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Relationship between Parent Stress, Psychological Well-Being and Coping Strategies among Parents with Down Syndrome Children

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Abstract
Background: *Effective parenting is vital for a child's intellectual, physical, social, and emotional development. Psychological wellbeing of parent with Down syndrome children has a major influence on of a child's development regardless of the child's intellectual functioning.*
Aim of the study: *This study aims to assess the levels of parents stress, psychological well-being, and coping strategies among parents with Down syndrome children, and investigate the relationship between parents stress, psychological well-being, and coping strategies among parents with Down syndrome children.*
Research design: *A descriptive correlational design was utilized to fulfill the aim of this study. Setting: The study was conducted at genetic outpatient in specific children hospital in Benha City, Kaluobia Governorate, which is affiliated to the Ministry of Health. Sample: Purposive sampling of 50 parents with Down syndrome children was recruited..*
Tools: *Tools (1):- Structured Interviewing Questionnaire Sheet. Tools (2):- Parental Stress Scale. Tools (3):- Brief Cope Inventory, and Tools (4):-Ryff'sPsychological well-being scale.*
Results: *The result concluded that nearly to half of the studied parents had high level of stress, while more than one third of them had moderate level of stress, more than half of the studied parents had low level of their coping strategies, two thirds had low level of psychological wellbeing, and there is no statistically significant correlation between parental stress, psychological wellbeing, and coping strategies among parents with Down syndrome children. Conclusion: Nearly to half of the studied parents had high level of stress, while more than one third of them had moderate level of stress, more than half of the studied parents had low level of their coping strategies, two thirds had low level of psychological wellbeing.*
Recommendations: *The study suggested, psycho-educational training program focused on reducing parental stress and training mothers to parent under stress, and family psychological counseling to improve psychological wellbeing and necessity of training in effective coping strategies.*
Key Words: *Parent Stress, Psychological Well-Being, Coping Strategies, Down Syndrome*

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I. Introduction

Down syndrome (DS) also known as trisomy 21 is the commonest chromosomal disorders in the world; affecting all countries, all races, and both sexes. According to World Health Organization; the predictable incidence of DS is between 1 in 1,000 to 1 in 1,100 live births all over the world ***(Al-Biltagi, 2015).***The incidence of DS in Egypt varies between 1:555 and 1:770 ***(Abou-Youssef et al., 2014).***Children with DS exhibit persistent intellectual, developmental, and health issues that require medical and habilitation services, both of which can impact family systems. Although each person with DS is an individual with a particular physicality, some more common physical features may include poor muscle tone, a protruding tongue, flattened facial features, and shortened height. Developmental differences that can include speech, language, cognition, and motor skills, all of which can impact education and life-long work skills, are also associated with DS ***(Centers for Disease Control and Prevention, 2016).***

Certain health-related complications may also be present, such as heart defects, immune system abnormalities, obesity, and airway obstruction ***(Mayo Foundation for Medical Education and Research, (2014).*** Aside from its effects on appearance, 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).***

On being told their newborn baby has impairment, parents tend to react with a mixture of shock and disbelief, followed by denial ***(Zappella, 2016).*** It is not surprising that families may feel the desire to hide the diagnosis, or even the individual with disability, from the world in order to avoid societal censure and ridicule. Coming to terms with a diagnosis of disability in a child is never easy. Families almost always go through a process of grieving with emotions that may range from confusion, guilt, shock, frustration, anger, denial, anxiety, shame, resentment, inadequacy, depression, and to the question "*Why me*?" ***(Tripathi, 2015).***Torn between powerful and conflicting emotions, parents live through a stressful period in which coping depends on support from one another, from extended families, friends, support groups, and skilled professionals ***(Yildirim et al., 2012).***

Parents have focused and spent a lot of time in bringing up their children but if parents have children with any kind of disability that can be physical or mental makes the rearing process difficult and problematic for the parents as they become bound and they spend much time of their lives in bringing up their children. Parents of disabled children are affected badly due to this problem as they have to face stressful events in their lives The demand of the family of children with DS is significantly higher because the family must actively participate in the care of the child due to the delay in development, the limitations in activities of daily living related to self-care such as dressing, personal hygiene, walking, and talking, and aspects related to health, education, and leisure ***(Hayat & Zafar, 2015)***.

Generally, parents of children with DS are having plenty of problems in their life in physical, psychological and social compared to the parents of normal children. Parents 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, 2016).***

A recent meta-analysis suggested that parenting stress is higher in parents of children with DS than in parents of typically development children ***(Hayes & Watson, 2013).*** Other studies have shown that the stress levels of mothers of children with DS are higher than those of mothers of non-disabled children ***(Esdaile, 2009).***The stress experienced by parents not only negatively impacts their ability to care for their child, but also affects their own mental and physical health, as well as the quality of the relationship with their child ***(Peer & Hillman, 2014).*** The stress experienced by parents of children with Down syndrome depends on multiple factors. Some of them are related with the child's characteristics (e.g., age, temperament, behavioral problems), others with the parent's characteristics (e.g., the coping strategies they employ), others yet with the characteristics of the social environment (social support or parent's empowerment ***(Pisula, 2012).***

When people experience stress, they use certain strategies to cope with this stress to regulate their emotions ***(Lazarus & Folkman, 1984).*** 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 requires a cognitive reappraisal of the situation to manage it properly. Positive adaptation can occur in the form of changed world views concerning life and disability, gaining sense of coherence, and an appreciation of the positive contribution made by children to family members and society as a whole ***(Choi, 2015).*** Utilization of effective coping strategies has been identified as an important mechanism of managing parental stress and promoting well-being (***Ludlow et al., 2012; & Seymour et al., 2013).***

Parents are burdened with many additional duties which affect their psychological well-being ***(Johansen et al., 2013).*** Furthermore, the daily challenges of caring are many and affect the parent's health and ability to manage the needs of the child and family ***(Bonis, 2016).*** In the other hand, sometimes caring for a child with disability can be for its parents a source of a better understanding of the sense of life and paying attention to basic human values like love, friendship and kindness ***(Kózka & Przybyła-Basista, 2016)***.

Lower family well-being creates a bidirectional, negative cycle that can exacerbate the child's problem behaviors as well as reducing the positive effects of therapeutic interventions. Conversely, improved family functioning can positively impact child outcomes. In past most of researches have been done on the perception and attitudes of the parents towards these children but in the recent decades the researchers have now moved on further to the implications and problems that are related to the psychological distress, psychological well-being and coping approaches of the parents with developmentally incapacitated offspring (***Baker et al., 2011; & Osborne et al., 2008)***.

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 behavioural, emotional and health problems ***(Al-Aama et al., 2012; Broers et al., 2012; & Roizen et al., 2014)***.On the other hand, parents 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" ***(Stirn, 2012)***.

