

Effectiveness of Coping Strategies Intervention on Quality of Life for Mothers having Children with Down Syndrome

Seham Mohammed Elmwafie¹, Amany Ibrahim Abdalla Ibrahim², Huwida Hamdy Abdelmonem³, Mervat Amin Sayed⁴, Soad Ahmed⁵

1) Assistant Professor of Pediatric nursing, Faculty of Nursing, Beni-Suef University

2) Lecturer of Pediatric Nursing, Faculty of Nursing, Fayoum University, Egypt

3) Assistant Professor of Pediatric Nursing, Faculty of Nursing, Fayoum University, Egypt

4) Assistant Professor of Community Health Nursing, Faculty of Nursing, Fayoum University

5) Lecturer of Community Health Nursing, Faculty of Nursing, Fayoum University

Abstract:

Background: Caring child with Down Syndrome (DS) requires special challenges, and mothers can go through a period of difficulty adapting. So, coping strategies with positive attitudes are considered effective in improving quality of life for mothers and their children. **Aim:** The study aimed to evaluate the effectiveness of coping strategies intervention on quality of life for mothers having children with Down Syndrome. **Method:** A quasi-experimental research design (one group pre/posttest) was used. **Setting:** This study was conducted at the Genes Clinics of DS in the Specialized Clinics of Pediatric Hospital affiliated to Ain Shams University. **Sample:** A purposive sample consisted of (75) mothers and their children with down syndrome recruited from the above-mentioned setting. **Tools:** Five tools were used pre /post intervention to collect data; A structured interviewing questionnaire to assess mothers' knowledge related to DS; Self-reliance assessment to assess level of independence of DS children regarding daily living activities as reported by their mothers; Needs' scale to assess cognitive, economical, psychological, social, and physical needs experienced by the mothers; Coping patterns scale to assess the mothers' coping patterns toward their DS children, and Family quality of life scale to assess health related Quality of Life (QoL) for mothers of children with down syndrome. **Results:** There was a highly statistically significant improvement was observed between the studied mothers' knowledge, QoL, needs, and coping patterns pre and post intervention program, where $p < 0.001$, also there was a positive correlation between total self-reliance of the studied children and total mothers' needs, quality of life and coping at pre and post intervention program ($p = < 0.001$). **Conclusion:** Implementation of coping strategies intervention had a positive effect on the improvement of mothers' knowledge, level of needs, coping patterns and quality of life. **Recommendations:** Conducting frequent educational program focused on encouraging mothers to cope effectively with their children with DS.

Keywords: Children with Down syndrome, Coping, Mothers Quality of life.

Introduction:

Down Syndrome (DS) is the most frequent chromosomal abnormality in infants which is caused by an extra copy of chromosome 21 (trisomy 21). In terms of their care requirements, every child with DS is a special case. It is a most common pediatric genetic disorder that not only effect on the child's physical health but also, effect on mental, social and psychological child health. It is one

of the most prevalent chromosomal disorders in the world. It affects about one out of every 700-800 live births each year. The prevalence of DS is 10 per 10,000 live births on average throughout the world. In Egypt, there are between 1:555 and 1:770 live births each year with DS (Andrew and Harish, 2021 & Center for Disease Control and Prevention, 2021).

Down syndrome accounting for about 25% of intellectually delayed children. It affects

a variety of body systems, including the musculoskeletal, neurological, and cardiovascular systems. Short stature, muscular hypotonia, atlantoaxial instability, reduced neuronal density, cerebellar hypoplasia, intellectual disability and congenital heart abnormalities are frequent symptoms in children with DS. Also, hypothyroidism, autoimmune illnesses, obstructive sleep apnea, epilepsy, hematological abnormalities, recurrent infections, anxiety disorders, and hearing & visual problems. Therefore, hearing loss is presenting in about three-quarters of children with DS which is often related to anatomical ear disorder (Stylianios, et al., 2020 & Marilyn and Bull, 2020).

Mothers of children with DS have many challenges in the physical, psychological, and social aspects of life, and they also deal with a lot of negative feelings including stress, anxiety, and sadness. Additionally, they are more worried about their own and their children's futures, which will negatively affect their wellness as a result of their incapacity to deal with the situation, which in turn lowers the quality of life for their family (QoL). Therefore, coping is the process of dealing with external or internal needs that are assumed to be greater than the mothers' ability to care for the affected child and lead a meaningful life. Meanwhile, coping has various functions for mothers, including: increasing the motivation of mothers to cope with their children under stress, enhancing a healthy sense of self, preserving mental stability, and enabling mothers to thrive and develop strong relationships with those around them (Gashmard, et al., 2020).

Mothers are the primary caregiver for their children with DS, they assume the responsibility of caring, assistance, supporting any need for their children's' daily living activities, as well as their permanent integration in society aimed to improving their health status. Pediatric nurse plays a crucial role in providing family centered care to children with DS, promoting growth and development, preventing complications & problems and helping mothers to successfully care of their children, cope and adapt with child's needs and other family

members. Also, pediatric nurse can aid in providing a safe environment for mothers to verbalize their frustrations or conflicting emotions and help mother identify stressors, community resources, coping strategies, regular follow up and compliance with treatment and effective means of communication for the entire family (Zaki, et al., 2020).

