Assessment of Mother's Knowledge and Practice among Primary School Child with Down Syndrome

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Abstract

Background: Down syndrome is a chromosomal disorder characterized by intellectual impairment and physical abnormalities caused by an extra copy of chromosome 21. The support and nurturing provided by mothers are vital for the health and happiness of children with Down syndrome. **Aim of this study:** to assess mother's knowledge and practice among mothers of Down syndrome children in primary school . **Design: A** descriptive study design was consumed. **Setting:** The study was directed at three special needs schools, including two branches of Altarbih EL fikria and El shahid Mohamed Youssef at Fayoum governorate. **Sample:** A purposive sample was consumed; there were 70 mothers and their children. **Tools**: **Tool I:** The structured interviewing questionnaire includes 3 parts: **Part 1,** socio-demographic characteristics for mothers and their children, **Part 2,** family and medical history for mothers and their children, **Part 3,** and mothers' knowledge concerning Down syndrome. **Tool II:** Assessing mothers' practices regarding the care of their children with Down syndrome. **Tool III:** Mothers' needs for caring for their children suffering from Down syndrome. **Results:** The findings discovered that 61.4% of mothers had in acceptable total knowledge regarding Down syndrome; total, 47.1% of mothers reported consistently applying supportive caregiving practices, and 60% of mothers had a high level of total needs. **Conclusion:** Statistical analysis showed a strong positive correlation between knowledge and practice but a significant negative correlation with total needs. **Recommendation:** Apply directed educational programs to help mothers learn more about how to care for their children.

Keywords: Down syndrome, Primary School Child, and Special need care.

Introduction

Down syndrome (DS), also denoted to Down's syndrome or trisomy 21, is a genetic disorder caused by an extra complete or partial copy of chromosome 21. This surplus genetic material disrupts the typical development of the body and brain, resulting in a variety of physical and cognitive difficulties that can differ significantly among individuals. It is the most prevalent chromosomal cause of intellectual disability in children. Each year, between 3,000 and 5,000 children worldwide are born with DS **(Sobiech et al., 2024).**

Down syndrome is generally not passed down genetically; instead, it arises from an error in cell division during the early stages of fetal development. The likelihood of having a child with Down syndrome increases as maternal age rises, especially after the age of 35. While children diagnosed with Down syndrome may experience various health issues, such as heart defects and hearing impairments, progress in medical treatment and early support allows many to enjoy fulfilling, healthy lives, with access to education, job opportunities, and independence (**Ahmed & Tamim, 2025).**

The stage of primary school age (roughly between 6 and 12 years old) is a crucial time for children with Down syndrome. In this period, children embark on their formal education, acquire fundamental academic skills, learn to take care of themselves, establish friendships, and gradually gain independence. It's also a moment when early behavioral patterns, communication abilities, and cognitive development become more defined. Thus, the mother's influence during this time is particularly significant in shaping the child's health, educational progress, and social adaptation, learning, and social adjustment **(Northey et al., 2025).**

Mothers often possess limited knowledge about Down syndrome, yet this understanding is essential for effective caregiving and successful family adjustment. This knowledge encompasses awareness of the child's condition, developmental milestones, health risks, and available support services. When mothers are well-informed with accurate and thorough information, they are more inclined to pursue suitable care, make educated decisions, and foster positive interactions with their child's development **(Zhang et al., 2025).**

Mothers of children with Down syndrome face many challenges that affect their physical, emotional, and psychological well-being. The daily care of a child with developmental delays and medical needs can be demanding and requires constant attention, patience, and adaptability. These challenges often include managing frequent medical appointments, dealing with behavioral or learning difficulties, and addressing social stigma or misunderstandings from others **(Chirac et al., 2023).**

The community health nurse plays a vital role in supporting families of children with Down syndrome at the

community level. She provides health education, early screening, home visits, and continuous follow-up to ensure that mothers are equipped with the knowledge and skills needed for daily caregiving. Community nurses also help connect families to local resources, rehabilitation services, and support networks, promoting both the child's development and the mother's well-being **(Mengoni et al., 2025).**

