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Effect of Orem Self-Care Model on School-Age Children and Teenagers with Autism and their Parents

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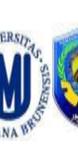
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Abstract

Background: The definition of autism as significant impairments in social interaction, deficits in communication and the presence of rigid behaviors and restricted interests. **Aim:** Assess self-care daily living activities of school-age children and teenagers with a mild level of autism and their parents. Design and implement Orem's self-care model as a valid basis for delivering care. Evaluate the effective self-care training on school-age and teenagers with a mild level of autism and their parent. **Design:** One group quasi-experimental design was used in the current study. **Setting:** Conducted in pediatric outpatient clinics at Benha University Hospital. **Sample:** A purposive sample of all available school-age children and teenagers with a mild level of autism and their parents (n= 36). **Tools: Data was collected through:** (1): A structured interviewing questionnaire composed of two parts: 1st part: was concerned with characteristics for school-age children and teenagers and their parents. 2nd part: Parents knowledge regarding autism. (2): Orem self-care models and an observational checklist to assess self-care practice. **Results:** about two third of children was male (61.1%). More than half of parent stated obstacles toward self-care was inadequate training and teaching. Also, there was the improvement in parents' knowledge post-Orem self-care model implementation. Positive correlation coefficient between parent practices and their age and education level post-Orem self-care model implementation. Also, there was the statistically significant difference between school age children and teenagers practice pre and post-Orem self-care model implementation in all items except the ability to feeding, personal hygiene and elimination. **Conclusion:** Orem self-care model was effective which improved school-age and teenagers and their parent's self-care practice. **Recommendations:** Continuing application of Orem self-care models to keep parent updated in their knowledge and practice regarding self-care of their children with autism is mandatory.

Keywords: Orem Self-care Models- Autism -School-age and Teenagers- Parent.



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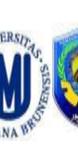
Introduction

Autism is identifying by social and language impairment, typically diagnosed between the ages of eighteen months and three years (Marion, et al., 2011; Norlin, & Broberg, 2013). The incidence of autism in children about 1 in 68 according to estimates from (CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network, 2015).

The ASD causes still unknown, some research found that both genes and the environment play a role. The ASD are reported to occur in all racial, ethnic, and socioeconomic groups and almost 5 times more common among boys (1 in 42) than among girls (1 in 189) (Hallmayer, et al., 2011). Small percent from premature or with low birth weight are a greater risk for having ASD (Ozonoff, et al., 2011). Between identical twins, if one child has autism, then the other is likely to be affected 75-90% of the time (Rosenberg, et al., 2009). Parents having a child with an ASD have a 2-10% chance of having a second child also affected (DiGuseppi, et al., 2010). There are some evidence related exposures to factors in the environment such as viruses or infections may play a role in causing some forms of autism. Parents have an important role in planning and implementing interventions after an ASD is detected (Lindgren & Doobay, 2011).

There are currently three criteria for a diagnosis of autism spectrum disorder present before 3 years of age. The first is qualitative impairment in social interaction, including an inability to use nonverbal behaviors to guide interactions, impairment in the use of eye-to-eye gaze, facial expression, body postures and gestures to regulate social interaction. This also includes a failure to develop peer relationships, a lack of social and emotional reciprocity and lack of seeking to share interests. The second criteria include communication impairments, manifested as the lack of spoken language, inability to initiate conversation and repetitive use of words. The third criteria include the display of repetitive and stereotyped patterns of behavior, interests and activities (Gorsky, 2014).

Educational training about self-care programs by using Orem self-care model designed for higher functioning school-age/teenagers with autism,/ also can support management of



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anxiety, depression, anger control and /social skill development. Nursing care also is needed to manage associated problems with seizures, gastrointestinal problems, dietary imbalances, or disrupted sleep patterns. In addition increase communication skills and improve independence in activities of daily living (**Lindgren & Doobay, 2011**).

