

## Autism and Medication use Between Parents Willing and Worries

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### Abstract

**Abstract:** Medications are used widely in treating autism this study was conducted to elaborate on parents knowledge about medications used on autism and to explore parents beliefs on the benefit of these medications to their children, in addition to highlight on their worries and burden in using medication.

**Method:** A cross sectional study was conducted in Saudi Arabia, One hundred parent participated and completed survey questionnaire assessing their knowledge as well as their worries in medication use for their autistic children.

**Results:** Indicated that there was 60% of participants believe on the benefit of medication while 62% were worrisome to use medication to their children.

**Conclusion:** Although majority of parents has various medications worries and concerns, they are willing to use medications to help their children overpass their challenges.

**Keywords:** Autism; Medication; Worries; Saudi Arabia

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### Introduction

Autism is a life long developmental disability characterized by weak social communication skills and language impairment combined with stereotype, repetitive behaviors [1]. In addition behavior and psychiatric problems such as attention deficit hyperactivity disorder, aggression and anxiety disorder are common in individuals with autism [2].

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Majority of autistic individuals require medications to treat complex behavior problems, Lynn K., *et al.* 2013 found that around 30% to 60% of autistic children are being on one or more prescribed medication [3]. Treatments options for are variable including psychotherapy and psychopharmacology, for instance atypical antipsychotic medication has been used widely to reduce behavioral problem in autism disorders [4]. Risperidol Considered as one of the atypical antipsychotic medication that has been approved by food and drug administration (FDA) and used extensively in autism [4]. The safety and long term efficacy of atypical antipsychotic in treating challenging behaviors in individuals with autism were explored in Lynn K., *et al.* 2013 study [3].

Raising child with autism is considered as a hard mission for the parents, furthermore the decision to use medication for their children could be challenging, hold countless worries and this could be due to several factors including: inadequate drug information, fear of medication side effect and lack of evidence about medication efficacy on children [5], moreover researches measuring parents knowledge and satisfaction in using medications to their children with autism are limited (Frances, 2005; Kasari, 2002; Lord., *et al.* 2005; Rogers & Vismara, 2008; Scahill & Martin, 2005; Volkmar, Lord, Bailey, Schultz, & Klin, 2004). In our practice in Saudi Arabia (SA), we found parents attitude towards using medication.

Is similar to what was described in literature globally, parents are reluctant to use Medication to their children with autism, lacking knowledge and access to drug information, in addition to the fear of social stigma are common barriers in using medication. This observations had been noticed in other studies such as Metz., *et al.* (2005), determine in their study the factors affecting parents decisions in treatment plan [6]. Moreover parents choices on treatment plan were explored by Anne Bowker study (2011) [6].

In Saudi Arabia researches in Autism are limited, further no studies were found addressing parents perception about medication use in children with autism as far as we know, this is the first study conducted to addresses the problem from parents perspective. In addition, we are aiming to add evidence to our observation on this important topic.

Study aims to assess parents knowledge and believes about medication use for their autistic children

- To assess parents knowledge about the medication use in autism
- To assess parents worries about using medication
- To assess perception difference according to gender
- To assess compliance rate in medication use

## Methods

### Study design and participants

A cross sectional study was conducted in Riyadh, the capital of Saudi Arabia, Survey questionnaire were distributed to tertiary care hospitals with specialized autism clinics running on regular basis (King Abdullah specialized children hospital, King Fahad Medical City Military hospital). In addition to autism rehabilitation center and to Families attending community autism related activities during the month of April 2016 which corresponds to the international autism awareness month.

Parents and relatives of autistic children who were on medication (atypical antipsychotropic agents were included) to assess their knowledge about medication use on autism and elaborate on the factors interfere with their decision, inclusion criteria was both males and females, autistic children on medication, care given directly involved with child's care and medication administration.

### Measure

A Twenty three survey questions were developed by the authors in English and Arabic Languages to assess parents perception in medication use in autism, it was reviewed by biostatistician, Pharmacist and experts who are working with autism patients, content and face validity were done, a self administered questionnaire were handed to the parents by clinical coordinators and volunteer. Questionnaire filled and returned back after 10 to 20 minutes.

