Mother's Coping among Primary School Child with Down Syndrome

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Abstract

Background: Down syndrome (DS) or Down's syndrome, also known as trisomy 21, is a genetic disorder caused by the presence of all or part of a third copy of chromosome 21. When mothers of children with DS experience stress, they use certain strategies to cope with this stress to regulate their emotions. **Aim of this study:** to assess mother's coping among primary school child with DS. **Design**: A descriptive study design was used. **Setting:** The study was conducted at three special needs schools (ALtarbih ELfikria) at Fayoum governorate. **Sample:** A purposive sample was used, they were 95 mothers, and their children. **Data collection tools:** First tool structured interviewing questionnaire, to assess demographic characteristics of mothers, children, history of DS child, and to assess mother's knowledge about DS. Second tool: physical examination sheet for DS children. Third tool: mothers' coping scale. Fourth tool: mothers' needs scale. **Results:** The study results showed that, three fifths of mothers had negative coping patterns, in which more than two fifths of them never able to cope with their children disability also, study results reported that the economic needs were most important needs for mothers. **Conclusion:** More than two-thirds of mothers had unsatisfactory level of knowledge regarding of Down syndrome. Religious and doctrinal coping was the most coping strategy used by mothers, in which more than half of mothers were always able to cope religiously. **Recommendation:** Provide premarital counselling including necessitate investigation, insure proper antenatal care for pregnant women and provide educational program to parents with DS child and encourage them to participate in mentoring programs and receive rehabilitation services for their children.

Keywords: Down Syndrome – Coping pattern – primary school child, mothers' needs for caring child with DS.

Introduction:

Down syndrome (DS) or Down's syndrome, also known as trisomy 21, is a genetic disorder caused by the presence of all or part of a third copy of chromosome 21. It is usually associated with physical growth delays, mild to moderate intellectual disability, and characteristic facial features **(Munny, 2019)**.

The prevalence of DS is 1 in every 700 babies born in the world. Its estimated incidence is 1 per 1000 live births. Annually, 3000 to 5000 children across the world are born with DS**.** Children with DS exhibit persistent

intellectual, developmental, and health issues that require medical and rehabilitation services, both of which can impact family systems **(Gashmard et al., 2020).** Besides deficits in cognitive and social areas, children DS often have other comorbid chronic health conditions, such as congenital heart defects, gastrointestinal disease, hypothyroidism, respiratory disorders, ophthalmologic problems, and hearing problems, which make extra-care and extra-attention necessary and may be an additional source for parents‟ worries and fears. As a result, on the one hand, families of these children have to spend much energy and patience in managing the child's behavioral, emotional and health problems **(Kazemi & Kheirollahi, 2016).**

Down syndrome can cause a number of medical complications, some of these complications are more serious than others, but most of them can be treated. The most serious complications of DS include heart defects, blood disorders that can include leukemia (cancer of the blood), hormonal disorders, skeletal problems and immune system problems **(Ostermaier, 2019**).

Parents (specially mothers) of children with DS face different challenges arising from necessity of dealing with social consequences of the illness like potential threat of stigmatization. Intra-psychic, they may undergo a painful process in losing the imagination of having a "normal" child and to accepting that their child is "different", On being told their newborn baby has impairment, parents tend to react with a mixture of shock and disbelief, followed by denial (**Singh, 2016).**

Generally, mothers of children with DS are having plenty of problems in their life in physical, psychological and social compared to the mothers of normal children. Mothers of children with intellectual and developmental disabilities as DS are facing lots of negative emotions like stress, anxiety, depression and they also have more fear about their future and their child's future which will have adverse effect on the wellbeing due to inability to cope with this situation. In spite of that some parents accept the reality and tend to lead a positive life it developing their coping skills and self-esteem **(Parameswari & Eljo, 2017).**

When mothers of DS child experience stress, they use certain strategies to cope with this stress to regulate their emotions. Coping strategies can be adaptive (i.e., leading to less distress) or maladaptive (i.e., leading to more distress) and can be executed behaviorally, such as seeking emotional support, or cognitively, such as attaching positive thoughts to a stressful situation. Coping with a physically or intellectually disabled child is a highly individual process, and there is evidence to suggest that some families may never adjust fully to this event **(Ganjiwale et al., 2016).**

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

Significance of the study:

