

Effectiveness of Supportive Psychoeducational Program on Burden and Feeling of Hopelessness among Family Caregivers of Children with Down Syndrome

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Abstract

Caregivers of children with disabilities are exposed to burdens with subjective and objective dimensions. The subjective burden depends upon how the caregiver perceives the burden of care and may be felt strongly by one person and not at all by another. The objective burden includes consequences of the caregiving tasks on the caregivers' economic resources, household activities, health, and leisure. Therefore, this study aimed at assessing the effect supportive psychoeducational program on burden and feeling of hopelessness among family caregivers of children with down syndrome. A **quasi-experimental design** was selected for this study. The sample consisted of sixty-two family caregivers of children with down syndrome. **Three tools of data collection** were used in this study: (1) A structured interviewing questionnaire sheet, (2) Family Burden Evaluation Scale (FBES), and (3) Beck Hopelessness Scale (BHS). **The main results showed that**, there was significant reduction on mean score regarding domain of hopelessness in the post-program implementation phase compared to the preprogram phase, including felling about the future, loss of motivation and future expectation & there was highly statistically significant improvement in all subscales of burden among the family caregiver at post program than preprogram. **Conclusion:** the result of this study supported hypothesis of psychoeducational program for families caring children with down syndrome have appositve effect on reduce feeling of hopelessness and minimize level of burden. **This study recommended that**, designing training program for caregivers regarding coping patterns for their roles to their children with down syndrome and provision a guideline booklet to all newly admitted mothers having children with DS in Genic clinic and rehabilitation center to help them in improving their knowledge and practices.

Keywords: Supportive Psychoeducational Program - Down Syndrome - Burden – Feeling of Hopelessness

Introduction

Down syndrome (DS) or trisomy 21, as the most common cause of mental developmental, and educational disabilities, is caused by genetic disorders. Individuals with DS face many health-related issues, such as delayed motor neuron development, impaired cognitive function, and poor hand-eye coordination (Azhar., AlShammasi, and Higgi 2016).

Caregivers of children with disabilities are exposed to burdens with subjective and objective dimensions. The subjective burden depends upon how the caregiver perceives the burden of care and may be

felt strongly by one person and not at all by another. The objective burden includes consequences of the caregiving tasks on the caregivers' economic resources, household activities, health, and leisure (Alam El-Deen et al., 2020).

The burden of caring for a disabled child can harm parents' quality of life. Some parents experience pessimism, anger, guilt, and despair. Finally, parents' depression and feelings of hopelessness may reduce their ability to properly care for the children and cause negative consequences for the children. The parents of children with DS often care for these

children throughout their lives due to the extent and permanence of the symptoms of this disorder (Alibakhshi et al., 2020).

Hope is generally regarded as a critical predictor indicating the parent's acceptance of their child's disability. It is a calming force against anxiety and depression and a predictor of individuals' satisfaction and happiness in life. It plays a crucial role in improving mental health, quality of life, and resilience in the parents and families of children with developmental disorders (Alibakhshi et al., 2021).

Nurses are essential in providing family centered care to children with chronic illnesses like DS and their families. Nursing management focuses on providing supportive measures such as providing support and education to the child and their mothers, promoting growth and development, and preventing complications and problems. Parents and caregivers need support and education continuously (Hegazy and Baraka 2021).

The psycho-educational intervention is a set of systematic interventions based on supportive, handling and upgrading the lives of mentally retarded children depend on the participation, support from families and family needs. The intervention is focused on increasing family knowledge about disease, better adjustment to illness, communication and facilitating problem solving skills (Esther, Kerry, and Manfred 2018).

Significance of the study:

Down syndrome (DS) is a syndrome of mental retardation from mild to severe, as the most common cause of mental, developmental, and learning disabilities, is caused by genetic disorders. The prevalence of DS is 1 in every 700 babies born in the world. Its estimated incidence is 1 per 1000 live births. Annually, 3000 to

5000 children across the world are born with DS (Gashmard, Ahmadi, and Kermanshahi 2020).

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).

Families with mentally retarded children need ongoing and long-lasting care. This can place an additional burden on the family to care for. This has an impact on the roles, responsibilities, and relationships of the family as a caregiver for children with mental retardation. The increasing burden of caring for a mentally retarded child will affect family functioning (Harkoma and Saswati 2021). It is known that the levels of hopelessness of parents who have mentally disabled children are high and that hopelessness negatively adds to the family burden (Tétreault et al., 2014).