Survey questionnaire consisted of introductory cover page, consent form, followed by survey questionnaire which include 3 sections, the first section include questions related to demographic characteristic of the participants, (age, gender, marital-status, and educational level), the second section includes questions related to believes and worries related to medication use and the third section covers questions related to compliance with medication used and satisfaction about drug information given to them as well as other drug information resources, all items are rated on a 3-point Likert scale 1 as Yes, 2 as No and 3 as I don't know.

### Statistical analysis

Descriptive statistics for categorical data were displayed as number and percentage and mean  $\pm$  Standard deviation (SD) or median  $\pm$  Inter Quartile range (IQR) for continuous data. The group differences for categorical variables were assessed with Fisher's exact test or the Chi square test A P value of  $<0.05$  was considered statistically significant. A statistical Analysis system version 9.4 was used for data analysis.

### Ethical Considerations

The proposal was approved by ethical board (IRB) at King Abdullah Research center (KAMRC) Participation in the study was voluntary, Informed consent provided to the study participants before data collection. All the data kept under lock and key, only the PI and co-PI will have access to it. The confidentiality and anonymity of the participants were kept all through out of the study and in the dissemination phase.

### Results

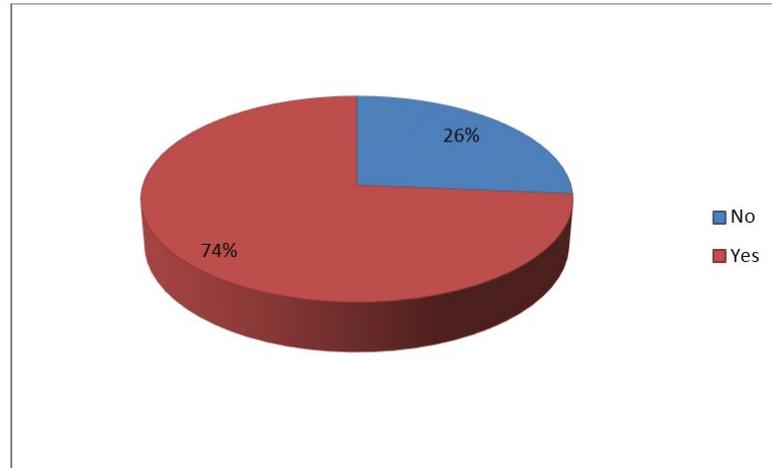
Two hundred questionnaire were distributed to parents of autism spectrum disorders and 100 were returned (50% return rate). Majority of respondents were females (84%). The 32% of responders were from 31 years to 40 years old. In regard to educational level 59% has university degree and 21% has secondary education, Marital status 65% were married and 17% were singles. For more detail please refer Table 1.

		Total (N = 100) n (%)
Gender	Male	16 (16.0%)
	Female	84 (84.0%)
Education	Uneducated	3 (3.0%)
	Primary	9 (9.0%)
	Intermediate	4 (4.0%)
	Secondary	21 (21.0%)
	University	56 (56.0%)
Age (Years)	Other	7 (7.0%)
	19 or less	12 (12.0%)
	20-30	19 (19.0%)
	31-40	32 (32.0%)
	41-50	27 (27.0%)
Marital Status	Older than 50	10 (10.0%)
	Single	17 (17.0%)
	Married	63 (63.0%)
	Divorced	13 (13.0%)
	Widowed	6 (6.0%)

Income (Saudi Riyal)	less than 5000	23 (23.0%)
	5000-10000	32 (32.0%)
	More than 10000	38 (38.0%)