Nursing care for autism children is best facilitated using self-care theory approach. The Orem nursing model supports the practice increases the potential for positive child outcomes with autism (**Gorsky, 2014**). The Orem self-care theory focuses on the activities that individuals initiate and perform on their own also to maintain life, health, and well-being (**Cardinal Stritch University Library, 2011**). Self-care comprises everything can be done to maintain health, prevent illness, seek and adhere to treatment, treat symptoms, and side effects, fulfill recovery and rehabilitation, and manage the impact of long-term illness and disability (**Macduff, & Sinclair, 2008**).

Significant of the study:

Autism in Western Africa (Extrapolated Statistics) the incidence rate of autism in Egypt is 152,234 (**Right Diagnosis, 2014**). Self-care is pertaining to the decisions and actions that a person takes to enhance health, prevent disease, limit illness and restore health. Orem's self-care model describes a structure for the nurses to assists the child/teenagers in their needs and maintain an adequate level of self-care (**Sitzman and Eichelberger., 2011**). Design the degree of nursing care and intervention depends on the degree of the child/teenagers which can be able or unable to meet self-care needs. Usually, all children with autism are independently in their completion of daily routine skills, such as getting dressed, eating and using the toilet. Assessing children needs, then training and teaching by using Orem model self-care demonstrated to be effective for children with autism (**Stephen, et al., 2009**). Parents having school-age and teenagers with autism is essential to gain insight and find appropriate and valuable self-care interventions to alleviate their effects and increase its resiliency. There is a lack of research in this area while the diagnosis of ASD continues to rise every year, it is important to implement an

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education program for parents to encourage and adaption of new interventions and establish self-care of their children.

Aim of the study:

The aim of the current study was to:

- Assess self-care daily living activities of school-age children and teenagers with a mild level of autism and their parents.
- Design and implement Orem's self-care model as a valid basis for delivering care.
- Evaluate the effective self-care training on school-age and teenagers with a mild level of autism and their parent.

Research hypothesis

- The Orem self-care model well be effective in training the parent having school-age and teenagers with a mild level of autism
- The school-age and teenagers with autism will have improved the ability for self-care in different aspects post training.

Subjects and methods

Design: One group quasi-experimental design was used in the current study.

Setting: The study was conducted in pediatric outpatient clinic at Benha University Hospital.

Sample: A purposive sample of all available school-age and teenagers with a mild level of autism and their parents were recruited in the study (n= 36) with inclusion of criteria as a mild level autism , chronological/mental age, free from any other disease or disorders, both gender, age from 8-18 years, and accompanying parents.

1-Tools Used for Data Collection:

Two tools were developed and used by the researchers after extensive review of related literature to collect necessary data from the study subjects:

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Tool (I): A structured interviewing questionnaire that developed by the researchers and composed of two parts:

1st part: was concerned with characteristics for school-age children and teenagers (as age, gender, age at diagnosis) and their parents (as age, gender, education level, siblings, residence and obstacles related self-care).

2nd part: Parents knowledge regarding autism, it includes 5 items: definition of autism, causes, signs and symptoms, management, and children needs.

The scoring system for parent's knowledge regarding autism, the responses for each item was scored (3) for good, (2) for average and (1) for poor knowledge. Parent's total knowledge was considered satisfactory if the percentage was $\geq 60\%$, while parent's knowledge was considered unsatisfactory if the percentage was $< 60\%$.

Tools (II): Orem self-care model and an observational checklist to assess self-care practice of school age children and teenager and their parents filled by the researcher. It includes 9 items; nutrition, personal hygiene, elimination, exercise, sleep and rest, clothes, using telephone, shopping, and using transportation.

The Scoring system for school-age children and teenagers and their parents related to self-care was level one Independent (3), level two partial dependent(2), level three wholly dependent (1).

2. Operational Design

Preparatory Phase

This phase included reviewing the available literature and the different studies related to autism and self-care to cover various aspects of the research problem, develop the study tools for data collection by and using books, articles, magazines, and the internet.

