

Concerns of parents of students with autism spectrum disorders (ASD) towards the safety of COVID-19 Vaccination in Saudi Arabia (SA)

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Abstract

Background: Although previous scientific studies have confirmed that vaccinations are safe and do not result in harm to students with and without disabilities, some parents of students with autism spectrum disorders (ASD) had concerns that vaccines might cause potential medical issues for their children. These concerns may have an impact on these parents' decision to vaccinate their students against COVID-19. Therefore, this study aims to explore and understand the concerns of parents of students with ASD about the safety of the COVID-19 vaccination and to what extent these concerns can diminish the willingness of parents of students with ASD to vaccinate their children against COVID-19 in Saudi Arabia (SA).

Methods: a qualitative design was adapted through a developed semi-structured interview. Participants included eight parents of students aged 12 years and over with ASD, who were enrolled in two male state-funded institutions that provide educational services to those with developmental disabilities, including ASD in Riyadh, SA. The study was conducted between 17th of September and the 15th of November 2022.

Results: The results indicated that parents had several concerns regarding the safety of the COVID-19 vaccines. However, their concerns have not diminished their willingness to vaccinate their children. To increase parents' knowledge and relieve their concerns, several recommendations should be applied such as strict penalties being imposed on parents who refuse to have their children vaccinated, because they put their children in a risky position and the authorities in this matter and using the media to convince the community of the importance of the vaccine and the necessity of addressing it.

Conclusion: The current study emphasized the need to provide more care and support for parents with children with disabilities. An urgent intervention should be provided for children with ASD because they are more likely to be at a higher risk of COVID-19 illness due to the increased prevalence of underlying health conditions, suboptimal vaccination rates, and systemic inequities.

Keywords: COVID-19, vaccines, autism, Saudi Arabia

Introduction

COVID-19 has affected communities worldwide, including people with disabilities. At the beginning of 2020, most countries enforced lockdowns that required people to stay in their homes or institutions, withdrawn from freedom of movement and communication with others. At the beginning of 2021, governments represented by the Ministry of Health announced that vaccinations have been made and are ready to be used for human beings. The demand from disabilities organizations in the USA, providing vaccines for students with developmental disabilities such as autism spectrum disorder (ASD) was an urgent priority due to their specific circumstances [22].

ASD is a neurodevelopmental disorder characterized by deficits in social communication along with restricted, repetitive patterns of behaviour, interests, or activities. The reported prevalence of ASD has continued to increase in recent years, with current estimates now being 1 in 54 children in the United States (USA) [20]. While in SA, there is no exact percentage, however, there are about 53,282 students who have been diagnosed with ASD [26].

Students with developmental disabilities such as ASD may be at an increased risk of contracting COVID-19 or experiencing more severe illness if infected because of their health conditions. In a cross-sectional study of >64 million US patients of all ages, COVID-19 incidence was three times higher among students with ASD than in those without disabilities. Among those with COVID-19, twice as many students with ASD, were hospitalized, admitted to the Intensive care units (ICU), or died, compared to those without disabilities [22].

Decreased immunization reduces an individual's protection from vaccine-preventable diseases. Individuals with ASD were nine times more likely to be hospitalized following COVID-19 infection and were nearly six times more likely to have an elevated length of hospital stay compared to those without ASD. These findings point to prioritizing access to vaccines to prevent COVID-19 infection and morbidities [12,16].

Statement of the problem:

Even though an increasing number of academic studies have focused on vaccine concerns and hesitancy in the last few years [18], little is known about the concerns regarding the safety of COVID-19 vaccination of children with developmental disabilities such as ASD [15,22]. Furthermore, the authors reviewed the related literature, and they found a lack of studies that discussed this issue in the Saudi context, which gives this study great scientific value. They also noticed that most of the studies focused on the hypothesised relationship between vaccines and ASD for parents with children without disabilities. Based on that, this is the first paper we know of that explores the concerns of parents of students with ASD regarding the safety of COVID-19 Vaccination in SA.

