

# Meet the Professionals' Day; Evaluation of the Autistic Children Caregivers' Knowledge, Concerns, and Needs

Eman Ahmed Zaky\*<sup>1</sup>, Eman Abdel Aziz<sup>1</sup>, Reham Elhossiny<sup>1</sup>, Randa Khalaf<sup>1</sup>, Asmaa Wafik<sup>1</sup>, Sally Zahra<sup>1</sup>, Walaa Youssef<sup>1</sup>, Shereen Mostafa<sup>1</sup>, Rana Abdel Hakim<sup>1</sup>, Aya Hassan<sup>1</sup>

<sup>1</sup>Department of Pediatrics' Faculty of Medicine, Ain Shams University, Egypt

**Short Title:** Autistic caregivers' Meet the Professionals Day

## Corresponding Author

Professor Eman Ahmed Zaky\*, MD, PhD, DPP  
Department of Pediatrics, Faculty of Medicine, Ain Shams University  
Head of Child Psychiatry Clinic, Children's Hospital, Ain Shams University, Cairo, Egypt  
E-mail: emanzaky@hotmail.com

**Abstract:** Background: Autistic caregivers are continuously under extreme stress; on one hand, tortured because of seeing their children living a denied childhood and on the other, facing silent or expressed accusations from others. Objective: Our Clinic first Meet the Professionals Day (MPD) for autistic caregivers has been designed as a preliminary cross sectional study to evaluate their knowledge, Concerns, and needs from the clinic, community, and future autism scientific research. Methodology: Caregivers of 25 autistic children under regular follow up at the Child Psychiatry Clinic, Children's Hospital, Ain Shams University, Egypt were recruited; ten joined our Clinic first MPD events (group I) and 15 did not join those events (group II). Socioeconomic Standard Questionnaire, Autism Parental Knowledge Assessment Questionnaire (APKAQ), and Caregivers' Views and Caregivers' Needs open ended questionnaires were filled by all enrolled caregivers. The latter three questionnaires were filled twice by group I; before and after MPD educating sessions. Results: The mean value of the total APKAQ score was significantly improved for group I after MPD educating sessions compared to it before those sessions. On the other hand, the educating sessions of our first MPD significantly improved the caregivers knowledge about autism etiology, symptomatology, and prognosis. Conclusion: Assessment of the knowledge of autistic caregivers about a disorder that they are obliged to live with, every day of their lives, is crucial in helping professionals to arrange for educational and supportive programs that meet their needs, dealing with their concerns, and empower them to help their children in a more efficient way.

**Keywords:** Autism spectrum disorders (ASDs), Childhood Autism Rating Scale (CARS), Autistic caregivers, autistic caregivers educational programs

## 1. Introduction

There is an agreement among all professionals that autism is one of the most puzzling diseases. It is a complex neurodevelopmental disorder, the prevalence of which has surged in the last 2 decades [1]. It is usually diagnosed before the age of three years with striking 4:1 male to female ratio [2]. It is characterized by defiance in social reciprocity and in language skills that are associated with repetition behavior and restricted interests [3].

Pediatricians play an important role in early recognition of autism spectrum disorders (ASD), because they usually are the first point of contact for parents. Parents are nowadays much more aware of the early signs of these disorders because of frequent coverage in the media; if their child demonstrates any of the published signs, they will most likely raise their concerns to their child's pediatrician [4].

Pediatricians have an important role not only in early recognition and evaluation of autism spectrum disorders but also in their chronic management. The primary goals of treatment are to maximize the child's ultimate functional independence and quality of life by minimizing the core

autism spectrum disorder features, facilitating development and learning, promoting socialization, reducing maladaptive behaviors, and educating and supporting families [5].

## 2. Problem Definition

Childhood is synonymous of play and looking at a child who doesn't socialize and is not able to play like all other children is very sad. It is such a denied childhood. Often all autistic behaviors are considered by people who do not live autism as manners due to bad education [6]. Accordingly, autistic caregivers are continuously under extreme stress; on one hand, tortured because of seeing their children living such a denied childhood and on the other, facing silent or expressed accusations from others. The role of Pediatricians in educating and supporting autistic caregivers to empower them in helping their children and alleviating their own stress because of their parenthood worries and community accusations and stigma is crucial.

## 3. Study Objectives

Our first Meet the Professionals' day for autistic caregivers has been designed to evaluate their knowledge, Concerns, and needs from the clinic, community, and future autism scientific research.

Volume 4 Issue 9, September 2015

[www.ijsr.net](http://www.ijsr.net)

Licensed Under Creative Commons Attribution CC BY

#### 4. Meet the Professionals day design & research methodology

The current pilot cross sectional study was carried out in accordance to the code of ethics of the *World Medical Association (Declaration of Helsinki, 1989)* [7] for experiments involving humans. Written informed consent of legal caregivers of enrolled autistic children was taken and the study protocol was approved by Ain Shams Faculty of Medicine Ethical Committee.

