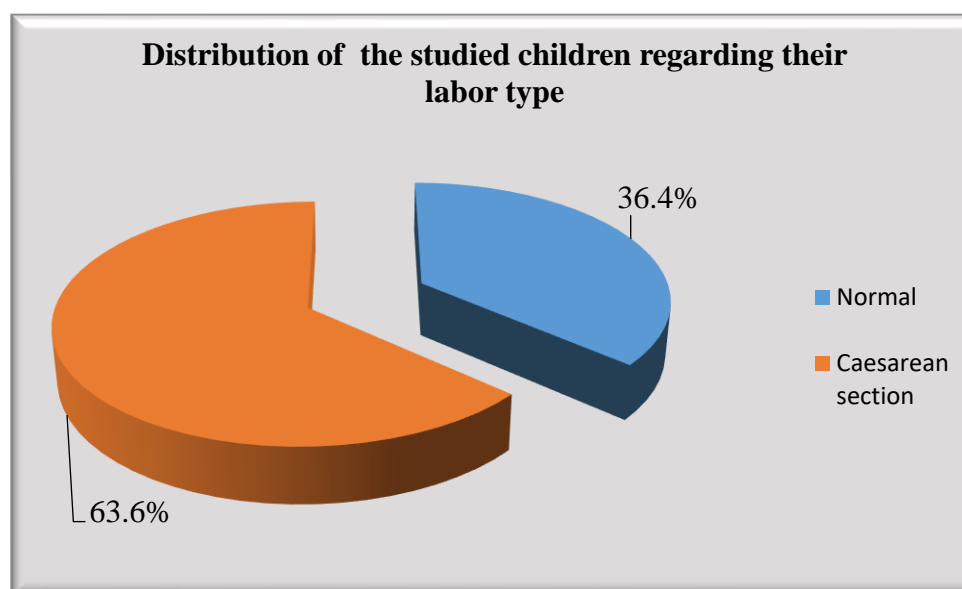


**Figure (1): Percentage distribution of the studied mothers regarding their educational level (n=55).**

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**Table (2): Distribution of the studied children regarding their personal characteristics (n=55)**

Characteristics of children	No.	%
<b>Age</b>		
From birth < 2 years	3	5.5
2 years < 4 year	31	<b>56.4</b>
4 year to 5 years	21	38.2
<b>Mean ±SD</b>	<b>3.46 ±0.937 years</b>	
<b>Gender</b>		
Male	8	14.5
Girl	47	<b>85.5</b>
<b>Child's age when diagnosed with down syndrome</b>		
Birth < 6 months	34	<b>61.8</b>
6 months < 1 year	21	38.2
<b>Child birth order (child ranking)</b>		
First	14	25.5
Second	16	29.1
Third	20	<b>36.4</b>
Others four	5	9.1



