

Effect of Supportive Educational Intervention for Mothers of Female Adolescents with Cerebral Palsy on Their Caring Practices

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ABSTRACT

Context: Cerebral palsy is a major cause of poor physical, mental, and social health and one of the biggest risk factors for underachievement in later life. Mothers are caring for children with disabilities experience several challenges. Parents of children with cerebral palsy (CP) must know about the disease and its management to improve the outcome.

Aim: To assess the effect of supportive educational intervention for mothers of female adolescents with cerebral palsy on their caring practices.

Methods: A quasi-experimental (pre/post-test) design was employed at the neurology outpatient clinic at Pediatric Hospital, Ain Shams University, with a convenience sample of 50 mothers of female adolescents with cerebral palsy. The researcher used two tools: A predesigned questionnaire includes three parts to assess the demographic characteristics of the mothers and their daughters with cerebral palsy and their knowledge regarding the disease. The second tool is a mothers' reported practice checklist regarding caring for a female adolescent with CP.

Results: There was a highly significant difference between mothers' knowledge about normal physical and physiological needs of adolescents, physical needs and problems of handicaps, menstrual-related discomfort, and premenstrual manifestation between pre and post-intervention at p-value <0.001 except problems related to adolescent period. There was a highly significant difference between mothers' reported practice about routine care and routine perineal care during and after menstruation at p-value <0.001.

Conclusion: Implementing a supportive educational program for mothers regarding the care of their female adolescents with cerebral palsy had a positive effect on their knowledge and reported practice. The study recommended continuous training for mothers related to managing the child's physical needs and psychosocial ones. Future studies to examine the relationship between maternal psychological well-being and CP severity, using standard measures for CP severity. Further studies are needed to assess predictive factors affecting mothers' knowledge and practice regarding the care of an adolescent with cerebral palsy.

Keywords: Supportive, educational intervention, female adolescent, cerebral palsy, mothers, caring practice

1. Introduction

Cerebral palsy (CP) is the most common neurologic disorder in pediatrics and is described as a permanent motor change caused by non-progressive disorders occurring in the developing fetal or infant brain. The core problem of CP is abnormal movement and posture, which manifests very early in development. The nature of functional impairments may change as the child develops. Various neurological patterns of dysfunction characterized by abnormal motor and posture control and can involve communication difficulties (Clutterbuck *et al.*, 2020).

Cerebral palsy is a neuro-developmental disorder that is the main cause of physical disability in children and occurs in 2 to 2.5 cases per 1,000 live births. It affects from 8,000 to 10,000 infants and 1,200 to 1,500 pre-school-aged children each year. Around 764,000 people currently live with cerebral palsy, with 500,000 children and teens (Philip *et al.*, 2020).

Cerebral palsy is a major cause of poor physical, mental, and social health and one of the biggest risk factors

for underachievement in later life. Children with CP require higher education and health care costs because they have more contact with emergency services, outpatient clinics, and health care providers. Early identification and treatment may help reduce these costs and the burden on family and society. The cornerstone to treat children with CP is the conventional rehabilitation program based on the neurodevelopmental approach that has been done for decades (Zuurmond *et al.*, 2020).

An individual with a handicap transitioning from childhood to adolescence poses new challenges for parents, particularly mothers who often assume a caregiving role. As the adolescent develops an independent sense of self, mothers often explore how to best help her with the transitions. This assistance can include ways to teach adolescents with handicaps about the potential limitations of their disability (Kwon *et al.*, 2020).

Recognizing the critical role that family plays in integrating and providing care for children living with complex disabilities such as CP has shifted from focusing on the child to consider the whole family's needs. Therefore, family-centered care has become a cornerstone

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of rehabilitation services. The family-centered practice encompasses collaboration with families on child-related goals and evaluating family values, beliefs, and needs to design interventions targeted at positive family outcomes. This practice means that each family can choose its optimal service delivery and should, for example, be given options concerning their level of involvement (Donkor et al., 2019).