Significance of the study:

Mothers of children with down syndrome face a wide range of difficulties, including navigating the health care system, financial issues due to out-of-pocket expenses for the child's care, lost income due to the condition of the child, accessing medical and nonmedical services being difficult, high levels of stress, and restrictions on the caregivers' own daily activities. Resulting in unmet needs of mothers having children with DS can impact in coping and wellbeing of the entire family and quality of life (QoL). However, coping with a child with Down syndrome can be very stressful and difficult for their mothers, requiring them to make changes in their social lives. Coping is a unique personal approach that needs for a cognitive appraisal of the circumstances to manage the situation effectively. This can enhance quality of life and lessen the consequences of unmet needs (Thomas, et al., 2022).

The existence of DS children in any family can trigger a lot of internal and social problems and higher stress for parents. Therefore, Children with DS require more attention because they are unable to maintain their own activities due to delayed development, which restricts simple everyday self-care tasks including getting dressed, brushing one's teeth, walking and communicating. According to the researchers' views, it is crucial to teach parents, especially mothers, positive coping skills by giving them encouragement. This will assist to ensure that they grow up with a strong sense of self-worth and confidence to enhance their quality of life. Therefore, the purpose of this study was to evaluate the effect of coping

strategies intervention on the quality of life for mothers of children with down syndrome.

Aim of the study:

The current study aimed to evaluate the effectiveness of coping strategies intervention on the quality of life for mothers having children with Down syndrome through:

1. Assessing mothers' knowledge about down syndrome.
2. Assessing activity of daily living for children with DS.
3. Assessing mothers' coping strategies toward their children with down syndrome.
4. Assessing needs of mothers having children with down syndrome.
5. Assessing quality of life for mothers having children with down syndrome.
6. Designing and implementing coping strategies intervention for mothers having children with down syndrome.
7. Evaluate the effect of coping strategies intervention on mothers having children with down syndrome.

Research hypothesis:

- Mothers who engage in the intervention program will have higher level of knowledge post coping intervention than before.
- Mothers who engage in the intervention program will acquire positive coping strategies post coping intervention than before.
- Mothers who engage in the intervention program will have improved quality of life post coping strategies intervention than before.

Theoretical frame work:

The theoretical framework of this study based on a combination between two theories:

1- Learning theory: to promote critical thinking, problem solving and parent support (*Knowles, 1984*).

2- Self-regulation theory: It is one component of the coping program which permitting adaptation, emotional and functional coping for mothers to increase their ability to positively coping with their children to enhance quality of life (*Jean, 1997*). Also, the framework suggests six aspects of coping strategies include; physical, psychological, social, emotional, educational and religious coping.

Subjects & Method:

1-Technical design:

Research Design

A quasi-experimental (one group pre/post-test) design was utilized to achieve the aim of the study.

Research Setting:

This study was conducted at the Genes Clinics of DS in the Specialized Clinics of Pediatric Hospital affiliated to Ain Shams University at the first floor of the hospital. The clinic consists of three rooms, the first room for follow up, the second for genetic screening and the last room for intravenous fluid administration. Each room contains 2 beds and 6 chairs; also, it has good ventilation and many light sources. In addition to large laboratory specified for metabolic and genetic tests. This setting is selected due to the high attendance of children with down syndrome and also serves the biggest region.

Subjects of the study:

Sample size:

The estimated sample size was 75 children with DS and their mothers out from 220 mothers who attend at the previous mentioned setting, at confidence level 90%. The sample size calculation was done based on the power analysis (*Thompson, 2012*).

$$n = \frac{N \times p(1-p)}{\{N-1 \times (d^2 \div z^2)\} + p(1-P)}$$

Which: n= Sample size, N= Total size, Z= The standard value corresponding to confidence level 95% which is (1.65).

d= Error level 5%.

p= 0.50.

- Type I error with significant level (α) = 0.5.

- Type II error by power test (1-B) = 95%.

Sample type:

A purposive sample was obtained and including available mothers of children with down syndrome and their children attending to previous mentioned setting and fulfilled the following criteria:

Inclusion criteria for children with down syndrome; available confirmed diagnosed with DS children aged from 6 to 12 years old from both genders.

Inclusion criteria for mothers; mothers who give direct care to their DS children and free from any psychiatric illness. The studied subjects were interviewed either individually or in groups.

Tools of data collection:

Five tools were designed by the researchers after reviewing the related literature review.

Tool I: A structured interviewing questionnaire (one group pre/post-test) based on relevant studies and reference **Jan, et al., (2017)**. It consisted of the following parts:

Part I:

- Personal characteristics of children with DS like age, gender, rank, duration of illness, Intelligence Quotient (IQ) and family history of DS.

- Sociodemographic characteristics of mothers as age, level of education, employment, marital status, family monthly income,

residence place, family size, crowding index, and consanguinity between parents.

- Current health problems for the child include problems in heart, digestive system, auditory, thyroid and other chronic illness.

- Assessment of developmental retardation include: delayed in walking, movement & gait, attention and speech.

- Assessment of child growth include: weight, height and body mass index (BMI) using growth chart tools {Centers for Disease Control and Prevention (CDC), 2000} to determine the normal from abnormal measures.

Intelligence Quotient (IQ) formula (Kaufman, 2016):

$$IQ = \text{Mental age} / \text{Chronological age} \times 100$$

IQ ("deviation IQ")	Range	IQ Classification
130 and above		Extremely High
120–129		Very High
110–119		High Average
90–109		Average
80–89		Low Average
70–79		Very Low
69 and below		Extremely Low

Crowding Index (CI) equation:

$$\frac{\text{No. of persons in home}}{\text{No. of rooms in home}}$$

Classification of crowding index:

Dwellings with more than one person per room are considered "crowded" and dwellings with more than 1.5 people per room are "severely crowded".