The influence of stress on parents' psychological well-being is lower when parents have such resources like social support ***(Kozka & Przybyła-Basista, 2016).*** A strong social network gives parents a chance to divide the responsibilities and worries among other people like friends, family members, and neighbours, and to gain emotional support and coping with stress (***Marchal et al., 2013).*** So, this study aims to assess level of parents stress, psychological well-being, and coping strategies among parents with DS children**.**

Significance of the study:

Down Syndrome, the most common chromosomal disorder associated with mental retardation, not only impedes the development of the child involved, but also threatens the psychological well-being of all other family members, especially the parents. Raising a child with Down syndrome is a particular challenge for parents ***(Alexander & Walendzik, 2016)***.Meaningful psychological, physical and social demands, arising out of the particular life situation of families with children with Down syndrome with very unique characteristics, may overstrain the families' capacities and resources, and result in increasing risk of parents' psychological problems, like depression, anxiety and somatisation symptoms ***(Norizan & Shamsuddin, 2010; &Nes et al., 2014).***

Aim of the study:

The aim of this study was to:-

1-Asseess the levels of parents stress, psychological well-being, and coping strategies among parents with Down syndrome children.

2- Investigate the relationship between parents stress, psychological well-being, and coping strategies among parents with Down syndrome children.

Research questions:

The study was done by keeping in view the following research questions:

1-What is the level of parents stress, psychological well-being, and coping strategies among parents with Down syndrome children?

2- Is there is a relationship between parents stress, psychological well-being, and coping strategies among parents with Down syndrome children?

Operational Definitions of Variables:

1-Psychological Well-Being:

Psychological well-being is operationally defined as scores on Ryff's Psychological well-being scale ***(Ryff& Keyes, 1995)***. This scale has a multidimensional view on autonomy, Environmental mastery, personal growth, positive relation with others, purpose in life and self – acceptance.

2-Stress:

Stress is operationally demarcated as scores of defendants on Parental Stress Scale ***(Berry & Jones 1995).*** High score would mean high level of stress and low scores would indicate low level of stress.

3-Coping strategies:

Coping strategies were operationally defined as scores on Brief COPE ***(Carver, 1997)*** which is assessed in terms of problem-focused coping, religious/denial coping, positive coping and active avoidance coping. The high score on separate subscale is suggestive of more use of that specific coping strategy.

3.1. Active Avoidance Coping:

Active avoidance coping included all of the items from the original Brief COPE subscales for the substance use, behavioral disengagement, self-blame, venting of emotions, and one item from the distraction scale (item 1, 4,6, 9, 11, 13, 16, 19, 21, 26).

3.2. Problem-Focused Coping

Problem-focused coping included all the items from the original Brief COPE, subscales for planning, active coping, seeking instrumental social support, and one item each from the acceptance and emotional social support scales (12, 15, 17, 18, 20, 24, and 28).

3.3. Religious/Denial Coping
Religious/Denial coping is a varied factor that included all the brief cope items for religious coping and denial (3, 8, 22, 27).

3.4. Positive Coping
Positive coping includes all items of Brief cope of active coping, use of emotional support, planning, and use of instrumental support (2, 7, 5, 10, 15, 14, and 25).

II. Subject and Methods

Research design:
A descriptive correlational design was utilized to fulfill the aim of this study.
Research setting:
The study was conducted at genetic outpatient in specific children hospital in Benha City, Kaluobia Governorate, which is affiliated to the Ministry of Health.
Research sample:
Purposive sampling of 50 parents with Down syndrome children was recruited**.**
Tools of Data Collection:
The following tools were used for data collection.
Tools (1):- Structured Interviewing Questionnaire Sheet.

It was designed by the researchers after reviewing related literature, which includes two parts. *Part 1*:- socio-demographic data about parent`s age, sex, marital status, occupation, educational level, family history, family support, economic status, income, family number, number of children, and residence. *Part 2*:- Socio-demographic data about child age, sex, child order, level of education, with whom the child come to hospital, child caregiver, duration of disease, and other child with down syndrome.

Tools (2):- Parental Stress Scale.

Parental Stress Scale, originally developed by ***Berry & Jones (1995),*** was used to measure parental stress for both mothers and fathers. It is a self-report measure that contains 18 items representing pleasure or positive themes of parenthood (emotional benefits, self-enrichment, and personal development) and negative components (demands on resources, opportunity costs and restrictions). Parents were asked to rate each item on a five-point scale: strongly disagree (1) disagree (2), undecided (3) agree (4) strongly agree (5). To compute the parental stress score, items 1, 2, 5, 6, 7, 8, 17, and 18 should be reverse scored as follows: (1=5) (2=4) (3=3) (4=2) (5=1). The item scores are then summed. Higher scores on the scale specify greater stress and low scores indicates minor scores. Higher scores on the scale specify a high level of parent stress and low scores indicates low level of parent stress. Overall possible scores on the scale range from 18-90.

Tools (3):- Brief Cope Inventory.

Brief cope is a briefer form of cope inventory developed by ***Carver, (1989)***, used to categorize the coping strategies used by parents. This scale consisted of 28 items categorized into Active avoidance coping included all of the items from the original Brief COPE subscales for the substance use, behavioral disengagement, self-blame, venting of emotions, and one item from the distraction scale (item no. 1, 4,6, 9, 11, 13, 16, 19, 21, 26). Problem-focused coping included all the items from the original Brief COPE, subscales for planning, active coping, seeking instrumental social support, and one item each from the acceptance and emotional social support scales (12, 15, 17, 18, 20, 24, and 28). Religious/Denial coping is a varied factor that included all the Brief COPE items for religious coping and denial (3, 8, 22, 27). Positive coping includes all items of Brief COPE of active coping, use of emotional support, planning, and use of instrumental support (2, 7, 5, 10, 15, 14, and 25). Items are arranged in a 4-point Likert format (1=Never, 2= Very less, 3= Sometimes, and 4= A lot).

Tools (4):- Ryff's Psychological Well-being Scale.

Ryff's Psychological well-being scale developed by ***Ryff& Keyes, (1995)***, used to know the level of psychological wellbeing among the parent. This scale has 18 items consist of a multidimensional view on autonomy, The Autonomy subscale items are Q15, Q17, Q18. The Environmental Mastery subscale items are Q4, Q8, Q9. The Personal Growth subscale items are Q11, Q12, Q14. The Positive Relations with Others subscale items are Q6, Q13, Q16. The Purpose in Life subscale items are Q3, Q7, Q10. The Self-Acceptance subscale items are Q1, Q2, and Q5.the scale scored as1 = strongly agree; 2 = somewhat agree; 3 = a little agree; 4 = neither agree or disagree; 5 = a little disagree; 6 = somewhat disagree; 7 = strongly disagree. Q1, Q2, Q3, Q8, Q9, Q11, Q12, Q13, Q17, and Q18 should be reverse-scored. To calculate subscale scores for each participant, sum respondents' answers to each subscale's items. Higher scores mean higher levels of psychological well-being.

