

Knowledge, Attitudes and Reported Practices of Mothers with Down Syndrome Children at Kafr El-Sheikh Governorate

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Abstract

Background: Mothers are the main carers for their families, and they have a fundamental need to be knowledgeable of the potential health issues that their Down syndrome children can encounter. **Aim:** Assess knowledge, attitudes and reported practices of mothers with Down syndrome children. **Setting:** Nine schools for children with special needs at Kafr El-Sheikh Governorate. Numbers of all children with Down Syndrome affiliated to those schools constitute 120 children. **Subjects:** Mothers with Down Syndrome children attending schools for children with special needs. **Tools:** **Tool (I):** Mothers' Knowledge Structured Interview sheet, **Tool (II):** Mothers' Attitude Scale and **Tool (III):** Mothers' reported Practices toward their Down Syndrome Children Interview sheet. **Results:** Less than two-thirds of the studied children aged 5 to less than 10 years, and more than one half of them were male and in primary grades. Less than half of mothers had good knowledge about Down Syndrome compared to more than one tenth for poor knowledge. The majority of mothers had positive attitude toward Down syndrome child and the total mean score of mothers' practices were 56.7% for good practices. **Conclusion:** Study reveals that knowledge about Down syndrome was good among less than half of the mothers, and this was highly correlated with their practices. Also, most of mothers recognized the necessary of information for improving their attitudes toward DS. **Recommendations:** Provide life skills coaching program for the caregivers of DS children with the updated rearing practices.

Keywords: Attitudes, Down Syndrome, Knowledge & Practices.

Introduction:

Early childhood is a period of formation and construction that necessary for growth and development. Children grown more rapidly during this period than at any other time in their lives, these early years of development are critical for providing a firm foundation to cognitive, language, and motor development, as well as social, emotional, regulatory, and moral development. (United Nations Children Fund [UNICEF], 2014).

Children may be born with genetic disorders caused by an anomaly in the genetic code of the individual (Alhaddad et al., 2018). Although the precise causes of various birth defects are often unclear, all pregnant women have the reasonable chance of giving birth to a child who has a birth defect. The risk of having a child with a birth defect also increases in the presence of any of the following factors: a family history of birth defects or other genetic disorders; drug, alcohol, or smoking use during pregnancy; a mother's age of 35 or older; inadequate prenatal care; and women with pre-existing medical conditions, such as diabetes (A-Kubaisy, 2017).

Down syndrome is the main reason in intellectual and developmental impairment and the most common chromosomal disorder that persists throughout one's life which is caused by an extra copy of chromosome

21 in every cell of the body (Ternby et al., 2015). According to World Health Organization [WHO] (2018), the incidence of Down Syndrome is between 1 in 1,000 to 1 in 1,100 live births worldwide. In Egypt the incidence of DS is between 1 in 555 to 1 in 770 live births which is high (Centers for Disease Control and Prevention [CDC], 2018).

Children with DS may have multiple malformations, medical conditions, and impaired cognitive functioning. The most common physical signs include flat face with an upward slant to the eyes, short neck, abnormally shaped ears, protruding tongue, small head, deep increase in the palm of the hand with relatively short fingers, white spots in the iris of the eye, poor muscle tone, loose ligaments, excessive flexibility, small hands, and feet. As well, mental, and physical developments are usually slower in people with Down Syndrome than for those without the condition (Blacher et al., 2013; Centers for Disease Control and Prevention [CDC], 2018). Each child with DS is a unique individual regarding their care (Ternby et al., 2015). As a result, the mother of a child with Down syndrome must be aware of the health and educational differences between the child and other children (Sukbunpant et al., 2013).

Mothers' mental health was significantly impacted by their child's behavioral issues, health problems,

societal misconceptions about children with DS, work-life balance, schooling, future planning, and financial situation. Mothers repeatedly worry about the future and social acceptance of their children, and this concern can result in anxiety disorders (Parameswari & Eljo, 2016).

Meaningfully mothers need to be educated about the possible health problems that their children with Down syndrome may have because they are the family's primary caregivers. Prompt awareness of the child's unique needs is expected to help positive parental and familial adaptation. The degree to which mothers are able to care for their children who have Down syndrome depends on their level of knowledge about the disorder (Nagarkar et al., 2014; Centers for Disease Control and Prevention [CDC], 2021). Although stress about the future can have an impact on a mother's knowledge, high levels of mother well-being and overall family functioning suggest successful adaptation, increasing a mother's ability to respond positively to adversity and emerge strengthened, more resourceful, and confident. Thus, the presence of protective variables, such as family resources, fosters this resilience or adaptability, whereas risk factors limit it (Odom et al., 2011; Shaw et al., 2011).

Mother's attitude has a fundamental influence on the harmony and balance of the lives, just as knowledge has a significant role in creating the meanings, mother should constructs from the efforts to deal with the continuing challenges and difficulties of parenting a child with DS (Sheets et al., 2011). An assessment of the level of understanding of attitudes among the mothers would help to press the point and identify the efforts for increasing awareness and eradicating misinformation about DS in a more targeted and effective manner (Hickey et al., 2012). Moreover, study done in India for mothers of children with DS, it was found that the mothers' attitude, and resources available to them were influenced by their culture, which is concerned with inner virtue, morality, and respect for the community and its values (Amit et al., 2016). Also, mothers' attitudes is associated with the severity of the child's Down syndrome, the child's communication skills, and the level of the child's behavioral difficulty (Alcantara & Castronuevo, 2016).

Mothers' practices also play a major role in promoting adjustment and outcomes related to their DS children since the mother's responsibility is prominent at all phases of a child's life (Pereira & Oliveira, 2015). Mothers have an influence on their children's lives and their primary responsibility is to nurture children (Alexander & Walendzik, 2016) and training them about the healthy practices to help them master skills for independence through self-care like feeding and

dressing, fine and gross motor skills, using toilet and personal hygiene (Sukeri et al., 2017) and finally work to make sure they grow up to be responsible, contributing members of society (Alexander & Walendzik, 2016).

The community health nurse has no less role in helping these children and their families. The nurse should establish the care plan based on the values, beliefs, abilities, and resources of each family (Hippman et al., 2012). She should offer support, good communication, information, and proper care that help families of children with DS to lead full and productive lives and positively adapt to their child's diagnosis (Shobana & Saravanan, 2014). The nurse continues to assess, monitor, and encourage independence with daily living activities and self-care. The role of a nurse in this field is not fixed, nurses may have to carry out different kinds of responsibilities based on the type and extent of special need (de Boer & Munde, 2015). Hence, this study was carried out with the aim to assess knowledge, attitudes and practices of mothers having children with DS.

The significance of the study:

The number of research in this field are limited and very weak especially in Egypt, and through this research the researcher will identify knowledge, attitudes, and practices of mothers during dealing with their down syndrome children and what are the challenges facing every day for improving their children's lives. The numbers of down syndrome people in Egypt expected for increasing in the next years. The viewpoint of many of people that the Down syndrome people consider stow on the community and there isn't any advantage from them. So, the significance of the study for this research is very important to correct the misconceptions and ensure community support toward the Down syndrome people and their families.