Part II:

- Knowledge of the studied mothers about down syndrome that includes: meaning,

causes, types, signs and symptoms, complications, treatment, and follows up.

- Knowledge of the studied mothers about care of their children with down syndrome, include; movement (7items), level of independence (6 items), and difficult in language (5items).

Scoring system:

A correct and complete answer take two grades, while incomplete answer had 1 grade and zero was for an incorrect or unknown answer. The total scores converted to percentage and then classified as following, less than 60% considered as unsatisfactory, while score of 60% or more was considered as satisfactory level of knowledge.

Tool II: Self-reliance Assessment: It was developed by the researchers to assess level of independence of DS children regarding daily living activity as reported by their mothers. It included 8 items such as Nutrition, Mobility, Walking, Clothing, Bathing, Evacuation, Contact with others and Mouth care.

Scoring system:

Each item of the daily activities has score according to level of dependency as: full dependent (1) partial dependent (2) independent (3) grades. The total score of the daily activities' performance was 24. The score from 0 to < 50% denoted full dependent, 50 < 75 % score was partially dependent, while score from 75 ≤ 100% considered independent.

Tool III: Needs' assessment scale: The scale was adapted from **Leyser & Dekel, (1991)**. It was modified and translated by the researchers into simple Arabic language to suit nature of the study. It was used to assess cognitive, economical, psychological & social, and physical needs experienced by the studied mothers.

Scoring system:

Mothers' needs assessment scale consists of 4 components (32 items): cognitive

(10) items, economical (9) items, psychological and social (9) items, and physical (4) items. The scale has been scored as, never need it =1 grade; need it moderately=2 grades and need it very much =3 grades. The total optimal score of mothers' needs were 96. Score of less than 50%, considered mothers never had needs, the score between 50-<75% was mothers had moderate needs and equal or more than 75% was mothers had very much need.

Tool IV: Coping patterns scale: This scale was adopted from **Flaherty and Glidden (2000)** to assess the mothers' coping strategies toward their children with DS. It was modified and translated into simple Arabic language by the researchers to suit the study nature. The content validity was assessed and secured by expert consultant before its use. The scale was composed of 40 statements. It included physical, psychological, social, emotional, educational, and religious coping.

Scoring system:

The total optimal scores of mother's coping scale were 80 and each scored question is rated as a 3-point scale as occurring "usually" take one score, "sometimes" take two scores and "never" take three scores. The items of the questionnaire are reverse-scored, so that higher scores consistently indicated problem in coping. Ratings scale is consisting of 40 statements divided into six subscales; (8) physical, (7) psychological, (7) social, (4) emotional, (9) educational and (5) items for religious coping. A total coping score is calculated and ranged from 40 to 120. The minimum total score is 40 and the maximum is 120. Score of less than 60% was negative coping pattern and equal or more than 60% was positive coping pattern.

Tool V: Family quality of life scale inventory version 4.0: (The PedsQL4.0 generic core scale) which adopted from **Varni, et al., (2004)**, to assess health related quality of life for mothers of children with down syndrome. This scale was consisted of 36 items: (6 items) for physical functioning, (5 items) for psychological functioning, (4 items) for social

functioning, (5 items) for intellectual functioning, (3 items) for communication, (5 items) for worry, (3 items) for daily activities and (5 items) for familial relations.

Scoring system:

Each item has a score ranging from 0 – 4. Where, 4= it is never a problem, 3= it is almost never a problem, 2 = it is sometimes a problem, 1= it is often a problem and 0= it is almost always a problem. After that the items are reverse scored and linearly transformed as 0 = 100, 1 = 75, 2 = 50, 3 = 25 and 4 = 0. So that the higher scores indicate better health. Quality of life is classified accordingly into;

Low quality of life: <60% of total score

Moderate quality of life: 60–75% of total score

High quality of life: >75% of total score.

2- Operational design

1. Preparatory phase

Tools of data collection were designed, developed and adopted by the researchers based on the literature review under supervision of experts in the field of pediatrics nursing. A guiding booklet was prepared by the researchers. It was specially designed in a simple Arabic language to meet the studied sample educational needs. The study tools and guiding booklet were evaluated for its content validity and clarity by expert consultant.

2. Exploratory phase

Validity and Reliability:

Face and content validity were achieved through five experts; 3 professors from the Pediatric Nursing and 2 from Community Health nursing. All experts were affiliated to Ain Shams University, Egypt who reviewed the tools for content accuracy. The items on which

most of the experts have agreed were included in questionnaire. And the required correction and modifications were done for some statements as the following; removal of unnecessary or repetitive statements, rephrasing, and paraphrasing. To ascertain relevance and clarity such as use of the sentence and added some statements to cover all aspects of mothers' needs (cognitive, economical, psychological & social, and physical) regarding their children with down syndrome needs as to have the ability to support children's physical, mental and psychological health throughout his or her life span and to have awareness about the places that providing the suitable services for children with down syndrome, to be aware about the appropriate job for children with down syndrome when they reach to adulthood stage, to know how to deal with my child's psychological problems resulting from his illness as anxiety, Stubbornness and tension.

