Factors that Influence Parents Toward Detection of Autism Spectrum Disorder

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Abstract

Background: the younger age of children at the time of parents' initial concerns about their children's development associated with the younger age of their children at detection of ASD. Higher levels of parental education associated with earlier detection of ASD. Aim of the study: The aim of this study was to assess factors that influence parents toward detection of autism spectrum disorder. Research design: A descriptive exploratory design. Setting: The study was conducted at autism outpatient clinic at El -Abbasia Mental Hospital. Subjects 100 parents having children with ASD. Tools: The data were collected using an interview questionnaire aimed at assessing factors that influence parents toward detection of autism spectrum disorder. The fieldwork: started from September 2015 to March 2016. Results: The study findings revealed fifty- four percent of the participants were early detected, while forty-six of the participants were late detected. Furthermore, fifty-six percent of the participants had a late diagnosis, while fortyfour percent of the participants had early diagnosis. Conclusion: first concerns and level of education are positively correlated. The positive predictors of early detection are parent's early initial concerns and parent's level of education, while household income and parent's self-efficacy are not correlated to detection of autism spectrum disorder. Recommendations: The study recommends that, programs for increasing parent's knowledge and awareness of the early signs of ASD (red flags) and the impact of having a child with ASD on the future outcome of their children might lead parents to seek help earlier. Programs for educating and training nurses to recognize and assist parents to navigate toward earlier detection of ASD. Further research is needed for following development of high-risk infants as early as possible and to confirm reliable age of detection.

Key words: Factors toward detection, Parents, Autism spectrum disorder.			
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Introduction	a heterogeneous group, with children and adults exhibiting dissimilar profiles,		
Autism spectrum disorder (ASD) is a lifelong developmental condition. characterized by severe damages in communication, social interaction and limited and repetitive interests and performances (Spain et al., 2015). (ASD) is	therefore, supporting the concept of a spectrum (Matson & Cardon, 2016). The definite cause of ASD is not exactly recognized, but several environmental and genetic factors are linked with ASD (Kabatas et al., 2015). In spite of several interventions and services now in use		

relatively, few have been tested scientifically (Mills & Marchant, 2011).

According to **Gaber**, (**2016**) the prevalence rate of major psychiatric disorders among children and adolescents in the Arab Republic of Egypt is parallel to that in other areas of the world, one in every 68 children so children with autism in Egypt range from 900,000 to one million. Although services for children and adolescents having psychiatric disorders are insufficient in Egypt till now, attention has been developing in improving such services (**Hussein et al., 2012**).

The early detection of children who may be at risk for autism has a number of important probable benefits, encompassing: earlier diagnosis and more probable for strategic planning of educational and care facilities (**Pasco**, **2011**). Increasing evidence of early intervention programs on consequences highlights the need for early detection of individuals with (ASD) (**Sappok et al., 2015**).

The nurse can be a child and family supporter by offering respite care. constructing parent's support groups and promoting for individual school programs (Lendenmann, 2010). Nurses interact and offer care for the children and their families and a warranty that nursing staff will have a great role in patient care and recovery (Smith, 2014). A multi-disciplinary team should consist of a physician and nurses who can play an influential role in helping with developmental assessment and autism screening of children with ASD (Inglese, 2009; Lendenmann, 2010). Nurses meet patients with ASD across all locations, so continuing education programs direct the clinical practice requirements of nurses regarding ASD (Mcintosh, 2013)

Significance of the Study:

Early diagnosis of ASD enables early intervention which may improve developmental outcomes. So, numerous screening tools for ASD in young children were developed during the last two decades. Some of these tools use a mixture of the clinical judgment of professionals such as community doctors and parental report (**Dereu et al., 2012**). Early detection requires training of practitioners who see young children, including pediatricians and nurse. Multidisciplinary teams essential to be encompassed in the comprehensive judgment of children with ASD (**Lubetsky et al., 2011**).

Aim of the study:

The study is aimed at assessing factors that influence parents toward detection of autism spectrum disorder.

Subjects and methods

Research design and setting: A descriptive exploratory design was conducted at autism outpatient clinic at El–Abbasia Mental Hospital.

