### Knowledge and attitude of Mothers and Health Care Professional related to Autistic Children

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#### Abstract

The increase in reported Autism spectrum disorder (ASD) prevalence may reflect greater increased awareness of ASD among professionals and the mothers'. Therefore, it is important that there is awareness and accurate understanding of ASD which can help individuals with ASD to be identified and receive appropriate supports as early as possible. The aim of the study was to assess Knowledge and attitude of mothers and Health Care Professional toward Autistic Children. A descriptive exploratory research design was utilized. This study was conducted at the Abassia mental health hospital, outpatient clinic of autism and psychiatric clinic at pediatric out- patient clinic pediatric hospital of Cairo University. A convenient sample consists of (55) 40 mothers' and 15 health care professionals were working in outpatient clinics in the previous settings. Three tools were used to collect the data for the present study. personal data sheet for mothers and their autistic children, and health care professional, Mothers knowledge and attitude toward autistic child questionnaire and Health professional' knowledge and attitude toward autistic child questionnaire. Study's results revealed that most of mothers' had positive attitude toward their autistic children regarding their role in care and effectiveness of treatment with no significant difference between mothers' and Health care professional in total attitude scores. On the other hand there was statistical significant difference between mothers' and health professionals in total knowledge scores. The study concluded that, the issue of knowledge and attitude toward child with autism and perceptions regarding their abilities to be included in the community are complex. The study recommended that need for further researches in order to find out the most effective way to induce positive changes in this area, and how treatment decisions are made particularly with regard to the importance of mothers' attitude.

Key words: Health care professional, autism, attitude, knowledge

#### Introduction:

Autism spectrum disorder (ASD) is a neurodevelopment disorder in which individuals show persistent deficits in social communion and interaction (such as difficulties with sustaining conversations and developing friendships) and restricted, repetitive patterns of behavior or interests (such as stereotyped movements, insistence on routines, and narrow preoccupations)<sup>[1].</sup> <sup>•</sup> Epidemiological studies have reported an increasing prevalence of ASD. In the United States in 2008, the Autism and Developmental Disabilities Monitoring Network estimated that 1 in 88 children had an ASD, with prevalence rates being five times greater in boys than girls <sup>[2]</sup>. The increase in reported ASD prevalence may reflect greater inclusion of individuals with milder ASD as well as increased awareness of ASD among professionals and mothers'. Therefore awareness and understanding can help children with ASD to be identified and receive appropriate supports as early as possible. Despite increasing awareness of ASD, recent studies of both professionals and mothers' find continuing misconceptions or inadequate training regarding the causes, symptoms, and treatments of ASD<sup>[3].</sup>

Children with ASD depend on their families for daily care and support that are essential for the successful implementation of any therapeutic intervention. Therefore, it has been acknowledged that the needs of all the family members should be taken into consideration when designing an intervention. The author stressed the importance of active parental participation in the therapeutic process, which results from the proper cooperation with mental health professional. However, many mothers' claim that their participation in their children's therapy is minimal and restrained six-monthly to briefing meetings, while they are not informed that they could be more actively involved in the treatment process. Mothers' must be treated during partners the planning, as implementation, and evaluation of the therapeutic approach and not just as observers or clients<sup>[4]</sup>

Care givers\ mothers are the decision makers in matters of health care for children with special health care needs; thus, they play an important role in achieving the best oral health outcomes for their children. Since mothers' are responsible for almost all health issues related to their children, their role in modeling their children toward practicing preventive oral health throughout life is crucial. Thus, mothers' should be educated about importance of oral health care that in turn also influences general health of their children. There is a lack of studies which have elicited parental knowledge, attitudes, and practice (KAP) behaviors towards children with ASD<sup>[5]</sup>

According to, the mothers' first reaction following a diagnosis is to look for information and practical advice. This response, be it immediate or gradual, brief thought to facilitate or intense, is adjustment and adaptive coping. Searching for information may also be an alternative way of handling the diagnosis as opposed to seeking emotional support. It may help mothers' to respond more effectively to a range of life-changing events that may invoke stress. It may also give mothers' a greater sense of empowerment in managing daily routines and activities as well as increase family adaptation<sup>[6].</sup>

Researchers stated that mothers' of children diagnosed with ASD often have concerns about their children's development long before their children receive a formal diagnosis. Their concerns often begin during the first two years of their children's life and include concerns about: (a) language development (e.g., little babbling by 12 months of age), (b) atypical social development (e.g., reduced shared attention, weak eye to-eye gaze), and (c) challenging behaviors (e.g., tantrums, crying, and sleep issues) <sup>[7].</sup> Other researchers added that manv mothers' first seek answers for their

concerns from their family physician. They are often told there is "no need to worry" or that their children "will grow out of it". Frequently, mothers' experience long wait lists because of referrals to a variety of professionals before they finally obtain a diagnosis of ASD for their children. Consequently, many children are not diagnosed with ASD until 4- 6 years of age, missing the benefits of early intensive intervention <sup>[8].</sup>

American Academy of Pediatrics (AAP)<sup>[9]</sup> emphasized that children with ASD have unique abilities and needs which require special considerations in designing, implementing and evaluating their educational programs. Educators need a better understanding of the educational approaches and program structures that are effective for these children. In recent years, research in neurobiological, behaviorist, developmental and approaches has emphasized the critical period of major brain development in the first five years of life when development has more plasticity and stimulation plays an important role. This has led to an interest in the concept of "Early Intervention" throughout the world. [10]

Children with ASD may experience high levels of stigmatization in society. Stigma may affect not only autistic individuals but also the family as well. Such families often find that public reaction to them is stereotypical and negative.<sup>[11]</sup>

Child's disability tended to produce feelings of shame and guilt among Arab societies. Parental perceptions about the causes of disability have a tremendous impact on mothers' behaviors in terms of seeking help or intervention for their children or the kind of help they look for, and their support of the treatment process, disagreements may exist between the mothers' attitude about physical, supernatural, and metaphysical causes of disability, and the professionals' beliefs <sup>[12]</sup>. This conflict may lead the mothers' to seek some alternative cures like sociocultural, folk, or religious remedies. Studies also reveal that even mothers' from the same cultural backgrounds may hold different beliefs, based on their level of acculturation, socioeconomic status, and education. [11,12]

