

Effectiveness of Instructional Guidelines on Parenting Stress and Coping Mechanism among Mothers of Children with Down Syndrome

1Mariana Erian Shehata, 2Neama Salah Abd Elaziz Soliman Elgendy, 3Manal Mohamed

Ahmed Ayed, 4Alzahraa Abdel Aziz Omar Abdel Rahman, 5 Huda Shawky Mahamud

1Lecture in Pediatric Nursing Department, Faculty of Nursing, Cairo University

2Pediatric Nursing Fellow, Students Hospital, Mansoura University

3Assistant Professor of Pediatric Nursing, Faculty of Nursing, Sohag University

4Assistant Professor of Psychiatric mental health nursing Faculty of nursing Minia University

5Assistant Professor of Nursing Department, Faculty of Nursing, Helwan University

Abstract

Background: Mothers may experience a period of difficulty adjusting when caring for a child with Down syndrome (DS). Thus, it is thought that using constructive coping mechanisms can reduce stress. Among the many disabilities that negatively affect moms' health and stress levels is Down syndrome. To adopt strategies to regain their equilibrium between resources and disability needs, mothers may need instructional guidelines on how to use available support resources or search for alternative ones. This will help them develop appropriate and effective coping strategies to manage the stresses associated with their children's Down syndrome. **This study** aimed to evaluate the effectiveness of instructional guidelines on parenting stress and coping mechanisms among mothers of children with Down syndrome. **Design:** A quasi-experimental design (one group pre/posttest) was used to apply this study. **Setting:** This study was conducted at the Genes Clinics of Down syndrome affiliated with Sohag University Hospitals. **Subjects:** A purposive sample from the previously mentioned settings consisted of (100) mothers and their children with Down syndrome. **Tools of data collection:** Tool (1) A structured interviewing questionnaire to assess **children and mothers'** personal data and health assessment of children with Down syndrome, Tool (2): **Mothers'** Knowledge about Down syndrome, Tool (3) Parent Stress Index Scale, and Tool (4) Coping patterns scale. **Results:** The study results revealed that there was a highly statistically significant improvement was observed in the studied mothers' knowledge of **instructional guidelines** implementation. Also, there was a highly statistically significant difference between pre and post-**instructional guidelines** implementation regarding total level stress level and coping **mechanism** among mothers having children with Down syndrome, also there was a positive correlation between studied mothers' knowledge, stress, and their coping **mechanism** pre and post **instructional guidelines** implementation. **Conclusion:** It was concluded that **instructional guidelines** implementation had a positive effect on improving knowledge levels, alleviating stress, and promoting coping strategies among mothers of children with Down syndrome. **Recommendations:** Conducting educational programs focused on reducing mothers' stress and training parents on how to cope effectively with their disabled children under stress.

Keywords: Coping mechanism, Mothers of children with Down syndrome - Parenting stress.

Introduction:

Down syndrome (DS) is a chromosomal condition that is highly prevalent worldwide, primarily responsible for mental, developmental, and learning difficulties in children. According to Andrew and Harish (2021), it characterizes the situation of genetic abnormalities that take into account not only the physical but also the mental and psychological aspects of the child, including moderate

retardation, as well as other medical issues. This illness causes DS kids to have more trouble combining and using language, understanding information, and developing emotionally (Nurmalita, 2019). Over the world, the average number of cases with DS per 10,000 live births is 10. Annually, between 1:555 and 1:770 live births in Egypt are affected by Down syndrome (Centers for Disease Control and Prevention, 2021).

To properly care for and raise children with physical and mental problems, the family is essential. A child with Down syndrome is likely to have a wide range of effects on the family structure. Raising a child with Down syndrome is generally linked to higher levels of parental stress, sources of caregiver strain that vary over the child's life, particularly during transitions, more symptoms of anxiety and depression, and a lower quality of life when it comes to health than for family caregivers of typically developing children. In addition, it has been observed that children diagnosed with Down syndrome (DS) tend to experience a higher disease burden, more unfulfilled demands, and a higher likelihood of family consequences such as financial difficulties and job loss (**Kiami, 2019 and Gashmard et al., 2020**).

For parents, having DS children can lead to emotional and social issues. Parents of children with Down syndrome typically experience more physical, psychological, and social challenges in their lives than parents of typical children. The future of both themselves and their child, which will negatively impact their well-being owing to their incapacity to handle this circumstance, is a major source of worry for parents of children with intellectual and developmental impairments, or DS. Despite this, some parents learn to live with the situation and have happy lives where they build their resilience and self-worth (**Parameswari & Eljo, 2016; Cless, 2019**).