Mothers of adolescents with intellectual disabilities also experience high levels of stress and mental health problems. This stress can be related to subjective factors such as social isolation and life dissatisfaction, so mothers seek to comprehend their adolescent's disability and endeavor to find the appropriate way to integrate themselves and their adolescents with disabilities into the community. This endeavor could be in conjunction with early intervention and educational programs which help mothers and families successfully navigate the adolescent period (Shaba et al., 2020).

2. Significance of the study

In Egypt, according to the statistical department of Pediatric Hospital affiliated to Ain Shams University (2018), the prevalence of Cerebral Palsy (CP) is high; the reported cases that are managing in the pediatric outpatient clinic of Ain Shams University Hospital are 7000 cases (Khalil et al., 2018).

Parents of children with cerebral palsy must know about the disease and its management. This knowledge would help in planning therapy to achieve functional abilities and improve quality of life. At present, there are very few studies available regarding parental knowledge of cerebral palsy. A review of the current literature shows that most parents of children with CP lack the basic knowledge regarding the disease, its causation, prognosis, treatment modalities, and the outcome. (Taylor et al., 2018).

3. Aim of the study

This study aimed to assess the effect of supportive educational intervention for mothers of female adolescents with cerebral palsy on their caring practices through:

- Assess mothers' knowledge about the handicap of their female adolescents with cerebral palsy.
- Assess mothers reported caring practices for their female adolescents with cerebral palsy.
- Design and implement a supportive educational intervention for mothers regarding the care of their female adolescents with cerebral palsy.
- Evaluate the effect of a supportive educational intervention on mothers' care for their female adolescents with cerebral palsy.

3.1. Research hypothesis

H1: Implementing a supportive educational intervention for mothers regarding the care of their female adolescents with cerebral palsy will positively affect their knowledge and practice.

4. Subjects & Methods

4.1. Research design

A quasi-experimental (pre/post-test) design was utilized to achieve the aim of this study. Quasi-experimental methods are designed to explore the causal effects of an intervention, treatment, or stimulus on a unit of study. However, these methods have many attributes associated with scientific experiments. They lack the benefits of the random assignment of treatments across a population that is often necessary for broad generalizability (Anderson et al., 2017).

4.2. Research setting

The current study was conducted at Neurology outpatient specialized clinic at the Pediatric Hospital Ain Shams University located on the second-floor clinic building behind pediatric Hospital and consisted of three rooms. The first is a big room for diagnosis. The second room is for case registration, and the third is for children and their caregivers waiting.

4.3. Subjects

A convenience sample of 50 mothers of female adolescents with cerebral palsy at the previously mentioned setting regardless of age, educational level, and residence.

4.4. Tools of the study

4.4.1. A Structured Interview Questionnaire

The researcher developed this tool that is divided into three parts:

Part I was concerned with assessing the demographic characteristics of mothers as age, educational level, job, and residence.

Part II was concerned with the characteristics of children, their female adolescents, as age, type of handicap, and mental retardation.

Part III was designed by the researcher to assess the level of mothers' knowledge about CP after reviewing relevant literature Maggioni and Araújo (2020) (Pre & post). It included seven domains as normal physical needs of adolescent, normal psychological needs of adolescent, physical needs related to handicaps (such as physiotherapy, nutritional rehabilitation, physiotherapy for respiration), need for relieving of menstruation discomfort, problems related to the adolescent period, physical problems related to handicaps (such as feeding problems swallowing difficulties, respiratory problems as pneumonia), and premenstrual syndrome manifestations.

Scoring system

Each question scored as correct answer takes one score, while incorrect take zero score and total score categorized as satisfactory if score $\geq 60\%$ and unsatisfactory if score 60% or less.

4.4.2. Mothers' Reported Practice Checklists

The researcher was designed to assess the level of mothers' reported practice about CP, which was designed after reviewing relevant literature Maggioni and Araújo,

(2020) (Pre & post). It included thirteen items as morning care, general personal hygiene, daily partial bath, complete daily bath, routine physical exercises, physiotherapy, breathing exercise, and feeding rehabilitation. Besides, the correct position of the female during care, solutions used for care, the technique of care, diaper care, and exercises for pelvic relaxation and comfort measures during care.