In addition, Mothers' of young children with disabilities had to face major challenges in seeking help and supports from professionals, because society viewed children with disabilities as unworthy people that made mothers' feel devalued, services available to children with disabilities during tat period were short in supply and low in quality <sup>[13]</sup>

Health care professionals need to understand parental attitude about autism and use that understanding to foster a mutually trusting, and collaborative approach to the child's medical care. The attitude and the assumptions that health care professional hold regarding parental contribution to the appearance and maintenance of their children's problematic behaviors and disorders greatly affect their choice of offered therapies and the intervention strategies that they use when interacting with the specific families.<sup>[14]</sup>

Caring for children with autism requires the services of health care professional as pediatricians, psychiatrists, nurses, clinical psychologist and social worker. Nurses are usually members of multidisciplinary team; they play the most significant role in autism recognition and diagnosis, this places nurses at a critical juncture because they must be increasingly knowledgeable, understanding and supportive of the mothers' and children afflicted with this condition. The nurses' level of understanding of autism can have a great impact on the prognosis of autism. <sup>[15,16]</sup>

Mothers' of children with autism have the right to choose the appropriate services and interventions for their children. Health care professional recognize that mothers' possess specialized knowledge that they lack. Mothers' use their knowledge to decide what they want and what they need for their children. The role of Health care professional is guiding mothers' to make more effective and appropriate decisions. Also it is necessary that, mothers' and Health care professional play an active role in promoting positive attitude toward autistic children.<sup>[17]</sup>

Therefore, the aim of the current study is to investigate mothers' and health care professionals' knowledge and attitude toward autistic children.

#### Significant of the study:

The Centers for Disease Control and Prevention (CDC) (2014) estimates that 1 in 68 children (or 14.7 per 1,000 eightyear-olds) in multiple communities in the United States has been identified with ASD. This new estimate is roughly 30 percent higher than previous estimates reported by CDC (2012) of 1 in 88 children (11.3 per 1,000 eight year olds) being identified with an autism spectrum disorder <sup>[18]</sup>

In Egypt, <sup>[19]</sup> reported that in the society's early years, nearly 80 percent of children with autism had been previously incorrectly diagnosed with intellectual disabilities or cerebral palsy, which is not even similar. The biggest pediatricians of Egypt tend to misdiagnose and tell mothers' to leave their children in an institute and forget about them. Although there is no official data on the number of Egyptian children with autism, the international rate of approximately 1 in 68 children to come up with an estimate of 1 million. If diagnosed early enough, children with autism may have a better chance of "mainstreaming" going to regular schools and adapting to society. Age 18 months is the ideal to begin working with these kids.

In Egypt, There are lots of gaps in Egyptian understanding of autism. The public seems to have lack good information or experience with children with autism. A lack of knowledge can lead to the negative attitudes towards autistic individuals and families. Also, lack of knowledge about autism is major barrier to improve the health and wellbeing of children with autism <sup>[12 &19]</sup>. Thus, this study sought to assess

The results of the current research will be beneficial in nursing as one of the health care professional team in education, practice and care to develop and apply programs for autistic children and their mothers'.

#### Aim of the Study:

The aim of the current study is to assess mothers and Health care professional 'knowledge and attitude toward autistic children.

#### **Research questions:**

-What are mothers and Health care professional' knowledge and attitude related autistic children?

- What is the difference between mothers and Health care professional in knowledge and attitude regarding autistic children?

#### **Subjects and Method**

#### **Research design:**

A descriptive exploratory research design was utilized to investigate knowledge and attitude of mothers' and health care professional toward Autistic Children

#### Setting:

The present study was conducted at Abassia mental health hospital, outpatient clinic of autism and psychiatric clinic in the pediatric out- patient clinic pediatric hospital at Cairo University.

#### Subjects

A convenient sample consists of (55) mothers and health professional. 40 mothers and 15 health care's professional were working at outpatient clinics in the above previous mention settings. All participants were informed that the study hasn't any risk for them. After have been exposed to the rules of ethics, the participants were briefed on the objective of the study and encouraged to actively participate.

#### Data collection tools:

Three tools were used for data collection was developed by the researchers after extensive reviewing of related literature using structured interview scheduled included:

**1-Personal data sheet**: It included two parts.

**Part one**: It included data about the Health professional' personal data (3 questions): gender, job and years of clinical experience.

**Part two**: mothers data sheet include (6 questions) : mothers' age, level of education, residence, child age, gender and child 's rank.

# 2- Mothers' Knowledge and Attitude toward Autistic Child Questionnaire:

It is composed of 37 items (15 items to mothers' assess knowledge about Behaviors Characteristics to diagnose autism as language delays, Autism is a neurological disorder that affects the functioning of the brain , Social interaction difficulties and 22 statements to assess mothers' attitude about ASD as my child's autism will last for a short time, autism is a serious disorder. Answers were rated on a 5-point Likert scale ranging from 1 (Strongly Disagree) to five (Strongly Agree). It takes 45-60 minutes to be completed. Total score ranged from 37 to 185.

### 3- Health professional' knowledge and attitude related autistic child questionnaire:

It is composed of 37 items categorized into domains First domain two behaviours/characteristics diagnose to autism included 15 items related to diagnostic criteria of autism. Second one refers to professionals' attitude about autism. This domain included 22 items. Answers were rated on a 5-point Likert scale ranging from 1 (Strongly Disagree) to five (Strongly Agree). It takes 45-60 minutes to be completed. Total score ranged from 37 to 185.

#### Validity and reliability

The content validity of this questionnaire was checked by five experts in the field of mental health, pediatric nursing and statistics. Necessary modifications were done. The reliability of the scale was measured by alpha coefficient and it was equal to 0.80.

#### **Pilot Study**

A Pilot study was carried out with 5 of mothers' and Health care professional to test the clarity, feasibility and the applicability of the study tools. Some items required specific clarifications and explanations from the researchers, those participants whom involved in the pilot study weren't included in the actual study.