The adjustment process for families with an intellectually impaired kid is quite individual, and some may never fully recover (**Ganjwale et al., 2019**). To handle the situation effectively, a cognitive reappraisal is needed. According to **Choi (2019)**, effective coping strategies include obtaining a feeling of coherence, changing one's perspective on life and disabilities, and realizing the beneficial contributions that children make to their families and society at large. According to **Ludlow et al. (2022) and Seymour et al. (2023)**, using useful coping mechanisms is a key component of stress management for parents and a means of fostering wellbeing.

Mothers of children with Down syndrome face numerous obstacles in their lives, encompassing physical, psychological, and social domains. Additionally, they must cope with an array of adverse emotions such as tension, fear, and melancholy. Their inability to handle the circumstance will have a detrimental effect on their wellness because they are also more concerned about the future—both their own and their children's. Consequently, coping refers to the method of addressing demands, either internal or external, that are thought to exceed a mother's capacity to raise her affected child and lead a fulfilling life. For women, on the other hand, coping serves a variety of purposes, such as boosting their drive to manage their children under stress, strengthening a positive self-image, maintaining mental stability, and enabling mothers to thrive and develop strong relationships with those around them (**Gashmard, et al., 2020**).

Mothers are the major caregivers for their children who have Down syndrome (DS); they take on the role of providing care, support, and help for their children's everyday needs as well as facilitating their permanent integration into society with the goal of enhancing their health. Children with Down syndrome require family-centered care, and pediatric nurses are essential in fostering growth and development, preventing difficulties and issues, and assisting mothers in effectively tending to their children's needs as well as those of other family members. Additionally, pediatric nurses can help moms identify stressors, community resources, coping mechanisms, regular follow-up and treatment compliance, and efficient family communication channels in addition to offering a safe space for moms to express their frustrations or conflicting emotions (**Zaki, et al., 2020**).

A vital part of assisting parents in adapting is played by nurses. When parents can effectively manage the requirements of their family, their Down syndrome child, and other family members, they are exhibiting successful adaptation. By giving parents a secure space to express their frustrations or conflicting feelings, nurses can help parents achieve this balance. Parents won't be condemned for their emotions

if they can express them in a safe environment. Identifying stresses, community resources, coping mechanisms, and efficient family communication techniques are all things that nurses may assist parents with (Coren et al., 2018).

Significance of the study:

Mothers of children with Down syndrome encounter many challenges, such as navigating the health care system, dealing with money problems stemming from out-of-pocket costs for the child's care, losing income because of the child's condition, finding it difficult to access medical and nonmedical services, experiencing high levels of stress, and having their daily activities restricted. Unmet demands can affect coping for mothers whose children have Down syndrome. On the other hand, mothers of children with Down syndrome may find it extremely taxing and challenging to raise their children, necessitating societal adjustments. To properly manage a problem, coping requires a cognitive assessment of the conditions, which is a uniquely personal approach (Thomas et al., 2022).

Approximately 25% of children with intellectual disabilities have Down syndrome. It impacts multiple body systems, including as the neurological, cardiovascular, and musculoskeletal systems. Children with Down syndrome often have short stature, hypotonia in the muscles, atlantoaxial instability, hypoplasia in the cerebellum, low neuronal density, intellectual impairment, and congenital heart problems. Additionally, autoimmune diseases, obstructive sleep apnea, epilepsy, hypothyroidism, hematological abnormalities, recurring infections, mental disorders, and issues with hearing and vision. According to Stylianos et al. (2020) and Marilyn and Bull (2020), around 75% of children with Down syndrome present with hearing loss, which is frequently associated with anatomical ear disorders.

Any family might have a great deal of social and internal issues as well as increased stress for the parents when there are DS children around. Since delayed development makes it difficult for children with DS to

maintain their activities, such as walking, brushing their teeth, dressing themselves, and talking, these children need additional care. The experts believe that encouraging moms in particular to learn healthy coping mechanisms is essential.

Mothers of children with Down syndrome face a greater demand because of the child's developmental delay, limitations in self-care activities like dressing, grooming, walking, and talking, and issues with health, education, psychology, leisure, and coping mechanisms. All of these factors combine to make motherhood of children with DS extremely difficult. The purpose of this study was to determine whether or not mothers of children with Down syndrome could effectively manage stress through parenting by using the instructional guidelines.

