



COPING PATTERN AND NEEDS OF MOTHERS OF CHILDREN SUFFERING FROM DOWN SYNDROME

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Abstract

Background: Down syndrome is a genetic disorder caused by the presence of all or part of a third copy of chromosome 21. When mothers of down syndrome children experience stress, they use certain strategies to cope with this stress to regulate their emotions. **Aim of the study:** To assess coping pattern and needs of mothers of children suffering from down syndrome. **Design:** A descriptive research design was used. **Setting:** The study was conducted at AL-Tarbiyah EL-Fikria school for special need children in Fayoum Governorate. **Sample.** A Convenience sample compromise 100 of Down syndrome children & their mothers. **Tools:** First tool: Structured interviewing questionnaire include 3 parts : Socio-demographic characteristics for children &their mothers, family and medical history for mother and their children, and mothers' knowledge regarding down syndrome. Second tool: Mothers' needs for caring of their children suffering from down syndrome. Third tool: Mother coping patterns with their children suffering from down syndrome. **Results:** Illustrated that, 62% of mothers had unsatisfactory total knowledge regarding down syndrome, 65% of mothers were had very much levels of needs , 36 % of mothers positively coping with their down syndrome children **Conclusion:** There was highly statistically significant positive correlation between total knowledge score and total coping pattern. **Recommendation:** Provide educational program to parents of children with down syndrome regarding their needs and coping pattern.

Keywords: *Coping Pattern, Mothers' Needs, and Down Syndrome .*

Introduction

Down Syndrome (DS) is the most common chromosomal malformation due to an extra chromosome number 21 (trisomy21). Each child with DS is a unique regarding their condition and care needs .it is usually associated with physical growth delays, mild to moderate intellectual disability, and characteristic facial features. Annually, 3000 - 5000 children across the world are born with DS (**Gashmard et al., 2020**).

Down syndrome can cause a number of medical complications. Some of these are more serious than others .It affects a variety of body systems, including the musculoskeletal, neurological, and cardiovascular systems. The most serious complications of DS include heart defects, blood disorders that can include leukemia (cancer of the blood), hormonal disorders, immune system problems and skeletal problems (**Stylianios et al., 2020**).

Alongside deficits in cognitive and social part, DS children often have other comorbid chronic health conditions, such as gastrointestinal disease, congenital heart defects, respiratory disorders, hypothyroidism, ophthalmologic problems, and hearing problems, which make extra-care and extra-attention more necessary and may be an additional source for parents' worries and fears. As a result, families of these children should spend much energy and patience in managing the child's behavioral, emotional and health problems (**Ostermaier, 2019**).

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. (**Zaki, et al., 2020**).

Coping has various functions for mothers, including: increasing the motivation of mothers to recover from stress, preparing mothers to face problem every possibility and adapting to bad situations, maintaining emotional stability, maintaining a positive self-image, and making mothers able to survive and build good relationships with the people around them (**Sood, 2020**).

Mother is the primary care giver for their DS children. They are in a deepest need to be aware of the expected health status that might be experienced by their DS children. Prompt awareness is expected to reinforce positive accommodation on parental and familial level with the child's unique condition.,Needs express by mothers of children with DS vary from mother to mother. Some of them need Informational,,economic, psychological, Social need and physical need, ,Genetic Counselling,.etc (**Alsharaydeh et al., 2019**).

The community health nurse should give the caregivers of DS children complete necessary correct information regarding DS, coordinate to meet their needs and give them a chance to exchange their information & experiences. The community health nurse must teach the family caregivers of DS children how to provide care for their children with or without little strain, in addition to provide them with psychological support and helping them identify the factors that mediate a positive coping pattern (**Choi, 2020**).

Significance of the study

Down syndrome affects not only the child with down syndrome but also family members and the family is affected as a unit. The incidence of down syndrome is 1 / 1000 - 1100 births worldwide. The incidence of down syndrome in Egypt is 1/700. It considers overwhelming problem for the parents especially his \her mothers that feeling with negative emotion like anxiety, depression , also have guilt and shame and more fear about their children future(*Alwakeel et al., 2020*).

