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Autism Research

Exploring the Parental Experiences in the Media: A Qualitative Analysis of Articles Written by Parents of Children with Autism in Bosnia and Herzegovina

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Abstract

Aim: This paper presents a qualitative study of the experiences of parents raising children with autism, as reflected in the media. The study aimed to explore the most recurring themes expressed by parents of children with autism in media articles.

Method: We searched for media articles written by parents of children with autism. In total 20 articles were identified and included in the study. The articles were then subjected to a content analysis which involved systematic and objective categorization to identify recurring themes. The articles were selected from a range of sources, including newspapers, magazines, and online news portals.

Results: We identified four major themes: support, education, spousal relationships, and future. It should be noted that these themes are often intertwined.

Conclusion: The findings highlight the importance of providing support and resources to parents of children with autism and the need for greater awareness and understanding of the challenges they face. The implications of these findings for policy and practice are discussed, and suggestions for future research are presented.

Keywords: parents, children with autism, content analysis, Bosnia and Herzegovina

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1. Introduction

Autism Spectrum Disorder (referred to autism in this paper) is a neurodevelopmental condition characterized by difficulties in social communication and social interaction across multiple contexts, and restricted, repetitive patterns of behavior, interests, or activities (American Psychiatric Association, 2013). According to current estimates, autism is a relatively common condition, with a median prevalence rate of approximately 1%, and a median ratio of 4.2 males to 1 female (Seidan et al., 2022).

Autism is a lifelong condition, and although some individuals may make significant progress through treatment, many experience challenges throughout their lives, particularly in social contexts (Fombonne, 2003). Caring for a child with autism can be a challenging experience for caregivers (Bonis, 2016; Griffith et al., 2010). The characteristics that are associated with autism, such as difficulty with communication, social interactions, and sensory processing, can be complex and might require specialized attention. As a result, parents and caregivers of children with autism often experience increased levels of stress and emotional burden (Stanojević et al., 2017). This was particularly noticeable during the COVID-19 pandemic, as it disrupted family schedules, exacerbated symptoms in children, and increased the burden on parents (Massoni et al., 2023). Parents of children with autism are more vulnerable to negative outcomes and experience higher levels of stress compared to parents of children with other disabilities (Dunn et al., 2001). Autism is a complex disorder that can have a significant impact on the child's quality of life and that of their families (Memisevic et al., 2022). Understanding the unique challenges associated with autism is essential for parents and researchers in developing effective interventions and support systems for those affected by this condition. Many studies have investigated parental perspectives regarding the challenges they face in caring for their children with autism. Qualitative studies have often been used to investigate these perspectives, especially through interviews with parents (Chu et al., 2020; Gona et al., 2016; Ludlow et al., 2011).

Numerous challenges regarding raising a child with autism have been identified in the literature. Insufficient awareness and understanding of their child's condition was a common issue within the child’s nuclear family. Mothers reported experiencing intense feelings of sadness, and reported that having a child with a disability significantly impacted their social life, work, and family relationships. Financial concerns were also reported as a major challenge faced by these families (Sen & Yurtsever, 2007). In a review article by Gomes et al. (2015) on family challenges in Brazil, the authors found that the main challenges faced by families with children with autism, particularly mothers, include parental emotional overload due to diagnostic delay. In addition, challenges arose from difficulties dealing with the diagnosis and associated symptoms, and lack of access to health services and social support. Parents of children with autism describe initial confusion and distress upon diagnosis but are often quick to mobilize resources to support their child in any way possible (Altiere & von Kluge, 2009). These authors also stress that despite the hardships, many parents also report positive experiences from raising a child with autism.

The task of raising a child with autism is challenging and complex, impacting multiple aspects of family life, as highlighted by the overview of challenges faced by their families. The psychological functioning of parents caring for a child with ASD varies across different cultures (Raju et al., 2023). Additionally, different perspectives exist among parents from different cultures regarding that which is essential in supporting their children, as Preece et al. (2017) noted. For example, priorities in developing countries are related to efficient approaches to early intervention, empowerment of families, and addressing preventable causes of poor health (Tomlinson et al., 2014). Therefore, it is crucial to gain insight into parental views in each culture, as priorities and challenges faced by parents are not universal. The representation of autism in the media can significantly affect public awareness and perception of this condition. Several scholars suggest that media content can also contribute to the propagation of negative attitudes and beliefs about autism, which can further lead to stigmatization (Tang & Bie, 2016).