Scoring system

Each item scored as correct answer takes one score, while incorrect take zero score and total score categorized as satisfactory practice if score $\geq 60\%$ and in satisfactory practice if score 60% or less.

4.5. Procedures

The tools were revised for their content validity by five experts in pediatric nursing and neurological medicine, and the recommended modifications were made. Cronbach's alpha coefficient test assessed the reliability of the tool. It was 0.862 for the predesigned questionnaire and 0.857 for the practice tool.

Ethical Considerations: All ethical issues were considered before conducting the study. The researchers explained the aim and all the objectives of the current study to the mothers. Verbal consent was gained from each participant before including her in the study. Every mother informed that her participation is voluntary; she can withdraw from the study at any time. Mothers were assured that the collected data would remain confidential and that no personal identification was needed by any means.

A pilot study was done on five mothers (10%) to ascertain the study tools' clarity, applicability, and relevance. After obtaining the results of the pilot study, the required modifications of tools were done. A final format was developed. Mothers involved in the pilot were excluded from the study.

Phases of Fieldwork: The study enrolled 50 mothers of female adolescents with cerebral palsy at the Neurology outpatient clinic at Pediatric Hospital, Ain Shams University. Each participant took approximately 30-35 minutes to complete the tool. Four phases were adopted to fulfill the study's purpose as follows: Assessment, planning, implementing, and evaluation phase. The four phases of data collection took six months, from April 2020 to November 2020.

Assessment phase: Each mother was interviewed to assess their demographic characteristics, knowledge, and reported practice through a predesigned questionnaire and reported practice checklists (pre-test). The obtained data during this phase have constituted the baseline for further evaluation of the effect of the implemented educational program.

Planning phase: After comprehensive reviewing of the relevant academic literature, from journals, textbooks, bulletins, and the electronic media, the researchers developed an educational program that was administered at the end of the pre-test aimed to promote daily care, physiotherapy, breathing exercise, feeding rehabilitation, exercise for pelvic relaxation. The program's general

objective was to provide a supportive intervention for mothers of female adolescents with cerebral palsy.

The program's content was a brief introduction to the concept of cerebral palsy, normal physical needs, and problems of the adolescent stage. Furthermore, handling needs and problems related to their handicaps, premenstrual syndrome manifestations and dealing with it, correct female position during perineal care, care technique, the solution needed, diaper care, pelvic exercises for comfort and relaxation. Also, routine daily care as morning care, general personal hygiene, daily partial and complete path, routine physical exercises, breathing exercise, and feeding rehabilitation (Khalil et al., 2018).

Implementation Phase: After the preparation of the program, the researchers started its implementation. The design of a tailored educational program was based on the pre-existing women's knowledge regarding the care of female adolescents with CP. The program consisted of four sessions, each session lasting 30-45 minutes.

- 1st session (introduction session): The researchers welcomed the mothers, explained the program's aim, identify the participants' expectations, distributed the pre-test, and determine the time of the next sessions.
- 2nd session: The researcher clarified to the mothers the normal physical and psychological needs of adolescents and physical needs related to handicaps.
- 3rd Session: The researchers explained the definition, causes, signs/symptoms, and treatment of cerebral palsy.
- 4th session: The researcher clarified the mothers' needs and problems of children with CP and mothers' role in caring for their children.

The researcher divided the studied mothers into small subgroups, and these sessions were repeated to each subgroup of (4-6) mothers. Different methods of teaching were used, such as discussion, brainstorming, demonstration, and re-demonstration. Instructional media included videos contain all content of the supportive educational intervention. The researchers constructed the educational booklet in a simple Arabic language after reviewing the academic-related literature and were distributed it to all recruited mothers to achieve its objectives.

Evaluation phase: During this phase, the immediate evaluation after the program was conducted as a post-test. The researchers' distribution of Post-test was done using the same pre-test format for the mothers to evaluate the effect of the educational program.