III. Methods

The study was executed according to the following steps:

Administrative approval:

An official permission was obtained from the hospital authorities in the identified setting to collect the necessary data, and parent consent was be obtained to participate in study.

Pilot study:

After the development of tools, a pilot study was carried out on 10% of the studied subjects (5) parents with Down syndrome children who were excluded from the main study sample. The purpose of the pilot study were to ascertain the clarity, applicability relevance and content validity of the tools, estimate the time needed to complete the sheet, and the necessary changes were undertaken.

After conducting the pilot study, it was found that:

(1) The tools were clear and applicable; however, few words were modified.

(2) Tools were relevant and valid.

(3) No problem that interferes with the process of data collection was detected.

(4) Following this pilot study the tools were made ready for use**.**

Validity:

Content validity was done to assure that the utilized tools measure what it was supposed to measure. Tools developed by the researchers were examined by a panel of five experts to determine whether the included items clearly and adequately cover the domain of content addressed.

Reliability:

Reliability was applied by the researcher for testing the internal consistency of the tool, by administration of the same tools to the same subjects under similar conditions on one or more occasions. The Cronbach's coefficient alpha of Parental Stress Scale is (.81) for total score, while Cronbach's alpha of Psychological Wellbeing is (.70) Cronbach's alpha of coping strategies is (.72).

Ethical considerations:

- Approvals of parents were obtained before data collection and after explaining the purpose of the study.
- Anonymity was assured as the filled questionnaire sheets were given a code number (not by names).
- The parent was ensured that questionnaire sheet will be used only for the purpose of the study and will be discarded at the end of the study.
- The patients who participated in the study were informed about having the right to withdraw at any time without giving any reason.

Field work:

The actual field work was carried out from the beginning of Jun 2019 to the September 2019. The study setting was visited one times/week started from 9Am to 12 Pm. At the beginning of interview the researcher greeted the parents, introduced herself to each patient, explained the purpose of the study, took oral consent to participate in the study, filled interviewing questionnaire sheet and then each parents was asked to fill the tools.

Statistical analysis:

The results were statistically analyzed by using SPSS version 22. Numerical data were expressed as mean ± SD. Qualitative data were expressed as frequency and percentage. Relations between different variables were tested using Chi square. Pearson's Correlation analysis was used to show strength and direction of association between two quantitative variables. P value < 0.05 is considered significant.

IV. Results

Table (1): Distribution of the studied parents according to their socio-demographic characteristics (N= 50).

Socio-demographic characteristics	N	%	X^2	P
Age (years)				
• 18-24	4	8.0		
• 25-31	10	20.0		
• 32-38	27	54.0	38.60	<0.001**
• 39-45	5	10.0		
• ≥46	4	8.0		
Mean ±SD	35.48 ± 5.58			
Sex				
• Male	18	36.0	3.09	<0.05*
• Female	32	64.0		
Marital status				
• Married	38	76.0		
• Divorced	7	14.0	70.80	<0.001**
• Wildwood	4	8.0		
• Separated	1	2.0		
Level of education				
• Illiterate	5	10.0		
• Read and write	3	6.0		
• Primary	12	24.0	14.60	<0.006**
• Secondary	18	36.0		
• Graduate of high education	12	24.0		
Occupation				
• Employee	28	56.0		
• Unemployed	19	38.0	19.24	<0.001**
• Retired	3	6.0		
Family history				
• Yes	12	24.0	13.52	<0.001**
• No	38	76.0		
Family support				
• Yes	42	84.0	23.12	<0.001**
• No	8	16.0		
Economic status				
• Low	11	22.0		
• Moderate	27	54.0	9.64	<0.008**
• High	12	24.0		
Income				
• Insufficient	16	32.0		
• Barely sufficient	24	48.0	5.92	<0.05*
• Sufficient	10	20.0		
Family number				
• 3	15	30.0		
• 4	27	54.0	11.08	<0.004**
• ≥ 5	8	16.0		
Number of children				
• 1	8	16.0		
• 2	18	36.0	9.84	<0.05*
• 3	18	36.0		
• ≥ 4	6	12.0		
Residence				
• Urban	32	64.0	3.92	<0.05*
• Rural	18	36.0		

Table (2): Distribution of children with Down syndrome according to their socio-demographic characteristics (N= 50).

Socio-demographic characteristics	N	%	X^2	P
Age (Years)				
• 1- <5	12	24.0		
• 5-<10	28	56.0	28.88	<0.001**
• 10 - < 15	7	14.0		
• 15- ≥ 20	3	6.0		
Mean ±SD	**5.57 ± 2.06**			
Sex				
• Male	26	52.0	0.08	>0.05
• Female	24	48.0		
Child order				
• First	5	10.0		
• Second	22	44.0	20.88	<0.001**
• Third	19	38.0		
• Fourth	4	8.0		
Level of education				
• None	13	26.0		
• Nursery	22	44.0		
• Primary	13	26.0	16.08	<0.001**
• Secondary	2	4.0		
• Graduate	0	0.0		
With whom the child come to hospital				
• Father	12	24.0		
• Mather	31	62.0	41.36	<0.001**
• One of sibling	6	12.0		
• One of relatives	1	2.0		
Child caregiver				
• Father	17	34.0		
• Mather	27	54.0	33.52	<0.001**
• Sister/brother	5	10.0		
• Other relatives	1	2.0		
Duration of disease				
• One year	6	12.0		
• 2-3 year	14	28.0	17.92	<0.001**
• ≥ 4 year	30	60.0		
Other child with down syndrome				
• Yes	9	18.0	20.48	<0.001**
• No	41	82.0		

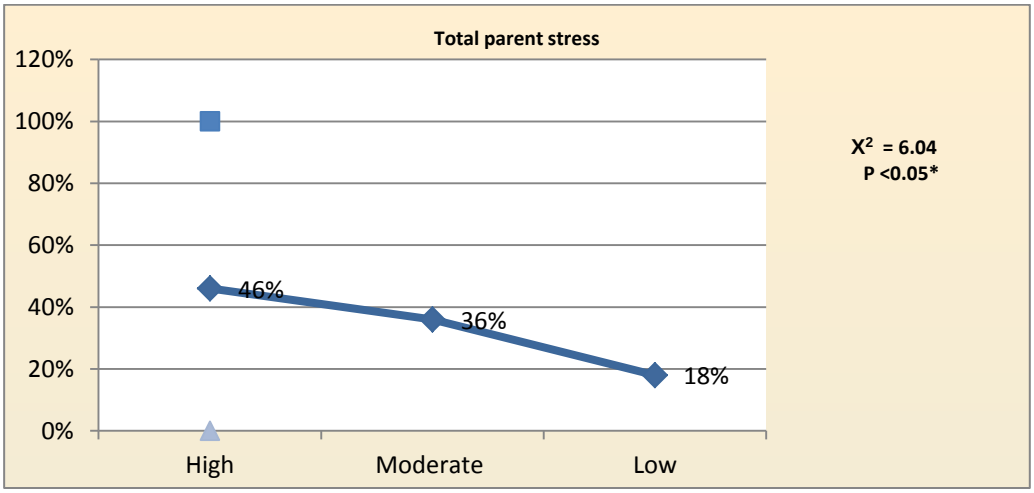

Figure (1): Distribution of the studied parents according to their total level of stress.

