

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 enhancement 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 appositive effect on reduce feeling of hopelessness and reduce 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, also known as trisomy 21, is a genetic disorder causing mental and intellectual disabilities, including impaired cognitive function, poor hand-eye coordination, delayed and motor neuron development (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 significantly impact parents' quality of life, leading to feelings of pessimism, anger, guilt, and despair. Depression and hopelessness can also hinder their ability to care for the children, causing negative consequences for them. Parents of children with DS often care for them throughout their lives due to their persistent symptoms (**Alibakhshi et al., 2020**).

Hope significantly impacts a parent's tolerance for their child's infirmity, calms anxiety and depression, and improves life satisfaction and happiness, especially in families with developmental disorders. (**Alibakhshi et al., 2021**).

Nurses play a vital role in providing family-centered care for children with chronic illnesses like down syndrome, focusing on supportive measures like education, growth promotion, and prevention of complications, while also providing continuous support and education to parents and caregivers (**Hegazy and Baraka 2021**).

Psycho-educational intervention is a systematic method aimed at improving the lives of children with intellectual disabilities by increasing family knowledge, adapting to illness, refining communication, and increasing critical thinking skills. (**Esther, Kerry, and Manfred 2018**).

Significance of the study:

Down syndrome (DS) is a genetic disorder affecting intellectual disabilities in 1 in 700 babies globally, with an incidence of 1 per 1000 live births, and

3000 to 5000 children are born with DS annually. (**Gashmard, Ahmadi, and Kermanshahi 2020**).

In Egypt, 1 in 700 children have Down syndrome (DS), reinforcing gendered household responsibilities and increasing stress for burdened wives and mothers due to the high incidence of DS. (**Alwakeel et al., 2020**).

Families with children with intellectual disabilities require continuing, lifelong-lasting care, which can add additional burdens to their roles, responsibilities, and relationships. This increasing burden can negatively impact family functioning, as it affects the overall functioning of the family (**Harkoma and Saswati 2021**). It is recognized that the high levels of hopelessness among parents with children with intellectual disabilities significantly contribute to the family burden (**Tétreault et al., 2014**).

McKee et al., (2019) added that a correlation between hope, child problem behaviors, and depression, with parents with lower levels of hope and more child behavior problems experiencing more depression symptoms and less positive affect.

Addressing families with intellectually disabled children involves defining burdens, fostering future hopes, providing information, enhancing coping skills, and offering emotional sharing and psychosocial support. The educational program aids families in adjusting to their current situation, reducing hopelessness and burden, allowing them to express their emotions, adapting to their child's inadequacies, and increase coping skills

(Balci., Kizil., Savaşer., Dur., and Mutlu 2019).

So, the application of a Supportive Psychoeducational Program has become a crucial component of psychiatric nursing in order to reduce burden and feeling of hopelessness for family caregivers of children with down syndrome.

Aim of the Study

The study aims to assessing the effect of a supportive psychoeducational program on the burden and feeling of hopelessness of family caregivers of children with Down syndrome through:

1. Assessing the levels of burden and levels of hopelessness among family caregivers of children with Down syndrome
2. Designing and applying a psycho-educational program to reduce burden and enhance hope among families caring for children with down syndrome.
3. Evaluating the effect of the program on burden and feeling of hopelessness among family caregivers of children with Down syndrome.

Research hypothesis:

This study hypothesized that:

A psycho-educational program for families caring of children with Down syndrome have a positive effect to reduce level of burden and feeling of hopelessness.

Subjects & Methods

Research design.

The study aim was achieved via a quasi-experimental research design, including a one-group pretest post-test.

Setting:

This study was conducted at the Genes Clinics of DS, which are specialist clinics of the university pediatric hospital at Ain Shams University Hospitals. Each clinic offers two beds and six seats, as well as plenty of ventilation and lighting. This setting was chosen because it serves the largest region and has a high attendance of children with Down syndrome.