4.6. Data Analysis

Data entry was analyzed by using the Statistical Software Package for Social Sciences, version 20.0. Qualitative data were presented as frequency and percentage. The following tests were done: Chi-square (χ^2) test of significance was used to compare proportions between qualitative parameters. A t-test is a type of inferential statistic used to determine if there is a significant difference between the means of the two groups. Highly

statistically significant difference at $p < 0.01$, and statistically significant difference at $p < 0.05$.

5. Results

Table 1 reveals that the mean age of studied mothers was 47.2 ± 8.2 years, 46% had middle education, and 54% were housewives. 72% of mothers were residing in urban areas.

Table 2 reveals that the mean age of studied female adolescents was 15.2 ± 1.7 years; 32% of them suffered from Quadriplegia. The level of mental retardation reveals that 34% of them had severe levels.

Table 3 shows a highly statistically significant difference between mothers' knowledge about normal physical and physiological needs of adolescents, physical needs related to handicaps, needs related to menstrual discomfort, physical problems related to handicaps, and premenstrual syndrome manifestation at pre and post-intervention at p -value < 0.001 . In contrast, there was no significant difference in mothers' knowledge of problems related to the adolescent period at pre and post-intervention at p -value 0.115. The table shows a statistically significant difference between the total knowledge of studied mothers at pre and post-intervention with t -test 9.565 and p -value < 0.01 .

Figure 1 illustrates that 88% of studied mothers had unsatisfactory total knowledge at pre-intervention, while 64% had satisfactory post-intervention knowledge.

Table 4 shows a highly statistically significant difference between mothers' practice about morning care, general personal hygiene, daily partial bath, complete daily bath, routine physical exercise, breathing exercise, and feeding rehabilitation at pre and post-intervention at p -value < 0.001 . While there was a significant difference in mothers' practice related physiotherapy at pre and post-intervention at p -value < 0.025 .

Table 5 reveals a highly significant difference between mothers' practice about the correct position of the female during care, solutions used for care, the technique of care, diaper care, and exercises for pelvic relaxation and comfort measures during care at pre and post-intervention at p -value < 0.001 . The table also denotes a highly significant difference between the total reported practice of studied mothers at pre and post-intervention with t -test 10.447 and p -value 0.01.

Figure 2 clarifies that 86% of studied mothers had unsatisfactory reported practice at pre-intervention, while 68% had satisfactorily reported practice post-intervention.

Table 6 reports a highly significant correlation between the total knowledge of studied mothers and their reported practice pre and post-intervention at p -value < 0.01 .

Table (1): Frequency and percentage distribution of studied mothers' demographic characteristics (n = 50).

Demographic characteristics	No.	%
Age in years		
30 > 40	12	24
40 > 50	15	30
50 years and more	23	46
Mean \pm SD	47.2 \pm 8.2	
Educational level		
Cannot read and write	15	30
Read and write	10	20
Middle education	23	46
High education	2	4
Job		
Worked	23	46
Housewife	27	54
Residence		
Rural	14	28
Urban	36	72

Table (2): Frequency and percentage distribution of studied female adolescents with cerebral palsy according to their demographic characteristics (n = 50).

Demographic characteristic	No.	%
Age in years		
12- >14	16	32
14- >16	13	26
16- ≥18	21	42
Mean ± SD	15.2±1.7	
Type of physical handicap		
Paraplegia	13	26
Hemiplegia	11	22
Triplegia	10	20
Quadriplegia	16	32
Level of mental retardation		
Mild	14	28
Moderate	10	20
Severe	17	34
Profound	9	18

Table (3): Comparison of the studied mothers' knowledge regarding needs and problems of their female adolescents at pre and post-intervention implementation (n = 50).

