

Effectiveness of Promoting Mothers' Caring Practices Regarding Their Down Syndrome Children on the Family Coping

Samya Mohamed Ahmed Hegazy*, Nagwa Ibrahim Mabrouk Baraka

Pediatric Nursing, Faculty of Nursing, Tanta University, Egypt

*Corresponding author: samyusef38@yahoo.com

Received January 01, 2021; Revised January 15, 2021; Accepted January 24, 2021

Abstract Down Syndrome is a lifelong chromosomal disorder caused by an extra copy of chromosome number 21 inside each of the body's cells. This genetic disorder, causes mental retardation and developmental delays. **Aim of this study was to** determine the effect of promoting mothers' caring practices regarding their children with Down Syndrome on the family coping. **Subjects and Method:** A quasi-experimental research design used for sixty mothers and their children with Down Syndrome at Pediatric Outpatient Genetic Clinic of Tanta University Hospital. **Three tools** were used for data collection: **Structured Interview Schedule** to assess socio-demographic and mothers' knowledge about Down Syndrome, **Mothers' Care Reporting Sheet** and **Family Crisis Oriented Personal Scales**. **Results:** The total scores of knowledge for more than three quarters of mothers were low before educational program while, more than half of them had moderate level of knowledge and less than half of them had high level immediately after program. The total scores of most mothers' reported care were unsatisfactory before educational program while, the majority of them had satisfactory care immediately and one month after program. Family adaptation for nearly two thirds of caregivers was fair before program while, all of them had good adaptation immediately after program. **Conclusion:** There was a significant improvement of mothers' knowledge, reported care and family adaptation towards crises. **Recommendations:** Continuous health education program should be applied to mothers of children with Down Syndrome in health care facilities to improve their knowledge and practice that affect family adaptation.

Keywords: Down Syndrome, Family Adaptation

Cite This Article: Samya Mohamed Ahmed Hegazy, and Nagwa Ibrahim Mabrouk Baraka, "Effectiveness of Promoting Mothers' Caring Practices Regarding Their Down Syndrome Children on the Family Coping." *American Journal of Nursing Research*, vol. 9, no. 2 (2021): 53-63. doi: 10.12691/ajnr-9-2-3.

1. Introduction

Down Syndrome (DS) is the most common chromosomal malformation in newborns due to an extra chromosome number 21 (trisomy21). Each child with DS is a unique individual regarding their care needs [1,2]. In Europe, DS accounts for 8 percent of all reported cases of congenital abnormalities. Globally, the average prevalence of DS is 10 per 10,000 live births. The incidence of DS in Egypt varies between 1:555 and 1:770 and its screening by triple test is becoming increasingly popular nowadays [3].

The most accurate and discriminatory signs of DS are hypotonia, small ears, large gap between the 1st and 2nd toe, small inter nipple width, brush field spots, nuchal skin fold, brachycephaly, flat face, eye split upward slant, flat nasal bridge, microgenia (an abnormally small chin), macroglossia due to small oral cavity, almond shape to the eyes caused by an epicanthic fold of the eyelid and oblique palpebral fissures [4,5].

The health problems of DS children include mental retardation, several dysmorphic features and delayed psychomotor development. In addition children with Down Syndrome are at higher risk for Congenital Heart Defect (CHD) and vision issues that could be detected in almost half of children with DS. Hearing loss may be detected in up to three-quarters of children with Down Syndrome. Hearing loss is often related to anatomical ear disorders [5,6].

Unmonitored infections are important health problem for Down Syndrome children that increase their death probability more than other children. In addition, there is increased risk for hypothyroidism and blood disorders like leukemia, anemia and polycythemia among Down Syndrome children than others [7,8]. Weak muscle tone and malformed bone lead to delays in fine and gross motor development among Down Syndrome children [9,10]. Many DS children have altered sleeping pattern due to obstructive sleep apnea. Gum disease, dental problems, epilepsy, digestive problems, celiac disease, mental and emotional problems are important caring issues for Down Syndrome children [11,12].

Down Syndrome is a chronic disease that may impact family functioning. When parents are informed unexpectedly that the newborn has DS, they may experience emotions that are both intense and confusing. They may feel overwhelmed with shock, frustration, disappointment, ambivalence and even anger. Most families have additional roles, obligations and problems; the child's extra care needs, recognition and access to educational and medical facilities, payment for services, potential instability, emotional grief, stigmatizing community reactions, social isolation and loss of social opportunities [13]. Anxiety, depression, guilt and grief are common problems for parents especially for mothers who often play the main role in taking care of the child. Family relationships are more prone to dissatisfaction, disagreements, disputes and sometimes aggravated marital issues [14].

Mother is the primary care giver for their families. They are in a deepest need to be aware of the expected health status that might be experienced by their Down Syndrome children. Prompt awareness is expected to reinforce positive accommodation on parental and familial level with the child's unique condition [14]. The study conducted by [15] reported that parents living with a child with DS encounter various challenges and difficulties and significant improvement was observed in the family adaptation after inclusion in family supportive intervention.

Pediatric nurses are essential in providing family centered care to children with chronic illnesses as DS and their families. Nursing management focuses on providing supportive measures such providing support and education to the child and their mothers, promoting growth and development, preventing complications and problems. Parents and caregivers need support and education continuously. Some families may see it as a lifelong tragedy to have a child with DS, while others may see it as a healthy growing experience [16]. The nurse should assess how this experience is described and handled by the family. The nurse should base the care plan on the values, beliefs, abilities and resources of each individual family. Support, good communication, information and proper care help families of children with DS to lead full and productive lives and positively adapt to their child's diagnosis [17,18].

1.1. Significance of the Study.

Down Syndrome is the most common genetic pediatric disorder. It is associated with multiple health implications either for the child or their families [19]. These children may have medical problems that affect multiple body systems and lead to developmental delays of varying degrees. These difficulties will influence the capacity of a child to conduct daily tasks and result in significant family time, emotional and financial costs. The medical costs for a child with DS from birth to 4 years are 12 to 13 times more than those without Down Syndrome [20]. Families of children with developmental and intellectual disabilities often schedule between 5 and 10 medical or therapy appointments, and some are unable to reach the necessary services due to funding and information gaps [21]. In addition they do not receive as much public attention as families with children with other health problems through scientific reports, advocacy, and the media [22]. Parents

need up to date detailed information concerning their child condition and treatments and caring facilities.

