

Assessment of Psychological Well-Being and Coping Strategies among Family Caregivers of Children with Down syndrome

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Abstract

Background: Family caregivers of children with Down Syndrome are frequently unstable and forego their psychological well-being, suffer additional economic difficulties, ill health and cope ineffectively than families without disabilities. **Aim:** This study aimed to assess 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 Down Syndrome in the specialized clinics of the university pediatric hospital affiliated to Ain Shams University Hospitals. **Subjects:** A sample of 60 family caregivers of children with Down Syndrome. The study tools were: 1) Interviewing Questionnaire, 2) Brief-COPE inventory (Carver, 1997) and 3) Ryff's Psychological well-being scale (1989). **The results:** The study showed that family caregivers of children with Down Syndrome depended mainly on emotion-focused coping strategies in managing burden of child caregiving and the most frequent used emotion focused coping strategies were religion, acceptance and venting while the most frequent used problem-focused coping strategy was use of instrumental support. Concerning to psychological well-being, more than half of family caregivers of children with Down Syndrome had psychological well-being less than usual. **Conclusions:** There was a negative statistically significant correlation between psychological well-being and all types of emotion-focused coping strategies except for humor, acceptance and religion. Meanwhile, there was a positive statistically significant correlation between level of psychological well-being and all subscales of problem-focused coping strategies. **Recommendations:** Future research to assess challenges encountered by siblings of Down Syndrome children and to apply supportive intervention that promotes positive relationships and attitudes as well as Establishment of counseling clinics for parents and siblings to improve their psychological well-being and coping strategies.

Key words: Down syndrome, Psychological well-being, Coping strategies, Family caregivers.

Introduction

DS affects not only the child with DS but other family members and the family as a unit. The incidence of DS is 1 in every 1000 to 1100 births worldwide. The incidence of DS in Egypt is 1 in 700. The birth of a child with DS reinforces the highly gendered divisions of responsibilities in the household, common in the country, adding to the stress of

already overburdened wives and mothers. (Alwakeel, et al, 2020).

In some cases, the result is a disruption of conjugal relations, leaving a mother to cope alone. Children with DS and their families still face stigmatization and exclusion (Darla & Bhat, 2020). The source of stress may be a matter of strained emotional relationships, necessarily limited family activities and reduced career aspirations, reduced opportunities for social and leisure

pursuits, problems of fitting to treatment demands and appointments, educational disadvantages, and the ongoing difficulty in coming to terms with the disability (van Ewijk, et al, 2020).

About the impact of coping strategies on psychological well-being, Halstead, et al, (2017) claimed that individuals who combine active (i.e., problem-focused) and non-active (i.e., emotion-focused) coping strategies in dealing with stressors may experience less psychological costs than people who exclusively rely on other more active strategies.

There are multiple studies deliberate problems of the family caregivers of children with DS but there are very few studies that touched their psychological well-being and coping strategies. Ineffective coping may lead to poor outcomes for the child and decreased family caregivers' capacity to provide appropriate care. Therefore, the study aims at assessing psychological well-being and coping strategies among family caregivers of children with DS.

Aim of the study

To assess psychological well-being and coping strategies among family caregivers of children with DS.

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 DS?

2.What are the coping strategies used by family caregivers of children with DS?

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

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 60 family caregivers of children with DS 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).
- Age :(6-12) years old.
- Sex: both sexes.

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.
- Have only one disabled child.
- Free from any psychiatric illness.

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

It was designed by **Mohammed, et al, (2018)** and it included two parts:

A-First part: included data related to socio-demographic characteristics of family caregivers including age, sex, address, level of education, social status, relation to child, occupation, income and history of psychiatric or mental illness within the family.

B-Second part: included data related to demographic characteristics of DS child and health status including age, sex, education, number of siblings, rank, IQ and data related to physical complains and disabilities of the child such as heart disease, Gastro Intestinal Tract Disorders (GIT) and other chronic diseases “renal or hepatic or bone diseases”.

2-Brief-COPE inventory

It was originally developed by **(Carver, 1997)** and adapted by **Mohammed, et al, (2018)**. It was used to assess coping strategies among family caregivers of children with DS. 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”.

3- Ryff’s Psychological well-being scale (1989):

It was adapted by **Mohammed, et al, (2018)**. It was used to assess the level of psychological well-being among the sample. It consists of 42 items classified into 6 subscales including: (Autonomy, Environmental mastery, Personal growth, Positive relations, Self-acceptance and Purpose in life), each subscale consists of 7 items.