Significance of the study

Down syndrome is one of the greatest usual genetic disorders and is the result of chromosomal disorder. The occurrence of Down syndrome is nearly **1 in every 1000 to 1100** childbirths universally. The incidence of Down syndrome in Egypt is approximately **1 in every 800 to 1000 live** childbirths. It is considered the irresistible problem for the parents, especially mothers, who feel negative emotions like guilt, stress, or anxiety, especially when they lack access to clear information, professional guidance, or social support **(Esmael et al., 2025).**

Aim of the study:

This study aimed to assess mother's knowledge and practice among mothers of primary school child with Down syndrome, through: -

1. Assessing health status of child with Down syndrome.
2. Assessing mothers' knowledge toward Down syndrome.
3. Assessing mothers' practice toward their Down syndrome children.
4. Assessing mothers' needs for caring their Down syndrome children.

Research Questions:

1. What is health status of child with Down syndrome?
2. What is mothers' knowledge toward Down syndrome?
3. What is mothers' practice toward Down syndrome?
4. What are mothers' needs for caring their Down syndrome children?

Subjects and Method:

1. **Technical Item:**

Research design:

A descriptive cross-section research design was employed in this study to accurately portray and analyze the mothers' knowledge and practices regarding the care of their primary school children with Down syndrome.

Setting:

The study was directed at three special needs schools, including two branches of Altarbih EL fikria and El shahid Mohamed Youssef which are affiliated with the managing of Fayoum education and the Fayoum governorate, and these three schools are the only special needs schools in the Fayoum governorate. This study was conducted at the three main schools in Fayoum Governorate that provide intellectual education services for children with special needs.

1. **The Intellectual Education School in Bandar Al-Fayoum**— a particular school devoted to the education of children with intellectual in capacities, offering

tailored curricula and services to meet their developmental needs.

2. **The Intellectual Education School in Sinnuras**—another specialized institution serving students with intellectual disabilities in the Sinnuras district, contributing to the regional support network for special education.
3. **El Shahid Mohamed Youssef School in Bandar Al-Fayoum**—an inclusive (mainstream) school that operates under the integration education model, which accommodates students with Down syndrome and other intellectual disabilities alongside typically developing, peers.

Sample size:

The study sample contained 70 mothers of sons with Down syndrome enrolled in the primary stage at special education and inclusive schools under the control of the Fayoum Educational Directorate.

Type of Sample: Purposive sample used in the study.

Inclusive criteria for children with Down syndrome:

1. Child identified with Down syndrome.
2. Age between 6 and 12 years (primary school stage).
3. Sex: both sexes.
4. Children living in rural areas.

Inclusive criteria for mothers of children with Down syndrome:

1. Mothers who are the main caregivers delivering direct daily care to the child.
2. Free from any diagnosed mental illness.
3. Inhabiting in rural areas.

Exclusive criteria for children with Down syndrome:

1. Children have other severe infirmities (e.g., cerebral palsy, autism spectrum disorder).
2. Children with long-lasting medical diseases that may affect daily functioning (e.g., uncontrolled epilepsy).
3. Children diagnosed mental illness (checked by a psychiatrist).

Exclusive criteria for mothers of children with Down syndrome

1. Mothers with a diagnosed mental disorder.

Tools for data collection:

Tool I: A structured interview questionnaire:

This tool was developed by the investigator after studying pertinent literature**.** It was planned to collect the essential data. It involved three parts:

Part 1: Socio- demographic characteristics for mothers & their children

A. Mothers' characteristics include 11 questions such as: Age, educational, family member, family type, the family shared a residence; the family's house consists of, number of rooms and good ventilation in the rooms of the house.

B. Children characteristics include 3 questions as: Age, sex, Number of siblings in the family.

Part 2: Family and medical history for mothers and their children

I. Kid family history contain 5 questions as if one of the spouses has a family history of Down syndrome, degree of this relationship, there is a family relation between the parents , degree of this relation , is there others siblings with down syndrome.
II. Mothers' medical history was designed to evaluate medical history. It included 13 questions as, the age of the mother during pregnancy, is there medical follow up for mother during pregnancy, is the mother suffered from any health problems during pregnancy, if yes what are these health problems, did the mother take any medications during pregnancy, If yes, were these medications taken, if yes what are these medications, did the mother exposed to radiation during pregnancy.
III. Child medical history include 8 questions such as, is the child entered the incubator, the time of discovering that the child has Down syndrome, the child diagnosed with Down syndrome, presence of any changes in the child's general appearance , presence of delay in growth and development.