##### Participants:

Caregivers of 25 autistic children were recruited consecutively from those who were under regular follow up in the Child Psychiatry Clinic, Children's Hospital, Ain Shams University, Cairo, Egypt, for 6 months prior to our Clinic first Meet the Professionals' Day (MPD) assigned date. They were classified into the following groups:

##### Group I (Caregivers who joined MPD events)

It included ten caregivers who agreed to join the events of our Clinic first MPD. They were 10 mothers; joined by the father in 2 cases and by the grandfather in another 2 cases.

##### Group II (Caregivers who did not join MPD events)

It included 15 caregivers who did not join the events of our Clinic first MPD for some reason or another but agreed to join our study and filled the 4 implemented questionnaires at the Clinic setting instead. They were all mothers.

##### Procedure

**I. For all the recruited caregivers, the following data were retrospectively gathered from their autistic children' Clinic files:**

- **DSM IV TR (2000)** diagnostic criteria for Autism Spectrum Disorders (ASDs) that were used to settle the diagnosis of these disorders for the enrolled caregivers' children [8, 9].
- **Psychometric assessment:**
  - a. The scores of an Arabic validated version of Childhood Autism Rating Scale (CARS) that was used for both identification and rating of autism [10]. This test was used to determine the severity of autistic manifestations and their regular monitoring [11,12]. The average of the last 2 recorded scores was calculated for each case.
  - b. The scores of an Arabic validated version of Vineland Adaptive Behavioral Scales (VABS); that was used in assessment of enrolled caregivers' autistic children. It formed an aid in diagnosing and classifying their degree of intellectual disability [13] and represented a diagnostic tool that helped in measuring the capabilities of those children in dealing with everyday's life [14, 15].

##### II. MPD events:

- The events of the day were carried out in a well equipped educational hall at our Children's Hospital, Ain Shams University in which all the participating caregivers could sit comfortably and interact freely with each other and with the members of our team. The day started with an hour of "let us introduce ourselves" in which the professional team

members introduced themselves to the participating caregivers and asked them to introduce themselves as well. Then, four types of questionnaires were distributed among the attendants and they were asked to fill each one of them in 10 minutes. These questionnaires were as follows:

1. Socioeconomic Standard Questionnaire of Elshakhs (2006) [16] which is an Arabic validated scale consists of different items including Parents' occupations, educational level, and family income. The Socioeconomic Standard Questionnaire scores were interpreted as follows: 10-19= very low, 20-29 = low, 30-39 = sub moderate, 40-48 = moderate, 49-58 = over moderate, 59-68 = high, and 69-77 = very high.
2. Autism Parental Knowledge Assessment Questionnaire (APKAQ) designed by the head of our team to evaluate the enrolled caregivers' knowledge about autism. It was filled by the enrolled caregivers twice; once before MPD educating sessions and the other after them. It consisted of 6 domains: the definition of autism, its etiology, its clinical manifestations, the available psychometric assessment, therapeutic modalities, and prognosis. Each domain included 4 statements with 3 options for each of them; yes, no, and I do not know. The right answer scored with 0.5 for each statement and the wrong and do not know answers scored with 0.00. The complete total score of the used APKAQ was 12.
3. Caregivers' Views open ended questionnaire designed by the head of our team and included questions about the level of caregivers satisfaction concerning our clinic provided services, their autistic children savant abilities, how do they see the condition of their children after 10 years from now, what do they want to know about autism, and their opinion about the idea of MPD. It was filled by the enrolled caregivers twice; once before MPD educating sessions and the other after them.
4. Open ended questionnaire designed by the head of our team and inquired about the needs of the participating caregivers from our clinic, community, and future autism research. It was filled by the enrolled caregivers twice; once before MPD educating sessions and the other after them.
  - **MPD educational sessions about autism:** Four sessions were given by members of our team; the topics of which were: definition and etiology, clinical manifestations, different types of autism psychometric assessment tools, and treatment and prognosis, respectively. A break of 30 minutes was given after the first 2 sessions. The timing of each session was 30 minutes; 20 minutes for the professional educating material and 10 minutes to answer caregivers' questions about it.
  - At the end of the day, the enrolled autistic caregivers had the chance to say goodbye to each other and to our team members and take memorial pictures together.

**Caregivers who did not join MPD events (group II)** have been asked to fill the four implemented questionnaires; Socioeconomic Standard Questionnaire, Autism Parental Knowledge Assessment Questionnaire, Caregivers' Views open ended questionnaire, and Caregivers' Needs open ended questionnaire, only once, at the Clinic setting, in 10 minutes for each.

### Data analysis:

Analysis of the obtained data was done by IBM computer using *SPSS (statistical program for social science version 16)* [17] as follows: description of quantitative variables as means, SDs, and ranges, description of categorical variables as numbers and percentages. Chi-square test was used to compare categorical variables between groups and unpaired t-test was used to compare quantitative variables while paired t test was used to compare the mean values of the total APKAQ score of group I before and after MPD educating sessions. Results were considered statistically insignificant at  $p>0.05$ , significant at  $p<0.05$ , and highly significant at  $p<0.01$ .