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. The reliability of the tools was assessed using the questionnaires and reassessment was done after (7) days on the same subjects, the results were the same each time.

Pilot study

The Pilot study was carried out for 10% of the sample (6 family caregivers of children with DS) to test the reliability, clarity of questions and applicability of the tools, and the time needed to complete them. 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 and exclusion criteria.

-Data was collected during morning and afternoon 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 60 family caregivers of children with DS who agreed to be involved in the study sample.

-The working time of the Genes Clinics of DS was throughout week days except Friday.

-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 7 to 8 caregivers monthly.

- Data collection lasted for eight months, from July 2020 to February 2021.

Ethical considerations

Ethical approval obtained from the Scientific and Ethical Committee of Nursing Faculty of Ain Shams University, The researcher clarified the aim of the study to the family caregivers included in the study, Anonymity and confidentiality of the data were assured and maintained. Family caregivers were informed that they are allowed to participate or not in the study and that they have the right to withdraw from the study at any time, and the researcher clarified that all information would be used for scientific research and for the benefits of the family caregivers.

Statistical Design

The statistical analysis of data was done by using the Statistical Package for Social Science (SPSS), Version 20.0. Armonk, NY: IBM Corp. 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). For quantitative data by chi-square tests-correlation by Linear Correlation Coefficient [r] tests. Linear Correlation coefficient was used for detection of correlation between two quantitative variables in one group. The validity and reliability tests were confirmed using the Cronbach Alpha Coefficient test. Degree of significance results were:-

- P. Value>0.05(Not Significant)
- P. Value≤0.05(significant)
- P. Value≤0.001(Highly Significant)

Results

Table (1): indicates that all family caregivers (100%) were mother and more than half (55%) were in age group (35-<55) years old, the married caregivers were more than two thirds (70%), the illiterate caregivers represented (55%), the majority of the study sample were unemployed and had not enough family income which constituted (86.7%) and (91.7%) respectively , and more than half (60%) lived in rural areas. According to family history, all family caregivers (100%) had no family history for psychiatric illness or DS.

Table (2): illustrates that more than half of family caregivers (56.7%) had psychological wellbeing less than usual.

Table (3): reveals that family caregivers used different emotion - focused coping strategies and the most common used strategies were religion (93.3%) and acceptance (91.7%) but substance use was the least used one which represented (0.0%).

Table (4): shows that family caregivers used different problem-focused coping strategies, the most common used strategy was use of instrumental support

(66.7%) but positive reframing was the least used one (21.7%).

Table (5): indicates that there was a negative statistically significant correlation between level of psychological well-being and emotion-focused coping strategies except for subscales of humor, acceptance, and religion.

Table (1): Distribution of socio-demographic characteristics among family caregivers of children with Down Syndrome (N=60)

Socio-demographic characteristics	N	%
Types of caregiver		
•Father	0	0
•Mother	60	100
Age of Mother		
•15-<35	16	26.7
•35-<55	33	55
•55 and more	11	18.3
Mean±SD		37.65±5.67
Marital Status		
•Married	42	70.0
•Widowed	13	21.7
•Divorced	5	8.3
Level of Education		
•Illiterate	33	55.0
•Primary School	7	11.7
•Secondary School	6	10.0
•University	8	13.3
•Postgraduate	6	10.0
Occupation		
•Employed	8	13.3
•UN Employed	52	86.7
Residence		
•Urban	24	40.0
•Rural	36	60.0
Family Income		
•Enough	5	8.3
•Not Enough	55	91.7
Family History for Psychiatric Illness		
•Yes	0	0
•No	60	100
Family History for DS		
•Yes	0	0
•No	60	100

Table (2): Level of psychological well-being among family caregivers of children with Down Syndrome (N=60)

Table (6): reveals that there was a positive statistically significant correlation between level of psychological well-being and all subscales of problem-focused coping strategies.

