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DOES INFORMATION PROVIDED BY PHARMACIST AND DOCTORS ABOUT THE USE OF MEDICATION MEET THE NEEDS OF PARENTS OF AUTISTIC CHILDREN

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ABSTRACT

Children with autism more often using medication to help controlling comorbid medical and behavior problems associated with the disorder. Pharmacist and physician are the primary source to Parents drug related information. The objectives of this study was to assess the extent of drug information delivered by pharmacist and physician and to assess what other resources parents use to get more information about the medication they use for their children with autism and to explore the influences of these resources on parent's decision in using medication. Method; A cross sectional study was conducted on April 2016 (Autism awareness month), Riyadh, Saudi Arabia, survey questionnaire was used to assess parent's perceptions about drug information resource. A total of 100 participants responded and filled the questionnaire. Results showed that 38.30% the drug information delivered by primary doctor comparing to 28.72% delivered by pharmacist and 17.20% received information about side effect in which 15.30% were taught how to deal with the side effect by the pharmacist. Conclusion; study conclude that the information delivered by health care providers, pharmacist and doctors are rigorously inadequate for major disorder that could be potentially dangerous with subsequent increase risk of medication error that could lead to harmful results on child health.

KEYWORD: Autism, Medication use, Pharmacist, Parents, Quality of life, Health care providers, Saudi Arabia.

INTRODUCTION

Children with Autism most likely use multiple medications throughout their life. [1] There are different reasons to use pharmacotherapy in ASD children in order to treat co morbid co morbid behavior problems such as aggression, depression, hyperactivity and anxiety. [2] However, risks associated with medication using such as; dose, adverse reactions and medication administration error are common.[3] Parents of children with autism usually carry numerous hard responsibilities to their children in which medication use considered one of the most challenging burden for them. [4] and this could be related to many factors of these, weak evidence, uncertainty of drug effectiveness and associated adverse reaction that could happen with medication use. [4,5] In addition, parents involved in all aspect of child care which is time, effort, energy, and financial consumer. Moreover, quality of life studies for parents of children

with ASD found that stressful lifestyle and psychiatric problems such anxiety and depression rate are higher in parents of autistic kids comparing to parents of healthy population or children with other chronic disabilities. [6] Yet safety measures during medicine administration is critical issue that should be considered all the time to avoid the risk of medication errors that can lead to harmful unwanted effect.^[7] Pharmacist and physicians are the main primary sources and back up for any queries parents have about the medicine prescribed for their child and its use. Furthermore, pharmacist has crucial role in pharmacotherapy plan and delivered vital information in regard drug use indications, dosage, precautions, possible risks and benefits and how to deal with side effects. Also, pharmacist has essential part in family counseling to improve better medication adherence.[8] Several studies elaborate on parents satisfaction about the information given by pharmacist. [9] a study done by Abraham et.al 2016 explore parents and children with

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chronic illness perception in using medication and explore the role of pharmacist in medication use counselling. This study was conducted in Riyadh, Saudi Arabia, to explore parent's satisfaction about the information delivered to them by pharmacist and physician about medication use and to elaborate on other sources of information parents use to fulfil their needs.

METHODS

The data used in this study was extracted from data base of original study (autism and medication use between Parents willing and worries).

Abbreviations

Autism spectrum disorder (ASD), Quality of life (QoL), Health care providers (HCPs)

Study design and participants

A cross sectional study was conducted in Riyadh, Saudi Arabia, Survey questionnaire were distributed to tertiary care hospitals with specialized Autism clinics running on regular basis, 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 medications were approached aiming to assess their perception about the information given to them by pharmacist and primary doctors, regarding medication used to their children with autism, and to explore whether parents looked for other resources to have more information about the medications they used .in addition to elaborate if these resources affect their decision to use medication for their children .Inclusion criteria was; both mothers and fathers and other caregivers with direct care for the child, autistic children on medication.

Measure

A Twenty-three survey questions were developed by the authors in English and Arabic Languages to assess parent's perception in medication use in autism, it was reviewed by bio station, Pharmacist and experts who are working with autism patients, content and face validity was done, a self-administered questionnaire was handed to the parents by clinic coordinators and volunteered.

Questionnaire filled and returned 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, martial-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 .(Section 1,3 of the questionnaire were used in current study). All items are rated on a 3-point Likert scale1 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 and only the PI will have access to it. The confidentiality of the participants was kept all throughout the study phases

RESULTS

A respond rate of 50%. One hundred participants filled the questionnaire and returned back out of 200.Majority of respondents were females (84%). 32% of the participants were middle age between 30 to 40 years old and 65% were married and 17% were singles and around (56%) had university education. Furthermore, study found that around 38.30% received information about medication effect and side effects from their doctors where 61.70% didn't receive any information (Fig 1).

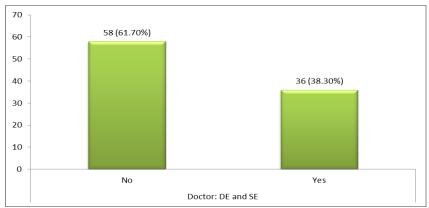


Figure 1: Percentages of Information received from Doctor about Drug effect (DE) and Side effect (SE).