Prompt management of DS health problems and teaching care gives the suitable care practices for the child, regular follow up and compliance with treatment are important elements in decreasing disability effect and improving family life [18]. So that, the aim of the study was to determine the effectiveness of promoting mothers' caring practices regarding their Down Syndrome children on their family coping.

1.2. Aim of the Study

Determine the effectiveness of promoting mothers' caring practices regarding their Down Syndrome children on their family coping.

2. Subjects and Method

2.1. Research Design

A quasi-experimental research design was used in the present study.

2.2. Setting

Pediatric Outpatient Genetic Clinic of Tanta University Hospital.

2.3. Subjects

A convenience sample of sixty mothers and their children with Down Syndrome were included in the study

2.4. The Inclusion Criteria for Mothers

- All educational levels were included

2.5. Inclusion Criteria for Children

- Age ranged from birth -12 years
- Both sexes

2.6. Tools of Data Collection

Tool I: Structured Interview Schedule: it was constructed by the researcher after reviewing the related literature [18] to assess mothers' knowledge about Down Syndrome and included three parts:

Part I: Socio-demographic Characteristics of:

- a- Mothers such as: age, level of education, occupation, residence and consanguinity.
- b- Children such as: age, gender, birth order and number of siblings.

Part II: Medical History included the following:

- a-Mothers' medical history during pregnancy including question related to mothers' age at time of pregnancy, medical follow up, the occurrence of specified health problems during pregnancy, history of drug intake or x- ray exposure during pregnancy and type of delivery.
- b- Children's past medical history and hospital admission: including questions related to the occurrence

of lactation problems, walking, dentition and speech delay and history of hospital admission including questions related to frequency of admission and reasons.

c- Children's Current Health Problems Associated with Down Syndrome: It included the problems experienced by the studied children such as: mental retardation, nutritional, respiratory, speech, hearing and visual problems,....ect.

Part III: Mothers' Knowledge about Down Syndrome

It was constructed by the researcher to assess mothers' knowledge about Down Syndrome such as: definition, causes, signs and symptoms, health problems, care of Down Syndrome and complications that may occur.

Scoring System for Mothers' Knowledge

This part contained seven closed ended questions about Down Syndrome. Each question was scored from (0-2 grades). The correct and complete answers were scored (2), correct and incomplete answers scored (1) and wrong answers or not answered questions scored (zero). The sum of all questions was 14.

The total scores of mothers' knowledge were calculated and classified as follows:

- < 50 % was considered low level of knowledge.
- 50 -75 % was considered moderate level of knowledge.
- > 75 % was considered high level of knowledge.

Tool II: Mothers' Care Reporting Sheet:

It was constructed by the researcher after reviewing the related literature to assess mother's care provided to their children with Down Syndrome (care of obesity, constipation, incontinence and skin dryness, dental, hearing, speech and visual care, prevention of accidents and respiratory infection).

Scoring System for Mothers' Reporting Care:

Mothers' care reporting sheet included ten questions. Each question scored as: (2) for correct and complete care, correct and incomplete care scored (1) and wrong care scored (zero). The sum of total items was 20.

The total Scores of Mothers Reporting Care: were calculated and classified as:

- < 60 % was considered unsatisfactory care.
- 60 % or more was considered satisfactory care .

Tool III: Family Crisis Oriented Personal Scales (F-COPES)

It was developed by (23) and adapted by the researcher to assess the coping strategies with problems or crises adopted by the caregivers of children with DS. This scale consisted of 22 items. . Each item was scored from (1- 5 grades).with 1, "Strongly disagree", and 5, "Strongly Agree". The sum of all items was 110. **The total scores of Family Crisis Oriented Personal Scales were categorized into three categories:**

- Poor family coping with crises when the total scores ranged from 0 to less than 37.
- Fair family coping with crises when the total scores ranged from 37 to less than 74.
- Good family coping with crises when the total scores ranged from 74 up to 110.

2.7. Method

The study was accomplished through the following steps:

1- Administrative Process:

An official permission was obtained from Faculty of Nursing, Tanta University directed to administrators of Pediatric Outpatient Genetic Clinic of Tanta University Hospital to obtain their approval and cooperation for carrying out this study.

2- Ethical and Legal Considerations:

Mothers were informed about the confidentiality of the information which obtained from them. The nature of the study not cause any harm or pain to their children. Mothers were assured that, the data collected were used only for the purpose of the study. Mothers' oral consents were obtained to participate in the study after explaining the aim of the study.

3- Developing the Tools

The study tools were developed by the researcher (tool I & II) based on the review of related literature. And tool III is a scale was translated into Arabic by the researchers and tested for content validity by submitting the Arabic and English copy to five experts in the field of the study. No modifications are suggested.

4- **The Face Validity** was 95% based on experts' opinion after calculating content validity index (%) of its items.

5- Content Reliability

The study tools were tested by the pilot subjects at first session for calculating Cronbach's Alpha which was 0.894.

6- **A pilot Study** was conducted on 10 % of study sample to test clarity, reliability, visibility and applicability of the study tools. The Pilot study was excluded from the study sample.

7- **Data Collection Procedure:** was designed through three phases:

I-Assessment Phase:

It was carried out by the researcher for all study subjects to collect baseline data. The researcher assessed mothers' knowledge about Down Syndrome using **Tool 1 (Part III)**.

- Mothers' care provided to their children with Down Syndrome such as: (care of obesity, constipation, incontinence and skin dryness, dental, hearing, speech and visual care, prevention of accidents and respiratory infection) was assessed before, immediate and after one month of program implementation by using **Tool II**.

- Family Crisis Oriented Personal Scales (F-COPES) was assessed before, immediate and after one month from application of educational program using **Tool III**.

- Mothers with their children were interviewed individually or in the group to fill the questionnaire sheet. The researcher wrote the answers of illiterate mother (Deleted).

- The average time needed for each mother was 10 minutes.

- The researcher ensured that all questions were answered and asked the mothers to fill any missed questions, and wrote the answers for the illiterate mothers.

2- Implementation Phase included the following steps:

-Setting objectives.

-Preparation of the content which covered the reasons behind the application of the sessions.

- The educational intervention program was conducted in Pediatric Outpatient Genetic Clinic of Tanta University

Hospital at morning (one day weekly) through four sessions.

- Time of each session was about 10 minutes.

- At the beginning of the first session, mothers were oriented about the educational intervention content, purpose, and its importance for their children's health status.

-Each session was started by a summary about what had been discussed in the previous session and the objectives of the current session, using simple Arabic language and different teaching media (lectures, demonstration, group discussion and audiovisual material) to facilitate mothers, understanding.