Subjects: The subjects of the present study included 100 parents having a child with autism spectrum disorder, which was selected as all except parents having children with mental retardation.

Data collection tools: A personal interview sheet for parents and their children: It was constructed by **Barrie**, (2010) and adapted by the investigator after reviewing literature in this field; This section included brief personal profile questions about parents and their children as sex, age, marital status and relation to the child

Interview questionnaire about factors that influence parents toward detection of ASD. It was constructed by **Barrie**, (2010) and adapted by the investigator after reviewing literature in this field. Maternal education, household income, initial concerns, age at diagnosis. Concerning to parental concerns or early concerns or developmental concerns or first concerns or initial concerns have the meaning meanings.

Early concerns

it is the time when parents identify abnormal developmental milestones (red flags) with their children at or before the child is 30 months of age.

Concerning to early identification or early diagnosis or diagnosis or early detection have the meaning meanings.

Early detection of ASD it is the time when the child is diagnosed with ASD at or before the child is 30 months of age, While the investigator adapted that early detection means either early diagnosis (the time when the child is diagnosed with ASD at or before the child is 30 months of age) or early detection means early seek a professional medical help (the time when parents seek a medical help at or before the child is 30 months of age) as parents realize that their children are in a real challenge.

B- General self-efficacy

The GSE subscale is a list of 17 statements that measure the expectations an individual has in their ability to achieve a broad range of stressful or challenging demands. Participants are asked to respond to each item on a forced-choice 5-point Likert scale indicating to what extent they agree or disagree with each statement.

Three additional questions related directly to parents" confidence in their ability to perform behaviors to access help for their children were created specifically for this study. "I am confident in my ability to decide what help my child needs," "I am confident in my ability to find the help my child needs," and "I am confident in my ability to get professionals to take action to get the help my child needs. And adapted by investigator to a list of 20 statements with a forced choice 3-point Likert scale with each statement (agree – sometimes – disagree)

The scoring system of interviewing general self-efficacy sheet:

The scale was used to assess the effect of general self-efficacy on detection of autism spectrum disorder.



Some items scored according to (reverse values)



Tools were reviewed by a jury group consisting of three experts in the field of pediatric nursing department and psychiatric and mental health nursing department from the Faculties of Nursing at Ain-shams and Cairo Universities for face and content validation. Modifications and rephrasing were done based on experts' opinions.

Pilot study: A pilot study was conducted on 10 parents representing almost 10% of the main study sample size to determine the clarity and applicability of the tools, and the time consumed in filling them out. Necessary modifications were done accordingly. These 10 parents were not included in the main study sample. The pilot study also served to assess the reliability of the tool and it proved to be high with Cronbach alpha coefficient 0.77.

Fieldwork: The actual fieldwork started in September 2015 and was completed by March 2016. Official permissions were obtained from pertinent authorities. The researcher met with the parents and explained to them the aim and the nature of the study and the method of filling in the forms. This was done individually. The time consumed in answering the questionnaire ranged between 20 and 30 minutes. This was done in the presence of the researcher to clarify any ambiguities.

Administrative Design: An official letter requesting permission to conduct the study was submitted from the Dean of the faculty of nursing for the mangers of El – Abbasia Mental Hospital.

Ethical considerations:

The study proposal was approved by the Ethics Committee of the Faculty of Nursing, Ain Shams University. Official permissions to conduct the study were secured from pertinent authorities. All parents gave their oral consent to participate in the study. They were informed about the study purpose and about their rights to refuse or withdraw at any time without giving reasons. The confidentiality of information was ascertained. The study maneuvers could not entail any harmful effects on students.

Statistical analysis: Data entry and statistical analysis were done using SPSS 22 statistical software package. Cronbach alpha coefficient was calculated to assess the reliability of the tool through its internal consistency. Spearman rank correlation was used for assessment of the interrelationships among qualitative variables and ranked ones.

Results:

Table (1) shows that all of the studied caregivers sample were females. The table also showed that 91% of the subjects were married, while 6% were divorced and 3% were widowed. In most families, the caregiver was the mother

(98%). The majority of caregivers were mothers 98% and 2% were grandmother.

