

Efficacy of Educational Training on Performance of Caregivers of Children with Down syndrome

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Abstract

Down syndrome (DS), known as Trisomy 21, is the most common chromosomal abnormality among live born infants and is associated with hypotonic and delayed motor development. The study aimed to identify the effect of educational training on performance of caregivers of children with Down syndrome. The study design was a quasi- experimental on a sample of 30 caregivers of Down syndrome children. Two tools were used for collecting data in the study; the first tool was structured interview questionnaire for caregivers such as demographical data, clinical data, caregivers' knowledge of Down syndrome and therapeutic massage. The second tool was a structured clinical checklist to evaluate caregivers' practice regarding therapeutic massage. The results revealed statistically significant improvement in performance of the studied caregivers regarding Down syndrome and therapeutic massage. Therefore, it could be concluded that educational training program to caregivers of Down syndrome children had improved their knowledge and practice regarding Down syndrome and therapeutic massage. Based on the results, it could be recommended that Continuous educational training programs should be developed and implemented for nurses and caregivers of Down syndrome children about Down syndrome and therapeutic massage.

Keywords: Educational training, down syndrome and Therapeutic massage

INTRODUCTION

Down syndrome or Trisomy 21 is the most common genetic cause of intellectual disability. The syndrome is caused by an extra copy of chromosome 21 (Loane et al., 2013). It has an incidence (in U.S.) of 1 in 800 births and prevalence of 300,000 persons. The predominant sex of Down syndrome is male: female ratio of 1.3: 1.0 (Ferri, 2020). There is an association with increased maternal age (1 in 880 at 30 years rising to 1 in 100 at age 40 years). 95% are due to non-disjunction during meiosis and 3% are due to an unbalanced translocation; 1% is mosaics, with only a proportion of cells within the body having Trisomy 21 (Mail et al., 2016). Down syndrome children have a characteristic pattern of dysmorphic features including a flattened occiput, midfacial hypoplasia, depressed nasal bridge, upward-slanting palpebral fissures, epicanthic folds, grayish speckling of the iris, Micrognathia, single palmar creases and clinodactyly (Gardner et al., 2016). They also have various problems, such as delays in gross motor skill development, cognitive limitations, neurological disorders, sensor motor integration impairments, obesity, psychosocial functioning and health impairments and delays in speech and language skill development (Kent & Vorperian, 2013 and Pitetti et al.,

2013). Caregivers and children benefit when the caregiver has a higher level of education and training which provide the highest quality of care to children. Educated caregivers are more involved and affectionate with the children in their care. The amount of training and education caregivers receive has demonstrable effects on the quality of care they provide and significant consequences for children's behavior and development (Clarke- Stewart & Miner, 2009). The first years of life are a critical time for a child's development, because children undergo rapid and volatile changes developmentally, acquiring essential life skills that will form the basis for more complicated skills later in life. Basic physical, cognitive, language, social, and self-help skills are achieved during these early years of life. These foundational skills precede future progress, and because children with Down syndrome usually face developmental delays, early intervention is highly recommended (Skallerup, 2008). An advantage of beginning intervention early in life is children receive more exposure to the motor patterns and behaviors they may struggle with in the future. Increased exposure and major goals of early intervention (EI) programs aim to increase the "rate of acquiring motor skills" and counteract "secondary problems resulting from the child's use of compensatory strategies" (Mahoney et al., 2001).

AIM OF THE STUDY

1. Assess the effect of the educational training of Down syndrome on caregivers' performance of children with Down syndrome.
2. Determine the effect of the educational training of therapeutic massage on caregivers' performance of children with Down syndrome.

Research hypothesis

- 1- Caregivers of Down syndrome children will show improvement on their knowledge and performance regarding Down syndrome and therapeutic massage after the educational training.

SUBJECTS AND METHODS

Research Design

A quasi- experimental design (Pre and Post).

Settings

The study was conducted at the following settings:

1. Pediatric genetic outpatient clinic at Zagazig university hospital.
2. Pediatric psychiatric and neurological outpatient clinic at Zagazig university hospital.
3. Pediatric cardiac outpatient clinic at Zagazig University hospital.
- C. Patients: A purposive sample of 30 caregivers of Down syndrome children who accepted to participate in the current study.

