

## Relationship between Psychological Well-Being and Coping Strategies among Family Caregivers of Children with Down syndrome

Amgad Said Mohammed<sup>1</sup>, Sahar Mahmoud Eliwa<sup>2</sup>, Rania Abdel-Hamid Zaki<sup>3</sup>  
Psychiatric/Mental Health Nursing Faculty of Nursing Ain Shams University.

### Abstract

**Background:** Rearing a child with Down Syndrome requires use of effective coping strategies that may have a buffering effect on psychological well-being of family caregivers. **Aim:** This study aimed to assess the relationship between psychological well-being and coping strategies among family caregivers of children with Down syndrome. **Design:** A descriptive research design was utilized in this study. **Setting:** This study was carried out in the Genes Clinics of DS in the specialized clinics of the university pediatric hospital affiliated to Ain Shams University Hospitals. **Subjects:** A sample of 120 family caregivers of children with Down syndrome. The study tools were: 1) Interviewing Questionnaire, 2) Ryff's Psychological well-being scale (1989) and 3) Brief-COPE inventory (Carver, 1997). **The results:** The study showed that family caregivers of children with DS combined between emotion-focused and problem focused coping strategies in managing burden of child caregiving and the most frequent used emotion focused coping strategies were acceptance and religion while the most frequent used problem-focused coping strategy was use of instrumental support. Concerning to psychological well-being, near two thirds of family caregivers of children with DS had psychological well-being less than usual. **Conclusions:** There was a negative significant correlation between level of psychological well-being and emotion-focused coping strategies except for use of emotional support, acceptance, self-distraction, venting, humor and religion. Meanwhile, there was a positive significant correlation between level of psychological well-being and problem-focused coping strategies except for positive reframing. **Recommendations:** Future research to assess factors that may influence role of caregiving and different challenges faced by family caregivers in rearing different aged children with DS.

**Key words:** psychological wellbeing, coping strategies, Down syndrome

### Introduction

Down Syndrome, the most common genetic cause of intellectual disability, is generally associated with a unique phenotype and may involve delayed growth, additional health problems and difficulties in carrying out activities of daily living as well as intellectual deficits. Family caregivers of

children with DS may encounter numerous challenges including, but not limited to, developmental, medical, educational, social and financial issues (Pisula, 2017).

Family caregivers of children with DS use arrange of coping strategies and resources to face burden of care. They use both adaptive (e.g., positive reframing;

seeking social support) and maladaptive (e.g., behavior disengagement) coping strategies, with an inclination towards adaptive coping methods such as seeking social support and positive reframing (Bonab, Motamedi & Zare, 2017).

Negative and positive reactions to raising a child with DS may not fall on the opposite ends of the continuum. Family caregivers of children with disabilities may experience positive psychological changes, and these changes may co-occur with negative symptoms such as distress and depression. So, assessing coping strategies and psychological well-being among family caregivers of children with DS is crucial and vital issue (Hayat, 2016).

### Significance of the study

Parenting a child with DS presents extraordinary challenges to family caregivers who often must assist their children with everyday living skills, manage their symptoms and co morbid behavior problems as well as navigating the complex disability service system. These challenges are not limited to the early childhood years, but extend into the period of adolescence and adulthood. Children with DS often continue to reside with their family caregivers and thus family caregivers continue to have higher levels of day to day caregiving responsibilities, stress and burden. Utilization of effective coping strategies has been identified as an important mechanism of managing family caregiver's burden and promoting their psychological well-being. So, Addressing coping and psychological well being of family caregivers of children with DS is necessary in order to improve their

overall health and quality of life as well as those of other family members.

### Aim of study

Assess the relationship between psychological well-being and coping strategies among family caregivers of children with Down syndrome.

**Research Questions:** This study is based on answering the following questions:

1.What is the level of psychological well-being among family caregivers of children with Down syndrome?

2.What are coping strategies among family caregivers of children with Down syndrome?

3.Is there a relationship between psychological well-being and coping strategies among family caregivers of children with Down syndrome?

### Subject and Methods

**Research Design:** A descriptive design has been utilized to fulfill the aim of the study and answer the research questions.

**Setting of the Study:** This study was conducted in the Genes Clinics of DS in the specialized clinics of the university pediatric hospital affiliated to Ain Shams University.

**Subjects:** A sample of 120 family caregivers of children with Down syndrome who agreed to participate in the study and fulfilled the following criteria:

### **Inclusion criteria for children with Down syndrome:**

- Intelligence Quotient (IQ) from (25-70).
- Sex: both sexes (males and females).
- Free from any neurological or psychiatric illness.

### **Exclusion criteria for children with DS:**

- Have another disability that is not associated with DS.
- Have a sibling or another family member with a disability.

### **Inclusion criteria for family caregivers of children with Down syndrome:**

- Family members who give direct care to the child.
- Had only one disabled child.
- Free from any psychiatric illness.
- Took care of the child for at least one year.

### **Exclusion criteria for family caregivers of children with DS:**

- Have more than one disabled child
- Have a physical disability or psychiatric illness.