The aim of this study is to:

Assess knowledge, attitudes and reported practices of mothers with Down syndrome children.

Research Questions:

1. What are the levels of knowledge of mothers with Down Syndrome children?
2. What are the levels of attitudes of mothers with Down Syndrome children?
3. What are the levels of practices of mothers with Down Syndrome children?

Materials and Methods

Materials

Research design: A descriptive research design was utilized in this study.

Setting: The study was conducted at the nine schools at Kafr El-Sheikh governorate namely: Kafr El-Sheikh School, Desouk school, Fewa School, Kellen School, Sedi Sallem School, Baltim School, Al Hamaul School, Metobas School, Beila School with special needs.

Subjects: Mothers with DS children attending previously mentioned setting

Sample size: All available schools for children with special needs which represents the 9 out of 10 zones of Kafr El-Sheikh Governorate were included into the study. While the 10th zone named EL- Reyad was excluded because it hasn't school for children with special needs. Numbers of all children having Down Syndrome affiliated to Kafr El-Sheikh schools for children with special needs constitute 120 children.

Tools of data collection: Three tools were used to collect the data.

Tool (I): Mothers' Knowledge Structured Interview sheet.

It was developed by the researcher based on extensive review of recent and relevant literature (Warner et al., 2017). It was consisted of two parts:

Part I: Personal data and health profile

Child personal data and health profile included: personal data, health profile, difficulties facing child, anthropometric measurement, Intelligence Quotient (IQ) (Moeschler et al., 2014) score, availability of health insurance and rehabilitation services for child

Mothers' personal data and health profile included: personal data, reproductive history, medical history, family history of genetic disorder

Part II: Assessment of Mothers' Knowledge about Down Syndrome:

It was used to assess mother's knowledge about Down Syndrome which included: definition, causes, risk factors and complication.... etc. It consists of 15 questions. Each question's answer scored as follow: Correct complete answer = (2), Correct incomplete answer = (1), Wrong, missed answer = (0). Summing the score of the scale items and divided by the number of items in the scale was computed the score. Thus, the total scale scores range from 0 to 30.

Mothers' knowledge level was categorized by using scoring system: -

- < 50% (less than 15 points) = Poor level of knowledge.
- 50% < 75% (15-less than 23 points) = Fair level of knowledge.
- 75%-100% (23-30 points) = Good level of knowledge.

Tool (II): Mothers' Attitudes Scale:

The originally English version was developed by Antonak and Harth (1994) was used to measure participants' attitudes toward the inclusion of people with DS. (Antonak et al., 1994). It was adopted and

translated into Arabic by the researcher to assess mothers' attitudes toward their Down Syndrome children. It consists of 29 items and comprising four subscales, using a 4-point Likert scale which included **Strongly Disagree (1) to Strongly Agree (4)** for responses. There are some reverse statement items (**1, 4, 6, 13, 16, 18, 20, 23, 25, 27**) which included **strongly Disagree (4) to Strongly Agree (1)** for responses. Three subscales composed of **integration-segregation, private rights, and subtle derogatory belief**, where they have seven items and **social distance** consists of eight items. **A total score** is the sum of the responses, and a higher score suggests more positive attitudes toward individuals with DS.

Tool (III): Mothers' Reported Practices Toward their Down Syndrome Children Interview sheet.

This tool was developed by Leicester, Leicestershire & Rutland (June 2016), and was **adapted** by the researcher to assess mothers' practices toward their Down syndrome children (**University Hospitals of Leicester and Leicestershire Partnership NHS Trusts, 2016**). It was translated into Arabic. It consists of (46) statements to assess mothers' practices measuring 7 dimensions: Feeding, personal hygiene, follow up, self-reliance, social, cognitive skills and sleeping pattern. The statements were responded by the subjects according to 3-point Likert scale. - Each positive statement responded by the subjects according to 3-point Likert scale (Always = 2, Sometimes = 1 and Never = 0). However, negative statement number 6, 7, 24 and 25 responded by the subjects according to 3-point Likert scale (Always = 0, Sometimes = 1 and Never = 2). Scoring was performed by summing the total items completed and dividing by the number of items completed. The total scores range from (0 to 92).

Mothers' practices level was categorized by using scoring system as:

- < 50% (less than 46 points) = Poor level of practices.
- 50% < 75% (46 to less than 69 points) = Fair level of practices.
- 75% - 100% (69-92 points) = Good level of practice.

Methods

The study was executed according to the following steps:

Administration process: An official letter from the Faculty of Nursing-Damanhour University was directed to the responsible authorities of the previously mentioned study setting to obtain their permission for conducting the study after explanation of research purpose.

Development of the study tools:

- Development of the tool (I) was done by the researcher based on extensive review of recent and relevant literature.
- Tool (II) was **adopted** and translated into Arabic.

- Tool (III) was **adapted** and translated into Arabic.
- Tools II, III were tested for content validity by a jury of 5 experts in community health nursing and pediatric nursing fields at Faculty of nursing, Damanhour University.
- The tools were revised, reconstructed, and made ready for use. The recommended modifications were done, and the final form was prepared after proving valid.
- Tools were checked for their reliability by test-retest technique Cronbach' Alpha at result as follows: Tool (I) was 0.908, Tool (II) was 0.817, Tool (III) was 0.905.

Pilot study was conducted on 12 mothers from the previously mentioned settings (and they were included again to the selected sample). It was conducted to ascertain the relevance and content validity, identify obstacle that might interfere with the process of data collection, and estimate the time needed to complete the tool.

Collection of data

- Collection of data was done after introducing the researcher and explaining the purpose of the study to each mother, and then securing the subject's informed written consent.
- Collection of data covered a period of 6 months started from the beginning of September 2020 until the end of February 2021, three days per week.
- The researcher contacts the mothers to set up an appointment to perform the interview.

Results

Table (1): Studied subjects (D S children) according to personal data (n=120)

Items	Total (n=120)	
	No.	%
Age (years)		
- 5-	76	63.3
- 10-	41	34.2
- ≥ 15	3	2.5
Min – Max 5-16		
Mean \pm SD 8.79 \pm 2.716		
Gender		
- Male	70	58.3
- Female	50	41.7
Birth order		
- First	48	40.0
- Second	39	32.5
- Third	22	18.3
- Fourth and more	11	9.2
Number of siblings		
- One	37	30.8
- Two	48	40.0
- Three	24	20.0
- Four	11	9.2
Min – Max 1-4		
Mean \pm SD 2.07 \pm 0.936		
Educational academic grades		
- Primary grade	79	65.8
- Preparatory grade	41	34.2

- In order to get the required data from the mothers, the researcher stayed at school during school hours.
- After collecting data from all the mothers at one school, the researcher proceeded to another to gather data there.
- Each mother was individually interviewed for 30 - 40 minutes by the researcher.

