



Educational Program Among Caregivers of Children with Down Syndrome

Ahmed BurhanAbdulameer^{a*}, Arafat Hussein Al-Dujaili.^b

^{a*} Researcher, Faculty of Nursing/ University of Kufa, Iraq, E-Mail :
ahmedb.alabbas@uokufa.edu.iq

^bResearcher, Faculty of Medicine / University of Kufa, Iraq, E-Mail :
Arafat.aldujili@uokufa.edu.iq

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Abstract

Down's Syndrome (DS), also referred to as Trisomy 21 or the 'congenital type' is the most common chromosomal abnormalities, with neonatal incidences of 1/800–1/600, Trisomy 21 is characterized by irreversible mental retardation, moreover, Trisomy 21 is the most common hereditary causes of low intelligence and account for 90% of all neonatal chromosomal diseases. The current study used a quasi-experimental (study) design to determine the effectiveness of an educational program among caregivers of children with Down syndrome. Between the 4th of April 2022 and the 2nd of July 2022. In order to assess the effectiveness of educational program among caregivers of children with Down syndrome. A non-probability sampling technique (purposive sample) of (42) caregivers of children with Down syndrome at Al'Raja Institute and Dima Institute in Najaf city. The study found that the majority of caregivers between the ages of 27 – 36 (50%), mother caregivers (66.7 %), those who are graduated from secondary school (31 %), those who are married (90.5 %) ; those who are employed (45.2 %) ; those who live in urban areas (92.9 %) ; those who are freehold owning their houses (57.1 %) ; those who were not trained for down Syndrome (76.2 %) ; those with no physical disease (83.3 %) ; those with no psychiatric disorder (88.1 %) . The results of the study revealed that the educational program was effective and there is a significant relationship ($P < 0.05$) between the overall assessment of the knowledge of the caregivers of children with down syndrome and some of the socio-demographic characteristics (age, residency area). The present study recommends that further programs are required for educating families of children with Down syndrome about the disease, its symptoms, and how to interact with the patient. Along with expanding down syndrome-specific schools and institutions, as there aren't many of them in the Najaf province and some of them are located far from where the children live.

Keywords –education program, Caregivers, Down Syndrome

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Introduction

The most prevalent chromosomal defect known to be linked to intellectual disability (ID), recognizable physical characteristics, and health issues is known as Down syndrome (DS)⁽¹⁾. In roughly 1–1.5 out of every 1000 live births, DS occurs. The most frequent genetic contributor to mental retardation (MR) is DS. More frequently than the average population, those with MR experience behavioral, emotional, and mental issues.

DS exhibits distinctive neurodevelopmental, neurocognitive, and psychopathological patterns when compared to other genetic syndromes leading to ID, albeit higher than the general population⁽²⁾. A 28.9% of the children with DS have psychiatric comorbidity⁽³⁾. Children with Down syndrome have many unmet requirements that are not being covered by services, and the level of unmet need is correlated with caregiver distress. These high levels of distress are likely to have an



impact on the parents' health and capacity to care for their children.⁽⁴⁾ Due to a child's disability, parents may be required to pursue educational and recreational accommodations to ensure that the child has the same opportunities as a child who is not disabled, caring for a child with a chronic condition (such as a child with Down syndrome or DS) causes caregivers to experience additional stress, which may lead to caregiver distress⁽⁵⁾. The family caregiver is the primary person with total or higher responsibility for the care provided to the person receiving care, and there is no financial remuneration for the care supplied.^(6,7) Parents are the most common caregivers, since they look after their children in all aspects of their lives⁽⁸⁾. The majority of family caregivers are women who perform time-consuming and demanding activities such as personal care, aside from the physical, emotional, and financial effect, there are also limitations in social and recreational activities⁽⁹⁾. Down syndrome is associated with greater levels of within-syndrome fluctuation and prognostic uncertainty regarding the degree of developmental problems, problem behaviors, and other medical conditions; Despite receiving a diagnosis for their kid, parents of children with DS frequently deal with ongoing misunderstanding about their child's condition. Only a tiny degree of ambiguity may be minimized by understanding the diagnosis and its prognostic implications.