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Validity and Reliability:

The study tools were tested for validity by three experts; two from the Faculty of nursing (pediatric and psychiatric nursing departments) and one expert of statistics. Reliability Cronbach's Alpha coefficient test for all measures was (0.860 to 0.929).

Pilot study:

A pilot study was carried out on 10% (4 parents) and (4 school-age children and teenagers) of the study sample to test tools for clarity, applicability and the time required for filling in the tools. Data was analyzed and accordingly the necessary modifications and included to the main study sample.

Field work:

The actual field work was carried out from the beginning of January, / 2014 until the end of August, / 2014 in the previously mentioned setting, an official approval to carry out the study was obtained from the directors of Benha University Hospitals.

Program construction

The nursing intervention was constructed in four phases:

Assessment phase: In this phase, the researchers collected the following data:

- Demographic data of the children and their parents.
- Parents' knowledge about autism.
- School age children and teenagers and their parents' practice related to self-care of daily living activities.

Planning Phase

Based on the results obtained from the assessment phase, the Orem's self-care model was designed by the researchers.



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General objective: Improve self-care practice of school age children and teenagers with autism and their parents through designed Orem self-care model.

Content: The important knowledge about the meaning of the autism, causes, and managements and application of self-care practice.

Implementation Phase

The Orem self-care model was implemented for 8 months; it was carried out in 5 sessions; 2 sessions for theory and 3 sessions for practice. The duration of each session ranged between 30-45 minutes. The practice was implemented in groups from 2 to 4 school age children and teenagers with their parent. At the first of each session, the researchers started with feedback about the previous session and purpose of the new session, taking into consideration using simple and clear language to be suit for children and their parents. Teaching methods were used as small group discussion, lectures, and demonstration. The teaching aids were used as brochures, colored posters, and videos.

Evaluation Phase: The Orem self-care model was evaluated through post-test; by using the same tool of pretest and was conducted immediately after implementation the model.

3. Administrative Design

Official letters were issued from the Faculty of Nursing, to the administrators of Benha University Hospital. Explaining the purpose of the study and taking permission for data collection.

Ethical Considerations

The agreement of the parents and their school-age and teenagers with a mild level of autism to participate in the study was taken verbally. Participants were assured that all information was taken from them would be secure and confidential and used for the research only. The approval of the ethics committee of nursing college and Benha University hospital was taken for agreeing to hold research.

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4. Statistical Design

Data was analyzed using the statistical Package for Social Sciences (SPSS) version 20. The first part of data was descriptive data, which were revised, coded, tabulated and statistically analyzed using the proportion percentage, arithmetic means, and standard deviation. A comparison between qualitative variables carried out by using parametric Chi-square test. Correlation among variables was done using Pearson correlation coefficient. Degrees of significance of the results were, non-significant (NS), if $p > 0.05$, significant (S), if $p < 0.05$, highly significant (HS), if $p < 0.001$

Results:

Table 1: Socio-demographic data related to school-age and teenagers with autism (n=36)

Items	No	%
Age		
• 8<10	1	2.7
• 10 <12	13	36.1
• 12<14	5	13.9
• 14<16	9	25.0
• 16≤ 18	8	22.3
Mean ±SD	11.97±3.24	
Age at diagnosis		
• At birth	12	33.3
• 1-<3 years	10	27.8
• 3≤5 years	14	38.9
Gender		
• Male	22	61.1
• Female	14	38.9

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Table (1) represents socio-demographic data of school age children and teenagers with autism. It was clear that, 36.1% of school-age and teenagers were aged 10<12 years. 38.9% of them were age ≤3-5 years at diagnosis of autism. Moreover, more than half of them were male (61.1%).