Part 3: Mothers' knowledge regarding down syndrome comprise 11 MCQ as meaning, causes, types, signs & symptoms, diagnosis, complications, Down Syndrome treatable , type of treatment for down syndrome, monitoring of a child with Down Syndrome necessary, the child regularly followed up with a physiotherapist, the child followed up with a speech therapist

Scoring systems for mothers' knowledge:

Mothers' knowledge scale using (correct =1, incorrect =0) the total score of knowledge was 11 points. Score of less than 70% (<8grades) was unsatisfactory and the score equal or more than 70% (8-11grades) was satisfactory.

Tool II: Assessing Mothers' Practices Regarding the Care of Their Children with Down syndrome

This tool was adapted and modified by the investigator after reviewing the relevant literature and consulting experts in the field **(Esmael et al., 2025).** It was designed to assess the actual care practices followed by mothers of children with Down syndrome at the primary school stage.

The questionnaire consists of **7 domains** with a total of **46 items**, including the following areas: Nutrition (13 items), Personal Hygiene (9 items), Medical Follow-up (3 items), Self-Reliance Skills (6 items), Social Skills (6 items), Cognitive Skills (7 items) & Sleep Habits (2 items):

Scoring systems for mothers' practice:

The total score of practice was 46 points. Mother's practice scale has been scored as, Always=3 Sometime =2 never =1.

The total optimal score of mother's practice scale 138. Score of less than

60% (<83) was never. The score between 60% to <75% (83- <104) was Sometime and the score equal or more than 75% (104-138) was Always.

Tool III: Mothers' needs for caring for their children suffering from Down syndrome guided by (**Samir, et al., 2022).** It was used to assess the perceived needs of mothers in caring for their children with Down syndrome at the primary school stage.

Cognitive: Contain 10 items as: Need more information about potential occasions to educate their children with down syndrome, to know the suitable careers that their children with down syndrome can train and work in the future, to know methods of behaviour modification to address their children's behavioral problems, simple books and scientific publications that help me deal with their children, need information about the characteristics of their children with Down syndrome, information on medical intervention methods with their DS children.

Economical: Comprise 9 items as: Need to deliver suitable work for the incapacitated children after their training, transportation to take their children to school or institute, children needs more state assistance to meet the expenses of my disabled child (such as food, treatment and transportation), to provide regular funds to attend specialized training courses that are provided to families to improve their dealings with their disabled child, more help to pay for the games our disabled child needs, to allocate funds to provide additional support services to my child (verbal training).

Psychological and social: Embrace 9 items as: Need the school or institute to animate their children to share in educational, sports and recreational events, help to do recreational activities, people in society to understand their children's disability, to hold sessions with my children's staff at school or institute to follow up on their child's performance, to get rid of depression because of the condition of their disabled child.

Physical needs: Composed of four components: the necessity for a balanced and nutritious diet, external dietary supplements, adequate sleep and relaxation, and proper exercise to alleviate stress.

Scoring systems for mothers' needs:

Mother's needs scale involved 4 constituents (32 items): Mother's needs scale has been scored as,

I never need it =1

I need it moderately=2

I need it very much =3.

The whole optimal score of mother's needs measure 96. Score of less than 60% (<58) was never. The score between 60% to <75% (58-<72) was Moderate and the score equal or more than 75% (72-96) was much.

II. Operational Item:

Validity:

Adjustment of the tools was done by a panel of 5 expertise in Community Health Nursing Faculty of Nursing,

Fayoum University to measure the content validity of the tools and the necessary modifications were done accordingly.

Reliability

The consistency was scaled as follows: <0-0.25 weak reliability, 0.25-0.75 moderate reliability, 0.75-<1strong reliability and 1 is optimum. The reliability for this questionnaire was 0.81.