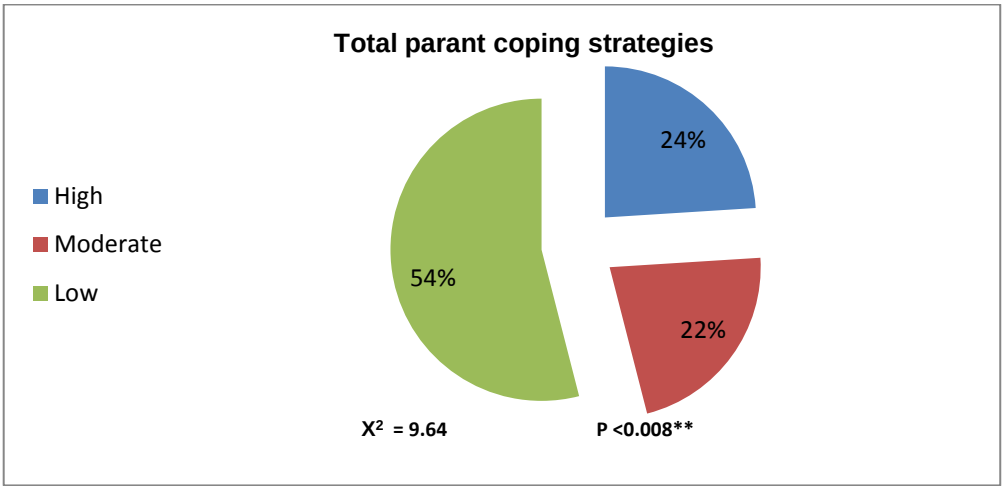

Figure (2): Distribution of the studied parents according to their total level of coping strategies.

Table (3) Distribution of the studied parents according to total level of coping strategies subscales (N=50).

Coping strategies	Low		Moderate		High		X^2	P
	N	%	N	%	N	%		
Religious / denial coping	26	52.0	17	34.0	7	14.0	22.69	<0.002**
Active avoidance coping	13	26.0	31	62.0	6	12.0	24.88	<0.009**
Problem focused coping	35	70.0	3	6.0	12	24.0	34.92	<0.001**
Positive coping	30	60.0	5	10.0	15	30.0	37.36	<0.001**

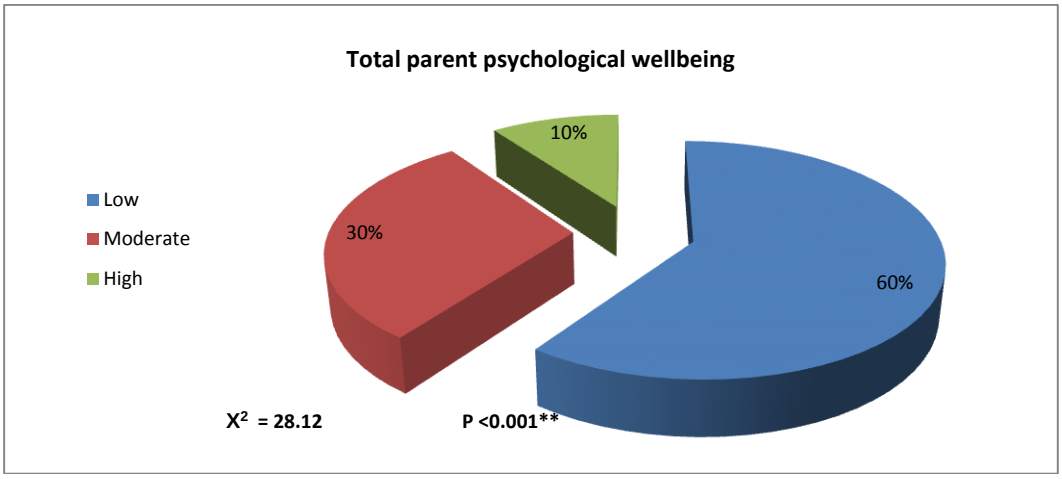

Figure (3): Distribution of the studied parents according to their total level of psychological wellbeing (N=50).

Table (4): Distribution of the studied parents according to their total level psychological wellbeing subscales (N=50).

Psychological wellbeing	Low		Moderate		High		X^2	p
	N	%	N	%	N	%		
Autonomy	21	42.0	6	12.0	23	46.0	10.36	<0.001**
Environmental mastery	26	52.0	10	20.0	14	28.0	8.32	<0.05*
Personal growth	26	52.0	9	18.0	15	30.0	8.92	<0.05*
Positive relation with others	22	44.0	4	8.0	24	48.0	14.56	<0.001**
The purpose in life	26	52.0	8	16.0	16	32.0	9.76	<0.008**
The self-acceptance	25	50.0	3	6.0	22	44.0	17.08	<0.001**

Table (5): Correlation between total parental stress, coping strategies and psychological wellbeing among parents with Down syndrome children (N=50).

Total Scales	Parental stress		Coping strategies	
	r	p	r	p
Parental stress	-	-	0.19	>0.05
Coping strategies	0.19	>0.05	-	-
Psychological wellbeing	0.125	>0.05	0.12	>0.05

Table (6): Correlation between coping strategies and psychological wellbeing subscales among parents with Down syndrome children (N=50).

Psychological wellbeing	Coping strategies							
	Denial coping)Religious /		Active avoidance coping		Problem focused coping		Positive coping	
	r	p	r	p	r	p	r	p
Autonomy	0.07	>0.05	0.01	>0.05	0.08	>0.05	0.17	>0.05
Environmental mastery	0.18	>0.05	0.06	>0.05	0.27	<0.05*	0.16	>0.05
Personal growth	0.16	>0.05	0.06	>0.05	0.05	>0.05	0.11	>0.05
Positive relation with others	0.15	>0.05	0.12	>0.05	0.21	<0.05*	0.13	>0.05
The purpose in life	0.24	<0.05*	0.00	>0.05	0.28	<0.05*	0.15	>0.05
The self-acceptance	0.29	<0.05*	0.03	>0.05	0.07	>0.05	0.28	<0.05*
Total	0.44	<0.01**	0.11	>0.05	0.17	>0.05	0.19	>0.05

Table (7): Relationship between parental stress and their socio-demographic data (N= 50).