### **Data Collection tools**

#### **1-Interviewing                      Socio Demographic                      Questionnaire "Appendix I"**

It was designed by the researcher after reviewing related literature and it included two parts:

**A-First part:** included data related to socio-demographic characteristics of family caregivers such as; age, sex, address level of education, etc.

**B-Second part:** included data related to socio-demographic characteristics of Down syndrome child such as; age, sex, education, etc.

#### **2-- Ryff's Psychological well-being scale (1989):**

It was adapted by the researcher. It was used to assess the level of psychological well being among the sample. It consists of 42 items.

#### **3- Brief-COPE inventory**

It was originally developed by (Carver, 1997) and adapted by the researcher. It was used to assess coping strategies among family caregivers of children with Down syndrome. It consists of 28 items presented in the form of a coping statement and respondents are asked to rate whether they have or have not been using each way of coping on a fully anchored three- point scale ranging from "I haven't been doing this at all" to "I've been doing this a lot".

#### **Tools validity and reliability**

To achieve the criteria of trustworthiness of the tools of data collection in this study, the tools were tested and evaluated for their face and content validity, and reliability. Face and content validity are tested by five experts from faculty members in the nursing and psychology field from Ain Shams and Tanta Universities.

### **Pilot study**

The Pilot study was carried out for 10% of the sample (12 family caregivers of children with Down syndrome) to test the reliability, clarity of questions and applicability of the tools, and the time needed to complete them then the tools were modified according to the findings of the pilot study. Subjects who shared in the pilot study were excluded from the main study sample. The time needed to fill out the tools was about 10 to 15 minutes.

### **Field work**

-Data collection of this study was carried out once permission was granted to proceed with the study.

-The Purpose of the study was simply explained to the family caregivers who agreed to participate in the study prior to any data collection.

-Voluntary participation and confidentiality were assured by the researcher for each family caregiver through clarifying to them that all information will be used for scientific research only.

-Sample was selected according to the inclusion criteria.

-One day per week (each Sunday) through using the study tools by the researcher

- Data was collected during morning at the working time of the Genes Clinics of DS in The Specialized Clinics in The University Pediatric Hospital affiliated to Ain Shams University Hospitals.

- The researcher met 120 family caregivers of children with Down syndrome who agreed to be involved in the study sample.

- The researcher started the interview with each family caregiver individually using the data collection tools.

- The questionnaire was read, explained, and choices were recorded by the researcher. The time consumed to fill out the questionnaire sheet ranged from 10 to 15 minutes, so the collection of the data ranged from 4 to 6 caregivers weekly.

- Data collection lasted for six months, from 3 September 2017 to 4 March 2018.

### **Ethical considerations**

The research approval of each participant to share in the study was taken. The researcher clarified the objectives and aim of the study to subjects. The researcher maintains anonymity and confidentiality of subject's data. Subjects are allowed to choose to participate or not to participate, and they have the right to withdraw from a study any time without penalty.

### **Statistical Design**

The statistical analysis of data was done by using the Statistical Package for Social Science (SPSS), version 22. The first part of data was descriptive data which was revised, coded, tabulated and statistically analyzed using percentage, arithmetic mean(x) and standard deviation (SD). The following tests were

used to test relations for significance. For quantitative data by chi-square tests-correlation by Pears on correlation.

Degree of significance results were:-

## Results

**Table (1):** It clarifies that, the highest proportion (91.7%) of family caregivers was mother, and more than half (60.9%) were in age group (35-<55) years old, the married caregivers are more than two thirds of the study sample (69.2%), also the illiterate caregivers represents (55.8%), the majority of the study sample (86.7%) are unemployed, most of the sample (75.8%) have not enough family income, and more than half (59.2%) live in rural areas. According to family history, the highest percentage has no family history for psychiatric illness or Down syndrome. They represent (95.8%) and (85.8%) respectively.

**Table (2):** clarifies that more than two thirds of family caregivers (70.8%) had no self acceptance, while more than one quarter (27.5%) had positive relations and purpose in life and one quarter (25.0%) had personal growth.

**Table (3):** illustrates the level of psychological wellbeing among the study sample and indicates that near two thirds of family caregivers (65.83%) had psychological wellbeing less than usual

## Discussion

The birth of a baby with Down syndrome or finding out that a child suffers from Down syndrome can be a

• P. Value>0.05(Not Significant)

• P.Value≤0.05(significant)

• P.Value≤0.001(Highly Significant)

and only (3.3%) have psychological wellbeing better than usual.

**Table (4):** explains that family caregivers used different emotion - focused coping strategies and the most common used strategies were acceptance (100%) and religion (96.67%) but substance abuse was the least used one (1.67%).

**Table (5):** indicates that family caregivers use different problem-focused coping strategies, the most common used strategy is use of instrumental support (89.17%) but active coping is the least used one (45.83%).

**Table (6):** indicates that there was a negative significant correlation between level of psychological wellbeing and emotion-focused coping strategies except for subscales of use of emotional support, acceptance, self-distraction, venting, humor and religion.