## 5. Results

All autistic children of the enrolled caregivers of both groups were males (100%). Their ages ranged between 4 and 12 years with a mean value of  $8.34\pm 1.48$  years for group I and  $7.98\pm 2.55$  years for group II ( $p>0.05$ ). There were statistically insignificant differences between autistic children of both groups regarding total CARS and VABS scores ( $p>0.05$  for both); **Table (1)**. Also, both enrolled autistic caregivers' groups showed statistically insignificant differences concerning maternal and paternal mean ages, and mean family income/month. Meanwhile, the mean value of Socioeconomic Standard Score was significantly lower in group II compared to group I ( $p=0.018$ ); **Table (1)**. The frequency distribution of different socioeconomic standards of both studied autistic caregivers' groups is shown in **Table (2) and Fig (1)**.

Autistic children savant abilities were reported in 50% of group I and 40% of group II; they were in the form of drawing, painting, and music playing. Mild to moderate autism was recorded in 60% of group I and 66.67% of group II, severe autism in 40% of group I, and 33.33% of group II. On the other hand, mild, moderate, and severe intellectual disabilities were recorded in 30%, 50%, and 20% of group I respectively and in 33.33%, 46.67%, and 20% of group II respectively;  $P>0.05$  in all possible statistical comparisons; **Table (2)**.

Comparison between studied groups concerning frequency distribution of residency type, different levels of maternal and paternal education, different types of current maternal and paternal jobs, levels of family income/month, and numerical categories of family members living together and number of rooms they are living in is shown in **Table (3)**;  $P>0.05$  in all possible statistical comparisons except for that of maternal job type where being a house wife was slightly significantly more encountered in group I ( $p=0.0477$ ).

The mean value of the total Autism Parental Knowledge Assessment Questionnaire (APKAQ) score was significantly higher for group I after MPD educating sessions ( $10.33\pm 1.22$ ) when compared with that before those sessions ( $8.79\pm 1.06$ ); paired "t" test = -3.01,  $p=0.0076$  while the comparison of the mean value of total APKAQ score of group I before educating sessions and Group II ( $9.22\pm 1.66$ ) was statistically insignificant (student "t" test = 0.79,  $p=0.4337$ ), **Fig (2)**. On the other hand, the interpretation of the answers of the different statements of the implemented APKAQ revealed that both groups satisfactorily defined

autism (90% before and after educating sessions (ES) in group I and 86.67% in group II;  $p>0.05$ ) but wrongly recognized its etiology in 70% of group I before ES compared to 40% of the same group after ES and 40% of those not enrolled in MPD events ( $p<0.0001$  for both). Clinical presentation was well recognized by 80% of caregivers of group I before ES and group II compared to 100% of group I after ES ( $p<0.0001$  for both). The available psychometric assessment tools for autism were known to 80% of group I both before and after ES and 66.67% of group II while 90% of caregivers in group I both before and after ES correctly identified the available therapeutic modalities for autism compared to 93.33% of group II ( $p>0.05$  for all). Lastly, prognosis was significantly more identified by 80% of group I before ES and 90% of them after ES compared to 53.33% of group II ( $p<0.05$ ); **Table (4)**.

Regarding the studied caregivers' views about their satisfaction concerning the services provided by our clinic, it was accepted for 40% of group I before MPD ES, 10% of them after MPD ED, and 6.67% of group II while it was good for 40% and 30% of group I before and after MPD ES respectively and 66.67% of group II. On the other hand, 20% and 60% of group I before and after MPD ES respectively described those services as excellent with 26.67% of group II. Unawareness of the society about the suffering of autistic children and their caregivers was upsetting to 80% of group I both before and after MPD ES and 60% of group II ( $p<0.05$ ) while the society negative concepts about autism were disturbing to 20% of group I both before and after MPD ES and 40% of group II. Highly significant improvement of believing that their autistic children will be better in the future was reported for group I after MPD ES (70%) compared to 40% before those sessions and 26.67% of those who did not attend MPD events;  $p<0.0001$  while 50% and 30% of group I before and after MPD ES respectively and 73.33% of group II were afraid to think about it. This decline in perception of fear of thinking about their children's future was statistically highly significant ( $p=0.0039$ ). Caregivers wanted to know everything about autism in 60% of group I before MPD ES compared to none of them after these sessions ( $p<0.0001$ ) and 20% of group II. How they can help their children was the main concern of 60% of group I after MPD ES compared to 10% of them before those sessions and 46.67% of group II. The idea of MPD was considered as an excellent one by 90% of group I after MPD ES compared to 60% of them before these sessions and 53.33% of group II;  $p<0.0001$  while it was a good idea in 10% of group I after MPD ES compared to 40% of them before these sessions and 46.67% of group II; **Table (5)**.

Availability of all services for autistic children in the same Clinic was a demand of all enrolled caregivers of group I (100% before and after MPD ES) and 86.67% of group II. On the other hand, continuous access to autistic special diet items was needed by 70% of group I after MPD ES compared to 20% of them before those sessions and 40% of group II ( $p<0.01$  comparing group I after MPD ES and group II) while availability of drugs controlling autistic children' challenging behavior was a demand of 20% group I

after MPD ES compared to 70% of them before those sessions and 33.33% of group II; **Table (6)**.