Items	Pre				Post				x ²	P-value
	Satisfactory		Unsatisfactory		Satisfactory		Unsatisfactory			
	N	%	N	%	N	%	N	%		
Normal physical needs of adolescent	15	30	35	70	40	80	10	20	25.25	0.000
Normal psychological needs of adolescent	3	6	47	94	33	66	17	34	39.10	0.000
Physical needs related to handicaps	22	44	28	66	43	86	7	14	8.64	0.003
Need for relieving of menstruation-related discomfort	12	24	38	76	28	56	22	44	10.67	0.001
Problems related to adolescent period	33	66	17	44	40	80	10	20	2.49	0.115
Physical problems related to handicaps	24	48	26	52	44	88	6	12	18.38	0.000
Premenstrual syndrome manifestations	15	30	35	70	38	76	12	24	21.24	0.000
Total	6	12	44	88	32	64	18	36	9.565	<0.01

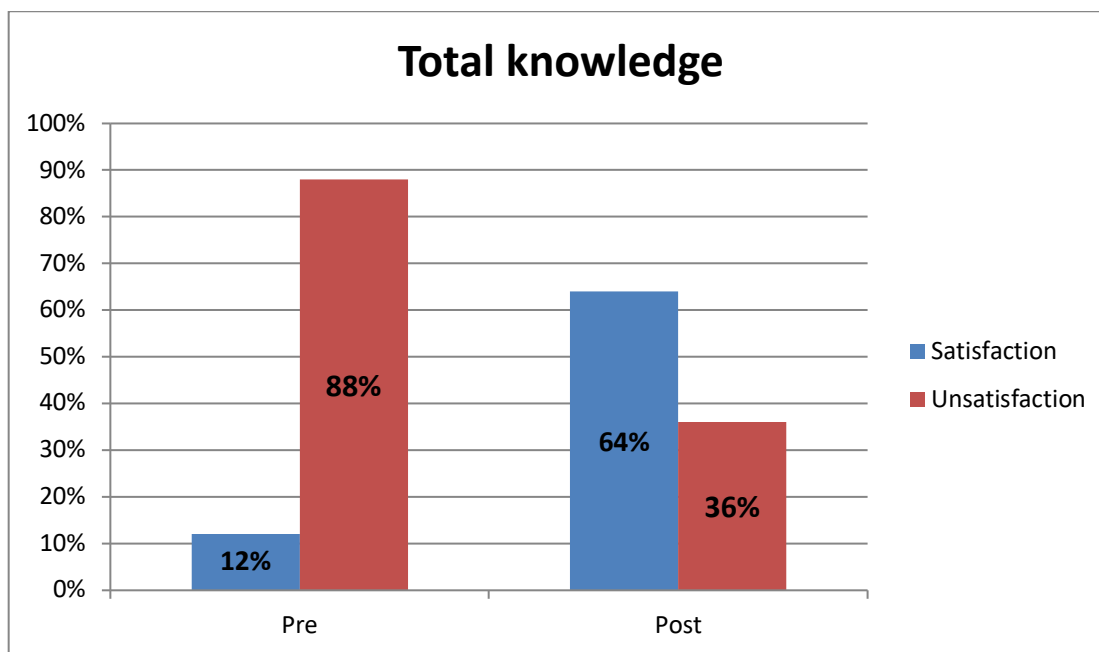


Figure (1): Percentage distribution of studied mothers' total knowledge regarding needs and problems of their female adolescents with cerebral palsy pre and post-program implementation (n=50).

Table (4): Comparison of the studied mothers' reported practice regarding routine daily care for their female adolescents at pre-and post-intervention (n = 50).

Caring practices	Pre				Post				t-test	P-value
	Satisfactory		Unsatisfactory		Satisfactory		Unsatisfactory			
	No.	%	No.	%	No.	%	No.	%		
Morning care	33	66	17	44	47	94	3	6	12.25	0.000
General personal hygiene	19	38	31	62	42	84	8	16	22.24	0.000
Daily partial bath	39	78	11	22	50	100	0	0	12.36	0.000
Daily complete bath	13	26	37	74	43	86	7	14	36.53	0.000
Routine physical exercises	19	38	31	62	40	80	10	20	18.23	0.000
Physiotherapy	21	42	29	58	38	76	22	44	4.99	0.025
Breathing exercises	7	14	43	86	33	66	17	44	28.17	0.000
Feeding rehabilitation	11	22	39	78	35	70	15	30	23.19	0.000