Socio-demographic data	Parental stress						X^2	p
	Low (n=9)		Moderate (n=18)		High (n=23)			
	N	%	N	%	N	%		
Age (years)								
• 18-24	0	0.0	2	4.0	2	4.0		
• 25-31	0	0.0	4	8.0	6	12.0	6.00	>0.05
• 32-38	6	12.0	9	18.0	12	24.0		
• 39-45	2	4.0	1	2.0	2	4.0		
• ≥46	1	2.0	2	4.0	1	2.0		
Sex								
• Male	2	4.0	8	16.0	8	16.0	1.31	>0.05
• Female	7	14.0	10	20.0	15	30.0		
Marital status								
• Married	7	14.0	13	26.0	18	36.0		
• Divorced	1	2.0	2	4.0	4	8.0	2.89	>0.05
• Wildwood	1	2.0	2	4.0	1	2.0		
• Separated	0	0.0	1	2.0	0	0.0		

Level of education								
• Illiterate	0	0.0	1	2.0	4	8.0	5.85	>0.05
• Read and write	0	0.0	1	2.0	2	4.0		
• Primary	2	4.0	6	12.0	4	8.0		
• Secondary	4	8.0	5	10.0	9	18.0		
• Graduate of high education	3	6.0	5	10.0	4	8.0		
Occupation								
• Employee	4	8.0	11	22.0	13	26.0	1.01	>0.05
• Unemployed	4	8.0	6	12.0	9	18.0		
• Retired	1	2.0	1	2.0	1	2.0		
Family history								
• Yes	5	10.0	4	8.0	3	6.0	6.45	<0.05*
• No	4	8.0	14	38.0	20	40.0		
Family support								
• Yes	6	12.0	15	30.0	21	42.0	2.93	>0.05
• No	3	6.0	3	6.0	2	4.0		
Family number								
• 3	0	0.0	5	10.0	10	20.0	10.54	<0.05*
• 4	9	18.0	9	18.0	9	18.0		
• ≥ 5	0	0.0	4	8.0	4	8.0		
Number of children								
• 1	1	2.0	5	10.0	2	4.0	11.38	>0.05
• 2	1	2.0	4	8.0	13	26.0		
• 3	6	12.0	7	14.0	5	10.0		
• ≥ 4	1	2.0	2	4.0	3	6.0		
Residence								
• Urban	8	16.0	6	12.0	18	36.0	11.79	<0.003**
• Rural	1	2.0	12	24.0	5	10.0		

Table (8): Relationship between coping strategies and parent socio-demographic data (N= 50).

Socio-demographic data	**Coping strategies**						**X^2**	**p**
	Low (n=27)		**Moderate(n=12)**		**High (n=11)**			
	N	**%**	**N**	**%**	**N**	**%**		
Age (years)								
• 18-24	3	6.0	1	2.0	0	0.0	7.98	>0.05
• 25-31	6	12.0	2	4.0	2	4.0		
• 32-38	14	28.0	6	12.0	7	14.0		
• 39-45	2	4.0	3	6.0	0	0.0		
• ≥46	2	4.0	0	0.0	2	4.0		
Sex								
• Male	10	20.0	4	8.0	4	8.0	0.05	>0.05
• Female	17	34.0	8	16.0	7	14.0		
Marital status								
• Married	23	46.0	8	16.0	7	14.0	5.56	>0.05
• Divorced	2	4.0	2	4.0	3	6.0		
• Widowed	1	2.0	2	4.0	1	2.0		
• Separated	1	2.0	0	0.0	0	0.0		
Level of education								
• Illiterate	5	10.0	0	0.0	0	0.0	13.61	>0.05
• Read and write	2	4.0	0	0.0	1	2.0		
• Primary	4	8.0	3	6.0	5	10.0		
• Secondary	11	22.0	3	6.0	4	8.0		
• Graduate of high education	5	10.0	6	12.0	1	2.0		
Occupation								
• Employee	13	26.0	8	16.0	7	14.0	2.33	>0.05
• Unemployed	12	24.0	4	8.0	3	6.0		
• Retired	2	4.0	0	0.0	1	2.0		

Family history								
• Yes	7	14.0	3	6.0	2	4.0	0.26	>0.05
• No	20	40.0	9	18.0	9	18.0		
Family support								
• Yes	23	26.0	10	20.0	9	18.0	0.07	>0.05
• No	4	8.0	2	4.0	2	4.0		
Income								
• Insufficient	10	20.0	3	6.0	3	6.0		
• Barely sufficient	16	32.0	5	10.0	3	6.0	10.48	<0.05*
• Sufficient	1	2.0	4	8.0	5	10.0		
Family number								
• 3	7	14.0	3	6.0	5	10.0		
• 4	12	24.0	9	18.0	6	12.0	9.37	<0.05*
• ≥ 5	8	16.0	0	0.0	0	0.0		
Number of children								
• 1	4	8.0	1	2.0	3	6.0		
• 2	11	22.0	1	2.0	6	12.0	13.06	<0.05*
• 3	10	20.0	6	12.0	2	4.0		
• ≥ 4	2	4.0	4	8.0	0	0.0		

Table (9): Relationship between studied parents sex and total level of stress (N=50).

Sex	**Total stress**						**X^2**	**P**
	Low (n=9)		Moderate (n=18)		High (n=23)			
	N	%	N	%	N	%		
Male (18)	2	4.0	8	16.0	8	16.0		
Female (32)	7	14.0	10	20.0	15	30.0	1.31	>0.05
	Total coping strategies						X2	P
Male (18)	10	20.0	4	8.0	4	8.0	0.50	>0.05
Female (32)	17	34.0	8	16.0	7	14.0		
	Total psychological wellbeing						X2	P
Male (18)	12	24.0	4	8.0	2	4.0	0.81	>0.05
Female (32)	18	36.0	11	22.0	3	6.0		

V. Results

Table [1]: showed that more than half of the studied parents (54.0%) age ranging between 32-38 years with Mean ±SD 35.48 ± 5.58, and more than half of them were female; more than three quarters (76.0%) were married. More than one third of them (36.0%) their level of education were secondary, also more than the studied parents (56.0%) were employee; more than three quarters of them (76.0%) has no family history, the majority (84.0%) have family support. More than half (54.0%) their economic status moderate and nearly to half (48.0%) their income barely sufficient. Concerning to family number more than half (54.0%) have four member, while more than one third (36.0%) have two and three children respectively; nearly to two thirds (64.0%) living in urban area.