**Table (7):** reveals that there was a positive significant correlation between level of psychological wellbeing and problem-focused coping strategies of family caregivers of children with Down syndrome except for subscale of positive reframing.

traumatic event for family caregivers and can have profound effects on the entire family. Family Caregivers of children with Down syndrome face a set of physical, emotional, financial and social

problems, which directly affect the management of children and the psychological wellbeing of family caregivers. When family caregivers experience stress, they use certain strategies to cope with this stress to regulate their emotions. Problem-focused coping strategies are usually directed at acquiring resources to help deal with the underlying problem while emotion-focused coping may reduce the level of stress in the short term, but can affect psychological wellbeing in the long term.

#### **Socio-Demographic Characteristics of family caregivers of children with Down syndrome**

The current study results reveal that the highest proportion of family caregivers is mother. This reflects emotional ties between mother and child. So, mother who gives up her job or career to stay home and take over most of the child care responsibilities.

The current study results represent that more than two thirds of the study sample are married. This reflects emotional stability among parent caregivers that enables them to be able to do their best to face burden of child caregiving.

The findings of the current study represent that illiterate caregivers represent more than half of the study sample. It may be because more than half of the study sample live in rural areas and the majority of them are women above age of 35 Years old.

The current study results explain that the majority of the study sample are unemployed. It may be because the family caregivers, usually the mother, are

forced to stay at home longer to provide care for the disabled child.

The current study results represent that most of family caregivers have not enough family income. It may be because most of mothers are housewives and father is the only breadwinner as well as increased additional expenses for the provision of remedies and rehabilitation, for special home furniture, for clothing and food, for special toys or books.

#### **Level of Psychological Wellbeing of family caregivers of children with Down syndrome**

The current study results show that that majority of family caregivers have psychological wellbeing less than usual. This may be because some family caregivers may still feel stigmatized by the condition of their children, and are not willing to socialize, which may lead to stress and thus affect negatively their psychological wellbeing. In congruence with this, **McGuire and Chicoine (2002)** clarified that such a negative attitude to socialize may limit important opportunities for developing positive relations with others, and may lead to social isolation that lead to decreased psychological wellbeing. Also, The caregiver's psychological wellbeing can also be influenced by contextual factors, child factors (level of disability, presence of behavioral problems and overall child adjustment), caregiver related characteristics (coping strategies, support from family and friends), and also by education and other demographic factors). In congruence with this, **Hayat (2015), indicated** that family caregivers of Down syndrome children have experienced stress, anxiety, and low level of life satisfaction, do not have a good parent-

child relation and thus having psychological wellbeing less than usual. Additionally, **Parameswari and Eljo (2016)**, reported that more than half of the family caregivers of children with Down syndrome have low level of psychological well being.

#### **Emotion- Focused Coping Strategies of family caregivers of children with Down syndrome:-**

The current study results represent that family caregivers use different emotion - focused coping strategies and the most common used strategies are acceptance and religion through accepting the reality and becoming satisfied of it, considering the child disability as a test from Allah, seeking help from Allah to solve the child problems. It may be attributed to good faith and religiosity that are highly prevalent in our community where a disabled child might be considered as a gift from God. Such optimistic attitude may help to improve caregivers' adaptation. This is in the same line with an Indian study by **Sharma and Gupta, (2017)**, who reported that family caregivers often find relief in religious propitiation and surrender to the will of God when faced with child disability. This study result is also congruent with a study done by **Karen and Eva, (2016)** who found that acceptance and religion had the highest mean scores of the coping strategies sub-scales.

The current study results represent that substance abuse is the least used emotion-focused coping strategy where there are no family care givers has been using sedatives or barbiturates to be out of painful reality. It is may be due to religiosity that are highly prevalent in our community where substance use isn't

socially acceptable strategy for coping and increased caregivers awareness of dangers accompanied by substance use. This result is congruent with **Hayat, (2015)**, who reported that substance use is the least common emotion-focused strategy used by family caregivers of children with Down syndrome.

#### **Problem- Focused Coping Strategies of family caregivers of children with Down syndrome:-**

The current study results represent that as regards with use of instrumental support; the majority of family caregivers have been getting help and advice from psychiatrist, psychologist or social worker. So, instrumental support represents the most reported coping strategy. It may be due to their needs to know more about their child disability, their child physical complains associated with disability, changing behaviors of Down syndrome child, how to deal with those difficulties and how to cope with burden. This study is congruent with **Tajrishi, Azadfallah, Garakani, &Bakhshi, (2015)** who reported that family caregivers of children with Down syndrome use instrumental support with high percentages as instrumental support may alleviate the impact of stress appraisal by providing a solution to the problem, by reducing the perceived importance of the problem, by tranquilizing the neuroendocrine system so that people are less reactive to perceived stress, or by facilitating healthful behaviors. On the other hand, This current result is incongruent with **Hayat, (2015)** who reported that family caregivers of children with Down syndrome stressed more use of Problem-focused coping strategies and the most

reported coping strategy was planning and active coping.

The current study results represent that as regards with positive reframing, most of family caregivers use positive reframing where they have been concentrating on a good thing as achieving certain degree of the child autonomy. It may be due to acceptance that pushes family caregivers to look at the problem from its positive side. This result is in the same line with **Parameswari and Eljo, (2016)**, who reported that some family caregivers accept the reality and tend to lead a positive life in developing their coping skills and self-esteem; it also develops confidence to help their child considering their future and achieving certain degree of the child autonomy.