Aim of the study:

The current study aimed to evaluate the effectiveness of instructional guidelines on parenting stress and coping mechanisms among mothers of children with Down syndrome through:

1. Assessing mothers' knowledge level regarding down syndrome.
2. Assessing mothers' stress level regarding down syndrome.
3. Assessing mothers' coping mechanism toward their children with Down syndrome.
4. Designing and implementing coping mechanisms for mothers having children with Down syndrome.
5. Determining the effectiveness of instructional guidelines on parenting stress and coping mechanisms among mothers of children with Down syndrome.

Research hypothesis:

- Mothers who receive the instructional guidelines will have a higher level

of knowledge post-coping mechanism implementation than pre-implementation.

- Instructional guidelines may have a positive effect on alleviating stress among mothers of children with Down syndrome post-coping mechanism implementation than pre-implementation.

- Instructional guidelines may have a positive effect on promoting coping mechanisms among mothers of children with down syndrome post-coping mechanism implementation than pre-implementation.

Subjects & Method:

Research Design

Using a single group pre-and post-test, a quasi-experimental approach was employed for this study.

Research Setting:

This study was conducted at the Genes Clinics of Down syndrome affiliated with Sohag University Hospital.

Subjects:

Sample size:

Out of the 250 moms that attended the previously described setting, a sample of 100 mothers and their Down syndrome-affected infants was recruited, with a 90% confidence level. Based on the power analysis, the sample size was determined (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:

The following conditions were met to create a purposive sample that included mothers of Down syndrome children who were available and whose children were attending the previously indicated setting:

Inclusion criteria for children with Down syndrome:

Available confirmed diagnosed with

Down syndrome from both sexes and also, from 6- to 12 years.

Inclusion criteria for mothers:

Mothers who are free of mental illnesses and provide their DS children with direct care. Interviews with the research subjects took place in groups or one-on-one.

Tools of data collection:

Tool (1) A structured interviewing questionnaire to assess **children and mothers'** personal data and health assessment of children with Down syndrome; By the literature study, the researchers created an instrument to evaluate mothers' personal information as well as the health of their DS kid.

Mothers' data: It includes data such as; age, sex, residence, level of education, occupation, and consanguinity.

a. **Personal data and health assessment of DS child:** It includes data related to personal data of DS child such as; age, sex, education, order of birth, and data related to the child's category of mental retardation, physical complaints, disabilities, and previous hospitalization.

Tool (2): Mothers' Knowledge about Down syndrome: Knowledge of the studied mothers about Down syndrome that includes: meaning, causes, types, signs and symptoms, complications, treatment, and follow-up (Hegazy & Baraka, N. (2021); Jafarzadeh et al., 2018)

- Knowledge of the studied mothers about the care of their children with Down syndrome, includes; movement (7 items), level of independence (6 items), and language difficulty (5 items).

Scoring system:

Two grades are awarded for a complete and accurate response; an incomplete response receives one grade, and an erroneous or unknown response receives zero. Once the total scores were converted to a percentage, they were categorized as follows: a score of 60% or higher was deemed to represent a satisfactory

level of knowledge, while less than 60% was deemed unsatisfactory.

Tool (3) Parent Stress Index Scale to measure mothers' stress of children with Down syndrome: It was produced in 1990 by Abidin. The PSI is a 36-item self-reported survey that was created to gauge the amount of stress parents of 6- to 12-year-old Down syndrome children experience. Parental distress, dysfunctional parent-child contact, and challenging children comprise the three subscales of the scale. The parental distress subscale, which consists of three 12-item subscales, examines parents' judgments of their behavior, including perceived competence, marital conflict, attitudes toward social support, and life limits due to the demands of parenting.

Parent-child dysfunctional relationship sub-scale gauges how parents perceive their interactions and expectations for their children. The parents' opinions on their child's compliance, demandingness, and temperament are measured by the difficult child sub-scale. Strongly disagree (1 on the scale) to strongly agree (5 on the scale) are the range of items.

Scoring System

If the total parental stress scale score is less than 90, it suggests that the degree of stress is minimal. However, a value above 90 denotes a noticeably elevated stress level. In the meantime, a high level of stress is indicated only by a total score of above 27 on the parent-child dysfunctional interaction subscale, which also indicates a high level of stress, along with a score of above 33 on the difficult kid subscale.

