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Differences in Parents' Attitudes Towards the Causes of Neurodevelopmental Disorders

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ABSTRACT

Neurodevelopmental disorders are a heterogeneous group of clinical conditions characterized by deficits in one or more aspects of development, with the most prevalent subgroups being autism spectrum disorders and intellectual developmental disorders. Longitudinal studies have shown a significant increase in the number of children with autism spectrum disorders over the past few decades compared to the stable prevalence of intellectual developmental disorders. The aim of this study was to examine and compare the attitudes of parents of children with autism spectrum disorders and parents of children with intellectual developmental disorders regarding genetics, vaccination, and stress as causes of these disorders. The sample consisted of 80 parents, with 40 parents of children with intellectual developmental disorders and 40 parents of children with autism spectrum disorders. The study used a survey as the instrument, employing content analysis, interviewing, and scaling techniques. Data were statistically analyzed using quantitative methods in the JASP program. The results showed that parents' attitudes towards genetics as a cause did not statistically differ, with the most of parents not considering genetics as a cause of neurodevelopmental disorders (40%). There was a notable difference between these two subgroups of neurodevelopmental disorders in the number of children who had undergone genetic testing. A third of the participants expressed a negative attitude towards genetic testing in the future. A statistically significant difference was confirmed in attitudes towards vaccination as a cause of disorders. While most parents did not believe that stress caused their child's disorder, a higher number of parents with children who have intellectual developmental disorders cited stress as a contributing factor. Well-informed parents about the origins of neurodevelopmental disorders influence the lives of entire families, reducing the risk of unnecessary exposure of children to various interventions and treatments.

Keywords: neurodevelopmental disorders, parents, genetics, vaccination, stress

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Introduction

Neurodevelopmental disorders include a range of conditions that manifest during developmental periods, characterized by deficits in one or more aspects of development such as cognition, emotional development, behavior, and/or social skills. The American Psychiatric Association first distinguished neurodevelopmental disorders as a distinct diagnostic group in 2013 in the latest revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). In 2018, the eleventh revision of the International Classification of Diseases (ICD-11) also introduced neurodevelopmental disorders as a separate diagnostic group (Stevanović, 2021). According to the ICD-11, there are nine specific categories of neurodevelopmental disorders that can be diagnosed individually or in combination. The two most prevalent subgroups are autism spectrum disorders, characterized by impaired social functioning, communication difficulties, restricted interests, and stereotyped/repetitive behaviors; and intellectual developmental disorders (ili disorders of intellectual development), characterized by reduced intellectual functioning and poorer adaptive behavior.

A longitudinal study conducted in the United States covering the period from 1991 to 2010, which oversee children aged 8 years, showed that the prevalence of intellectual developmental disorders ranged from 1.1% to 1.3% (Van Naarden Braun et al., 2015). The number of individuals with intellectual developmental disorders remained consistent and stable over the years, with a higher representation in the male population. The study indicated that the majority of eight-year-olds diagnosed with intellectual developmental disorders had mild intellectual disability (63.7%). On a global scale, intellectual developmental disorders may affect less than 1% of the population (McKenzie, 2016). In contrast, autism spectrum disorders showed significant fluctuations in prevalence. In the same study, the number of identified children with autism spectrum disorders increased by 269% (Van Naarden Braun et al., 2015). In 1996, the prevalence of children with autism spectrum disorders was 0.42%, rising to 1.55% in 2010. For the first time in 2010, the study recorded a higher number of children with autism spectrum disorders compared to intellectual developmental disorders (15.5 children diagnosed per 1000 with autism spectrum disorders compared to 13.6 with intellectual developmental disorders). The results indicated that prevalence among boys was 4.2 times higher than among girls. Prevalence across all races and ethnic groups was approximately the same. The causes of intellectual developmental disorders can stem from various etiologies, categorized as prenatal, perinatal, and postnatal. These causes can be innate, genetically determined, or acquired due to external factors such as toxins, viruses, injuries, and CNS trauma. The etiology of autism spectrum disorders is still under investigation. Throughout history, there have been different interpretations regarding the origins of autism. The causes have ranged from psychological influences during upbringing, such as Kanner's theory of "refrigerator mothers" (Cohmer, 2014), to modern research focusing on genetic predisposition and environmental influences.
An international research team from Denmark and the USA discovered the first genetic risk markers for autism (Grove et al., 2019), and it has been proven that the risk of inheritance increases among relatives (Sandin et al., 2014). Similar studies investigating genetic factors in autism have extensively involved twins. One such study suggests that autism will manifest in both twins in 98% of cases among identical twins (Tick et al., 2016). Evidence regarding certain environmental factors correlating with genetic predispositions influencing the onset of autism spectrum disorders remains incompletely understood.