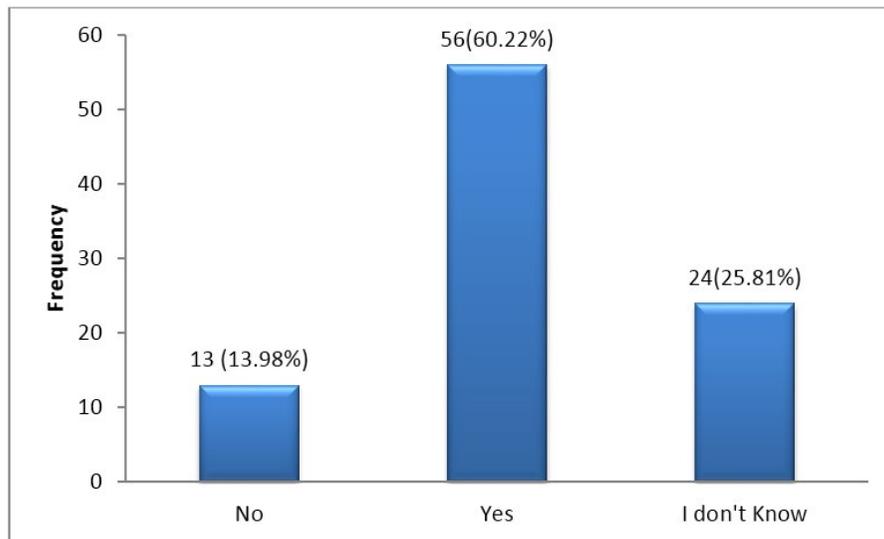
**Table 1:** Summary of Parent demographics.

The majority of parents had 74% of Compliance rate and adherence to medication . However, only 24% of parents could not adherence to medication due to unknown reasons. (Figure 1)



**Figure 1:** Percentatge of Compliance.

Out of 100 participants, 60% of participants had fair knowledg about benefits and effect of medication, whereas 14% of participants believed to have no prior knowledge about it. There were 26% of participant who were not very sure about the benefits of medications ( Figure 2).



**Figure 2:** Respondent knowledge about benefit of medication.

The 61% believed that medication can be used to treat the comorbid conditions associated with autism while 25% believed that medication can cure autism. However, 14% believed in dual effect of the medication Figure 3.

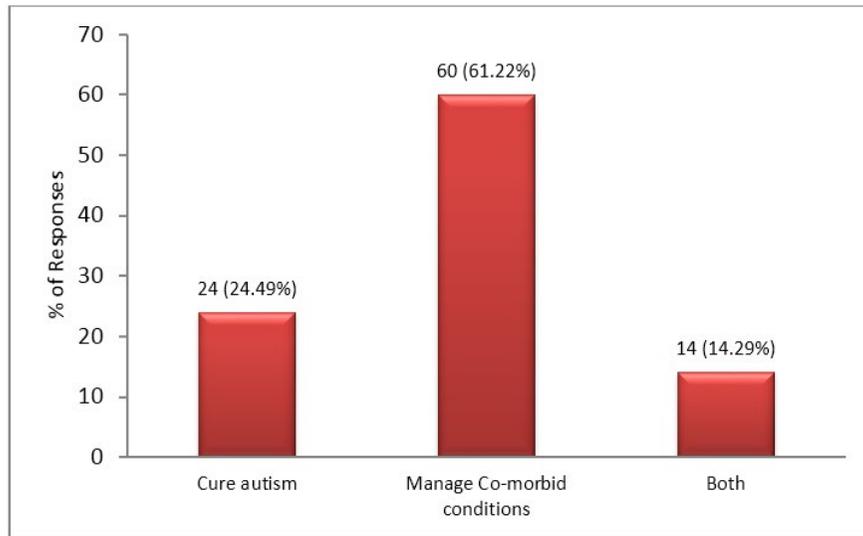


Figure 3: Percentages of responses for parent's believe in Autism medication.

More than half of the participants were worried to use medication to their children (Figure 4).