The birth of a child with DS can be a traumatic event for mothers and can have profound effects on entire family. Mothers of children with DS face a set of physical, emotional, financial and social problem, which directly affect the management of children and the psychology well-being of mothers. When mothers experience stress, they use certain pattern to cope with stress to regulate their emotions (*Munny, 2019*). Therefore, this study will be conducted to assess coping pattern for mothers with their children suffering from down syndrome .

Aim of the Study

This study aims to assess coping pattern and needs of mothers of children suffering from down syndrome, through the following objectives: -.

1. Assessing mothers' knowledge about down syndrome.
2. Determining of coping pattern for mothers with their children suffering from down syndrome
3. Appraising mothers' needs for caring of their down syndrome children.

Research Questions:

1. What are mothers' knowledge about down

syndrome ?

2. What are coping pattern for mothers with their children suffering from down syndrome ?
3. What are mothers' needs for caring of their children suffering from down syndrome ?
4. Is there relationship between mothers knowledge and coping pattern regarding their children suffering from down syndrome ?

Subject and methods

The subject and methods for this study were portrayed under the four main Items as follows:

- | | |
|----------------------------|-----------------------|
| I- Technical Items. | II-Operational Items. |
| III- Administrative Items. | IV-Statistical Items. |

I-Technical Items

The technical Item include: research design, setting, subject and tools of data collection.

Research design:

A descriptive research design was utilized in this study

Setting:

The study was conducted at AL-Tarbiyah EL-Fikria governmental school for special needs at Fayoum Governorate.

Sampling:

A Convenience sample of all down syndrome children include 100 child & their mothers.

Tools for data collection:

1st Tool: A structured interviewing questionnaire: It developed by the investigator after reviewing the relevant literature to collect the data required and it was written in Arabic language and filled in by the investigator, it consisted of three parts:

Part 1: Socio- demographic characteristics for

children & their mothers

A) Children characteristics : It included 3 questions as: Age, gender, child birth order.

B) Mothers characteristics : It included 8 questions as: Age, educational level ,occupation ,place of residence, family monthly income, number of family member, number of rooms and crowding index.

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

A) **Child family history :** It included 5 questions as as if there is consanguinity between the parents, degree of this consanguinity, is there others siblings with down syndrome, is there family history of down syndrome, if the answer is yes who is.

B) **Mothers medical history :** It was designed to assess medical history. It included 11 questions as, the age of the mother during pregnancy, is there medical follow up for mother during pregnancy, is the mother suffered from any health problems during pregnancy, if yes what are these health problems, did the mother take any medications during pregnancy, if yes what are these medications , did the mother exposed to radiation during pregnancy, baby's weight during childbirth, place of birth, type of delivery, and presence of injuries during childbirth.

C) **Child medical history :** It included 6 questions as, is the child entered the incubator, presence of abnormalities in the external shape of the child, presence of delay in growth and development, if yes what are the type of these delay, presence of child movement difficulties ,and if yes what are the type of these movement difficulties.

Part 3: Mothers' knowledge regarding down syndrome : It included 11 MCQ questions as meaning, causes, types, signs & symptoms, diagnosis, complications, who is the team of treatment of down syndrome, type of treatment for down syndrome,

occupational follow-up importance for DS child, physiotherapy importance for DS child, and speech therapy importance for DS child.This adapted from **Jan et al., (2017)**, and modified by the investigator.

Scoring systems for mothers knowledge:

It was composed of 11 questions = 22grades

- Complete correct =2
- Incomplete correct =1
- Incorrect or don't know= 0 .

Total mother's knowledge was classified into the following ;

- Satisfactory knowledge $\geq 50\%$ (≥ 11 grades)
- Unsatisfactory knowledge $< 50\%$. (< 11 grades)

2nd Tool: Mothers' needs for caring of their children suffering from down syndrome adopted from Leyser & Dekel, (1991).