Level of psychological well-being	N	%	Chi-square p- value
Less than usual	34	56.7	<0.001**
Same as usual	14	23.3	
Better than usual	12	20.0	

Table (3): Distribution of emotion- focused coping strategies among family caregivers of children with Down Syndrome (N=60)

Emotion- Focused Coping Strategies	No		Sometimes		Yes		Chi-square
	N	%	N	%	N	%	P-value
Self-distraction	6	10.0	11	18.3	43	71.7	0.000
Denial	5	8.3	12	20.0	43	71.7	0.000
Substance use	59	98.3	1	1.7	0	0.0	0.000
Use of emotional support	10	16.7	13	21.7	37	61.7	0.000
Behavioral disengagement	9	15.0	14	23.3	37	61.7	0.000
Venting	3	5.0	6	10.0	51	85.0	0.000
Humor	7	11.7	9	15.0	44	73.3	0.000
Acceptance	0	0.0	5	8.3	55	91.7	0.000
Religion	0	0.0	4	6.7	56	93.3	0.000
Self-blame	3	5.0	12	20.0	45	75.0	0.000

Table (4): Distribution of problem-focused coping strategies among family caregivers of children with Down syndrome (N=60)

Problem-focused coping strategies	No		Sometimes		Yes		Chi-square
	N	%	N	%	N	%	P-value
Active coping	37	61.7	5	8.3	18	30.0	0.000
Use of instrumental support	3	5.0	17	28.3	40	66.7	0.000
Positive reframing	34	56.7	13	21.7	13	21.7	0.000
Planning	33	55.0	12	20.0	15	25.0	0.000

Table (5): Correlation between psychological well-being and emotion-focused coping strategies among family caregivers of children with Down syndrome (N=60)

Emotion-focused coping strategies	Psychological well-being	
	R	P-value
Self-distraction	-0.248	0.039*
Denial	-0.490	<0.001*
Substance use	-0.047	0.723
Use of emotional support	-0.265	0.041*
Behavioral disengagement	-0.327	0.011*
Venting	-0.745	<0.001*
Humor	0.347	0.007*
Acceptance	0.240	0.064
Religion	0.519	0.003*
Self-blame	-0.755	<0.001*

Table (6): Correlation between psychological well-being and problem-focused coping strategies among family caregivers of children with Down syndrome (N=60)

Problem-focused coping strategies	Psychological well-being	
	R	P-value
Active coping	0.966	<0.001*
Use of instrumental support	0.239	0.046*
Positive reframing	0.500	<0.001*
Planning	0.329	0.015*

Discussion

Family caregivers of children with DS present emotional, physical, and financial burden as well as restrictions on social and leisure activities. Needs of family caregivers of children with DS may involve the need for psychological and social support and assistance to alleviate stress as well as developing appropriate and effective coping strategies to reduce the level of stress and helping to make the necessary changes to reduce exposure to psychological stress (Masefeld, et al, 2020).

Stresses arising from the caregiving role as well as from other major life events have the potential to produce psychological distress as a result of ineffective coping. Family caregivers develop different positive and/or negative coping strategies to combat this psychological stress. These coping strategies also predict the outcomes of their distress, which may increase or decrease depending on the ways of coping (Baker, et al, 2020).

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

The current study results indicate that all family caregivers were mothers. This may be as according to Egyptian culture, it is usually the mother who provides care for the disabled child and is

forced to give up her job or career to stay home and take over most of the child care responsibilities whereas fathers assume the provider role. This study result is congruent with Pastor-Cerezuola, et al, (2021), in their study of "Parental stress and resilience in autism spectrum disorder and Down syndrome", who reported that the mother is the primary caregiver for children with DS and clarified that this reflects emotional ties between mother and child where mothers tend to involve themselves more in the emotional roles of caring for the well-being of family members whereas fathers assume the bread winner.

The current study results reveal that more than two thirds of the family caregivers were married. This may be as the parents of children with DS tend to maintain stable marital relation in order to be able to confront caregiving challenges as well as other life stressors. This study result is in the same line with Sheikh, et al, (2018), in their study about "Psychiatric morbidity, perceived stress and ways of coping among parents of children with intellectual disability in Lahore, Pakistan" who indicated that parents with DS children report comparative advantage of being less likely to get divorced because they are often better experienced, old aged and they tend to maintain emotional stability that enables them to face burden of child caregiving.

The current study results reveal that illiterate caregivers represented more than half of the study sample. It may be due to decreased chances of these family caregivers for education because near two thirds of the study sample lived in rural areas, all family caregivers were women and the majority was above age of 35 Years old. This study result is incongruent with **Alwakeel, et al, (2020)**, in their study of “Burden of family caregivers of Down syndrome children: a cross-sectional study”, who reported that family caregivers of children with DS are often better educated. This current study result is also not in the same line with **Kózka & Przybyła-Basista, (2018)**, in their study about “Perceived stress, ego-resiliency, and relational resources as predictors of psychological well-being in parents of children with Down syndrome”, who founded that the majority of parents (mothers and fathers) had secondary education.