In Egypt, Down syndrome is the result of a chromosomal disorder and is one of the most common causes of intellectual disability. The incidence of Down syndrome (DS) in Egypt varies between 1:555 and 1:770 and its screening by triple test is becoming increasingly popular nowadays **(Abou-Yossef et al., 2014., Antonarakis, 2017).**

It considers overwhelming problem for the parents that may cause feeling of guilt and shame. Therefore, this study will be conducted to assess maternal coping strategies toward their children with Down syndrome. Coping efforts seek to manage, master, tolerate, reduce or minimize the demands of a stressful environment and to solve the daily life stressors and problems. Moreover, coping aims at minimize the physical, psychological, or social harm of an event or situation through helping family to manage or deal with this stressful situation **(Baqutayan, 2015).**

Aim of the study:

This study aims to assess mother's coping among primary school child with down syndrome **through:-**

1. Assessing health status of child with DS.
2. Assessing mothers' level knowledge toward down syndrome.
3. Assessing of mothers' coping patterns toward their children with DS
4. Assessing of mothers' needs for caring their children with Down syndrome.

Research Questions:

1. What is health status of child with DS?
2. What are mothers' level of knowledge toward Down syndrome?
3. What are of mother's coping patterns toward their children with DS?
1. 4.What are mothers' needs for caring their children with Down syndrome?

Subjects and Methods:

I- Technical Design:

Includes research design, setting of the study, subjects of the study and tools for data collection

A. Research design:

A descriptive study design was used to assess mothers coping patterns that used to cope with their primary school students with Down Syndrome and assess their needs for caring their children's.

Setting:

The study was conducted at three special needs schools (ALtarbih ELfikria) affiliated to the management of Fayoum education, Fayoum governorate, and these three schools are only special needs schools at Fayoum Governorate.

Sample:

Sample was composed of 95 mothers of primary students with DS and their children at special needs schools affiliated to the management of Fayoum education, who agreed to participate in the study.

-The data collection was started and finished at 5 months from the begging of October 2018 to the end of March 2019.

-The recruited children and their mothers were chosen according to the following inclusive criteria:

Inclusion criteria for children with Down syndrome:

1- Child diagnosed with DS
2. Age from 6 to 12 years (primary school age)
1. Gender: both sex.

Inclusion criteria for mothers of children with Down syndrome:

1- Mothers who give direct care to the child.
3. Free from any psychiatric illness.

Tools of Data Collection:

The data for this study were collected by using three tools:

Tool I: Interviewing Questionnaire

It was designed by the investigator based on reviewing related literatures and revised by supervisors. It was divided into 3 parts:

Part I: Socio-demographic data:

To assess socio-demographic data for mothers and their children, it included data about child gender, age, birth order, mother's age, educational level, occupation, family' type, family monthly income, residence place family size, and crowding index.

Part II Child history:

A- Child past health history: It was designed to assess mother's medical history during her pregnancy, child medical history during his\her birth and after birth

B- Child's family history: It was designed to determine if there is consanguinity between the parents, degree of this consanguinity, and family history of Down syndrome.

C- Current health status of DS child: It included data about child's intelligence quotient, complication resulting from Down syndrome, presence of other chronic disease.

Part III: Mothers' knowledge regarding of Down syndrome

It was modified from **(Jan et al., 2017)** included items related to meaning of down syndrome, causes, types, S/S, complication, treatment of down syndrome, and follow up.

- **Scoring system for mother`s knowledge**:

It was composed of 8 questions (optimal score 27), (correct=1, incorrect=0). Total mother's knowledge was classified into the following scale, satisfactory knowledge up to 50%, while unsatisfactory knowledge less than 50%.

Tool II:

Physical examination sheet for down syndrome child. It was designed to evaluate the child for evidence of dysmorphic features. This tool is adapted from **Liptak, G. S. (1998**) and modified by investigator. It includes assessment of child vital signs, anthropometric measurement's, an evaluation of overall symmetry and body appearance, assessment of body systems, and skin condition.

Tool III: **Coping patterns questionnaire of mothers toward their children with down syndrome**

It was designed to assess the mothers' coping patterns toward their DS

children. This tool is adapted from **(Jalowiec and power 1991)** & **(Yeh 2001)**. It modified by the investigator. The scale was composed of 40 statements.