McKee, et al., (2019) added that there were associations between hope and child problem behaviors and depression. Parents who reported lower levels of hope and more child behavior problems also reported more symptoms of depression and less positive affect. Thus, child behavior and symptom severity may contribute to parental hope. Addressing particularly families with intellectually disabled children that emphasize defining the family burden, fostering the hopes for the future, answering the need for more information, increasing coping skills, providing opportunities for emotional sharing and psychosocial support.

The educational support efforts help families to adapt to the situation in which they have found themselves, to decrease the level of hopelessness and family

burden vent their emotions and thoughts about their feelings and their child to accept their child's inadequacies and improve their coping skills **Balci., Kizil., Savaşer., Dur., and Mutlu (2019)**. Therefore, the development and implementation of a Supportive Psychoeducational Program has become a vital element of psychiatric nursing to minimize burden and feeling of hopelessness among family caregivers of children with down syndrome.

Aim of the Study

This study aimed at assessing the effect supportive psychoeducational program on burden and feeling of hopelessness among family caregivers of children with down syndrome through:

1. Assessing the levels of burden among families caring for children with down syndrome.
2. Assessing the levels of hopelessness among families caring for children with down syndrome.
3. Develop and implement a psycho-educational program to minimize burden and enhance hope among families caring for children with down syndrome.
4. Evaluating the effect of the s program on burden and hopelessness among families caring for children with down syndrome.

Research hypothesis:

This study hypothesized that: Psychoeducational program for families caring for children with down syndrome will minimize level of burden and reduce feeling of hopelessness.

Subjects & Methods

Research design

A quasi-experimental (one group pre/post-test) design was utilized to achieve the aim of the study.

Setting:

This study was conducted at the Genes Clinics of DS in the specialized clinics of the university pediatric hospital affiliated to Ain Shams University Hospitals. Each clinic contains 2 beds and 6 chairs; also, it has good ventilation and many light sources. This setting was selected due to the high attendance of children with down syndrome and serves the biggest region.

Subjects:

Sample size:

The sample size was calculated based on considering the level of significance of power analysis of 0.95 ($\beta=1-0.95=0.5$) at alpha .05 (one-sided) with a large effect size (0.5) was used as the significance, 0.001 was used as the high significance.

Sample type:

A purposive sample of (62) families' caregivers of children with down syndrome and their children attending to previous mentioned setting and completed the intervention program during the study period based on following criteria.

Inclusion criteria for children with DS:

1. Intelligence Quotient (IQ) from (25-70).
2. Age: (6-12) years old.
3. Sex: both sexes.

Exclusion criteria for children with DS:

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

Inclusion criteria for family caregivers of children with DS:

1. Family members who give direct care to the child.
2. Have only one disabled child.
3. Free from any psychiatric illness.

Exclusion criteria for family caregivers of children with DS:

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

Tools for data collection:

The data was collected using a self-administered questionnaire that included three sections as follows:

1- A structured interviewing

questionnaire sheet: It contains two parts.

a- Demographic Data of Family Caregivers: includes data includes age, sex, marital status, level of education, occupation, residence, adequacy of family income.

b- Demographic Data of DS Child: includes age, sex, child rank, level of education, Child IQ, and levels of child dependency.

2- The Family Burden Evaluation Scale (FBES):

This scale was developed by **Sarı and Başbakkal in (2008)** to evaluate the burden perceived by families with children with intellectual disabilities. it comprised of 43 questions and divided into 6 subfactors as follow:

- Perception of Inadequacy: (8) items
- Social burden: (6) items
- Physical Load: (5) items
- Emotional burden: (11) items
- Time requirement: (7) items
- Economic Burden: (6) items

Scoring systems

Each item was rated on 5-point Likert scale ranged from strongly agree to strongly disagree., 1= strongly disagree., 2 = disagree., 3 = undecided., 4 = agree and 5= strongly agree.

The total score range 43: 215 classifieds as following:

- 43: < 129 mild burdens
- 129 :< 172 moderate burdens
- 172: 215 severe burdens

3- Beck Hopelessness Scale (BHS):

It is originally developed by **Beck et al., (1974)** for measure aspect of hopelessness. It consisted of 20 items. divided into three subitems:

- Feelings about the future:6 items
- Loss of motivation: 8 items
- Future expectations: 6 items

Scoring systems

Each item scored on true and false responses. 1 = true., 0 = false., items (1, 5, 6, 8, 13, 15 and 19) are negatively scored. The total score rang from 0:20. classified as follows.

- 0-3 None or minimal
- 4-8 Mild
- 9-14 Moderate.

May not be in immediate danger but requires frequent regular monitoring.