Ethical consideration:

- Research approval was obtained from ethical committee at faculty of nursing Damanhour university
- Written consent from subjects was obtained.
- Keeping subjects' privacy, right to withdrawal at any times as well as assuring confidentiality of their data.

Statistical analysis:

The collected data was revised, categorized, coded, computerized, tabulated and analyzed using statistical package for social sciences (SPSS) version 20.

The following statistical measures were used:

- 1- Cross tabulation with frequency distribution and percentages were used to explore relationships between variables.
- 2- Arithmetic mean and standard deviation were used as a summary statistic for quantitative data.
- 3- Appropriate tests were used as Monte Carlo, ANOVA test, Pearson Correlation and Chi-square at 0.05 level of significance.
- 4- For graphical presentation: Graphs were done for data visualization using Bar and Pie charts.

Table (2): Studied subjects (DS children) according to health profile (n=120)

Items	Total (n=120)	
	No.	%
Intelligence quotient (IQ)		
- 50-	21	17.5
- 55-	53	44.2
- 60-65	46	38.3
Min – Max 50-64		
Mean ± SD 57.74 ± 3.102		
Have a chronic disease		
- No	33	27.5
- Yes#	87	72.5
▪ Diabetes mellitus	28	32.2
▪ Cardiovascular diseases as heart failure	18	20.7
▪ Vision problems as blindness	12	13.8
▪ Renal diseases	10	11.5
▪ Respiratory diseases as bronchial asthma	9	10.3
▪ Thyroid diseases as hypothyroidism	7	8.0
▪ Hearing problems	6	6.9
▪ Epilepsy	4	4.6
- Have developmental delay		
- No	15	12.5
- Yes #	105	87.5
▪ Attention deficit	52	49.5
▪ Motor development as walking	32	30.5
▪ Speech	31	29.5
▪ Physical growth (weight, height)	26	24.8
- Teething eruption	24	22.9
- Duration of developmental delay (months)	(n = 105)	
- 12 months	49	46.7
- 24 months	35	33.3
- 36 months	19	18.1
- 48 months	2	1.9
Min – Max 1-5		
Mean ± SD 1.73 ± 0.812		

More than one answer

Table (3): Total mean scores of (D S children) according to difficulties' levels

Items	Total N=120		Min – Max	Mean ± SD	Mean Percent Score	Rank
	No.	%				
Personal hygiene						
- No	11	9.2	0.0-12.0	6.92 ± 3.504	57.67%	1
- Mild	26	21.7				
- Moderate	38	31.7				
- High	45	37.5				
Feeding						
- No	6	5.0	0.0-12.0	6.08 ± 2.938	50.67%	3
- Mild	48	40.0				
- Moderate	42	35.0				
- High	24	20.0				
Self-reliance						
- No	0	0.0	1.0-24.0	13.08 ± 4.784	54.50%	2
- Mild	46	38.3				
- Moderate	53	44.2				
- High	21	17.5				
Total scores of children levels of difficulty						
- No	0	0.0	1.0-48.0	26.08 ± 9.122	54.33%	
- Mild	43	35.8				
- Moderate	63	52.5				
- High	14	11.7				

Table (4): Studied subjects mothers' according to personal data

Items	Total (n=120)	
	No	%
Age (years)		
- 25-	16	13.3
- 30-	27	22.5
- 35-	36	30.0
- ≥ 40	41	34.2
Min – Max 25 – 49		
Mean \pm SD 36.53\pm6.496		
Marital status		
- Married	105	87.5
- Divorced\ Separated	15	2.5
Level of education		
- Illiterate	11	9.2
- Read & Write	14	11.7
- Primary education	14	11.7
- Preparatory education	9	7.5
- Secondary / technical education	42	35.0
- University education	30	25.0
Employment status		
- Housewife	71	59.2
- Working	49	40.8
Place of residence		
- Urban	54	45.0
- Rural	66	55.0
Type of family		
- Nuclear	67	55.8
- Extended	53	44.2
Sufficiency of income		
- Not enough	45	37.5
- Hardly enough	68	56.7
- Enough	7	5.8
Parents' consanguinity		
- No	59	49.2
- Yes	61	50.8
▪ First degree	34	55.7
▪ Second degree	27	44.3

Table (5): Studied subjects mothers' according to their health profile

Items	Total (n=120)	
	No	%
▪ Reproductive history:		
Number of gravidas		
- 1	3	2.5
- 2	36	30.0
- 3	57	47.5
- 4	22	18.3
- 5	2	1.7
Min – Max 1 – 5		
Mean \pm SD 2.87\pm0.798		
Mothers' age when their pregnant at Down Syndrome child		
- <20	13	10.8
- 20-	30	25.0
- 25-	42	35.0
- 30-	15	12.5
- 35-40	20	16.7
Min – Max 16 – 40		
Mean \pm SD 26.75\pm6.103		

Items	Total (n=120)	
	No	%
History of abortion/still birth		
- No	112	93.3
- Yes	8	6.7
▪ Once	6	75.0
▪ Twice	2	25.0
Presence of pregnancy risk factors		
- No	23	19.2
- Yes#	97	80.8
▪ Age (↓18 years, ↑35 years)	18	18.6
▪ Hereditary factors	31	32.0
▪ Exposure to radiation	10	10.3
▪ Taking multiple medications	38	39.2
Pregnancy accompanied by complications		
- No	49	40.8
- Yes#	71	59.2
▪ Bleeding	29	40.8
▪ Preeclampsia	22	31.0
▪ Placenta previa	16	22.5
▪ Gestational diabetes	6	8.5

#More than one answer

Table (5) Cont.: Studied subjects mothers' according to their health profile

Items	Total (n=120)	
	No	%
▪ Medical history		
Have chronic diseases		
- No	52	43.3
- Yes#	68	56.7
▪ Diabetes	27	39.7
▪ Hypertension	23	33.8
▪ Bronchial asthma	13	19.1
▪ Heart diseases	5	7.4
▪ Kidney diseases	3	4.4
▪ Thyroid diseases	2	2.9
Family history of genetic disorders		
- No	82	68.3
- Yes	38	31.7
▪ Grandparents	17	44.7
▪ Cousin/nephew	11	29.0
▪ Uncles/ Aunts	10	26.3

#More than one answer

Table (6): Correlation between DS children's difficulty levels and their mothers' knowledge, attitude, and Reported practices levels regarding Down Syndrome

Mothers' Practices	Mothers' Attitude	Mothers' Knowledge	Children's difficulty		
				r	Children's difficulty
				p	
			0.158	r	Mothers' Knowledge
			0.085	p	
		0.452	0.152	r	Mothers' Attitude
		0.000*	0.096	p	
	0.275	0.334	0.306	r	Mothers' Practice
	0.002*	0.000*	0.001*	P	