Subjects:

Sample size:

The sample size was calculated using a power analysis significance level of 0.95 ($\beta=1-0.95=0.5$) at alpha. The significance level was set at 0.05 (one-sided) with a large effect size (0.5), with 0.001 indicating the high significance.

Sample type:

A purposive sample of (62) families who are caregivers of children with Down syndrome and their children attend a previous mentioned setting.

Inclusion criteria for children:

- An IQ of between 25 and 70.
- Age: range between 6 and 12 years.
- Sex: male and female.

Exclusion criteria for children:

- They have another disability unrelated to Down syndrome.
- Have a family member with a disability, such as a sibling.

Inclusion criteria for family caregivers:

- Members of the child's family who provide direct care.
- Only have one child with a disability.

Exclusion criteria for family caregivers:

- The family has over one child with disabilities.
- The family has a mental disease or physical infirmity.

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 **Sari 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: (1. perception of inadequacy - 2. social burden - 3. physical load - 4. emotional burden - 5. time requirement - 6. economic burden)

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):

Beck originally develops it **et al., (1974)** for measure aspect of hopelessness. It consisted of twenty items. divided into three subitems:

(1. Feelings about the future – 2. Loss of motivation – 3. Future expectations)

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.

Pilot study:

A pilot study was conducted on six family caregivers to assess tool clarity and feasibility, resulting in a 25–30-minute completion time, and the tools were modified based on findings.

Data Collection procedure:**Field Work:**

The actual fieldwork was carried out between April 2021, and December 2021, a period of nine months and the actual field work composed of following three phases:

1. Assessment phase:

After the study's approval to proceed was received, data collection was conducted, and before any data was collected, the study's purpose was briefly

described to the sample of subjects who volunteered to take part. The researcher informed each family caregiver that all information would be utilized completely for scientific research, ensuring their voluntary involvement and anonymity.

The research participants were chosen based on the inclusion and exclusion criteria, and data was collected from sixty-two family caregivers of children with DS who agreed to participate in the study during the morning time at previously mentioned setting.

2. Implementation phase:

The researchers initiated the family caregiver intervention program sessions after the pre-assessment was finished. Family caregivers were divided into five groups to conduct the intervention program and twelve family caregivers made up each group. The intervention program was taught for each group on Saturday or Wednesday every week.

Supportive Psychoeducational Program.

The supportive psychoeducational program's aims to reduce the level of burden and reduce the feeling of hopelessness of family caregivers of children with down syndrome. Based on relevant recent literature, a researcher designed the program. It written in Arabic language and composed of two parts as the following:

Part I- Theoretical part: It was focused on knowledge about the problems and needs of children with down syndrome, available services, effect of child disability on family, parents hope and family burden under the following sessions:

Orientation session (1): initially researchers introduced themselves and established relationships with family caregivers and provided them with program goals, objectives, and data collection tools for the first assessment.

Session (2): The session offered family caregivers an overview of Down syndrome, its definition, affecting problems, intellectual disabilities effects on those children, and the needs of DS children.

Session (3): This session supported family caregivers with effective methods to address Down syndrome children's problems, foster self-care, and improve social skills. Topics covered included managing problems, the benefits of community participation, and skills that enable DS children to become more self-responsible.

Sessions (4&5): Family caregivers learned therapeutic methods for regulating and enhancing positive behaviors, including acceptable behavior enhancement, better communication with others, play, role modeling, and positive reinforcement.

Session (6): This session provided an overview of the burden of care for family caregivers, including definitions, types, and factors affecting it.

Session (7): The session involved an overview of the meaning, core features, facilitators, and predictors of hope among parents of children with Down syndrome.

These sessions were performed by using brainstorming, open discussion, pictures, and handouts.

Part II- Practical part: It was applied the role of a family caregiver in enhancing a child with Down syndrome's behaviors, active coping strategies, problem-solving, communication skills, relaxation techniques, anger management, and decision-making.

Sessions (8-12): These sessions were performed to help family caregivers learn techniques to reduce their burden of care, including stress and time management, self-esteem enhancement, critical problem-solving techniques, relaxation techniques, and skills on how to stop negative feelings and promote them towards their children.