Acceptance without stigmatization was a strong need of 60% of group I before MPD ES compared to 30% of them after those sessions and 53.33% of group II while more public awareness about autism was a concern of 30% of group I before MPD ES compared to 60% of them after those sessions and 33.33% of group II. Resources for more services for autistic children were demanded by 10% of group I before MPD ES compared to 40% of them after those sessions and 13.33% of group II; **Table (6)**.

Drawing the attention of the society to the problems facing the autistic children and their caregivers represented the hope from future scientific research on autism in 100% of group I before MPD ES compared to 70% of them after those sessions and 46.67% of group II while reaching a definitive curative treatment of autism was needed by 90% of group I before MPD ES compared to 50% of them after those sessions and 80% of

group II. Lastly, reaching the exact etiology of autism represented a need for 10% of group I before MPD ES compared to 50% of them after those sessions and 20% of group II; **Table (6)**.

*"Our children are not odd, they are just different"*

*"We do not need to change our children to be just copies of others not suffering from autism but we just need them to be understood, accepted, and treated fairly"*

*"I have just started to see the hope at the end of the dark tunnel"*.

These were testimonies of some mothers who participated in our Clinic first MPD and these sincere passionate words were really our prize at the end of the day. They have given us the power and energy to continue to serve, help, and support these special children and their devoted caregivers.

**Table 1:** Statistical comparison between enrolled groups as regards the mean values of the studied quantitative variables

Group	Group I Autistic caregivers enrolled in MPD ES (No = 10)		Group II Autistic caregivers not enrolled in MPD ES (No =15)		"t" test	IVS II P
	Mean	±SD	Mean	±SD		
Autistic children mean age	8.34	1.48	7.98	2.55	0.45	0.66
Total CARS score	33.54	2.27	34.11	1.36	-0.71	0.49
Total VABS score	55.20	16.50	54.98	15.92	0.03	0.97
Maternal mean age	33.80	4.56	35.11	3.28	-0.78	0.45
Paternal mean age	38.80	7.34	40.43	5.92	-0.59	0.57
Mean family income/month	1000	400	800	200	1.46	0.17
Mean socioeconomic standard score	31.51	8.50	22.80	7.78	2.60	0.018*

t = unpaired t-test was used for statistical comparison, MPD ES= Meet the Professionals' Day Educating Sessions  
 CARS = Childhood Autism Rating Scale, VABS = Vineland Adaptive Behavior Scales  
 P>0.05 = statistically insignificant, p<0.05\* = statistically significant

**Table 2:** Frequency distribution of autistic children categorical data:

Studied categorical variables	Subcategories	Group I Autistic caregivers enrolled in MPD ES (No = 10)		Group II Autistic caregivers not enrolled in MPD ES (No =15)	
		No	%	No	%
		Autistic children sex distribution	Males	10	100
Autistic children savant abilities	Yes	5	50	6	40.00
	No	5	50	9	60.00
Autistic severity level according to CARS	Mild-Moderate	6	60	10	66.67
	Severe	4	40	5	33.33
Intellectual disability grading according to VABS	Mild	3	30	5	33.33
	Moderate	5	50	7	46.67
	Severe	2	20	3	20
Socioeconomic standard	Very low	2	20	6	40.00
	Low	3	30	4	26.67
	Submoderate	3	30	3	20.00
	Moderate	2	20	2	13.33

X<sup>2</sup>= Chi-square-test was used for statistical comparison, only when the numbers of studied subcategories permitted statistical comparison.

MPD ES= Meet the Professionals' Day Educating Sessions  
 P>0.05 = statistically insignificant in all possible statistical comparisons

**Table 3:** Frequency distribution of studied autistic caregivers categorical data:

Studied categorical variables	Subcategories	Group I Autistic caregivers enrolled in MPD ES (No = 10)		Group II Autistic caregivers not enrolled in MPD ES (No =15)	
		No	%	No	%
Residency	Urban	9	90	13	86.67
	Rural	1	10	2	13.33
Level of maternal education	Tertiary	5	50	7	46.67
	Secondary	5	50	8	53.33
Level of paternal education	Tertiary	2	20	2	13.33
	Secondary	5	50	8	53.33
	Primary/illiterate	3	30	5	33.33
Current maternal job	House wife*	9	90	12	80.00
	Otherwise	1	10	3	20.00
Current paternal job	Government employee	2	20	4	26.67
	Private sector employee	6	60	10	66.67
	Self employed	2	20	1	6.67
Family income /month	≤600 Egyptian pound	5	50	8	53.33
	>600-1200	3	30	6	40.00
	>1200-2000	2	20	1	6.67
Number of family members living together	3-5	9	90	13	86.67
	>5	1	10	2	13.33
Number of rooms/house	2	7	70	11	73.33
	3	3	30	4	26.67

$X^2$ = Chi-square-test was used for statistical comparison, only when the numbers of studied subcategories permitted statistical comparison.  $P > 0.05$  = statistically insignificant (non shaded rows),  $p < 0.05^*$  = statistically significant