Cognitive needs: Includes 10 items as: Need more information about future opportunities to educate my son with down syndrome, to know the appropriate professions that my son with down syndrome can train and work in the future,etc

Economical needs: Included 9 items as: Need to provide suitable work for the disabled son after his training, transportation to take my son to school or institute,etc

Psychological and social needs: Included 9 items as: Need the school or institute to encourage my son to participate in educational, sports and recreational activities, help to do recreational activities,etc

Physical needs: Included 4 items as : Need to have a balanced and healthy diet, external food supplements, to sleep and take a lot of rest and relaxation and need to exercise properly to help me get rid of stress.

Scoring systems for mothers' needs:

Mother's needs scale consisted of 4 components (32

items): Mother's needs scale has been scored as, I never need it =1,

I need it moderately=2, I need it very much =3.

- The total optimal score of mother's needs scale were 96 grades categorized as follows.

- Low if the score < 50% (< 48grades)

- Moderate if the score between 50-<75% (48<72grades)

- High if the score $\geq 75\%$ (≥ 72 grades)

3rd Tool : Mother coping patterns with their children suffering from down syndrome adopted from Glidden et al., (2009), it include:

Physical coping: Included 8 items as: Get rid of stress by physical activity or exercise, drink alcoholic beverage, take a coffee-tea , etc

Psychological coping: Included 7 items as: Try to get the problem out of my mind and think about something else, get rid of the tension by laughing because I think things can get worse,etc

Social coping: Included 7 items as: Resort to help from family and friends whenever possible, prefer not to go to family parties to avoid pity looks, etc

Emotional coping: Included 4 items as: There is someone who can listen to my interests and feelings , there is someone who cares about my health, etc

Educational coping: Included 9 items as: Read books and articles about my son's disability, try to contact people who have had the same problem as me ,..... etc

Religious and doctrinal coping: Included 5 items as: Pray and put my trust in God, ask God for healing by practicing religious rites, etc

Scoring systems for mothers' coping patterns:

Coping scale consisted of 6 coping components

included 40 items:

- Never = 0, sometimes =1 , always = 2 .

The total score of mother's coping scale were 80 grades categorized as follows:

- Negative coping pattern if the Score < 60% (< 48 grades)

- Positive coping pattern if the Score $\geq 60\%$ (≥ 48 grades)

Content validity:

Revision of the tools was done by a panel of 5 expertise in Community Health Nursing, Faculty of nursing, Helwan and Fayoum University to measure the content validity of the tools and the necessary modifications were done accordingly.

Tools reliability:

To assess reliability, the study tools were tested by the pilot subjects at first session and retested after 2 weeks a test - retest reliability for calculating Cronbach's alpha was 0.830 for the questionnaire.

Alpha cronbach reliability analysis of the used tools

Items	Alpha Cronbach
Total knowledge	0.795
Total needs	0.835
Total coping pattern	0.856

Ethical considerations:

An official permission to conduct the proposed study was obtained from the Scientific Research Ethics Committee, Faculty of Nursing, Helwan University. Participation in the study was voluntary and subjects were given complete full information about the study and their role before signing the informed consent. The ethical considerations include explaining the purpose and nature of the study, stating the possibility to

withdraw at any time, confidentiality of the information were not be accessed by any other party without taking permission of the participants. Ethics, values, culture and beliefs was respected.

II- Operational Item:

Preparatory phase:

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

Pilot study:

It was carried out on 10% (10) of mothers with down syndrome child under the study to test the applicability, clarity and the efficiency of the tools. Mothers in the pilot study chosen randomly and then was included in the study sample later, because there were no modifications founded after pilot study.

Field work:

- Approval litter was issued from the Dean of the Faculty of Nursing, Helwan University directed to the director of special needs school (AL-Tarbiyah EL-Fikria).
- Informed consent from participant mothers was obtained after explaining the aim of the study.
- Voluntary participation and confidentiality were assured by the investigator for each mother through clarifying to them that all information was used for scientific research only.
- Data collection was started and finished within 3 months from beginning of October to end of December 2022.
- The investigator started the interview with each mother individually to collect the data using the data collection tools from 9 a.m to 2 p.m.
- The Investigator meet mothers to collect data

during the periodic meetings of the parents' council and while mother take the child to school, as well as when attend to take child to home.