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On the pharmacist role in providing drug information to parents and other care givers, study found that around 28% of participants received information about medication effect, where 17% had information about

possible side effect and only 15% of participants received information on how to deal with side effect (Fig 2).

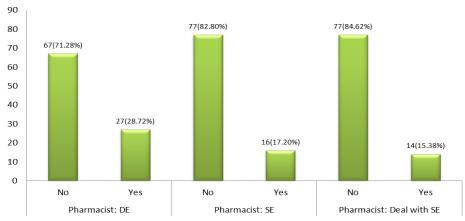


Figure 2: Percentages of Information received from Pharmacist about Drug effect (DE) and Side effect (SE) and how to deal with side effect.

Participants respond when they were asked what other resources, they used to get more information about the medication prescribed for their children and the answers showed in figure 3. as the following, around 70% of the

parents used media related resources such as Media & Newspaper, Internet, Social Network and 31% have their information from family members and friends.

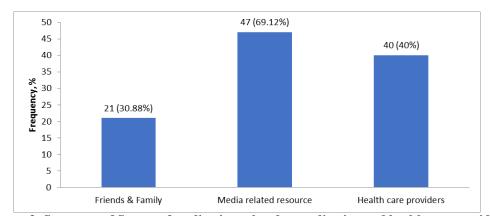


Figure 3: Summary of Source of medication related to medication and healthcare provider.

Table 4. Explore the influence of information sources on parent's decision. Study showed that more than half of the responder's decision to use medication to their children did not affected by these resources (friends and relatives, Media related resources and health care providers (58.82%, 54.35%, 69.39%) and P- value of (0.75,0.20).

Table 1: Comparison between Source of Information and its Influence on parents decision.

| | Influence on parent's decision | | |
|--|--------------------------------|-----------------------|---------|
| Source of Information | Yes (N=32) n (%) | No (N=56) n (%) | P-value |
| Friends & Family | 7 (41.18%) | 10 (58.82%) | 0.7510 |
| Media related resource | 21 (45.65%) | 25 (54.35%) | |
| Health care provider (Pharmacist /Physician) | | | |
| Yes | 17 (43.59%) | 22 (56.41%) | 0.2087 |
| No | 15 (30.61%) | 34 (69.39%) | |

P-value is calculated using Chi-square test.

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DISCUSSION

Parents of autistic children usually have hectic daily schedule in addition to other responsibilities they have to do for their children and for themselves which keep them physically and mentally busy all the time. Moreover, their job become harder if the child has disability and using medications. A study by Bonis, 2016 found that the stress level is higher among parents of autistic children comparing to parents of children with other disabilities. [10] moreover many studies determined that the stress level among the majority of parents of ASD children 80% exceeds their abilities to cope (Bitsika, Sharpley, & Bell, 2013).

In light of these facts, this study was conducted to highlight very critical topics related to medication safe administration and usage at home which required parent's full knowledge and awareness about the medicine they used for their children in order to prevent medication errors that can cause serious harm and might lead to fatal results.[11] Unfortunately, there is limited data about the incidence of medication errors at home particularly in children. The role of pharmacists and primary physicians are essential.in providing sufficient information to parents of ASD children about the medication prescribed. [12] Furthermore, pharmacist can promote medication adherence. In addition, many children with ASD using psychotropic drugs. [13] in which parents had many questions and queries about these medications pharmacist role is vital in these cases.^[14] pharmacist can decrease parent's anxiety level by discussing medication effectiveness and explain the possible side effect and how to deal with it in case it happened.

Critically this study found that a significant percentage of parents did not receive enough information from primary doctors or pharmacists (62%-72%) about the medications they used for their children with ASD. Furthermore, study elaborate on what other sources parents used to get more information about the medication, results showed that around 70% of parent's access media related resources such as; newspaper, internet, social network while 31% of respondents have their information from family members and friends. In comparing to other studies in same matter, a study by Matson et al. 2013 showed that around 88% of parents got their information from media related sources. [15,16] which is higher parentage comparing to current study population, and this could be explained by the unavailability or insufficiency of drug information in Arabic language (Native language for study group) in addition to the technical difficulties in accessing internet or other social media. Study also explored the influences of information resources in parent's decisions in using medications, results confirmed that these resources did not affect the treatment decisions of parents of ASD children. Indeed, parents still choose to use medication for their children looking for improvement. N.A. Call et al. 2015 study explored the different reasons that influences parents decision in treatment choices^[17] This study determined the extreme deficiency in the information received by parents from HCPs, and call to improve the communication and information delivery services parents need.

CONCLUSION

Parents of children with ASD as well as other parents who use medications for their children are in tremendous need for education and counselling by healthcare providers including primary care physicians and pharmacists about the prescribed medicine, to ensure appropriate and safe medication use.

In addition to minimize the risk of medication error. Unfortunately, this study determined the extreme insufficiency in the information parents received from HCPs. Study recommend to enhance drug information and medication counselling skills among pharmacists, Physicians and other HCPs.

Conflict of interest: The author declares no conflict of interest

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