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RESEARCH ARTICLE

AWARENESS ABOUT THE SAFE USE OF MEDICATION AMONG PARENTS OF CHILDREN WITH AUTISM

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ABSTRACT

The aim of this study was to describe parental awareness towards the safe use of medications to their children with autism. Method: Cross-sectional study was conducted on April 2016, Riyadh, Saudi Arabia one hundred parents out of two hundred (Response rate of 50%) were answered validated survey questionnaire assessing their awareness about the safe use of medication to their children with autism. Results: this study indicate that around 49% knew that the medication dose can change by using different dosing devices, around 64% believed that self-dose increment above the recommended dose will not give better results, and 54% agreed that same medicine could be available in different forms. **Conclusion:** The hard mission to raise a child with autism become harder if the child on medication. Child condition can improve if the medication used appropriately and safety measures were considered as a priority, on the other hand, the wrong administration of medicine can lead to harmful consequences, this study showed that parents has fair knowledge about safety measures in using medication for children with autism.

INTRODUCTION

Children with chronic illnesses most likely using medication for long time (Feinstein *et al.*, 2019). Autism spectrum disorder (ASD) for instance is a chronic lifelong developmental disability in which medication frequently used for long period of time to treat comorbid behavioral or health problems (Feinstein *et al.*, 2019; Howes *et al.*, 2018). Multiple medications might use throughout the life of autistic children to treat their complex health problems, Murray *et al.*, 2014, found that psychostimulants and psychotropic medication use in autism is much higher comparing to general population. Additionally, antidepressants, anxiolytics, hypnotic and sedative medications are commonly used to treat comorbid conditions that could occur in children with autism such as; depression, sleep disorder, aggression and anxiety (Dove *et al.*, 2012; Williamson *et al.*, 2017). Moreover alternative and complementary medicine (CAM) are commonly used by parents of ASD children and this could be explained by the weak evidence of the effectiveness of conventional medicine in treating autism (Dove *et al.*, 2012; Hanson *et al.*, 2007). Although parents decision in using medication for their autistic children could be hard, unfavorable due to countless reasons such as lack of knowledge about prescribed medicine, doubt of effectiveness and fear of side effect (Bashir and Qadri, 2014). Still there are many parents choose to use medication for their children looking for improvements and better outcomes With the availability of many treatment options either conventional,

alternative or supplements, the risk of medication error increase, which can lead to harm and sometimes fatal results. This critical subject should be explored seriously in researches. Medication error could happen accidentally for varieties of reason such as; lacking of medication knowledge, same medication can be found in different formulas and preparations (capsule, syrup, tablets). Medicine can be dispensing by different generic names that has same active ingredients, where parents can't recognize it easily (Kaushal, 2001), consequently life threatened complications in medication administration and dosage error may occur. Marja Härkänen *et al.* 2019 study explored the association between mortalities and drug administration errors in hospitals inpatients settings. Moreover a study on medication error done by Ferner and McDowell 2014, Found that deaths were caused by wrong medications and drug adverse reactions. In the same context, parents play critical role in all medication related issues for their children, starting from the decision to use medication through administration, monitoring, and recognizing adverse reactions and signs of improvements (Article and Enfermagem, 2017), therefore medication safety measures should be taken as a priority throughout treatment time. In daily clinical practice We encounter the challenges and confusion parents face during medication use, in addition to their hard job to keep child and family needs (Alharbi *et al.*, 2018). Although, there is a significant number of researches addressing medication safety in health care setting (Hong *et al.*, 2017; Brown *et al.*, 2011), unfortunately few studies are available exploring medication

errors and what safety measures were used by parents and other caregivers at home. The objectives of this study were to explore parent's basic knowledge on safety measures that should be taken during medication use to prevent medication errors that could lead to serious unwanted complications to their children, moreover to address the critical needs for more researches to be conducted on medication safety at home.

METHODS

Data used in this study was obtained from the data base of same author previous study "Autism and medication use between Parents willing and worries "Current Opinions in Neurological Science, 2018, Volume 3 Issue1.

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 aiming to assess their attentiveness in the safety measures in using medication and explore on the factors that interfere with their decision ,inclusion criteria was; both males and females ,autistic children on medication, care giver 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 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 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 includes 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 scale1 as Yes, 2 as No and 3 as I don't know .Participants Reponses in survey questionnaire section 3 were used in current study .

Statistical analysis: Descriptive statistics for categorical data were displayed as number and percentage and mean± Standard deviation (SD) or median ± 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 and anonymity of the participants were kept all throughout the study and in the dissemination phase.

RESULTS

One hundred participants filled the survey questionnaire and returned back out of 200 with 50% response rate. Majority of respondents were females (84%). The 32% of responders were from 31 years to 40 years old. More than half 59% of the responders held university degree, and 21% has secondary education, Majority 65% were married and 17% were singles.

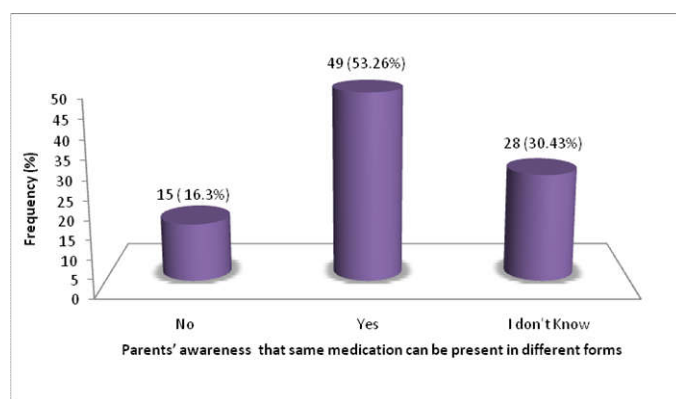


Figure 1. Parents knowledge about the presence of same medicine in different forms

Fig.1 Assess if the parents' aware that same medication can be present in different forms like (Capsule, syrup, injection and others) results showed that around 54% of parents aware comparing to 31% who don't know and 16% not aware of this information.