Table [2]: revealed that distribution of the parent children with Down syndrome according to their socio-demographic characteristics. This table shows that half of parent children(56.0%) with Down syndrome age ranging 5-<10 years with Mean ±SD 5.57 ± 2.06; and more than half (52.0%) were male, while nearly to half (44.0%) child order is the second. Concerning to level of education, nearly to half child (44.0%) in nursery, more than half (62.0%, 54.0%) child come to hospital with their mother, and mother is caregiver respectively. While more than half the duration of disease ≥ 4 year, and the majority (82.0%) has no other child with Down syndrome.

Figure [1]:illustrated that nearly to half (46%) of the studied parents had high level of stress, while more than one third of them (36%) had moderate level of stress. **Figure [2]:** revealed that more than half (54%) of the studied parents had low level of their coping strategies, and more than fifth of them (24%) had moderate level of coping strategies.

Table [3]: revealed that low level of religious / denial coping, problem focused coping and positive coping of parent coping strategies subscale. Also, moderate level of active avoidance coping of parent coping strategies.

Figure [3]: showed that two thirds (60%) of the studied parents had low level of psychological wellbeing, while about one third (30%) had moderate level of psychological wellbeing.

Table [4]: showed that; high level of autonomy and positive relation with others (46.0%, 48.0% respectively) of psychological wellbeing among the studied parents, while there is low level of the studied parents regarding environmental mastery(52.0%), personal growth (52.0%), the purpose in life(52.0%), and the self-acceptance (50.0%).

Table [5]: revealed that; there is no statistically significant correlation between parental stress, coping strategies and psychological wellbeing among parents with Down syndrome children.

Table [6]: showed that; there is statistically significant correlation between denial /Religious coping with the purpose in life and the self-acceptance. There is statistically significant correlation between problems focused coping with environmental mastery, positive relation with others, and the purpose in life. There is statistically significant correlation between positive coping and the self-acceptance. Furthermore, there is highly statistically significant correlation between denial / Religious coping with total of psychological wellbeing among parents with Down syndrome children.

Table [7]: showed that a statistically significant relation between parent stress and family history and family number, while there is a highly statistically significant correlation between parental stress and residence. **Table [8]:** reveals that; a statistically significant relation between coping strategies with income, family number, and number of children.

Table (9) illustrated that; relationship between studied parents sex and total level of stress, total coping strategies, and total psychological wellbeing. this table shows that about one third of parent are female had high level of stress, and one third of parent are female have low level of coping strategies, while more than one third of parent are female have low level of psychological wellbeing comparing to parent male.

VI. Discussion

Down syndrome (DS) is the commonest chromosomal disorder causing mild to moderate intellectual disability. The worldwide incidence is 1 in 733 live births ***(Marcdante & Nelson, 2015).***Down syndrome child in a family is usually a serious stress factor for parents. It often requires reorientation and re-evaluation of family goals, responsibilities and relationships ***(Azeem et al., 2013).*** Multifaceted factors like social isolation, financial constraints, poor marital relationships, behavioral, health and developmental problems of the child and above all limited family and social support have made parents vulnerable to stress.

Parents of children with DS perceived more care giving difficulties and child related stress like distractibility, demanding or unacceptable behavior. Parent related stress like incompetence; depression and health problems were also more in these parents. Stress in addition to compromising the mental and physical health of the caregiver, can also negatively influence the relationship between the caregiver and the child. Parenting, due to the involvement of different movements - satisfaction, rewards, demands and overloads - can harm the physical, emotional, and social well-being of parents ***(Skreden et al., 2012).***This study was aimed to assess the levels of parents stress, psychological well-being, and coping strategies among parents with DS children, and to investigate the relationship between parents stress, psychological well-being, and coping strategies among parents with DS children.

The results of the present study revealed that more than half of the studied parent's age ranging between 32-38 years with Mean ±SD 35.48 ± 5.58, meaning that the subjects were still at productive ages. In the other side, this result not consistent with ***Parameswari & Eljo, (2018)*** who founded that majority of the respondents belong to the age group of 21–40 years. Also this result disagreement with ***Hayat & Zafar, (2015)*** who founded that the age of parents fall from the 25-56 years.

The results of the present study showed that more than half of the sample were female; this may be due to mothers were the primary caregivers in all families that she actually go to doctor with his children for follow up and checkup more than father. As children with DS are associated with many medical problems that need extra care, follow-up and even hospitalizations that need from parents spent more time with their children. This result agreement with ***Salas et al., (2017)*** who founded that more than half of the sample was women. Also this result agreement with the result by ***Barros et al., (2017)*** who founded that the study group presented higher percentage in his study. The study shows more than three quarters of the studied sample were married. This may be due to that most of the sample in the age of marriage and female. This result agreement also with ***Kózka & Przybyła-Basista, (2018)*** who founded that all parents were married.

Concerning to level of education more than one third of the parents their level of education were secondary. This result consistent with ***Kózka&Przybyła-Basista, (2018)*** who founded that the majority of parents (mothers and fathers) had secondary education. Also ***Sangeetha et al., (2017)*** founded that even though the majority of mothers had up to secondary education and above. The result inconsistent with ***Marchal, (2017)*** who stated that the majority of the parents received higher education.

The present study revealed that more than the studied parents were employee. This result similar to ***Cooke, (2010)*** who reported that more than half of the sample were employed outside of their home. In the same side, this result consistent with ***Salas et al., (2017)***. In the other side the result disagreement with a study by***Norizan & Shamsuddin, (2010)*** who found that most parents were housewives. Concerning to presence of family support among parents with DS children, the result showed that the majority have family support. This result similar to ***Swanepoel & Haw, (2018)*** his result illustrated that the majority of parents have family support.

The present study illustrated that more than half their economic status moderate and nearly to half their income barely sufficient. This agreement with ***Kózka & Przybyła-Basista, (2018)*** who founded that parent described their financial situation as sufficient. Concerning to family number more than half have four member. This result consistent with ***Richter, (2017)*** who founded that the majority had other children, varying from three to four children total. The present study reveals that more than one third of the study parents has two children. This result similar to the result by ***Jaramillo et al., (2015)*** who founded that more than one third have two and three children. Also the result similar to ***Marchal, (2017)*** which found that most of the children two.

Concerning to distribution of the of parent children with DS according to their socio-demographic characteristics. The result of the present study showed that more than half parent children with Down syndrome age ranging 5-<10 years with Mean ±SD 5.57 ± 2.06. This result similar to the result of a study by ***Jaramillo et al., (2015)*** who found that the average age of the DS children was 7.5 years (SD 2.9). This result disagreement with ***Katkic et al., (2017)*** who founded that children included in his study were aged from 1 to 13 years, (mean=5.21, SD=3.09).The study revealed also that more than half of children were male. Thisresult similar to result of a study by ***Daulay et al., (2018)*** who founded that most of the children in the study boy. In the other hand, this result inconsistent with ***Richter, (2017)*** who stated that more than half had a child with DS who was female.