The current study results represent that family caregivers use active coping and planning with low percentages. It may be due to the nature of study sample where the majority of family caregivers are illiterate, poor and unemployed. All these factors lead family caregivers to have little chances for planning or active coping. This result is incongruent with **Hayat, (2015)** who reported that family caregivers of children with Down syndrome stressed more use of Problem-focused coping strategies and the most reported coping strategy was planning and active coping.

#### **Correlation between psychological wellbeing and emotion-focused coping strategies:-**

The current study results represent that there is a positive significant correlation between psychological wellbeing and emotion-focused coping

strategies regarding subscale of **use of emotional support**. psychological wellbeing of the family caregivers who get emotional support is good because in Egyptian setting, family plays an important role in providing support to the distressed members and the members stay together at the time of crisis and this emotional support introduced by spouse, other family members, relatives, friends or neighbors help family caregivers to express their feelings and become involved with individual and community and thus alleviate their anxiety and improve psychological wellbeing. This result is congruent with **Alexander and Walendzik, (2016)**, who reported that Family caregivers of Down syndrome who prevalently use adaptive coping strategies, such as emotional support find opportunities to grow from the specific challenges of their life situation. This helps them to be at a low risk for psychological and physical health problems, compared to family caregivers using rather dysfunctional strategies to cope with stressful factors in their lives.

The current study results represent that there is a positive significant correlation between psychological wellbeing and emotion-focused coping strategies regarding subscale of **acceptance**. This result may be attributed to good faith and religiosity that are highly prevalent in our community where a disabled child might be considered as a gift from God. Such optimistic attitude may help to improve caregivers' adaptation and psychological wellbeing. This result is congruent with **Parameswari and Eljo, (2016)**, who reported that family caregivers who accept the reality of their child disability tend to lead a positive life in developing their coping skills and self esteem; it also

develops confidence and thus improves their psychological wellbeing. On the other hand, This current study is incongruent with **Penley et al., (2012)**, who reported that most types of emotion - focused coping such as accepting responsibility were related to higher stress responses and less psychological wellbeing. This current study result is also incongruent with **Woodman, Hauser-Cram, (2013)**, who reported that emotion-focused styles of coping such as acceptance of responsibility were related to low levels of psychological wellbeing.

The current study results represent that there is a negative significant correlation between psychological wellbeing and emotion-focused coping strategies regarding subscale of **denial**. It may be because use of denial coping strategy serves to be out of reality leading to less life satisfaction, less positive affect, bad parent-child relation, increased mental suffering and desperateness as well as increased levels of psychiatric morbidity and burnout. This study is congruent with **Bonab, Motamedi, &Zare, (2017)** who found that use of denial as an emotion-focused coping strategy serves to avoid actually confronting the problem, and has been reported to show a positive association with depression and negative association with satisfactory outcome. However, the results from the present study are contrary to those reported by **Kraaij and Garnefski, (2016)**, who found that strategies involving perceptual distortions of reality (e.g. denial) are adaptive, especially when the stressful situation was unavoidable. It could be possible that these discrepancies are related to the nature of the stressor being experienced.

The current study results represent that there is a negative significant correlation between psychological wellbeing and emotion-focused coping strategies regarding subscale of **substance use**. It may be because substance use doesn't provide permanent solution for problems and lead to negative effects through affecting intellectual functioning of family caregivers and their ability to confront problems or to deal with current situation or to provide proper alternatives for child caregiving. So, substance use negatively affects psychological wellbeing of family caregivers. This study is congruent with **Pisula, (2010)**, who reported that substance use as a means of coping was associated with poorer psychological functioning.

The current study results represent that there is a negative significant correlation between psychological wellbeing and emotion-focused coping strategies regarding subscale of **behavioral disengagement**. It may be because it serves to avoid confronting problems and thus affects problem solving and stress management and leads to less psychological wellbeing. This result is congruent with **Shelley, Kraaij, and Garnefski, (2014)**, who reported that Avoidant coping strategies or behavior disengagement are also related to more depression and anxiety in family caregivers of children with Down syndrome. On the other hand, **Pisula and Kossakowska, (2010)**, reported that behavior disengagement can be useful in specific situations, particularly those that are short term and uncontrollable, but can lead to increased distress when the stressor persists.

The current study results represent that there is a negative significant correlation between psychological wellbeing and emotion-focused coping strategies regarding subscale of **self-blame**. It may be because self-blame leads to different emotional consequences such as anger, dissatisfaction, depressed mood and loss of interest that may lead to inhibition of future problem-focused activity and thus less psychological wellbeing. This result is congruent with **Allen and Leary, (2010)**, who found that blaming others was related to more depressive and angry feelings. This study is also congruent with **Folkman and Lazarus, (1988)**, who reported that blaming had a negative effect on psychological wellbeing.

The current study results represent that there is no significant correlation between psychological wellbeing and emotion-focused coping strategies regarding subscale of **self-distraction**. It may be because emotion-focused coping such as self-distraction does not provide a long term solution and requires combination with other problem-focused strategies to enhance coping and improve psychological well-being. This study is in the same line with **Moosa and Munaf, (2012)**, which found that distraction-oriented coping (a form of emotion-focused coping) does not correlate with either better psychological wellbeing, whereas a combination of distraction-oriented coping with task-oriented (i.e., problem-focused) coping leads to more positive outcomes.