R= Pearson Correlation * Statistically significant at p ≤ 0.05

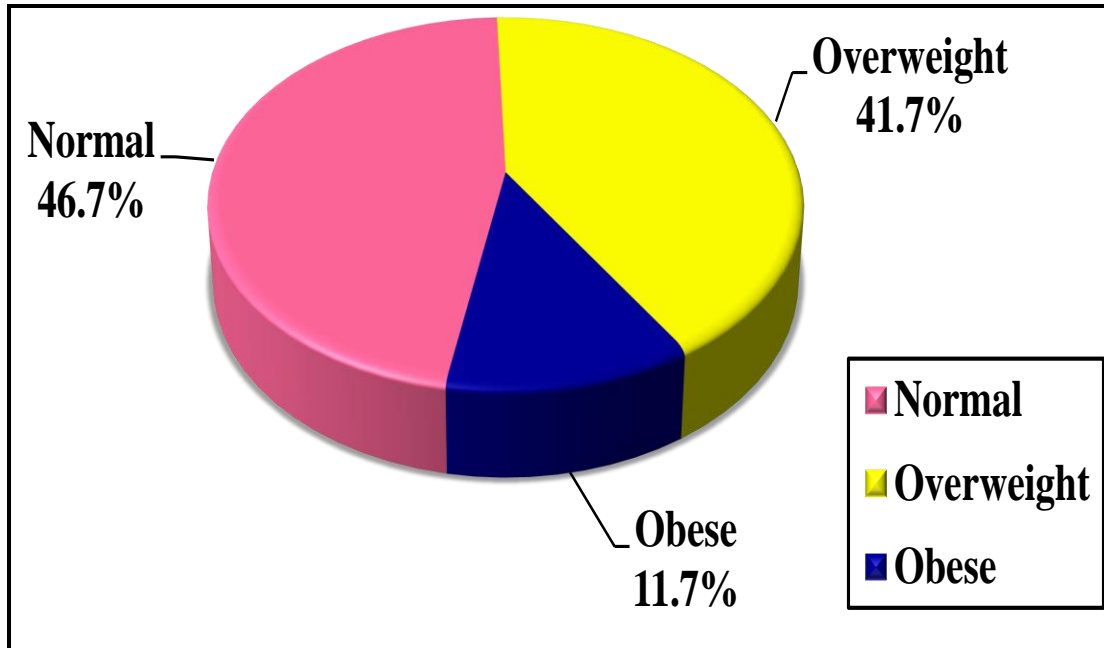


Figure (1): The studied subjects (Down Syndrome Children) Body Mass Index

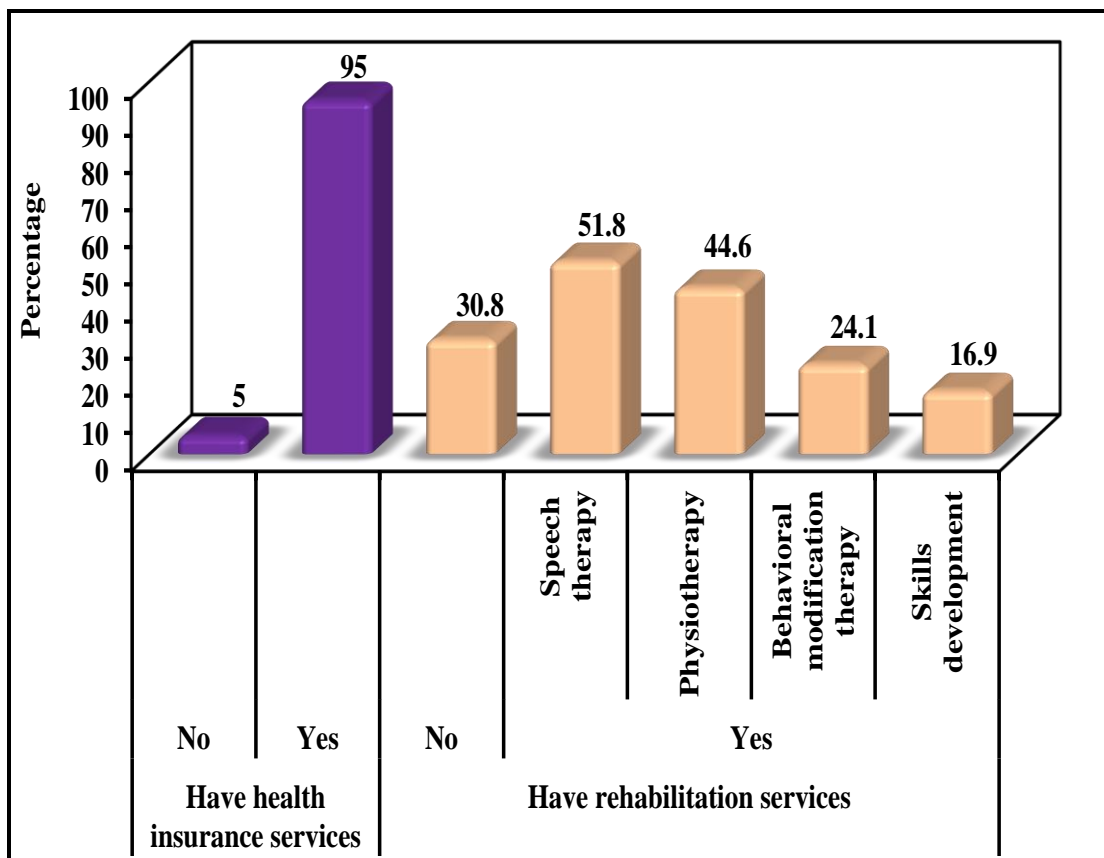


Figure (2): Distribution of (DS children) according to utilization of health insurance and rehabilitation services

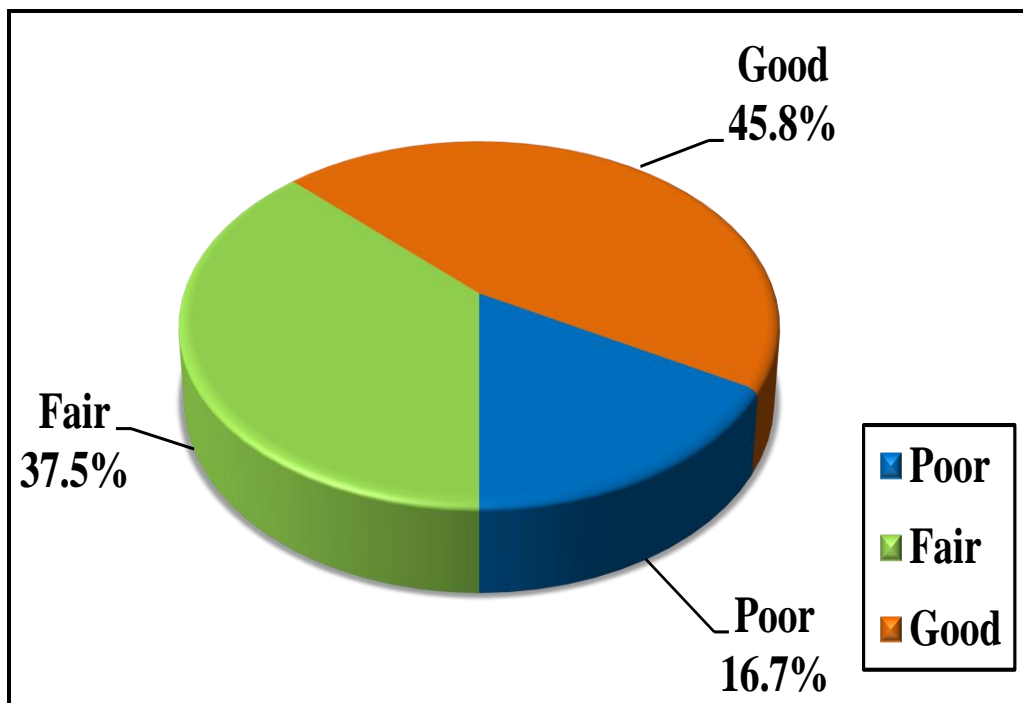


Figure (3): The studied subjects (mothers) according to their total knowledge score about Down Syndrome