The present study was conducted to investigate the relationship between parent stress, psychological wellbeing, and coping strategies among parents with DS children. The main objective of the study was to identify levels of parent stress, psychological wellbeing, and coping strategies among parents with DS children. It is well acknowledged in literature that parents raising a child with developmental disabilities face difficulties that are not shared by parents of normally developing children. Also, parents having children with special needs are prone to stress, they experience more stress, depression, anxiety and other mental health problems ***(Ilias et al., 2018).***

The result of the present study illustrated that; nearly to half of the studied parents had high level of stress, while more than one third of them had moderate level of stress. This may be due to children with DS need extra-care and extra-attention necessary due to deficits in cognitive and social areas, limitedness such as children's dependence on parent and other causes of stress that children with DS often have other comorbid chronic health conditions, also fears concerning children's everyday medical and social situation, parents are also worried about their difficult-to-predict future.

The reviewed literature showed that the mothers are the ones who suffer most from emotional overload or stress since they are the main caregivers of children with Down syndrome ***(Oliveira et al., 2016).***'The demands are diverse and the mothers receive little or no support to meet the challenges; they suffer for not being able to take care of the other children and for not giving attention to the husband' ***(Ribeiro et al., 2016).*** Caring for the child with DS continues throughout life and is largely associated with feelings of anxiety and uncertainty, and above all related to the need for long-term care and the impact this will have on the personal life of these caregivers ***(Rocha, & Souza, 2018).***

Another cause of emotional stress is due to the fact that mothers need to give up their studies and work, so they do not have time for personal activities, such as looking after their appearance or doing physical activities, as well as feeling tired due to the poor collaboration of other family members in relation to the care of the child. Mothers have difficulty getting back to their life plans. Most continue to live for their children even when they are teens or adults because they need to accompany and supervise them and do not feel secure in leaving them alone or with other caregivers ***(Ribeiro et al., 2016).***The results of this study correspond with the results of other similar studies, proving that most of the parents with children with DS were in the clinical range of stress, which is alarming and that more counseling needs to be given to these parents ***(Tripathi, 2015).***Also this result consistent with the result of a study to assess parenting stress in mothers of children with Down syndrome in preschool age which shows significantly elevated parent stress ***(Sarimski, 2017).***

A recent meta-analysis suggested that parenting stress is higher in parents of children with autism spectrum disorders or DS than in parents of typically development children ***(Hayes & Watson, 2013).*** It is recognized that disability impacts the whole family ***(Earnhart, 2015).*** Raising a child is always stressful, but raising a child with developmental disabilities (DD) can present special challenges for parents. Higher stress levels in parents whose children have DD are significantly higher than those of parents with typically developing children ***(Yoong & Koritsas, 2012).*** Furthermore, ***Jaramillo et al., (2015)*** his result showed that mothers of children with DS are more likely to be emotionally exhausted and depressed than their partners. In

the other side, this result inconsistent with ***Amireh, (2019)*** who founded that the parents of Down syndrome children showed the lowest stress comparing to other group. Also, many researchers notice that parents of children with Down syndrome experience lower levels of stress than parents of children with different disabilities, such as autism or cerebral palsy ***(Pisula, 2007; & Richman et al., 2009).***

The result of the present study revealed that more than half of the studied parents had low level of their coping strategies. This may be depend on economic and educational status of parents and their constant contact with the health care system, and availability of intervention services in the community. Other courses, support groups that allow sharing, contact with each other, and provide information about the child's condition and assistance in choosing healthy coping, social relationship can be attributed to the joint family culture in general and support provided from the spouse as well as the society which helps these parents in dealing with severe stress. The spouse support in taking care of the child as well as supporting each other helped them in care taking. Some of the mothers had left their jobs and sit the whole day in the school with the child to see and repeat the same activities at home. It also helps the parent in the emotional release; parents regarded family cohesion and co-operation as the factor most helpful for coping. All this reasons help to cope with the situation relatively well and are able to continue their life normally. This result consistent with other result from a study aims to make comparison with parents of children with other disorders; parents of children with Down syndrome are relatively well-adjusted and slightly better cope with stress ***(Pisula, 2012).*** Other finding not supported the result ***Van Riper, (2007)*** who reported that many families taking care of children with DS are able to cope well in spite of many challenges and misfortunes.

The result of the present study revealed that low level of problem focused coping and positive coping of parent. There can be many reasons for using problem focused and active emotional (both positive) coping in parents of children with DS. The parents felt that a realistic outlook of the child's disability and acceptance of the situation had helped them to cope. After the information provided by the schools and other agencies about the supporting systems available, they were more optimistic about the future of the child. Putting the child in a special school helps the parents to find out other parents who are also facing the same problems and sharing of their concerns and problems helps them cope better. Informal support from friends and relatives was regarded as essential for managing in everyday life. Parental positive perceptions about children with disabilities might also serve as an adaptive function by helping parents to cope with relatively high levels of stress. Because of the acceptance of their child's status, parents had a realistic and optimistic attitude towards their own and their child's life and future. Since all the children were from special schools, this also indicates parents' positive approach to give a better platform to their child. This result consistent with the result by ***Ganjiwale et al., (2016)***who founded that Problem focused coping and positive coping was mainly used by parents of child with DS.

Concerning to the level of psychological well-being among parents with DS children, the result of the present study revealed that two thirds of the studied parents had low level of psychological wellbeing. In our opinion, these parents have adapted to their situation of raising a child with disability better than the parents who perceive their parenthood as a burden or challenge. It is possible that parents who struggle with many stressful hardships and demands have difficulties achieving satisfaction and an optimal level of psychological well-being and adaptation. This result consistent with ***Parameswari & Eljo, (2016)*** who found that more than half of the respondents have low level of psychological wellbeing and nearly half having high level of psychological wellbeing. The result inconsistent with ***Hayat & Zafar, (2015)*** who found that results indicated that fathers had greater psychological well-being as compared to mothers. They were found low on depression, anxiety and stress as compared to mothers who experience more depression, anxiety and stress. This result inconsistent with previous research on the impact of a child's disability on parental psychological well-being the result has demonstrated that mothers of children with Down syndrome often fare psychologically better than do mothers of children with other forms of mental retardation ***(Abbeduto et al., 2004).***

The result of the present study shows that high level of autonomy and positive relation with others among the studied parents psychological wellbeing, while there is low level of the studied parents regarding environmental mastery, personal growth, the purpose in life and the self-acceptance. This result consistent with ***Parameswari & Eljo, (2016)*** who founded that the result based on the findings related to the dimensions that nearly half of the parents are having low level of positive relation with others, and more than half of the respondents are having low level of self-acceptance. Next to that based on the environment there are more than half of the resonance are having low level of environmental mastery, regarding purpose in life majority of the parents are having low level of purpose in their life. In the other side, ***Parameswari & Eljo, (2016)*** stated that about the autonomy and personal growth there are more than half of the parents are having high level of autonomy and personal growth.