On the other hand, this study is incongruent with **Dilys, (2017)**, who reported that distraction lead to better psychological well-being (i.e., lower stress responses and better performance)

by enhancing the effectiveness of problem-focused coping because it may provide individuals with the opportunity for rest and detachment from the stressful situation. The current study result is also incongruent with **Jason, (2015)**, who found that distraction fosters recuperation. As a result, family caregiver's well-being may be enhanced.

The current study results represent that there is no significant correlation between psychological wellbeing and emotion-focused coping strategies regarding subscale of **venting**. It may be because venting provides only false reassurance, does not provide a long term solution and requires use of active strategies to improve coping and psychological well-being. This study result is incongruent with **Cramm and Nieboer , (2011)** who found that some emotion-focused coping styles (e.g. focusing on or venting emotions) are associated with greater psychopathology compared to adaptive emotion-focused strategies.

The current study results represent that there is no significant correlation between psychological wellbeing and emotion-focused coping strategies regarding subscale of **humor**. It may be as humor doesn't provide long term solutions for the problem and leads to waste of time if it is used at improper time. This result is congruent with **Ganjiwale, Ganjiwale, Sharma, and Mishra (2016)**, who found that family caregivers try to make fun of the situation which can provide an outlet for stress for some time but which is more of an escape tendency which does not help them realistically in dealing with the situation in the long run and combination with

problem-focused coping strategies is necessary.

The current study results represent that there is no significant correlation between psychological wellbeing and emotion-focused coping strategies regarding subscale of **religion**. It may be as religion represents only as a supportive strategy to help family caregivers have acceptance of the reality and satisfaction of their life but family caregivers still need for use of problem-focused strategies beside religion to help them confront their stressors and have better psychological wellbeing. This result is not in the same line with **Jason, (2015)**, who found that family caregivers may turn the problem over to a 'higher power' and appear to involve themselves with religion to a greater extent in more stressful situations than in less stressful moments of their life specially when religion is more available to them and if it is already a part of their lifestyle where religion improve their psychological wellbeing. Also, this current result is incongruent with **Sharma and Gupta, (2017)** who reported that family caregivers often find relief in religious propitiation and surrender to the will of God when faced with intractable problems. This current result is also incongruent with a study done by **Hayat, (2015)**, who found that there was a positive relationship between religion and psychological wellbeing.

#### **Correlation between psychological wellbeing and problem-focused coping strategies:-**

The current study results represent that there is a positive significant correlation between psychological wellbeing and problem-focused coping

strategies of family caregivers of children with Down syndrome regarding **active coping**. It may be because active coping is usually directed at acquiring resources to help deal with the underlying problem and change the circumstances of the situation. All these factors that contribute to improve psychological well-being of family caregivers. This result is congruent with **Hayat, (2016)**, who found that problem-focused coping strategies such as active coping were positively correlated to psychological well-being.

The current study results represent that there is a positive significant correlation between psychological wellbeing and problem-focused coping strategies of family caregivers of children with Down syndrome regarding **use of instrumental support**. It may be as instrumental support occurs by obtaining information from physician, social worker, psychologist or family caregivers of other children with the same disability. This information helps family caregivers to deal with child disability and changing behavior and thus affect positively psychological wellbeing. This study result is in the same line with **Glenn, Dayus, Cunningham, and Horgan (2015)**, who reported that instrumental support helps family caregivers to provide proper care to Down syndrome children that may have a positive impact on family caregivers, such as increased self-respect or self-satisfaction from fulfilling a responsibility and experiencing positive consequences of having a Down syndrome child, and not just the negative. For example, some family caregivers become better able to appreciate the important things in life. These positive emotions, in turn, fuel the family caregivers' ability to cope with day-to-day life and thus improve their

psychological wellbeing. This result is also congruent with a study done by **Paterson, Jones, Rattray, & Lauder, (2013)** who examined the importance of instrumental support and its impact on raising a child with Down syndrome and found that family caregivers with high stressors and high support had fewer outcome problems compared to family caregivers with low support and high stressors.

The current study results represent that there is a positive significant correlation between psychological wellbeing and problem-focused coping strategies of family caregivers of children

with Down syndrome regarding **planning**. It may be due to positive effects that follow use of planning as a problem-focused coping strategy. It helps family caregivers to manage their time, find proper plans to deal with child problems and be able to provide appropriate care for their child with Down syndrome resulting in reducing anxiety and burden associated with child caregiving and improving psychological wellbeing of family caregivers. This result is congruent with **Folkman and Lazarus, (1988)**, who reported that planning coping strategy was associated with an improved psychological wellbeing.