1- **Physical coping**, it consists of 8 questions.
2- **psychological coping**, it consists of 7 questions.
3- **Social coping,** it consists of 7questions.
4- **Emotional coping**, it consists of 4 questions.
5- **Educational coping,** it consists of 9 questions.
6- **Religious coping,** it consists of 5 questions**.**

❖ **Scoring system:**

The total optimal score of mother's coping scale 80. Score of less than 60% was negative coping pattern and equal or more than 60% was positive coping pattern.

Tool IV: Mothers' needs questionnaire regarding care of their Down's syndrome children

It was designed to assess the mothers' needs for care their Down's syndrome child. This tool adapted from **(Leyser & Dekel 1991), (Simeonsson & Baily 1988)** and modified by investigator. It includes:

1- **Cognitive needs**, it consists of 10
2. questions.
2- **Economical needs,** it consists of 9 questions.
3- **Psychological and social needs,** it consists of 9 questions.
4- **Physical needs,** it consists of 4 questions.

❖ **Scoring system:**

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 96. Score of less than 50% was I never need it and the score between 50-<75%was I need it moderately and equal or more than 75% was I need it very much.

II. Operational Design:

Includes preparatory phase, content validity, pilot study and field work.

a) Preparatory phase:

Includes reviewing of related literature and theoretical knowledge of various aspects of the study using books, articles, scientific journal and internet with the aim of acquiring in-depth knowledge about the study.

b) Content validity:

Revision of the tools was done by a panel of expertise composed of 5 professors of Community Health Nursing to measure the content validity of the tools and the necessary modifications was done accordingly**.**

c) 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 from the study sample later. There were no modifications found after pilot study. The pilot showed very high levels of reliability by using alpha cronbach reliability test.

d) Field work:

- The approval to conduct the study was obtained orally after explaining the aim of the study.
- Data collection was started and finished at 5 months from the begging of October 2018 to end of March 2019.
- Sample was collected during the period of mothers attending at (ALtarbih ELfikria) school from 9a.m to 2p.m and during the periodic meetings of the parents' council.
- The structured interviewing questionnaire sheet was filled by the investigator from each participant in the study individually. It took about 20- 30 minute to be filled.

III. Administrative Design:

A written consent was obtained from each subject after explaining the aim of the study. To carry out the study, an approval was obtained from the Directors of special needs schools (ALtarbih ELfikria) at Fayoum city. A letter was issued to them from the Faculty of Nursing Ain Shams University explaining the aim of the study in order to obtain permission and cooperation.

They were informed about confidentiality of data collected and that it will be used for the research purpose only. They were also informed that they have the right to withdraw at any time without giving a reason.

Ethical considerations:

The research approval was obtained from scientific ethical committee in faculty of nursing at Ain Shams university before starting the study. The investigator clarified the objective of the study to mothers with down syndrome child included in the study to gain their confidence and trust. The investigator assured maintaining anonymity and confidentiality of subjects' data. Mothers were informed that they are allowed to choose to participate or not in the study and that they have the right to withdraw from the study at any time.

IV. Statistical Design:

The data was collected, coded and entered to a personal computer. It was analysed with the program statistical package for social science (SPSS) version 20. The collected data were organized, revised, analyzed and presented in numbers and percentage in tables, figures and diagram. Proper and suitable statistical tests were used to test the significance of results obtained.

Mean = $\frac{\Sigma x}{n}$

Where Σ = sum & n = number of observations.

Standard Deviation [SD]:

$$SD = \sqrt{\frac{\Sigma |x - x|^2}{n - 1}}$$

Chi-square:

The hypothesis that the row and column variables are independent, without indicating strength or direction of the relationship. Pearson chi-square and likelihood-ratio chi-square. Fisher's exact test and Yates' corrected chi-square are computed for 2x2 tables.

Linear Correlation coefficient was used for detection of correlation between two quantitative variables in one group. >0.05 Non significant <0.05* significant <0.001** High significant.

Results:

Table (1): Shows that, 56.8% of children were male and mean of their age was 7.84±3.2. 32.6% of them were the first child in their families. The mean of mother's age was 36.25±5.84 and 35.8% of them were illiterate. 36.8% of mothers were live in rural area and 61.1% of families their monthly income not enough to their family needs.63.2% of families their crowding index was >2.

Figure (1): Show that, total satisfactory mothers knowledge regarding of Down syndrome was 31.6% and 68.4% was the total unsatisfactory mother's knowledge regarding of Down syndrome.

Figure (2): Shows that, 26.3% of mothers always able to cope with their Down syndrome children, 32.6% of them sometimes able to cope, and 41.1% of them never able to cope.