The current study results indicate that the majority of the study sample were unemployed. This may be as all family caregivers of children with DS were mothers who had to spend more time at home with the child for dealing with their children dependence, health problems and behavioral issues that may characterize their child disability. This study results is not in the same line with **Barakat & Mohamed, (2019)**, in their study about “Relationship between Parent Stress, Psychological Well-Being and Coping Strategies among Parents with Down Syndrome Children”, who revealed that more than half of the parents of children with DS were employe.

The findings of the current study reveal that the majority of the study sample had not enough family income. This may be as most of mothers were housewives who were forced to stay at home longer to take over most of the

child care responsibilities and father was the only breadwinner for all family members. This study result is congruent with **Hegazy & Baraka, (2021)**, in their study of “Effectiveness of Promoting Mothers’ Caring Practices Regarding Their Down Syndrome Children on the Family Coping” who found that families of DS children had more financial difficulties due to increased additional expenses for the provision of remedies and rehabilitation as well as increased expenses for meeting basic needs of DS child including, but not limited to, developmental, educational and social needs.

Level of Psychological Wellbeing among family caregivers of children with Down syndrome

The current study results reveal that that more than half of family caregivers have psychological wellbeing less than usual. This may be because family caregivers often feel stigmatized of their child disability and are not willing to socialize, leading to stress and affecting negatively their psychological wellbeing. This study result is consistent with **Crnic, et al, (2017)**, in their study of “Intellectual disability and developmental risk: Promoting intervention to improve child and family well-being” who indicated that family caregivers of DS children have experienced stress, anxiety, and low level of life satisfaction, do not have a good parent-child relation and have psychological wellbeing less than usual.

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

The current study results reveal that family caregivers used different emotion - focused coping strategies and the most common used strategies were

religion and acceptance where majority of family caregivers had been reassuring themselves that things will be better soon (Patience is the key of vulva), had been considering the child disability as a test from Allah and had been 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. Such optimistic attitude may help to enhance caregivers' adaptation. This is congruent with **Sharma and Gupta, (2017)**, in their study about "The Every Day Lives and Coping Strategies of Women in Delhi: Discerning Roots of Psychological Empowerment", who reported that family caregivers of children with DS had accepted the situation and tried to look for something good in it. This study result is also congruent with **Isa, et al, (2017)**, in their study about "Perceived Stress and Coping Styles among Malay Caregivers of Children with Learning Disabilities in Kelantan", who clarified that when being under stress, caregivers of Children with disabilities had turned to religion as religion serves as a source of emotional support, a vehicle for positive reinterpretation and growth and a tactic of active coping with a stressor.

The current study results indicate that **substance abuse** was the least used emotion-focused coping strategy. This may be as the family caregivers didn't rely on substance use in dealing with child problems due to religiosity that are highly prevalent in our community where substance use is illegal and socially unacceptable method for coping and due to increased caregivers awareness of dangers accompanied by substance use. This result is congruent with **Barakat & Mohamed, (2019)**, in their study about "Relationship between Parent Stress, Psychological Well-Being and Coping Strategies among Parents with Down Syndrome Children", who reported that

substance use was the least common emotion-focused strategy used by family caregivers of children with DS because it was considered as a socially unacceptable coping method that may represent as a barrier for delivery of an effective child caregiving.

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

The current study results indicate that family caregivers used different problem-focused coping strategies, the most common used strategy was use of instrumental support but positive reframing was the least used one.

As regards to **use of instrumental support**, family caregivers sought help and support for overcoming their child disability and facing the physical, cognitive and behavioral problems associated with

DS disability through getting advices from other families with DS child, psychologists, social workers and physiotherapists who supported them by increasing their awareness about the nature of DS child and methods of dealing with child problems. These results are congruent with **Krueger, et al, (2019)**, in their study about "Understanding the systems, contexts, behaviors, and strategies of parents advocating for their children with Down syndrome" who indicated that parents of children with DS dealt with their children frequently with different actions, attitudes, motivations, and outcomes based on information and advices obtained from other parents of children with DS and health care providers.