III-Administrative Item:

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

IV-Statistical Item:

Upon completion of data collection, data was computed and analyzed using Statistical Package for the Social Science (SPSS), version 24 for analysis. Descriptive statistics tests as numbers, percentage, mean \pm Standard Deviation (\pm SD), was used to describe the results. Appropriate inferential statistics such as "F" test or "t" test was used as well.

Statistical Significant is considered as :

- Statistically Significant when P- value < 0.05
- Non significant when P- value > 0.05
- Highly Statistically significant when P- value < 0.001

Results:

Part I: Socio- demographic characteristics for children with down syndrome & their mothers.

Table (1): Frequency Distribution of Children and their Mothers according to Socio-Demographic Characteristics (n = 100)

Child Socio- Demographic Characteristics	No. (%)
Age of child (years)	
6- <8	28
8- <10	28
10 or more	44
Mean \pm SD	9.24 \pm 2.7
Gender	
Male	48
Female	52
Birth order	
The first	44
The second	20
The third	20
Other-mentioned	16
Mothers Socio- demographic characteristics	
Age of mother (years)	
20- <30	12
30- <40	28
40 or more	60
Mean \pm SD	32.68 \pm 4.55
Educational level	
No read & write	12
Read & write	8
Basic education	28
Secondary	44
University	8
Mother's occupation	
Working	28
House wife	72
Place of residence	
Rural	32
Urban	68
Family monthly income	
Enough to family needs	64
Not enough to family needs	36

Number of family member	
3- <5	68
5- <7	28
7 or more	4
The number of rooms in the home	
2- 4	84
More than 4	16
Crowding index	
<2	88
2	12

Table (1): Shows that, 52% of children were female , 44 % of children age was 10 years or more , and were the first child in their families, 60% of mother's age was 40 years or more and 12% of them were no read & write. 32% of mothers were live in rural area and 36% of their family monthly income not enough to their family needs and 88% their crowding index was < 2 .

Part II: Mother's Knowledge regarding down syndrome.

Answering research question (no 1) What are mother's knowledge about down syndrome?

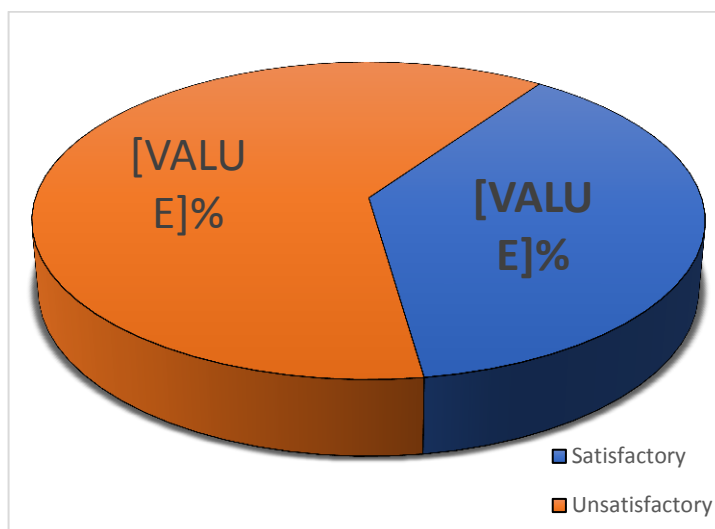
Table(2):Frequency Distribution of the Mothers according to their Knowledge regarding Down Syndrome (n = 100)

Knowledge Items	Complete Correct	Incomplete Correct	don't know
	No. (%)	No. (%)	No. (%)
Meaning of down syndrome	15	46	39
Causes of down syndrome	24	35	41
Types of down syndrome	12	32	56
Signs and symptoms of down syndrome	25	28	47
Methods of diagnoses down syndrome	32	36	32
Complications of down syndrome	20	42	38
The team of treatment of down syndrome	42	0	58
Method of treatment for down syndrome	30	37	33
Occupational follow-up importance for DS child	31	0	69
Physiotherapisy importance for DS child	37	0	63
Speech therapy importance for DS child.	35	0	65

Table (2): Presents that, 46 % of mothers had incomplete correct answer about meaning of DS and 35% of mothers had incomplete correct answer about causes of DS and 20% of them had complete correct answer about DS Complications.