15+ Severe. Please reach out for support.

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:

A pilot study was carried out on (6) family caregivers representing around 10% to test the clarity of questions and applicability, of the tools, and the time needed to answer them then the tools were modified according to the findings of the pilot study. The time needed to fill out the tools was about 25 to 30 minutes.

Data Collection procedure:

Field Work:

The study was conducted over a period of (9) months from the first of May 2021 to the end of January 2022. The field work was divided into three phases:

1. Assessment phase:

Data collection of this study was conducted once permission was granted to proceed with the study.

The aim of the study was simply explained to the sample 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 reporting that all information will be used for scientific research only.

The subject was selected according to the inclusion and exclusion criteria. Data was collected during the 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 researchers met 62 family caregivers of children with DS who agreed to participate in the study sample.

2. Implementation phase:

After the pre assessment was completed, the researchers started the intervention program's sessions with family caregivers. The intervention program was implemented by classifying family caregivers into 5 groups. Each group consisted of 12 family caregivers.

The intervention program was introduced for each group separately due to the clinic's size that leads to difficulty in gathering all family caregivers involved in the study sample at the same time. Each group attended The Genes Clinics once per two weeks either on Saturday or Wednesday.

Supportive Psychoeducational Program.

The aim of the supportive psychoeducational program was to minimize the level of burden and reduce the feeling of hopelessness of family caregivers of children with down syndrome. It was designed by a researcher based on related recent literatures. It was written in a simple Arabic language and included two parts as the following:

Part I- Theoretical part: It was concerned with knowledge about the problems associated with DS, needs of children with DS, available services, impact of child disability on family, parents hope and family burden.

Part II- Practical part: It was concerned with the role of family caregiver in modifying behaviors of a child with DS, skills of problem solving, communication skills, decision making skills, skills of time management and relaxation skills.

The content of the intervention program was achieved through (20) sessions, covered in (20) hours; 6 theoretical hours, 12 practical hours and 2 hours for data collection and orientation. By the end of the program, family caregivers of children with DS acquired the necessary knowledge and skills required to minimize feeling of hopelessness and decrease the level of burden. This is achieved through.

Session (1) Orientation Session

Objective: At the end of this session, each family caregiver of children with DS acquainted the educational intervention program content and its objectives and answered questions of data collection tools (first assessment). First, the researcher established rapport with the family caregivers, introduced themselves, and each family caregiver introduced herself as well. The researchers explained the program, its objectives and meeting time.

Session (2) Awareness of Child Problems

Objective: At the end of these sessions, each family caregiver of children with DS obtained an overview about child problems and determined her own child needs. These sessions included definition of DS, problems of children with DS, definite criteria of children with DS, impact of mental retardation on children with DS and needs of children with DS.

This was done by using open discussion, brainstorming and handout.

Sessions (3&4) How to Deal with Child Problems

Objective: At the end of these sessions, each family caregiver of children with DS was able to apply methods of dealing with child problems and developing independence skills of self-care, social skills, and educational skills. These sessions included methods of dealing with DS child problems, occupational therapy for children with DS, improving DS child communication with others, importance of engaging DS child in community, educational skills, and methods of enhancing self-responsibility for DS child. This was done by using open discussion and brainstorming.

Session (5) Role of family caregivers in controlling child behaviors:

Objective: At the end of these sessions, each family caregiver of children with DS was able to follow therapeutic methods for controlling behaviors and enhancing positive behaviors of his own child.

These sessions included methods of accepting children with DS, importance of learning by play and role modeling in modifying DS child behavior, positive reinforcement, methods of enhancing acceptable behavior. This was done by using open discussion, brainstorming, pictures, videos, and handouts.

Session (6) Overview about burden of care

Objective: At the end of this session, each family caregiver of children with DS obtained an overview about burden of care. This session included definition, types of burden of burden and factors affecting burden of care. This was done by using brainstorming, open discussion, and handout.

Session (7) Overview about the experience of hope among parents

Objective: At the end of this session, each family caregiver of children with DS obtained an overview about meaning of hope, core feature of hope, facilitators, and predictors of hopes. This was done by using brainstorming, open discussion, and handout.

Sessions (8:11) Applying Methods for reducing burden of care.

Objective: At the end of these sessions, each family caregiver of children with DS was able to apply methods decrease burden of care. These sessions included methods of reducing the burden of care. These sessions included guidelines for enhancing self-esteem, anger management skills, time management skills and relaxation techniques. This was done using open discussion, brainstorming, demonstration, role play, videos and handout and evaluated by asking questions, oral feedback, and re-demonstration.