Environmental factors studied for their impact on autism spectrum disorders include parental age, prenatal influences such as hormonal effects, maternal obesity, diabetes, hypertension, infections, and immune responses during pregnancy, medication use, ultrasound,

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smoking, alcohol consumption, exposure to toxic substances, plastics, vaccinations, stress, and psychosocial factors (Bölte et al., 2019). According to Happe (2016), hundreds of genes may influence the occurrence of autism, with the role of external influences and pollution being less significant than commonly thought. Furthermore, given that autism spectrum disorders involve neurological or psychological development, there are significant disorders whose cause can be viewed as a de novo variant (Greenspan, 2018). Previous research exploring parental beliefs about the origins of neurodevelopmental disorders has shown that parents believe genetics play a role in autism spectrum disorders (Herbert & Koulouglioti, 2010; Mercer et al., 2006).

One of the controversial theories regarding the origin of autism is the impact of the MMR vaccine proposed by Dr. Andrew Wakefield in 1998, while working at the Royal Free Hospital in London, and published in The Lancet journal. Wakefield hypothesized that "the measles virus caused inflammatory lesions in the intestines, disrupting gut permeability through which neurotoxic proteins enter the bloodstream and brain, thereby causing autism" (Davidson, 2017, p. 5). Following numerous studies, this theory was rejected, The Lancet retracted the article, and the British Medical Association initiated disciplinary proceedings against Wakefield. Despite abundant scientific evidence to the contrary, the belief linking the MMR vaccine to autism persists in public consciousness, raising questions about what constitutes evidence, perception, and communication of evidence between scientists and the public (Davidson, 2017). A study analyzing publications on Google Scholar and PubMed found 19 scientific articles as references among 13,890 records that examined the connection between immunization and autism (Mohamed et al., 2022). None of these 19 articles supported a link between immunization and autism. Nevertheless, the consequence of Wakefield's theory has been a decrease in vaccination rates globally, including in Serbia. Data from the World Health Organization on global MMR vaccination coverage in 2022 shows a decline to 83%, negatively impacting herd immunity and measles outbreak prevention (WHO, 2022). In Serbia, the number of children vaccinated with the MMR vaccine significantly dropped from over 92% in 2013 to only 81% in 2016 (Maksimović & Kisić-Tepavčević, 2018). By the first half of 2017, it was as low as 34.6%, a decrease of 77.5% over the previous 7 years. According to previous studies examining parental beliefs about the causes of neurodevelopmental disorders, half of the parents are undecided about the vaccine's impact (Mercer et al., 2006).

Stress as a factor in the onset of autism during pregnancy has been the subject of various studies (Centers for Disease Control and Prevention - CDC, 2006). It has been proven that mothers who experience stress during pregnancy have an increased number of children with autism spectrum disorders (Ward, 1990; Baversdorf et al., 2005). The stress experienced is linked to certain life events in the mother. A stressful event occurring in the last few months of pregnancy has a greater impact on the occurrence of autism than if the stressful event occurred in the first three months (Baversdorf et al., 2005; Kinney et al., 2008). These studies have limitations because they mainly rely on maternal reports, and empirically verified evidence would involve testing stress factors during pregnancy and exposing mothers to stressful situations, which conflicts with ethical codes (Kinney et al., 2008b). Therefore, research focuses on natural disasters as an objective stressful event. Natural disasters such as tropical storms and hurricanes have been used as stress factors during pregnancy, showing that the prevalence of autism spectrum disorders increased in Louisiana following hurricanes (Kinney et al., 2008).

Parental beliefs about the causes of neurodevelopmental disorders influence their future decisions regarding regular vaccination and family planning offspring planning (Herbert & Koulouglioti, 2010). Additionally, these beliefs affect the interventions and treatments they choose for their children.

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The research aims to examine the attitudes of parents whose children have the most common neurodevelopmental disorders (intellectual developmental disorders and autism spectrum disorders) regarding the causes of these disorders such as genetics, vaccination, and stress, and to identify differences in parental attitudes. The research results are intended to contribute to improving practices in working with parents and children. Well-informed parents can prevent exposing their children to unfounded interventions and foster better collaboration with professionals working with their children.