#### **Ethical Consideration**

An official permission was obtained from directors of Abassia mental health hospital and pediatric hospital Cairo University also from the head of directors of outpatient clinic of autism and psychiatric outpatient clinic for pediatric to conduct the study. ethical rules of research The are guaranteed for each participant not to refrain. The subject was assured that the data are confidential and used only for research purposes. The researcher arranged time with health care professional and mothers' after finishing her child follow up. Researchers made full description of the study aim and procedures, written informed consents were introduced by Health care professional and mothers' of autistic child who agreed to participate. Reliability, confidentiality and privacy were assured. Researcher assured Health care professional and mothers of autistic children that no harm will expose if they express his / her opinion regarding knowledge and attitude toward autistic child.

#### **Procedure:**

Data collection was conducted over a four months period extending from February to May 2016. Researchers introduced themselves to Health care professional and mothers' of autistic child and explained the

aim of the study and the content of the tools to establish an initial rapport between Health care professional and mothers' of autistic child and researchers. All questions were answered and detailed explanation was given to obtain their acceptance and cooperation during conducted the interview session. Data collected through individual interview with Health care professional and mothers' of autistic child using different tools.Mothers' knowledge attitude toward autistic and child questionnaire and Health professional' knowledge and attitude toward autistic child questionnaire.

#### Statistical analysis

The data were analyzed using the Statistical Package for the Social Sciences statistical software (SPSS 20). Descriptive data were expressed as mean and standard deviation. Qualitative data were expressed as frequency and percentage. Chi-square was used to detect the relation between mothers' knowledge based on their selected personal variables. Comparison of means was performed using paired-sample t-test. Correlation among variables was done using Pearson correlation coefficient. Level of significance at p<0.05, 0.001 were used as the cut of value for statistical significance

#### Results

The results of the current study are divided into three parts: the first part refers to the results pertinent to personal characteristics of mothers', autistic children, and health care professional .As regards personal characteristics of mothers', table (1) reveals more than one third of mothers' level of education was bachelor degree (37.5%) and one quarter of them were illiterate, their mean age was 31.6± 8.9 years old. According to mothers' place of resident 75% of mothers' were from urban area. Regarding child gender, more than two thirds half of children were males (67.5%) while the rest of them were females (32.5%). Their mean age was  $5.2\pm$  3.1 years old. About more than half of the children (55%) were first child in their family.

Table (2) represents that more than half of Health care professional were females (60%) and 40% were males, 40% of them were psychologist, about more than one quarter of them were nurses (26.7%). According to years of experience in autistic child care, more than one third two fifths (40%) had more than 10 years and one third (33.3%) had from 1-5 years of experience. The second part of the study results evident that there was no significant differences between mothers' and health care professional regarding knowledge about autism in some items as child's Autism will last for a short time, it will last for a long time, and it does not have much effect on mothers' life (0.476,0.116,0.084,0.553,0,111

respectively), while there was highly statistically significant differences in other items as child's Autism is likely to be permanent rather than temporary, will last for the rest of his/her life, and it is a serious disorder. has major consequences on mothers' life, and it has serious financial consequences(0,001,0.084, 0,014, 0.000,0.045, 0.000 respectively) . As regard to autism symptoms most of mothers' and Health care professional (45%,40%, 55%, 40%, respectively) disagree about "The symptoms of autistic child change a great deal from day to day, and come and go in cycles, with no statistically significant differences (1.24, .430 respectively). (Table 3)

As clarified in table (4) there was significant difference in attitude of mothers' and health care professional regarding mothers' role in care of their autistic children as nothing mothers' do will affect child's autism , the course of child's autism depends on mothers', (.040, .021, respectively), and highly significant difference toward effect of treatment as most of mothers' strongly agree (42%) about treatment will be effective in curing child's autism, while more than of Health care professional (53.3%) strongly disagree (p= .000).

Regarding the impact of treatment in prevention of negative effects of child's autism, table (5) revealed that more than one third of mothers' (37.5%) strongly agree, on the other hand ,less than half of health professional strongly disagree about the same item, with high statistically significant difference (p=.000). More than half of mothers disagree about 'child's Autism doesn't make sense to his/ her mothers', while more than one third of health care professional (33.3%) agree about the same item, a highly statistically significant difference was found (p=.000). Concerning to mothers' understanding of autism, less than half of mothers' (42.5%), select somewhat, while two thirds of health care professional (66.7%) agree about the same item with high statistically significant difference (p=.000).

Regarding to mothers' reaction in relation to mothers' and health care professional attitude toward autistic child, table (6) revealed that more than one third of both think that autism is very unpredictable, also half of mothers' and more than one third of Health care professional think that child's autism gets mothers' upset and makes them feel anxious to somewhat, (35%, 33.3%, 50%,40% 52.5%,40%

with significant respectively), no .881. .093. difference (p=.372. respectively). Both of mothers' and health care professional disagree about child goes through cycles in which the symptoms of autism get better and worse, and autism makes mothers' feel angry, (30%, 53.3%, 45%, 46.7% respectively) with no significant difference(p=.276, .,595, respectively).

- As noted from results regarding relation between mothers ' education, residence and their total attitude and total knowledge scores, there was no significant difference relation among mothers' personal data as , residence, education and their mothers total attitude and total knowledge scores (.175, .269, .085, and .921 respectively ).
- It is evident from study results that there was significant difference relation between child's gender, rank in the family and mothers' total attitude scores (p= 0.034, 0.040 respectively), and no significant difference relation among child's , age, , and their mothers total attitude

and total knowledge scores (p=0.84 0.86, 0.732, 0.476, respectively).

Regarding relation between health care professionals' personal data and their total attitude and total knowledge scores, results revealed that there was no significant difference relation among health care professionals' gender, job differences, and years of experience and their total knowledge and attitude scores (.981, 804,.074, .440, .065 respectively).