D. Tools for data collection:

Tool (I): A Structured interview questionnaire

A Structured interview questionnaire was developed by the researcher under supervision of the supervisors after reviewing the relevant and current scientific literature and articles to collect the required data. It was consisted of the following parts:

- Demographical data: such as child's age, sex, caregivers' age, level of education and

occupation.

- Medical and Family history of the studied caregivers: such as health problems during pregnancy, health problems during labor and time of diagnosis.
- Caregivers' knowledge of Down syndrome: such as definition, causes, risk factors and physical findings of Down syndrome
- Caregivers' knowledge of therapeutic massage: such as definition, types, benefits and styles of therapeutic massage.

Tool (II): A structured clinical checklist

A clinical checklist was formulated by the researcher to evaluate caregivers' practice regarding therapeutic massage.

Development of the Program (Appendix V)

The program was developed to evaluate the effect of the educational training program on caregivers' knowledge and performance regarding Down syndrome and therapeutic massage.

General objectives of the program:

The program aims to identify the effect of the educational training program on caregivers' knowledge and performance regarding Down syndrome and therapeutic massage.

Specific objective of the educational training program:

- 1) Assess the effect of the educational training of Down syndrome on caregivers' performance of children with Down syndrome.
- 2) Determine the effect of the educational training of therapeutic massage on caregivers' performance of children with Down syndrome.

The program was developed through the following phases:

(1) Assessment phase

Through this phase each caregivers were interviewed individually to obtain their personal and medical data, to assess their knowledge about Down syndrome and therapeutic massage (Tool I) and to evaluate their practice regarding therapeutic massage (Tool II).

(2) Planning phase

Based on the results obtained from the assessment phase, pilot study and reviewing the related relevant literature the program was developed by the researcher. Detected needs, requirements and deficiencies were translated into aims and objectives of the program. Contents of the program were selected on the basis of identified needs. The program composed of three main parts educational (theoretical) includes all knowledge needed by the caregivers and training (practical) part including training methods about therapeutic massage techniques and practical sessions of therapeutic massage for Down syndrome children. Various teaching methods were selected to suit teaching in small groups in a form of lectures, group discussion, role play, demonstration and reinforcement. Teaching media were prepared as colored posters and video tapes by using lab top, booklets as well as brochures that covered theoretical and practical information. The researcher took also a course and completed a training program about therapeutic massage

(3) Implementation phase

The delivery of educational training was implemented through six sessions and Down syndrome children caregivers' were divided into small groups (5-7 caregivers in each group)

to facilitate the learning process. The length of each session varied according to the content, time available and caregivers' response and ranged 20-30 minutes.

- The first session was about definition, causes, physical findings, health problems, diagnosis, risk factors, regular checkup and therapeutic rehabilitation programs of Down syndrome. The second session was about definition, benefits, contraindications, parts, timing and content of therapeutic massage sessions. The third was about types, principles and styles of therapeutic massage. The fourth and fifth sessions were about the application of different types of massage (effleurage, petrissage, tapoment, friction and vibration). Finally, the sixth session was about revision theoretical and practical parts of educational training program.
- Each session started with a summary of the previous session, and objective of the new one. Sessions were explained in simple Arabic language that suits the level of the studied caregivers' understanding.
- Motivation and reinforcement during each session were used to enhance caregivers' active participation and foster learning. Telephone follow up calls were performed to the caregivers to remind them about the next session and their appointments.

(3) Evaluation the impact of the intervention

After implementation of the program, the studied caregivers were reassessed (posttest) using the same pre format to examine the current research hypothesis.

II. Operational Design

The operational design included the preparatory phase, content validity, pilot study and field work.

A. The Preparatory phase. Review the current related literature in the various aspects of the problem was done to develop the tools for data collection and prepare for field work.

B. Validity and reliability:

For validity assurance purpose, tools were developed after review of the related literature then submitted to a Jury of five medical and nursing professors including: one Professor of physical therapy, one professor of children with special needs, one of genetics and two professors from the faculty of nursing (medical surgical and Pediatric department). The recommended modifications were done and the final forms were ready for use. Internal consistency and reliability coefficient for the components of tools were done by using Cronbach's Alpha test.

▪ Reliability of tool (I) (knowledge) was 0.699 (questionable consistency).

▪ Reliability of tool (II) (Practice) was 0.723 (acceptable consistency).

C. Pilot study

A pilot study was carried out on 10% of the studied caregivers (3) to evaluate the content of the tools, their clarity, feasibility, arrangement, applicability of its items, as well as to estimate the time needed for filling the data.