Sessions (13-16): These sessions designed to help family caregivers enhance their hopeful view for their future by implementing methods such as enhancing hopeful thinking, setting care goals, improving active coping strategies, seeking practical support, practicing health management, and managing daily challenges.

Sessions (17-20): These sessions operated to improve the lifestyle of family caregivers by promoting a balanced diet, adequate sleep, physical activity, and access to supportive and educational services.

These sessions were implemented by using open discussion, role play, brainstorming, demonstration, pictures, and booklet and assessed via asking questions, feedback, and re-demonstration.

3. Evaluation phase:

Finally, the researchers provided post-assessment feedback and expressed gratitude to all family caregivers who

participated in this study post implementing the intervention program.

Ethical consideration:

The study, approved by Ain Shams University Scientific and Ethical Committee, was explained to family caregivers, ensuring data anonymity and confidentiality.

The researchers informed family caregivers about their participation and withdrawal rights and stated that all information would be used for scientific research.

Statistical analysis:

The data was analyzed using the SPSS program for Windows Version 22.0, using percentage, arithmetic mean, and standard deviation. Tests were used to test relations and correlations, including chi-square tests for quantitative data and Linear Correlation Coefficient [r] tests for correlation with statistical significance at p-value <0.05 and P <0.001 highly significant.

Results:

Table (1): found that (100%) of family caregivers were mothers, with over half (58.1%) were in age group (35-<55) years old, married caregivers comprising over two-thirds (72.6%), and (37.1%) finished secondary school education. The highest percentages were unemployed (62.9%) and (61.3%) had insufficient family income and living in rural areas.

Table (2): reveals that (74.2%) of DS children are aged 8-10 years, 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): illustrates that the highest percentage of children (45.2%) are dependent on their parents.

Table (3): Indicates a significant improvement in subscales of burden among family caregivers, including perception of inadequacy, social burden, physical load, emotional burden, and time requirement post-program compared to pre-program ($P \leq 0.001$), but no significant differences were found in economic burden post-program ($p>0.05$).

Figure (2): shows a significant decrease in burden levels post-program compared to pre-program ($p \leq 0.05$).

Table (4): Explain a significant decrease in mean score of feeling of hopelessness in the post-program implementation phase compared to the preprogram phase, including feelings of despair, motivation, and future expectations ($p<0.001$).

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

Table (5): clarifies a significant positive correlation between family burden and feeling of hopelessness post-program implementation, with a r value of 0.736 at $p = 0.000$.

Table (1): Demographic data of studied family caregivers (no.=62)

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): Demographic data of Children with Down Syndrome (no.=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	
Sex		
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

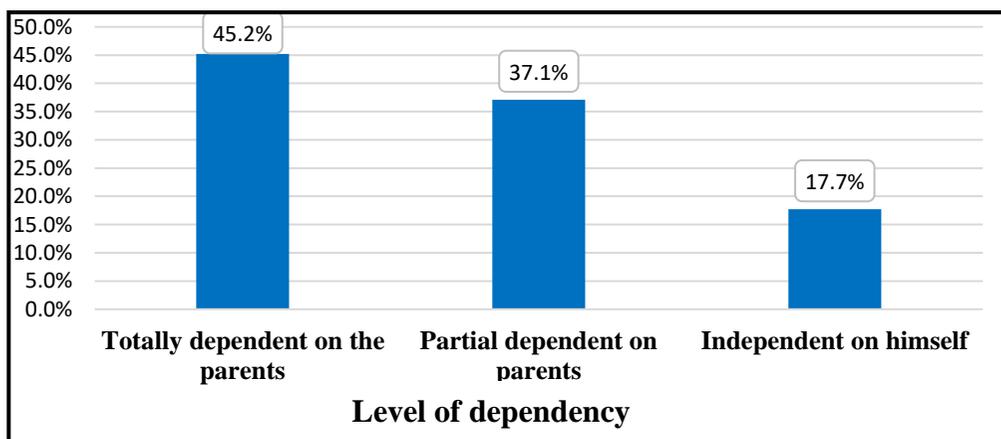


Figure (1): Distribution of levels of dependency of children with Down Syndrome (no.=62)

Table (3): Distribution of the burden subscales pre/post program intervention among studied family caregivers (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

(*) A statistically significant= $p \leq 0.05$ (**) A highly statistically significant= $p \leq 0.001$, non-Significant at $p < 0.05$.