Materials and Methods

Design of the Study:

A quantitative, quasi-experimental pre-test and post-test study design was carried throughout the present study to assess the effectiveness of education program among caregivers of children with Down syndrome during the period from 4th of April 2022 and the 2nd of July 2022.

Setting of the Study:

The study was conducted at Al-Najaf city \ Al-Raja Institute and Dema Institute for special needs children.

Sample of the Study:

A non-probability sampling technique (purposive sample) of (42) caregivers of children with Down syndrome are included in the study.

Instrument of the study:

The researcher constructed a self-administrative questionnaire for the purpose of present study. The final research instrument is made up of two components.

Part I: Caregiver's Socio-demographic Characteristics:

A socio-demographic characteristics sheet of (12) items, including case number (ID), who are caregiver, age, family member, marital status, level of education, participation in trainings about down syndrome, job, residency area, the house ownership (property), do you have any physical disorders and do you have any psychiatric disorders.

Part II: Parent Knowledge scale:

An educational program was built to accomplish the goals of the current study, and on the basis of the program, a questionnaire was produced as a tool for data collecting. The instructional curriculum was developed and built using previous research, guidelines, and literature.

Reliability of the Study Instrument: In order to evaluate the current study questionnaire for its competence, relevance, intelligibility, and clarity in fulfilling the stated objectives, a panel of (18) experts (with more than five years of experience in the medical and nursing professions) was contacted. All experts received hard copies of the questionnaire, and they were requested to evaluate them



in order to determine the tool's appropriateness and content clarity.

Data Collection:

The evidence was acquired using the self-reporting technique with the care providers who participated in the study and the Arabic version of the questionnaire, as well as by segmenting the sample into groups and using the prepared questionnaire. The questionnaire, which had four sections, one for each week of the program, was then given out by the researcher before and after the educational program. The program will run for a month, with each segment lasting an hour, after receiving verbal consent from the caregivers to participate in the program and receiving their responses to

Results

the questionnaire both before and after the program. The data collection process took place between 1st May and 3rd June, 2022.

Statistical analysis:

The data were analyzing through application of the descriptive and inferential data analysis methods, included:

1. Descriptive Data Analysis:

- Tables (Frequencies, and Percentages).
- Statistical figures (Bar Charts).
- Statistical mean and standard deviation.
- Mean of Score (MS).

2. Inferential Data Analysis:

- T-test
- Pearson's correlation

Items	Rating And Intervals	Frequency	Percent
Caregivers	Father	10	23.8
	Mother	28	66.7
	Other	4	9.5
Age	<= 26	6	14.3
	27 – 36	21	50.0
	37 – 46	10	23.8
	47+	5	11.9
Family members	<= 3	7	16.7
	4 – 6	29	69.0
	7+	6	14.3
Marital status	Single	1	2.4
	Married	38	90.5
	Divorced	2	4.8
	Widowed	1	2.4
Level of education	Illiterate	1	2.4
	Literate	7	16.7



	Primary	5	11.9
	Secondary	13	31.0
	Institute	6	14.3
	College	10	23.8
Training about Down Syndrome	not once	32	76.2
	Once	3	7.1
	two times	4	9.5
	three or more	3	7.1
Job	Employed	19	45.2
	free work	10	23.8
	Unemployed	13	31.0
Residency area	Urban	39	92.9
	Rural	3	7.1
House ownership	free hold	24	57.1
	Rental	18	42.9
Physical diseases	Yes	7	16.7
	No	35	83.3
Psychiatric disorders	Yes	5	11.9
	No	37	88.1
	Total	42	100.0

Table (3.1) Statistical distribution of study sample (caregivers) by their demographic data

Table (3.1) shows the statistical distribution of the study samples according to socio-demographic data, and it describes that the caregivers subgroup has the highest percentage of: caregivers between the ages of 27 – 36 (50%), mother caregivers (66.7 %), those are graduated from secondary school (31 %), those who are married (90.5 %) ; those who are employed (45.2 %) ; those who live in urban areas (92.9 %) ; those who are freehold owning their houses (57.7 %) ; those who were not trained for down Syndrome (76.2 %) ; those with no physical disease (83.3 %) ; those with no psychiatric disorder (88.1 %) .