Figure (3): 40% of mothers had very much cognitive needs, 41.1% of mothers had moderate economic needs and 45.3% of mothers had very much social and psychological needs.

Figure (4): Shows that, 43.2% of mothers were had very much levels of needs, 46.3% of them were had moderate level of needs, and 10.5% of them were never had needs.

Table (2): This table shows that, a highly statistically significant relationship between the age of mothers and their coping, mothers over the age of forty were had more coping with their children' disability than other mothers. Also, there was statistically significant relation between the mothers' occupation and their coping, working mothers were more coped than housewives.

Table (1): Distribution of mothers and their children according to their demographic characteristics (N = 95).

Items	N	%
Gender		
Male	54	**56.8**
Female	41	43.2
Age		
6 < 8 Y	33	34.7
8 <10 Y	34	35.8
10-12 Y	28	29.5
Mean ±SD	**7.84±3.2**	
Child Order		
The first	31	**32.6**
The second	17	17.9
The third	19	20.0
The fourth or more	28	29.5
Mother's data		
Age		
> 20	2	2.1
20< 30	28	29.4
30< 40	43	45.3
over 40	22	23.2
Mean ±SD	**36.25±5.84**	
Education level		
Illiterate	34	**35.8**
Read & write	13	13.7
Diploma	37	38.9
Bachelor	11	11.6
Mother's occupation		
Working	27	28.4
House wife	68	71.6
Family and home data	N	%
Residence place		
Rural	35	36.8
Urban	60	63.2
Family type		
Nucleus	59	62.1
Extended	36	37.9
Family Monthly income		
Enough to family needs	37	38.9
Not enough to family needs	58	**61.1**
Number of family member	5.79±1.92	
The number of rooms in the home	2.78±0.77	
Crowding index		
<2	35	36.8
>2	60	**63.2**

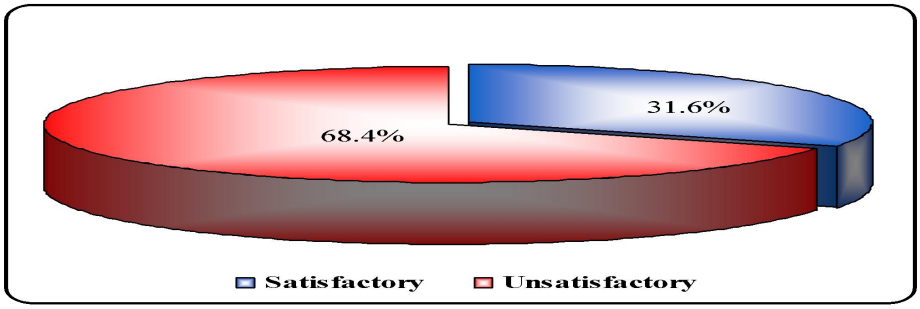

Figure (1): Distribution of mothers according to their total satisfactory and unsatisfactory knowledge regarding of Down syndrome **(N=95).**

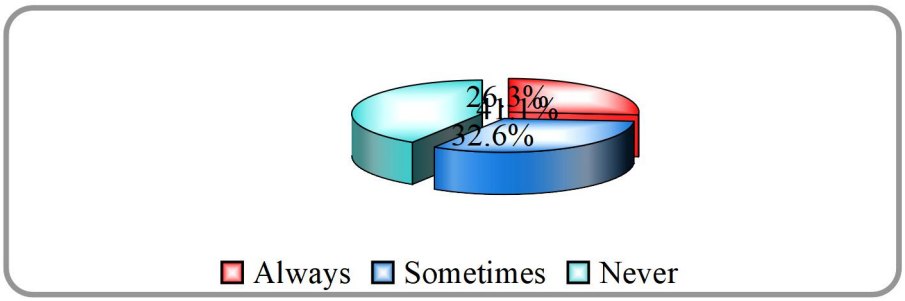

Figure (2): Distribution of mothers according to their total level of coping.