Methods

The primary hypothesis of this study is that there is a statistically significant difference in parental attitudes regarding the causes of neurodevelopmental disorders between parents of children with intellectual developmental disorders and parents of children from the autism spectrum. Specifically, the study aims to investigate differences in attitudes towards genetics, vaccination, and stress as potential causes of these disorders.

Sample

The study sample consisted of 80 parents, 40 parents of children with intellectual developmental disorders, and 40 parents of children from the autism spectrum. Sampling was conducted through random selection. Participants had not previously participated in a similar study.

Instrument

The survey was used as a research instrument to examine parental attitudes toward the causes of neurodevelopmental disorders. The survey consisted of a total of 19 items. Four questions in the survey were open-ended, allowing parents to describe their experiences related to stressful situations they have encountered and examinations they have undergone with their children. The remaining 15 questions were closed-ended (Likert scale with 3 responses: Yes, No, I don't know).

Independent variables in the survey included questions related to the type of disorder and the child's age, as well as a question related to stress as a cause: "During which period did the stressful event occur?" (during pregnancy, at birth, in the first three years of the child's life, from 3 to 6 years). All independent variables were measured ordinally.Dependent variables i ncluded questions concerning parents' attitudes toward genetics, vaccination, and stress as causes of disorders in their children. All dependent variables were measured on an interval scale.

Procedure

Parental surveys were conducted in the presence of researchers from January to March 2020. The study was carried out in the city of Banja Luka, specifically at the premises of the Public Institution Center "Zaštiti me," which focuses on the upbringing and education of children with developmental disabilities, and at the premises of the Association for Assistance to Persons with Autism "Children of Light."

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Data Analysis

We analyzed the obtained results using analytical-descriptive methods and utilized the statistical software JASP for this purpose. The instrument's validity was checked by calculating Cronbach's alpha coefficient. To present basic statistical indicators, we used mean, mode, and standard deviation. Chi-square and Shapiro-Wilk tests were used for sample analysis. Independent samples t-test was employed to compare attitudes.

Results

Sample (N=80) consists of parents of children with neurodevelopmental disorders. According to the type of disorder, the sample is divided into two groups: parents of children with intellectual developmental disorder $f1$=40 and parents of children from the autism spectrum disorder $f2$=40.

In our sample, a statistically significant association was observed between the age of children and neurodevelopmental disorder ($\chi^2 = 10.74$, $df = 4$, $rc = .34$, $p = .03$). In the $f1$ group, the majority of parents have children aged older than 12 years (55%), while in the $f2$ group, the highest proportion of parents have children aged 9 to 12 years (45%). The fewest parents have children aged 0 to 6 years ($f1 = 0$, $f2 = 3$).

Cronbach's alpha coefficient (£ = .96) indicates high reliability of the measurement instrument for the three main items (genetics, vaccination, and stress). According to the Shapiro-Wilk test, there were no deviations from normal distribution ($p < .001$).

Table 1. Display of descriptive statistics for variables: genetics, vaccination, and stress

Cause	Disorder	N	M	SD	SEm
Genetics	Group 1	40	2.07	.85	.13
	Group 2	40	2.30	.64	.10
Vaccination	Group 1	40	2.77	.47	.07
	Group 2	40	2.00	.67	.10
Stress	Group 1	40	2.00	.90	.14
	Group 2	40	2.27	.71	.11

The first hypothesis was not confirmed. The difference in the belief that genetics is the cause of neurodevelopmental disorders between parents $f1$ and $f2$ is not statistically significant ($t = -1.32$, $df = 72.55$, $p = .19$). The majority of parents from both groups do not believe that genetics is the cause of disorders in their children (40%). There is a difference in parents' responses regarding genetics as a cause, although not statistically significant, indicating that parents of children with intellectual developmental disorders are more likely to believe genetics is the cause compared to parents of children with autism spectrum disorders, among whom the majority are undecided or do not know if genetics is the cause. The study revealed a difference between these two groups of parents in the number of participants who have undergone genetic testing. Most parents of children with autism spectrum disorders have not undergone genetic testing ($M = 3.00$). Additionally, the results showed that 20% of parents of children with autism spectrum disorders would not undergo genetic testing even if offered. Parents of children with intellectual developmental disorders have undergone genetic testing in 52% of cases, and 10% of parents who have not been tested expressed unwillingness to undergo genetic testing if offered.