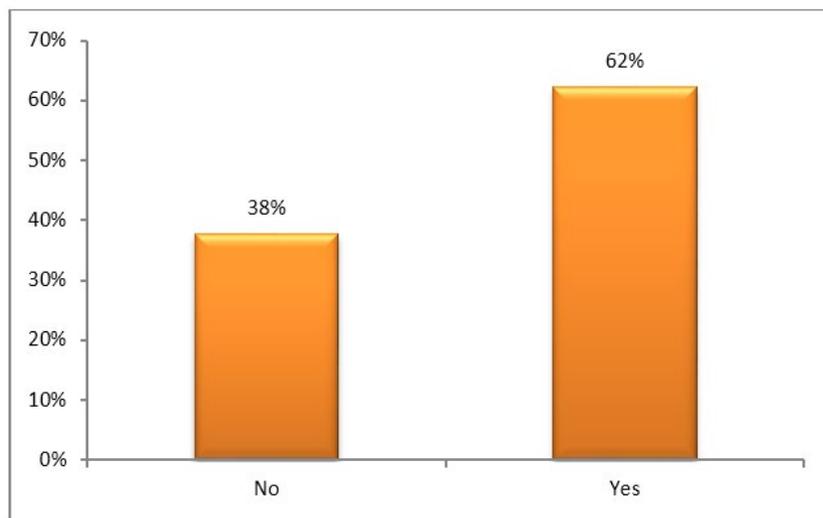


Figure 4: Percentages of use of medication is worrisome.

Responses	Autism medication considered to be Psychiatric medication	Medication cause sedation	Medication cause addiction
No	16 (16.16%)	36 (37.11%)	34 ( 34%)
Yes	60 (60.61%)	35 (36.08%)	38 ( 38%)
I don't Know	23 (23.23%)	26 ( 26.8%)	28 ( 28%)

Table 2: Summary of Perception towards type of medication.

It is the evidence from the above table that majority of participants 61% believed that autism as psychiatric medication whereas 16.2% had believed that it was not an psychiatric medication. There were 23% of participants who were not sure whether autism medication is psychiatric medication or not.

The majority of participants who believed autism as psychiatric medication had reported that these medication were not sedative or addictive in nature.

	Response	Treatment adherence			P-value
		Manage Comorbid conditions	Cure autism	Both	
Parents worries	Yes	35 (36.46%)	16 (16.67%)	8 (8.333%)	0.8125*
	No	23 (23.96%)	8 (8.333%)	6 ( 6.25%)	
Parents' beliefs	Yes	25 (25.77%)	19 (19.59%)	7 (7.216%)	0.0104^
	No	23 (23.71%)	3 (3.093%)	2 (2.062%)	
	I don't Know	11 (11.34%)	2 (2.062%)	5 (5.155%)	

**Table 3:** Comparison of parents' beliefs and worries with adherence to treatment.

^Fisher exact test was used to calculate p-value at 5% level of significance

\*Chi square test was used to calculate p-value at 5% level of significance

There were 59 participants who expressed their worries about the adherence to treatment whereas, 37 participants were not worried about the treatment adherence. 35 out of 96 participants (36.5%) expressed their uncertainties whether medication can treat.

Co morbid conditions or not whereas 24% of participant had no concerns about it. 16% of participants had concerns if medication can cure autism whereas 8% of participants and no worries about it. There were only 8% of participants who expressed their worries about the medication that it can treat both comorbidity and autism, while 6% of participants had not worries about it. However, the comparison between parent's worries and treatment adherence was no statistical significant (p-value: 0.8125).

The 51 out of 97 participants believed to have treatment adherence whereas, 46 participants had no belief and 18 participants were not sure about it. The parents' beliefs found to be statistically significant with treatment adherence (p-value:0.0104).

	Response	Gender		P-value
		Female (N=84)	Male (N=16)	
psychiatric medication	No	14 (16.67%)	2 ( 12.50%)	0.7982^
	Yes	49 (58.33%)	11 (68.75%)	
	I don't Know	20 ( 23.83%)	3 ( 18.75%)	
	Missing	1		
Cause Sedation	No	28 (33.33%)	8 (50.0%)	0.2870*
	Yes	30 (35.71%)	5 (31.25%)	
	I don't Know	24 (28.57%)	2 (12.50%)	
	Mising	2	1	

Cause Addiction	No	28 ( 33.33%)	6 ( 37.50%)	0.9365*
	Yes	32 ( 38.09%)	6 ( 37.50%)	
	I don't Know	24 ( 28.57%)	4 ( 25.0%)	
	Missing	0	0	

**Table 4:** Comparison of Parents perception about Autism medication by gender Consideration of Autism medication.

^Fisher exact test was used to calculate p-value at 5% level of significance

\*Chi square test was used to calculate p-value at 5% level of significance.