**Table (1): Distribution of Socio-demographic Characteristics among Studied Sample (n=120)**

| Items   | N                 | %    |
|---|-------------------|------|
| <b>Types of caregiver</b>                     |                   |      |
| • Father                                      | 10                | 8.3  |
| • Mother                                      | 110               | 91.7 |
| <b>Age of father</b>                          |                   |      |
| • 15-<35                                      | 2                 | 20.0 |
| • 35-<55                                      | 7                 | 70.0 |
| • 55 and more                                 | 1                 | 10.0 |
| <b>Mean±SD</b>                                | <b>39.21±4.39</b> |      |
| <b>Age of Mother</b>                          |                   |      |
| • 15-<35                                      | 29                | 26.4 |
| • 35-<55                                      | 67                | 60.9 |
| • 55 and more                                 | 14                | 12.7 |
| <b>Mean±SD</b>                                | <b>37.65±5.67</b> |      |
| <b>Marital Status</b>                         |                   |      |
| • Married                                     | 83                | 69.2 |
| • Widowed                                     | 27                | 22.5 |
| • Divorced                                    | 10                | 8.3  |
| <b>Level of Education</b>                     |                   |      |
| • Illiterate                                  | 67                | 55.8 |
| • Primary School                              | 13                | 10.8 |
| • Secondary School                            | 12                | 10.0 |
| • University                                  | 16                | 13.4 |
| • Postgraduate                                | 12                | 10.0 |
| <b>Occupation</b>                             |                   |      |
| • Employed                                    | 16                | 13.3 |
| • UN Employed                                 | 104               | 86.7 |
| <b>Residence</b>                              |                   |      |
| • Urban                                       | 49                | 40.8 |
| • Rural                                       | 71                | 59.2 |
| <b>Family Income</b>                          |                   |      |
| Enough  | 13                | 10.8 |
| Barely Enough                                 | 16                | 13.3 |
| Not Enough                                    | 91                | 75.8 |
| <b>Family History for Psychiatric Illness</b> |                   |      |
| Yes   | 5                 | 4.2  |
| No  | 115               | 95.8 |
| <b>Family History for Down syndrome</b>       |                   |      |
| Yes   | 17                | 14.2 |
| No  | 103               | 85.8 |

**Table (2): Distribution of the total Psychological Wellbeing of family caregivers of children with Down syndrome (N=120)**

| Items                 | Yes |      | Sometimes |      | No |      | Chi-square     |          |
|-----------------------|-----|------|-----------|------|----|------|----------------|----------|
|                       | N   | %    | N         | %    | N  | %    | X <sup>2</sup> | p- value |
| Autonomy              | 27  | 22.5 | 17        | 14.2 | 76 | 63.3 | 74.775         | 0.000    |
| Environmental mastery | 41  | 34.2 | 10        | 8.3  | 69 | 57.5 | 65.325         | 0.000    |
| Personal growth       | 30  | 25.0 | 6         | 5.0  | 84 | 70.0 | 119.700        | 0.000    |
| Positive relations    | 33  | 27.5 | 11        | 9.2  | 76 | 63.3 | 81.975         | 0.000    |
| Purpose in life       | 33  | 27.5 | 10        | 8.3  | 77 | 64.2 | 86.925         | 0.000    |
| Self-acceptance       | 26  | 21.7 | 9         | 7.5  | 85 | 70.8 | 119.325        | 0.000    |

**Table (3): Level of Psychological Wellbeing of family caregivers of children with Down syndrome (N=120)**

| Level of Psychological wellbeing | N  | %     | Chi-square     |          |
|----------------------------------|----|-------|----------------|----------|
|                                  |    |       | X <sup>2</sup> | p- value |
| Less than usual                  | 79 | 65.83 |                |          |
| Same as usual                    | 37 | 30.83 | 70.650         | <0.001** |
| Better than usual                | 4  | 3.33  |                |          |

**Table (4): Total Emotion- Focused Coping Strategies of family caregivers of children with Down syndrome (N=120)**

| Total Emotion- Focused Coping Strategies | Yes |       | Sometimes |       | No  |       | Chi-square     |          |
|--|-----|-------|-----------|-------|-----|-------|----------------|----------|
|  | N   | %     | N         | %     | N   | %     | X <sup>2</sup> | P- value |
| Self-distraction                         | 63  | 52.50 | 4         | 3.33  | 53  | 44.17 | 74.775         | 0.000    |
| Denial                                   | 31  | 25.83 | 10        | 8.33  | 79  | 65.83 | 93.825         | 0.000    |
| Substance use                            | 2   | 1.67  | 4         | 3.33  | 114 | 95.00 | 308.100        | 0.000    |
| Use of emotional support                 | 83  | 69.17 | 12        | 10.00 | 25  | 20.83 | 107.175        | 0.000    |
| Behavioral disengagement                 | 55  | 45.83 | 16        | 13.33 | 49  | 40.83 | 33.075         | 0.000    |
| Venting                                  | 102 | 85.00 | 3         | 2.50  | 15  | 12.50 | 218.925        | 0.000    |
| Humor                                    | 96  | 80.00 | 4         | 3.33  | 20  | 16.67 | 181.200        | 0.000    |
| Acceptance                               | 120 | 100.0 | 0         | 0.0   | 0   | 0.0   | 360.000        | 0.000    |
| Religion                                 | 116 | 96.67 | 0         | 0.00  | 4   | 3.33  | 325.200        | 0.000    |
| Self-blame                               | 62  | 51.67 | 2         | 1.67  | 56  | 46.67 | 81.900         | 0.000    |