Tool (4) Coping patterns scale to assess the mothers' coping mechanism toward their DS children: To evaluate the mothers' coping mechanisms for their children with Down syndrome, Flaherty and Glidden (2000) developed this scale. To fit the purpose of the study, the researchers changed it and translated it into plain Arabic. Before being used, a qualified consultant evaluated and verified the content's correctness. There were forty statements on the scale. Coping mechanisms encompassed social, emotional, psychological, educational, and religious aspects.

Scoring system:

Mother's Coping Scale had an overall ideal score of 80. Points were awarded on a 3-point rating system, with "usually" receiving one score, "sometimes" receiving two, and "never" receiving three. Higher scores consistently indicated difficulties in coping, as the questionnaire's elements are assessed in reverse order. The 40 statements that make up the rating scale are broken down into six subscales: (8) physical, (7) psychological, (7) social, (4) emotional, (9) educational, and (5) elements related to religious coping. The overall coping score, which falls between 40 and 120, is computed. A total score of 40 is the lowest possible and 120 is the highest. A negative coping pattern was scored less than 60%, and a positive coping pattern was scored equal to or higher than 60%.

Preparatory phase

It included reviewing current, past, local, and international related literature and theoretical knowledge of various aspects of the study using books, articles, the internet, periodicals, and magazines to develop tools for data collection.

Validity and Reliability:

Five experts—three pediatric nursing professors and two psychiatry health nursing professors—achieved face and content validity by reviewing the instruments for content accuracy. The questionnaire contained the topics on which the majority of experts concurred. To ensure clarity and relevancy, some statements were added and the sentence was used. There were no changes made.

Using Cronbach's alpha to evaluate for reliability, the produced tools showed high internal consistency with a score of 0.792. The reliability was ranked from <0 to 0.25 for weak reliability, 0.25-0.75 for moderate reliability, 0.75 to <1 for high reliability, and 1 for optimal reliability.

Pilot study:

To estimate the time needed to complete the tools and assess the relevance, clarity, and applicability of the examination questions, a

pilot research was conducted on 10% of mothers and their DS children at random from the previously indicated setting before the commencement of data collection. Requirements were adjusted accordingly. The mothers and Their children were part of the primary study sample.

Administrative design:

Through an official letter from the dean of the faculty of nursing, the administrators of the Genes Clinics of DS in the hospital linked with Sohag University granted the necessary clearance to collect the data required for the current study. In the specialist clinics, the researchers met with the directors, briefed them on the purpose of the study and its methods, and requested their involvement.

Ethical Considerations:

The Scientific and Ethical Committee of Nursing, a Sohag University affiliate, granted ethical approval. After describing the purpose of the study and obtaining their informed verbal agreement, the subjects were allowed to participate in it. Achieve total anonymity and privacy while ensuring that the data is only used for study. Participants in the study were advised that they might leave at any moment.

Fieldwork:

The fieldwork was conducted from May 1st, 2023, to September 30th, 2023. The scientists were accessible three days a week from nine in the morning until noon. Interviews about knowledge, stress, and coping mechanisms were conducted one-on-one with each mother by the researchers (pretest). Every mother took an average of 25 to 35 minutes to finish the questionnaire.

Phase of implementing instructional guidance sessions: After having given the mothers of children with DS an explanation of the purpose and goals of the educational sessions, the researchers conducted interviews with the mothers.

Mothers were given coping mechanisms by the researchers based on an actual needs assessment. The mothers of children with Down syndrome were divided into five groups, each with twenty moms, to apply the instructional guidelines. Due to the small size of the clinics, which makes it difficult to collect all studied mothers at once, the instructional guidelines were introduced individually for each group.

Depending on how many subjects were present during the session, the researchers applied the coping method. The nine sessions, each lasting 45 to 60 minutes, focused on improving mothers' knowledge, reducing stress, and enhancing their capacity to positively cope with their children's condition. They also strengthened parents' self-reliance regarding their children, emphasized social skills, and provided the necessary support to improve mothers' quality of life. The period of implementation of the coping mechanism was completed in four to five weeks and consisted of six sessions for the theoretical part and three sessions for the practical part.

Contents of coping program:

The researchers conclude the conclusion of each session and solicit participant comments. Additionally, the researchers evaluate and talk about what they learned from the previous session at the start of each subsequent one. The following sections are covered in the booklet's content:

The first was the theoretical section, which dealt with educating mothers of children with Down syndrome about the condition's definition, problems, specific criteria, critical needs, available services, and how to deal with a child who has the disorder.