Items	Alpha Cronbach	f	P-value
Knowledge	0.785	14.067	<0.001*
Practice	0.824	21.119	<0.001*
Needs	0.809	19.318	<0.001*

Pilot Study:

A pilot study was conducted on 10% of the total sample (7 mothers of children with Down syndrome) to check the applicability, clarity, and efficiency of the data collection tools. The pilot study was carried out in the same settings as the main study. The mothers were chosen haphazardly and were later included in the final sample, as no modifications were required based on the results of the pilot study. This ensured that the data collection tools were valid and applicable without introducing any bias.

Field work:

- Contribution was completely voluntary, and all data was treated with accurate confidentiality. Mothers were reassured that the information collected would be used solely for scientific research purposes.
- The majority of mothers were nearby during school hours while waiting for their children, which facilitated the data collection process. Additional opportunities to reach participants occurred during regularly scheduled parents' council meetings and during routine drop-off and pick-up times at the school.
- Data collection was carried out over a three-month period, from the beginning of March to the end of May 2025.
- The investigator was present at the study locations two days per week, directing face-to-face interviews with mothers using the organized data collection tools.
- Each interview was conducted individually in a quiet, private setting, and lasted approximately 40 to 45 minutes.
- On ordinary, three mothers were interviewed per day.
- The investigator gave the structured questionnaire by reading each item aloud, clarifying any ambiguous points, and recording the mothers' answers to ensure consistency and accuracy in data collection.

III. Administrative item:

An approval to carry out this study was obtained from Dean of Faculty of Nursing, Fayoum University and official permission was obtained from the director of the special needs school at Fayoum

Governorate for conducting this study.

Ethical considerations:

Official permission to conduct the planned study was obtained from the Scientific Research Ethics Board, Faculty of Nursing, Fayoum University. Sharing in the study was voluntary, and participants were given complete, whole information about the study and their role before signing the informed consent. The ethical considerations include explaining the purpose and nature of the study, stating the likelihood to disavow at any time, and ensuring the confidentiality of the information, which will not be accessed by any other party without taking permission of the participants. Ethics, values, culture, and beliefs were respected.

IV. Statistical analysis:

Data gotten from the current study were statistically investigated using IBM SPSS Statistics for Windows, Version 20.0 (Armonk, NY: IBM Corp.). Quantitative data were expressed as mean and standard deviation. An unpaired Student's *t*-test was applied to compare means between two independent groups. Analysis of approval studied means across different time points within the same group. Pearson's correlation coefficient was used to assess the linear relationship between two continuous variables within the same group.

Results:

Table (1): illustrates that the majority of mothers were aged 40 years or more (81.4%), with a mean age of **41.14 ± 3.24 years**. Most of them were not working (95.7%) and all belonged to nuclear families (100%). In terms of education, the largest proportion was illiterate (38.6%), followed by those with secondary education (35.7%). More than half of the families (58.6%) reported insufficient monthly income. Concerning family size, the majority had 5 to <7 members (58.6%). Over half of the families lived in houses consisting of two floors (52.9%), and almost all had 2–4 rooms (95.7%) with good ventilation (94.3%). Additionally, most families (90.0%) resided in shared housing.

Table (2): shows that slightly more than half of the children were males (51.4%). The majority were aged 8 to <10 years (64.3%), with a mean age of **9.36 ± 0.85 years**. Concerning family size, the largest proportion of children (60.0%) belonged to families with more than four children.

Figure (1) shows that, the majority of mothers (61.4%) had an unsatisfactory level of knowledge regarding Down syndrome, while only 38.6% demonstrated satisfactory knowledge.

Figure (2) shows that among the six domains assessed, the most consistently practiced area was social skills, with 57.1% of mothers reporting "always" engaging in supportive behaviors. Nutrition followed at 52.9%, while cognitive skills and self-reliance had lower rates of consistent practice (42.9% and 41.4%, respectively). The least

practiced domains, based on "always" responses, were self-reliance and sleep-related routines (both under 46%).

Table (3): shows that nearly half of the mothers (47.1%) consistently practiced supportive behaviors with their children with Down syndrome. Meanwhile, 30.0% reported engaging in such practices occasionally, and 22.9% did not apply them at all.