**Table 4:** Frequency distribution of the interpreted categories of caregivers' answers to the provided Autism Parental Knowledge Assessment Questionnaire (APKAQ):

Question domain	Answer evaluation	Group I <sub>a</sub> Autistic caregivers before MPD ES (No = 10)		Group I <sub>b</sub> Autistic caregivers after MPD ES (No =10)		Group II Autistic caregivers not enrolled in MPD ES (No =15)	
		No	%	No	%	No	%
Definition of autism (What is autism?)	Correct	9	90	9	90	13	86.67
	Wrong	1	10	1	10	2	13.33
Etiology	Correct	1	10	3	30	2	13.33
	Not all correct	2	20	3	30	7	46.67
	Wrong**	7	70	4	40	6	40.00
Clinical presentation	Correct**	8	80	10	100	12	80.00
	Not all correct	2	20	0	0	3	20.00
Investigations	Correct	8	80	8	80	10	66.67
	Not all correct	2	20	2	20	5	33.33
Treatment	Correct	9	90	9	90	14	93.33
	Not all correct	1	10	1	10	1	6.67
Prognosis	Correct*	8	80	9	90	8	53.33
	Not all correct	2	20	1	10	1	6.67
	Wrong	0	0	0	0	6	40.00

$X^2$ = Chi-square-test was used for statistical comparison, only when the numbers of studied subcategories permitted statistical comparison.  $P > 0.05$  = statistically insignificant (non shaded rows),  $p < 0.05^*$  = statistically significant,  $p < 0.0001^{**}$  = statistically highly significant

**Table 5:** Frequency distribution of the different answers to provided Caregivers' Views open ended questionnaire:

Question domain	Answer category	Group I <sub>a</sub> Autistic caregivers before MPD ES (No = 10)		Group I <sub>b</sub> Autistic caregivers after MPD ES (No =10)		Group II Autistic caregivers not enrolled in MPD ES (No =15)	
		No	%	No	%	No	%
		Satisfaction level concerning the clinic provided services	Accepted	4	40	1	10
	Good	4	40	3	30	10	66.67
	Excellent**	2	20	6	60	4	26.67
How do you see the society view about autistic children?	No awareness*	8	80	8	80	9	60.00
	Very negative	2	20	2	20	6	40.00
How do you see your child condition after 10 years from now?	Better**	4	40	7	70	4	26.67
	The same	1	10	0	0	0	0
	Afraid to think**	5	50	3	30	11	73.33
What do you want to know about autism?	Everything**	6	60	0	0	3	20.00
	Available drugs and their role	1	10	4	40	2	13.33
	How can I help my child?	1	10	6	60	7	46.67
	Prognosis	1	10	0	0	2	13.33
	Recurrence risk possibilities	1	10	0	0	1	6.67
What is your opinion about Meeting the Professionals day?	Excellent**	6	60	9	90	8	53.33
	Good	4	40	1	10	7	46.67

X<sup>2</sup>= Chi-square-test was used for statistical comparison, only when the numbers of studied subcategories permitted statistical comparison. P >0.05 = statistically insignificant (non shaded rows), p<0.05\* = statistically significant, P<0.01\*\* = statistically highly significant

**Table 6:** Frequency distribution of the different answers to provided Caregivers' Needs open ended questionnaire:

Question domain	Answer category	Group I <sub>a</sub> Autistic caregivers before MPD ES (No = 10)		Group I <sub>b</sub> Autistic caregivers after MPD ES (No =10)		Group II Autistic caregivers not enrolled in MPD ES (No =15)	
		No	%	No	%	No	%
		From the clinic	Access to autistic special diet**	2	20	7	70
	Access to available drugs	7	70	2	20	5	33.33
	More personnel and care	1	10	1	10	4	26.67
	Availability of all services in the same place	10	100	10	100	13	86.67
From the society	More awareness**	3	30	6	60	5	33.33
	Resources for more services	1	10	4	40	2	13.33
	Acceptance without stigmatizing us or our children**	6	60	3	30	8	53.33
From the future scientific research	Definition of the exact cause	1	10	5	50	3	20.00
	Definitive curative treatment**	9	90	5	50	12	80.00
	Drawing the society attention to our problems**	10	100	7	70	7	46.67

X<sup>2</sup>= Chi-square-test was used for statistical comparison, only when the numbers of studied subcategories permitted statistical comparison. P >0.05 = statistically insignificant (non shaded rows), P<0.01\*\* = statistically highly significant