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According to the obtained results, the second hypothesis is confirmed. Regarding the belief that vaccination is the cause of neurodevelopmental disorders, we can reject the null hypothesis because there is a statistically significant difference between parents of children with intellectual developmental disorders and parents of children with autism spectrum disorders (t = 5.89, df = 78, p = .00). Parents of children with intellectual developmental disorders do not share this belief. The results showed that a quarter of parents (22.5%) of children with autism spectrum disorders believe that vaccination is the cause of the disorder in their child. The majority of surveyed parents of children with autism spectrum disorders (55%) do not know if vaccination is the cause of the disorder in their children.

The third hypothesis is not confirmed. When considering the claim that stress is the cause of neurodevelopmental disorders, no statistically significant difference in attitudes is observed among parents (t = -1.50, df = 74.03, p = .13). The majority of respondents who reported experiencing stress stated that it had occurred during pregnancy. Overall, 41.2% of respondents in both subgroups believe that stress is not the cause of the disorder. More parents of children with intellectual developmental disorders, compared to those of children with autism spectrum disorders, believe that stress during pregnancy is the cause of the disorder in their child ($f1$ = 16, $f2$ = 6). The largest number of parents of children with autism spectrum disorders are undecided (42.5%).

Table 2. Statistical values

Cause	f1	f2	t	df	p
Genetics	40	40	-1.32	72.55	.19
Vaccination	40	40	5.89	78	.00***
Stress	40	40	-1.50	74.03	.13

*** $p < .001$

Discussion

The number of children with neurodevelopmental disorders has significantly increased in the last few decades, primarily among children with autism spectrum disorders (Maenner et al., 2021; Van Naarden Braun et al., 2015). A range of potential causes of neurodevelopmental disorders has been identified, particularly related to autism spectrum disorders (Bölte et al., 2019). In this study, we examined attitudes towards three causes. The first is the genetic factor, which has a scientific basis (Tick et al., 2016; Bölte et al., 2019; Grove et al., 2019), but lacks prenatal diagnostics and the ability to determine autism spectrum disorders before they manifest, unlike prenatal diagnostics that identify various syndromes characterized by intellectual disability as part of their clinical picture. Our assumption that parental attitudes would differ regarding genetics as a cause of neurodevelopmental disorders was not confirmed. Parents of children with intellectual developmental disorders and parents of children with autism spectrum disorders equally believe that genetics is not the cause of neurodevelopmental disorders in their children. The study showed that the highest percentage of parents of children

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with autism spectrum disorders are undecided and unsure whether genetics is the cause. Such a result was expected because only 10% of parents and children with autism spectrum disorder underwent genetic testing, unlike parents and children with intellectual developmental disorders, where half of the participants underwent genetic testing (50%). The study showed that the most of patients with neurodevelopmental disorders did not undergo genetic counselling. It is interesting that one-third of all surveyed parents expressed a negative attitude towards future genetic testing. Genetic testing can have both positive and negative effects on the family (Johannessen et al., 2017).

Referral to genetic testing for patients with neurodevelopmental disorders is a standard procedure, and the role of genetic counselling centers in working with parents and families in coping with and understanding neurodevelopmental disorders is indispensable and extremely important (Blesson & Cohen, 2019). The significance of genetic counselling centers can be beneficial even for parents who do not wish to undergo genetic testing because they will be provided with explanations of the neurobiological basis of neurodevelopmental disorders. Understanding the origins and potential causes of neurodevelopmental disorders will provide parents with a better critical assessment of various therapies and interventions that are offered but not sufficiently researched. Blesson & Cohen (2019) argue that genetic counsellors should play an essential role in the field of neurodevelopmental medicine and in paediatric clinics. The obtained research results are not consistent with previous studies on parental beliefs regarding the causes of autism spectrum disorders in North America (Herbert & Koulouglioti, 2010; Mercer et al., 2006). Obviously, genetic testing on a global level is not equally accessible to all parents, nor are the parents equally informed in different countries. There is a need to examine parental attitudes toward genetic testing and the outcomes of these studies on family life on a larger sample (Johannessen et al., 2017). Parental beliefs and inadequate understanding of the essence of autism spectrum disorders lead to exposing children to various treatments and interventions (Herbert & Koulouglioti, 2010; Davidson, 2017). For example, one approach considered to improve functioning in children is the gluten-free casein-free diet (GFCF), although not all research has been objectively evaluated (Mary Jane Weiss et al., 2008). In our experience, 40% of children with autism spectrum disorder use the GFCF diet (Ćirić & Bojanić, 2022).