Sessions (12-15) Applying Methods for enhancing hope.

Objective: At the end of these sessions, each family caregiver of children with down syndrome was able to apply methods for enhancing hopeful view for child future. These sessions included methods of enhancing hopeful thinking through, establishing goals of care, enhance active coping methods, searching for practical support, practicing health methods for managing child problems and managing daily hassles. This was done using open discussion, role play, brainstorming, demonstration, videos, and handout and evaluated by asking questions, oral feedback, and re-demonstration.

Sessions (16-19) Enhancing healthy lifestyle for family caregivers for children with down syndrome.

Objective: At the end of these sessions, each family caregiver of children with DS was able to practice a healthy lifestyle including eating a complete balanced diet, getting a restful sleep, physical exercise, and access to supportive and educational services.

Session (20) Closure Session (Post Assessment)

Objective: At the end of this session, each family caregivers of children with DS was able to fill in the data collection tools.

3. Evaluation phase:

Finally, the researcher gave feedback and made post assessment after the intervention program had been completely applied. The researcher provided thanks for cooperation to all family caregivers who participated in this study.

Ethical consideration:

Ethical approval was obtained from the Scientific and Ethical Committee of Nursing Faculty of Ain Shams University, the researcher explained the purpose of the study to the family caregivers involved 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 reported that all information would be used for scientific research and for the benefits of the family caregivers.

Statistical analysis:

The statistical analysis of data was done using the Statistical Package for Social Science (SPSS) program, for Windows 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). The following tests were used to test relations and correlations for significance. For quantitative data by chi-square tests-correlation by Linear Correlation Coefficient [r] tests.

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 (58.1%) were in age group (35-<55) years old, the married caregivers were more than two thirds (72.6%), the secondary school level of education represented (37.1%), the highest percent of the study sample were unemployed and had not enough family income which constituted (62.9%) and (61.3%) respectively, and more than half (61.3%) lived in rural areas.

Table (2): The table shows that two thirds of DS children (74.2%) were in age group (8-<10) years old, and more than half of DS children (56.5%) were male and had IQ from (40-<55), as regards to number of siblings and child's rank, more than third (40.3%) had two siblings and their rank was first.

Figure (1): Indicates that the highest percentage of children (45.2%) are totally dependent on their parents.

Table (3): Reveals that there was highly statistically significant improvement in subscales of burden among the family caregiver including perception of inadequacy, social burden, physical load, emotional burden, time requirement at post program than preprogram ($P \leq 0.001$). While there were no statistically significant differences in subscale of burden among the family

caregiver including economic burden post program than preprogram at ($p>0.05$).

Figure (2): Illustrates that there was a significant decline in the level of burden at post program than preprogram ($p\leq 0.05$).

Table (4): Explain that there was significant reduction on mean score regarding domain of hopelessness in the post-program implementation phase compared to the preprogram phase, including feeling about the future, loss of

motivation and future expectation ($p<0.001$).

Figure (3): Display that there was significant enhancement in the level of hopelessness at post program than preprogram ($p\leq 0.05$).

Table (5): clarified that, there was positive strong statistically significant between family burden and feeling of hopelessness post program implementation in which $r = 0.736$ at $p = 0.000$.

Table (1): Distribution of demographic data of family caregivers of children with Down Syndrome

Items	N	%
Types of caregivers		
Father	0	0
Mother	62	100
Age of caregivers		
20-<35	14	22.6
35-<55	36	58.1
55 and more	12	19.4
Mean \pm SD	35.98 \pm 6.92	
Marital Status		
Married	45	72.6
Widowed	11	17.7
Divorced	6	9.7
Level of Education		
Primary School	19	30.6
Secondary School	23	37.1
University	17	27.4
Postgraduate	3	4.8
Occupation		
Governmental employe	16	25.8
Private job	7	11.3
Un employed/ housewife	39	62.9
Residence		
Urban	24	38.7
Rural	38	61.3
Adequacy of family income		
Enough	2	3.2
Sufficient To Some Extent	22	35.5
Not Enough	38	61.3

Table (2): Distribution of Demographic data of Children with Down Syndrome (62)

Items	N	%
Age (years)		
6-<8	14	22.6
8-<10	46	74.2
10-12	3	4.8
Mean \pm SD	9.54+2.33	
Gender		
Male	35	56.5
Female	27	43.5
Number of Siblings		
Non	10	16.1
One	21	33.9
Two	25	40.3
More than two	6	9.7
Child's Rank		
First	20	32.3
Second	14	22.6
Third	11	17.7
More than third	17	27.4
Level of Child Education		
Basic education	42	67.7
Educational	20	32.3
Child IQ		
25-<40	26	41.9
40-<55	32	51.6
55-70	4	6.5