Table (4): shows that the majority of mothers (60.0%) reported a high level of overall need in caring for their children with Down syndrome, while 32.9% indicated a moderate level of need. Only 7.1% reported having no significant needs.

Table (5): show that there was a strong positive correlation between mothers' total knowledge and their total practice in caring for children with Down syndrome ($r = 0.772$, $p < 0.001$), indicating that higher knowledge levels are associated with better caregiving practices.

Table (1) Frequency distribution of socio-demographic characteristics of mothers of children with Down syndrome (N=70)

Socio-Demographic Characteristics	N=70	100%
1- Age (years)		
<35	**4**	**5.7**
35- <40	**9**	**12.9**
40 or more	**57**	**81.4**
Mean±SD	**41.14 ± 3.24**	
2-Education Level		
Illiterate	**27**	**38.6**
Read and write	**14**	**20.0**
Intermediate	**25**	**35.7**
University	**4**	**5.7**
3-Occupation		
Works	**3**	**4.3**
Not working	**67**	**95.7**
5-Monthly income		
Sufficient	**29**	**41.4**
Insufficient	**41**	**58.6**
6-Number of family members		
3- <5	**19**	**27.1**
5- <7	**41**	**58.6**
7 or more	**10**	**14.3**

7-Family type		
Nuclear	70	100.0
8-The family housed in a shared home		
Yes	63	90.0
No	7	10.0
9-The house in which the family is housed consists of		
One floor	33	47.1
2 floors	37	52.9
10-Number of rooms in the house		
2-4 rooms	67	95.7
more than 4	3	4.3
11- Good ventilation in the rooms of the house		
Yes	66	94.3
No	4	5.7

Table (2) Frequency distribution of demographic characteristics of primary school children with Down syndrome (N=70)

Child Demographic Characteristics	N=70	100%
1-sex		
Male	36	51.4
Female	34	48.6
2-Age		
8- <10	45	64.3
10 or more	25	35.7
Mean±SD	9.36 ± 0.85	
3-Number of children in the family		
1–2 children	12	17.1
3–4 children	16	22.9
more than 4	42	60.0

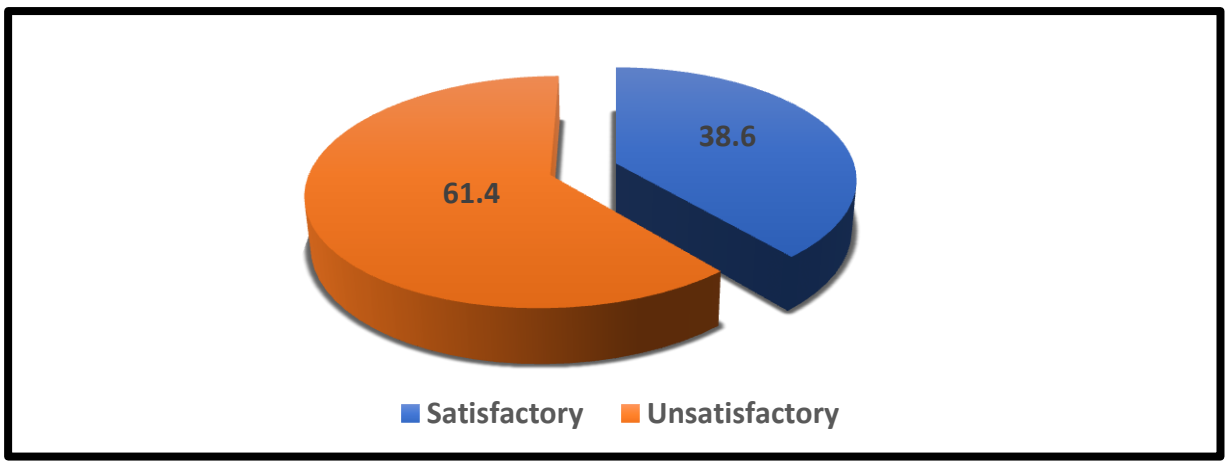

Figure (1) Frequency distribution of mothers' total knowledge level about Down syndrome (N=70).