Table (3.2) Overall assessment of the knowledge of caregivers of children with Down syndrome before & after applying the educational program.

		Frequency	Percent	MS	Asses.
Pre-test	Poor	6	14.3	1.52	Fair
	Fair	29	69.0		
	Good	7	16.7		
Post-test	Poor	2	4.5	1.70	Good
	Fair	6	13.6		
	Good	34	81.8		

Freq: Frequency; **MS:** Mean of Scores; **Poor:** MS = 1-1.33; **Fair:** MS = 1.34-1.67; **Good:** MS ≥ 1.68.

Table (3.2) gives the overall assessment (mean and ratio of scores) of assessment of the knowledge of the caregivers of children with Down syndrome before and after applying the educational program for the study subjects. They show that the overall assessment of the knowledge of the caregivers of children with down syndrome before applying the educational program is (fair) with mean of scores = **1.52**, while after applying the educational program it is considered (good) with mean of scores = **1.70**.

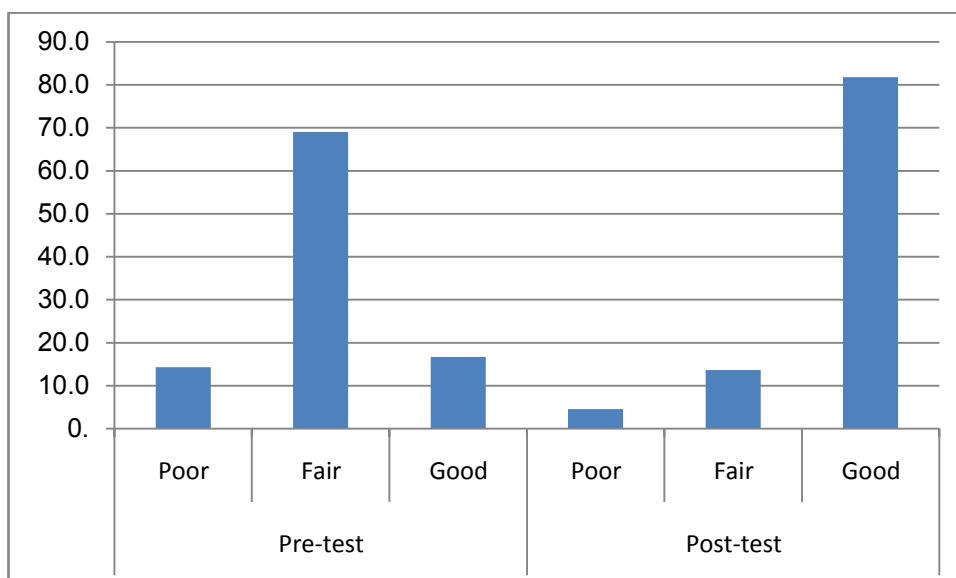


Figure (3.1) Bar chart of Overall assessment of the knowledge of caregivers of children with the Down syndrome before and after applying the educational program.



Table (3.3) The Paired sample t-test table to evaluate the effectiveness of educational program for caregivers of children with Down syndrome.

	N	Mean	Std. Deviation	Df	Sig
Pre-test	42	1.52	0.17	41	0.0001*
Post-test	42	1.79	0.10		

* Significant at **P<0.01**

Table (3.3) advances the effectiveness of the educational program for caregivers of children with Down syndrome. It revealed that the program was effective at **P<0.01**.

Table (3.4): Relationship between total score assessment of education program for caregivers and their demographic data.

Items	Interval	MS	SD.	F	Sig.
Caregivers	Father	1.42	0.16	2.66	0.06
	Mother	1.54	0.17		
	Other	1.59	0.07		
Age	<= 26	1.68	0.23	2.51	0.04*
	27 – 36	1.51	0.12		
	37 – 46	1.46	0.18		
	47+	1.49	0.19		
Family members	<= 3	1.58	0.21	0.85	0.43
	4 – 6	1.50	0.16		
	7+	1.55	0.18		
Marital status	Single	1.56	-	0.46	0.71
	Married	1.52	0.17		
	Divorced	1.41	0.13		
	Widowed	1.63	-		
Level of education	Illiterate	1.56	-	0.96	0.45
	Literate	1.43	0.29		
	Primary	1.45	0.18		
	Secondary	1.58	0.14		