**Figure (2): Percentage distribution of the studied children regarding their type of labor (n=55)**

**Table (3): Distribution of the studied mothers regarding their obstetric history (n=55).**

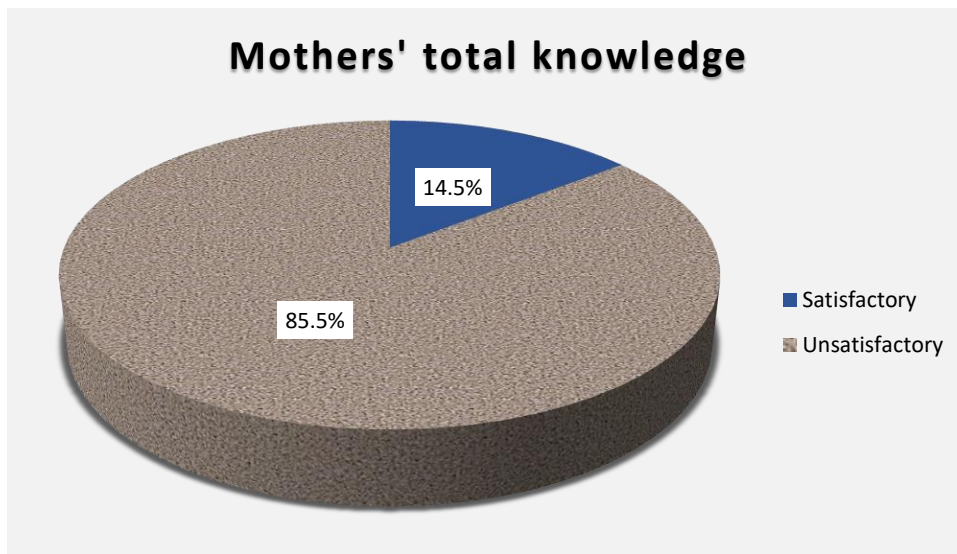
Mothers' obstetric history	No.	%
<b>The mother's age during pregnancy in the child with down syndrome</b>		
Less than 20 years	3	5.5
20 < 30 years	27	<b>49.1</b>
30 < 40 years	20	36.4
≥ 40 years	5	9.1
<b>Mean ±SD</b>	<b>28.25±5.38 years</b>	
<b>Medically follow up for pregnancy</b>		
Yes	39	<b>70.9</b>
No	16	29.1
<b>Mothers' problems during pregnancy</b>		
Yes	19	34.5
No	36	<b>65.5</b>
<b>Type of problems (n=19).</b>		
High blood pressure during pregnancy	16	<b>29.1</b>
Premature labor	3	5.5
<b>Taking medications during pregnancy without consulting a doctor</b>		
Yes	8	14.5
No	47	<b>85.5</b>
<b>If yes type of medications (n=8)</b>		
Antibiotics	3	37.5
Medications for hypertension	5	62.5
<b>Exposure to any radiation during pregnancy</b>		
Yes	3	5.5
No	52	<b>94.5</b>
<b>Type of radiation (n=3)</b>		
x-ray	3	<b>100.0</b>

**Table (4): Distribution of the studied mothers regarding their medical and family history (n=55)**

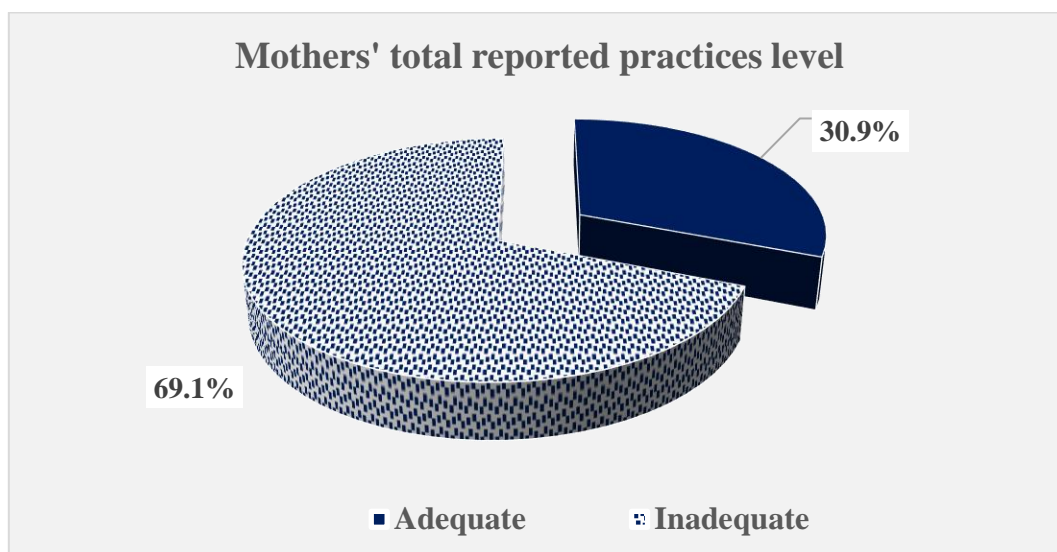
Medical and Family history	No.	%
<b>Mothers suffer from any chronic diseases</b>		
Yes	20	36.4
No	35	<b>63.6</b>
<b>Type of chronic diseases (n=20).</b>		
Blood pressure disease	16	<b>80.0</b>
Thyroids disease	4	20.0
<b>Mothers have other children with Down syndrome</b>		
No	55	<b>100.0</b>
<b>There is a history of down syndrome or genetic disorders in the family</b>		
Yes	8	14.5
No	47	<b>85.5</b>
<b>If yes; Degree of kinship with the child (n=8)</b>		
Father's brother	3	37.5
Mother's brother	5	<b>62.5</b>