This study

There is limited literature regarding parental experiences of raising children with autism in Bosnia and Herzegovina. Existing studies have examined parental perspectives regarding the educational opportunities for their children (Mujkanovic et al., 2016; Mujkanovic et al., 2017) and the family quality of life (Disdarevic et al., 2022). In relation to education, parents feel there should be more treatment options for their children, and they should be made more widely available to children with autism. In relation to family quality of life, parents of children with autism had lower quality of life than parents of children with mild intellectual disability and parents of typically developing children. Apart from these studies, there is still a large research gap regarding the experiences of parents raising children with autism in Bosnia and Herzegovina. Thus, the present study aimed to examine parents' perceptions of children with autism in Bosnia and Herzegovina from a different research perspective. To the best of the authors' knowledge, no studies in peer-reviewed journals have examined the experiential stories of parents as told in media articles. The analysis of media articles written by parents of children with autism might provide a clearer picture of the types of challenges that parents of children with autism face. This approach allowed us to gain insight into the lived experiences and perspectives of parents of children with autism in Bosnia and Herzegovina, which is an important and often underrepresented group in academic research. The use of this methodology has several important advantages, such as: 1. Accessibility: Popular media articles are easily accessible to a wide range of people, including parents of children with autism who may not have access to academic journals or research database; 2. The richness of data: Popular media articles can provide rich and diverse insights into the experiences and perspectives of parents of children with autism, as they often reflect a wide range of voices and opinions; 3 Relevance: Popular media articles are often written in a way that is accessible and relevant to the general public, making it more likely that the findings of the study will be widely disseminated and have an impact beyond the academic community; and 4. Novelty: While there have been some studies that have examined media representations of autism, there has been little research that has specifically analyzed media articles written by parents of children with autism. This novel approach can provide unique insights into the experiences of this group. By examining these articles, we hope to contribute to a better understanding of the challenges faced by families with children with autism in Bosnia and Herzegovina and to inform the development of culturally sensitive interventions and support systems for this population.

2. Method

We performed a search of online media articles written by parents of children with autism in Bosnia and Herzegovina in the period of 2019 to 2022. We used the following keywords in the Bosnian language: "parents", "mother", "father", "autism". A total of 20 such articles were identified, with each featuring at least one parent of a child with autism. Three articles were in the form of an interview with parents of children with autism, while 17 articles were written by parents and published in newspapers/magazines and online news portals. The media featuring parents' stories are presented in the Table 1.

Table 1. Media sites featuring articles written by parents of children with autism.

Media name	Number of articles
Klix	4
Gracija	7
Analisiraj.ba	1
Interview.ba	2
Oslobođenje	1
Aljaseera Balkan	4
Buka	1

The content analysis was conducted by coding the articles for recurring themes related to parental experiences of caring for a child with autism. The coding process involved identifying recurring themes and patterns within the articles and categorizing them according to their relevance to the research question: What are the key themes or topics present in the media articles written by parents of children with autism? Two independent coders conducted the analysis to ensure inter-rater reliability, and any discrepancies were resolved through discussion and consensus.

After selecting themes, we provided a sample statement from the media articles that, in our opinion, best reflected the identified theme. It is important to note that the first author of the present article is a parent of a child with autism and one of the parents who wrote a media article analyzed in this paper. This is an example of participatory research involving parents of children with autism in the research process, including the design, implementation, and interpretation of findings, which provides a unique perspective and personal insight into the experiences discussed in this study.

Content analysis was chosen as the research method because it is a systematic and objective approach to analyzing written material. It allows for identifying patterns, themes, and trends within the data, which can provide valuable insights into the experiences and perspectives of parents of children with autism.

Ethical Considerations: This study involved the analysis of publicly available data and did not involve direct interaction with human subjects. As such, ethical approval was not required for this study. However, to ensure anonymity, we have not identified the 20 articles that constitute the dataset for the article.

3. Results and discussion

We identified four major themes that appeared in the media articles. These are: 1. Support/assistance; 2. Education; 3. Marital relationships; and 4. Environmental challenges.

Support/assistance

One of the main identified topics was related to support/assistance. These themes were used in different contexts. One of the most common contexts was in relation to looking for expert assistance after they (parents) noticed peculiar inappropriate behavior in their child. This is best reflected in this passage:

"He started to pull out the dishes out of dishwasher machine, climb the furniture, had uncontrollable bursts of jumping and screaming. Because of that behavior we decided to look for expert support".

A similar case is reported by another parent:

"My son became agitated, hyperactive and talks less. When he plays, he does it in a peculiar way, turns the toy car and just spins the wheels. Or he spills the water from one glass to another for hours. If we stop him in that play, he starts to scream. He had sleep disorder, slept very little, but when he wakes up, he is refreshed. For all of us (the whole family) it was very exhausting, both psychologically and physically. So, we decided to ask for expert support". Similar experiences were reported by parents in other countries. For example parents of children with autism in North Wales also reported difficulties in understanding their child's behaviors and the confusion that resulted from their inability to make sense of these behaviors, as well as problems in obtaining a diagnosis (Midence & O'neill, 1999).

There was also one similar article written by a parent that provides recommendations for other parents. It says:

"A child with autism at birth, in most cases, shows no signs of having or having difficulty. Only after the first year of life, parents notice signs of deviation, and they become increasingly pronounced between 18 and 36 months. The most significant signs are not responding to their own name, overreacting to sounds, not making eye contact, not connecting with others through babbling, gesturing, or talking, not combining words, not showing interest in playing with others, stereotypically arranging toys, and more. In such cases it is necessary as soon as possible to look for expert support as early intervention is key in improving the outcomes of children with autism".