The second section focused on practical strategies to help mothers of children with down syndrome enhance their coping mechanisms. It included topics such as what constitutes a coping strategy, its various forms, the distinction between problem- and emotion-focused strategies, and instances of both types of strategies. It covered coping strategies on the physical, psychological, social, emotional, educational, and religious levels as well as time

management, emotional expression, positive thinking, and various relaxation techniques.

Evaluation phase:

The pre-assessment tools were used again at the end of educational sessions (post-test) to evaluate the effectiveness of instructional guidelines on parenting stress and coping mechanisms among mothers of children with Down syndrome

Statistical design:

After revision and coding, the topic data was input into a computer. For computerized data entry and statistical analysis, the SPSS software, version 24, was utilized. Using descriptive statistics, the gathered data was displayed as frequencies and percentages. The groups were compared using the *t* test (pre\post).

Results:

It's evident from **table (1)** that, more than two-thirds of mothers (68%) ranged from 30 to less than 45 years old and more than half of them (58%) have a secondary level of education. Concerning mothers' occupations, it was found that (70 %) of them are not working. About their residence, there were (80%) of them lived in urban areas. Meanwhile (65 %) of them had no consanguinity.

Table (2) shows that (70%) of the children understudy are from 6-< 9 years old and more than three-fifths (65%) of them are boys. About their birth order; it was found that more than half (54%) of them are the first child and the majority (88%) of them are illiterate.

Table (3) shows that GIT disorders, heart disease, and urinary incontinence are the most common physical complaints among children understudy which constitute

(35%), (32%) and (15%) respectively in addition to (80%) of them are previously hospitalized. There was a highly statistically significant differences post-instructional guidelines implementation. Also, these differences indicated improvement in mothers' knowledge regarding Down syndrome pre- and instructional guidelines implementation which reflected the positive effect of the instructional guidelines implementation.

It was clarified from **Figure (1)** that, (95%) of the studied mothers had an unsatisfactory level of total reported **Knowledge** of instructional guidelines implementation about Down syndrome, but post-implementation of the instructional guidelines, there was an improvement in their **Knowledge**, (88%) of them had a satisfactory level of total reported practice.

Table (5) illustrates the comparison of parental stress scale scores pre - post-**instructional guidelines**, it indicates that more than three-fifths (62%) of mothers, experienced a high level of stress before **instructional guidelines**, meanwhile in post-**instructional guidelines** there were the majority (85%) of them experienced a low level of stress. There was a highly statistically significant difference between mothers' stress scores pre - post-**instructional guidelines**, implementation with ($X^2=53.22$ at $P< 0.01$).

Table (6): It is clear from this table that, there were highly statistically significant differences between all coping **mechanisms** among the studied mother's pre and post-instructional guidelines.

Table (7) indicated that there is a positive correlation between studied mothers' **knowledge**, stress, and their coping **mechanism for** pre and post-**instructional guidelines** at ($p = < 0.001$).

Table (1): Mothers of children with Down syndrome distribution regarding their data (n=100)

Items	No. (50)	%
Age of accompanying parent		
20 -< 30 y	12	12
30 -< 45 y	66	66
45 and more	22	22
Mean \pm S D	31.78 \pm 5.22	
Educational level		
Illiterate	16	16
Read and write	14	14
Secondary education	58	58
High education	12	12
Mothers' occupation		
Working	30	30
Not working	70	70
Residence		
Urban	80	80
Rural	20	20
Presence of consanguinity		
Yes	35	35
No	65	65

Table (2): Personal data of children with Down syndrome distribution (n=100).

Items	No	%
Child's age (years)		
6 - < 9	70	70
9 - < 12	30	30
Mean \pm SD	8.5 \pm 0.87	
Sex		
Males	65	65
Females	35	35
Birth order		
First	54	54
Second	14	14
Third	14	14
Fourth and more	18	18
Level of education		
Illiterate	88	88
Normal school	12	12

Table (3): Health assessment distribution of children with Down syndrome (n=100)

Physical complaints and Disabilities associated with DS		
Heart Disease	32	32
Gastro-Intestinal Tract Disorders (GIT)	35	35
Other Chronic Diseases are “renal or hepatic or bone diseases”	6	6
Urinary Incontinence	15	15
Inability to Control Defecation	2	4
Visual Disability	0	0
Motor Disability	0	0
Hearing Disability	8	8
History of Previous Hospitalization for the Child		
Yes	80	80
No	20	20

Table (4): Mothers' knowledge about Down syndrome pre and post-instructional guidelines implementation (n=200).