Figure (1):Percentage Distribution of Mothers according to their Total level of Knowledge regarding Down Syndrome (n= 100).

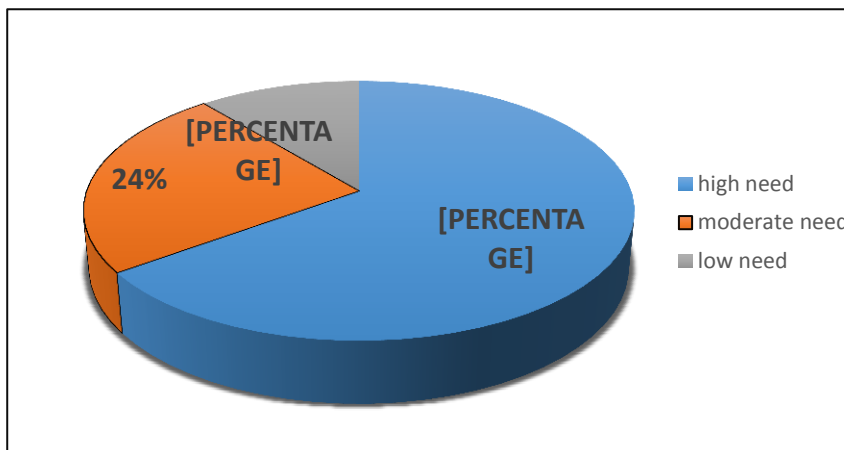
Figure (1): Shows that, 38% of studied mothers had satisfactory total level of knowledge regarding down syndrome, while 62% of them had unsatisfactory total level of knowledge regarding down syndrome.



Part III: Mothers' needs for caring of their children suffering from down syndrome.
Answering research question (no 3) What are mothers' needs for caring of their children suffering from down syndrome.

Figure (2): Percentage Distribution of Mothers according to their Total Level of Needs (n=100)

Figure (2): Illustrates that, 65% of mothers had high levels of total needs, 24% of them had moderate level of needs, and 11% of them had low level of needs.

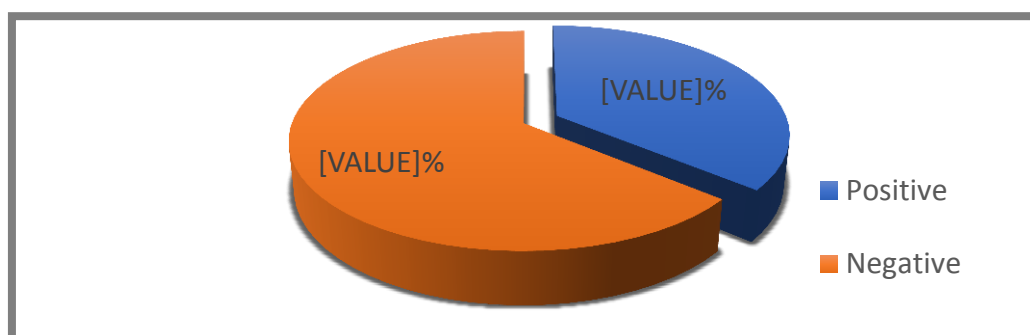


Part IV: Mothers coping pattern .

Answering research question (no 2) What are coping pattern of mothers with children suffering from down syndrome.

Figure (3):Percentage Distribution of Mothers according to their Total Level of Coping (n=100).

Figure (3): Shows that, 36 % of mothers had positive coping pattern with their children suffering from down syndrome and 64% of them had negative coping pattern with their children suffering from down syndrome.



Part V: Statistical relations and correlations between studied variables:

Answering research question (no.4): Is there relationship between mothers knowledge and coping pattern regarding their children suffering from down syndrome.

Table (4): Correlation between Total Knowledge , Needs and Coping Pattern Scores (n=100).