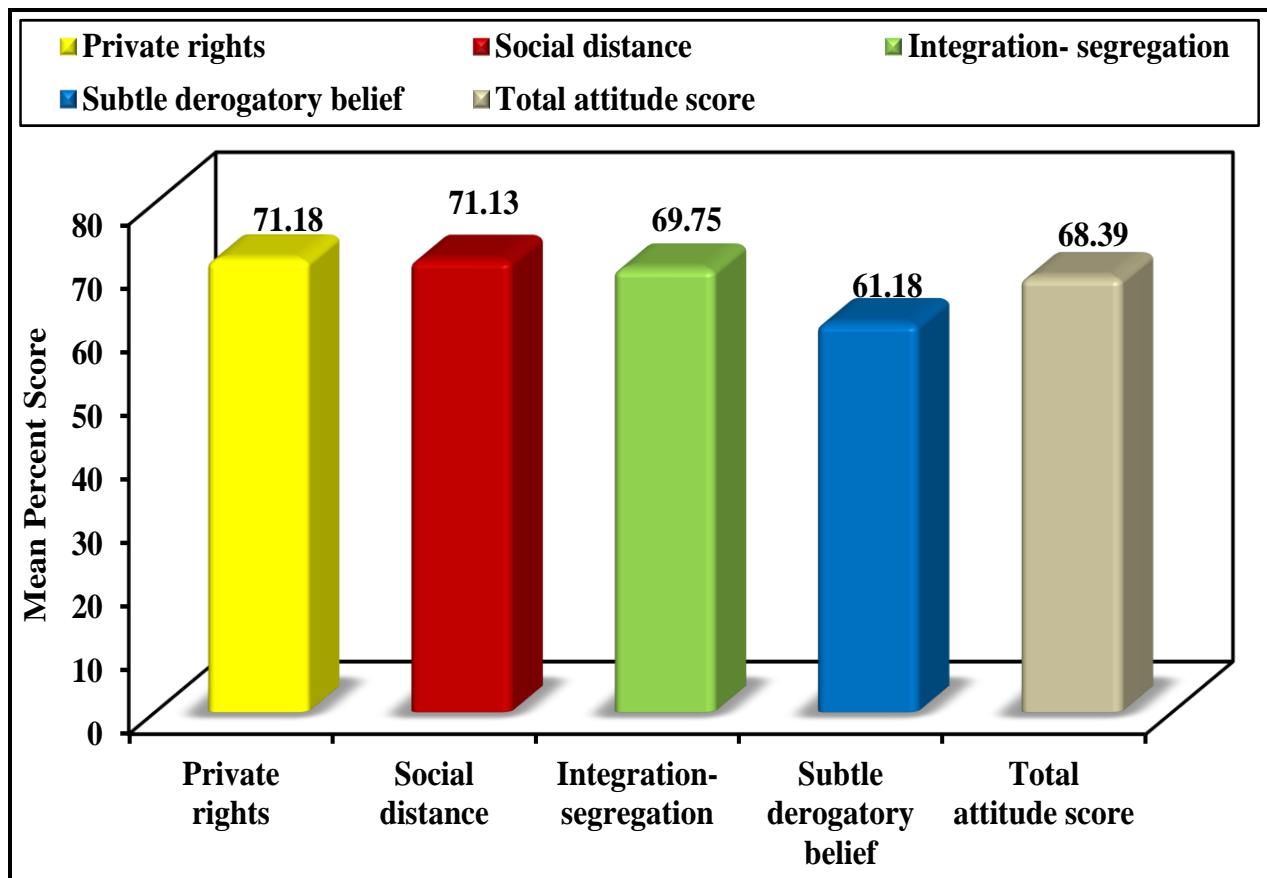


Figure (4): Attitudes of (mothers) with Down Syndrome children

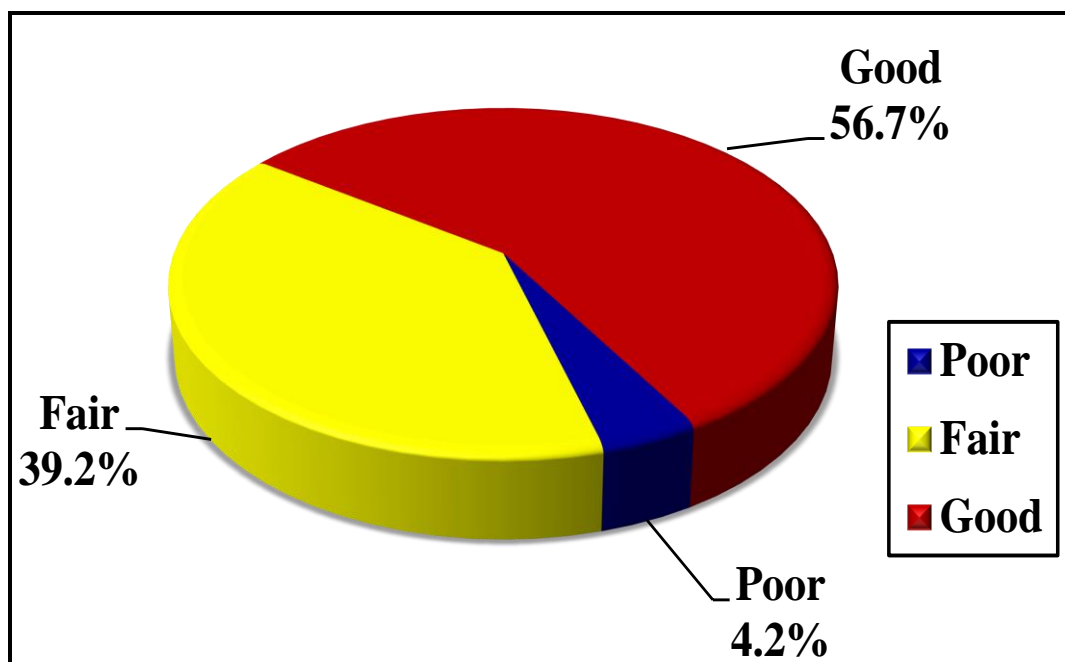


Figure (5): Total practices of mothers' total scores of practices' mothers of Down Syndrome children

Table (1): Shows the distribution of the studied subjects (Down Syndrome children) according to their personal data. Concerning age, it was ranged from 5-16 years as mean age of 8.79 ± 2.716 years, it was observed that less than two-thirds of the studied children 63.3% were aged 5 to less than 10 years, while more than one-third of them 34.2% aged 10 to less than 15 years. More than one half of them 58.3% were male. Two-fifths of them 40% were the first child, followed by less than one third of them 32.5% were the second child. While the minority of them (9.2%) were the fourth child or more between their siblings. Regards to the number of siblings, it was found that less than three quarters of them (70.8%) had one or two siblings, followed by (29.2%) had either three or fourth sibling with Mean \pm SD 2.07 ± 0.936 . Regarding Educational academic grades, it was found that less than three quarters of them 65.8% were primary grades.