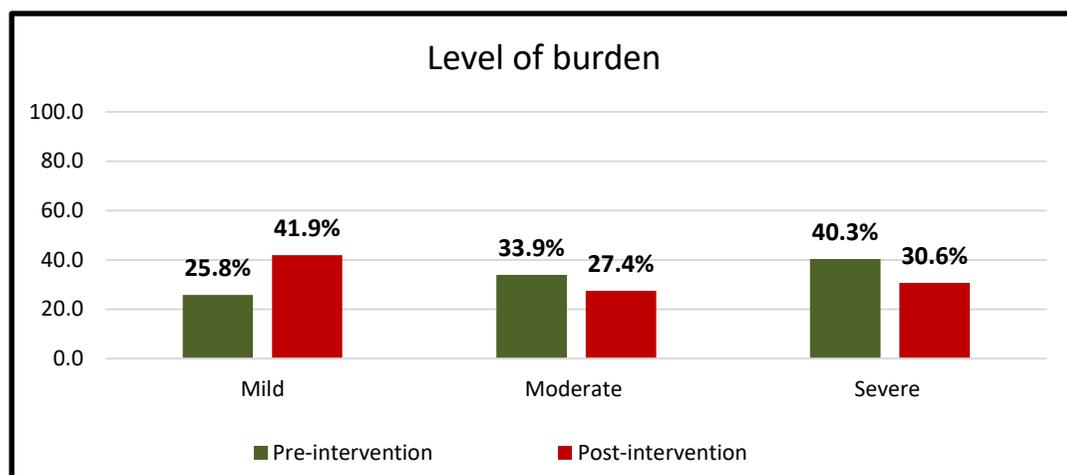


Figure (2): Frequency distribution of studied family caregivers as regard their burden levels pre/post program intervention (no.=62)

Table (4): Distribution of studied family caregivers regarding the domains of hopelessness pre/ 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

(*) A statistically significant= $p \leq 0.05$ (**) A highly statistically significant= $p \leq 0.001$

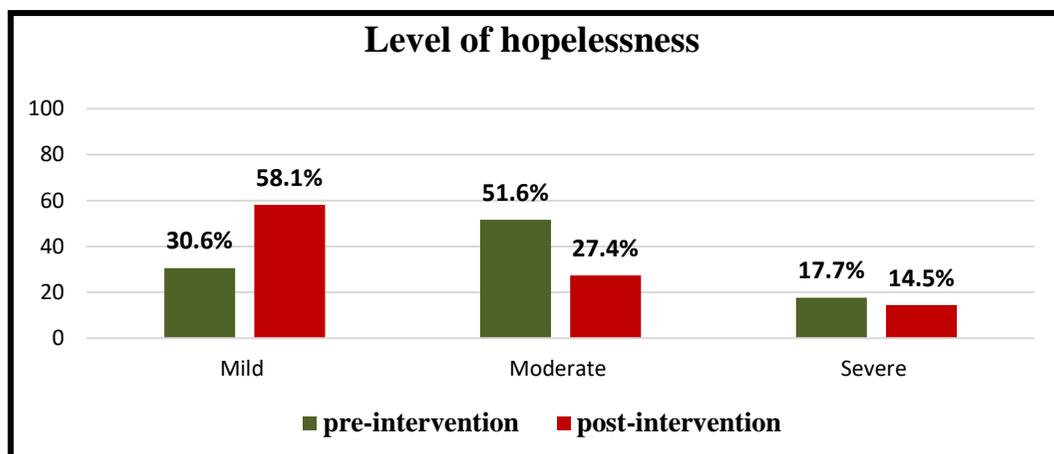


Figure (3): Frequency distribution of studied family caregivers toward their level of hopelessness pre/post program intervention (no.=62)