The developed tools were tested for reliability by using the Cronbach's alpha which detected excellent internal consistency with score (0.792). The reliability was scaled as follows: <0-0.25 weak reliability, 0.25-0.75 moderate reliability, 0.75-<1 strong reliability and 1 is optimum.

Pilot study:

Before starting data collection, pilot study performed on 10% of mothers and their DS children randomly from previously mentioned setting to estimate the time for completing the tools and examination questions' clarity, applicability and relevance. Necessary modifications were done. The mothers participated in the pilot study and their children were excluded from the main study sample.

Administrative design:

The necessary approval was taken from the administrators of the Genes Clinics of DS in the Specialized clinics of Children Hospital affiliated to Ain-Shams University Hospitals through official letter from the Dean of Faculty of Nursing, Fayoum University to collect the necessary data for the current study. The

researchers met the directors in the specialized clinics, explained the aim of the study and procedures, and asked for their cooperation.

Ethical Considerations:

Ethical approval obtained from the Scientific and Ethical Committee of Nursing, affiliated to Fayoum University. An informed verbal consent was taken from the subjects after explaining the aim of study to participate in the current study. Ensure that the collected data used only for research and maintain complete confidentiality and privacy. Researchers informed the subjects that allow withdraw from the study at any time.

Field work:

Th actual field work was carried out from the first of May 2021 to the end November 2021. The researchers were available 3 days /week from 9 o'clock a.m to 1 o'clock p.m. The researchers started to interview each mother individually about their knowledge, needs, coping and quality of life and then started to assess the reported care provided by mothers for their children in form of activity of daily living (pretest). The average time needed to complete the questionnaire for each mother was between 20–30 minutes. The researchers begin to measuring child weight, height, and body mass index guided by growth charts to assess the child for evidence of retarded growth. The researchers administered coping strategies intervention to mothers based on actual needs assessment. The intervention program was implemented by classifying the mothers of children with DS into 5 groups, each group consisted of 15 parents. The intervention program was introduced for each group separately due to the small size of the clinics that leads to difficulties in gathering all studied mothers at the same time and also due to the implementation of the preventive measures against COVID 19 in the hospital.

Implementation of the coping strategies was implemented by the researchers, according to the number of subjects during the visit. The period of implementation of coping strategies

intervention was achieved within weeks 4-5 weeks and covered over 9 sessions (6 sessions for theoretical part and 3 sessions for practical part), each session about 45 to 60 minutes aimed to improve mothers' knowledge and enhance their ability to positively cope with their children's condition, focusing on spirituality, teaching socially appropriate behavioural skills, strengthening parents' self-reliance regarding their children, and creating necessary assistance to enhance mothers' quality of life.

The implementation of coping strategies based on two main categories of coping. The first type of coping strategy is **problem-focused coping**, which aims to lessen demands on the environment or increase personal resources. This strategy encompasses all active efforts to change or get rid of stressors. The second type of coping is **emotion-focused coping**, which focuses on managing emotional reactions to stressful situations to control the emotions through acceptance of what has happened, receiving emotional support from friends and family, positive reframing or attempting to see it differently, praying, meditating, using spirituality, finding respite through self-distraction, and more. Modified lectures, group discussions, power points, role plays, flip charts, and videos about effective coping during stressful situations were among the teaching strategies that were produced. Additionally, there will be practice demonstrations and redemonstrations.

The researchers evaluated mothers' knowledge, coping, needs and quality of life as well as assessment of self-reliance of the studied children regarding daily living activities as reported by their mothers immediately after finishing the sessions (post-test) using the same pretest tools. After the post test, the guiding booklet distributed to all mothers.

Contents of coping program:

The content of the booklet covers the following parts:

a- The first was the theoretical part that concerning with providing the mothers of children with DS with knowledge about (DS) as definition, problems of children with DS, definite criteria of children with (DS), important needs of children with (DS) and the available services. In addition to the knowledge about quality of life and how to meet the mothers and their children needs. As well as, help mothers to improve their quality of life, which in turn decrease their needs.

b- The second was the practical part that concerning on improve the coping strategies of mothers having children with down syndrome as: definition of coping, types of coping methods, difference between problem-focused and emotion-focused coping methods, examples for both problem-focused and emotion-focused coping methods. As well as practices related to daily living activities such as nutrition, mobility, walking, clothing, bathing, evacuation, contact with others and mouth care.

Statistical design:

Data collected from subjects was revised, coded, and entered into a computer. The SPSS program, version 24, was used for computerized data entry and statistical analysis. The collected data was presented in the form of frequencies and percentages using descriptive statistics. The r test was used to compare the groups (pre/post).

Results:

Table (1): Revealed that the mean age of the studied children was 7.84 ± 3.2 years, 50.7% of them were males and 33.3% of them ranked as the first child. According to child's Intelligence Quotient, this table showed that, more than two thirds (68%) of the studied children was mild $55 < IQ < 69$.

Table (2): Detected that, mean age of the studied mothers was 33.73 ± 5.6 years. Related to education level, 36% of the studied mothers were not read and write. According to occupation level, 77% of them were doesn't

work. Regarding, family income, 61.3% of the studied mothers had insufficient income.

Table (3): This table showed that the majority (84%) of studied children had delayed speech; meanwhile, slightly less than three quarters (70.7%) of them had delayed walking and movement. Also, more than three quarters (77.3) of them had imbalance in their movement and gait.