	Institute	1.53	0.10		
	College	1.52	0.09		
Training about down syndrome	not once	1.49	0.14	1.25	0.31
	Once	1.58	0.37		
	two times	1.63	0.22		
	three or more	1.60	0.08		
Job	Employed	1.53	0.16	0.12	0.88
	free work	1.50	0.21		
	Unemployed	1.52	0.16		
Residency area	Urban	1.50	0.15	12.85	0.00*
	Rural	1.81	0.16		
House ownership	free hold	1.50	0.13	0.85	0.36
	Rental	1.55	0.21		
Physical diseases	Yes	1.51	0.18	0.03	0.87
	No	1.52	0.17		
Psychiatric disorders	Yes	1.47	0.29	0.39	0.53
	No	1.52	0.15		

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Discussion

According to table (3.1), the bulk of the samples (66.7%) were female (mothers) who made up the overall sample. This outcome is accompanied by the study of Abdulameer & Al-Dujaili, (2022) who found that most of the gender of parents (75.4%) subjects were female mother. According to the perspective that permeates our culture, as part of their everyday domestic duties, women in Iraqi households are in charge of caring for the family's children, elders, patients, and disabled members, while fathers spend the most of their time at work and have provider responsibilities for the family and home. The study found that

half of the study subjects (50%) are between the ages of 27 and 36. This finding is consistent with that of Alkazam & Al-Dujaili, (2022) who observed that the study sample's major age range (46.2%) falls between the ages of 26 and 36, with a mean age of 34.8 years. The overwhelming of the interviewees (90.5%) was married, as seen in (Table 1). This outcome is consistent with our culture, which favors early marriage for both men and women. This result comes along with Al-Dujaili & Al-Mossawy, (2017) who showed that (96.1%) of caregivers were married. In terms of the educational backgrounds of the subjects, the results show that the study sample as a whole has a secondary school level (31%). Concerning caregiver's job, the



study displays that nearly half of the subjects' job are employed (45.2%). This finding agree with the study of Al-Dujaily, (2015)who found that (64 %) of samples are employed. In regarding the training cycle about Down syndrome, the results show that the percentage of caregivers without training cycles is the largest. This outcome is consistent with a Al-Bahadli & Adai, (2019) who fund that the majority of subjects have no training cycle about Down syndrome.Regarding residence, the preponderance of the samples, or 92.9%, dwell in urban areas. This result is consistent with that of Al- Hamoodi & Al Dujaili, (2017)whose study revealed that a significant percentage of the study subjects—97.5%—live in urban areas.Table (3.2) and Figure (3.1) claim that after completing of the education program, caregivers of children with Down syndrome have a thorough understanding of Down syndrome compared to before. It explains that there was an increase in the caregivers' overall score after the educational program was implemented (1.70) in comparison to the caregivers' overall mean scores before the program was implemented (1.52).This study confirms that there are improvements in the total scores of caregiver's knowledge after the educational program implementation for their caregivers compared to total mean scores before educational program implementation.Tables (3.4) show that there is a significant relationship between total score assessment of caregiver's knowledge and age and residency area. This is, perhaps due to the increase in the sample number in these categories compared to other categories, the result was of significance.

Conclusions

The researcher has reached the following conclusions based on the discussion and analysis of the study findings:

1. The study supports the effectiveness of the education program and the improvement in caregivers' knowledge.
2. Ageand residency area were statistically significant while other parameters regarding socio-demographic characteristics of caregivers were not significant.
3. The caregivers were under the age of forty, and greater than 60% of the caregivers' children were females. The majority of the subjects were married, having a secondary school degree.

Recommendations

According to the findings of the present study, the researcher recommends the following:

1. Most of families of children with Down syndrome have required other programs for training them to deal with their children.
2. Further research, in the form of a survey, should be performed in the country.
3. There should be more Down syndrome-specific schools and institutions, as there aren't many of them in the Najaf province and some of them are located far from the children's homes.
4. Ministry of Education in Iraq is recommended to train primary school teachers about management of DS cases within school health services.



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