**Table (5): The total Problem-Focused Coping Strategies of family caregivers of children with Down syndrome (N=120)**

| Problem-Focused Coping Strategies | Yes |       | Sometimes |       | No |       | Chi-square     |         |
|-----------------------------------|-----|-------|-----------|-------|----|-------|----------------|---------|
|                                   | N   | %     | N         | %     | N  | %     | X <sup>2</sup> | P-value |
| Active coping                     | 55  | 45.83 | 0         | 0.00  | 65 | 54.17 | 91.875         | 0.000   |
| Use of instrumental support       | 107 | 89.17 | 2         | 1.67  | 11 | 9.17  | 254.025        | 0.000   |
| Positive reframing                | 88  | 73.33 | 11        | 9.17  | 21 | 17.50 | 131.475        | 0.000   |
| Planning                          | 62  | 51.67 | 20        | 16.67 | 38 | 31.67 | 33.300         | 0.000   |

**Table (6): Correlation between Psychological Wellbeing and Emotion-Focused Coping Strategies among family caregivers of children with Down syndrome (N=120).**

| Emotion-focused coping strategies | Psychological wellbeing |          |
|-----------------------------------|-------------------------|----------|
|                                   | R                       | P-value  |
| Self-distraction                  | -0.130                  | 0.156    |
| Denial                            | -0.257                  | 0.005*   |
| Substance use                     | -0.235                  | 0.010*   |
| Use of emotional support          | 0.185                   | 0.042*   |
| Behavioral disengagement          | -0.497                  | <0.001** |
| Venting                           | -0.110                  | 0.230    |
| Humor                             | -0.149                  | 0.104    |
| Acceptance                        | 0.192                   | 0.037*   |
| Religion                          | -0.021                  | 0.819    |
| Self-blame                        | -0.454                  | <0.001** |

**Table (7): Correlation between Psychological Wellbeing and Problem-Focused Coping Strategies among family caregivers of children with Down syndrome (N=120)**

| Problem-focused coping strategies | Psychological wellbeing |          |
|-----------------------------------|-------------------------|----------|
|                                   | R                       | P-value  |
| Active coping                     | 0.617                   | <0.001** |
| Use of instrumental support       | 0.392                   | <0.001** |
| Positive reframing                | 0.064                   | 0.487    |
| Planning                          | 0.315                   | <0.001** |

### Conclusion

On the light of the current study results, it can be concluded that, Family caregivers of children with DS combined between emotion-focused and problem-focused coping strategies in managing burden of child caregiving and the majority of family caregivers had psychological well-being less than usual.

There was a negative significant correlation between level of psychological well-being and emotion-focused coping strategies except for emotional support, acceptance, self-distraction, venting, humor and religion. Meanwhile, there was a positive significant correlation between level of psychological well-being and problem-

focused coping strategies except for positive reframing.

### Recommendations

Based upon the results of the current study, the following recommendations were suggested: Establishment of counseling clinics for family caregivers of children with DS to improve their coping strategies and applying educational interventional program for enhancement of psychological well-being of family caregivers of children with DS. Also, future research to assess factors that may influence role of caregiving and different challenges faced by family caregivers in rearing different aged children with DS. Finally, health care team should engage family caregivers in discussion related to available treatment options for children with DS in a trial to reduce burden of care.

### Financial support

No funding was received

### Conflict of interest

No

### References

- Alexander, T., & Walendzik, J., (2016):** Raising a Child with Down Syndrome: Do Preferred Coping Strategies Explain Differences in Parental Health? *Psychology*, 7, 28-39.
- Allen, A., & Leary, M., (2010):** Self-compassion, stress, and coping. *USA, Social and Personality Psychology Compass*, 4, 107-118.
- Baqutayan, S., (2015):** Stress and Coping Mechanisms: A Historical Overview, *International Journal of Humanities and Social Science, Malaysia*, v6n2s1p479.
- Beckmann, E., (2001):** Mental health giving emotional care, *W.B. Saunders Company, London*; pp 164 – 174.
- Bonab, B., Motamedi, F., & Zare, F., (2017):** Effect of Coping Strategies on Stress of Parent with Intellectual Disabilities Children, *USA, Asian Education Studies*, Vol 2, No 3, 266-270.
- Carver, C., (1997).** Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*, 56, 267-283.
- Cramm, J., & Nieboer, A., (2011):** Psychological well-being of caregivers of children with intellectual disabilities: Using parental stress as a mediating factor. *USA, Journal of Intellectual Disabilities Research*, (2):101-113.
- Dilys, Y., (2017):** Coping and Adaptation Strategies in Families with the Mentally Ill Member., *USA, Journal of Intellectual Disability Research*, 236-241.
- Eldars, W.; Eldegl, H; Yahia, S; AbouEla, M; & Hawas, S (2013),** Prevalence of community acquired infections in Down syndrome children, *Braz J Infect Dis* vol17 no.5.
- Folkman, S., Lazarus, R., (1988):** Stress processes and depressive symptomatology. *J. Abnorm. Psychol.* 1988;95:107-113.
- Folkman, S., & Lazarus, R., (1988).** *Stress, Appraisal and Coping. New York, Springer Publishing Company*, 111-120.
- Ganjiwale, D., Ganjiwale, J., Sharma, B., & Mishra, B., (2016):** Quality of life and coping strategies of caregivers