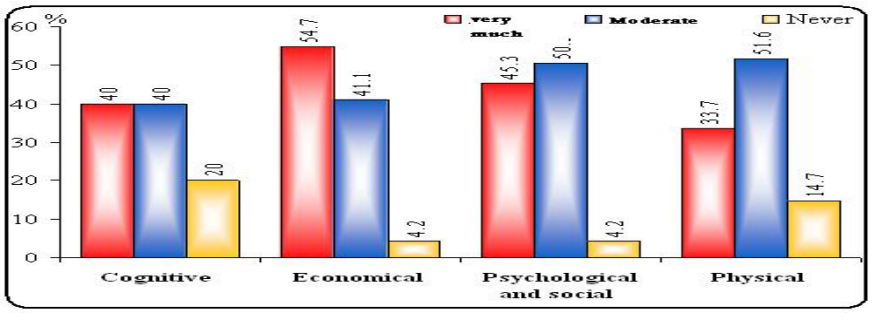

Figure (3): Distribution of mothers according to their sub- total level of needs **(N=95).**

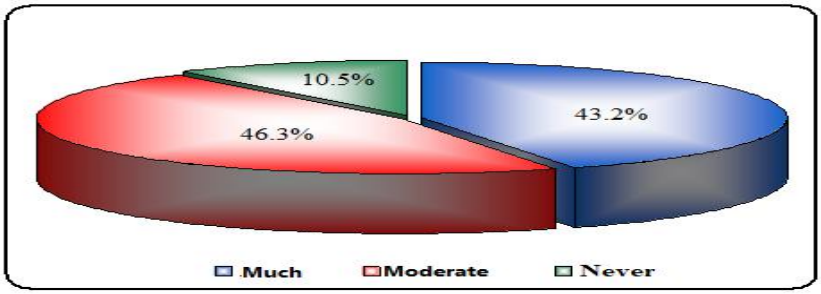

Figure (4): Distribution of mothers according to their total level of needs

Table (2): Relation between mothers coping patterns and socio demographic characteristics **(N=95)**.

Demographic data	Total Coping scale								
	Always		Sometimes		Never		Total	Chi-square	
	N	%	N	%	N	%		X^2	P-value
Age									
less than 20	0	0.0	1	50.0	1	50.0	2		
20 > 30	8	28.6	16	57.1	4	14.3	28	**26.955**	**<0.001****
30 > 40	13	30.2	13	30.2	17	39.5	43		
over 40	17	77.3	5	22.7	0	0.0	22		
Level of education									
Illiterate	17	50.0	12	35.3	5	14.7	34		
Read and write	5	38.5	8	61.5	0	0.0	13		
Basic education	1	20.0	4	80.0	0	0.0	5	31.694	<0.001**
Diploma	6	18.8	11	34.4	15	46.9	32		
Bachelor	9	81.8	0	0.0	2	18.2	11		
Work									
Work	19	70.4	7	25.9	1	3.7	27	**16.083**	**<0.001****
House wife	19	27.9	28	41.2	21	30.9	68		
Place of residence									
Rural	17	48.6	10	28.6	8	22.9	35	2.049	0.359
Urban	21	35.0	25	41.7	14	23.3	60		
Family type									
Nuclear	24	40.7	25	42.4	10	16.9	59	3.902	0.142
Extended	14	38.9	10	27.8	12	33.3	36		
monthly family income									
Sufficient for family needs	12	32.4	17	45.9	8	21.6	37	2.293	0.318
Insufficient for family needs	26	44.8	18	31.0	14	24.1	58		
Crowding index									
<2	10	28.6	17	48.6	8	22.9	35	3.881	0.144
>2	28	46.7	18	30.0	14	23.3	60		

**HS: <0.001 * S: 0.05 Insignificant: >0.05

Discussion:

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 with DS children. When mothers experience stress, they use certain strategies to cope with stress to regulate their emotions.

The aim of this study was to assess mothers coping toward their children with DS and assess their needs for caring them.

Regarding the primary school student`s socio-demographic characteristics, the current study results revealed that, more than half of children with DS were male, mean of children's age with DS was 7.84±3.2, and less than one third of children were the first child in their families. This finding is in agreement with **Corder et al., (2017**), who conducted study entitled "Demographics and co-occurring conditions in a clinic-based cohort with Down Syndrome in United Arab", who found that DS occurs more frequently in males than females.

The present study results showed that, more than two- thirds of mothers were had poor or unsatisfactory knowledge regarding of Down syndrome. This result is congruent with **Alhaddad et al., (2018)** who performed their study at Jeddah to assess knowledge and attitude towards Down syndrome among people and reported that two-thirds of mothers had poor knowledge regarding of down syndrome. Another study done by **Barnoy et al., (2017)** in US who reported that, all mothers displayed low 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 of society about Down syndrome.