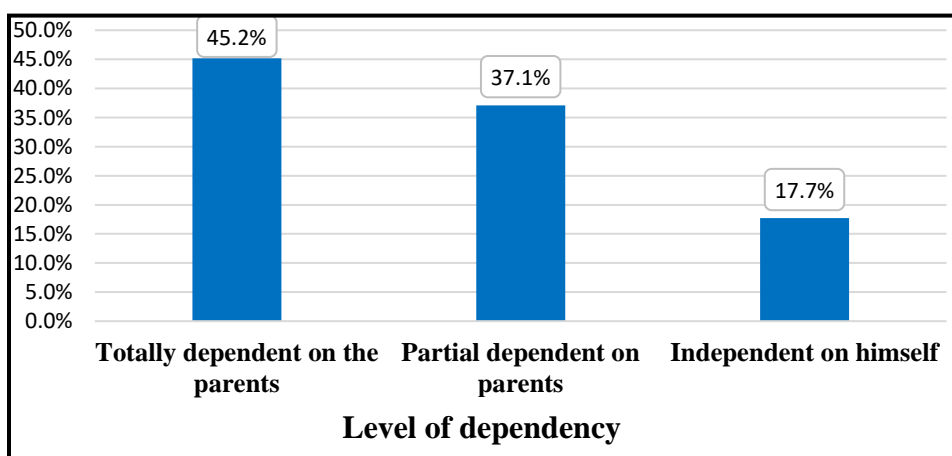
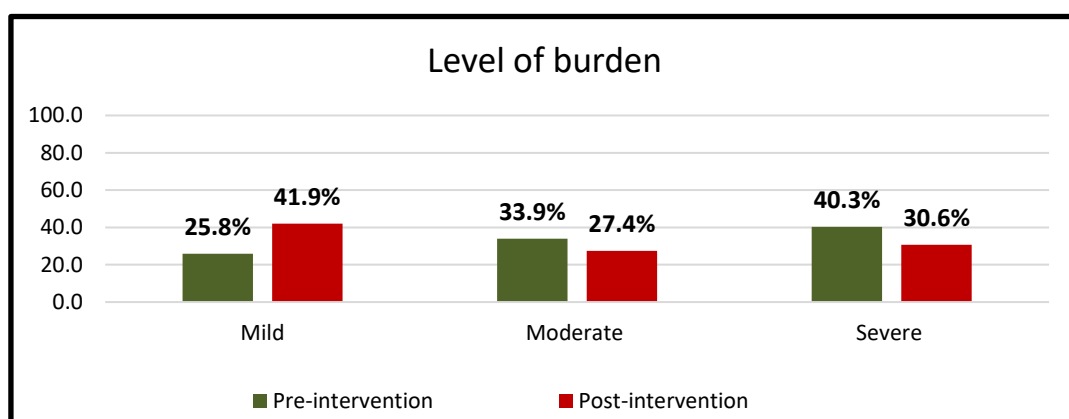
**Figure (1): Distribution of levels of dependency of children with Down Syndrome (no.=62)**

Table (3): Distribution of the burden subscales among family caregivers of children with Down Syndrome pre and post program intervention (no.=62)

Burden	Pre		Post		Paired t test	P value
	Mean	SD	Mean	SD		
Perception of Inadequacy	32.91	5.33	24.78	4.39	21.45	HS
Social Burden	19.87	6.36	15.46	7.19	31.97	HS
Physical Load	17.16	2.92	14.69	3.88	41.58	HS
Emotional Burden	48.99	3.39	29.98	9.33	10.74	HS
Time Requirement	24.27	2.21	17.42	7.26	29.47	HS
Economic Burden	21.31	4.81	20.96	5.81	1.66	NS
Total	164.51	25.02	123.29	37.86	6.330	HS

(*) Statistically significant at $p < 0.05$, (**) Statistically highly significant at $p < 0.001$, non-Significant at $p < 0.05$

**Figure (2): Frequency distribution of the studied family caregivers of children with Down Syndrome according to their level of burden pre and post intervention (no.=62)****Table (4): Distribution of the studied family caregivers of children with Down Syndrome according to the domains of hopelessness pre and post program intervention (no.=62)**