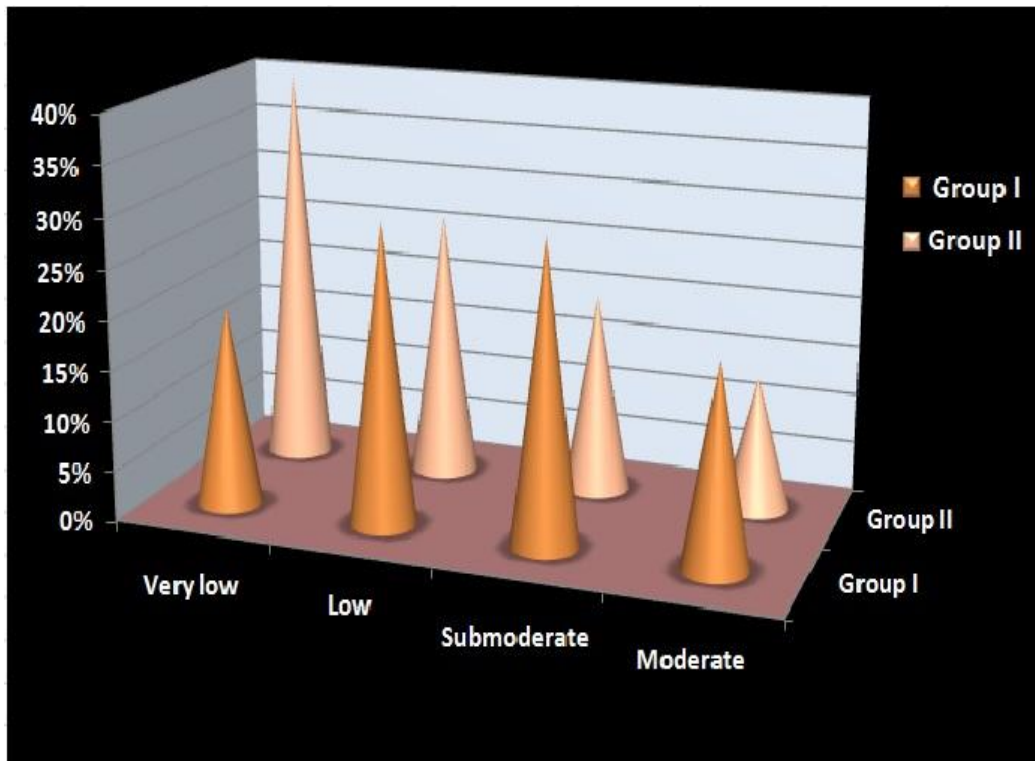


Figure 1: The frequency distribution of different socioeconomic standards of studied groups

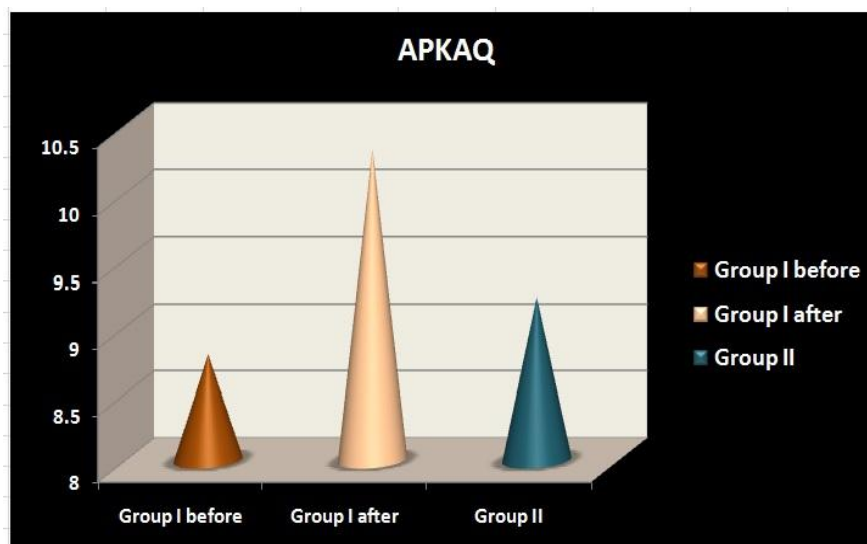


Figure 2: Diagrammatic representation of the mean total Autism Parental Knowledge Assessment Questionnaire (APKAQ) of studied autistic caregivers' groups

## 6. Discussion

Because it is important that pediatricians be able to recognize the signs and symptoms of autism spectrum disorders and have a strategy for assessing them systematically; our Child Psychiatry Clinic, Children's Hospital, Ain Shams University has been established. Pediatricians also must be aware of local resources that can assist in making a definitive diagnosis of and in managing, autism spectrum disorders (ASD) and be familiar with developmental, educational, and community resources as well as medical subspecialty clinics [4]. Pediatrician's awareness and knowledge about ASD will enable them to offer these children and their caregivers a better service and save a lot of their time and suffering that could be wasted

before starting their first steps in the long journey for a better future.

"Autism is a child with important sensory problems, a child who cannot tolerate sounds, noises, lights, a child who has a much falsified tactile sense. So, it happens that he doesn't want to get touched or does not want to touch things, it happens that he cannot tolerate certain clothes because labels or sewing are perceived like pins on his skin. He is a child who cries with no apparent reason, a child who screams and escape from his mother at a shopping center, a child who gets undressed innumerable times during the day with difficulty to accept changes to his rigid routine and inability to play with other children". With these very touchy sincere expressive words, Gallone (2015) [6] in her editorial on autism family care has described the autistic child. These

words can highlight in a very simple way the autistic caregivers suffering in watching their children growing denied from their childhood and might be seen as odd by others and forced with their families to live an isolated life.