-The sessions covered the following topics

The First Session: about (definition of Down Syndrome, causes and characteristics).

The Second Session: focused on (health problems and impact of Down Syndrome on growth and development).

The Third Session: related to (rehabilitation places and special vaccines improving immunity).

The Fourth Session: care of associated health problems (obesity, constipation, incontinence, skin dryness, dental, hearing, speech, respiratory infection and prevention of accidents)

-Each session ended by a summary of its content and feedback from the mothers was obtained to ensure that mothers got the maximum benefit.

3-Evaluation Phase:

The effects of the educational intervention program on mothers' knowledge, reported care and family coping strategies with crises were assessed through comparing the pre and posttest. This assessment was done three times: before, immediately after finishing the implementation phase, and then after one month.

-The data was collected over a period of four months from July 2020 to October 2020.

2.8. Statistical Analysis:

The collected data were organized, tabulated and statistically analyzed using (Statistical Package for the Social Science, (version 20, spss Inc., Chicago Il, USA). For qualitative data, comparison between two groups was done using Chi- Square testing (X^2). For quantitative data, the range, mean and standard deviation were used. Comparison between more than two means of parametric data, the F value of analysis of variance (ANOVA) test was calculated where Scheffe test was performed to compare between each more than two means. Correlation between variables was evaluated using Pearson's correlation coefficient (r). Significance was adopted at ($p < 0.05$) for interpretation of results of tests of significance.

3. Results

Table 1 demonstrates the percentage distribution of socio-demographic characteristics of studied mothers. It was observed that, the age of mothers was ranged from 23.5-48 years with the mean of (33.962±5.379). In relation to educational level, it was evident that, 30% of mothers read and write while, 26.67 % of them had secondary education, 26.67% were illiterate and the rest of them

16.66 % completed their university education. According to their job, it was found that, the majority of mothers (91.67%) were house wives while 8.33% are working.

As regards their residence, it was clear that, most of mothers (86.67%) were from rural areas. The study revealed that, the majority of mothers (90 %) had no consanguinity and 10 % had consanguinity.

Table 1. Percentage Distribution of Studied mothers According to Their Socio-demographic Characteristics

Socio-demographic Characteristics of Mothers	The Studied Mothers (n=60)	
	No	%
Age in (years)		
Range	23.5-48	
Mean ±SD	33.962±5.379	
Educational level		
Illiterate	16	26.67
Read and write	18	30.00
Secondary education	16	26.67
High education	10	16.66
Mothers, Job		
Working	5	8.33
House wives	55	91.67
Childcare		
Father	1	20.00
Aunt	2	40.00
Grandparent	2	40.00
Residence		
Rural	52	86.67
Urban	8	13.33
Consanguinity		
Yes	6	10.00
No	54	90.00

Table 2 presents the percentage distribution of studied children according to their socio - demographic characteristics. It was observed that, the age of children was ranged from 0.67-9 years with the mean of 3.128±1.982. More than half of them (55 %) were males and 41.67 % were the second child in the family.

Table 2. Percentage Distribution of Studied Children According to Their Socio-demographic Characteristics

Socio-demographic Characteristics of children	The Studied Children (n=60)	
	No	%
Age in (years)		
Range	0.67-9	
Mean ±SD	3.128±1.982	
Sex		
Male	33	55.00
Female	27	45.00
Birth Order		
First child	8	13.33
Second	25	41.67
Third	8	13.33
More than third	19	31.67

Table 3 demonstrates the percent distribution of studied mothers' medical history during pregnancy. It revealed that the mean age for mothers' at time of pregnancy was (30.817±4.864). Regarding medical follow up during pregnancy, 41.67 of the mothers followed up every two months during pregnancy. As regards to the occurrence of health problems during pregnancy 13.33% of the mothers suffered from hypertension and bleeding respectively and 30% had anemia. Regarding drug intake during pregnancy 13.33% and 6.67 % of the mothers respectively received antihypertensive drugs and toxoplasma treatments. None of the mothers exposed to X- ray during pregnancy and 33.33% of the delivery was cesarean section.

Table 3. Percentage Distribution of the Studied Mothers According to Their Medical History during pregnancy

Medical History of mothers	The Studied Mothers (n=60)	
	No	%
Maternal age at Pregnancy		
Range	22-45	
Mean ±SD	30.817±4.864	
Follow up		
Yes	51	85.00
No	9	15.00
Frequency of Follow up		
every month	17	28.33
every two months	25	41.67
every Three months	18	30.00
Problems happened during pregnancy		
No	12	20.00
Hypertension	8	13.33
Diabetes	10	16.67
Bleeding	8	13.33
Anemia	18	30.00
Toxoplasma	4	6.67
Drugs taken during pregnancy		
Antihypertensive	8	13.33
Hypoglycemic	10	16.67
Vitamins	18	30.00
VIT K	8	13.33
Toxoplasma drug	4	6.67
No drug intake	12	20%
X-ray exposure during pregnancy		
No	60	100.00
Types of Delivery		
Normal	40	66.67
Cesarean Section	20	33.33

Table 4 shows percentage distribution of studied children according to their medical history, hospital admission and developmental delay. The study revealed that, 33.33% had lactation problems, 40% had tachypnea and more than one thirds of them (35%) had aspiration during lactation. As regards hospital admission, it was found that, more than

one thirds of children (35 %) admitted hospital three times and more than half of them (53.33%) admitted to hospital because of pneumonia. In relation to developmental delay, more than two thirds of children (70%) had delayed dentition. While most of them (85%, 88.3%) had delayed walking and speech respectively.

Table 4. Percentage Distribution of Studied Children According to their Past Medical History, Hospital Admission and Developmental Delay

Lactation problems, Hospital Admission and developmental delay	The Studied Children (n=60)	
	No	%
Lactation Problems occurred during the first 2 years		
Yes	20	33.33
No	40	66.67
Types of Lactation problems		
Tachypnea	8	40.00
Vomiting	5	25.00
Aspiration	7	35.00
Hospital Admission		
Never admitted	15	25.00
Once	18	30.00
Twice	6	10.00
Three times	21	35.00
Causes of hospital admission		
Pneumonia	24	53.33
Surgery	18	40.00
Seizures	3	6.67
Dentition		
At proper time	18	30.00
Delayed	42	70.00
Walking		
At proper time	9	15.00
Delayed	51	85.00
Speech		
At proper time	7	11.67
Delayed	53	88.33

Figure 1 shows percentage distribution of studied children according to their current health problems. It was found that, all children (100%) had mental retardation and difficult communication. It was observed that, most of them (86.67 %) had obesity and overweight. while more than half of children (58.33%, 53.33%) had constipation and tooth decay respectively.