Feeling of Hopelessness	Pre		Post		Paired t test	P value
	Mean	SD	Mean	SD		
Feeling about the future	4.36	1.21	2.16	1.92	15.09	HS
Loss of motivation	6.94	1.33	4.23	0.98	24.396	HS
Future expectation	5.12	0.66	3.96	1.39	39.07	HS
Total	16.42	3.2	10.35	4.29	11.36	HS

(*) Statistically significant at $p < 0.05$, (**) Statistically highly significant at $p < 0.001$, non-Significant at $p < 0.05$

Figure (3): Frequency distribution of the studied family caregivers of children with Down Syndrome according to their level of hopelessness (no.=62)

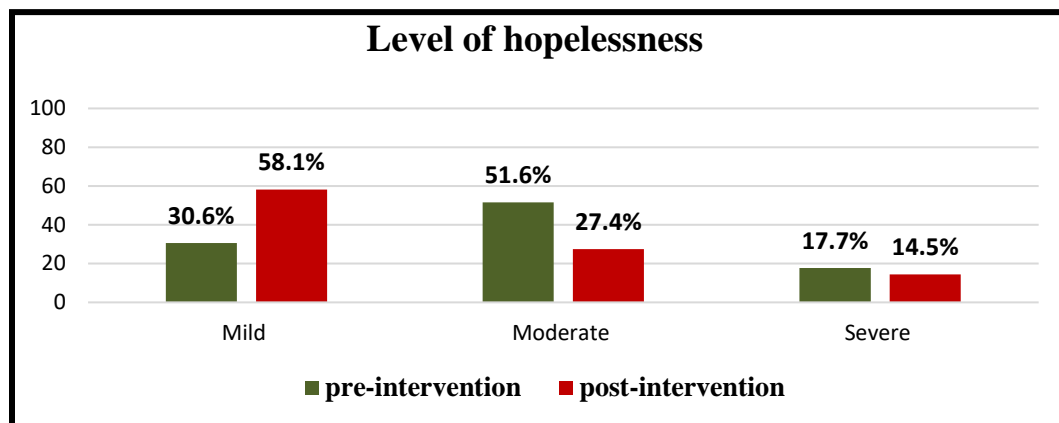


Table (5): Correlations matrix between family burden and feeling of hopelessness among family caregivers of children with Down Syndrome post program intervention (no.=62)

Variables	Post intervention	
	Family Burden Evaluation Scale (FBES)	Beck Hopelessness Scale (BHS)
The Family Burden Evaluation Scale (FBES)		0.736**
Beck Hopelessness Scale (BHS)	0.736**	

Discussion

Most children with down syndrome are dependent upon their families for care and support and the resulting burden placed on the family is a psychological burden that is related to the perception and interpretation of the various negative physical, emotional, social, and material manifestations of that burden. Hope is important in parenting children because it involves cognitive and behavioral flexibility in response to problems, as well as one’s belief that goals can be achieved. Parents with high levels of hope can find many ways to obtain their goals and are able to pursue their goals despite obstacles (Cenk et al., 2016).

Demographic data of Family Caregivers of Children with Down Syndrome

The result of present study indicate that all family caregivers are mothers this reflect the emotional bonds between children and their mother as well as in Egypt culture are compelled to assumes the caregiving role for his / her disabled child and other family members. the finding of this study explained that about two third of mother caregivers are married and housewife. This explained that the presence of children with down syndrome strength martial relations between partners. This reflects the positive perspective of having children with down syndrome.

The result agreement with **Singh et al., (2014)** study entitled study of burden in parents of children with intellectual disabilities. The result explained that highest percent of caregivers were married women and are housewife.

This result also agreement with **Mohamed., Elkhatab., and Mohamed (2020)** investigate the effect of the psycho-educational program on psychological stress and resilience among family caregivers of children with intellectual disabilities and found that highest percent of family caregivers are married women.

As regard to family income, the result clarified that high proportion of family caregivers had insufficient income this may be due to, the children with chronic disability which require expense treatment, continuous health care needs, follow up, and hospitalization.

About the demographic data of children with down syndrome the result of present study revealed that about two third of children with down syndrome in age group 8 <10 years more than half are male. The highest percentage of children have a basic education, about level of child dependency, the highest percent of children are totally dependent on their parents this may be related to 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 impaired of social function.

This result in the same line with **Tri, et al., 2017** in a study entitled "Activity daily living (ADL) of young people with intellectual disabilities" found that children with mental retardation experiencing limitation in trying to conduct their daily activities, thus they are highly dependent to others.

Burden among family caregivers of children with Down Syndrome pre and post program intervention.