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**Figure (3): Percentage distribution of the studied mothers' total level knowledge regarding Down syndrome (n=55)**



**Figure (4): Percentage distribution of the studied mothers' total level of reported practice regarding caring of their children with Down syndrome (n=55)**

**Table (5): Correlation between total mothers' knowledge score and their total reported practices score toward care of their children with Down syndrome**

Total mothers' reported practices score	Total mothers' knowledge score	
	r	p-value
	0.801	.000**

**Discussion:**

One of the primary roles of the mothers of children with DS is to provide emotional support to the child. Children with DS may face numerous challenges, including developmental delays and social stigmatization. Mothers often become the first and most steadfast advocates for their children, ensuring they receive the acceptance, understanding and encouragement needed to thrive. This involves being a constant source of love, comfort and reassurance, helping to build child's self-esteem and confidence. Moreover, mothers frequently advocate for their children in various settings, such as schools, medical appointments and community activities, ensuring their needs are met and their rights are respected (**Masefield et al., 2020**).

Regarding personal characteristics of the studied mothers, the present study findings showed that, less than half of them aged between 20-30 years with mean age  $28.85 \pm 6.11$  years. This finding disagreed with **Negm et al., (2022)**, who performed study about "Effect of educational intervention on psychological well-being and coping of mothers having children with down syndrome, in Egypt", who found that, 63% of the studied mothers aged more than 30 years old with mean was  $34.26 \pm 3.54$ . Also this finding came inconsistent with **Elmwafie et al., (2022)**, who carried out study about the "Effectiveness of coping strategies intervention on quality of life for mothers having children with Down syndrome, in Egypt", who found that; 42.7% of the studied mothers aged from 30 to less than 40 years old with mean age of  $33.73 \pm 5.6$ . This might be due to the criteria of sample selection.

Concerning marital status of the studied mothers, the present study findings showed that, all of them were married. This finding

was in the same line with **Subaşıa & Ocakçıb, (2021)**, who performed a study about "Determination of child abuse potential and related factors of mothers with children with down syndrome, in Turkey", and found that, 85.3% of the studied mothers were married. Also this finding was consistent with **Alosaimi et al., (2020)**, entitled "Knowledge of Down syndrome among down syndrome children's mothers in Riyadh care centers, in Saudi Arabia", who found that, 97.2% of the studied mothers were married.

As regard occupation of the studied mothers, the present study findings showed that, more than two-thirds of them were housewife. This finding was in the same line with **Elkazaz et al., (2021)**, who performed study about "Impact of educational program on stress and coping strategies among mothers caring for down syndrome children, in Egypt", who found that, 70% of the studied mothers were not working. Also this finding was congruent with the **Cless et al., (2018)**, who carried out study about "Hope, coping, and relationship quality in mothers of children with Down syndrome in the United States", and found that, 60.4% of the studied mothers were not working.

Regarding degree of kinship with husband, the present study findings showed that, most of them didn't have kinship with their husband. This finding disagreed with **Alrayes et al., (2024)**, who conducted a study about "Quality of life in children with Down syndrome and its association with parent and child demographic characteristics: Parent-reported measures, in Saudi Arabia", and found that, 76.8% of the studied mothers had kinship with their husband.