D. Field work

▪ Data collection took a period of 9 months from December 2018 to Augusts 2019.

▪ The researcher attended the study settings three days /week (Tuesday) at Pediatric Neurology Out-Patient Clinic; (Sunday) at Pediatric genetic outpatient clinic; (Monday) at Pediatric cardiac outpatient clinic for data collection and implementation of the program from 9:00 a.m. to 2:00 p.m.

- The researcher started with introducing herself and explaining the aim and process of the study and obtaining oral consent from caregivers of Down syndrome children who accepted to participate in the study. The researcher also, determined the place of meeting and timetable.

- Each caregiver was interviewed individually to collect the necessary data (personal and medical history) and to assess their knowledge about Down syndrome and therapeutic massage.

E. Ethical consideration

All ethical issues were taken into consideration during all phases of the study, the purpose and process of the study was explained to every caregiver of Down syndrome child and an oral consent was obtained from those who accepted to participate in the study. The researcher emphasized on the caregiver's right to withdraw from the study at any phase; also provided assurance of maintaining an anonymity and confidentiality of the data used for research purpose only.

III. Administrative Design

To carry out the study in the selected setting, an official permission was obtained from the directors of Out-patient Clinics Hospital "Pediatric Cardiac Clinic, Genetic Clinic", at Zagazig University Hospitals for data collection.

IV- Statistical analysis

The collected data were coded and entered to statistical software SPSS version 20.0 program by which the analysis was conducted applying frequency tables with percentages and cross tabulations.

The following statistical tests were used:

- According to types of data: frequencies and percentages were used for qualitative variables; mean \pm SD for quantitative variables.

Statistical tests included:

- Independent sample t-test: it is a parametric statistical test that is used to compare the mean for two independent groups for numeric data and following normal distribution.

- Pearson's chi square test (X²): it was used in the study for comparison of categorical variables to find the significant relation between two variables.

Level of significance:

- P value was statistically significant at < 0.05
- P value was highly statistically significant at < 0.001

RESULTS

Table (1) illustrates the characteristics of the studied children caregivers'. Regarding mother's age, the results revealed that 10% of the studied mothers were < 20 years with a mean of 29.1 ± 6.15 years. As regards mother's education, it was shown that 30% of the studied mothers were illiterate and 40% had average qualification, while 10% had high qualification. In relation to mother's occupation, the results clarified that 70% of the studied mothers were housewives. Concerning father's age, the results showed that 40% of the studied fathers were between $20 \leq 30$ years and 40% were ≥ 40 years with a mean of 35.3 ± 2.15 years. In relation to father's education, it was disclosed that 10% of the studied fathers were illiterate and 30%

had average qualification. As for father's occupation, it was found that 90% of the studied fathers were working and 10% were not working. The studied caregivers' total knowledge about Down syndrome through the program phases was shown on table (2). The results revealed that 16.7% of the studied caregivers had satisfactory results on the pre educational phase compared to 80% on the post educational phase. There was statistically significant difference with $p = .001$. Table (3) exhibits the studied caregivers' total knowledge about therapeutic massage throughout the program phases. On the post educational phase, 76.7% of the studied caregivers had satisfactory results about therapeutic massage; meanwhile 23.3% had unsatisfactory results. The studied caregivers' total practice about therapeutic massage for their children with Down syndrome is displayed on table (4) and highly statistically significant difference was found among the studied caregivers throughout the program phases with $p = .000$. The relation between characteristics of the studied mothers and their total knowledge about Down syndrome and therapeutic massage on the post educational program is displayed on table (5). There were statistically significant relations between mother's age, mother's age at child's birth and mother's education with their total knowledge about Down syndrome and therapeutic massage on the post educational program.

Table (1): Characteristics of the studied children caregivers

Characteristics	No=30	%
Mother's age (Year)		
< 20	3	10
20 -	15	50
30 -	9	30
≥ 40	3	10
$\bar{x} \pm S.D 29.1 \pm 6.15$		
Mother's age at child's birth (Year)		
< 20	6	20
20 -	15	50
30 -	6	20
≥ 40	3	10
$\bar{x} \pm S.D 27.5 \pm 8.75$		
Mother's education		
Illiterate	9	30
Read and Write	6	20
Average qualification	12	40
High qualification	3	10
Mother's occupation		
Working	9	30
Housewives	21	70
Father's age (Year)		
<20	0	0.0
20-	12	40