Table 2: Socio -demographic data related to parents of school age and teenagers with autism (n=36)

Items	No	%
Parents age		
• 0-30	16	44.4
• 30-35	9	25.0
• ≥35	11	30.6
Mean ±SD	30.44 ± 4.91	
Gender		
• Mothers	20	55.6
• Fathers	16	44.4
Education level		
• Read and write	3	8.3
• Primary	1	2.8
• Preparatory	7	19.4
• Secondary	6	16.7
• University	19	52.8
Sibling		
• Single	14	38.9
• 2-3	13	36.1
• >3	9	25.0
Place of residence		
• Rural	19	52.8
• Urban	17	47.2
Obstacles of parents for self-care		

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• Inadequate training and teaching	19	52.8
• Lack of time	8	22.2
• Health reasons for parents	6	16.7
• Imbalanced schedule	3	8.3

Table (2) revealed that socio-demographic characteristics data of parents. It was clear that, 44.4% of parents were aged <30 years. More than half of parents were the mother (55.6%). As regarding educational level, 52.8% of parents had the university education and living in rural area. Concerning to obstacles for parent's self-care was 52.8% of them had stated inadequate training and teaching.

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Table (5) Parents self-care practice to train school-age and teenagers pre and post-Orem self-care model implementation (n=36)

Item	Pre-Orem self-care model implementation						Post-Orem self-care model implementation						X ²	P
	Independent		Partial dependent		Wholly dependent on parents		Independent		Partial dependent		Wholly dependent on parents			
	N	%	N	%	N	%	N	%	N	%	N	%		
• Nutrition	8	22.2	19	52.8	9	25.0	20	55.6	14	38.8	2	5.6	18.00	<0.001**
• Personal hygiene	11	30.6	18	50.0	7	19.4	23	63.9	11	30.6	2	5.6	17.00	<0.001**
• Elimination	12	33.3	18	50.0	6	16.7	21	58.3	12	33.3	3	8.4	10.28	<0.001**
• Exercise	6	16.6	19	52.8	11	30.6	20	55.6	11	30.6	6	16.7	19.00	<0.001**
• Sleep and rest	9	25.0	19	52.8	8	22.2	21	58.3	12	33.3	3	8.4	15.21	<0.001**
• Clothes	7	19.4	20	55.6	9	25.0	23	63.9	9	25.0	4	11.1	21.00	<0.001**
• Using transportation	7	19.4	20	55.6	9	25.0	20	55.6	14	38.8	2	5.6	20.00	<0.001**
• Shopping	10	27.8	18	50.0	8	22.2	22	61.0	11	30.6	3	8.4	17.00	<0.001**
• Using telephone	11	30.6	19	52.8	6	16.6	24	66.7	12	33.3	0	0.0	17.37	<0.001**
• Total	12	33.3	17	47.3	7	19.4	22	61.1	14	38.9	0	0.0	15.21	<0.001**



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Table (5) documented that more than half of parents practice to train their school-age and teenagers with autism were (55.6%, 55.6%) had partial dependent related to clothes, and using transportation pre-Orem self-care model implementation respectively. While post-Orem self-care model implementation, 66.7%, 63.9% and 63.9% was had independent on own self-related to using the telephone, personal hygiene and clothes respectively. Also, this table showed there was the highly statistically significant difference between parents practice pre and post-Orem self-care model implementation in all items ($p < 0.001$).

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Figure 1: Parents knowledge pre and post-Orem self-care model implementation.