The study revealed that, half of them (50%) had visual anomalies and exposed to different types of accidents. Less than half of them (46.67%) had cardiac anomalies, chewing and swallowing difficulties followed by incontinence 41.67%, one quarters of them (25%) had hearing weakness and skin dryness.

Figure 2 show total scores of mothers' knowledge about Down Syndrome. It was observed that, more than three quarters of studied mothers (76.67%) had low knowledge before educational program while, more than half of them (51.67%) had moderate level and 48.33% had high level

of knowledge immediately after educational program and more than three quarters of them (76.67) had moderate level of knowledge after one month. There were statistically significant differences during three phases of educational program before-immediate, before -one month after program and immediate - after one month ($p < 0.001$, $p < 0.001$ and $p = 0.004$) respectively.

Figure 3 demonstrates total scores of mothers' reported care to their children with Down Syndrome. It was observed that, most of mothers' reported care (83.33%) was unsatisfactory before educational program while, the majority of them (96.67% and 91.67%) respectively had

satisfactory care immediately and after one month of educational program intervention. There were statistically significant differences between before-immediate, before -one month after program ($p < 0.001$).

Figure 4 illustrates total scores of family adaptation towards crises. It was found that, nearly two thirds of mothers or caregivers (61.67%) had fair adaptation before educational program while, all of them (100%) had good adaptation immediately and after one month of educational program intervention. There were statistically significant differences between before-immediate, before -one month after program ($p < 0.001$).

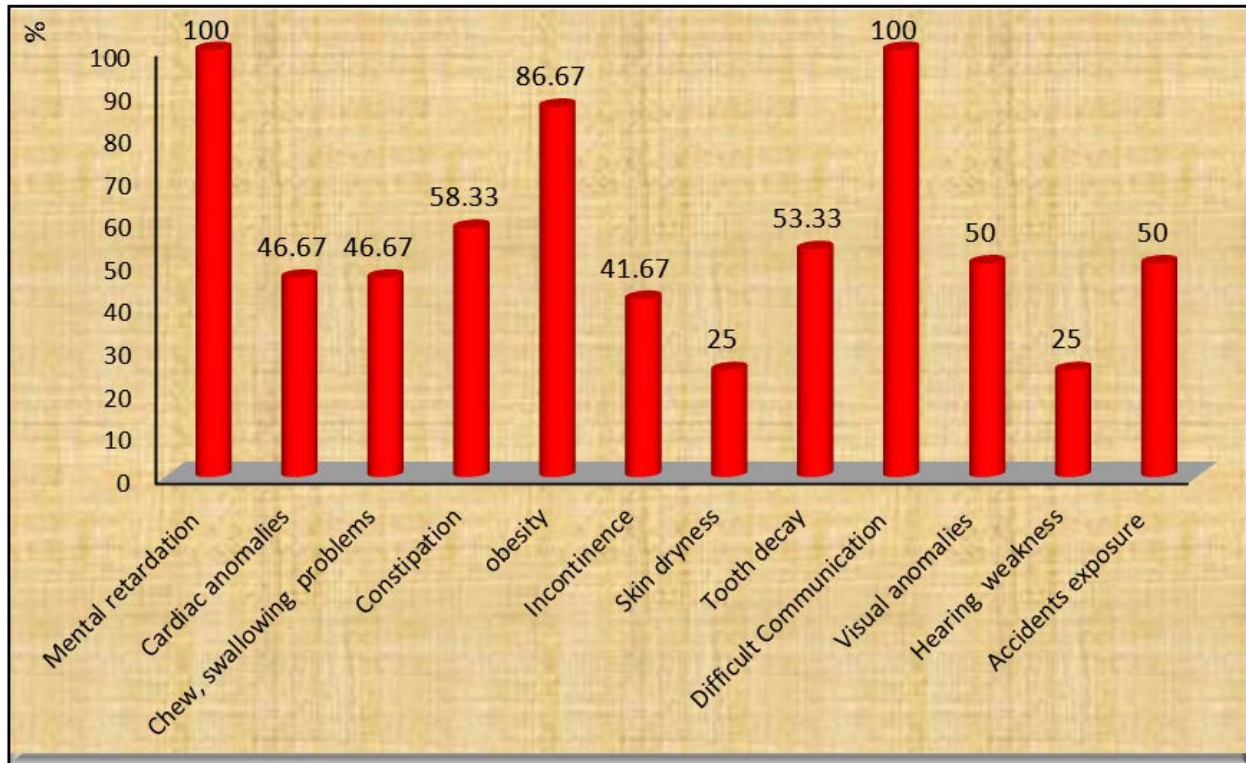


Figure 1. Current Health Problems of Children with Down Syndrome (*More than one answer is allowed)