The majority of female 58.3% (49/84) had perception that Autism medications are psychiatric medication whereas 68.75% (11/16) of male agreed with them. However, there were no enough evidence statistically to support that gender and perception for Autism as psychiatric medication had any association (P-value: 0.7982). The majority of male had perception that Autism medication are not sedative in nature whereas majority of female had not agreed with male. We had again not enough evidence statistically to support that gender and perception about Autism medication causes sedation had any association (P-value: 0.2870). The majority of female 38.09% had perception that Autism medications are addictive in nature whereas male had not clear perception about it.

**Discussion**

This study was conducted to assess parents’ beliefs and worries about medications use to their children with autism. Results showed good response rate all over 77% and this could be explained by the attention given to autism over years by different medical and non medical sources in the pupose of rasing knoweldge and awareness about autism. Majority of respondents were females 84% with more than half of participants had university education. Also this study found that 60% of the responders believed on the benefit of the medication and moreover around same percent 61% believe that medication were used to treat comorbid conditions more than it was used to cure autism 25% and these findings were consistant with previous studies.

A study by Zablotzky, *et al.* 2015 reported that 52.6% of parents using one medication or more to treat the comorbid conditions such as anxiety, attention deficit hyperactivity disorders and others [7,8]. Over all complianc rate and adherence to medication was 74% among study participants although, more than half of the total sample indicated that they are worried to start medication to their children, the difference between parents worries and treatment adherence was statistical non-significant (p-value: 0.8125). Meantime the parents’ beliefs found to be statistically significant with treatment adherence (p-value:0.0104). Compliance and treatment adherence rate in our study was higher than what was reported in previous studies (Logan., *et al.* 2014) and this results might be explained because parents do not have many treatment options available.

In addition by comparing parents perception about autism medications by gender, study showed that female participants had higher rate of fears and concerns than male and this could be explained by the higher number of female participants (84.0%) and this may considered as one of study limitation. Similar observation was noted in R Hock., *et al.* (2015) study [9] and this could be due to that mothers are the main caretaker of their autistic children. Also this study identified many factors that raise parents distress and affect their decisions to treat their autistic children including, 60% of participant considered autism medications as one of the psychiatric medications, while 36.08% felt that medication use has sedative effect, moreover less than half of parents worried from the addiction that could result from austim medications (38%).

Thease results could reflect the lack of knoweledge and right drug information among parents of autistic individuals, yet these results support the findings reported by previous studies (Bowker., *et al.* (2010), Bashir, *et al.* 2014 ). Never the less a study by Schieve., *et al.* (2018) reported that parents of autistic children encounter a signifiance stresses comparing to Parents of Children without Special health needs in which family centered treatment could be a valuable option for parents [10].

Lastly, Autism is a complex disorder with unknown etiology and little evidence-based research conducted on exciting treatment options that impact negatively on parents and leave them overwhelmed and subsequently make their decisions on treating their children more harder (Kasari 2002). Further family centered research on the autism treatment should be conducted to add more Evidence and knowledge about mysterious disorder. Study has several limitations First small sample size in which study results can't be generalized, second Missing date that can affect the power of the study and third Female represent the majority of study sample which might be a selection bias. Further studies with bigger sample size, both gender are recommended.

### Conclusion

Parents of autistic children are often encounter many challenges through out their journey to raise their children, they have blend feelings between willing to do "looking for better" and worries of wrong choice causing harm particularly in the absence of convincing evidence. Further researches should be conducted in the extent of parenting of children with special needs aiming to promote parents competence in decision making for their children treatments plan.

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### Conflicts of interest

The authors has no conflicts to declare. And no external fund was received

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