Table (2): Displays the distribution of the studied subjects (Down Syndrome children) according to their health profile. It was observed that 44.2% of the studied children their Intelligence Quotation was 55 to less than 60, while more than one third of them (38.3%) their Intelligence Quotation was 60-65. The least of them (17.5%) had IQ less than 50%. The Mean \pm SD of the subject's I.Q were 57.74 ± 3.102 .

The table also reveals that 72.5% of the Down Syndrome children having chronic disease whereas, 32.2% of them have Diabetes mellitus, (20.7%) have cardiovascular diseases as heart failure and 13.8% have vision problem as blindness.

As relate to delay in development, the majority of mothers with Down Syndrome children (87.5%) reported delay in their children development. Less than half of them had attention deficit (49.5%), followed by delay in motor development as walking which mentioned by less than one third of them (30.5%), then delay in speech was found in 29.5% of them. As regard duration of child's developmental delay, less than half of those children had developmental delay (46.7%) from twelve to less than twenty-four months. The Mean \pm SD of the subjects' age of developmental delay was 1.73 ± 0.812 .

Figure (1): Demonstrates the distribution of the studied subjects (Down Syndrome children) according to their (BMI). The figure reveals that more than half of the studied children had abnormal BMI were 41.7% for overweight and 11.7% for obese.

Table (3): Shows the distribution of the studied Down syndrome children according to their total scores of difficulties facing in their Daily Living Activities as perceived by their mothers. It was found that personal hygiene was the first ranked problem facing the Down syndrome children were 57.67%, followed by 54.5% for self-reliance as the second ranked difficulties. While the total with mean percent score for difficulties level was 54.33%, with Mean \pm SD was 26.08 ± 9.122 .

Figure (2): Reveals the distribution of the studied subjects (Down Syndrome children) according to the availability of health insurance and rehabilitation services. It was found that most of them (95.0%) have health insurance services and more than two thirds of

the studied DS children (69.2%) have rehabilitation services includes speech therapy as reported by half of them (51.8%), followed by 44.6% for physiotherapy, then 24.1% for behavioral modification therapy, and more than one tenth (16.9%) of the studied subjects reported receiving skills development services.

Table (4): Illustrates that more than one third of the studied mothers (34.2%) aged more than 40 years, while less than one third (30%) was aged more than 35 to less than 40 years. However, those mothers aged from 25 to less than 35 years old were 35.8%. More than one third of them had secondary or technical education, while one quarter (25.0%) of them had university education and 9.2% were illiterate. It was noted that 59.2% of them were housewife and 55.0% of them lived in rural areas. While more than half of them (56.7%) had hardly enough income. As for consanguinity between spouses, 50.8% of mothers stated had consanguinity, more than half of them (55.7%) of them had first degree, while 44.3% had second degree.

Table (5): Displays the distribution of the studied mothers according to their health profile. Regarding reproductive history, it was observed that less than one half of mothers (47.5%) had three gravida, with Mean \pm SD 2.87 \pm 0.798. While nearly half of the mothers (47.5%) reported that they became pregnant at the Down syndrome child at age of 25 to less than 35 years old.

Most of the studied mothers (93.3%) hadn't history of abortion or still birth. It was observed that more than three quarters of them (80.8%) had risky pregnancy especially because they take multiple medication during pregnancy were (39.2%) and 32.0% of mothers stated that they had heredity factor for Down syndrome. While more than one tenth of mothers (18.6%) reported their age as risk factors, where their age were less than 18 years or more than 35 years. In addition, more than one half of the studied mothers (59.2%) had some complications during pregnancy as bleeding (40.8%) and pre-eclampsia (31.0%).

Concerning mothers' medical history, it was found that more than one half of them (56.7%) had chronic diseases as diabetes mellitus and hypertension were 39.7%, 33.8% respectively. Relate to the presence of family history of genetic disorders, it was reported by mothers that more than two thirds of them (68.3%) didn't have family history of genetic disorder.

Figure (3): Illustrates mothers' total knowledge percent score; it was observed that less than half of mothers had good knowledge about Down Syndrome compared to more than one third for those had fair knowledge. The least one was mothers' poor knowledge (16.7%).

Figure (4): Displays the distribution of the mothers' attitudes mean scores regarding Down Syndrome, it was observed that more than three quarters of mothers (78.3%) had positive attitudes toward integration-segregation of Down syndrome child with Mean Percent Score 69.75%, while less than two thirds of them (61.7%) had positive attitude toward private rights of Down syndrome child with Mean Percent Score 71.18%. Also, less than two thirds of them (65.8%) had positive attitude toward subtle derogatory belief toward Down syndrome child with Mean Percent Score 61.18%, and the majority of them (84.2%) had positive attitude toward social distance toward Down syndrome child with Mean Percent Score 71.13%. As regards mothers' attitudes total score, it was found that 81.7% of mothers had positive attitude toward Down syndrome child with Mean Percent Score 68.39%. Mothers' attitudes related to private rights of DS were the first ranked one followed by social distance then integration-segregation.

Figure (5): Displays the distribution of mothers' practices mean percent score for their Down Syndrome children; it was observed that the total Mean percent score of mothers' practices were 56.7% for good practices compared to more than one third for fair practices (39.2%).

Table (6): Reveals a correlation between the children's difficulty levels and mothers' knowledge, attitude, and practice. There was significant correlation between children's difficulty level and mothers' practices ($P=0.001$). As well as significant correlation was found between mothers' knowledge and mother's attitudes. ($P=0.000$). Also, there was significant correlation between mothers' knowledge and mothers' practices ($P=0.000$), and between mothers' attitude and their practice ($P=0.002$).

Discussion

Down syndrome (DS) is a lifelong developmental disorder and is caused by trisomy of one or more chromosomes. Health problems related to the heart, gastrointestinal, immune, respiratory, endocrine, sensory, and orthopaedic system are common in children with DS. In addition, they may experience behavioural, social, and intellectual issues that negatively impact their daily lives (Avenevoli et al., 2013).