Concerning **positive reframing**, it was the least used problem-focused coping strategy where more than half of family caregivers hadn't been concentrating on a good thing as achieving certain degree of the child

autonomy and hadn't been looking at the child disability as a challenge to show their abilities. This may be due to absence of hope toward child development, lack of child self-responsibility and due to their caregiving responsibility. This result is inconsistent with **Miranda, et al, (2019)**, in their study about "Parenting stress in mothers of children with intellectual disability: coping strategies" who reported that the most frequently used coping strategy by parents of children with intellectual disability was positive reframing and it was associated with good health, positive affect, and improved social, cognitive, academic, and occupational performances.

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

The current study results revealed that there was a negative statistically significant correlation between psychological well-being and all types of emotion-focused coping strategies except for humor, acceptance and religion.

Regarding **denial**, there was a highly negative statistically significant correlation between psychological well-being and denial. This may be as use of denial serves to avoid actually confronting the problem leading to increased mental suffering and desperateness as well as increased burnout. These current study results are congruent with **Deng, (2021)**, who conducted "An Examination of Acculturation, Social Support, and Health Outcomes among Chinese American Parents of Children with Developmental Disabilities", and found that use of denial coping strategy was significantly and positively associated with maternal depressive symptoms.

Regarding **self-blame**, there was a highly negative statistically significant correlation between psychological well-being and self-blame. This may be as self-blame coping strategy serves to increase family caregivers' grief, shame, guilt, hopelessness, and helplessness and prevent the family caregivers from taking active steps toward solving problems and facing situations leading to depression and dissatisfaction. These current study results are consistent with **Megreya, et al, (2020)**, in their study about "Cognitive emotion regulation strategies, anxiety, and depression in mothers of children with or without neurodevelopmental disorders" who found that there was a highly negative statistically significant correlation between self-blame coping and psychological wellbeing among parents with DS children.

Regarding **venting**, there was a highly negative statistically significant correlation between psychological well-being and venting. This may be as use of venting as an emotion-focused coping strategy provides only false reassurance, doesn't provide solutions for the problem and may delay use of active coping strategies that aim at dealing with the cause of the problem and not only alleviating anxiety on the short run. These current study results are consistent with **Gupta & Kumar, (2020)**, who discussed the mediating role of positive perceptions on coping strategies and psychological well-being among mothers of children with intellectual disabilities and clarified that venting had been reported to show a positive association with depression and negative association with satisfactory outcome.

Regarding **self-distraction**, there was a negative significant correlation between psychological wellbeing and self-distraction. It may reflect the family caregivers' efforts to cope with their

child's DS by letting off steam and regulating emotion which were ineffective and didn't resolve the adverse situation that provoked the stress. These current study results are in the same line with **Kurowska, et al, (2020)**, in their study of "How to cope with stress?" Determinants of coping strategies used by parents raising children with intellectual disabilities, other developmental disorders and typically developing children. A cross-sectional study from Poland", who reported that use of self-distraction coping strategy may foster recuperation but it does not provide a long term solution and may have negative side effects as it delays the family caregiver dealing with the problem.

Regarding **behavior disengagement**, there was a negative statistically significant correlation between psychological well-being and behavior disengagement. This may be as use of behavior disengagement represents an ineffective coping strategy that doesn't resolve the adverse situation and thus provokes the stress leading to increased psychological distress and burnout. These current study results are consistent with **Adams, et al, (2018)**, in their study about "Coping strategies in mothers of children with intellectual disabilities showing multiple forms of challenging behavior" who found that anxiety and depression scores were positively associated with behavioral disengagement.

Regarding **use of emotional support**, there was a negative statistically significant correlation between psychological well-being and use of emotional support. This may be as use of emotional support serves to avoid actually confronting the problem or finding solutions and thus leads to time waste, increased mental suffering and hopelessness. These current study results are incongruent with **Alexander and**

Walendzik, (2016), in their study of "Raising a Child with DS: Do Preferred Coping Strategies Explain Differences in Parental Health?" who reported that family caregivers of children with DS who prevalently use emotional support find opportunities to grow from the specific challenges of their life situation and become at a low risk for psychological and physical health problems.

Concerning humor, there was a positive significant correlation between psychological wellbeing and humor. This may be as family caregivers tried to make fun of the situation through humor which can provide an outlet for stress for some time until being able to deal with the situation in the long run and thus leads to less psychological distress. This result is incongruent with **Ganjiwale, et al, (2016)**, in the study of "Quality of life and coping strategies of caregivers of children with physical and mental disabilities ", who found that family caregivers used humor to alleviate stress and improve the painful situation but this represented an escape tendency which didn't help them realistically in dealing with the situation in the long run and thus leads to less psychological wellbeing.