The third part of results proved that there was high statistically significant difference in knowledge total mean scores between mothers' and health care professional (P .136 ) . The results highlighted also that, there was no statistically significant difference concerning attitude of mothers and health care professional toward autistic children (P 0.000). (table7)

Table (1):Percentage distribution of Mothers and their Autistic Children related to personal characteristic (n=40)

| Mothers' characteristic | No                    | %    |
|-------------------------|-----------------------|------|
| Age/ years              |                       |      |
| 21-30                   | 25                    | 62.5 |
| 31+                     | 15                    | 37.5 |
| Me                      | ean ±SD 31.6± 8.9     |      |
| Level of education      |                       |      |
| Illiterate              | 9                     | 22.5 |
| Elementary School       | 5                     | 12.5 |
| Secondary School        | 11                    | 27.5 |
| Bachelor Degree         | 15                    | 37.5 |
| Residence               |                       |      |
| Rural                   | 10                    | 25.0 |
| Urban                   | 30                    | 75.0 |
| Child's characteristics |                       |      |
| Age/ years              |                       |      |
| <6                      | 28                    | 70.0 |
| 6+                      | 12                    | 30.0 |
| N                       | <br>Iean± SD 5.2± 3.1 |      |
| Gender :                |                       |      |
| Male                    | 27                    | 67.5 |
| Female                  | 13                    | 32.5 |
| Birth order:            | -                     |      |
| First                   | 22                    | 55.0 |
| Second                  | 10                    | 25.0 |
| Third                   | 8                     | 20.0 |

 Table (2): Percentage distribution of the Health Care Professionals related to Personal Characteristics (n=15)

| No  | %  |
|-----|--|
| II  |  |
| 6   | 40   |
| 9   | 60   |
|     |  |
| 2   | 13.3   |
| 4   | 26.7   |
| 3   | 20   |
| 6   | 40   |
| I I |  |
| 2   | 13.3   |
| 5   | 33.3   |
| 2   | 13.3   |
| 6   | 40   |
|     | $ \begin{array}{c ccccccccccccccccccccccccccccccccccc$ |

| Table (3): Percentage distribution of Mothers and Health Care Professionals related to |
|--|
| Knowledge about Autism (n=55):   |

| Items          | Strongly                               | D'             | Sama and        |              | Strongly  | $X^2$    | р     |  |
|----------------|--|----------------|-----------------|--------------|-----------|----------|-------|--|
|                | Disagree                               | Disagree       | Somewhat        | Agree        | Agree     |          |       |  |
|                | No (%)                                 | No (%)         | No (%)          | No (%)       | No (%)    |          |       |  |
| Child's Autist | Child's Autism will last a short time. |                |                 |              |           |          |       |  |
| Mothers        | 3 (7.5%)                               | 4(10.0%)       | 11(27.5%)       | 10(25%)      | 12 (30%)  | 3.511    | .476  |  |
| НСР            | 0                                      | 0              | 4 (26.7%)       | 6(40%)       | 5(33.3%)  |          |       |  |
| Child's Autist | m is likely t                          | o be permane   | ent rather thar | n temporary. |           |          |       |  |
| Mothers        | 4 (10%)                                | 20 (50%)       | 5 (12.5%)       | 3 (7.5%)     | 8 (20%)   | 19.748   | .001* |  |
| НСР            | 0                                      | 0              | 1 (6.7%)        | 4(26.7%)     | 10(66.7%) |          |       |  |
| child's Autisn | n will last fo                         | or a long time | ;               |              |           |          |       |  |
| Mothers        | 1 (2.5%)                               | 8 (20%)        | 8 (20%)         | 12 (30%)     | 11(27.5%) | 7.400    | .116  |  |
| НСР            | 0                                      | 1 (6.7%)       | 2 (13.3%)       | 2(13.3%)     | 10(66.7%) |          |       |  |
| child's Autist | m will pass                            | quickly        |                 |              |           |          |       |  |
| Mothers        | 3 (7.5%)                               | 9 (22.5%)      | 5 (12.5%)       | 12 (30%)     | 11(27.5%) | 9.714    | .084  |  |
| НСР            | 0                                      | 1 (6.7%)       | 7 (46.7%)       | 5(33.3%)     | 2 (13.3%) |          |       |  |
| I expect child | has Autism                             | for the rest o | of his/her life |              |           | <u> </u> |       |  |
| Mothers        | 2 (5%)                                 | 12 (30%)       | 12 (30%)        | 5(12.5%)     | 9 (22.5%) | 12.546   | .014* |  |
| НСР            | 0                                      | 1 (6.7%)       | 2 (13.3%)       | 1 (6.7%)     | 11(73.3%) |          |       |  |
| Autism is a se | erious disord                          | ler            |                 |              |           | <u> </u> |       |  |
| Mothers        | 0                                      | 15(37.5%)      | 11(27.5%)       | 10 (25%)     | 4 (10%)   | 26.190   | .000* |  |
| НСР            | 1 (6.7%)                               | 0              | 0               | 4(26.7%)     | 10(66.7%) |          |       |  |
| child's Autisn | n has major                            | consequence    | s on mothers    | life         |           | <u> </u> |       |  |
| Mothers        | 3(7.5%)                                | 19(47.5%)      | 6 (15%)         | 3 (7.5%)     | 9 (22.5%) | 9.740    | .045* |  |

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| НСР  | 1 (6.7%)                                       | 3 (20%)         | 3 (20%)        | 6 (40%)       | 2 (13.3%) |        |       |
|--|--|-----------------|----------------|---------------|-----------|--------|-------|
| Child's Autism does not have much effect on mothers' life. |  |                 |                |               |           |        |       |
| Mothers  | 6(15%)   | 15(37.5%)       | 9(22.5%)       | 5(12.5%)      | 5(12.5%)  | 3.029  | .553  |
| НСР  | 2(13.3%)                                       | 3 (20%)         | 6 (40%)        | 1(6.7%)       | 3 (20%)   |        |       |
| Child's Autisi   | n strongly a                                   | iffects the wa  | y others see h | nim/her.      |           |        |       |
| Mothers  | 2(50%)   | 10 (25%)        | 14(35%)        | 8(20%)        | 6(15%)    | 7.524  | .111  |
| НСР  | 0  | 2 (13.3%)       | 2(13.3)        | 8(53.3%)      | 3(20%)    |        |       |
| child's Autisn   | n has seriou                                   | s financial co  | nsequences     |               |           |        |       |
| Mothers  | 2(5%)  | 9(22.5%)        | 15(37.5%)      | 8(20%)        | 6(15%)    | 21.455 | .000* |
| НСР  | 0  | 0               | 2 (13.3%)      | 1(6.7%)       | 12 (80%)  |        |       |
| Child's Autisi   | n causes dif                                   | ficulties for t | hose who are   | close to him  | /her.     |        |       |
| Mothers  | 2(5%)  | 8 (20%)         | 13(32.5%)      | 11(27.5%)     | 5(15%)    | 6.691  | .153  |
| НСР  | 0  | 2 (13.3%)       | 4 (26.7%)      | 2(13.3%)      | 7 (46.7%) |        |       |
| There is a lot   | which moth                                     | ers can do to   | o control chil | d's Autism s  | ymptoms.  |        |       |
| Mothers'   | 5(12.5%)                                       | 14 (35%)        | 12(30%)        | 0             | 9(22.5%)  | 3.056  | .383  |
| НСР  | 0  | 7 (46.7%)       | 6 (40%)        | 0             | 2 (13.3%) |        |       |
| The symptom  | s of autistic                                  | child change    | a great deal   | from day to d | lay.      |        |       |
| Mothers'   | 3 (7.5%)                                       | 18(45%)         | 15(37.5%)      | 2(5%)         | 2(5%)     | 7.240  | .124  |
| НСР  | 5(33.3%)                                       | 6(40%)          | 2(13.3%)       | 1(6.7%)       | 1(6.7%)   |        |       |
| Child's Auti   | Child's Autism symptoms come and go in cycles. |                 |                |               |           |        |       |
| Mothers  | 1(2.5%)  | 22(55%)         | 7(17.5%)       | 6 (15%)       | 4(10%)    | 3.828  | .430  |
| НСР  | 1(6.7%)  | 6(40%)          | 1(6.7%)        | 5 (33.3%)     | 2(13.3%)  |        |       |