Table (4): Demonstrated that less than half (45.3%) of the studied children had heart defects. Regarding Presence of other chronic diseases; this table showed that 25.3% & 24% of the studied children had heart diseases and chronic pneumonia respectively.

Table (5): Revealed that, 48% & 46.7% of the studied children were normal and overweight respectively and the mean height was 127.6 ± 10.2 cm. Also, body mass index mean of them was 27.23 ± 6.2 kg/m².

Figure (1): Showed that one quarter (25.3%) of the studied mothers had satisfactory knowledge pre coping strategies intervention, while improved to the majority (85.3%) of them post intervention.

Table (6): It is clear from this table that, there was a highly statistically significant differences between all coping strategies among the studied mothers pre/post coping program where, $p < 0.001$.

Table (7): Detected that, there was a highly significant difference related to cognitive, economical, and psychological & social and physical needs of the studied mothers pre and post coping strategies intervention where, ($p < 0.001$).

Table (8): Regarding to mothers' quality of life, this table showed that, there was a highly statistically significant difference between all quality domains pre/post coping strategies intervention, where $p < 0.001$.

Table (9): Detected that, there was a highly significant difference in relation to the studied children self-reliance regarding activities of daily living including; feeding, mobilization, walking, dressing, hygiene measures, and elimination pre and post coping strategies intervention with p value <0.01.

Table (10): Clarified that there was a positive correlation between mothers' knowledge, quality of life, and coping at pre and post coping strategies intervention at $p < 0.001$.

Table (11): Detected that, there was a positive correlation between total self-reliance of the studied children and total mothers' needs, quality of life and coping at pre and post coping strategies intervention ($p < 0.001$).

Table (1): Distributions of the studied children regarding their characteristics (n= 75).

Items	No.	%
Child age (year):		
6 < 8	24	32.0
8 < 10	27	36.0
10-12	24	32.0
Mean \pmSD		7.84\pm3.2
Gender:		
Male	38	50.7
Female	37	49.3
Child rank:		
Frist	25	33.3
Second	14	18.7
Third	13	17.3
Last.	23	30.7
Crowding index:		
<2	20	26.7
2 – 3	47	62.7
3 and more	8	10.6
Child's Intelligence Quotient (IQ):		
Mild 55-<69	51	68.0
Moderate 40-<54	24	32.0

Table (2): Distribution of the studied mothers having children with Down syndrome regarding their socio-demographic characteristics (n=75)

Items	No.	%
Mothers' age/ year:		
less than 20	2	2.6
20 <30	23	30.7
30 < 40	32	42.7
40+	18	24.0
Mean ± SD	33.73±5.6	
Education:		
Not read and write	27	36.0
Read/write	11	14.7
Basic	4	5.3
secondary	25	33.3
University	8	10.7
Occupation:		
Work	17	22.7
Doesn't work	58	77.3
Family income (LE/month):		
Sufficient	29	38.7
Insufficient	46	61.3

Table (3): Distribution of the studied children according to their physical abnormality after birth (n=75)

Physical abnormality	No.	%
Growth and developmental retardation:		
Delayed in walking and movement	53	70.7
Delayed in growth (height and weight)	42	56.0
Delayed attention	43	57.3
Delayed speech	63	84.0
Movement difficulties:		
Imbalance of the child moves and gait	58	77.3
Lack of movement	5	6.7
Hyperactive disorder	12	16

* All items are not mutually exclusive

Table (4): Distribution of the studied children according to their current health problems (n=75)

Items	No.	%
Current health problems		
Heart problems	34	45.3
Digestive problems	9	12.0
Auditory problems	9	12.0
Visual problems	15	20.0
Behavioural and psychological problems	13	17.3
Thyroid problems	6	8.0
*Presence of other chronic diseases:		
Diabetes	8	10.7
Heart diseases	19	25.3
Anaemia	7	9.3
Chronic pneumonias	18	24.0

* All items are not mutually exclusive

Table (5): Distribution of the studied children according to their weight and height measurements (n=75).

Items	No.	%
Under weight	4	5.3
Normal	36	48.0
Over weight	35	46.7
Weight		45.06 ±13.2
Height		127.6±10.2
Body mass index		27.23±6.2

Figure (1): Distribution of the studied mothers according to their total knowledge about Down syndrome pre and post coping strategies intervention (n=75)

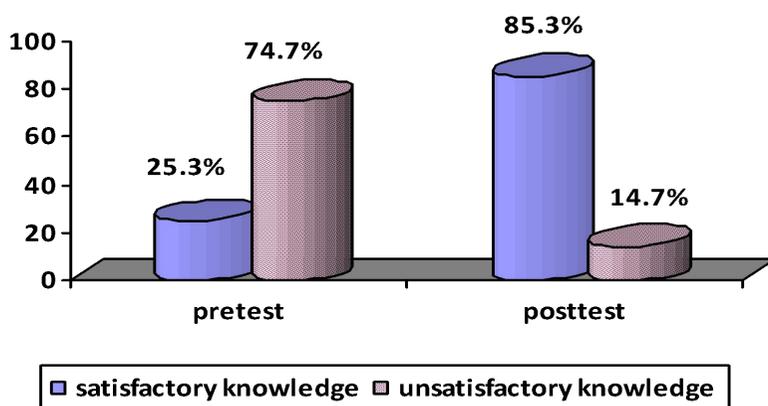


Table (6): Distribution of the studied mothers according to their coping strategies pre and post coping strategies intervention (n=75)