Down syndrome is the most genetic cause of severe learning disabilities in children associated with developmental delays, learning, and difficulties health complication and same physical abnormality (Aselefech, 2019). Moreover, people with Down syndrome will have some degree of intellectual impairment, though the level of impairment varies from person to person. In 1963 the American

Association for Mental Deficiency determined the cut off level of intellectual disability to an IQ of 70 (Anne, 2014).

The present study revealed that less than two-thirds of the studied DS children were aged 5 to less than 10 years and two-fifths of them (44.2%) their Intelligence Quotient was 55 to less than 60, more than one-half of them were male and almost all of them in the intellectual education. These results are like Minnes et al. (2015), Tavakol et al. (2018), & Presson et al. (2013), who reported that more than half of children with DS are male. Study done by Zappella (2016), showed an equal percentage of males and females. Moreover, Krahn & Fox (2014), found that more than half of children with DS had an intelligence quota of 50–69. Other study conducted by (Naaldenberg et al., 2015), disagreed with the present findings, which revealed that more than half of DS children's intelligence quotas were 35-50.

The results of the present study found that, two-fifths of Down Syndrome children were the first child in his family. These results were in line with Pranjic et al. (2016), who found that, less than one third of DS children in his study were the first child in their families. The findings of the present study can be explained by the fact that the occurrence of Down syndrome is not necessarily correlated with a child's birth order but depending on the genetic condition. This may be explained by the fact that the parents did not get premarital counselling, which may have helped to identify any genetic risk factors for having children with DS.

Children with Down Syndrome should have their body mass index routinely checked since anthropometric measurement rates are one of the most crucial indicators for tracking their growth and health condition (Tomaszewski et al., 2018). The present study revealed that more than half of the studied children had an abnormal BMI. These results agree with Chaudhary (2019) & Lee (2020), studies' results which shown that more than half of DS children in their studies have abnormal BMI. These abnormal BMI may be assigned to hormonal disturbances, and hypothyroidism.

Down syndrome is varying in severity and causes a lifelong intellectual disability and many chronic diseases among children (McGrath et al., 2011). The present study found that more than half of the studied down syndrome children suffering from chronic diseases as DM, Hypertension, Bronchial asthma. Similar findings were reported by Clark et al. (2012), & Rosser et al. (2018), they found that less than two thirds of DS children suffer from chronic illnesses and that genetic disorders may potentially impair all organs and functions of the body. Additionally, study done by Corder et al. (2017), reported that less than

half of DS children have chronic disorders. Actually, since chronic diseases are the common diseases associated with people with Down syndrome, so they need intensive care to avoid complications that affect the quality of their life.

Obviously, the state of special educational provision for children with disabilities is a contentious topic. The reality of schooling for children with intellectual disabilities and their families is likely to be complex and their experiences varied. Inclusion in a local mainstream school will undoubtedly have benefits and in some cases, it may be regarded as a wholly positive experience for all; pupils, families and schools alike (Dimitrova et al., 2016).

Education is regarded as a human right; however, it is only since 1975 that this right has been extended to all children in the UK, regardless of the abilities and disabilities they may have (Anne, 2014). The present study revealed that mothers place high value on their children's education and insist on that they should attend school at an early age. This findings corresponded with Alfaraj & Kuyini (2014) and Ghosh & Dey (2013), they reported that most children in the intellectual education schools have Down syndrome at the age of the primary stage compared to other educational stages. This indicates that, gradually with societal development, and attention to children with Down syndrome increases. The shift to include children with intellectual disabilities in education reflects the changing position of people with intellectual disabilities in society.

Most children with DS have a disability that is not a fixed condition, but it changes over time with circumstances and offered care. A single disability could be complicated by multiple disabilities if care, love, and support are lacking (Mashuda et al., 2014). Developmental delay is one of the main features in children with Down syndrome, but it differs from one child to another according to the severity and type of this delay, so rehabilitative services provided to DS children may vary from one to another (Mai et al., 2019).

People with Down syndrome face many different difficulties in their daily lives. The difficulties differ from one person to another depending on the extent to which the functions of the different body parts are affected, the extent of care for him and the support provided to him by the family and society (Cless et al., 2018). Children with Down syndrome have been found to demonstrate difficulties with working memory and verbal short-term memory. In addition, long term memory for words and pictures has also been found to be significantly difficult for children with Down syndrome. Language delays are characteristic of children with Down syndrome (Anne, 2014).

These were in line with the present study which revealed that nearly two thirds of the DS children had moderate to severe levels of difficulties in daily living activities. It was found that personal hygiene was the first ranked problem facing the Down syndrome children, followed by self-reliance as the second ranked difficulties. These results were consistent with **Reed & Berrier (2017)**, **Stensson et al. (2021)**, who found that more than two thirds of the DS children having severe DLA levels of difficulty.

Furthermore, the present study showed that about half of the DS children demonstrate attention deficit and less than one third of them have language and motor development delay. It wasn't surprising that more than two thirds of DS children have receiving rehabilitation services for speech therapy and physiotherapy. These findings agreed with **Moeschler et al. (2014)**, who found that the most impaired areas in children with DS were language and growth motor co-ordination. In line with **Couzens et al. (2011)**, who found that children with DS got lower scores than normal children regarding growth motor. Moreover, these results were agreed with **Warner et al. (2017)** This implies that most DS children struggle with DLA because of difficulties and delay in development. Consequently, detection of growth and development delay and seeking early intervention is important for reducing the exacerbation of this delay and help reduce it through sound rehabilitation programs. Conversely, the delay in detection and seeking early intervention and provision of sound afforded rehabilitation services, and the lack of governmental rehabilitation services in rural areas, as well poor socioeconomic status may hinder the parents of DS children from seeking rehabilitation services in urban centers.

Advanced maternal age, defined by the American Congress of Obstetricians and Gynecologists (ACOG) as being of age 35 or older at the time of delivery, is a well-established risk factor for chromosome abnormalities (**Wilkes, 2020**). Furthermore, there is a greater chance of having a child with Down syndrome if the mother's age is more than thirty-five (**De Clercq et al., 2022**). Crowe and Lyness (2014), found that the majority of studied mothers were over 35 years old. This is contradicted with the present study; it was found that more than one third of mothers' age when they are pregnant at Down Syndrome child were from 25 to less than 35 years old. This finding matched with **Channell et al. (2019)**, & **Salvi (2020)**, they found that less than half of the mothers of Down syndrome children were under 35 years of age. The findings of the current study may be explained by the fact that the maternal age factor is important, but not the main factor for having children with Down Syndrome. Moreover,

first-degree consanguinity between parents in our study among more than half of them may be additional crucial factor for the increase in the rates of having children with DS. Therefore, it is necessary to raise awareness about the dangers of consanguineous marriage, especially in rural areas.