Variable	Pre-structured educational package	post-structured educational package	X ²	P-value
Meaning of Down syndrome	34%	100%	68.33	<0.001**
Signs and symptoms of Down syndrome	33%	97%	82.23	<0.001**
Complications of Down syndrome	23%	92%	64.22	<0.001**
Treatment of Down syndrome	22%	95%	91.44	<0.001**
Follows up on Down syndrome	45%	98%	46.17	<0.001**
Care of their children with Down syndrome	40%	90%	74.15	<0.001**

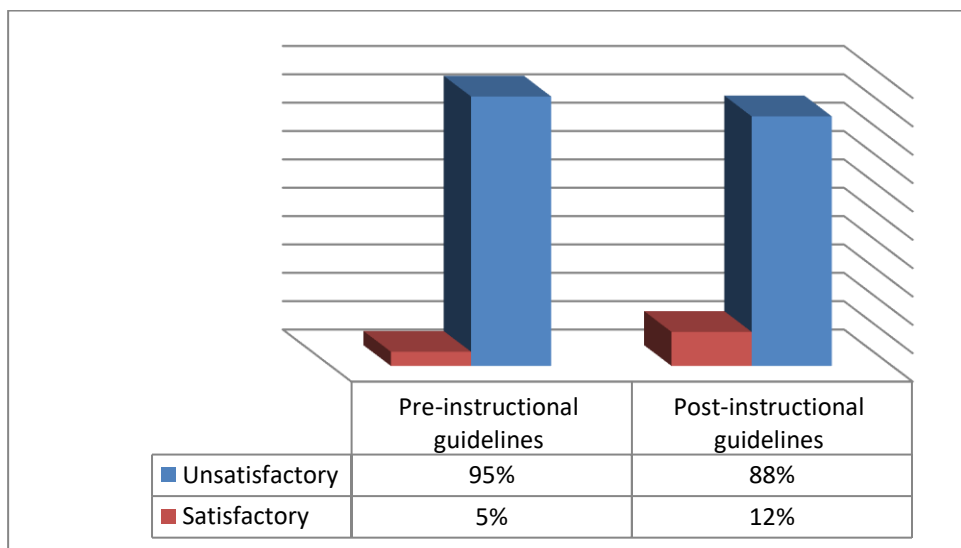
**Figure (1): Total Mothers' Knowledge Level about Down Syndrome Pre and post-instructional Guidelines**

Table (5): Comparison between the level of parental stress index pre and post-instructional guidelines

Items	Pre-intervention		Post-intervention		T-test	P-value
	No.	%	No.	%		
▪ low	38	38	85	85	53.22	<0.001
▪ High	62	62	15	15		

Table (6): Comparison between coping mechanisms of the studied mother's pre and post-instructional guidelines (n=100)

Positive Coping	Pre-intervention				Post-intervention				X ²	p-value
	Negative Coping		Positive Coping		Negative Coping		Positive Coping			
	No.	%	No.	%	No.	%	No.	%		
Physical coping	23	23	77	77	73	73	27	27	22.6	p<0.001
Psychological coping	20	20	80	80	80	80	20	20	19.3	p<0.001
Social coping	30	30	70	70	85	85	15	15	20.7	p<0.001
Emotional coping	34	34	66	66	90	90	10	10	33.5	p<0.001
Educational coping	15	15	85	85	82	82	18	18	24.4	p<0.001
Religious coping	44	44	56	56	96	96	4	4	17.8	p<0.001
Total coping	37	37	63	63	75	75	25	25	18.4	p<0.001

Table (7) Correlations between total mothers' knowledge, stress, and their coping mechanism for pre and post-instructional guidelines

Items	Total mothers' coping			
	Pre-intervention		Post-intervention	
	r	P-value	r	P-value
▪ Total mothers' knowledge	0.224	<0.001	0.352	<0.001
▪ Total mothers' stress	0.206	<0.001	0.333	<0.001

Discussion:

Mothers of disabled children are severely impacted by this issue because they have to deal with stressful situations in their lives. The burden of caring for a child with Down syndrome is particularly great because the family has to actively participate in the child's care because of the child's developmental delays, limitations in self-care activities like dressing, grooming, walking, and talking, as well as issues with health, education, and leisure (Parameswari & Eljo, 2019).