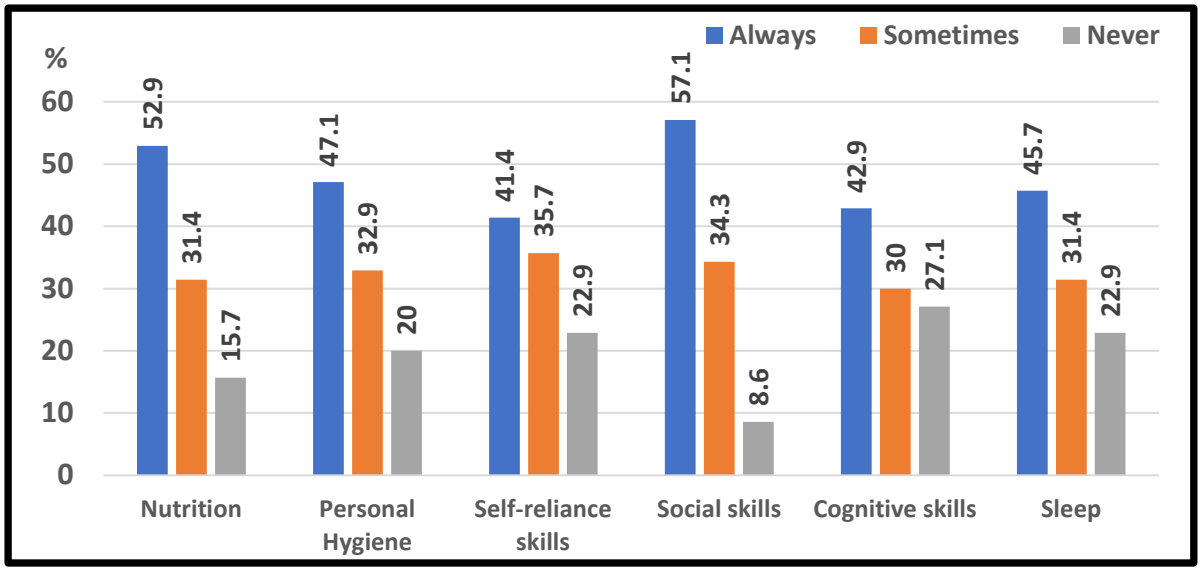

Figure (2) Frequency distribution of overall mothers' practices with children with Down syndrome across key life (N=70).

Table 3: Frequency distribution of mothers' total practice levels toward their children with Down syndrome (N=70).

Total practice	N	%
Always	33	47.1
Sometimes	21	30.0
Never	16	22.9

Table 4: Frequency distribution of total needs of mothers of children with Down syndrome (N=70).

Total needs	N	%
Much	42	60.0
Moderate	23	32.9
Never	5	7.1

Table 5: Correlation between mothers' total knowledge, practice, and needs regarding the care of children with Down syndrome

Variables	Total knowledge		Total practice	
	r	P-value	r	P-value
Total practice	0.772	<0.001*		
Total needs	-0.727	<0.001*	-0.496	<0.001*

Discussion

Down syndrome is the highest general chromosomal condition. The children with Down syndrome (DS) experience delay in their cognitive and physical development which causes difficulties to perform in self-work for the Down syndrome children. The mothers of children with Down syndrome have to provide more care for their children. They face challenges to maintain their position in life **(Ahmed & Tamim, 2025).**

Regarding demographic data, the results of the current study showed that about nearly four fifth of the studied mother of Down syndrome child were in age above 40 years. This finding disagreed with **Bajagain, et al., (2023).** Who studied entitle*" Knowledge regarding the prenatal testing for Down syndrome screening among the Nepalese pregnant women"* and show that nearly half of studied sample were from 20 - 30 years.

In relation to educational level among the studied mother, about nearly two fifth of the studied mothers had illiterate education. This finding not in accordance with the study carried out in Egypt by **El-Enen, et al., (2022).** Who study entitled *"Knowledge, Attitudes and Reported Practices of Mothers with Down Syndrome Children at Kafr El-Sheikh Governorate"* and showed about one third of studied mother were had university education.

On the subject of monthly income, the result of the current study showed that nearly two third had insufficient monthly income this result in the same line with the results conducted in Italy by **Scavarda, (2024).** Who study entitled *"The shame–blame complex of parents with cognitively disabled children"* and show that more than half of studied sample had insufficient monthly income.