Concerning level of education of the studied mothers, the present study findings showed that, less than half of them had secondary education or its equivalent and high education respectively. This finding disagreed

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with **AlJameel et al., (2020)**, who performed study about "Down syndrome and oral health: mothers' perception on their children's oral health and its impact, in Saudi Arabia", who found that, 40% of the studied mothers had no qualification. Also this finding came inconsistent with **Caldwell et al., (2023)**, who conducted study to assess "Mothers' perception of facilitators and barriers to health among young children with Down syndrome: a qualitative study, in United States", who found that, 36% of the studied mothers had postgraduate education.

Regarding personal characteristics of the studied children, the present study findings showed that, more than half of them aged between 2-<4 years, with mean of  $3.46 \pm 0.937$  years. This finding came inconsistent with **AboEl-Enen et al., (2022)**, who carried out a study about "Knowledge, attitudes and reported practices of mothers with down syndrome children at Kafr El-Sheikh Governorate, in Egypt", who found that, 63.3% of the studied children aged 5 to less than 10 years old with mean was  $8.79 \pm 2.716$ .

Concerning gender of the studied children, the present study findings showed that, majority of them were girls. This finding disagreed with **Pastor-Cerezuela et al., (2021)**, who conducted study about "Parental stress and resilience in autism spectrum disorder and down syndrome, in Spain", who found that, 65.2% of the studied children were boys. Also this finding was incongruent with **Barakat & Mohamed, (2019)**, who carried out study about "Relationship between parent stress, psychological well-being and coping strategies among parents with Down syndrome children, in Egypt", and found that, 52% of the studied children were boys.

As regard to child's age when diagnosed with Down syndrome, the present study findings showed that, less than two third of them aged from birth < 6 months when

diagnosed with Down syndrome. This finding disagreed with **Aprigio et al., (2023)**, who performed study about "Mothers of children with Down syndrome: a clinical and epidemiological study, in Brazil", who found that, 76.6% of the studied children diagnosed with Down syndrome during the prenatal period.

Regarding child's birth order, the present study findings showed that, more than one third of them were the third child. This finding was incongruent with **Dinc et al., (2019)**, who carried out study about "Mothers of 0–3-year-old children with Down syndrome: Effects on quality of life, in Ankara", who found that, 57.3% of the studied children were second birth order.

Regarding labor type of the studied children, the present study findings showed that, less than two thirds of them their labor type were caesarean section . This finding came inconsistent with the study conducted by **Zevanya et al., (2024)**, which entitled "Maternal age increases the risk of Down syndrome: a case-control study in Yogyakarta, in Indonesia", who found that, 67.6% of the studied children were born by vaginal birth. This might be due to cesarean deliveries in Down syndrome pregnancies increases over time and is greater when down syndrome is associated with structural abnormalities.

Regarding obstetric history of the studied mothers, the present study findings showed that, less than half of mother aged during pregnancy between 20< 30 years, with mean pregnancy age of  $28.25 \pm 5.38$  years. This finding came inconsistent with **Swanepoe & Haw, (2018)**, who carried out study about "A pilot study evaluating depression in mothers with children diagnosed with Down syndrome in state health care, in South Africa", they found that, 86.7% of the studied mothers aged ranged from 25 to 46 years. This might be due to the criteria of sample selection.

Concerning follow up the pregnancy medically, the present study findings showed that, more than two third of them followed up the pregnancy medically. This finding was in the same line with **Aprigio et al., (2023)**, who found that, 98% of the participated mothers followed up the pregnancy. Also this finding agreed with **Long et al., (2018)**, who carried out study about "Women's understanding and attitudes towards down syndrome and other genetic conditions in the context of prenatal screening, in Australia", who found that, 66% of the studied mothers followed up the pregnancy. This might be due to help find things like a birth defect or a chromosomal problem in the fetus.