\*significant <0.05 HCP Health Care Professionals

## Table (4): Percentage distribution ofMothers and Health Care Professionals related toAttitudeabout Autism (n=55)

| Items             | Strongly      | D:             | Como combo d  |               | Strongly      | $X^2$  | р     |
|-------------------|---------------|----------------|---------------|---------------|---------------|--------|-------|
|                   | Disagree      | Disagree       | Somewhat      | Agree         | Agree         |        |       |
|                   | N (%)         | N (%)          | N (%)         | N (%)         | N (%)         |        |       |
| What mothers      | do can de     | termine whet   | her child's A | utism gets be | tter or worse |        |       |
| Mothers           | 1(2.5%)       | 6(15%)         | 11(27.5%)     | 14(35%)       | 8(20%)        | 9.996  | .040* |
| НСР               | 2(13.3%)      | 6(40%)         | 5(33.3%)      | 1(6.7%)       | 1(6.7%)       |        |       |
| The course of     | child's Aut   | ism depends    | on mothers'.  |               |               |        |       |
| Mothers           | 3(7.5%)       | 11(27.5%)      | 15(37.5%)     | 5 (12.5%)     | 6 (15%)       | 11.579 | .021* |
| НСР               | 0             | 0              | 4 (26.7%)     | 6 (40%)       | 5 (33.3%)     |        |       |
| Nothing moth      | ers' do will  | affect child's | Autism        | <u>.</u>      |               |        |       |
| Mothers           | 10(25%)       | 18(45%)        | 8(20%)        | 0             | 4 (10%)       | 4.857  | .183  |
| НСР               | 3(20%)        | 3(20%)         | 7(46.7%)      | 0             | 2(13.3%)      |        |       |
| Mothers hav       | e the power   | to influence   | of child's Au | tism.         |               |        |       |
| Mothers           | 1(2.5%)       | 7(17.5%)       | 16 (40%)      | 12(30%)       | 4(10%)        | 9.233  | .056  |
| НСР               | 1(6.7%)       | 0              | 2(13.3%)      | 8(53.3%)      | 4(26.7%)      |        |       |
| Mothers' action   | ns will have  | no effect on   | the outcome   | of child's Au | ıtism.        |        |       |
| Mothers           | 6 (15%)       | 17(42.5%)      | 9 (22.5%)     | 6(15%)        | 2(5%)         | .985   | .912  |
| НСР               | 2(13.3%)      | 8 (53.3%)      | 3(20%)        | 1(6.7%)       | 1(6.7%)       |        |       |
| Child's Autis     | sm will impi  | rove with tim  | e.            | <u> </u>      |               |        |       |
| Mothers           | 0             | 5(12.5%)       | 5(12.5%)      | 16(40%)       | 14(35%)       | 16.378 | .003* |
| НСР               | 2(13.3%)      | 6(40%)         | 4(26.7%)      | 2(13.3%)      | 1(6.7%)       |        |       |
| There is little t | hat can mot   | hers' do to in | nprove child' | s Autism.     |               |        |       |
| Mothers           | 0             | 9(22.5%)       | 16(40%)       | 6(15%)        | 9(22.5%)      | 17.874 | .001* |
| НСР               | 4(26.7%)      | 7 (46.7%)      | 3(20%)e       | 0             | 1(6.7%)       |        | -1-   |
| child's treatme   | ent(s) will b | e effective in | curing his/he | er Autism     |               |        |       |
| Mothers           | 0             | 3(7.5%)        | 5(12.5%)      | 15(37.5%)     | 17(42.5%)     | 30.600 | .000* |
| НСР               | 8(53.3)       | 2(13.3%)       | 3(20%)        | 2(13.3%)      | 0             |        | -6-   |

Table (5): Difference between Mothers and Health Care Professional Regarding Attitude toward Autism (cont'd.) (n=55)