Table (2) reveals that the first concerns or early symptoms related to language problems were delayed speech and language skills represent (75%). followed by child does not pretend in play to feed a doll (32%). While the early symptoms related to social impairment a child did not respond to his name, avoided eye-contact were the same percentage (46%) and followed by a child Preferred to play alone (44%). Furthermore, early symptoms related to behavior problems slightly more than one third of studied sample had Flaps hands, rocks body, or spins self in circles (35%), while nearly one third (34%) Played with toys the same way every time.

Table (3) reveals that the mean age and its standard deviation at first concern was 31.37±17.021 months with a range from 6-84 months. Regarding to the person first concerned, nearly three quarters (76%) of the studied sample were mother, followed by father (13%), family member (4%), others (3%), childcare provider (2%), and clinician (2%). Besides, first actions taken were one quarter (25%) contacted speech and language pathologist, while slightly less than one quarter were neurologist (23%), psychiatrist (22%). Furthermore, the mean age and its standard deviation at first medical help was 34.90 ± 17.425 with a range from (7 - 90)months. Also the table clarifies that slightly less than one quarter (23%) of the studied sample helped by program in mass media, while nearly two thirds of participants (65%) were not helped by any methods, 9% helped by other methods, 2% knew someone has a child with (ASD) and the least reported to help caregiver 1% poster or flyer.

Table (4) reveals that the mean age and its standard deviation at first diagnosis was 38.79 ± 17.760 months with a range from 16 - 90 months. Regarding to the first diagnosis the majority of the

studied sample was autism (96%), followed by developmental disorder not otherwise specified (PDD-NOS 4%. Besides that, the table shows that three quarters of the specialist consulted for diagnosis was psychiatrist (75%), pediatrician 12%, both psychologist and neurologist 6% and the least reported was speech and language pathologist 1%.

Table (5) demonstrates that that more than half (57%) of the participants reported that their household income was enough, while (43%t) had not enough household income. Besides nearly two thirds (65%) of the subjects had high selfefficacy level, while (29%) had moderate self-efficacy level and (6%) had low selfefficacy.

Figure (1) demonstrates that more than one third (41%) of the studied sample were graduated from secondary school, while (28%) were graduated from university, (12%) were illiterate, (15%) read and write and (4%) postgraduate.

Figure (2) showed that more than half 54%) of the participants were early concerned, while (46%) of the participants were late concerned.

Figure (3) shows that more than half (56%) of the participants had a late diagnosis, while (44%) of the participants had early diagnosis.

Table (6) shows that subjects who were diagnosed at or before 30 months (early detected) had a Household Income compared to those who were diagnosed after 30 months (late detected) and the difference was not statistically significant (p>0.05).

Table (7) shows that subjects who were diagnosed at or before 30 months (early detected) had a level of general self-efficacy compared to those who were diagnosed after 30 months (late detected) and the difference was not statistically significant (p>0.05).

Table (8) shows a significant positive correlation between detection of ASD and first concern ($r = 0.635^{**}$, p<0.05). and there is a positive correlation between detection of high risk and first concerns.

Table (9) shows a negative correlation between detection of ASD and level of education (r = -.356-**, p<0.05) and there is a negative correlation between detection of high risk and level of education (r = -.337-**, p<0.05.

Items	%
Sex Female	100
Marital status Married Divorced Widowed	91 6 3
Relation to child Mother Grandmother	98 2

Table (1): Socio-demographic characteristics of the studied caregivers (n=100).

Table (2): First concerns (early symptoms and behaviors associated with ASD) related to language, social and behavior problems.

Items		No (%)
Delayed speech and language skills	75	25
Does not pretend in play (e.g., does not pretend to "feed" a doll)	32	68
Does not respond to his name	46	54
Avoids eye-contact	46	54
Prefers to play alone	44	56
Plays with toys the same way every time	34	66
Flaps hands, rocks body, or spins self in circles	35	65

Table (3): Percentage Distribution of the Studied Sample Related to First Concerns.