Keeping this in mind, the main objective of this study is to capture the whole picture by exploring the concerns of parents of students with ASD about the safety of COVID-19 Vaccination and to what extent these concerns can reduce the willingness of parents of students with ASD to vaccinate their children against COVID-19 in SA. Investigating these two matters will offer a deeper understanding of parents' concerns as to who is responsible for healthcare in SA such as the Ministry of Health. In addition, this is particularly relevant in the current situation of the COVID-19 pandemic, where high rates of vaccine hesitancy are observed disproportionately in communities at greater risk of more severe COVID-19 morbidity and mortality [14]. By understanding the parents' concerns, appropriate support can be provided to the students with ASD and their families.

Literature review

In the 18th century, concerns about the safety of vaccines appeared first in the USA over the first smallpox immunization campaigns. Over time, the communities' specific concerns have changed as new vaccines have been developed and research into vaccine safety has been conducted. Public health strategies to control vaccine-preventable diseases rely on a critical percentage of the population being vaccinated. The efforts of the national research community, play a significant role in highlighting parents' concerns regarding the safety of the vaccine [12,16]

A previous study confirmed that vaccines in general are safe and important for students, especially those with ASD. They also confirmed that there are no links between vaccines and developmental disabilities, such as ASD [5, 6]. However, other studies indicated that parents had some concerns about vaccine safety, which included causing autism, diabetes, developmental delays, hyperactivity, and attention-deficit disorders or the child's immune system being weakened by vaccinations, serious diseases to be prevented by vaccines and vaccines are not tested enough [7,17].

Another study, [12] found that a quarter of the parents who participated in the study had refused at least one recommended vaccine due to a serious adverse effect. This allegation was initially ignited by a publication suggested by Andrew Wakefield and colleagues in *The Lancet* in February 1998. The article described those 12 children with inflammatory bowel conditions and regressive developmental disorders, which is a symptom of ASD. In eight of the 12 cases, the children's parents or paediatricians believed that the mumps and rubella (MMR) vaccine might have contributed to the onset of behavioural problems because this onset followed shortly after vaccination. The study's authors hypothesized that the MMR vaccine may have been responsible for bowel dysfunction, which subsequently resulted in neurodevelopmental disorders.

The high vaccination coverage in SA stems from the bylaws that mandate completion of the vaccination schedule before issuing birth certificates or admitting children into schools. In fact, the efforts of the Ministry of Health in SA have translated to nearly achieving 100% of the vaccination rate by educating the community and raising awareness about vaccines [23]. Regarding COVID-19 vaccines, citizens in SA are not allowed to attend their jobs, universities, schools, or any private and public institutions without being vaccinated with two shots of a vaccine approved by the health department in SA.

The earlier argument justifies the published studies which generally indicated that parents have a high level of knowledge and awareness about vaccination regarding the preventive measures and importance of vaccination, which resulted in positive attitudes and practice patterns among most of them. However, they simultaneously showed concerns, which included fear of weakening the child's immunity and non-necessity of some vaccinations, and based on that, they prevented compliance with vaccinations [1].

The literature review showed that the concern of parents of children with ASD about the safety of COVID-19 vaccination is not well investigated, especially in SA; however, parents' hesitancy towards vaccination and confidence in vaccines has been discussed broadly in several studies. Parents hesitated in getting their children vaccinated because of some concerns and fears they had, which resulted in a delay in vaccination or not getting vaccinated at all. Therefore, to increase the rates of COVID-19 vaccinations, healthcare providers should adopt best practices that are recommended by the global scientific research.

This conclusion raises a red flag about the provided support and intervention to children with ASD because they are more likely to have a higher risk of developing COVID-19 illness due to the increased prevalence of underlying health conditions, suboptimal vaccination rates, and systemic inequities [22]. Other reasons reported by the parents for their concern about vaccinating their children were the beliefs that vaccines are unnecessary, inadequate, and information of the duration of immunity is unknown. This concern developed conspiracy theories and distrust in the government and healthcare professionals, creating more doubts and objections to vaccinations [19].

Confusion due to the constant circulation of false news influences and increases the public's fear of the side effects related to COVID-19 vaccines, raising additional questions and concerns about the vaccines [10]. Therefore, parents emphasized that transparent information surrounding vaccine development, efficacy, and safety must be provided by the national public health authorities so that they can make informed decisions about vaccination [3]. This was important after the incident when various European countries suspended the use of the Oxford/AstraZeneca vaccines supported by deaths arising from blood clots on 15th March 2021 [8, 11].