30-	6	20
≥40	12	40
\bar{x} S.D35.3 ± 2.15		
Father's age at child's birth (Year)		
< 20	0	0.0
20 -	12	40
30 -	9	30
≥ 40	9	30
\bar{x} S.D30.5 ± 5.70		
Father's education		
Illiterate	3	10
Read and Write	6	20
Average qualification	9	30
High qualification	12	40
Father's occupation		
Working	27	90
Not Working	3	10

SD: standard deviation

Table (2): The studied caregivers' total knowledge about Down syndrome through the program phases

Total knowledge about Down syndrome	Pre educational phase		Post educational phase		T. test	p-value
	No	%	No	%		
Satisfactory	5	16.7	24	80	27.01	.001**
Unsatisfactory	25	83.3	6	20		

Satisfactory >60%

Unsatisfactory <60%

Table (3): The studied caregivers' total knowledge about therapeutic massage through the educational program

Total knowledge about therapeutic massage.	Pre educational phase		Post educational phase		T. test	p-value
	No	%	No	%		
Satisfactory	2	6.7	23	76.7	23.071	.000**
Unsatisfactory	28	93.3	7	23.3		

Satisfactory >60%

Unsatisfactory <60%

Table (4): The studied caregivers' total practice about therapeutic massage for their children with Down syndrome through the program phases (n=30)

Total therapeutic massage's practice	Pre educational phase		Post educational phase		T. test	p-value
	No	%	No	%		
Satisfactory	2	6.7	23	76.7		

Unsatisfactory	28	93.3	7	23.3	27.09	.000**
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Satisfactory >60%

Unsatisfactory <60%

Table (5): Relation between characteristics of the studied mothers and their total knowledge about Down syndrome and therapeutic massage on the post educational program

Characteristics of the studied mothers		Total knowledge about Down syndrome and therapeutic massage				X2	P-Value
		Satisfactory (n=24)		Unsatisfactory (n=6)			
		N	%	N	%		
Age (year)	<20	3	12.5	0	0.0	9.500	0.041*
	20-<30	9	37.5	6	100		
	30-<40	9	37.5	0	0.0		
	≥40	3	12.5	0	0.0		
Age of mother at child's birth (Year)	<20	6	25	0	0.0	9.207	0.043*
	20-<30	9	37.5	6	100		
	30-<40	6	25	0	0.0		
	≥40	3	12.5	0	0.0		
Mother's education	Illiterate	3	12.5	6	100	17.500	.000**
	Read and Write	6	25	0	0.0		
	Average qualification	12	50	0	0.0		
	High qualification	3	12.5	0	0.0		
Mother's occupation	Working	21	87.5	6	100	4.226	0.361
	Not Working	3	12.5	0	0.0		

(*) significant at $p < 0.05$ (**) highly significant at $p < 0.01$

X2 = Pearson's chi square test

DISCUSSION

The studied caregivers' total knowledge about Down syndrome

Concerning answering the research question regarding the studied caregivers' total knowledge about Down syndrome throughout the program phases, the results of the current study revealed that the majority of the studied caregivers had unsatisfactory knowledge regarding Down syndrome on the pre educational phase of the program. This may be due to lack of training and educational workshops (awareness and educational campaigns) held for caregivers of Down syndrome children. These results are matched with Alhaddad et al (2018) who conducted a study of knowledge and attitude towards Down syndrome among people in Jeddah, Saudi Arabia and found that there are important deficits in the general knowledge about DS leading to unfavorable attitude towards people with DS, which results in a certain overestimation of their handicap. As well, it was revealed that one sixth of the studied caregivers had satisfactory results on the pre educational phase compared to more than three quarters on the post educational phase indicating that there was an improvement in their