The result of present study clarified that there was highly statistically significant improvement in the main subscales of burden in the post-program implementation phase than preprogram phase regarding perception of inadequacy, social burden, physical load, emotional burden, & time requirement. While there were no statistically significant differences in subscale of burden among the family caregiver including economic burden post program than preprogram.

This could be attributed to the positive effect of the supportive psychoeducational program implementation on minimizing burden that enhances the personal satisfaction regarding caring of the child with DS through increasing mother's knowledge and experience which help them in reducing burden of care and enhance their self-esteem, anger management skills, time management skills and relaxation techniques.

Regarding perception of inadequacy burden the was a significant difference between pre and posttest. This may be related to different factors throughout program sessions the mother having been understood that their crucial responsibility in shaping child future, gain a considerable knowledge and skills about caring child with down syndrome, express and sharing feeling with significant other, acceptance the child disabilities and seeing a positive aspect of caring child additionally there was a widespread attention from community toward child with a special need.

This result not parallel with **Dilek (2017)** assess family burden and associated factors among parents of children with intellectual disability and

found that the highest burden among Parents of Children with Intellectual Disability was feeling of inadequacy.

The result denotes that the observed decrease in social burden and physical load. This may be related to different factors., the family caregiver has been able to see positive outlook of caring child, during program session, they gain skill to enhance child level of independence, they realize nature of disabilities that their child needs a different type of support from community to preserve reasonable level of living additionally they are practicing different methods of stress management during program implementation.

This result contradicted with **Alibakhshi et al., (2020)** investigate the caregiver burden and related factors in parents of year 12 to 4 years old children with DS living in Tehran City. The result shows that the parents have an average level of social burden.

Also, this result similar with **O' Shea et al., (2018)** who reported that caregivers emphasized the importance of providing resources such as dedicated gymnasiums to improve their physical activity and prevent obesity in persons with DS. Meanwhile, **Alesi and Pepi (2017)** who showed that parental involvement is key to improving the time spent on physical activity by the persons with DS, and the need for dedicated physiotherapy and speech centers, which are vital for these children as they take longer than normal children to achieve milestones.

Concerning emotional burden, the finding of this study showed that the was a significant drop in the mean score at posttest and a was highly a significant difference between pre and posttest. this may be related to different reasons during program implementation they adopted

problem and practical coping methods, accepting child disabilities, express their worry about the future, perceive caring child is a gift from Allah in addition they are able to cope with social stigma of having child with down syndrome due to presence of good model of child with disabilities in social media.

This result in the same line with **Hassan, Hamid, and Eltayeb (2021)** explain subjective and objective burden on parenting caregivers who caring of children with different intellectual developmental disabilities, their treatments, and specific strategies to deal with such cases. Found that Mothers of children with Down syndrome display better psychological wellbeing than mothers of similarly aged children with other types of intellectual developmental disabilities. Also have less pessimism about their child 's future, more closeness in the relationship with their child, and fewer depressive symptoms and more likely to perceive that the child reciprocated feelings of closeness compared with mothers of children with other types of intellectual developmental disabilities.

About time requirement burden there was a highly significant difference between pre and posttest this may be related to the mother caregivers sharing responsibilities of caring child with other family member and have been able to meet the child needs.

Regarding the economic burden, the result clarified there was a non-significant decrease in mean score at posttest. This could be due to the mother and have been understood the child condition is lifelong require medical care and community support (educative approach), the services need a financial help which increase financial burden on family.

This result and explanation in the same line with **Farkas et al., (2019)** assess the ups and downs of Down syndrome: a qualitative study of positive and negative parenting experiences, this result concluded that a strongly agreed of financial burden for parents having children with down syndrome. Moreover, this result agrees with **Fridman et al., (2017)** who mentioned that the financial burden of the family automatically elevates when one of the parents, most likely the mother tries to reduce working hours or step out of the job to take care of their disabled child, which in turn will increase the financial burden of the family.

The results of the current study illustrate that there was a significant decline in the level of burden at post program test. This result may be due to the parents of children with DS are acquire the benefit of Supportive Psychoeducational Program and modifying their roles and responsibilities to relieve the burden experienced by the caregiver.

Moreover, nurses can be effective in reducing the physical and emotional burden of the parents by enabling other family members to participate in the care and training of the child with intellectual disability and by creating family support groups.

This result agreement with **Ferreira et al., (2015)**, who mentioned that the low percentage of caregivers with severe burden is expected since they undergo a process of psychosocial adaptation and have less negative perception of the situation, develop better care strategies, and what first appeared difficult, merely becomes a natural part of the family routine.