Table (5): Correlations matrix between family burden and feeling of hopelessness studied family caregivers 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

Down syndrome children often face a psychological burden due to their reliance on their families for care and support, resulting in negative physical, emotional, social, and material manifestations. Hope is crucial in parenting, involving cognitive and behavioral flexibility in addressing problems and believing in the possibility of achieving goals, enabling parents to overcome obstacles (Cenk et al., 2016).

Demographic data of studied family caregivers

The study's findings state that whole family caregivers are mothers this reflect the emotional bonds between children and their mother as well as in Egypt culture are compelled to assume 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

marital relations between partners. This reflects the positive perspective of having children with down syndrome.

The result agreement with **Singh et al., (2014)** who explained that highest percent of caregivers were married women and are housewife.

This result also aligns with **Mohamed., Elkhatib., and Mohamed (2020)** who found that highest percent of family caregivers are married women.

As regard to family income, the result clarified that a significant number of family caregivers have insufficient income, possibly due to the chronic disability of their children, continuous healthcare needs, follow-ups, and hospitalization.

About the demographic data of children, this study discovered 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, but the majority are completely dependent on their parents due to developmental delays, limitations in daily living activities, and impaired social function. This dependency may be attributed to limitations in self-care, dressing, hygiene, walking, and talking.

This results in the matching with **Tri, et al., (2017)** who found that children with intellectual disabilities face limitations in daily activities, making them highly dependent on others.

Burden among studied family caregivers pre/post program intervention.

The study found a significant improvement in subscales of burden of family caregivers post-program implementation compared to preprogram, including perception of inadequacy, social burden, physical load, emotional burden, and time requirement, but no significant differences were found in economic burden post-program.

This could be attributed to the supportive psychoeducational program has shown positive effects on reducing burden and enhancing personal satisfaction in caring for a child with Down syndrome by improving self-esteem, stress management, time management, critical problem-solving, relaxation techniques, and promoting positive feelings towards their children.

Regarding perception of inadequacy burden the was a significant difference between pre/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 is not parallel with **Dilek (2017)** who concluded 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.

The result conflicted **Alibakhshi et al., (2020)** who shows that the parents have an average level of social burden. Meanwhile, **Alesi and Pepi (2017)** who showed that that parental involvement is crucial for enhancing physical activity time for individuals with Down syndrome (DS), emphasizing the need for dedicated physiotherapy and speech centers to help these children achieve milestones.

Relating to emotional burden, the study revealed a significant decrease in the mean score at posttest and a significant difference between pre/posttest , this may be related to various 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 is in line with Hassan, **Hamid, and Eltayeb (2021)**, who mentioned that mothers of children with Down syndrome have better psychological wellbeing, are more hopeful about their child's future, have more contact relationships, have fewer depressive symptoms, and observe the child's reciprocating feelings compared to mothers of children with other disabilities.

About time requirement burden there was a significant difference is highly between pre/posttest this may be related to the mother caregiving 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)** who result concluded that a deeply agreed of financial burden for parents with children with down syndrome. Moreover, this result agrees with **Fridman et al., (2017)** who mentioned that when one parent takes time off work to care for their disabled child, the financial burden on the family increases.

The results of the study illustrate that there was a significant decline in the level of burden at post program test.

This result could be that parents of

children with Down syndrome (DS) benefit from a supportive psychoeducational program and modify their roles to alleviate caregiver burden.

Moreover, nurses can alleviate parents' physical and emotional burden by involving family members in the care and training of children with intellectual disabilities and establishing family support groups.

This outcome agreement with **Ferreira et al., (2015)**, who mentioned that caregivers with severe burdens tend to have a low percentage due to psychosocial adaptation, reduced negative perception, improved care strategies, and the difficulty becoming a natural part of family routine.