When it comes to medical, psychological, and social issues, parents of children with Down syndrome typically face more challenges in life than parents of typical children. Moms of children with intellectual and developmental disabilities, such as Down syndrome, experience a range of negative

emotions, including stress, anxiety, and depression. They also worry about the future, both for themselves and their child and how this will negatively impact their wellbeing because they are ill-equipped to handle the situation. Despite this, some parents learn to live with reality and have happy lives, growing in self-worth and coping mechanisms (Nurmalita, 2019). As a result, it's thought that parents who employ coping mechanisms and good attitudes might enhance the wellness of their children as well as their mother's well-being (Darlaa and Bhatb, 2021). Hence, this study aimed to evaluate the effectiveness of instructional guidelines on parenting stress and coping mechanisms among mothers of children with Down syndrome.

The current study's findings regarding the demographics of mothers of children with Down syndrome revealed that less than three-quarters of them are housewives, more than half of them live in urban areas, and their ages range from 30 to less than 45. These findings could be attributed to the fact that mothers historically shoulder more caregiving responsibilities, spend more time with their kids, and have strong emotional bonds with them. Mothers also frequently give up their jobs or careers to raise their children at home, and they are required to care for children with disabilities or chronic illnesses that require special needs.

That's why they tend to give their kids lots of love and support. These outcomes are consistent with **Said's (2018)** research, which examined the association between coping mechanisms and psychological well-being among family caregivers of children with Down syndrome and discovered that mothers make up the largest group of family caregivers without jobs.

Regarding mean age, these findings are in line with those of **Cless et al. (2018)** and **Mahmoud et al. (2022)**. Furthermore, **Laufer's (2019)** findings—which showed that over three quarters of the mothers in the study were unemployed—and the present results concurred. This might be the result of moms raising children with long-term disabilities, who need constant medical attention, follow-up, and hospital stays. Thus, a mother's capacity to work is hampered and the family's income is significantly impacted as a result of the mother having to spend more time caring for and supporting their child.

The current study's demographic data on children with Down syndrome indicates that almost three-quarters of them are male. **Choi (2022)**, who discovered the same results, supports these findings. The mean age and ranking of DS children in their families, as well as the features of the children under study, align with the findings of studies conducted by **Shoeib et al. (2021)**, **Richter (2019)**, and **Zaki et al. (2020)**.

This study's findings indicated that roughly one-third of people have heart disease. The study "Long-term trends in the prevalence

of congenital heart defects in patients with Down syndrome in southern Poland" by **Dobosz & Bik-Multanowski (2019)** revealed that almost 50% of the children under investigation had congenital heart defects. The results of the **Senses, et al., (2019)** study, which discovered congenital cardiac disease in almost half of the people with Down syndrome, conflict with this.

The current study's findings demonstrate that mothers' knowledge of down syndrome had improved both before and after the implementation of instructional guidelines, a finding that is highly statistically significant and reflects the beneficial effects of such implementation. The reason behind these results might be the parents' strong desire to get over their feelings of confusion and guilt about raising their children with Down syndrome. They may also be motivated by a desire to be good caregivers who provide positive reinforcement and feedback based on scientific evidence, enabling them to care for their children without any obstacles.

According to the study's findings, the majority of the mothers under investigation had unsatisfactory levels of total reported knowledge about Down syndrome before the implementation of instructional guidelines. However, after the guidelines were put into place, there was an improvement in their knowledge, and most of them reported satisfactory levels of total reported practice. These findings may be the result of behavior issues and a lack of understanding about child care among moms of children with Down syndrome before the establishment of instructional guidelines. Unlike in the post-intervention period, when they attended the sessions and workshops of the instructional guidelines implementation, they gained the knowledge they needed to care for their children and deal with it, making them more conscious of their situation that may help their children with Down syndrome.

The current study's findings showed that in the period before instructional guidelines, over three-fifths of mothers reported high levels of stress, while the majority reported low levels of stress following the instructions. Mothers' stress scores before and after the introduction of the instructional guidelines differed in a way

that was highly statistically significant. This might be the result of parents who are close to their children who have Down syndrome, which raises stress levels. While this was going on, more than three-quarters of them reported feeling less stressed after the intervention. This outcome demonstrated the beneficial impacts of the instructional guidelines' application on mothers that alleviate levels of stress by using the positive coping strategy.

Improvements to the instructional guidelines' implementation can be attributed to their content, which was created with the needs of the mothers in mind, as well as to their clarity, simplicity, and picture-based illustrations. **Zaki's (2021)** study provides support for this finding. It examined the impact of a psycho-educational training program on the practice, stress, and coping strategies of parents of children with ADHD. The results showed a statistically significant improvement in all stress scale items following the implementation of instructional guidelines, as compared to the pre-implementation phase.