Education is one of the most important elements of the country's progress in all areas of society. Paying attention to the education of mothers helps in providing a generation that can build their societies (**Parker and Ford, 2013**). The present study found that less than two-thirds of the studied mothers had either secondary, technical, or university education. These results agreed with **Barnoy et al. (2017)**, and **Mohammed et al. (2020)**, who found that less than half of mothers of DS had secondary or technical education. Additionally, the present study found that more than half of the studied mothers were housewives with residence in rural areas and majority of them reported poor or hardly enough income. This in accordance with **Al-Zoubidy & Al-Shugairi (2014)**, who reported that a higher prevalence of disabilities has been noted amongst poor children and those of mothers with relatively little education, particularly children with moderate and severe disabilities and propose that children's disabilities may vary according to their mothers' education levels and, conversely, that better maternal education prevents mild disabilities from escalating. **Moreover, Garner et al. (2020)**, found a higher incidence of disabilities in younger children and those living in rural areas. The lifestyle of rural communities and the lack of work opportunities are the causes of this outcome.

According to presence of pregnancy risk factors, it was found that more than three quarters of them had risky pregnancy as age (\downarrow 18 years, \uparrow 35 years), hereditary factors, exposure to radiation, and taking multiple medications. The present study agreed with **de Graaf et al. (2019)**, who found that almost of mothers with DS children had pregnancy risk factors and abnormal symptoms.

Family history is one of the most important factors that shows the extent of its' role in having a child with DS. The existing study reported that more than two thirds of the studied mother didn't have a family history of genetic disorders. These findings are consistent with **Shields et al. (2018)**, who discovered that almost all studied mothers had no genetic disorder in their family history. However, **Huiracocha et al. (2017)**, found that one-half of them had a family history of genetic disorder, which contradicted with the current study.

He cornerstone of effective social, educational, and vocational provision for children with disabilities (CWD) is the presence of knowledge and its

articulation in child-centered practice, informed by positive attitudes of individuals and communities (Garner et al., 2020). However, mothers as the primary caregivers for children with mental disabilities, face many challenges and stressors that may lead to maternal distress if they are not well-adjusted (Hegazy & Baraka, 2021).

Undoubtedly, adequate knowledge of mothers who have children with Down syndrome positively affects their children. It also works to increase the awareness of mothers, reduce their constant fears and anxiety, and address any obstacles they face while caring for their children (Lee et al., 2021).

The present study found that less than half of mothers had good knowledge level regarding Down Syndrome. These finding is like Williams et al. (2017), Buyukavci et al. (2019), and Hegazy & Baraka (2021), they found that the majority of mothers had good knowledge regarding Down Syndrome. Other studies conducted by Mbazima (2016), Kalyoncu et al. (2018), in contrast to the present study results which found that less than half of mothers had poor knowledge regarding Down syndrome. Hence, the absence of such knowledge often means children do not access services. Consequently, the greater number of educated mothers in the present study is responsible for this positive outcome. Gaining information and the required understanding about all facets of life, not only concerning Down syndrome, is aided by education. Higher education levels enable mothers of children with Down syndrome to support and care for their offspring more effectively and giving them the best possible care (Shin et al., 2010).

Mothers who have children with Down syndrome, their attitudes and the extent to which accept this reality are the most important steps in the lives of children. Rather, it affects the mothers and the extent of their satisfaction and acceptance, presenting the children to society without shame or fear, and working and probing their equality with healthy children. If the mothers' attitudes are negative about Down syndrome, this affects the life and future of the child because the mother is the first line of defence for their children, either strengthening them and defying difficulties or surrendering (Skotko et al., 2011).

The current study findings shows that more than three-quarters of mothers had a positive attitude towards having children with Down Syndrome. These results agreed with Leach (2016), Binjahlan et al. (2017), Marshall et al. (2019), and Rahimi & Khazir (2019), who found that more than half of DS mothers had positive attitude towards Down Syndrome. Additionally, research by Ahmed et al. (2015), revealed that the majority of participants had

a positive attitude toward people with Down syndrome. These was contrary with Aldhwayan et al. (2015), who indicated that more than half of mother had an unfavourable opinion toward Down syndrome children. The attitudes of mothers in the present study were positive due to good knowledge level and the presence of support from their husbands and siblings for DS children.

Garner et al. (2020), indicates that parents' attitudes vary according to a range of factors, including availability of support services, and cultural orientations. Aselefech (2019), reported that the response of most parents indicated that their neighbors, relatives and other members of the society did not attempt to discriminate children with down syndrome rather than beyond sympathy can be cited as a positive result of this study.

The mothers' practices for their children with DS aid in their development and enhance child's physical and psychological health, such as caring for their foods that provide the body's essential nutrients and enable them to continue and improve their conditions to the best of their abilities (Harris et al., 2012). According to the findings of the current study, more than half of mothers had good practices toward their children with Down Syndrome. These findings are similar to those of Gabel and Kotel (2018), & Gómez et al. (2020), who discovered that almost all mothers had good practices toward their Down Syndrome children. Less than half of the studied mothers exhibited negative practices toward their children with Down Syndrome, according to another study by Choi & Van Ripper (2020), which disagree with the current findings.

The findings of the current study may be linked to the mothers' good practices for their Down syndrome children in the study because of their understanding of the condition and their positive attitudes toward their children as an outcome of receiving care. Also, most mothers of DS children are married, so there is family stability that helps the mother to provide the required care for their children. While more than half of them lived in nuclear families, which had a good chance of providing full care for the DS children. Finally, the mothers' knowledge, attitudes, and practises were good and positive enough but also, there was a percentage that was poor and negative because of some obstacles, such as no financial or social support, so it is necessary to shed light on the increased interest in children with Down syndrome from mass media, as well as the increase in awareness and rehabilitation programmes for mothers who have children with Down syndrome, and attention to awareness programmes on the importance of pre-marital examinations.

Conclusion and Recommendations

Based upon the results of the present study, it could be concluded that:

The present study reveals that knowledge about Down syndrome was good among less than half of the mothers and this highly correlated to their practices. Also, attitude towards DS children is very important in the inclusion of these children in the community.

Based on the findings of the present study, the following recommendations are suggested:

For Ministry of Health and population:

- Develop life skills coaching program for the parents of DS children and caregivers with the updated rearing practices.
- Raising health awareness about DS not only among mothers of DS children but also among the general population.
- Work to reduce the incidence of disability through primary health care activities and various community awareness programs.

For Ministry of Education:

- Developing a model for academic integration in the education sector, both governmental and non-governmental.
- Inclusion of persons with DS in their communities in all educational sectors such as kindergartens, schools, and vocational workshops.
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For Ministry of Social Solidarity:

- Increase financial support for mothers and families of children with DS to help cover the financial expenses that are increasing due to disability and thereby alleviate the financial pressures affecting mental health.
- Raising awareness about disability issues to create an appropriate social environment to change society's negative perceptions and behavior toward people with disabilities and their families.

For Families and parents:

- Strengthen the role of parents and family members being a home caregiver for children with DS as a providers and supporters of childcare.
- Make necessary living arrangement for the home to be convenient for rendering care.
- Training the parents is important to meet the Childs' needs and to be able to independently take care of their needs using available resources.

Future research:

- Evaluate the quality of health care services provided for DS children.

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