The second cause of neurodevelopmental disorders that we examined is the impact of vaccination on the occurrence of these disorders. The results have shown that our assertion is correct, and that the attitudes of parents of children with intellectual developmental disorders differ from those of parents of children with autism spectrum disorders. Parents of children with autism spectrum disorders are more likely to believe that vaccination affects the occurrence of neurodevelopmental disorders, although these beliefs are not scientifically substantiated (Davidson, 2017; Mohamed et al., 2022). However, half of the surveyed parents of children with autism spectrum disorders indicated that they are unsure whether this claim is true, which is consistent with other research findings (Mercer et al., 2006). This data is significant because it indicates that these parents seek accurate and verified information, highlighting their need for education. The consequences of incorrect beliefs in the theory linking MMR vaccine to autism are far-reaching, and today we are facing a significant decline in the number of vaccinated children, posing a threat to herd immunity (Maksimović & Kisić-Tepavčević, 2018). Davidson (2017) highlights that it is not surprising that the purported discovery linking etiology to toxicity has led to a range of treatments such as vitamin A and B supplements, minerals, antiviral and antifungal drugs, γ-globulin, gluten-free and casein-free diet (GFCF), hyperbaric chamber, aromatherapy, and electrotherapy. Autistic children have also been administered injections of Lupron, a drug approved for treating prostate cancer and

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precocious puberty, and for castration of sex offenders, with serious side effects. To ensure that only scientifically grounded and validated interventions are used in working with children on the autism spectrum, it is necessary to enhance the relationship between scientists and the public (Davidson, 2017).

The third cause we examined is stress as a factor in the occurrence of neurodevelopmental disorders. Stress as a cause of neurodevelopmental disorders is a subject of research and is associated with life events (Ward, 1990; Baversdorf et al., 2005). Our hypothesis that there would be differences in attitudes among parents of children with neurodevelopmental disorders regarding stress as a cause was not confirmed. Both sets of parents equally share the view that stress is not the cause of neurodevelopmental disorders. The majority of parents of children on the autism spectrum indicated that the mother experienced a stressful event during pregnancy, mostly related to the death of close relatives. Unexpectedly, parents of children with intellectual developmental disorders expressed an opinion in a higher percentage that stress is the cause of their child's disorder, despite the etiology of intellectual developmental disorders being much clearer and more precise.

Conclusion

The expectations that attitudes of parents of children with neurodevelopmental disorders would differ based on trends in prevalence in the population were not entirely accurate. Our assumption that parents of children with autism spectrum disorders would express greater disagreement regarding the influence of genetics on the emergence of neurodevelopmental disorders compared to parents of children with intellectual disabilities was not confirmed. Both groups equally, and predominantly, believe that genetics is not the cause of neurodevelopmental disorders. The attitudes of parents toward genetics and genetic testing require further empirical investigation on a larger scale. Additionally, the study highlighted the need for professionals and the public to invest more effort in educating and providing accurate information to parents, as well as in the development of genetic counselling services. The assumption that parents of children with autism spectrum disorders believe more strongly that vaccination is the cause of neurodevelopmental disorders in their children has been confirmed. These parental attitudes are not based on scientific evidence but are prevalent in the population. Parents of children with intellectual disabilities, as expected, do not share this belief. A reason for optimism is that half of the parents of children with autism spectrum disorders expressed uncertainty about this belief. Given the societal implications, it is necessary to continuously educate parents and the public about the negative consequences for herd immunity arising from these misconceptions.

Parents of children with intellectual disabilities and parents of children with autism spectrum disorders share the belief that stress is not the cause of neurodevelopmental disorders. Stress as a cause has scientific support for the occurrence of autism spectrum disorders, but these studies are limited. Research has not shown a link between stressful life events and the onset of intellectual disabilities. Contrary to expectations, more parents of children with intellectual disabilities hold the belief that stress is the cause of their child's disorder and that this stress occurred during pregnancy.

Although neurodevelopmental disorders were first introduced as a distinct group in the international classification in 2018, we can conclude that parents' views on the causes of neurodevelopmental disorders are largely homogeneous. There is inadequate awareness among parents regarding genetics, vaccination, and stress.

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