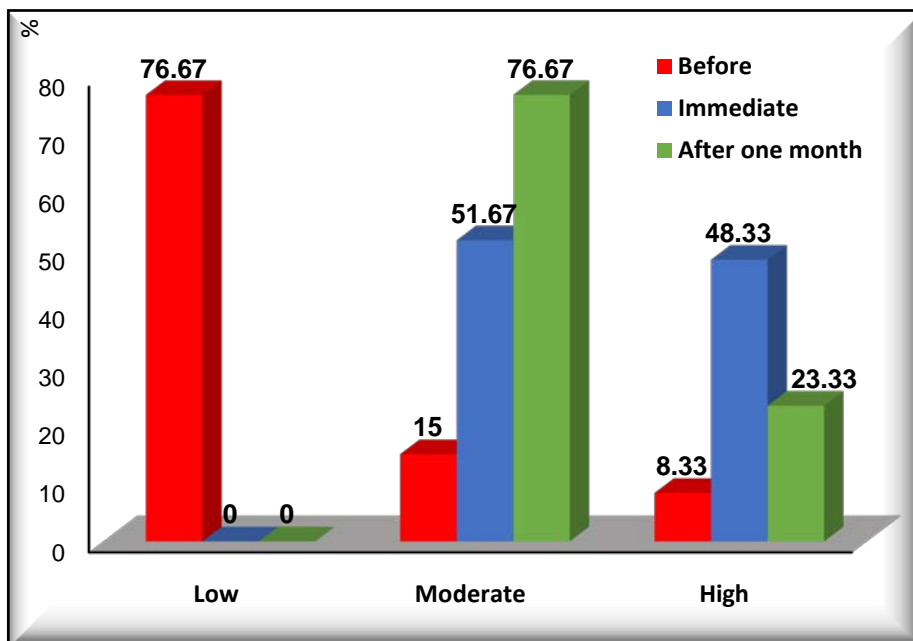


Figure 2. Total Scores of Mothers' Knowledge about Down Syndrome

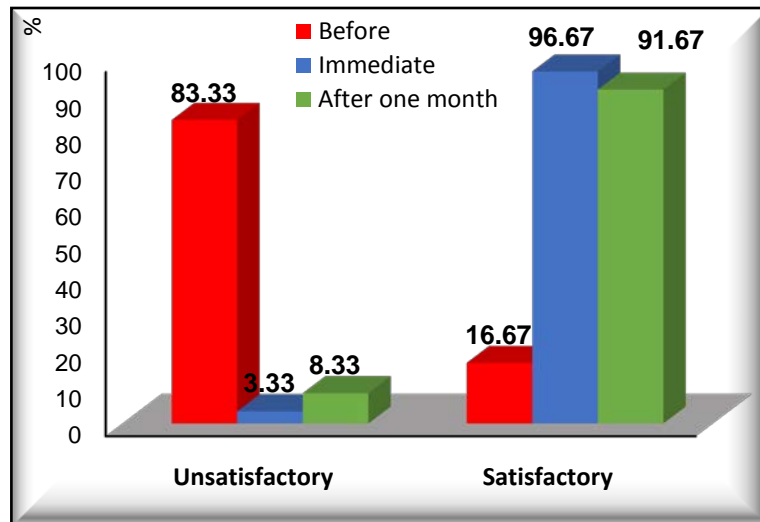


Figure 3. Total Scores of Mothers' Reported Care to their Children with Down Syndrome



Figure 4. Total Scores of Family Adaptation towards Crises

Table 5 illustrates relation between mean scores of mothers' knowledge and their socio demographic characteristics. It was noticed that, there were statistically significant difference between mean scores of mothers' knowledge and their educational level before, immediate and one month later of educational program ($p < 0.001$) with the highest mean for mothers who had high education before, immediately and one month later (10.400 ± 0.966 , 13.700 ± 0.483 and 12.600 ± 0.843) respectively.

The study showed that, there were statistically significant differences between mean scores of mothers' knowledge and their job before, immediate and one month later of educational program ($p < 0.001$) with the highest mean for working mothers (10.200 ± 1.924 , 13.400 ± 0.894 and 12.000 ± 1.225) respectively before, immediately and after one month of program implementation. Regarding residence, it was observed that, there was statistically significant differences between mean scores of mothers' knowledge and their residence ($p < 0.001$) with the highest mean for urban mothers (8.250 ± 3.370 , 13.000 ± 1.414 and 11.625 ± 1.847) respectively before, immediately and after one month of program implementation.

Table 6 illustrates relation between mean scores of mothers' reported care and their socio demographic characteristics. It was noticed that, there were statistically significant difference between mean scores of mothers' reported care and their educational level ($p < 0.001$) before, immediately and after one month of program implementation. The study revealed that there were statistically significant difference between mean scores of mothers' reported care and their job and residence before, immediately and after one month of program implementation ($p < 0.001$, $p = 0.001$, $p < 0.001$ and $p = 0.001$, $p = 0.005$, $p < 0.001$) respectively. On the other hand no statistically significant differences between mean scores of mothers' reported care and Consanguinity before, immediately and after one month of program implementation ($p = 0.495$, $p = 0.609$ and $p = 0.444$) respectively

Table 7 shows that, there were statistically significant difference between mean scores of family adaptation and mothers' education before, immediately and after one month of program implementation ($p = 0.001$, $p = 0.001$ and $p < 0.001$) with the highest mean for mothers who had high education immediately and one month later (102.000)

± 3.432 and 97.100 ± 3.381) respectively. The study clarifies that, there were statistically significant difference between mean scores of family adaptation and residence immediately and after one month of program implementation ($p= 0.011$ and $p= 0.002$) respectively with the highest mean for urban mothers (102.875 ± 2.588 and 98.125 ± 2.167) respectively.

Table 8 represents correlation between mothers' knowledge, reported care and family adaptation. It was found that, there were statistically significant correlation between mothers' knowledge and reported care before, immediately and one month after educational program

($r= 0.888$, $p= <0.001$ and $r= 0.641$, $p= <0.001$ and $r= 0.784$, $p= <0.001$) respectively. It was observed that there were statistically significant correlation between mothers' knowledge and family adaptation before, immediately and one month after educational program ($r=0.360$, $p= 0.005$ and $r= 0.397$, $p= 0.002$ and $r=0.448$, $p= <0.001$) respectively.

The study clarified that, there was statistically significant correlation between mothers' reported care and family adaptation before and after one month of program implementation ($r= 0.319$, $p=0.013$ and $r= 0.345$, $p= 0.007$) respectively.

Table 5. Relation between Mean Scores of Mothers' Knowledge and Their Socio Demographic Characteristics

Mothers, Socio Demographic Characteristics		Mean Scores of Mothers' Knowledge												
		No	Before		ANOVA or T-Test		Immediate		ANOVA or T-Test		After one month		ANOVA or T-Test	
			Mean \pm SD	F or T	P-value	Mean \pm SD	F or T	P-value	Mean \pm SD	F or T	P-value			
Education	Illiterate	16	1.438 \pm 1.209	160.60	<0.001*	9.625 \pm 0.885	55.593	<0.001*	7.625 \pm 0.719	67.532	<0.001*			
	Read -write	18	3.222 \pm 1.003			9.833 \pm 0.786			8.000 \pm 0.767					
	Secondary	16	5.563 \pm 1.031			11.563 \pm 1.153			9.313 \pm 1.302					
	High Education	10	10.400 \pm 0.966			13.700 \pm 0.483			12.600 \pm 0.843					
Job	Work	5	10.200 \pm 1.924	4.801	<0.001*	13.400 \pm 0.894	3.761	<0.001*	12.000 \pm 1.225	3.950	<0.001*			
	Not work	55	4.055 \pm 2.792			10.655 \pm 1.601			8.745 \pm 1.797					
Residence	Rural	52	4.000 \pm 2.815	-3.876	<0.001*	10.558 \pm 1.539	-4.218	<0.001*	8.615 \pm 1.670	-4.682	<0.001*			
	Urban	8	8.250 \pm 3.370			13.000 \pm 1.414			11.625 \pm 1.847					
Consanguinity	Yes	6	4.333 \pm 4.179	-0.186	0.853	10.889 \pm 1.941	-0.074	0.941	8.833 \pm 1.941	-0.238	0.812			
	No	54	4.593 \pm 3.135			10.889 \pm 1.723			9.037 \pm 1.990					

Significance at level $p < 0.05$.