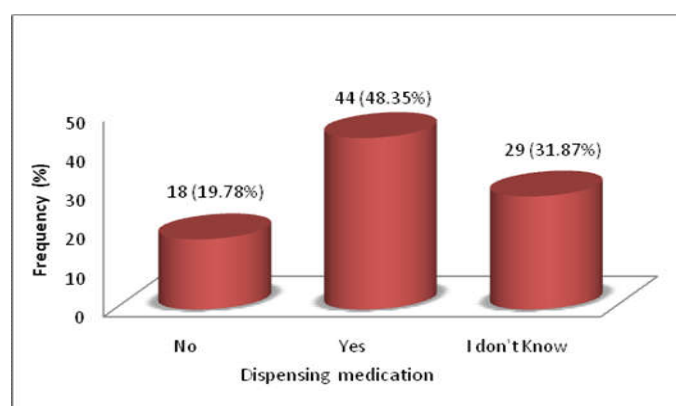


Figure2. Parents knowledge about the medication dose change according to the delivery device used

Fig.2 Explore if parents recognized that the dose can be change by changing delivery device used to give medications, the response was around 49% has positive response while 32% don't know and 20% don't think changing delivery device can change the dose.

Figure 3 Assess the parents believe on dose effect, approximately 64% believe that self- dose Increment will not give better results, while around 7% believe so and 30% don't know

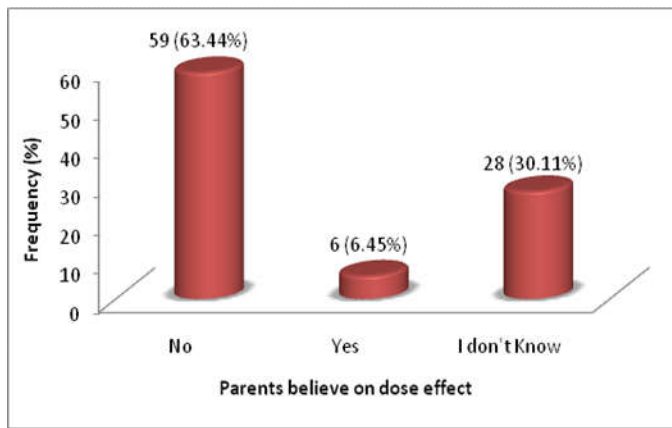


Figure 3. Parents believe on dose change effect

DISCUSSION

Studies have shown that majority of children with chronic illness including children with autism are on long term medication use (Feinstein *et al.*, 2019, Dove *et al.*, 2012, Nath 2016). The rate of chronic use among children was tremendously increased over years, a recent study found that around 1 in 5 children with Medicaid used chronic medication in USA (Feinstein *et al.*, 2019). The consequences of this use can hold benefits and risks in the same time which should be taken in consideration. This study was conducted in Saudi population in which parents' access to conventional and complimentary therapy consider relatively easy and the decision of using medication to the child primarily is parents' choice even with lack of evidence on the efficacy of medication in treating autism (Scahill *et al.*, 2008; Alqahtani, 2012). This study elaborate on the importance of assessing parents competency in fundamental safety measures during drug administration to their children. Study found that 54% Parents knew about the presence of same medicine in different forms (like, syrup, tables, capsules, injection). While 31% lack this information which can lead to duplicate same medication, that can lead to harmful effect on the child. Also, critically less than half of the study participants 48.35% aware that, the medication dose can change by changing the delivery device used for oral medication. (example using spoon or bigger or smaller syringe other than the one specific for the medicine), this in turn, can be a serious cause of medication error through increasing the risk of overdosing and adverse reactions that eventually lead to hazard of morbidity and mortality.

Moreover, study found that more than half of the parents 64% comparing to 7% believe that self- increasing medication dose without healthcare advice will not give better results. In this study the uncertainty rate of 30% in parents response to survey questionnaire is alarming in serious subject in which medication might be used daily with children with chronic disabilities. In addition, although this study found low rate of wrong believe between 7% to 20% (wrong answer) to the survey questionnaire, but this is considered very critical and clinically significance because the sequelae of this wrong practice can lead to major morbidities and mortalities. The lake of data on medication errors and safety measures used by parents at home comparing to the availability of huge data on the same topic at different health care settings, make this study unique and on the other hand this could affects the comparison part of the study furthermore it could be one of study limitations.

Conclusion

Medicine can be vital in child treatment plan, meanwhile, medication use can be associated with benefits and risks, taking in consideration that medication errors could lead to fatal results. Safety measures while using medications to the child should be a priority in all settings. In addition, parents of autistic children need appropriate guidance, education and opportunity to practice through hand on short workshops teaching them how to deal with medications safely to achieve desired outcomes. Correspondingly, the support given by health care providers should be a continuous process in order to help parents overcome their challenges while raising their child with autism

Conflict of interest: The author declares no conflict of interest

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