	Total knowledge score		Total needs score	
	r	P-value	r	P-value
Total needs score	-0.758	<0.001*		
Total coping pattern score	0.764	<0.001*	-0.449	<0.001*

r= correlation coefficient test

Table (4) :Shows that there was highly statistically significant negative correlation between total needs score with total knowledge score(r = -0.758} and total coping pattern score with total needs (r = -0.449) in addition there was highly statistically significant positive correlation between total knowledge score and total coping pattern score (r = 0.764)

Discussion:

Part I: Socio-demographic characteristics for children with down syndrome and their mothers

The current study results revealed that, more than half of children with DS were female, (**table 1**). This finding was in disagreement with **Corder et al., (2017)** in United Arab, who conducted study entitled “Demographics and co- occurring conditions in a clinic-based cohort with Down Syndrome” (n=221), who found that DS occurs more frequently in 62.9% of males than females.

The current study results revealed that more than two fifths of children were the first child in their families .This finding was in disagreement with **Richter, (2017)** in USA, added in his study about “Adopting Children with Down Syndrome in University of Arkansas, Fayetteville” (n=33) In relation to ranking of DS children in their families, 29% of children were the first child in their families.

The current study revealed that, more than half of mothers were ages 40 or more, This results were in the same line with study done by **Mohammed et al., (2020)**, in Egypt, in their study about “ Relationship between psychological well-being and coping strategies among family caregivers of children with down syndrome ” (n=120) , who reported that 60.9% were in age group 35- <55 years old,

The current study showed that more than two fifth of the mothers their educational level was secondary education. the current study were in accordance with study done by **Kózka & Przybyła-Basista, (2018)** in Ketowice , who stated in their study “Perceived stress, ego-resiliency, and relational resources as predictors of

psychological well-being in parents of children with down syndrome ” (n=126), who found that 38.89% of mothers of children with DS had secondary education .

As observed from the present study, more than two thirds of mothers were housewives and more than one third of families their family’s monthly income not enough. This finding agreed with **Elmwafie et al., (2022)** in Egypt , in their study entitled “Effectiveness of coping strategies intervention on quality of life for mothers having children with down syndrome” (n=75) , who reported that 77.3% of mothers of children with DS were housewives and 61.3% of them described their financial situation as insufficient . This may be due to DS are associated with many medical problems that need extra care, follow-up and even hospitalizations that need from mothers spent more time with their children .

Part II: Mother's knowledge regarding Down syndrome

According to Research question (1). What are mothers' knowledge about down syndrome?

The current study revealed that less than half of mothers were had incomplete correct answer about meaning of down syndrome. This finding go in the same line with that of study conducted by **Shalabi et al., (2020)** in Riyadh, in their study to“ assess awareness level toward down syndrome” (n=402) who mentioned that 25.9% of mothers reported that meaning of down syndrome is caused by chromosomal mutation.

From investigator's point of view, this is due to the low educational level of mothers with down syndrome children in the intellectual education schools in Fayoum Governorate.

Also, in present study about one third of mothers were had incomplete correct answer about causes of

down syndrome. This result was supported by **Barnoy et al., (2017)** in America, in their study entitled “Social inclusion of children with down syndrome: Jewish and muslim mothers' knowledge, attitudes, beliefs, and behavioral intentions” (n=79), who reported that 32% of mothers thought that DS increased due to advanced mother age.

Considering of sign and symptoms of DS that appear on child, more than one quarter of mothers had incomplete correct answer about clinical manifestation of DS children . This study result was incongruent with a study done by **Deakin & Jahoda, (2020)** in Britain, to assess “mothers’ perceptions of their child’s developing awareness of down syndrome” (n=20) who mentioned that, 73% of mothers knew that enlarged tongue and change the facial features were the most clinical manifestation associated with DS children.

Considering of treatments of DS, less than one third of mothers were had complete correct answer about methods of treatment therapies for DS . This study result is incongruent with a study done by **John & Gayathri, (2020)** in India who reported that, 55% of mothers had satisfactory knowledge of the various available therapies for DS, but some knew only about physical therapy and occupational therapy.