Table 6. Relation between the Mean Scores of Mothers' Reported Care and Their Socio Demographic Characteristics

Mothers' Socio Demographic Characteristics		Mean Scores of Mothers' Reported care												
		No	Before		ANOVA or T-Test		Immediate		ANOVA or T-Test		After one month		ANOVA or T-Test	
			Mean \pm SD	F or T	P-value	Mean \pm SD	F or T	P-value	Mean \pm SD	F or T	P-value			
Education	Illiterate	16	4.313 \pm 1.621	133.807	<0.001*	15.188 \pm 1.223	24.537	<0.001*	12.750 \pm 1.183	51.388	<0.001*			
	Read -write	18	5.111 \pm 1.079			15.278 \pm 1.487			13.056 \pm 1.259					
	Secondary	16	8.188 \pm 1.276			15.625 \pm 2.277			13.688 \pm 1.448					
	High Education	10	14.600 \pm 1.647			20.000 \pm 0.000			18.400 \pm 0.843					
job	Work	5	13.400 \pm 3.435	4.162	<0.001*	19.200 \pm 1.789	3.334	0.001*	17.400 \pm 2.191	3.713	<0.001*			
	Not work	55	6.745 \pm 3.422			15.855 \pm 2.172			13.727 \pm 2.112					
Residence	Rural	52	6.673 \pm 3.513	-3.491	0.001*	15.808 \pm 2.105	-2.940	0.005*	13.635 \pm 1.981	-3.719	<0.001*			
	Urban	8	11.375 \pm 3.777			18.250 \pm 2.712			16.625 \pm 2.925					
Consanguinity	Yes	6	8.333 \pm 4.227	0.687	0.495	15.667 \pm 3.386	-0.515	0.609	13.333 \pm 2.422	-0.771	0.444			
	No	54	7.185 \pm 3.851			16.185 \pm 2.216			14.111 \pm 2.336					

Significance at level $p < 0.05$.

Table 7. Relation between the Mean Scores of family adaptation and The Mothers' Socio Demographic Characteristics

Mothers' Socio Demographic Characteristics		Mean Scores of family adaptation												
		No	Before		ANOVA or T-Test		Immediate		ANOVA or T-Test		After one month		ANOVA or T-Test	
			Mean \pm SD	F or T	P-value	Mean \pm SD	F or T	P-value	Mean \pm SD	F or T	P-value			
Educat-ion	Illiterate	16	70.500 \pm 8.173	6.073	0.001*	98.500 \pm 4.442	6.367	0.001*	93.563 \pm 4.516	7.004	<0.001*			
	Read -write	18	67.444 \pm 7.477			96.667 \pm 4.589			91.167 \pm 3.915					
	Secondary	16	76.563 \pm 4.871			101.438 \pm 2.065			95.563 \pm 2.366					
	High Education	10	75.700 \pm 6.617			102.000 \pm 3.432			97.100 \pm 3.381					
Job	Work	5	74.400 \pm 5.941	0.696	0.489	100.400 \pm 2.608	0.581	0.563	96.200 \pm 3.347	1.251	0.216			
	Not work	55	71.855 \pm 7.948			99.218 \pm 4.454			93.764 \pm 4.225					
Residence	Rural	52	71.500 \pm 7.979	-1.450	0.153	98.769 \pm 4.296	-2.619	0.011*	93.327 \pm 4.067	-3.250	0.002*			
	Urban	8	75.750 \pm 5.471			102.875 \pm 2.588			98.125 \pm 2.167					
consanguinity	Yes	6	71.333 \pm 11.183	-0.241	0.810	98.500 \pm 7.148	-0.484	0.630	93.833 \pm 7.195	-0.081	0.935			
	No	54	72.148 \pm 7.464			99.407 \pm 3.993			93.981 \pm 3.829					

Significance at level $p < 0.05$.

Table 8. Correlation Between Mothers' knowledge, Reported Care and the Family Adaptation Before, Immediately and After one month of program implementation

Correlations					
Time		Knowledge		Reported care	
		R	P-value	R	P-value
Before	Reported care	0.888	<0.001*		
	Family adaptation	0.360	0.005*	0.319	0.013*
Immediate	Reported care	0.641	<0.001*		
	Family adaptation	0.397	0.002*	0.245	0.059
After one month	Reported care	0.784	<0.001*		
	Family adaptation	0.448	<0.001*	0.345	0.007*

*Significance at level $p < 0.05$.

4. Discussion

Down Syndrome is a lifelong developmental disability that with huge medical and social costs, caused by trisomy of whole or part of chromosome. Children with DS have many associated health problems, such as cardiac, gastrointestinal, immunological, respiratory, endocrine, dental, sensory, and orthopedic conditions. However, there are also intellectual, social and behavioral problems that may impact their life negatively [24].

Mothers are the primary caregivers for children with mental disabilities, face many challenges and stressors that may lead to maternal distress if is not well-adjusted and adapted. Most children with DS, their disability is not a fixed condition, but it is changed over time with circumstances and offered care. A single disability could be complicated by multiple disabilities if care, love and support are lacking [25,26].

Regarding the reasons behind child hospital admission, it was found that more than half of children admitted hospital because of pneumonia. This result can be explained in the light of children with DS have abnormal parameters of the immune system that include T and B cell lymphopenia, marked decrease of naive lymphocytes and reduced specific antibody responses to immunizations. Anatomical abnormalities of the airways associated with DS may impair clearance of secretions and facilitate infections. Gastro-oesophageal reflux, dysphagia and poor pharyngeal muscle tone increase the risk for aspiration into airway causing lung inflammation [27].

The present study was in agreement with Uppal et al., (2015) [28] who revealed that pneumonia is seen as the largest contributors to hospital mortality in children with Down Syndrome. Similarly, Stanley et al., (2019) [29] who reported that, infants with DS are at an increased risk for dysphagia and silent aspiration, both of which are risk factors for pneumonia.