To conclude, different studies showed a decrease in vaccine acceptance, either directly through quantitative results in SA, for example [21] or indirectly through reduced turnout for scheduled vaccinations in Ecuador. The exact reason for not showing up for the vaccinations is also unclear, which justifies the importance of studying the parents' concerns about the safety of COVID-19 vaccinations.

Research questions

1. What are the concerns of parents of students with ASD regarding the safety of COVID-19 Vaccination?
2. To what extent can the COVID-19 Vaccine safety concerns diminish the willingness of parents of students with ASD to vaccinate their children?

Method

Participants and Setting

The study used a qualitative design to explore the concerns of parents of students with ASD regarding the safety of the COVID-19 vaccine. A semi-structured interview was developed to better explore their vaccine safety concerns and to understand to what extent these concerns can diminish the willingness of parents of students with ASD to vaccinate their children against COVID-19. The target population of the current study were all parents of students with ASD, who were enrolled in either of the two male state-funded institutions that provide educational services to those with ASD in Riyadh, SA.

These two institutions serve 88 students with ASD, aged between 6–22 (Department of Education in Riyadh, 2021). The students' ages of the parents involved in the current study had to be between 12–22 years so that they would be qualified to receive the vaccines, according to the Ministry of Health [23]. The Saudi authority announced that students aged 12 years and over can be vaccinated with two doses of Pfizer or Moderna, which are approved and recommended by both the food and drug administration in the USA and SA [24]. The study was conducted between 17th of September and the 15th of November 2022 in Riyadh, SA.

The participants in the present study were eight parents of students with ASD (4 males and 4 females) from two male institutions that provide educational services to those with ASD. (See Table 1 for participant demographics). The participants were aged from 39 to 50 years and the majority had a high school certificate, except three participants who had a bachelor's degree as their highest academic qualification. The age of students with ASD ranged from 12 to 18 years, with an average age of 14 years. Four of the 10 students were vaccinated with Pfizer vaccine, and four were not.

Procedure:

Before the study was conducted, ethical approval from Hail University and permission from the Ministry of Education was obtained. The authors communicated with the principals of both institutions and explained to them the aims and procedures of the study. The principals

Table 1. Parent Participant Demographics

Number	Gender	Parent's age	Academic qualification	Student's age	Vaccination status of the students
1	Male	43	Bachelor	15	Yes (Pfizer)
2	Male	50	High school	18	No
3	Male	45	High school	13	Yes (Pfizer)
4	Male	41	Bachelor	16	Yes (Pfizer)
5	Female	49	High school	17	No
6	Female	40	High school	14	No
7	Female	39	Bachelor	12	No
8	Female	50	High school	19	Yes (Pfizer)

agreed to play a role in the study by contacting the parents in both institutions by sending an SMS to the parent's phone numbers that included an online link containing the invitation, information about the study, and a consent form, which they could fill-in if they agreed to participate in the interviews.

A total of 12 questions were developed to obtain in-depth data including demographic questions. All questions were open, and parents were asked to express their beliefs as completely and deeply as possible until they had nothing more to say. These questions were derived from the research questions and the review of the literature [13,14,15,19,18].

To establish confidence in the validity of the interview questions, a Saudi panel of four people who hold a PhD in special education and the medical field were invited to review the interview questions and make sure that each was relevant to the aims of the study and that all were clearly worded. Each interview was privately conducted by the authors in person, according to the participants' preferences. The interview questions were presented in Arabic, were verified by all authors, and were then provided to the participants before the interview.

Data analysis:

Due to the importance of increasing the consistency of the findings of qualitative studies [9], the study followed a model (4) for the analyzing process. The reason for using this model was for adding more information to sort data. The function of this comprehensive framework was to develop a thematic analysis by following the six steps given by [4].

Results

Developed themes have emerged through the recursive analysis of the transcripts of the interviews with the eight parents of students with ASD. The four key themes that are reported below are: parents' concerns about the safety of COVID-19 vaccines, beliefs surrounding the safety of COVID-19 vaccines, the relationship between ASD and COVID-19 vaccines, and to increase the parents' knowledge and relieve their concerns.