As regard to problems during pregnancy, the present study findings showed that, almost two thirds of them didn't have any problems during pregnancy. This finding agreed with the study performed by **Asgarova, (2019)**, entitled "Mothers' experiences of continuing their pregnancy after prenatally receiving a diagnosis of Down syndrome, in Canada", who reported that, 73.9% of the studied mothers didn't have any problems during pregnancy. This might be due to 70.9% of them followed up the pregnancy medically.

Regarding taking medications during pregnancy without consulting a doctor, the present study findings showed that, majority of the studied mothers didn't take any medications during pregnancy without consulting a doctor. This finding disagreed with **Abdel Aziz et al., (2024)**, who carried out study about "Effect of instruction module on mothers' knowledge and coping patterns regarding care of children with mental retardation, in Egypt", who found that, 78.3% of the studied mothers took medications during pregnancy without consulting a doctor. This might be due to drugs or medication taken in pregnancy can cross the placenta and impact on the developing baby. There are a range of

possible effects that may include infant withdrawal from substances, low birth weight.

Concerning exposure to any radiation during pregnancy, the present study findings showed that, most of the studied mothers didn't expose to any radiation during pregnancy. This finding was consistent with the study performed by **Bajagain et al., (2023)**, entitled "Knowledge regarding the prenatal testing for Down syndrome screening among the Nepalese pregnant women, in Nepal", who found that, 65.36% of the studied mothers didn't expose to any radiation during pregnancy. This might be due to receiving radiation in very high doses during the first two weeks after conception could cause a miscarriage. High doses of radiation during the first eight weeks after conception raise the risk of some birth defects.

As regard to family history, the present study findings showed that, less than two thirds of the studied mothers didn't have family history of chronic diseases. This finding was in the same line with the study performed by **Batiha et al., (2024)**, who studied "Identification of maternal risk factors for having down syndrome cases in Jordan", who found that, 81.7% of the studied mothers didn't have family history of chronic diseases.

Regarding having other children with Down syndrome, the present study findings showed that, all of the studied mothers didn't have other children with Down syndrome. This finding was incongruent with **Huang et al., (2020)**, who conducted study about "Pregnant women's attitudes and decision-making regarding prenatal Down syndrome screening and diagnosis: scale development and validation, in Taiwan", who found that, 71.97% of the studied mothers had other children with Down syndrome. This might be due to the women chance of having a baby with Down syndrome increases as they get older.

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Concerning a history of Down syndrome in the family, the present study findings showed that, majority of the studied children didn't have a history of Down syndrome in the family. This finding came inconsistent with **Musdalipa et al., (2021)**, who conducted study about "Maternal age distribution of down-syndrome at pediatric growth and development clinic, in Indonesia", who found that, 48.28% of the studied children had a history of Down syndrome in the family. This might be due to most cases of Down syndrome aren't inherited. When the condition is caused by trisomy 21, chromosomal abnormality occurs as a random event during the formation of reproductive cells in a parent.

Concerning total mothers' knowledge level regarding down syndrome, the present study findings showed that, majority of them had unsatisfactory level of knowledge regarding down syndrome and minority of them had satisfactory level of knowledge regarding down syndrome. These findings were in the same line with the study conducted by **Mahmoud et al., (2022)**, entitled "Mother's coping among primary school child with down syndrome, in Egypt", who found that, 68.4% of the studied mothers had total unsatisfactory level of knowledge regarding of down syndrome, and 31.6% of them had total satisfactory level of knowledge regarding of down syndrome. This might be due to health care providers don't give sufficient knowledge regarding down syndrome to the studied mothers.

Regarding the studied mothers' total level of reported practices regarding caring of their children with Down syndrome, the present study findings showed that, more than two thirds of them had inadequate level of total reported practices regarding caring of their children with Down syndrome. While less than one third of them had adequate level of total reported practices regarding caring of their

children with Down syndrome. This finding was in the same line with **Atia et al., (2024)**, who performed study about "Coping strategies of mothers having primary school students with down syndrome, in Egypt", who found that, 52.5% of the studied mothers had unsatisfactory level of their total reported practices, and 47.5% of them had satisfactory level of their total reported practices regarding down syndrome.