Items	%
Children's age at first concerns (months) Mean ± SD Minimum Maximum	31.37±17.021 6 84
First Concerned person Mother Father Family member Childcare provider Clinician Other	76 13 4 2 2 3
First actions taken -Talked to person has a child with (ASD) -Talked to children educational staff -Went to medical doctor -Contacted speech pathologist -Contacted audiologist -Pediatrician -Neurologist -Psychiatrist -Specialist in genetic diseases	7 3 3 25 9 6 23 22 2
Children's age at first medical help (months) Mean ± SD Minimum Maximum	34.90±17.425 7 90
Methods helped caregiver Poster or flyer Program in mass media Knew someone has a child with (ASD) Others No	1 23 2 9 65

Items	%
Children's age at first diagnosis (months) Mean ± SD Minimum Maximum	38.79±17.760 16 90
First diagnosis Autism Developmental disorder not otherwise specified (PDD-NOS)	96 4
Specialist consulted Pediatrician Psychiatrist Psychologist Speech and language pathologist Neurologist	12 75 6 1 6

Table (4): Percentage Distribution of the Studied Sample related to first diagnosis

(5): Factors that influence parents toward detection of ASD.

Items	%
Household Income	
Enough	57
Not enough	43
Self-efficacy level	
High	65
Moderate	29
Low	6

Figure (1) levels of caregivers' education.





Figure (2): Distribution of first concerns (early indicators and symptoms of ASD.





 Table (6): Relation between caregivers' household income and detection of autism spectrum disorder among studied sample (n=100)

	Detection					
	Early	%	Late	%	Chi ²	P value
Household Income Enough Not enough	26 18	59.1 40.9	31 25	55.4 44.6	0.154	0.695

*p value is considered significant < 0.05

	Detection				Chi ²	P voluo
	Early	%	Late	%	CIII	1 value
Self-efficacy High Moderate Low	28 16 0	63.6 36.4 0	37 13 6	66.1 23.2 10.7	4.134	>0.05

Table (7): Relation between total score of general self-efficacy and detection of autism spectrum disorder among studied sample (n=100)

Table (8): correlation between detection of autism spectrum disorder and first concern among studied sample (n=100).

	Detection of high risk	Detection of ASD
Spearman's rho		
First concern		
Correlation Coefficient	0.734	0.635**
p value	0.000	.000
N	100	100

*p value is considered significant < 0.05

Table (9): correlation between detection of autism spectrum disorder and level of education among studied sample (n=100)

	Detection of high risk	Detection of ASD
Spearman's rho		
Level of education		
Correlation Coefficient	337-	356-**
p value	.005	.003
N	100	100

*p value is considered significant < 0.05

Discussion:

According to socio-demographic data the present study indicated that, all of the studied caregivers sample were females, nearly all caregivers were mothers. This result nearly consistent with the study conduct by **Samadi & Mcconkey**, (2014) in most families, the primary caregiver was the mother but others reported that it was shared equally with mothers and fathers.

Based on the findings of the current study, all caregivers were females may be due to men and women respond differently to caring for a child with ASD. Mothers tend to take a more personal responsibility for their child's problem than fathers. Mothers are more likely to question their own parenting abilities, often believe they are being blamed, judged and stressed by others. Consequently, children with ASD affect the family and marital relationship.

In relation to marital status of parents most of the subjects were married, while less than one-tenth were divorced and widowed. These results are consistent with the study conducted by **Lendenmann**, (2010) who stated that more than three-quarters were married while less than one-quarter were separated and single. Also, Samadi & Mcconkey, (2014) showed that nearly all were married. While, these findings are inconsistent with Morrison, (2013) who stated that the majority of subjects were married, onefifth were divorced while, less than one fifth were single, and widowed.

Based on the findings of the current study, most of the subjects were married may be due to having a child with ASD did not affect marital relationship due to Egyptian cultural factors that consider having a child with ASD may be a test from Allah. Although raising a child with a disability report more stress than parents raising a child without a disability that can be destructive to any marital relationship. Marital satisfaction is negatively impacted by a child's disability so marriages are more likely to end in divorce when partners are unable to support each other.