This could be because the mothers who were researched had a strong desire to learn scientifically about the disability of their child so they could care for them without any difficulties. The findings aligned with those of **Hegazy & Baraka (2021)**, who found that almost three-fourths of the moms in the research had inadequate knowledge before the training program. This result was also in contrast to a study by **Alosaimi et al. (2020)** that was carried out in Saudi Arabia and found that most of the moms knew about Down syndrome in the study.

The present study's results regarding coping mechanisms among moms of children with Down syndrome demonstrated that there were highly statistically significant disparities between all of the mothers' coping mechanisms before and after receiving instructional guidelines. This finding may be explained by the fact that, following the intervention, mothers of children with Down syndrome learned about the various coping mechanisms, their examples, application techniques, benefits, and drawbacks of each coping mechanism. This knowledge enabled the mothers to use coping mechanisms to help their children deal with life's stresses

and their tendency to positively engage with their imperfect children.

The findings align with the research conducted by **Choi and Van Riper (2020)** on the topic of "Health family adaptation intervention for families of young children with Down syndrome." The study found that there were improvements in active coping between the pre-and post-test scores, and it was explained that these improvements could be attributed to parents becoming more aware of effective coping strategies after participating in a program that discussed coping strategies for parents of disabled children. Moreover, **Burton et al. (2018)** discovered in their research "The Nurturing Program: An Intervention for Parents of Children with Special Needs" that providing parents with coping skills training enabled them to use a range of coping strategies that improved family dynamics and lessened the challenges associated with raising children with illnesses, developmental disabilities, or impairments.

The current study's findings showed a positive association between the mothers' knowledge, stress levels, and coping strategies for both the pre-and post-instructional recommendations. This might be because of the beneficial effects of the teaching guidelines on mothers' sense of security regarding how to get demands that address their children's issues and improve their coping mechanisms and methods for reducing the stress brought on by their children's illnesses.

This may be the result of the moms of children with Down syndrome also likely to benefit from educational guidelines and adjust their roles and responsibilities to alleviate the additional burden on the primary caregiver. This outcome aligns with the research conducted by **Susanty et al. (2020)** titled "Benefits and Cultural Adaptations of Psychosocial Interventions for Parents and Their Children with Intellectual Disabilities in Low- and Middle-Income Countries: A Systematic Review." The authors presented their findings, which indicated that the interventions decreased the likelihood of depression and stress, encouraged the parents to employ coping mechanisms, and improved the parents' perceptions of how their families functioned.

Hsiao (2018) corroborated this conclusion by stating the same results.

These results are corroborated by **Gregorius et al.'s (2021)** study, "Psychological, Sociocultural and Economic Coping Strategies of Mothers or Female Caregivers of Children with a Disability in Belu district, Indonesia," which found that mothers' awareness of laws about childhood disabilities, the availability of resources, services and support networks, and the school system's procedures and framework helped them minimize their child's needs and reduce stress. Additionally, a significant negative correlation was found between parenting stress, positive reappraisal coping in parents of children with autism spectrum disorder (ASD) by **Ni'matuzahroh et al. (2022)** found A significant negative correlation was found between parenting stress and positive reappraisal coping in parents of children with autism spectrum disorder (ASD) in the study "The Association between Parenting Stress and Positive Reappraisal Coping, in Parents with Autism Spectrum Disorder (ASD) Children: A Systematic Review." Low levels of good coping were linked to parenting stress.

Conclusion

Based on the findings of this study, it was concluded that the implementation of **instructional guidelines** had a positive effect on improving knowledge levels, alleviating stress, and encouraging mothers of Down syndrome children to use coping mechanisms.

Recommendations

In light of the current study's findings, the following suggestions are made:

- Holding educational workshops aimed at lowering mothers' stress levels and teaching parents how to manage their impaired children under pressure.
- Providing psycho-educational training meant to lessen mothers' stress and equip them with the skills necessary to handle their impaired children under pressure.

- Increasing societal consciousness regarding the difficulties faced by DS kids and their families to foster social support.

- Offering mothers of children with Down syndrome supportive care to improve their well-being, reduce stress, and foster constructive coping mechanisms for their children's issues.

- Give all recently admitted moms at the Genic Clinic and Rehabilitation Center who are raising children with Down syndrome a guidebook to help them strengthen their practices and understanding.

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