In relation to developmental delay, the present study revealed that most of children had delayed walking and speech. This could be explained in the light of neuroanatomical and physiological changes that cause muscle hypotonia, alterations in primitive reflexes, joint hypermobility and they also, have a bearing on postural control and muscle synergy. Such alterations directly interfere with exploitation of the environment, causing a reduction of crucial stimuli and experiences for the development of language, cognition and socialization [30].

This finding was in agreement with Jiar et al., (2012) [31] who found that children with DS got lower scores than typically developing children in measuring child development including gross motor. Similarly, Malak et al., (2015) [32] who added that Motor development, especially standing position and walking ability, is delayed in children with Down Syndrome. Santos et al., (2010) [33] found that the most impaired areas in children with DS were language and fine motor co-ordination.

Concerning associated health problems, it was observed that, all children had difficult communication. This finding was in agreement with Ferreira and Lamônica (2012) [34] who compared DS children and typically developing children with mental age matched and they found that the receptive and expressive performance on Down Syndrome is lower than the typically developing ones.

The current study showed that, most of children had obesity and overweight due to disabilities that make children sedentary and experience more barriers to physical activity participation because of physical, sensory and cognitive impairments. Other factors associated with obesity include the higher rate of poverty reported among caregivers of children with DS that make it difficult to purchase healthier food items such as fruits and vegetables.

Other families constantly offer food that is high in calories, as reinforcers for good behaviors, or the fear of appearing not to be a caring parent and lack of knowledge about lifestyle behaviors may predispose to weight gain. The finding was in line with Chaudhary (2019) [35] who observed that slightly more than half of studied children with DS were obese.

The study revealed that, less than half of children had cardiac anomalies. This could be attributed to the chromosomal abnormality associated with presence of extra copy of genetic material on chromosome 21 in DS. On the same line, Benhaourech et al., (2016) [36] added that, congenital heart disease is frequently described in patients with DS and is the main cause of death during the first two years of life.

Regarding total scores of mothers' knowledge about Down Syndrome. It was observed that, more than three quarters of studied mothers had low knowledge before educational program. This may be due to their low educational level, poor health facilities in rural areas, decrease health teaching programs that were provided to families and social stigma.

The findings with in agreement with Alhaddad et al., (2018) [16] who reported that there are deficits in the general knowledge about DS leading to unfavorable attitude towards children with DS. Similarly, Barnoy et al., (2017) [37] who found that, mothers had low level of knowledge about DS. On the other hand, The study was incongruent with Alosaimi (2020) [38] who found that, mothers of DS children had good general knowledge about DS in special care centers.

It was observed that, more than half of mothers had moderate level and less than half of them had high level of knowledge immediately after implementation of educational program. This could be attributed that the content of program was developed based on mothers' and children needs, using of audiovisual materials, program clarity and simplicity, availability of the researcher in the field for more clarification and repetition to fix the knowledge. These factors played an important role in improving mothers' knowledge.

The result was in agreement with El Shazali et al., (2018) [39] who added that counseling and information should be given to parents of children with DS to promote effective management, increase family adaptation and decrease the level of discomfort. Similarly, Kalyoncu and Giray (2018) [40] who stated that high-level information and guidance must be provided to parents so that they properly look after DS patients.

Regarding total scores of mothers' reported care to their children with Down Syndrome. It was observed that, most of mothers' reported care was unsatisfactory before educational program while, the majority of them had satisfactory care immediately and after one months of educational program intervention. This may be due to the new knowledge and skills that mothers acquired from standard educational intervention program that focused on care of associated health problems and the mothers become able to apply it for their children. This finding was in line with Ismail (2018) [41] who reported that, There were significant differences among the means of the experimental group concerning care methods in the pre and posttests favored the post test for mothers of children with Down Syndrome.

The study showed that, there were statistically significant positive correlation between mothers' knowledge, reported care and family adaptation. This could be attributed to the educational intervention program learn mothers new skills, care of associated health problems, use community services and social support which affect mothers' attitude and adaptation positively. The result was in line with Alosaimi (2020) [38] who found that, The majority of mothers had good knowledge and favorable attitude toward caring for their children with DS.

5. Conclusion

Regarding the findings of the current study, it is concluded that there was an improvement in families coping with their Down Syndrome children after implementation and promotion of mothers' practices regarding the care of their Down Syndrome children.

6. Recommendations

1. Upgrade the care givers of Down Syndrome children with the updated rearing practices that promote social development.
2. Assessment of the challenges encountered by sibling of Down Syndrome children and providing supportive intervention that promote positive relationships and attitudes.
3. Elevate social awareness of the challenges encountered by the Down Syndrome children and their families to promote the social support for them and limit the bullying practiced some times against the child and their families.

Financial Support and Sponsorship

None.

Conflicts of Interest

There are no conflicts of interest.

References

- [1] Asim A, Kumar A, Muthuswamy S, Jain S, Agarwal S. Down syndrome: an insight of the disease. *J BS*. 2015; 22(1): 41.
- [2] Rahimi T and Khazir Z. Perceived Experiences of Life Problems for Parents with a Down Syndrome. *J Heal Edu Heal Promo*. 2019; 7(3): 147-54.
- [3] Centers for Disease Control and Prevention. Birth Defects. 2018. Available at: <http://www.cdc.gov>. Retrived at January 15, 2018.
- [4] Wajuihian S. Down syndrome: An overview. *J Afr Vision Eye Health*. 2016; 75(1): 1-6.
- [5] Hockenberry M and Wilson D. *Wong's Essentials of Pediatric Nursing*. 9th ed. United States of America: Elsevier Co., 2013; 81, 82, 576.
- [6] Skallerup S. *Babies with Down Syndrome: A New Parents' Guide*. 3rd ed. United States of America: Woodbine House Co., 2008; 2-9.
- [7] Stead L and Kaufman M. *First Aid for the Pediatrics Clerk ship*. 3rd ed. United States of America: Mc Graw- Hill Co., 2011; 97-9, 377.
- [8] Bull M and the Committee on Genetics. Health supervision for children with Down syndrome. *J Pediatr*. 2011; 128(2): 393-406.
- [9] Fitzgerald P, Leonard H, Terri J, Bourke J, Hammond G. Hospital Admissions in Children with Down Syndrome: Experience of a Population-Based Cohort Followed from Birth. *J Plos One*. 2013; 8(8): 1-10.
- [10] Davidson M. Primary care for children and adolescents with Down syndrome. *J Pedia Clin Nor Ameri*. 2008; 55 (5): 1099-1111.
- [11] Jensen K, Sevick C, Seewald L, Halbower A, Davis M. Greater risk of hospitalization in children with Down syndrome and OSA at higher elevation. *J Chest*. 2015; 147(5): 1344-51.
- [12] Vadakedom S, Krishnan D, Mammen D, Antony J. Medical problems in children with Down syndrome. *J Intern Advan Medic*. 2018; 5(5): 1290.
- [13] Kaakinen J, Coehlo D, Steele R , Tabacco A .*Family Health Care Nursing: Theory, Practice, and Research*. 5th ed .United States of America: F.A Davis Co., 2015; 237-75.
- [14] Caples M, Martin A, Dalton M, Riper M. Adaptation and Resilience in Families of Individuals with Down Syndrome Living in Ireland. *J Lear Dis*: 2018; 46(9): 1-9.
- [15] Choi H and Van Riper M. mHealth Family Adaptation Intervention for Families of Young Children with Down Syndrome: A Feasibility Study. *J Pediatr Nurs* Jan-Feb 2020; 50: e69-e76.