Concerning acceptance, there was a positive significant correlation between psychological wellbeing and acceptance. This may reflect good faith and religiosity that are highly prevalent in our community where a disabled child might be considered as a gift from Allah. Such optimistic attitude may help to enhance caregivers' adaptation and psychological wellbeing. This result is congruent with **Parameswari and Eljo, (2016)**, in their study about "A Study on Psychological Well Being among the Family caregivers of Children with Intellectual and Developmental Disabilities ", who clarified 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 as well as developing confidence and improved psychological wellbeing.

Concerning **religion**, there was a positive significant correlation between psychological wellbeing and religion. This may be as the family caregivers used to turn their problems over to a 'higher power' and involve themselves with religion that represents as a supportive strategy to help family caregivers have acceptance of the reality and satisfaction of their life. These current study results are congruent with **Sharma and Gupta, (2017)**, in their study of "The Every Day Lives and Coping Strategies of Women in Delhi: Discerning Roots of Psychological Empowerment", who reported that family caregivers often find relief in religious propitiation and surrender to the will of God when faced with intractable problems.

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

There was a positive statistically significant correlation between level of psychological well-being and all subscales of problem-focused coping strategies.

Concerning **active coping**, there was a highly positive statistically significant correlation between psychological well-being and active coping. This may be because engagement in active practices of caregiving activities helps the family caregivers to find out appropriate community resources and services for DS child and thus helps in confronting stressors and burden of care and thus better psychological wellbeing of family caregivers. These study results are in the same line with **Estes, et al,**

(2019), in their study about "The effects of early autism intervention on parents and family adaptive functioning" who found that parents who used active coping showed a greater reduction in anxiety and family dysfunction.

Concerning **positive reframing**, there was a highly positive statistically significant correlation between psychological well-being and positive reframing. This may be because positive reframing represents serious efforts exerted by the family caregivers to solve the problem or do something to actively change one's perception of a stressor for the purpose of reducing or managing the feelings of distress and thus leads to better psychological well-being. These study results are congruent with **Salas, et al, (2017)**, in their study about "The role of coping strategies and self-efficacy as predictors of life satisfaction in a sample of parents of children with autism spectrum disorder" who found that positive reframing was positively correlated with life satisfaction and psychological well-being and added that some family caregivers become better able to appreciate the important things in life.

Concerning **use of instrumental support**, there was a positive statistically significant correlation between psychological well-being and use of instrumental support. This may be because use of instrumental support includes getting advices from physician, social worker and psychologist and family caregivers of other children with the same disability. These advices help the family caregivers to handle multiple problems associated with child disability and represent as guidance for the family caregivers in their life and thus lead to better psychological wellbeing. This study result is in the same line with **Choi & Van Riper, (2017)**, in the study of

“Adaptation in families of children with Down syndrome in East Asian countries: an integrative review”, who reported that instrumental support had a positive effect on family caregivers such as increased self-respect or self-satisfaction from fulfilling a responsibility.

Concerning **planning**, there was a positive statistically significant correlation between psychological well-being and planning. This may be as planning coping strategy includes identifying problems, setting goals, determining priorities, suggesting alternatives and then taking active steps toward achieving the intended goals. So, planning represents an effective coping strategy that results in decreased stress, burnout and enhanced psychological well-being. These study results are in the same line with **Susanty, et al, (2020)**, in their study about “Benefits and cultural adaptations of psychosocial interventions for parents and their children with intellectual disabilities in low-and middle-income countries: A systematic review” who found that planning coping strategy was associated with an improved psychological wellbeing.

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 more than half of family caregivers had psychological well-being less than usual. There was a negative statistically significant correlation between psychological well-being and all types of emotion-focused coping strategies except for humor, acceptance and religion. Meanwhile, there was a positive statistically significant correlation between level of psychological well-

being and all subscales of problem-focused coping strategies.

Recommendations

Based upon the results of the current study, the following recommendations were suggested:

- Applying educational interventional program for enhancement of coping strategies and psychological well-being among families of children with DS in different institutions.
- Establishment of counseling clinics for parents and siblings to improve their psychological wellbeing and coping strategies.
- Conducting periodic scientific seminars for nurses about strategies of effective coping and methods of enhancing psychological well-being for family caregivers of children with DS.
- Future research to assess the challenges encountered by sibling of DS children and providing supportive intervention that promote positive relationships and attitudes.

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