| Items           | Strongly<br>Disagree | Disagree        | Somewhat       | Agree         | Strongly<br>Agree | $X^2$    | р      |
|-----------------|----------------------|-----------------|----------------|---------------|-------------------|----------|--------|
|                 | N0 (%)               | N0 (%)          | N0 (%)         | N0 (%)        | N0 (%)            |          |        |
| The negative of | effects of ch        | ild's Autism    | can be preve   | nted (avoide  | d) by his/her     | treatmen | t(s).  |
| Mothers         | 0                    | 7(17.5%)        | 9 (22.5%)      | 9 (22.5%)     | 15(37.5%)         | 22.781   | .000** |
| НСР             | 6 (40%)              | 5(33.3%)        | 1(6.7%)        | 2(13.3%)      | 1(6.7%)           |          |        |
| Child's treatm  | ient(s) can c        | control his/he  | r Autism.      |               |                   |          |        |
| Mothers'        | 1(2.5%)              | 6 (15%)         | 10(25%)        | 10(25%)       | 13(32.5%)         | 7.111    | .130   |
| НСР             | 3(20%)               | 4(26.7%)        | 3(20%)         | 3(20%)        | 2(13.3%)          |          |        |
| There is nothi  | ng which ca          | in help child'  | s Autism.      |               |                   |          |        |
| Mothers         | 8(20%)               | 21(52.5%)       | 6(15%)         | 4(10%)        | 1(2.5%)           | 19.457   | .000** |
| НСР             | 0                    | 1(6.7%)         | 8(53.3%)       | 4(26.7%)      | 2(13.3%)          |          |        |
| The symptom     | s of child's         | Autism are p    | uzzling to his | s/ her mother | s'                |          |        |
| Mothers         | 5(12.5%)             | 8(20%)          | 16(40%)        | 9 (22.5%)     | 2(5%)             | 3.878    | .423   |
| НСР             | 3(20%)               | 6(60%)          | 4(26.7%)       | 2(13.3%)      | 0                 |          |        |
| Autistic child  | is a myster          | y to his/ her 1 | nothers'       |               |                   |          |        |
| Mothers         | 4(10%)               | 11(27.5%)       | 11(27.5%)      | 11(27.5%)     | 3(7.5%)           | 2.297    | .681   |
| НСР             | 1(6.7%)              | 4(26.7%)        | 7(46.7%)       | 2(13.3%)      | 1(6.7%)           |          |        |
| I don't under   | stand child's        | s Autism        |                |               |                   |          |        |
| Mothers         | 4(10%)               | 10(25%)         | 15(37.5%)      | 6 (15%)       | 5(12.5%)          | 2.047    | .727   |
| НСР             | 2(13.3%)             | 2(13.3%)        | 8(53.3%)       | 1 (6.7%)      | 2(13.3%)          |          |        |
| child's Autisn  | n doesn't ma         | ake sense to l  | nis/ her moth  | ers'          |                   |          |        |
| Mothers         | 6 (15%)              | 24(60%)         | 8(20%)         | 0             | 2(5%)             | 25.672   | .000** |
| НСР             | 1(6.7%)              | 1(6.7%)         | 4(26.7%)       | 5(33.3%)      | 4(26.7%)          |          |        |
| Mothers' have   | e a clear pic        | ture or under   | standing of c  | hild's Autisn | n                 |          |        |
| Mothers'        | 0                    | 10(25%)         | 17(42.5%)      | 3 (7.5%)      | 10(25%)           | 25.618   | .000** |
| НСР             | 1(6.7%)              | 1(6.7%)         | 1(6.7%)        | 10(66.7%)     | 2(13.3%)          |          |        |
| *significant<(  | ).05                 | l               |                | ** High Si    | gnificant < 0     | .001     |        |

# Table (6): Difference between Mothers and Health Care Professional regarding Attitude Toward Autism (cont'd.) n=55

| Items          | Strongly     | Disagree       | Somewhat     | Agree         | Strongly        | $X^2$  | р    |
|----------------|--------------|----------------|--------------|---------------|-----------------|--|------|
|                | Disagree     |                |              |               | Agree           |  |      |
|                | N (%)        | N (%)          | N (%)        | N (%)         | N (%)           |  |      |
| Child's Auti   | sm is very u | npredictable   |              |               | Į               | <u>.                                    </u> |      |
| Mothers'       | 2(5%)        | 13(32.5%)      | 14(35%)      | 8(20%)        | 3(7.5%)         | 1.181  | .881 |
| НСР            | 2(13.3%)     | 4(26.7%)       | 5(33.3%)     | 3(20%)        | 1(6.7%)         |  |      |
| Child goes t   | through cycl | es in which th | ne symptoms  | of his/her Au | itism get bette | er and wo                                    | rse. |
| Mothers'       | 2(5%)        | 12(30%)        | 12(30%)      | 5(12.5%)      | 9(22.5%)        | 5.112  | .276 |
| НСР            | 1(6.7%)      | 8(53.3%)       | 4(26.7%)     | 2(13.3%)      | 0               |  |      |
| I get depresse | ed when I th | ink about chi  | ld's Autism. |               |                 |  |      |
| Mothers        | 4(10%)       | 8(20%)         | 14(35%)      | 6(15%)        | 8(20%)          | 7.040  | .134 |
| НСР            | 0            | 6(40%)         | 5(33.3%)     | 4(26.7%)      | 0               |  |      |
| When I think   | about child  | 's Autism I g  | et upset.    |               |                 | <u></u>                                      |      |
| Mothers        | 4(10%)       | 4(10%)         | 20(50%)      | 6(15%)        | 6(15%)          | 7.963  | .093 |
| НСР            | 0            | 3(20%)         | 6(40%)       | 6(40%)        | 0               |  |      |
| Autistic child | l makes mot  | hers' feel ang | ry.          |               | 1               | <u>.</u>                                     |      |
| Mothers        | 4(10%)       | 18(45%)        | 9(22.5%)     | 5(12.5%)      | 4(10%)          | 2.784  | .595 |
| НСР            | 3(20%)       | 7(46.7%)       | 4(26.7%)     | 1(6.7%)       | 0               |  |      |
| Child's Aut    | ism does no  | t worry mothe  | ers'.        |               |                 |  |      |
| Mothers        | 3(7.5%)      | 10(25%)        | 12(30%)      | 7(17.5%)      | 8(20%)          | 5.334  | .255 |
| НСР            | 0            | 1(6.7%)        | 5(33.3%)     | 6(40%)        | 3(20%)          |  |      |
| Autistic child | l makes mot  | hers' feel anx | ious.        | <u> </u>      | Į               | <u> </u>                                     |      |
| Mothers        | 3(7.5%)      | 5(12.5%)       | 21(52.5%)    | 7(17.5%)      | 4(10%)          | 4.260  | .372 |
| НСР            | 0            | 1(6.7%)        | 6(40%)       | 6(40%)        | 2(13.3%)        |  |      |