Theme (1): Parents' concerns about the safety of COVID-19 vaccines:

Participants expressed their concerns regarding the safety of COVID-19 vaccines. They feel that giving the vaccine to their children who are under 18 years is not easy. To be more specific, their concern about the vaccine is not related to the vaccine itself, but instead about vaccinating those under 18 years.

Giving it to anyone under the age of 18 should be cancelled because of its uncontrollable symptoms. Where the vaccine may affect the level of development of the child at this age and make him vulnerable to other diseases (P2)

Another response determined that the negative side effects of the vaccine on those under 18 years such as having a stroke were a great concern for the parents. Parent 7 said: *"The negative side effects on the growth and mental abilities of my son, which include poor memory, distraction, and some motor problems. The great concern is the stroke. I heard about a person, one of his sons under 18 years, who had blood clots, and it was kept secret before it was officially published."*

In relation to parents' concerns, the type of vaccine determined to what extent they were concerned about the side effects. Parent 3 explained: *"It is true that I gave my son a dose of the Corona vaccine, but I am frankly afraid of the side effects of this vaccine, even though he got Pfizer, which is considered a high reputation in terms of mild side effects. However, as my son developed a high fever after taking the first dose, he was hospitalized for a week. The side effects that come after the first dose are my biggest fear about corona vaccines. I also think that other vaccines have worse side effects, such as the Moderna vaccine"*.

Respondents also reported that the foundation of these kinds of concerns is rumoured. One respondent stated: *"rumours about the futility of the vaccine and whether it is successful or not. Such as: causing infertility, memory loss and negative impact on the vital functions of the body (P5). She also reported the reason that makes these rumours believable according to her: "The speed of the vaccine industry is one of the main concerns affecting parents. And the feeling that it is a conspiracy hatched in secret to eliminate humanity" (P5).*

Theme (2): Beliefs surrounding the safety of COVID-19 vaccines:

Even though parents completed their children's vaccination schedule, they were not convinced about its benefits, and they still needed to take it. This is because they were being forced to take it or had lost faith in its benefits, Parent 6 reported: *"No, I did not refuse to receive any vaccines for my son, despite my conviction that it is useless, but I am obligated to it towards my children, as they will not be able to obtain an academic or job seat until after completing all the doses"*. Another parent mentioned an interesting comment, which questions the benefit of the vaccine: *"The effectiveness of the vaccine has not been proven, and the reason is you will still be infected by the virus even if you had two shots of the vaccine. Also, the vaccine contains modern techniques that have not been used before, which gives an indication to do something new (P7)"*

However, one of the parents refused to show up in the hospital to give his son a vaccine due to the adverse effects: Parent 1 said *"I had previously refrained from going after my child received the measles vaccine, which affected him to the point where he was admitted to the hospital, which made me refrain from giving it to my next son until I discussed this problem with the pediatrician, who explained to me its importance and the reason for the appearance of some accompanying symptoms, which are considered justification for the case and eventually was given to him on time. My son's failure to go to the health center previously was a precautionary measure to ensure the safety of the vaccine for use for my son's condition and to avoid any side effects."*

Regarding vaccination safety, there is disagreement between the parents. Some of them believed that the vaccine is safe for several reasons. For instance:

"I believe that the vaccine is safe, and the reason is because the whole world got it and it was approved by official bodies, with the exception of vaccines that were stopped because of their effect on the body. Why isn't it safe? (P1, P4 and P8)"

However, others believe that the vaccine is useless and not effective because it was produced very fast. Parent 5 commented: *"No, it's not safe because the speed of vaccine production was fast and illogical, despite many diseases like cancer which are old and still exist with no vaccines being available for them so far". In addition, Parent 6 said: "I think that vaccine is useless and has no benefit that can be mentioned, but it is a commodity sold for business purposes only"*.

Theme (3): Relationship between ASD and COVID-19 vaccines:

Most of the parents believed that there is a link between ASD and all types of vaccines. Parent 5 reported: *"Without a doubt vaccine causes the main reason for having ASD in vaccines. ASD rates rise due to the increase in the number of vaccinations worldwide, despite the disappearance of the diseases that these vaccines target, such as German measles"*. They also doubted the study's outcomes and believe that there is no link between them: Parents 6 and 7 said *"without official confirmation of this, doubt remains. ASD has not yet known its causes, and studies that deny this accusation have not presented the causes of autism"*.