The present study results showed that, less than two -thirds of mothers were had unsatisfactory knowledge regarding of down syndrome (**figure 1**). This result is in congruent with **Alhaddad et al., (2018)** in jeddah, Saudi Arabia, who performed their study about “ Knowledge and attitude towards down syndrome among people” (n=1253) and reported that 63% of mothers had poor knowledge regarding down syndrome. Another study done by **Negm et al., (2022)** in Egypt, entitled “Effect of

educational intervention on psychological well-being and coping of mothers having children with down syndrome” (n=100) who reported that, 65% of mothers had unsatisfactory knowledge level about DS.

From investigator's point of view, it may be due to low of mothers’ educational level and lack of media awareness in our society about down syndrome.

Part III: Mothers' needs for caring of their children suffering from down syndrome .

According to Research question (3). What are mothers' needs for caring of their children suffering from down syndrome.

Concerning the needs of mothers with DS children, present study showed that more than half of the studied mothers had high physical needs. This study is congruent with **Negm et al., (2022)** who reported that concerning the needs of mothers with DS children, 52% of the studied mothers had moderate physical needs.

In addition the present study showed that three fourths of mothers had moderate economic need and more than half of mothers had very much social and psychological needs. This result is congruent with another study conducted by **Elmwafie et al., (2022)** in Egypt, entitled “Effectiveness of coping strategies intervention on quality of life for mothers having children with down syndrome” (n=75) mention that 58.7% of mothers had high economic needs and 41.3% had very much social and psychological needs.

Part IV: Coping pattern for mothers with their children suffering from down Syndrome.

According to Research question (2). What are

mothers' needs for caring of their children suffering from down syndrome.

As regards mothers' physical coping, the current study results represented that, no mother used drink alcoholic beverage as physical coping strategy. This result is congruent with **Mohammed et al., (2020)** in Egypt, in their study to " assess relationship between psychological wellbeing and coping strategies among parents with DS children" (n=120) who reported that, substance abuse is the least common strategy used by mothers of children with DS (3.3%) because it was socially unacceptable strategy .

From the investigator's point of view, it may be due to religiosity that are highly prevalent in our community where substance abuse is illegal and socially unacceptable strategy for coping and due to increase mothers' awareness of dangers accompanied by substance abuse.

The current study results illustrated that more than three fifths of mothers were had total negative coping pattern and more than one third of them had positive pattern (**figure 3**), This result inconsistent with **Cless et al., (2017)** in US who reported that, 52.8% of mothers had a positive coping outcome and 47.2% had a negative coping outcome and mothers tend to adopt coping strategies when facing the condition of DS children and overcoming bad conditions.

From the investigator's points of view, this may be due to lack of social and communication skills of mothers and increased behavioural problems contribute to greater psychological distress for mothers.

Part V: Statistical relations and correlations among studied variables

The present study showed that there was

highly statistically significant positive correlation between total knowledge score and total coping pattern. This result finding was agreed with **Mahmoud et al., (2022)** who clarified that, a highly statistically significant correlation between mother's knowledge and their coping strategies when p-value was <0.001. where mothers who were had satisfactory knowledge about DS were able to always cope religiously with their children

Conclusion

Based on the present results and research questions the study can be concluded that, More than three fifths of mothers had unsatisfactory total level of knowledge regarding of down syndrome. As well, more than one third of mothers had positive coping pattern with their children suffering from down syndrome and near two thirds of mothers had negative coping pattern with their down syndrome children, two thirds of mothers were had very much levels of needs, As well there was positive correlation between total knowledge score and total coping pattern.

Recommendation

In the light of the study findings, the following recommendations are suggested

Based on the finding of the present study the following recommendations are suggested:

- 1) Counseling program for parents of children with DS to improve psychological wellbeing and develop better coping patterns also helping the parent to lead their life in a positive way.
- 2) Provide educational program for parents of children with DS about importance of participation in mentoring programs about their needs.

- 3) Organized educational programs to improve mothers' knowledge and coping pattern with down syndrome child care.
- 4) Further researches are required for studying needs coping pattern of mothers with child of DS on long scale and different settings.

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