Items	Pre-intervention				Post-intervention				X ²	p-value
	Positive Coping		Negative Coping		Positive Coping		Negative Coping			
	No.	%	No.	%	No.	%	No.	%		
Physical coping	15	20	60	80	52	69.3	23	30.7	18.6	p<0.001
Psychological coping	18	24	57	76	54	72	21	28	20.01	p<0.001
Social coping	22	29.3	53	70.7	60	80	15	20	17.9	p<0.001
Emotional coping	25	33.3	50	66.7	68	90.7	7	9.3	23.9	p<0.001
Educational coping	10	13.3	65	86.7	54	72	21	28	25.7	p<0.001
Religious coping	35	46.7	40	53.3	72	96	3	4	14.9	p<0.001
Total coping	23	30.7	52	69.3	55	73.3	20	26.7	16.3	p<0.001

Table (7): Distribution of the studied mothers according to their needs pre and post coping strategies intervention (n=75).

Needs	Pre-intervention						Post-intervention						X ²	p-value
	Never		Moderate		Very much		Never		Moderate		Very much			
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%		
Cognitive need	15	20	28	37.3	32	42.7	44	58.7	18	24	13	17.3	19.63	p<0.001
Economical need	9	12	22	29.3	44	58.7	22	29.3	27	36	36	48	12.96	p<0.001
Psychological & Social need	4	5.3	40	53.3	31	41.3	35	46.7	30	40	10	13.3	36.25	p<0.001
Physical need	15	20	35	46.7	25	33.3	40	53.3	23	30.7	12	16	33.01	p<0.001
Total needs	8	10.6	38	50.7	29	38.7	42	56	22	29.3	11	14.7	52.77	p<0.001

(**) highly statistically significant at p<0.001.

Table (8): Distribution of the studied mothers according to their QoL domains pre and post coping strategies intervention (n=75).

QoL domains	Pre intervention						Post intervention						X ²	p-value
	High		Moderate		Low		High		Moderate		Low			
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%		
Physical functioning	4	5.3	16	21.3	55	73.3	49	65.3	20	26.7	6	8	24.30	p<0.001
Psychological functioning,	7	9.3	22	29.3	46	61.3	50	66.7	20	26.7	5	6.6	23.01	p<0.001
Social functioning	10	13.3	25	33.3	40	53.3	52	69.3	18	24.0	5	6.7	28.01	p<0.001
Intellectual functioning	8	10.7	20	26.7	47	62.7	50	66.7	20	26.7	5	6.6	26.00	p<0.001
Communication	10	13.3	26	34.7	39	52	54	72	15	20	6	8.0	20.17	p<0.001
Worry	5	6.7	18	24	52	69.3	46	61.3	20	26.7	9	12.0	21.21	p<0.001
Daily activities	6	8	20	26.7	49	65.3	46	61.3	20	26.7	9	12.0	24.50	p<0.001
Total QoL	8	10.7	21	28.0	46	61.3	51	68.0	18	24.0	6	8.0	29.8	p<0.001

(**) highly statistically significant at p<0.001.

Table (9): Distribution of studied children according to their self-reliance regarding activities of daily living pre/post coping strategies intervention (n=75).

Activities of daily living					X ²	p-value
	Pre- intervention		Post intervention			
	No.	%	No.	%		
Feeding						
Dependent	15	20	7	9.3	11.5	<0.001
Partial dependent	39	52	18	24		
Independent	21	28	50	66.7		
Mobilization						
Dependent	16	21.4	10	13.3	50.9	<0.001
Partial dependent	53	69.3	29	38.7		
Independent	4	5.3	36	48		
Dressing						
Dependent	18	24	8	10.7	53.4	<0.001
Partial dependent	53	70.7	33	44		
Independent	4	5.3	34	45.3		
Hygienic measures						
Dependent	17	22.7	6	8	5.1	<0.001
Partial dependent	54	7	35	46.7		
Independent	4	5.3	34	45.3		
Elimination						
Dependent	18	24	9	12	52	<0.001
Partial dependent	53	70.7	46	61.3		
Independent	4	5.3	20	26.7		
Communication						
Dependent	23	30.7	14	18.7	6.1	<0.05
Partial dependent	43	57.3	23	30.7		
Independent	9	12	38	50.6		

(**) Highly significant at P<0.001

Table (10): Correlation between total mothers' knowledge, needs, quality of life, and coping strategies pre and post coping strategies intervention (n=75).

Items		Total knowledge		Total needs		Total quality of life	
		Pre	Post	Pre	Post	Pre	Post
Total knowledge	r						
	p						
Total needs	r	-0.375	-0.451				
	p	0.007**	0.001**				
Total quality of life	r	0.487	0.563	-0.415	-0.499		
	p	0.000**	0.000**	0.001**	0.000**		
Total coping strategies	r	0.502	0.581	-0.509	-0.543	0.625	0.688
	P	0.000**	0.000**	0.000**	0.000**	0.000**	0.000**

R= correlation coefficient test. P= p-value **highly significant at p < 0.001.

Table (11): Correlation between the studied children self-reliance and total mothers' needs, quality of life, and coping strategies pre and post coping strategies intervention (n=75).