\*significant<0.05

## Table (7): Mothers and Health Care ProfessionalsDifferences regarding TotalKnowledge and Attitude Mean Scores

| Variables              |         | Mean  | SD   | t     | р       |
|------------------------|---------|-------|------|-------|---------|
| Total knowledge scores | Mothers | 83.57 | 9.03 | 4.173 | .000**. |
|                        | НСР     | 79.73 | 7.97 |       |         |
| Total attitude scores  | Mothers | 32.37 | 6.35 | 1.533 | .136    |
|                        | НСР     | 40.33 | 6.27 |       |         |

\*significant<0.05

\*\* high significant  $\leq 0.001$ 

#### Discussion

The current study aimed to investigate mothers' and health care professional knowledge and attitude toward autistic children. The distribution of the sample according to mothers' level of education, type of resident, child gender, child number in family showed that, more than one third of mothers' level of education were bachelor degree while others had elementary school, more than two thirds of mothers' were from urban, the rest of the sample was rural. Regarding child gender, more than half of the sample was males while the rest of the sample was females. About half of the children were first child in the family, while quarter of children was second child number in family. These results may be autism is pervasive developmental disorder occurs regardless mothers' education, and type of residence. Girls are less likely to develop autism, when they do they are more severely impaired.

In the same line autism is commonly reported in literature to have higher incidence in males than females. Previous studies had reported significant association of the ratio of 5.5:1 in Sweden Fernell, et al.(2010) <sup>[20].</sup> In another study by Hussein, et al,(2011) <sup>[12]</sup> found that, the male to female ratio among their study sample in Egypt and Saudi Arabia was 1.6:1, being nearly equal in both groups (1.5:1 in Egyptian and 1.8:1 in Saudi group) which is less than that reported in other studies. Approximately the same ratio (1.6:1) was also found in another study on a sample of patients from Egypt, Saudi Arabia and Jordan in which the number of boys was 37 and the girls 23. In the same context, in the Saudi group, patients were significantly older in birth order when compared to the Egyptian group; also their results reported that High paternal and maternal education and high employment among mothers' of autistic children were significantly more preponderant in the Egyptian group

The importance of birth order was also emphasized in the study of Juneja et al (2005)<sup>[21]</sup> who reported that, the age of presentation was significantly earlier in firstborn children (2.28 years) as compared to later-born children (3.6 years). This observed difference might be attributable to mothers' spending more time with first born children.

Another explanation might be masculine cultural influence which is still especially evident in the same previous study. Another important finding was that the patients were significantly older in terms of birth order in the Saudi group than in the Egyptian group. Observationally, Saudi culture is characterized by younger age of marriage among males and females as well as higher birth rate which is no longer the case except in rural Egyptian culture. Due to better educational background, the stoppage rule may be acting more in the Egyptian group.

These results in the current study should be taken with caution as the sample is not a community representative sample neither with respect to sample size nor methodology of recruiting patients, thus cannot be granted high value for discussing sex ratio. It might only indicate that families of patients are nearly equally concerned with affected male and female offspring and not essentially with males.

Regarding professional health characteristics include gender, type of job and years of experience, more than half of Health care professional were females, 40% of them were psychologist, about quarter of Health care professional were nurses. According to their years of experience in autistic child care more than one third had more than 10 years and one third had from 1-5 years of experience. These results were in agreement with Tipton and Blacher, (2014)<sup>[22]</sup> found that, the participants whose age ranged from 26 to 60 years. The years of practice ranged from 1 to 33 years. Most of the participants practiced in a tertiary health facility and the same number of participants were either specialists or specialists in training.

Out of the participants who were general practitioners were females.

Regarding the first research question concerned with mothers' knowledge and attitude toward autistic child, the current research findings revealed that, the highest of mothers' knowledge and attitude toward autistic child were optimistic about the treatment effectiveness on their child, and their significant role toward their child which illustrate in the statements like, " child's Autism will pass quickly, child's treatment(s) will be effective in curing child's Autism will his/her Autism, improve in time, The negative effects of child's Autism can be prevented (avoided) by his/her treatment(s), child's treatment(s) can control his/her Autism, There is a lot which mothers' can do to control child's Autism symptoms, What mothers' do can determine whether child's Autism gets better or worse, while the lower mean scores were about child's Autism will last for a long time and there is little that can mothers' do to improve child's Autism. These findings could be interpreted as parental perceptions about the disability have a tremendous impact on mothers' behaviors in terms of seeking help or intervention for their children or the kind of help they look for, and their support of the treatment process.

These findings were congruent with Hebert and Koulouglioti (2010)<sup>[23]</sup> who revealed that, mothers' hold a wide variety of attitude about their child's autism. Some mothers' are pessimistic about their child's future while others are hopeful that new strategies will be developed. Some trust that society will become more accepting of their child's idiosyncrasies. Mothers' attitude about the cause of their child's autism has been found to have an impact on decisions regarding future health care, family planning, and maternal mental health. The link between parental attitude and their choices for interventions has not yet been empirically explored. Studies focusing on the importance of exploring parental attitude during the process of treatment planning is discussed.

But in many parts of Egypt, especially the poorest areas, lack of knowledge and access to resources about autism can have harmful consequences for the mothers' and delay treatment. In suburban or rural areas, people say children with autism have been touched by the devil or cursed — and sometimes mothers' even cage them, they're very poorly treated. The stigma doesn't stop after a child's diagnosis especially in Egyptian culture, where reputation and status are important across all social classes. Mothers' hide it from the grand mothers' and other members of the family. They're worried that a diagnosis of autism could affect the child's marriage chances; or even discourage a prospective marital partner for a sibling. (Fathy ,2016)<sup>[24]</sup> In the same context, in a recent research by Mire et al (2015)<sup>[25]</sup> they found that mothers' of autistic child have strong attitude about chronic nature of the condition, negative consequences of the illness, and the cyclical nature of the illness and indicate positive attitude about how controllable the illness is and how well the illness is understood.