Concerning the first concerns or early symptoms related to language problems three quarters of the studied sample the first concerns or early symptoms related to language problems were delayed speech and language skills represent (75%). While the early symptoms related to social impairment a child did not respond to his name, avoided eye-contact were the same percentage (46%). Furthermore, early symptoms related to behavior problems slightly more than one third of studied sample had Flaps hands, rocks body, or spins self in circles (35%). In agreement with Hussein et al., (2011) who found delayed language development was also significantly higher in the Egyptian autistic children, while delay in all developmental milestones was more significant in the Saudi autistic children.

Based on the findings of the current study, three-quarters of the studied sample had delayed speech could be due to delayed speech is a prominent marker for detection of ASD. This is due to speech is the main source to interact with others, express what you feel and establish different relations consequently parents initially concerned with communication, then social interaction as parents noticing their children played alone and not interact other peers and behavioral issues such as flappy hands.

The current study reveals that the mean age and standard deviation at first concern was 31.37±17.021 and more than half of the participants were early concerned at or before 24 months, while less than the half of the participants were late concerned after 24 months. These findings are consistent with El-Baz et al., (2011) who found that most of the patients presented at the age of 18-36 months, whereas less than half of patients presented at age of 18 months, almost one third at age of 2 years, one fifth at age of 3 years. Also, Katazyna et al. (2006) and Rosenberg et al., (2011) reported that the earliest symptoms of autism often appear before a child's second birthday, but most children with autism are not diagnosed until they are in pre- school or elementary school.

The reasons for parents' late concerns may be related to lack of comprehension of parents about the illness and their level of denial. Consequently, the younger age of perceiving the symptoms may suggest more knowledge and less denial. This view is supported by Hussein et al., (2011) who stated that Egyptian culture is not good owing to lack of efforts governmental and nongovernmental institutes. Additionally, Egyptians are branded by their sincere emotions and their overprotective attitude towards their children, for this reason, the level of denial may be greater in the Egyptian culture

Regarding the person first concerned, nearly three quarters of the studied sample were mothers, followed by fathers, family members. These findings are consistent with that of **Barrie**, (2010) who stated that the majority of parents who completed questionnaires indicated that they were the first person to become concerned about their children's development. Parents reported that grandmothers, one tenth, then family physicians or others; speech and language pathologists first became concerned.

Based on the findings of the current study, three-quarters of persons who first concerned were mothers may be related to the mother is a significantly better historian of her children's developmental milestones and their daily activities than any one. She is the primary caretaker who often has most of these experiences with her children. Parents are accurate reporters of early signs of developmental delays or autism as they spend much time for their children that enable them to observe abnormal behavior in and out the home.

As regards, first actions taken were one quarter contacted speech and language pathologist, while slightly less than one quarter were neurologist and psychiatrist. This finding is not consistent with that of Hussein et al., (2012) showed that most parents first contacted either a pediatrician more than one third then a psychiatrist less than one third about their child's mental health condition. A smaller proportion contacted a general practitioner. Other specialties first contacted included neurology and neurosurgery and urology.

Based on the findings of the current study, speech and language pathologists were the first persons contacted by parents may be related to the concern, which first causes the parents to bring their son or daughter to the speech and language pathologist, is delayed speech. The specialist may inform the mother that "boys tend to talk later than girls" (which is true), tells mother not to worry and reassure mothers to wait and see. The mother feels relieved because the specialist is the professional to whom she turns for answers. Since the doctor is not concerned, the mother is no longer concerned.

Regarding the methods that helped parents to identify ASD the present study clarified that slightly less than one quarter of the studied sample helped by program in mass media, while nearly two thirds of participants were not helped by any methods. These findings are inconsistent with **Barrie**, (2010) study that showed parents reported seeing flyers on child development that cued their concerns about their children's development. Parents reported seeing the flyers, Speech and Language clinics, a day care center, a family physician's office and parent reported receiving a flyer in the mail from a district health unit.

Based on the findings of the current study, nearly two thirds of participants were not helped by any methods, although mass media have the ability to reach a large portion of the population may be due to maternal-child health care coverage by mass media is limited, whereas there is no specialized programs in children health to increase public awareness about primary, secondary and tertiary prevention or may be due to most Egyptian use of mass media is for fun and entertainment not for educational purpose.