knowledge about Down syndrome throughout the program phases. There was statistically significant difference with $p = .001$. These results can be attributed to the educational training provided to the caregivers in this study. These results are in harmony with Abou El Ella et al (2019) who conducted a study of Health Surveillance along with Application of Age-based Scheduled Training Program for Down syndrome which stated that an effective early intervention, positive home environment and continuous supportive training of mothers of children with DS are helpful in improving the overall functioning and productivity of these children. Also, these results are consistent with Mengoni & Redman (2019) who conducted a study for evaluating health visitors' existing knowledge of Down syndrome and the effect of a training workshop in UK and found that health visitors had low levels of existing knowledge of Down syndrome. A training workshop significantly increased knowledge and understanding about Down syndrome and has the potential to improve health outcomes for children with Down syndrome. These results go in line with Bryant et al (2016) who conducted a study for evaluation of training for health professionals about Down syndrome in UK and found that full-day training about Down syndrome has been found to improve knowledge of Down syndrome and confidence in communication about Down syndrome, with some evidence of behavior change in clinical practice. Similarly, the results of Santoro et al (2016) who conducted a study of stakeholder buy-in and physician education improve adherence to guidelines for Down syndrome in USA showed statistically significant increases in adherence following pediatrician education about Down syndrome. The comparison between the studied caregivers regarding knowledge about method of diagnosis showed that one fifth of the studied caregivers stated karyotyping as a method of diagnosis on the pre educational phase compared to the majority on the post educational phase. This goes on line with Santoro et al (2017) who conducted a study of integrating a geneticist in a multidisciplinary clinic for Down syndrome increases commitment to genetic counseling, and stated that integrating a geneticist resulted in significant improvement in adherence to genetic counseling recommendations ensuring that the correct genetic testing is completed. Less than one third of the studied caregivers stated that regular thyroid screening for Down syndrome children on the pre educational phase compared to less than three quarters on the post educational phase in the current study. Similarly, Fergeson et al (2009) who conducted a study of Low adherence to national guidelines for thyroid screening in Down syndrome and found that the level of adherence to the American Academy of Pediatrics guidelines for thyroid screening in children with Down syndrome is low. Concerning the therapeutic rehabilitative programs, it was shown that Less than one third of the studied caregivers mentioned physical therapy program is one of the therapeutic rehabilitative programs on the pre educational phase compared to Less than two third on the post educational phase of the program. Nearly, Christensen (2019) who conducted a study of The Use of Antecedent-Based Interventions to Increase Compliance Related to Physical Activity in Children with Down syndrome, found also an overall increase in the participant's compliance and accuracy of skill development throughout all stages of the experiment helping children with Down syndrome engage in exercise-related activities.

The studied caregivers' total knowledge about therapeutic massage

In relation answering the research question of the studied caregivers' total knowledge about therapeutic massage throughout the program phases, the results of the current study revealed that

the majority of the studied caregivers had unsatisfactory knowledge regarding therapeutic massage on the pre educational phase of the program. This may be due to lack of knowledge of our societies about alternatives methods for treatment and non-pharmacological intervention for cure especially therapeutic massage and they didn't receive any training program about therapeutic massage before. These findings highlighted the urgent need for implementing educational programs about therapeutic massage. After implementation of the educational training program for the studied caregivers, an improvement was declared on the post educational phase where more than three quarters had satisfactory knowledge. These results are consistent with AbdElateef et al (2018) who conducted a study of effect of educational training program on improving pediatric oncology nurses' performance regarding non pharmacological pain management in Egypt which found that the studied nurses had poor knowledge about therapeutic massage before the training program and the knowledge improved after the training program.

The studied caregivers' total practice about therapeutic massage

One of the main objectives of the current study was the assessment of the studied caregivers' total practice about therapeutic massage throughout the program phases. It was revealed that the majority of the studied caregivers had unsatisfactory practice regarding therapeutic massage on the pre educational phase of the program. This may be due to lack of knowledge of our societies about alternatives methods for treatment and non-pharmacological intervention for cure especially therapeutic massage and they didn't receive any training program about therapeutic massage before. An enhancement was disclosed on the post educational phase where more than three quarters of them had satisfactory practice after implementation of the educational training program. These results were in harmony with Barlow et al (2008) who conducted a study about the effectiveness of the training and support program for parents of children with disabilities in UK and found that there were trends toward improvement on parental ratings of children's mobility ($P=0.012$). The TSP about therapeutic massage is an effective means for supporting parents of children with disabilities.

CONCLUSION & RECOMMENDATIONS

Based upon the findings of the present study, it could be concluded that educational training program to caregivers' of Down syndrome children had improved their knowledge and practice regarding Down syndrome and therapeutic massage. In the light of the findings of the current study, the following recommendations are suggested:

- 1- Continuous educational training programs should be developed and implemented for nurses and caregivers of Down syndrome children about Down syndrome and therapeutic massage.
- 2- Sessions of therapeutic massage should be delivered to children by nurses. Duration and type of therapeutic massage depends on the diagnosis and condition of each child.

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