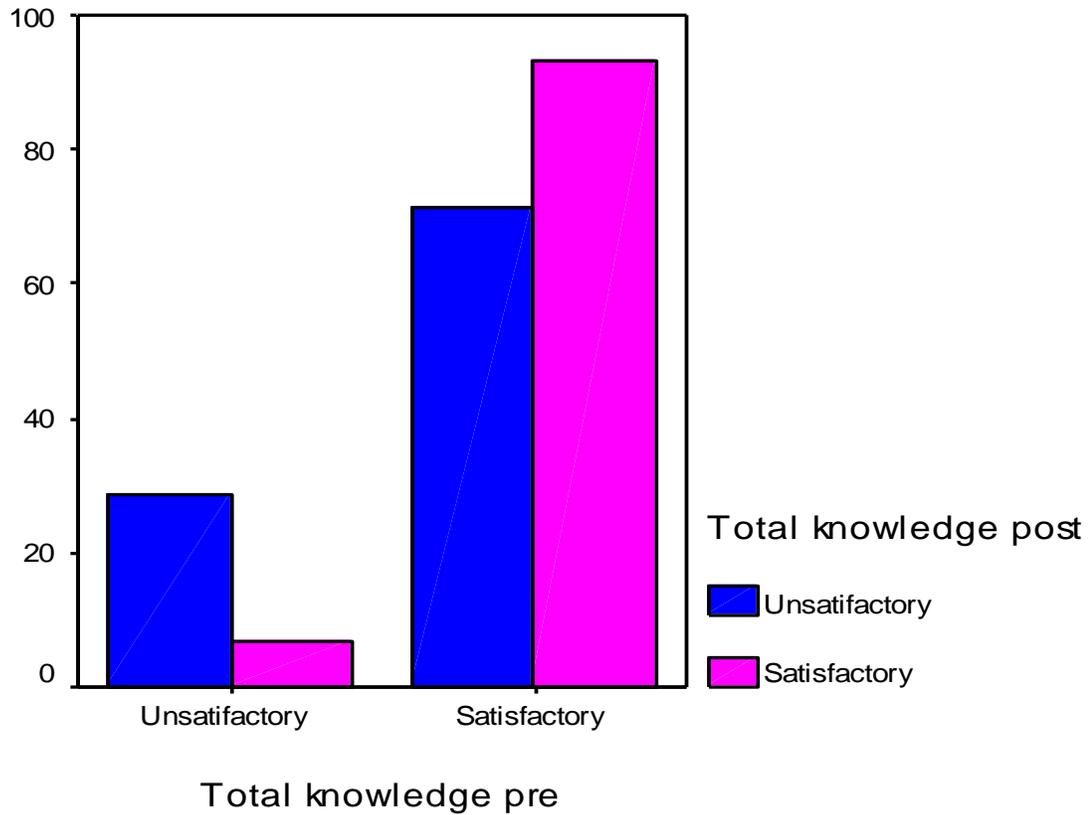


Fig 1: show that improves in satisfactory parent level of knowledge post than pre-Orem self-care model implementation.

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Figure 2: Correlation between parents practice and their Knowledge post-Orem self-care model implementation.

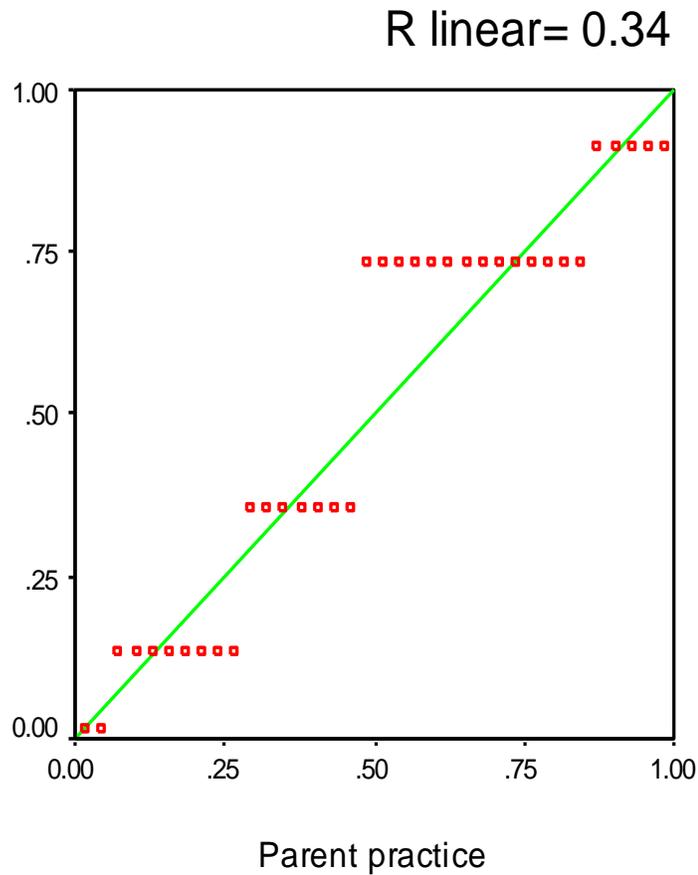


Fig 2: shows that there was a significant positive correlation between the score of knowledge and the score of practice ($r = 0.34$, $p < 0.01$).