In this study more than one fifth of mothers were had correct answer about that Down syndrome is a genetic condition that occurs when a child was born with 47 chromosomes instead of 46 and advanced mother age by about one third. This finding goes with same line with that of study conducted by **Shalabi et al., (2020)** in their study to assess awareness level toward down syndrome in Riyadh, who mentioned that 25.9% of mothers reported that Down syndrome is caused by chromosomal mutation. Also, in present study one third of mothers thought that Advanced mother age is most causes of DS. This result was supported by **Barnoy et al., (2017)** in their study entitled "Social Inclusion of Children with Down Syndrome: Jewish and Muslim Mothers' Knowledge, Attitudes, Beliefs, and Behavioral Intentions in US", who reported that around one third of mothers thought that DS rate increased with advanced mother age. As regards mothers' physical coping, the current study results represented that, use of medications-stimulants and drink alcoholic beverage were the least used physical coping strategy used by mothers and nearly half of mothers' always get rid of stress with physical activity or exercise. This result is congruent with **(Mohammed et al., 2020)** in their study to assess relationship between psychological wellbeing and coping strategies among parents with DS children in Ain Shams university- Egypt who reported that, substance abuse is the least common strategy used by mothers of children with DS because it was as a socially unacceptable strategy that may represent as a barrier for continuation of effective child caregiving. 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 present study results illustrated that as regards of religion coping, more than three quarters of mothers pray and put their trust in their God and more than two fifths of mothers think that God loves them, that's why he made them suffer by this **.**This study result is congruent with **Isa et al., (2017)**, in their study in Kelantan who clarified that, when being under stress, an individual might turn to religion for many reasons as religion serves as a source of emotional support, a vehicle for positive reinterpretation and growth, or a tactic of active coping with a stressor. From the investigator's point of view, it may be attributed to continuous effort exerted by mothers to help child accommodate within the environment, seeking for practical support from medical team as well as their need for patience and empathy to be able to care for the child with DS. So, they considered the child disability as a test from Allah and seek help from Allah to resume child caregiving as Religious is recognized as a major resource for mothers in our population when dealing with a stressful event.

This study finding showed that, more than one quarter of mothers were always able to cope with their children, nearly one third sometimes able to cope, and more than two fifths of mothers never able to cope**.** This result finding is congruent with **Nelson et al., (2016**) in their study in US who reported that, more than half of the mothers had low level of their coping strategies, in which more than two fifths of mothers never able to cope

As regard mothers' economical needs, more than two- thirds of mothers were need very much to allocate funds to provide additional support services to their children **.** This study is in the same line with **Sen & Yurtsever, (2007**) in their study about "Difficulties experienced by families with disabled children in Turkey", who reported that mothers were need to allocate funds to provide additional support services to their children was the most second economical needs for mothers.

Concerning to the psychological and social needs of mothers with DS children, the present study showed that more than two- third of mothers need to people in society to understand the disabilities of their children. It is possible that it occurs due to the lack of media programs in general in the field of educating the community about disability, and this leads to the spread of negative trends among members of society towards the disabled and his family. This study is congruent with **Sen & Yurtsever, (2007)** in their study about "Difficulties Experienced by Families with Disabled Children". who reported that most of mothers need to people in society to understand the disabilities of their

Conclusion:

- According to current study results, majority of children with DS had complication resulting from DS and nearly half of these complications were heart defects and two fifths of children with DS had chronic diseases. Also, the present study results showed that, more than two- thirds of mothers had poor or unsatisfactory knowledge regarding of Down syndrome**.**

- According to research questions, religious and doctrinal coping was the most coping strategy used by mothers in which more than half of mothers were always able to cope religiously. Also, the present study results showed that, more than half of mothers were had much needed economic needs and two fifths of mothers were had much needed cognitive needs.

Recommendations:

In the light of the findings of the present study, the following recommendations can be suggested:

1- rovide educational program to parents with DS child and encourage mothers and fathers to participate in mentoring programs and receive rehabilitation services for their children.

2- Conduct a long-term research study of parenting the children with DS during the transition period from childhood to adolescence and from adolescence to young adulthood and also, explore the core requirements for improving parenting and coping with school-age children with DS, such as knowledge, experience, psychological support, and accessibility for services.

3- Increase financial support for mothers and families of children with DS in order to help cover the financial expenses that are increasing due to disability and thereby alleviate the financial pressures affecting mental health.

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