From the investigator's point of view, this finding reflects that families of children with Down syndrome often require additional medical care, therapeutic interventions, educational support, and sometimes specialized equipment.

Regarding child age, the results of the current study showed that about two third of the studied child were in age between 8-10 years old. This finding accepted with **El-Enen, et al., (2022).** Who conducted a study at kafr El-Sheikh and showed more than two third of studied child were from 5-10 years.

From the investigator's point of view, children with Down syndrome in Fayoum often begin school at a later age due to developmental delays, challenges in readiness, or delays in accessing educational services.

Related to demographic data, the results of the current study showed that nearly half of the studied children were male**.** The finding attached with **Allah, et al., (2024).** Who conducted a study in Egypt entitled *"Coping Strategies of Mothers Having Primary School Students with Down Syndrome"* and show that nearly half of the studied child was male.

From the investigator's point of view, this is by chance as the two sexes are affected roughly equally.

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 **Ahmed, et al., (2025)**, entitled *"Assessment of Mothers' Knowledge and Practice toward Care of their Children with Down Syndrome, in Egypt"*, who found that, more than two third of the studied mothers had unsatisfactory level of knowledge regarding of down syndrome, and less than fifth of them had total satisfactory level of knowledge regarding of down syndrome.

From the researcher's point of view, this might be due to health care providers don't give sufficient knowledge regarding Down syndrome to the studied mothers.

Regarding mothers' total practice levels toward their children with Down syndrome; the present study findings revealed nearly half of the studied mother consistently practiced supportive behaviors with their children with Down syndrome. This result was inconsistent with **Ahmed, et al., (2025)**, who conducted a study in Baghdad about *"Assessment of Mothers' Knowledge and Practices toward Care of their Children with Down Syndrome"* and revealed that more than two thirds of them consistently practiced supportive behaviors with their children with Down syndrome.

From the investigator's point of view, this may be due to a significant portion of mothers may be facing challenges in delivering effective daily care—whether due to lack of knowledge, psychological and social stress, or limited resources.

Concerning the overall needs of mothers of children with down syndrome, the present study showed nearly two third of mothers had very much cognitive need, one third of mothers had moderate economic needs, more than two third of mothers had very much social and psychological needs and that more than one third of the studied mothers had moderate physical needs. This finding disagreement with **Elsayed, et al., (2022)**, who carried out a study about *"Effect of educational intervention on psychological well-being and coping of mothers having children with down syndrome"* and reported that more than one-third of mothers had very much cognitive need, more than half of mothers had moderate economic needs, more than two-fifths of mothers had very much social and psychological needs and that more than half of the studied mothers had moderate physical needs.

Related to the correlation between mothers' knowledge and caregiving practice, the current study showed a strong positive correlation ($r = 0.772$, $p < 0.001$), indicating that higher mothers' knowledge leads to better caregiving practices for children with Down syndrome. This finding aligns with in Egypt **Elsayed et al., (2022).** Called "*Assessment of Mothers' Knowledge and Practices toward*

Care of their Children with Down Syndrome" supports this link between knowledge and practice.

From the investigator's point of view, this strong association suggests that raising mothers' knowledge through implementing educational interventions such as colorful booklets and What's App support groups are supported by literature highlighting that accessible continuing education enhances caregiving quality and child's outcomes.

Conclusion

The current study showed that, significant health challenges for children with Down syndrome, including delayed growth, movement difficulties, and speech delays. Most mothers had unsatisfactory knowledge about Down syndrome. Also, less than half of mothers consistently applied positive caregiving behaviors, with social and nutritional practices being more common. Practices varied according to education level and residence, with higher levels observed among educated. Unmet needs were high, particularly for medical, psychological, cognitive, and economic support.

Recommendations:

The finding of the present study suggested the following recommendations:

- Organize regular educational programs for mothers to enhance their knowledge about Down syndrome and the physical, mental, and social needs of their children.
- Design practical training sessions to improve daily practices Focused on how mothers can support their children.
- Implement community awareness campaigns aimed at reducing stigma related to Down syndrome and encouraging community and school inclusion for children with Down syndrome.

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