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Figure 3: Correlation between parents practice and their school age children practice post-Orem self-care model implementation.

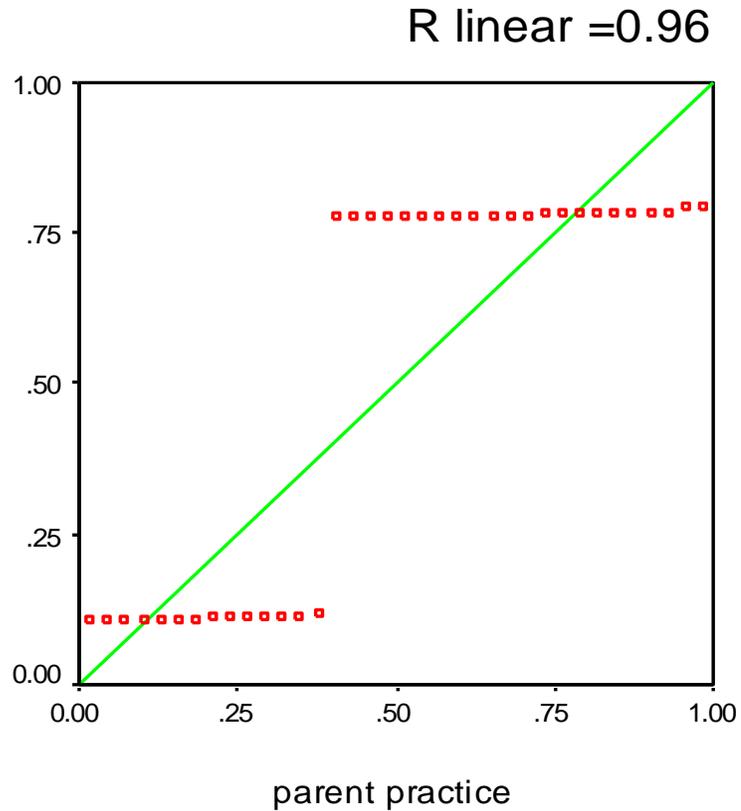


Fig 3: shows that there was a significant positive correlation between parents practice and school-age and teenagers practice ($r = 0.96$, $p < 0.01$).

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Table (6) Correlation between Parent’s knowledge, practice and their socio-demographic data pre and post-Orem self-care model implementation (n=36)

Socio-demographic	Knowledge				Practice			
	Pre-Orem self-care model		Post-Orem self-care model		Pre-Orem self-care model		Post-Orem self-care model	
	r	p	r	p	r	p	r	p
• Parent age	0.23	>0.05	0.39	<0.01*	0.12	>0.05	0.40	<0.01*
• Gender	0.32	>0.05	0.41	<0.01*	0.01	>0.05	0.08	>0.05
• Marital status	0.20	>0.05	0.18	>0.05	0.19	>0.05	0.17	>0.05
• Education level	0.13	>0.05	0.42	<0.01*	0.20	>0.05	0.38	<0.01*
• Sibling	0.03	>0.05	0.09	>0.05	0.06	>0.05	0.00	>0.05
• Residence	0.16	>0.05	0.18	>0.05	0.20	>0.05	0.18	>0.05

Table (6) clarified that there was positive correlation coefficient between parent’s knowledge and their age, gender and education level post-Orem self-care model implementation ($r = 0.39$, $p < 0.01$, $r=0.41$, $p<0.01$ and $r = 0.42$, $p<0.01$ respectively). While, there was positive correlation coefficient between parent practice and their age and education level post-Orem self-care model implementation ($r = 0.40$, $p<0.01$ and $r = 0.38$, $p<0.01$) respectively.