- [16] Alhaddad M, Anwer F, Basonbul R, Butt N, Noor M, Malik A. Knowledge and attitude towards Down syndrome among people in Jeddah, Saudi Arabia. *J Proceedings SZPGMI*. 2018; 32(1): 56-65.
- [17] Alvani S and Hosseini S. Living with chronic illnesses and disability. *J Inter Bus Hum Tech*. 2012; 2(5): 102-8.
- [18] Van Riper M and Choi H. Family-provider interactions surrounding the diagnosis of Down syndrome. *J Gen Med*. 2011; 13 (1): 714-16.
- [19] Marshall J, Krishnan R, Adam L, Slotnick, Paul Tanner J, Jason L. Salemi, and Russell S. Kirby. Family-Centered Perinatal Services for Children With Down Syndrome and Their Families in Florida. *J Reaserch* 2018; *JOGNN1* (48): 78-89.
- [20] Boulet, S. L., Molinari, N. A., Grosse, S. D., Honein, M. A., & CorreaVillasenor, A. Health care expenditures for infants and young children with Down syndrome in a privately insured population. *Journal of Pediatrics*, (2008). 153, 241-246.
- [21] McCabe, L. L., Hickey, F., & McCabe, E. R. Down syndrome: Addressing the gaps. *Journal of Pediatrics*, (2011). 159, 525-526.
- [22] Bull, M., & Committee on Genetics. American Academy of Pediatrics: Health supervision for children with Down syndrome. *Pediatrics*. (2011), 107, 442-449.
- [23] McCubbin H and Patterson J. The family stress process; The double ABCX model of adjustment and adaptation. *J Marri Fam Rev*. 1983; 6(1-2): 7-37.
- [24] Gómez L, Verdugo M, Rodríguez M. Adapting a Measure of Quality of Life to Children with Down Syndrome for the Development of Evidence-based Interventions. *J Psycho soci Interven*. 2020; 29(1), 39-48.
- [25] Kotch J. Maternal and Child Health Programs, Problems and Policy in Public Health. 3rd ed. United States of America: Jones and Bartlett Learning Co., 2013; 144-74.
- [26] Adelman R, Tmanova L, Delgado D, Dion S. Caregiver burden: a clinical review. *J JAMA*. 2014; 311(10): 1052-60.
- [27] Bull M. Pulmonary complications and chronic conditions of Down syndrome during childhood: an agenda for clinical care and research. *J Pediatrics*. 2011; 158(2): 178- 9.
- [28] Uppal H, Chandran S, Potluri R. Risk factors for mortality in Down syndrome: Risk factors for mortality in down syndrome. *J Intellect Dis Res*. 2015; 59(9): 873-81.
- [29] Stanley M, Shepherd N, Duvall N, Jenkinson S, Jalou H. Clinical identification of feeding and swallowing disorders in 0-6 month old infants with Down syndrome. *J Ameri Med Gen*. 2019; 179(2), 177-82.
- [30] Vasques T and Lamônica D. Motor, linguistic, personal and social aspects of children with Down syndrome. *J Appl Oral Sci*. 2015; 23 (4): 424-30.
- [31] Jiar Y, Satria H, Yahya S. Strength and weaknesses of children with Down syndrome (0-60months) and comparison with typically developing children. *J Internat Educ Inform Techn*. 2012; 6(2): 233-40.
- [32] Malak R, Kostiukow A, Wasielewska A. Delays in Motor Development in Children with Down Syndrome. *J Med Sci Monit*. 2015; 21(1): 1904-10.
- [33] Santos A, Weiss S, Almeida G. Assessment and intervention in the motor development of a child with Down syndrome. *J Rev Bras Educ Esp*. 2010; 16(1): 19-30.
- [34] Ferreira A and Lamônica D. Comparing the lexicon of children with Down syndrome and typically developing the same mental age. *J Rev CEFAC*. 2012; 14(5): 786-91.
- [35] Chaudhary A. Relationship between dietary intake and prevalence of obesity in children with down's syndrome. *J Adv Obes Weight Manage Control*. 2019; 9(2): 40-2.
- [36] Benhaourech S, Drighil A, El Hammiri A. Congenital heart disease and Down syndrome: various aspects of a confirmed association. *J Cardio-vasc Afr*. 2016; 27(5): 287-90.
- [37] Barnoy S, Biton A, Itzhaki M. Social Inclusion of Children With Down Syndrome: Jewish and Muslim Mothers' Knowledge, Attitudes, Beliefs, and Behavioral Intentions: Nursing Care of Children and Families. *J Pedia Nurs*. 2017; 35(1): 50-6.
- [38] Alosaimi M, Hakeem A, Alfentokh O. Knowledge of Down Syndrome among Down Syndrome Children's Mothers In Riyadh Care Centers. *J Inter Med Devel Count*. 2020; 4(10):1595-1600.
- [39] El Shazali O, Abdullahi H, Osman H. Assessment of quality of counseling for down syndrome in Sudan. *J Pedia Neon Care*. 2018; 8(5): 232-34.
- [40] Kalyoncu I and Giray F. Parent's attitudes and knowledge on oral health in a group of individual with Down syndrome in Turkey. *J Pak Med Assoc*. 2018; 68(9): 1368-72.
- [41] Ismail M. Effectiveness of Cognitive Behavior Program to Help Mothers Acquire Rearing Practices on Enhancing Independent Behavior to their Children with Down Syndrome. Published Doctoral thesis. Faculty of Education. Zagazig University. 2018; 2-8.