Accordingly, management of ASD should focus not only on the child but also on his family. Although parents once were viewed erroneously as the cause of a child's ASD, it is now recognized that parents play a key role in effective treatment [18]. Having a child with an ASD has been proven to exert a substantial pressure with dramatic effects on a family. Parents and siblings of children with ASDs experience more stress and depression than those of children who are typically developing or even those who have other disabilities [19, 20, 21, 22, 23, 24]

In life as well as in Medicine, it is always easier to talk about the problems of others instead of talking with them, or letting them talk about their problems. Many of us think that so long as they are the qualified professionals, they have both the ability and the right to speak on the behalf of others, especially their patients and their caregivers but unfortunately, this is totally untrue. Because of the foregoing facts about life, medicine practice, and autism, our Clinic first MPD was conducted to take a closer look at caregivers of autistic children under regular follow up at our clinic and to evaluate their knowledge, Concerns, and needs from the clinic, community, and the future autism scientific research.

The mean value of the total Autism Parental Knowledge Assessment Questionnaire (APKAQ) score was significantly higher for group I after MPD educating sessions when compared with that before those sessions. On the other hand, the interpretation of the answers of the different statements of the implemented APKAQ revealed beyond doubt that the educating sessions of our first MPD improved the caregivers knowledge about autism etiology, symptomatology, and prognosis. To show the importance of the parental knowledge about mental disorders, it is worthy to mention that in **2011, Chowdhury et al.**, [25] reported that the lack of knowledge about mental health was found to be the major cause of delayed referral to the psychiatric outreach services in Bangladesh (50%).

Thankfully, the level of satisfaction concerning our Clinic services for autistic children improved after the educating events of MPD for caregivers of group I as it was excellent for 60% of them after MPD ES compared to 20% before those sessions. Unawareness of the society about the suffering of autistic children and their caregivers was upsetting to 80% of group I both before and after MPD ES and 60% of group II while the society negative concepts about autism were disturbing to 20% of group I both before and after MPD ES and 40% of group II. **Youshii et al.**, (2013) [26] have found that integration of mental health awareness and related educational programs in the curricula of high school and vocational schools is essential to overcome stigma about mental disorders which is a global issue running from the beginning of every civilization till today.

It was very rewarding to report a highly significant improvement of group I caregivers beliefs that their autistic children will be better in the future after MPD ES compared to

before those sessions while 50% of group I before ES compared to 30% of them after those sessions were afraid to think about the prognosis of their children. This important decline in perception of fear of thinking about their children's future was statistically highly significant.

Caregivers wanted to know everything about autism in 60% of group I before MPD ES compared to none of them after those sessions. Also, there was a significant caregivers' turn towards a positive attitude facing their problems as "how they can help their children" was the main concern of 60% of group I after MPD ES compared to 10% of them before those sessions.

Lastly but by no means least, the perception of the idea of MPD was significantly improved after its ES as it was considered as an excellent idea by 90% of group I after MPD ES compared to 60% of them before those sessions while it was only a good idea in 10% of group I after MPD ES compared to 40% of them before these sessions. The results of our preliminary study proved that pediatricians are in a position to provide important medical, psychological, and educational care, both on the short run and on the long run, for autistic children and their families and to support and guide them to all possible interventions for autism.

## 7. Conclusion

MPD was very useful and fruitful in breaking the ice between the professionals and autistic caregivers paving the way for them to know each other in a comfortable setting outside the clinic and its restricted time and routine limitations. On the other hand, the preliminary results of our pilot study showed how important it was to assess the knowledge of autistic caregivers about a disorder that they were obliged to live with, every day of their lives. Such assessment will help us as professionals to arrange for educational programs that meet their needs, dealing with their concerns, and empower them to help their children in a more efficient way.

## 8. Future Scope

Future studies will be implemented on larger representative samples of Egyptian autistic caregivers to settle the validity and reliability of the used Autism Parental Knowledge Assessment Questionnaire (APKAQ). Repetition of MPD on regular basis is highly recommended with the same group of autistic caregivers and other groups that did not have the opportunity to join the first one. Such days will help in answering all the questions they have in their minds, let them express their fears, and face their concerns about the future of their children. Establishment of different national autistic parental support groups seems very worthy to let them share their feelings, fears, concerns, and experiences in taking care of their children with each other and with members of the professional teams and society. On the other hand, creating public awareness about the problems and difficulties the autistic children and their caregivers are obliged to live with, will make it easier for them to deal with such problems and difficulties and successfully overcome them that will certainly improve the quality of their lives. Meanwhile, raising the demands of autistic caregivers to political decision makers is crucial in enabling



them to attain their rights in enough resources for better facilities and services for autistics.