Discussion:

Self-care is an important element in every child’s daily life. Taking training to maintain a healthy balance in life is a key factor in overall health. Parents have an ASD child, this is even more important to adequate teaching and training to fill physical, and workplace needs should be a priority in parents’ lives (Cavkaytar, A. (2007) and (Batu, 2008).

The present study aimed to assess self-care daily living activities of school-age and teenagers with a mild level of autism and their parents. Design and implement Orem’s self-care model as a valid basis for delivering care. Evaluate the effective self-care training on school-age and teenagers with a mild level of autism and their parent.

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The current study represent socio-demographic data of school age children and adolescent with autism (table 1) found that nearly one-third of school-age and teenagers were aged 10<12 years. More than one-third of them also were age $\leq 3-5$ years at diagnosis of autism. Moreover, more than half of them were male. This result is consistent with **(Rhoades, et al., 2007)** who found that the average age of diagnosis was 4 years, 10 months, but the most frequent were 3 years, moreover, half of the sample was reportedly diagnosed after 3 years, 9 months. It may be due to insufficient parent's knowledge about autism.

As regard socio-demographic characteristics data of parents (table 2) was clear that, more than one-third of parents were aged <30 years. More than half of parents were mothers. Also, there was more than half of parents had the university education and living in rural area. In addition more than half of parent stated their obstacles were inadequate training and teaching. This matched with the study done by **(Gorsky, 2014)** who found the mean and standard deviation of age was 35.92 ± 5.03 . The majorities of parents 28.6% completed college. Also, 82.1% of them were married. In addition, the parent stated obstacles due to decrease awareness and time.

The study showed (figure 2) that there was a significant positive correlation between the parent knowledge and practice ($r = 0.34, p < 0.01$). This supported by the study done by **(Hashemi, et al., 2014)** who found that after two months from train self-care model, the quality of life of the cases improved from 73.33% to 83.78% and 98.12%, respectively ($P < 0.001$). Also, in the same line with the findings research done by **(Roberts, et al., (2011)** who support the provision of knowledge and skills for both children with autism and their parents was effective. In addition, the study was done by **(Mays and Heflin, 2011)** who found that elementary-school-aged children with autism, all students showed marked improvement in their performance following implementation of self-operated auditory prompting systems on independent self-care task.

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Regarding parents practice to train their school-age and teenager with autism (table 5) the current study documented that, more than half of parents had partial dependent related to clothes, and using transportation pre-Orem self-care model implementation respectively. While post-Orem self-care model implementation, more than two third was had independency on own self-related to using the telephone, personal hygiene and clothes respectively. Also this table showed there was the highly statistical significant difference between parents practice pre and post-Orem self-care model implementation in all items ($p < 0.001$). This matched with the study done by (Gorsky, 2014) who found that a significant correlation was found between the ASD child's current age and the amount of physical the self-care being utilized by parents. It was found that more than half of the older ASD child, independent related personal hygiene but other the physical self-care being conducted by parents.

The present study clarified that (table 6) there was positive correlation coefficient between parent's knowledge and their age, gender and education level post-Orem self-care model implementation ($r = 0.39$, $p < 0.01$, $r = 0.41$, $p < 0.01$ and $r = 0.42$, $p < 0.01$ respectively). While, there was positive correlation coefficient between parent practice and their age and education level post-Orem self-care model implementation ($r = 0.40$, $p < 0.01$ and $r = 0.38$, $p < 0.01$) respectively. This is consistent with the study done by (Gorsky, 2014) who found that there was a significant correlation between the parent higher level of education and amount of self-care being implemented.

Conclusions:

The study concluded that Orem self-care model was effective which improved school-age and teenagers and their parent's self-care practice.

Recommendation:

This study recommended that:

Continuing application of Orem self-care models to keep parents updated in their knowledge and practice regarding self-care of their children with autism is mandatory.



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