However, some parents disagreed with this assumption, and they believed that the cause of ASD *"is not yet clear (P1 and P3)"* or it is *"caused by genetics, not by vaccines (P4)"*. Parent 8 added that the reason for linking ASD to vaccines was that *"the emergence of autism coincided with the beginnings of the production and administration of the vaccine"*.

Even though the parents believed that vaccines at an early age can cause ASD, they did not believe that COVID-19 vaccines would cause ASD in normal children because they received it when they were at least 12 years old.

"Yes, vaccines cause ASD. The studies are supposed to be highly credible in this matter and come out with results confirming the relationship of ASD when children take vaccines at an early age. There is also ambiguity in the results related to the relationship of the vaccine to autism. And we all know that drug companies and vaccine factories cannot confirm this because they will lose their reputation and money if they declare this (P2)"

Theme (4): Practice to increase parents' knowledge and relieve their concerns:

Parents' knowledge regarding COVID-19 vaccines was poor, according to them. They believed that official authorities did not have enough time to educate people about the importance of taking the vaccine and that it is safe and does not cause any future problems. Parent 2

indicated the reason for not having enough time to educate people saying, *“The speed of manufacturing the vaccine and its adoption in a short period has not happened before. The Ministry of Health also did not clarify its position towards giving people who do not suffer from health or physical problems such as ASD and the extent to which they are negatively affected by taking the vaccine. This gave families an opportunity to refuse the vaccine and not accept it completely”*.

Responses associated the lack of parents' knowledge toward the importance of vaccines to the lack of specialists in the field of disability in general and ASD in particular. Parent 3 reported: *“The services for people with disabilities has a full back and the lack of specialists in the field of disability in general and ASD in particular at the top of the pyramid, which gives this group the necessary attention and care in everything related to their affairs, especially with regard to vaccination”*.

Generally, parents believed that the shortage of time to overcome this crisis justified stakeholders to force people worldwide including SA to take vaccines without questions. They suggested, *“increasing the level of efforts by targeting people with disabilities because of their individual differences, which make them distinguished in their health, physical and psychological conditions (P4 and 5)”*. Another suggestion is *“they should focus on people with disabilities in the daily press conference when they talk about the virus and the vaccines (P8)”*.

With regard to practice that increases parents' knowledge and relieves their concerns, one respondent recommended *“taking the vaccine by influential people in society (and this was activated by the Saudi government), Strict penalties being imposed on those who refuse to be vaccinated, not giving the parents, who refused the authorities in this matter and using the media to convince the community of the importance of the vaccine and the necessity of addressing it (P1,2 and 3)”*.

More importantly, parents highlighted the need for guidance in this matter. They think that parents with disabilities should receive more care regarding the case of vaccinations.

“There is a need for direct guidance to families with children with ASD so they can be supported by health centers and receive all the information that can convince them of the feasibility of the vaccine. Communicating with the families of people with disabilities to give them additional support in this matter is significant. This is because they may be unaware of their children's needs for the vaccine, especially when the disability is severe and prevents communication with others, such as ASD (P7 and 8)”.

Discussion and Conclusion

The current study aims to identify and understand the concerns of parents of students with ASD regarding the safety of COVID-19 vaccination in SA and to understand to what extent these concerns can diminish the willingness of parents of students with ASD to vaccinate their children against COVID-19 in SA. The findings indicate that most of the participants had several concerns regarding the safety of COVID-19 vaccines. One of their great concerns was not about the vaccine itself, but about the vaccine being administered to those who have not completed 18 years. An interesting result was that some of the parents feel that Pfizer is the only available safe vaccine that they can give their children, not only in SA but in the world, . This is an interesting outcome after the incident when various European countries suspended the use of the Oxford/AstraZeneca vaccines, supported by deaths arising from blood clots on 15th March 2021[11].

Participants also reported that the foundation of these concerns is rumours, which are believable, according to them. These concerns developed conspiracy theories and distrust in government or healthcare professionals, thus creating more doubts and objections to vaccination [19]. The qualitative results indicated that most of the participants completed their children's vaccination schedule. However, they were not convinced about its benefits but still had to take it. This is because they were forced to take it. This is because citizens in SA had to complete the vaccination schedule for their children if they wanted to issue birth certificates or admit their children into schools.