This result was agreed by the findings of **Mohan & Kulkarni (2018)**, who

mentioned that lifestyle modification for family caregivers of children with Down Syndrome could minimize their level of stress and improve their coping with daily life stressors and life demands in addition to child's care burdens.

Hopelessness among family caregivers of children pre and post program intervention.

The result of present study clarified that there was significant reduction in the mean score of domains of hopelessness in the post-program implementation phase compared to the preprogram phase about felling, about the future, and future expectation the significant reduction of mean score may be related to different factors; the mother caregivers during program implementation, they have been gain a realistic knowledge about the nature of child disabilities, focusing their abilities for caregiving, they take positive measure to lessening their anxiety and worry about future through practice guidelines of caring child and practice healthy life style and recognize different methods for support their child, all mother informed that they always caring the child they cannot give up of caring. Additionally, they explained support from Allah and good training of child they will be attain acceptable living condition for their child.

The result and explanation in same the line with **Golan (2016)** examines the conditions that may improve parental SWB and focuses on the construct of hope among parents of children with special needs. the results confirmed that mothers who were taking care of their intellectually disabled children had a high level of hope, self-efficacy, and quality of life.

This result agreement with **Truitt, et al., (2012)** investigate the relationships between perceived uncertainty, hope, and

adaptation in caregivers of children with Down syndrome. The result showed that mothers of children with Down syndrome have shown that higher levels of hope were associated with lower levels of worry and were a contributing factor to psychological wellbeing.

The result is contradicting with **Lalehgani et al., (2018)** compare the quality of life of mothers of children with intellectual disabilities, and mother of child with normal intelligence. The result showed that the mother of child with down syndrome have a low level of hope and worry about child future.

As regards the loss of motivation subitems the result of present study denoted that there was marked reduction in the mean score at posttest. this may be related to different reasons they have been engage in activate coping process, find appropriate support from medical staff, having an inner drive for helping their child, they gain skills that enable them to achieve caregiving process correctly, creating approaches that enable them of caring child, additionally they see bright site of caregiving such as family cohesiveness, patience and putting their own life circumstances in right way for the child future.

The results of the current study indicated that there was a significant enhancement in the level of hopelessness at post program test. This may be related to gain accurate knowledge about the child developmental tasks in each stage of development, community resources for support, methods that improve child independence level according to degree of intellectual abilities as well as they gain skills abouts time management, anger management and practicing relaxation exercise.

The findings in the same line with **Martin et al., (2019)** assess impact hope intervention program”, for parents of children with developmental disorders on hope and gratitude, and on parental anxiety symptom. The results explained the level of hope was significantly increased at posttest.

This result was disagreement with **Kore and Venkatraman (2017)** their study aimed to understand the impact of hope on perceived stress and self-efficacy among parents of children suffering from intellectual disabilities. The result clarified that the high percentage of parents had low level of hope.

Finally, these results of the present study clarified that there was a positive strong statistically significant between family burden and feeling of hopelessness post program implementation.

This may be related to frequent explanation during program sessions, simplicity of content, frequent feedback and all family care givers having a powerful desire to help their child.

This result is consistent with **Cenk et al., (2016)** evaluating the effectiveness of a structured supported education program for the parents of children with intellectual disability. The result explains there was a significant difference between pre and posttest regarding sense of hope and family burden.

This current study result is congruent 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 or psychological and physical health problems.

This result was consistent with a study carried out by **Bertrand (2019)** who explained that most parents were happy with a special child, to the extent that they said that these children had a positive impact on their lives.

Also, this result was supported by **Peer & Hillman (2014)** who noted that social support; open and predictable patterns of communication; a supportive family environment, including commitment and flexibility; family hardiness; internal and external coping strategies; a positive outlook on life; and family belief systems could improve the level of resilience among family caregivers of children with intellectual disabilities.

Conclusion:

Based on the findings of this study, it concluded that application of supportive psychoeducational program, supported the hypothesis of the study & had a positive effect on the minimize the level of burden and reduce the feeling of hopelessness among family caregivers of children with down syndrome.

Recommendations:

Based on the results of the present study, the following recommendations were suggested:

1. Increasing the public and society awareness about down syndrome through mass media and health education programs to reduce burden and feeling hopelessness.
2. Designing training program for caregivers regarding coping patterns for their roles to their children with down syndrome.
3. Provision a guideline booklet to all newly admitted mothers having children with DS in Genic clinic and rehabilitation center to help them in

improving their knowledge and practices.

4. Future research to assess factors that may influence the role of caregiving and different challenges faced by family caregivers in rearing different aged children with DS.

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