As regards, the mean age and its standard deviation at first diagnosis were 38.79 ± 17.760 months. The findings are consistent with some studies such as (Adelman 2010) who indicated that the average age of diagnosis is 37.78 months or about 3 years 2 months of age. However, the present study is inconsistent with many findings of Amr et al., (2012) who illustrated that most of the cases were diagnosed around the age of 8 years with a mean age of 8.36 ± 1.77 years. in the same line with Shawky et al., (2014) study showed that 80% of autistic children were diagnosed before the age of 3 years.

Based on the findings of the current study, late diagnosis could be due to the knowledge of parents about the illness and their level of denial affect directly on detection of ASD. This point of view is

supported by Hussein et al., (2012) who illustrated that children may have a wide range of mental health problems. However, health care providers and the public in Egypt are not as aware of this as they should be, which may delay the diagnosis these problems, with negative of consequences for the child's functioning and well-being. Because of the lack of practice guidelines for managing children with mental health problems, it is believed that it is important to study referral patterns for undiagnosed children in an urban governmental mental health service facility.

Regarding the first diagnosis almost all of the studied sample were diagnosed with autism, followed by developmental disorder not otherwise specified (PDD-NOS). These findings are consistent with the types of autism included in the studied sample by **Adelman**, (2010) who illustrated that participants included either parent of a child diagnosed with autism 65.9 % or pervasive developmental disorder, NOS 34.1%.

Based on the findings of the current study, almost all of sample diagnosed with autism could be due to age of emergence of symptoms and age of diagnosis of Asperger's Disorder significantly is different from that of other ASD and that it is difficult to make an early reliable diagnosis of Asperger's Disorder. Therefore, children with the diagnosis of Asperger's Disorder were not included in this study. While, incidence of retts syndrome 1:10, 000-15, 000 individuals consequently, not included in this study.

Concerning, setting of the diagnosis the current study revealed that more than half of the studied sample their diagnosis was done at a private clinic, almost one third at governmental hospital. These findings are consistent with that of **Hussein et al.**, (2011) study found that the Egyptians make considerable use of private services. Private clinics and hospitals are staffed for the most part by government doctors. These private services are all funded by private out-of-pocket spending. Services for children with autism are offered primarily in private clinics and hospitals in addition to university hospitals.

Based on the findings of the current study, two-thirds of parents use private facilities may be due to signs were impossible to ignore so frightening to fully acknowledge and they become hyperfocused and obsessed with wanting to recover their child quickly. Quite rightly, much emphasis is placed on not waiting, "the sooner, the better," doing all that can be done. But too often this fast action can result in fast burnout sometimes for one parent, sometimes for both.

Concerning, parental education the current study demonstrates that more than one third of the studied sample was graduated from secondary school, while less than one third was graduated from university. These findings are consistent with that of Abd ElHameed et al., (2012) who showed that, less than one – fourth of them were illiterate, two – fifths had secondary education and more than one. One tenth were university graduates. While, Elbahnasawy & Girgis, (2011) found that less than half of them had a university education and more than two thirds were not working.

Based on the findings of the current study, it could be due to higher paternal and maternal education among parents having children with autism in the included sample may explain earlier concerns, earlier detection of ASD and thus consultation for early treatment interventions.

Conclusion and Recommendations

In conclusion, based on the result of the current study; it can be concluded that:

There is a positive correlation between first concerns (early symptoms associated with ASD) and early detection of ASD. In addition, there is a negative correlation between caregivers' level of education and age of detection of ASD. While, detection of ASD is not influenced by household income and general selfefficacy.

The study recommends that educational preparations of nurses by incorporating early signs (red flags) of developmental disorders lessons into the nursing curricula for graduate and undergraduate students. Prospective studies should be conducted to follow the development of high-risk infants as early as possible and to confirm reliable age of detection. In nursing practice: Nurses should receive adequate training programs, in autistic children care (physically, emotionally and socially). A continuous educational program is needed specially for illiteracy caregivers to raise their awareness toward their autistic children regarding knowledge and practice for organization: provide appropriate delegation for nurses to monitor the child's development during early life may facilitate the early detection of developmental problems.

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