Items		Total children self-reliance	
		Pre	Post
Total needs	r	0.533	0.500
	P	0.000**	0.000**
Total quality of life	R	-0.560	-0.575
	P	0.000**	0.000**
Total coping strategies	r	-0.418	-0.452
	P	0.000**	0.000**

R= correlation coefficient test. P= p-value **highly significant at $p < 0.001$.

Discussion:

The presence of a child with DS in the family necessitates numerous adaptations. However, it is the parent's job to provide care, especially the mothers. Despite the fact that these parents' unmet demands are ultimately connected to stress and negatively affect their quality of life. Therefore, it is believed that coping strategies with positive attitudes used by parents can improve the wellbeing of both parents and children with DS (**Darlas and Bhatb, 2021**). The aim of the current study was to evaluate the effectiveness of coping strategies interventions on the quality of life for mothers of children with down syndrome.

The characteristics of the studied children are consistent with **Zaki, et al., (2020) & Shoeib, et al., (2021), and Richter, (2017)** in mean age, intelligent quotient, and ranking of DS children in their families. Meanwhile, the characteristics of the studied mothers are consistent with **Cless, et al., (2018) and Mahmoud, et al., (2022)** in mean age. Also, the current results agreed with the findings of **Laufer, (2017)** in which more than three quarters of the studied mothers doesn't work and more than half of them had insufficient monthly income. This could be due to mothers of children with chronic disability which require continuous health care needs, follow up, and hospitalization. So, mother must spend more time to provide adequate assistance and caring for their child which hinder the ability of the

mother to work and had negatively effect on family income.

Concerning growth and developmental retardation, this study observed that, more than two thirds of the studied children had delayed in walking and movement and imbalance of the child moves and gait. This could require more effort and burden in child family to treatment particularly physical therapy to improve child walking and conversation sessions to promote child communications. This finding goes in same line with study conducted by **Malak, et al., (2015)** in the study entitled "Delays in motor development in children with down syndrome in Poland" who reported that majority of children with DS had growth and developmental retardation especially in standing position and walking ability.

Regarding speech development, the current study results showed that the majority of the studied children had delayed speech. This was in agreement with a study conducted by **Wilson, et al., (2019)**, who studied "Estimates of the prevalence of speech and motor speech disorders in adolescents with Down syndrome" that, nearly all of the DS children had some type of speech disorder. Also, **Laguerre, (2019)** who discovered in the study about "The Latest Research on Down Syndrome Children and Speech" that, DS children had delays in speech and language development.

As regards to the children's current health problems, it was observed that, less than half of the studied children had heart defects. In accordance with **Dobosz & Bik-Multanowski, (2019)** study titled "Long-term trends in the prevalence of congenital heart defects in patients with Down syndrome in southern Poland" and found that, more than half of all studied children had congenital heart defects. This contradicts the findings of the **Senses, et al., (2019)** study, which found congenital heart disease in more than half of the down syndrome participants.

Concerning physical growth, the results of this study showed that slightly less than half of the studied children had overweight and the mean height of the studied children was 127.6 ± 10.2 cm. Also, mean of body mass index of them was 27.23 ± 6.2 kg/m². This result supported by **El Ashmawy, et al., (2019)** who studied "Anthropometric Measurement in Relation to Gait Parameters in Children with Down Syndrome" and revealed that, less than half of the children with down syndrome were overweight. This finding also supported by **Hegazy & Baraka, (2021)** who revealed in the study about "Effectiveness of Promoting Mothers' Caring Practices Regarding their Down Syndrome Children on the Family Coping" and found that, a majority of the children were obese or overweight. The current results contradicted the findings of **Wrzochal, et al., (2019)**, who reported in the study titled "Evaluation of diet in preschool-age children with Down syndrome—preliminary examination" that, the study group's mean BMI was 16.03 ± 2.23 kg/m².

Concerning the total knowledge about down syndrome among the study mothers. The study results stated that, the majority of them had satisfactory knowledge scores about down syndrome post coping strategies intervention. This may be due to the strong desire of the studied mothers to obtain scientific knowledge about the child's disability to care their children without any obstacles. This result was compatible with **Hegazy & Baraka, (2021)**, who discovered that, prior to the educational program, more than three-fourths of the mothers

in the study had low knowledge. Also, this finding contrasted with a study conducted in Saudi Arabia by **Alosaimi, et al., (2020)**, who found in the study about "Knowledge of Down Syndrome among Down Syndrome Children's Mothers in Riyadh Care Centers" that the majority of the mothers were knowledgeable about down syndrome.

As regards coping patterns of the studied mothers the present study results showed that, near to three quarters of the studied mothers had positive coping pattern post intervention. These results confirmed research hypothesis of the study. Also, mothers of children with down syndrome in post intervention became aware of the types of coping strategies to be positively play a more active role with their children and help them to overcome their needs and to provide adequate care without any stress. These results were consistent with **Zaki, et al., (2020)**, who discovered in the study about "Counseling Intervention for Parents of Children with Down Syndrome on their Needs, Stress and Coping Strategies" that more than two-thirds of study participants had negative coping in the pre-counseling intervention improved by reducing their negative coping to nearly one-quarter in the post intervention with a highly statistically significant difference between parent's positive and negative coping in pre - post counseling intervention.