Regarding to relation between personal data of mothers' and their knowledge and attitude toward scores toward autistic child, the current findings showed that, there was no significant differences detected regarding level of education, type of residence, while there was significant differences detected regarding child's gender and rank in the family and mothers' attitude toward autistic child . Studies by Amr, 2011 and Hadidi and Al <sup>[26,27]</sup> indicate that Khateeb (2016) mothers' perceptions of the nature of a disability may differ to some degree, based on their cultural values. In many Arab groups, violating a religious code is believed to be a cause of disability, especially when rational explanations of disability are not clear. The child's disability tended to produce feelings of

shame and guilt among Arab societies. In a study conducted by Daley, (2004)<sup>[28]</sup> regarding assessment of parent and professional perspectives about autism spectrum disorders in India reported that, over 50% of the mothers' of autistic child in India hoped that their children would be cured of their autism or that treatments would help them become normal. A majority of mothers' also spoke about their desire for the child to be accepted in the society.

As regards the factors such as socioeconomic status, education levels, access to formal and informal support for families and their children with disabilities, place of living (e.g., city or village), support from immediate and extended families, and personal practices of faith, etc., Ravindran ,(2012)<sup>[29]</sup> reported that all have a significant impact on families' attitude about disabilities and their hope and expectations for their child with a disability. Thus, it is crucial to consider the demographics of the participants in various studies.

Concerning the rates of diagnosis across the genders, Kreiser and White,(2014)<sup>[30]</sup> proposed that ASD may be under identified in affected females without cooccurring intellectual impairment, owing to a pattern of subtle yet potentially meaningful gender differences in symptom manifestation (e.g.,less unusual stereotyped and repetitive behaviors in females, increased prevalence of internalizing problems in females) and gender inequities in research on the ASD phenotype that potentially contributes to biases in assessment tools and diagnostic practices. We recommended for future research directions on gender differences in ASD.

As regard to second research question of professional knowledge and attitude about Autism, the current study revealed that, the care professional Health had high knowledge about behaviours/ characteristics to diagnose autism, and they had positive professionals' attitude elated to mothers' behavior of autistic child and their effective role on child treatment, and also as to treatment options in statements as parental behavior has not been found to be a cause of autism.

In the same context Ravindran and Myers  $(2015)^{[31]}$  reported that, the professionals identified the high level of focus on mothers' training and mother empowerment as being a unique feature. Mothers stayed with their children at school for the entire course of the day, and gained hands-on training in implementing treatment approaches with the children. [32] According to, Christon et al (2010) an overwhelming array there is of treatments available for autism, including behavioral, cognitive, pharmaceutical, sensory, relational, vitamin, and diet therapies

The current study findings answered the third research question which showed that, there was no significant difference between mothers' and health professional's attitude about Autism. In the same context while parental hopes related to social mainstreaming and cure of their disabled child are often universal and seen in most mothers' of children with disabilities. In India a study conducted by DeLambo et al  $(2011)^{[33]}$  found that less than half the mothers' believed that professionals had the ultimate say in decision making about or implementing treatments; however, these mothers', too, were positive and happy about this situation. Also the same study added thatm, disagreements may exist between the mothers' attitude and professionals' beliefs. This conflict may lead the mothers' to seek some alternative cures like sociocultural, folk, or religious remedies. Studies also reveal that even mothers' from the same cultural backgrounds may hold different beliefs, based on their level of acculturation, socioeconomic status, and education.

On the other hand, the findings of current study showed that there was statistical significant difference between mothers' and health care professionals in total knowledge scores. On the same context, in a study by Eseigbe et al.  $(2015)^{[34]}$  to assess knowledge of childhood autism and challenges of management among medical doctors in Nigeria, The study showed a good knowledge of autism among medical doctors who are specialists particularly pediatricians and psychiatrists and in those who had seen a case of autism in the past. Knowledge was limited in general practitioners and the knowledge gap was mostly about onset and comorbidities of autism. Dearth of specialist services, cost of accessing care, and poor caregiver perspectives were major challenges of management. The study highlights the need to improve the knowledge of childhood autism among medical doctors and address the challenges hampering its management. These would increase the level of autism awareness and facilitate the achievement of better outcomes.

There has been evidence in the literature to suggest that professionals and families maintained a variety of attitude about autism, no single view of autism has emerged (Plumb AM and Plexico, 2013) <sup>[35].</sup> Despite its limited scope and generalizability, the results of the current research provide evidence for the value of raising awareness and understanding about autism spectrum disorders among mothers', professionals, and the larger society, and call to attention the need for more services and resources in local communities.

In another study by Zwaigenbaum,et al (2015) <sup>[36]</sup> for early screening of autism spectrum disorder: recommendations for practice and research , showed that, improvements over time in health care professional academic and clinical training related to ASD, but also continuing weaknesses in identifying ASD diagnostic criteria, and in self-efficacy for working with children with ASD and their mothers'

The American Academy of Pediatrics (2016) <sup>[37]</sup> had supplemented their current standards of care by providing both pediatricians and mothers' with comprehensive, up to date information on the screening, diagnosis, assessment, and autism. Underlying treatment of the presentation of factual data are the strong message to mothers' of hope and connection to others who have similar experiences, and focus on how mothers' and pediatricians can partner effectively to optimize developmental outcomes.

#### Conclusion:

The primary focus of this study was to investigate knowledge and attitude of mothers and heath care professionals toward autistic children. Overall, our results revealed that most of mothers' had positive attitude toward their autistic children regarding their role in care and effectiveness of treatment, and there was no significant difference between mothers' and Health care professional in total attitude scores. As expected there was statistical significant difference in total knowledge scores between mothers' and heath care professionals. The current study highlights the need to improve the knowledge and attitude of childhood autism among mothers and health care professionals. Children with autism require further researches in order to find out the most effective way to induce positive changes in this area and to increase the level of autism awareness and facilitate the achievement of better outcomes in the region.

#### Recommendations

- Design of future studies focused on how treatment decisions are made, particularly with regard to the importance of mothers' attitude.
- Involving of various professionals in ASD treatment, planning and delivery, ultimately mothers' assume primary responsibility for choosing, consenting for, and following through with treatments.
- Professionals can provide accurate information about ASD characteristics treatment options, disseminate up todate research about evidence-based

therapies and news that may affect treatment recommendations, and advocate for whole-family needs.

- Exploring factors that influence mothers' treatment decisions will enhance professionals' abilities to support families experiencing ASD. As practitioners strive to collaborate with and meet the needs of affected children and their families
- Future studies will be implemented on larger representative samples of Egyptian autistic caregivers to settle the validity and reliability of the used Autism mother's knowledge Assessment Questionnaire.
- 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.

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