- of children with physical and mental disabilities , USA, Journal of family medicine and primary care, Volume:5, Page:343-348.
- Glenn, S., Dayus, B., Cunningham, C., & Horgan, M., (2015):** Mastery Motivation in children with Down Syndrome, Down Syndrome Research and Practice, USA, 7(2), 52-59.
- Groneberg, J., (2008):** Roadmap to Holland: How I Found My Way through My Sons First Two Years with Down syndrome, New York, New American Library, P55-60.
- Hayat, I., (2015):** Relationship between Psychological Well-Being and Coping Strategies among Family caregivers with Down syndrome children, International Journal of Humanities and Social Science, Pakistan Vol. 5, No. 7(1).
- High, J., (2015):** HOPE, COPING, AND RELATIONSHIP QUALITY IN MOTHERS OF CHILDREN WITH DOWN SYNDROME, Journal of Pediatrics, USA, PP: 130,540-565.
- Hobfoll, S., Cameron, R., Chapman, H., Gallagher, R., (1996):** Social Support and Social Coping in Couples. USA, Springer, PP 413-433.
- Holmes, (2006):** Diseases: Nursing process approach to excellent care. 4th ed., Philadelphia: Lippincott Williams and Wilkins, Welters kluwer comp, pp. 22-24.
- Jason, M., (2015):** Coping with Stress: Problem-Focused and Emotion-Focused Strategies, USA, Journal of Health and Psychology, P.222-233.
- Karen, A., & Eva, C., (2016):** Filipino Family Experiences in Coping for Children with Down Syndrome, USA, The Bedan Journal of Psychology, P:245-250.
- Kraaij, V., & Garnefski, N. (2016):** Cognitive Coping Strategies and Stress in Parents of Children with Down Syndrome: A prospective study, American Association on Intellectual and Developmental Disabilities, USA, Volume 47, Number 4: 295-306.
- McConnell, D., & Savage, A., (2015):** Stress and Resilience Among Families Caring for Children with Intellectual Disability: Expanding the Research Agenda, USA, Springer, Volume (2), PP.100-109.
- McGuire D.E., and Chicoine B.A. (2002):** Life issues of adolescents and adults with Down syndrome. In W. I. Cohen, L. Nadel & M. E. Madnick (Eds.), Down syndrome: Visions for the 21st century. New York, NY: Wiley-Liss, pp. 221-236.
- Moosa, E., & Munaf, S., (2012):** Emotion and Problem Focused Coping Strategies, A comparative Study of Psychiatric Patients and Normal Adults, International Journal of Project Management, 25(7), 666-673.
- Parameswari, S., & Eljo, J., (2016):** "A Study on Psychological Well Being among the Family caregivers of Children with Intellectual and Developmental Disabilities", IOSR Journal of Humanities and Social Science, India, PP 08-12.
- Paterson, C., Jones, M., Ratray, J., & Lauder, W., (2013):** *Exploring the relationship between coping, social support and health-related quality of life for prostate cancer survivors: a review of the literature.*, USA, Eur J Oncol Nurs, 17(6):750-760.
- Penley JA, Tomaka J. Wiebe S.** The association of coping to physical and psychological health outcomes: a

- meta-analytic review. *J. Behav. Med.* 2012;25:551–603.
- Pisula, D., (2010):** Parenting Stress and Coping Styles in Mothers and Fathers of Preschool Children with Autism and Down Syndrome, USA, *Journal of Intellectual Disability Research*, 54(3), 266–269.
- Pisula, E., & Kossakowska, Z. (2010).** Sense of coherence and coping with stress among mothers and fathers of children with autism, *New York, Journal of Autism and Developmental Disorders*, 40, 1485–1494.
- Ryff, C. (1989).** Scales of Psychological well being. *Journal of personality and social psychology*, 57, 1069–1081.
- Sharma, S., & Gupta, A., (2017):** The Every Day Lives and Coping Strategies of Women in Delhi: Discerning Roots of Psychological Empowerment .An Ethnographic Study, India, *International Journal of Indian Psychology*, Volume 4, Issue 2, No. 96.
- Shelley, M., Kraaij, V., & Garnefski, N., (2014):** Cognitive Coping Strategies and Stress in Family caregivers of Children With Down Syndrome: A Prospective Study, *International Journal of Evaluation and Research in Education*, USA, VOLUME 47, NUMBER 4: 295–306.
- Skinner, E., Edge, K., Altman, J., & Sherwood, H. (2013).** Searching for the structure of coping: A review and critique of category systems for classifying ways of coping. *Psychology*, 129, 216–269.
- Tajrishi, M., Azadfallah, P., Garakani, S., & Bakhshi, E., (2015):** The Effect of Problem-Focused Coping Strategy Training on Psychological Symptoms of Mothers of Children with Down Syndrome, *Iranian Journal of Public Health*, 44(2) 254–262.
- Woodman, A., Hauser-Cram, P., (2013),:** The role of coping strategies in predicting change in parenting efficacy and depressive symptoms among mothers of adolescents with developmental disabilities. USA, *Journal of Intellectual Disabilities*, 57(6):513–530.