Regarding needs of the studied mother, the current results found that, half of the studied mothers had moderate needs pre coping strategies intervention, and improved to more than half of them never had needs post coping strategies intervention with a highly statistically significant difference. From the researchers' point of view, these results could be due to increase mother's awareness post coping strategies intervention regarding important practical knowledge about their children needs and the rehabilitation centers and support resources for DS children in case of exposed to unexpected problems such as physical and behavior problems. This result agreed with **Zaki, et al., (2020)** who observed in the study that, the majority of parents of children with down syndrome had increased their level of

unsatisfied needs before counseling intervention. Meanwhile, after counseling intervention, the level of unsatisfied needs improved and transferred to upgraded level of satisfied needs with a highly statistically significant difference between pre and post program implementation.

Regarding quality of life of the studied mothers, it was observed that slightly less than two-thirds of the studied mothers had a low quality of life pre coping strategies intervention, while more than two thirds of them had high quality of life post intervention with a highly statistically significant difference pre/post coping strategies intervention. These results confirmed research hypothesis of the study, also, may due to the positive impact of the coping intervention on physical, social, emotional, intellectual, and communication domains of mother's quality of life. This finding was in the same line with **Senses, et al., (2019)**, who observed in study about "Mothers of 0–3-years-old children with down syndrome: Effects on quality of life" that mothers of children with DS have a lower quality of life. This result also was in accordance with **Jafarzadeh, et al., (2018)**, that was carried out in Tehran, the Iran's capital, to determine "The effectiveness of problem-focused coping strategies training on quality of life in pregnant women with genetic risk of fetal abnormality" and reported that, mothers' quality of life improved significantly after the intervention across various dimensions of quality of life. Meanwhile, these findings contradicted with those of **Vadakedom, et al., (2017)**, who discovered in the study about "Quality of life of mothers of children with Down syndrome" that, the most of mothers having down syndrome children had moderate quality of life.

The results of the present study clarified that there was a highly statistically significant difference pre/post coping strategies intervention regarding self-reliance related to daily living activity of the studied children including (feeding, mobilization, dressing, hygienic measures, elimination and communication). These results supposed that, improving knowledge and practices of mothers had positive effect on the daily activity of their

children. This result was in compatible with **Gashmard, et al., (2020)** who studied "Coping strategies adopted by Iranian families of children with Down syndrome; A qualitative study", they discovered that early self-help, sensory-motor, perceptual-motor, and emotional abilities actions adopted by parents to strengthen the self-reliance, achieve the maximum personal independence in everyday activities of children with DS. Additionally, **Al Shatti, et al., (2021)** showed in the study about "Caregivers' perceptions and experience of caring for persons with down syndrome in Kuwait: a qualitative study" that, the participants reported that their DS children avoided contact with other children due to their unusual behaviors or trouble communicating with others, and partially interact with other children due to their violent behaviour and inability to express themselves clearly. Additionally, children with DS had poor levels of physical activity and did not have access to independent oral healthcare.

Also, the current findings were in agreement with **Alghamdi, et al., (2021)** who clarified in the study about "Physical activity among children with down syndrome: maternal perception" that DS children's daily physical exercise is described as unorganized and lasting two to three hours, such as playing football, going on walks outside and dancing. However, the children with DS only engaged in light to moderate amounts and intensities of physical activity, so they don't follow the World Health Organization **WHO, (2020)** recommended guidelines for physical activity, which call for 60 minutes of moderate to vigorous-intensity activity.

The current study revealed that there was high significant statistical positive correlation between mothers' knowledge, quality of life, and coping at pre and post intervention. From the researchers' view, this may be due to that the positive impacts of the coping strategies intervention on increase the reassurance of mothers about how to accomplish their needs which provide a suitable solution for their children problem, enhance their use of coping and quality of life and resulting reduced their

needs. These findings supported by **Gregorius, et al., (2021)** who observed in the study about “Psychological, sociocultural and economic coping strategies of mothers or female caregivers of children with a disability in Belu district, Indonesia” that Mothers' knowledge of childhood disability-related laws, resources availability, services and supporting systems, and school system process/structure have been indicated to help women cope with the situation related to their child's condition, resulting in relieving stress and minimizing their needs. In addition, **Ni'matuzahroh, et al., (2022)** observed in the study about “The Association between Parenting Stress, Positive Reappraisal Coping, and Quality of Life in Parents with Autism Spectrum Disorder (ASD) Children: A Systematic Review” that there was a significant negative correlation between parenting stress, positive reappraisal coping, and QoL in parents with ASD children. Parenting stress was associated with low levels of positive reappraisal coping and a lower level of QoL.

Concerning correlation between self-reliance of the studied children regarding daily living activities and total mothers' needs at pre and post coping strategies intervention, the study findings showed that, there was high significant statistical positive correlation was observed. These results were in agreement with **Gashmard, et al., (2020)** who observed that, self-reliance in children with DS lowered familial care burdens, needs and parental consideration regarding their future life.

Conclusion:

The findings of the present study concluded that, there was a positive effect of coping strategies intervention on improving knowledge, positive coping skills and quality of life in addition decreasing needs for mothers having children with down syndrome. As well as enhancing daily life activities of their children.

Recommendations:

In the light of the current study, the following recommendations are suggested:

1. Providing supportive care to mothers having children with DS for promoting health, minimizing stress, and enhancing positive coping with their children problems.
2. Conducting frequent educational programs and counselling focused on encouraging mothers to cope effectively with their children with DS.
3. Provision a guideline booklet to all newly admitted mothers having children with DS in Genic clinic and rehabilitation center to help them in improving their knowledge and practices.

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