Table (5): Comparison of the studied mothers' reported practice regarding routine perineal care during and after menstruation for their female adolescents at pre and post-intervention (n = 50)

Caring practices	Pre				Post				t-test	P-value
	Satisfactory		Unsatisfactory		Satisfactory		Unsatisfactory			
	No.	%	No.	%	No.	%	No.	%		
Correct position of the female during care	27	54	23	46	47	94	3	6	20.79	0.000
Solutions used for care	11	22	39	78	39	78	11	22	31.36	0.000
Technique of care	13	26	37	74	40	80	10	20	29.27	0.000
Diaper care	16	32	34	78	42	84	8	16	27.75	0.000
Exercises for pelvic relaxation and comfort measures during care	8	16	42	84	33	66	17	44	25.84	0.000
Total mothers' reported practice	7	14	43	86	34	68	16	32	10.447	0.01

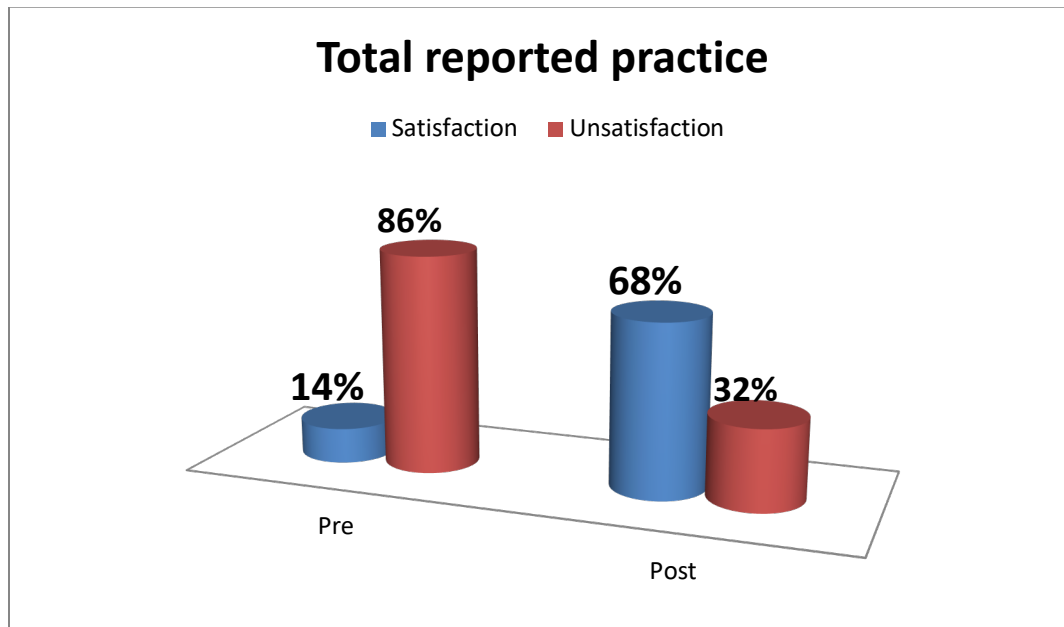


Figure (2): Percentage distribution of studied mothers' total reported practice regarding their female adolescents with cerebral palsy pre and post-intervention (n=50).

Table (6): Correlation between studied mothers' total knowledge and their total reported practice at pre and post-intervention (n=50).

		Total knowledge pre
Total practice pre	r	0.745
	p	<0.01
		Total knowledge post
Total practice post	r	0.699
	p	<0.01

6. Discussion

Most caregivers of children with CP had a low or moderate level of knowledge about appropriate caring for their children. Some caregivers do not receive any training in this area, or their training is not commensurate with their educational needs. To reduce or prevent their problems, these parents and caregivers must receive special training in caring for these children (Babu & Vanathi, 2018). So, the current study aimed to assess the effect of supportive educational intervention for mothers of female adolescents with cerebral palsy on their caring practices.