This finding corresponded to the findings of **Mohan & Kulkarni (2018)**, discovered that lifestyle modifications for family caregivers of children with Down Syndrome can reduce stress levels and enhance coping with daily life problems and care burdens.

Hopelessness among studied family caregivers pre/post program intervention.

The result of present study clarified that there was significant decrease 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)** who confirmed that mothers caring for their intellectually disabled children experienced high levels of hope, self-efficacy, and quality of life.

This result is matched with **Truitt, et al., (2012)** who discussed that mothers of children with Down syndrome reported higher levels of hope, lower worry levels, and a positive impact on their psychological wellbeing.

The result is contradicting with **Lalehgani et al., (2018)** whose result showed that mothers of children with Down syndrome have low levels of hope and worry about their child's future.

As regards the loss of motivation subitems, the result of current study denoted that there was marked reduction in the mean score at posttest. this may be due 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 finding of the present study appeared to show that there was a significant enhancement in the hopelessness level 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)** whose results explained the level of hope was significantly increased at posttest. Additionally, this result was disagreement with **Kore and Venkatraman (2017)** who highlight that a significant percentage of parents had a low level of hope.

Finally, these results of the current study showed that a significant positive correlation between family burden and feeling of hopelessness post-program implementation. This may be concerned with 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 coherent with **Cenk et al., (2016)** who explain that there was a significant difference in pre/posttest scores regarding sense of hope and family burden.

The study aligns with **Alexander and Walendzik's (2016)** who findings reported that emotional support from family caregivers of children with Down syndrome (DS) helps them overcome life challenges and reduces the risk of psychological and physical health issues.

This result was consistent with a study carried out by **Bertrand (2019)** who explained that most parents are satisfied with their special child, if they believe it positively impacts their lives.

Peer & Hillman (2014) provided additional support for this finding by pointing out that family caregivers of children with intellectual disabilities can develop their resilience through social support, honest communication, a caring environment, cooperation, family hardiness, coping mechanisms, a cheerful outlook.

Conclusion:

Based on the findings of this study, it concluded that application of supportive psychoeducational program, supported the hypothesis of this study & had a positive effect on the reduce 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:

- Increasing the public and society awareness about down syndrome through mass media and health education programs to reduce burden

and feeling hopelessness.

- Designing training program for caregivers regarding coping patterns for their roles to their children with down syndrome.
- 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.
- Future research should explore the factors influencing caregiving roles and the difficulties faced by family caregivers in raising various ages of children with Down syndrome.

References:

- Alam El-Deena., N. Alwakeela., A. El-Gilanyb., Hand Wahbaa., Y. (2021):** Burden of family caregivers of Down syndrome children: a cross-sectional study. *Family Practice*, Vol. 38, No. 2.160
- Alesi, M. and Pepi, A. (2017):** Physical activity engagement in young people with Down syndrome: Investigating parental beliefs. *Journal of Applied Research in Intellectual Disabilities: JARID*, 30, 71–83
- Alexander, T. &Walendzik, J., (2016):** Raising a Child with Down Syndrome: Do Preferred Coping Strategies Explain Differences in Parental Health? *Journal of Psychology*, 7, 28-39
- Alibakhshi., H. Azkhosh., M. Bahmani., B., Mohammad Saeed Khanjani., S.M. and Shahboulaghi., M. F (2021):** Hope Facilitators in Parents with Children Suffering from Cerebral Palsy: A Qualitative Study. *Archive of SID Corrected Proof Iran J Psychiatry Behav Sci*. June; 15(2): e107430.
- Alibakhshi., H. Ayoubi, K. Avaz., Azan., Z., Ahmadizadeh., Z. Siminghalam., M.and Tohidast., (2020):** investigating the caregivers' burden and Related Factors in Parents of 12 to 4 Years old children with down syndrome Living in Tehran city, Iran, 2020. *Archive of rehabilitation*. October. vol23 no 3.
- Alwakeel, A., El-Gilany, A. & Wahba, Y., (2020):** Burden of family caregivers of Down syndrome children: a cross- sectional study. *Family Practice*, 38(2):160-165.
- Azhar AS, AlShammasi ZH, and Higgi RE. (2016):** The impact of congenital heart diseases on the quality of life of patients and their families in Saudi Arabia Biological, psychological, and social dimensions. *Saudi Med J* 37.4.392
- Balci., E. Kızıl., H. Savaşer., S. Dur., S. and Mutlu., B. (2019):** Determining the burdens and difficulties faced by families with intellectually disabled children. *J Psychiatric Nurs*;10(2): 124-130
- Bertrand, R. (2019):** Parents' perspective on having a child with Down syndrome in France. *American Journal of Medical Genetics Part A*, 179, 770–781.
- Cenk., C.C, Muslu., K., Mand Sarlak., D (2016):** The Effectiveness of