The study also showed that some of the parents refused to show up in the hospital to give their children a vaccine due to the adverse effects. This is consistent with another study [4], which mentioned that some of the parents refused at least one recommended vaccine due to a serious adverse effect. This may be related to the consequences that their children may have if they received the vaccine.

Regarding vaccination safety, there is disagreement between the parents. Some of them believed that the vaccine is safe, and others believed that the vaccine is useless and ineffective because it was produced very fast. This indicated the important role of parents' knowledge and awareness about vaccination regarding the preventive measures and importance of vaccination, which results in positive attitudes and practice patterns among most of them [1,2].

Most of the parents believed that there is a link between ASD and all types of vaccines. They also doubted the studies' outcomes and believe that there is a link between them. This conflicts with many studies that confirmed that there are no links between vaccines and developmental disabilities such as ASD [5,6]. However, the outcomes of the current study were consistent with other studies, which indicated that parents had some concerns towards that vaccine safety such as causing autism [7,17].

Nevertheless, some parents disagreed with the assumption that vaccines cause ASD, and they believed that the cause of ASD is not yet clear, or it may be caused by genetic reasons. Moreover, they did not believe that the COVID-19 vaccines caused ASD in normal children because they received it when they were at least 12 years old. This is an interesting result that confirmed the lack of studies that focus on the causes of ASD based on the perceptions of parents of children with ASD.

Parents' knowledge regarding COVID-19 vaccines was found to be poor. They believed that official authorities did not have enough time to educate people about the importance of taking the vaccine and that it is safe and does not cause any future problems. Therefore, stakeholders worldwide including SA, forced people to take vaccines without question. This made people confused due to the constant circulation of false news influences and increased the public's fear of side effects related to COVID-19 vaccines, raising additional questions and concerns about the vaccines [10].

With regards to practices that increase the parents' knowledge and relieve their concerns, respondents recommended several practices, which included influential people in the society being vaccinated, strict penalties being imposed on those who refuse to be vaccinated, not giving the parents, who refused, the authorities in this matter and using the media to convince the community of the importance of the vaccine and the necessity of addressing it. These results show there is a need to address the parents' concerns regarding vaccinating their children with ASD since they will be the ones making decisions to vaccinate their children [15,22].

More importantly, parents highlighted the need for guidance in this matter. They think that parents with children with disabilities should receive more care regarding the case of vaccinations. This conclusion raises a red flag about the support and intervention provided to children with ASD because they are more likely to be at a higher risk of COVID-19 illness due to the increased prevalence of underlying health conditions, suboptimal vaccination rates, and systemic inequities [22].

Limitations of the Study

Several limitations have been identified in the present study. For instance, the study took place in two male state-funded institutions that provide educational services to those with developmental disabilities, which included ASD in Riyadh, SA. Even though the selection of these two institutions has been justified, the reliability and generalizability may have increased if other institutions and schools in multiple cities were explored.

Another limitation was the study did not include female students in state-funded institutions that provide educational services to those with developmental disabilities, which included ASD. The reason for this limitation is related to the ages of the female students, which was lower than 12 years. However, including female students may change the outcomes of the current study.

Implications for Practice

The most important implications are increasing the parents' knowledge and relieving their concerns by following the best practices. This can be done by giving the parents with children with ASD more care and support regarding the case of vaccinations. Authorities should give the parents the time to understand the whole process so they can decide positively and solve any problems or confusion that the parents had before and after receiving the vaccines for their students.

Having influential people publicly advertise the importance of vaccines to encourage hesitant parents and imposing strict penalties on those who refuse to be vaccinated, not giving the parents who refused the authorities in this matter and using the media channels to convince the community of the importance of the vaccine and the necessity of addressing it are suggested solutions to increase the rates of COVID-19 vaccinations in SA.

Implications for Future Studies

Future research should concentrate on the investigation of other disabilities such as intellectual disability. An investigation of the concerns of parents of children with intellectual disabilities will add great scientific value to the literature. The outcomes of the current study shed light on having more consideration for the parents' concerns regarding vaccinating their children with ASD since they are making decisions on behalf of them [15,22]. Future studies should investigate more in this matter.

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