## 9. Acknowledgement

The authors are grateful for the enrolled autistic caregivers as without their participation, this fruitful day would not have been accomplished

## 10. Conflict of Interest

The authors declare no conflict of interest, no financial, and or personal relationships with other people or organizations that could inappropriately influence our study or theirs

## References

- [1] Kidd PM (2002) Autism, an extreme challenge to integrative medicine. Part 1: The knowledge base. *Altern Med Rev*; 7 (4): 292-316.
- [2] McKusick VA (1998): Mendelian inheritance in man: Catalog of human genes and genetic disorder. Johns Hopkins University Press, 12<sup>th</sup> ed.
- [3] Eigsti IM, Shapiro T (2003): A systems neuroscience approach to autism: biological, cognitive, and clinical perspective mental retard. *Dev Disabil Res Rev*: 9: 105-15.
- [4] Johnson C P, Myers S M, and the Council on Children With Disabilities (2007): Identification and Evaluation of Children With Autism Spectrum Disorders. *Pediatrics* 120 (5): 1183-1215
- [5] Myers S M, Johnson C P, Johnson C P, Myers S M, and the Council on Children With Disabilities (2007): (2007): Management of Children With Autism Spectrum Disorders. *Pediatrics* 120 (5): 1162-1182.
- [6] Gallone G (2015): Autism family care: The experience of an Italian Association. *Autism Open Access* 5:1
- [7] Declaration of Helsinki (1998) The World Medical Association (WMA). The WMA declaration of Helsinki 1960 with recommendations on biomedical research on human subjects (modified in 1975, 1980 and 1989). *Chirurgia (Bucur)*; 93 (2): 138- 140.
- [8] Hassoun T (2004): A rapid guide to DSM IV TR, Arabic version, Syria  
تيسير سمون (2004): مرجع سريع الى المصير التشخيصية من الدليل التشخيصي والاصري المعدل الرابع. جراض القولية - من جمع عاالطن الى سى الاميكية
- [9] DSM IV TR (2000) American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text GH Revision. Washington, DC, American Psychiatric Association
- [10] Galal B (2013): The Childhood Autism Rating Scale (CARS), Arabic version. Trainee Guide, Help Centre, kwait. (مقياس تقييم الذاتى ٢٠١٣) : مقياس تقييم الذاتى  
مقياس تقييم الذاتى مقياس تقييم الذاتى
- [11] Schopler E, Reichler RJ and Renner BR (1988): The Childhood Autism Rating Scale (CARS). Los Angeles: Western Psychological Services.
- [12] Pilowsky T, Yirmiya N, Shulman C and Dover R (1998): The autism diagnostic interview-revised and the childhood autism rating scale: differences between diagnostic systems and comparison between genders. *J Autism Dev Disord*; 28 (2): 143-51
- [13] Eletibi BN (2004): Vineland Adaptive Behavior Scales: Arabic version. *J Academy of Special Edu*; 5 (2): 122-134
- [14] Raggio DJ, Massingale TW (1990): Comparability of the Vineland Social Maturity Scale and the Vineland Adaptive Behavior Scale Survey form with infants evaluated for developmental delay. *Perceptual and Motor Skills*; 71 (2): 415-418
- [15] Dulcan MK (2010): *Dulcan's Textbook of Child and Adolescent Psychiatry-Arlington, VA, American Psychiatric Publishing, INC*
- [16] Elshakhs A (2006): Socioeconomic Standard Scale, Arabic validated version, 3rd edition, Elanglo Elmasrya.
- [17] Statistical package for social science (2007): SPSS, program version 16. SPSS for windows, version 16, Chicago, released 2007, SPSS Inc.
- [18] National Research Council, Committee on Educational Interventions for Children with Autism (2001) *Educating Children With Autism*. Lord C, McGee JP, eds. Washington, DC: National Academies Press.
- [19] Hyman SL, Levy SE (2005) Introduction: novel therapies in developmental disabilities—hope, reason, and evidence. *Ment Retard Dev Disabil Res Rev* 11:107–109 239.
- [20] Bågenholm A, Gillberg C (1991) Psychosocial effects on siblings of children with autism and mental retardation: a population- based study. *J Ment Defic Res* 35:291–307 240.
- [21] Bouma R, Schweitzer R (1990) The impact of chronic childhood illness on family stress: a comparison between autism and cystic fibrosis. *J Clin Psychol* 46:722–730.
- [22] Dumas JE, Wolf LC, Fisman SN, et al (1991) Parenting stress, child behavior problems, and dysphoria in parents of children with autism, Down syndrome, behavior disorders, and normal development. *Exceptionality* 2:97–110 242.
- [23] Gold N (1993) Depression and social adjustment in siblings of boys with autism. *J Autism Dev Disord* 23:147–163 243.
- [24] Gray DE (2002) Ten years on: a longitudinal study of families of children with autism. *J Intellect Dev Disabil* 27:215–222 244.
- [25] Chowdhury NN, Yaseen F, Chowdhury NS, Hakim N (2011) Social stigma, care seeking, and socio-demographic profile of mentally ill patients in BSMMU. *British Journal of Psychiatry* 25 (1): 35-46.
- [26] Yoshii H, Watanabe Y, Mazumder AH, Kitamura H, Akazawa K (2013) Stigma towards schizophrenia among parents of high school students. *Global Journal of Health Science* 5 (6): 46-53.