- Structured Supported Education Programs for Families with Intellectually Disabled Children: The Example of Türkiye. *Archives of Psychiatric Nursing*.30 .408
- Dilek, F. (2017):** Family Burden Among Parents of Children with Intellectual Disability. *Journal of Psychiatric Nursing* ;8(1):9-16
- Esther, C., Kerry, R., and Manfred, G. (2018):** Parent training interventions for parents with intellectual disability, *Cochrane Developmental, Psychosocial and Learning Problems Group*, 2018 Jul; 2018(7): CD007987.
- Farkas L, Cless JD, Cless AW, Nelson Goff BS, Bodine E, Edelman A. The ups and downs of Down syndrome (2019):** a qualitative study of positive and negative parenting experiences. *J Fam Issues* 2019; 40:518-539.
- Ferreira MC, Di Naccio BL, Otsuka MYC, Barbosa AM, Corrêa PFL, Gardenghi G. (2015):** Assessing the burden on primary caregivers of children with cerebral palsy and its relation to quality of life and socioeconomic aspects. *Acta Fisiatr.* 2015; 22:9-13.
- Flood E, Gajria K, Sikirica V, Dietrich CN, Romero B, Harpin V. (2016):** The caregiver perspective on Paediatric ADHD (CAPP) survey: understanding sociodemographic and clinical characteristics, treatment use and impact of ADHD in Europe. *J Affect Disord.* 2016; 200:222–34.
- Ganjiwale, D., Ganjiwale, J., Sharma, B. & Mishra, B., (2016):** Quality of life and coping strategies of caregivers of children with physical and mental disabilities. *Journal of family medicine and primary care*, 5(2), 343.
- Gashmard R, Ahmadi F, and Kermanshahi SM. (2020):** Coping strategies adopted by Iranian families of children with Down syndrome: a qualitative study. *Medicine* 99:28(20753).
- Golan, S. V. (2016):** The subjective well-being of parents of children with developmental disabilities: The role of hope as a predictor and fosterer of well-being. *Journal of Social Work in Disability & Rehabilitation*, 15(2), 77–95
- Grosse SD. (2015):** Sociodemographic characteristics of families of children with Down syndrome and the economic impacts of child disability on families. *Int Rev Res Mental Retard.* 2015; 39:257–94.
- Harkoma., Sti. and Saswati., N (2021):** The effectiveness of supportive and psychoeducational family therapy: A linkage towards burden and anxiety of care for children with mental retardation. *Malahayati International Journal of Nursing and Health Science*, Volume 04, No.2, September: 103-111.
- Fridman M, Banaschewski T, Sikirica V, Quintero J, Erder MH, Chen KS. (2017):** Factors associated with caregiver burden among pharmacotherapy-treated children / adolescents with ADHD in the caregiver perspective on pediatric