The present study shows that there is no statistically significant correlation between parental stress, psychological wellbeing, and coping strategies among parents with Down syndrome children. This finding inconsistent with ***Cramm &Nieboer, (2011)*** who stated that stress could also have an adverse impact on parents'

psychological well-being as evidenced by increased anxiety and depression. This result inconsistent with ***Ludlow et al., 2012; & Seymour et al., (2014)*** who stated that utilization of effective coping strategies has been identified as an important mechanism of managing parental stress and promoting well-being. Parental stress has been identified as a major affecter of caregivers' psychological well-being and a risk increaser for unwillingly placing children with disabilities in the care of others. Recognition of effective means to ease care giving burdens must guide policymaking and will help to provide better and tailored support and intervention for the children ***(Cram & Nieboer, 2011)***.

There is statistically significant correlation between denial/Religious coping with the purpose in life and the self-acceptance. There is statistically significant correlation between problems focused coping with environmental mastery, positive relation with others, and the purpose in life. There is statistically significant correlation between positive coping and the self-acceptance. There is highly statistically significant correlation between denial/Religious coping with total of psychological wellbeing among parents with Down syndrome children. This result consistent with a meta-analysis by ***Moreire-Almeida et al., (2006)*** reported both positive and negative correlations between two. ***Van-der, (2009)*** indicated that the effects of religious coping depend on whether positive or negative religious coping are implemented. They concluded that positive religious coping strategies can serve adaptive functions, but negative strategies can add to the burden already placed on someone grappling with a stress situation.

The result shows that; a statistically significant relation between parent stress and family history and family number, while there is a highly statistically significant correlation between with residence. This result inconsistent with ***Abou-Dagga, (2013)*** who founded that there is no statistical significant relation between parent psychological stress and the parent socio-demographic characteristics. Also the study result reveals that; a statistically significant relation between coping strategies with income, family number, and number of children. Better educated and working parents were having to use coping strategies for decreasing stress. Working outside provided mothers with social contacts and friends, a different role, a change of daily demands and an increase in income. In Egypt mothers are the sole caregivers and they have to be involved in activities apart from care giving. Strategies focusing on the physical, mental and psychological wellbeing and up liftment of mothers have to be adopted. Fathers and other family members have to be motivated to play better roles in the care of their child with disability. When the family member is little in number of children this help to mother for caring his Down syndrome children and utilization of effective coping strategies has been identified as an important mechanism of managing parental stress.

Concerning to relationship between studied parents sex and total level of stress, total coping strategies, and total psychological wellbeing, this result showed that about one third of parent are female had high level of stress, and one third of parent are female have low level of coping strategies, while more than one third of parent are female have low level of psychological wellbeing comparing to parent male. Concerning to stress level of mother, about one third of parent are female had high level of stress. This may be due to mothers tend to bear more responsibility for childcare than fathers within families of children with developmental disabilities like Down Syndrome. Also, mothers were taking on the exhausting duty of everyday care, whereas fathers struggled with family finances and future planning. This result supported by ***McStay et al., 2014; & Jones, (2013)*** who showed that parenting stress is higher in mothers than in fathers.

Also ***Pozo, (2010)*** who stated that mothers of children with disabilities typically tend to be more involved in caregiving and housekeeping than fathers this causing more stress. In the other hand, this result not supported by the few studies that have included fathers of younger children with developmental disabilities indicate that fathers often report higher parenting stress and poorer psychological well-being than fathers of children without disabilities and similar levels of parenting stress as mothers ***(Hastings, 2003).*** In the same side, ***Davis and Carter (2008)*** found that mothers and fathers were equally affected by the child's behaviour problems, but by different aspects of it. Specifically, mothers were stressed by their child's regulatory problems such as feeding and sleeping, whereas fathers were stressed by their child's externalizing behaviours such as aggression.

Concerning to level of coping strategies of parents, the result showed that one third of parent are female have low level of coping strategies. This may be due to lack of social and communication skills and increased behavioural problems contribute to greater psychological distress for parents. This result agrees with ***Hodapp & Ly, (2005)*** stated that fathers' needs are reportedly different from mothers' particularly in their adjustment to stress and coping. Fathers tend to be concerned with the financial costs of rearing a child with special needs whereas mothers' tend to be concerned about childcare, receiving proper resources, and having a support network. Also the author found gender differences on two dimensions of coping as mothers used active avoidance coping more frequently than fathers. Active avoidance coping strategies are maladaptive in nature and can set in motion stress and other psychological problems. This finding disagree with ***Pisula, (2012)*** who observed that mothers of children with Down syndrome experience less stress and learn to adapt and cope better as compared to other disabilities such as autism. In the same side, ***Cless, (2017)*** stated that mothers of DS

children have higher scores than fathers in using coping strategies with a positive attitude when facing the condition of DS children and overcoming bad conditions around parents with these DS children.

Concerning to level of psychological wellbeing comparing to parent male. One third of parent are female have low level of psychological. This mean that mothers continue to report higher levels of emotional distress compared to fathers. Mothers are the sole caregivers in our country and they have to be involved in activities apart from care giving. This result agreement with the findings of study by ***Hayat & Zafar, (2015)*** revealed that mothers of Down syndrome children have lower level of psychological well-being as compared to fathers.

VII. Conclusion

The result of the present study concluded that nearly to half of the studied parents had high level of stress, while more than one third of them had moderate level of stress, more than half of the studied parents had low level of their coping strategies, and two thirds had low level of psychological wellbeing. About one third of parent are female had high level of stress, and one third of parent are female have low level of coping strategies, while more than one third of parent are female have low level of psychological wellbeing comparing to parent male. There is no statistically significant correlation between parental stress, psychological wellbeing, and coping strategies among parents with Down syndrome children.

VIII. Recommendations

Based on the results of the study, the following recommendations are suggested :

1. Psycho-educational training program focused on reducing parental stress and training mothers to parent under stress.
2. Family psychological counseling to improve psychological wellbeing and necessity of training in effective coping strategies.
3. Proper counseling services are also helps the parent to lead their life in a positive way.
4. Future studies are needed to better understand the contribution of emotional, extra-familial, and societal factors to parenting-stress and psychological distress in families of children with DS.

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