According to the demographic characteristic of studied mothers, the current study mothers' mean age was 47.2 ± 8.2 years, near half of them had middle education, more than half of them were housewives and more than two-thirds of mothers from urban areas. These results explained as the place of study is in a university hospital located in Cairo, so most of those who come to it are from urban areas. These results are consistent with the study performed by Lee *et al.* (2019), who performed a cross-sectional study on 180 mothers of children with CP recruited from clinical and school-based settings in Korea and found their mean age was 32.4 ± 4.1 and more than half had higher education. The results were also consistent with Glinac *et al.* (2017), who conducted a study on 141 mothers who participated in the research and found that most of them were unemployed and more than half had secondary education.

Regarding the demographic characteristics of the studied female adolescent, the current study states that the mean age of studied female adolescents was 15.2 ± 1.7 years. About one-third of them suffered from Quadriplegia. Their mental retardation level reveals that more than a third of them had severe levels. These results matched the study done by Makris *et al.* (2019), who reported that more than a quarter of the studied children suffered from bilateral CP, and about a third suffered severe cognitive impairment. In contrast, Baiee *et al.* (2019) found that about half of the studied children suffered from monoplegia CP.

Mothers' knowledge in the current study shows a highly significant difference between pre and post-intervention at p -value < 0.01 regarding mothers' knowledge of normal physical and physiological needs of adolescents, physical needs of handicaps, relieving menstrual discomfort, physical problems related to handicaps, and relieving menstrual syndrome manifestations. Also, it reveals a highly significant difference between the total knowledge of studied mothers pre and post-intervention. These results may be due to using different teaching methods such as discussion, brainstorming, demonstration, and re-demonstration. Also, the instructional media included videos contain all content of the educational intervention and educational booklet.

These results supported the study performed by Arora *et al.* (2016), who conducted the study on 53 mothers with CP children and concluded that CP's parental knowledge and intervention, such as an educational film, positively impacted the parents' knowledge. Also, Rao *et al.* (2019) reported that health education intervention positively

impacted mothers' awareness. A similar finding was revealed by Priyadharishini *et al.* (2017), who conducted a study on 40 primary caregivers and reported that the difference in the mean scores of knowledge, attitude, and selected skills of the primary caregivers of children with cerebral palsy after Community-Based Intervention Package (CBIP) was found to be statistically significant ($p < 0.001$).

According to the reported practice of studied mothers related to the care of their CP female adolescent, the current study reveals a highly statistically significant difference between pre and post-intervention regarding their reported practice of routine care of female adolescents and routine care during menstruation. The total reported practice of studied mothers at pre and post-intervention also shows a highly statistically significant improvement. These results explained as the researchers used a simple Arabic language during the training program and used illustrative methods as videos and photos.

These results consistent with the study conducted by Rashed *et al.* (2021) on 50 mothers and concluded that the educational module given to the studied mothers had a positive effect on improving their practice about the care of their children with cerebral palsy as there was a statistically significant difference throughout the three phases of the study. Also, it agrees with a study conducted by Omar *et al.* (2017) and stated that the training program has a beneficial effect on improving feeding practices of children with CP and their caregivers after ten training sessions, with positive consequences for both child and caregiver. These findings are supporting the current research hypothesis.

Regarding the correlation between studied variables, the current study reveals a highly statistically significant positive correlation between the total knowledge of studied mothers and their reported practice pre and post-intervention at p -value < 0.01 . These results are explained as knowledge from the base of practice. These results are supported by the study by Alruwaished *et al.* (2021); Mahmoud and Sabea (2020), who reported a high statistically significant positive correlation between caregivers' knowledge and practice at a p -value < 0.01 .

7. Conclusion

Implementing supportive educational intervention for mothers regarding the care of their female adolescents with cerebral palsy had a positive effect on their knowledge and practice that support the current research hypothesis. Additionally, there was a statistically significant positive correlation between mothers' knowledge and practice pre and post-intervention.

8. Recommendations

- Continuous training for mothers related to managing the child's physical needs as well as their psychosocial ones.
- Future studies are needed to examine the relationship between maternal psychological well-being and CP severity, using standard measures for CP severity.

- Further studies are needed to assess predictive factors affecting mothers' knowledge and practice regarding the care of an adolescent with cerebral palsy.

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