- ADHD survey in Europe. *Neuropsychiatr Dis Treat.* 2017; 13:373–86.
- Hassan, A.A Hamid, M.A and El Tayeb., H. N (2021):** Burden on Parenting of Children with Special Needs: Review Article. *EAS Journal of Nursing and Midwifery.* Vol-3, Iss-2 (Mar-Apr-2021): 63-75
- Hegazy, A.M S. & Baraka, M.I.N (2021):** “Effectiveness of Promoting Mothers' Caring Practices Regarding Their Down Syndrome Children on the Family Coping.” *American Journal of Nursing Research*, vol. 9, no. 2 53-63. doi: 10.12691/ajnr-9-2-3
- Kore., P. and Venkatraman's. (2017):** A study on Hope, Stress and Self-Efficacy in Parents of Children with Intellectual Disability. *Indian Journal of Mental Health*;4(3).
- Lalehgani Dezaki, M., Ghaedamini Harouni, G., Ahmadi, S., Vameghi, M., Sajjadi, H., & Ghafari, M. (2018):** Health related quality of life of mothers of children with intellectual disability. *Iranian Rehabilitation Journal*, 16(4), 361-370. <https://doi.org/10.32598/irj.16.4.361>.
- Martin, F. Clyne, W. Pearce, G and Turner., A (2019):** Self-Management Support Intervention for Parents of Children with Developmental Disorders: The Role of Gratitude and Hope. *journal of Child and Family Studies* (28) <https://doi.org/10.1007/s10826-018-01308-1>
- McKee, S. L., Liu, X., Truong, D. M., Meinert, A. C., Daire, A. P., & Mire, S. S. (2019):** The Family Adjustment Measure: Identifying stress in parents of youth with Autism. *Journal of Child and Family Studies*, 1-13. <https://doi.org/10.1007/s10826-019-01569-4>
- Mohamed., S.D, Elkhatib, D .M, Mohamed., M.M (2020):** Effect of Psycho-Educational Program on Psychological Stress and Resilience Among Families Caring for Children with Intellectual Disability. *Egyptian Journal of Health Care, EJHC Vol. 11 No. 4*
- Mohan, R., & Kulkarni, M. (2018):** Resilience in parents of children with intellectual disabilities. *Psychology and Developing Societies*, 30(1), 19-43.
- Peer, J. W., & Hillman, S. B. (2014):** Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and recommendations for practitioners. *Journal of policy and practice in intellectual disabilities*, 11(2), 92-98.
- Salamaa, A.A., Elkhateeb, Z., and Mohasseba., M.M (2023):** Predictor of perceived stress among mothers of children with Down syndrome. *Menoufia Medical Journal*, 35:522–527
- Singh., K. Kumar, R, Sharma., R and Nehra, K. (2014):** study of burden in parents of children with mental

retardation. Research Gate. Vol. 8, No. 2, ISSN: 0973-5755

Tétreault, S, Blais-Michaud, S, Deschênes, PM, Marier, P, Beaupré, P, Gascon, H, Boucher, N et al. (2014): How to support families of children with disabilities? An exploratory study of social support services. *Child and Family Social Work*, 19, 272–281. <http://dx.doi.org/10.1111/j.1365-2206.2012.00898.x>

Tri, Y., Cipta, N., Budhi, B., and Sahadi, S. (2017): Activity daily living (ADL) of young people with intellectual disabilities, *Journal of Advances in Social Science, Education and Humanities Research*,43(11), pp.485-492.

Truitt, M., Biesecker, B., Capone, G., Bailey, T., & Erby, L. (2012): The

role of hope in adaptation to uncertainty: The experience of caregivers of children with Down syndrome. *Patient Education and Counseling*, 87(2), 233– 238. <https://doi.org/10.1016/j.pec.2011.08.015>

Wahbaa, Y., El-Deena., A.N., Alwakeel, A. and El-Gilany., H.A. (2021): Burden of family caregivers of Down syndrome children: a cross-sectional study. *family Practice*, Vol. 38, No. 2.159 :164.

Wahbaa, Y., El-Deena., A.N., Alwakeel, A. and El-Gilany., H.A. (2021): Burden of family caregivers of Down syndrome children: a cross-sectional study. *family Practice*, Vol. 38, No. 2.159 :164.