Regarding correlation between total mothers' knowledge score and total mothers' reported practices score toward care of their children with down syndrome, the present study findings showed that, there was a highly statistical positive correlation between total level of the mothers' knowledge and their total reported practices level toward care of their children with down syndrome ( $P = < 0.001$ ). This finding was in the same line with the study conducted by **Atia et al., (2024)**, who found that, there were highly statistical positive correlation between total level of the mothers' knowledge and their total reported practices level toward care of their children with down syndrome.

### **Conclusion:**

The majority of the studied mothers have unsatisfactory level of knowledge regarding Down syndrome, and more than two thirds of the studied mothers had inadequate level of total reported practices regarding caring of their children with Down syndrome. Also there was a highly statistical positive correlation between the total level of the mothers' knowledge and their total reported practices level toward care of their children with Down syndrome.

### **Recommendations:**

- Raising awareness among mothers and their children through giving colored Arabic booklet about Down syndrome.
- Making WhatsApp group for mothers to improve their knowledge and practices



about care for their children with Down syndrome.

- Designing and implementing an educational program for mothers to improve their knowledge and practices about care for their children with Down syndrome.
- Further studies should be conducted on a large sample of mothers and their children with Down syndrome for generalization of the study findings.

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## تقييم معلومات وممارسات الأمهات تجاه رعاية أطفالهن المصابين بمتلازمة داون

منال أحمد محمد اسماعيل- مديحة حسن بيومي- سهام محمد عبد العزيز

متلازمة داون هي خلل كروموسومي يسبب ضعفًا فكريًا وتشوهات جسدية. يولد الطفل السليم مع ٤٦ كروموسوم، في حين أن الطفل المصاب بمتلازمة داون لديه نسخة إضافية من كروموسوم ٢١. الهدف من الدراسة: تقييم معلومات وممارسات الأمهات تجاه رعاية أطفالهن المصابين بمتلازمة داون. تصميم البحث: تم استخدام تصميم البحث الوصفي. مكان البحث: أجريت الدراسة في العيادة الوراثية الخارجية للأطفال بمستشفى الأطفال التخصصي التابع لأمانة المركز الطبي التخصصي بمدينة بنها. عينة الدراسة: عينة غرضية مكونة من ٥٥ من الأمهات المرافقات لأطفالهن. أدوات جمع البيانات: تم استخدام أداتين؛ الأداة الأولى: استمارة استبيان منظمة للمقابلة؛ تتكون من خمسة أجزاء؛ الجزء الأول: الخصائص الشخصية للأمهات المدروسة، الجزء الثاني: خصائص الأطفال المدروسين، الجزء الثالث: التاريخ المرضي للأطفال، الجزء الرابع: التاريخ الولادي السابق للأمهات، الجزء الخامس: معلومات الأمهات عن متلازمة داون. الأداة الثانية: ممارسات الأمهات المبلغ عنها تجاه رعاية أطفالهن المصابين بمتلازمة داون. النتائج: غالبية الأمهات اللاتي شملتهن الدراسة كان لديهن مستوى غير مرض من المعلومات فيما يتعلق بمتلازمة داون، و أكثر من ثلثيهن كان لديهن مستوى غير كافي من إجمالي الممارسات المبلغ عنها فيما يتعلق برعاية أطفالهن المصابين بمتلازمة داون. الاستنتاج: هناك علاقة إيجابية ذات دلالة إحصائية عالية بين المستوى الكلي لمعلومات الأمهات ومستوى ممارساتهن الإجمالية تجاه رعاية أطفالهن المصابين بمتلازمة داون. التوصيات: تصميم وتنفيذ برنامج تعليمي للأمهات لتحسين معلوماتهن وممارساتهن حول رعاية أطفالهن المصابين بمتلازمة داون.