However, it is not explicitly stated who is the main provider of "expert support". In most cases the first professional to deliver expert support is a pediatrician. Pediatricians usually refer children to psychologists or speech therapists and some parents have reported their dissatisfaction with these services. Individuals diagnosed with autism and who reside in countries with low to middle income, may have limited access to health and social care services (Guler et al., 2018). Probably, the lack of services contributes to parental dissatisfaction. Levels of satisfaction with pediatric services depend on several factors. Research has shown that parents with higher income are more likely to report being satisfied with the services received by their pediatrician (Hidalgo et al., 2015). In the study by Hidalgo et al. (2015), most families reported challenges with service delivery from medical professionals, especially pediatricians. On the other hand, it is crucial for parents to have positive experiences with first-line professionals during the diagnostic process, as it can have a considerable impact and form the basis for future relationships with other service providers (Boshoff et al., 2018).

The term 'support' is also used to relate to mutual support among parents and support from the community. In one article, a parent stated: "Parents need to be aware of different types of developmental disabilities and know about them, which is a positive (thing) as it enables mutual support among parents". Similarly, one parent reported: “If we want and expect sensibility from our environment, it is very important for us (parents) to be sensible and support to one another.” This support system can be invaluable in providing emotional and practical support, which can help alleviate some of the challenges that come with raising a child with a developmental disability. Additionally, the idea of parents supporting one another emphasizes the need for a collective effort to create a supportive and understanding environment for families of children with autism. Studies have shown that parent-to-parent supports are a good source of emotional support, advocacy, and knowledge related to their child’s diagnosis, and practical advice (Lee et al., 2023). Some parents featured in these articles have initiated the creation of their own non-governmental organizations (NGO) for assisting parents of children with autism. Parents often stress the lack of systemic support for their children; these NGOs might help overcome shortages of various support services.

Education

The second main theme occurring in these articles is related to education. One great challenge regarding the education theme was online classes due to the COVID-19 pandemic. In the words of one parent:

“This online school is terrible, everything is digital, and this form of schooling is very negative for our children and can even harm them. We tried to limit our children’s’ time with tablets, phones, and laptops… Our children need a human face, human gesture, movement, speech, and everything necessary for child’s development.” Such challenges and dissatisfaction of online school due to the pandemic were not the case just in Bosnia and Herzegovina but throughout the world. Parents reported similar experiences in Serbia (Stankovic et al., 2022), Indonesia (Daulay, 2021), and Hong Kong (Lau & Lee, 2021). However, it is important to note that some parents reported both positive and negative effects of the lockdown. For example, some parents reported benefits from additional time with their children during the lockdown (Boskus-Genc & Sani-Boskurt, 2022). In a study conducted in Australia, parents were asked how the COVID-19 pandemic had impacted their child’s education experience. Nearly half (48%) of the parents reported only negative impacts, 26% only positive impacts, 12% a mix of positive and negative impacts, and 9% little or no impact (Simpson & Adams, 2022). The topic of inclusive education is nearly ubiquitous in discussions related to education. As in one parent’s report: “As we advocate for the rights of inclusion in education and develop a professional approach for educating children with autism, we must not forget that children with autism also need support outside of school hours, and their parents need support in their daily lives. Part of the support system for children with autism are the services which serve as their only "school".”

This topic is also related to the “support” topic mentioned earlier. Parents advocate support systems through NGOs as systemic support from the state is lacking. Or in words of another parent:

“Many children and young people with autism, as well as other forms of disabilities, in Sarajevo do not go to school, much more than the 200 that have been recently talked about in the media. It is a big task for the authorities of Sarajevo Canton to ensure that, in addition to the legal obligation to support inclusive education, support services such as our "Give us a Chance" (NGO) have continuous and secured work.”.

Here, parents stress the problem of some children who do not attend school. Unfortunately, we do not have exact data on the number of children with autism or any other group of children with disabilities, who do not attend school for any reason in Bosnia and Herzegovina. It is important to note that Bosnia and Herzegovina have signed and ratified the UN Convention on the Rights of Persons with Disabilities and that we have a positive legislature regarding inclusive education. However, there are still many challenges to fully implement inclusive education. Lastly, not all parents of children with autism support or favor inclusion. In the words of one parent:

“I would be happiest if I could enroll my son in a typical school tomorrow without needing any assistance and being able to follow the classes normally. That is every parent's dream. Let's ask ourselves how many children are truly capable of that. Is it possible? Would you be willing to sacrifice a class of 30 children for a child with severe autism or aggression? Would that be fair to those children? Would that child benefit from such learning? Inclusion is possible in some cases, but I don't think it involves large numbers of children.” As can be seen from this statement, perspectives of parents regarding inclusive education are different.

Relationship between spouses

The next theme we identified is related to the relationship between spouses. This is a sensitive and complex issue, as the experience of having a child with autism can vary widely between families. Responsibilities for the child and lack of support make some aspects of life difficult. As one of the parents put it:

“"We all give up many of our passions, for example, I used to sing in a cultural society as a hobby, but since my child was diagnosed, no more. My husband and I, now that our child is almost eight years old, went out to dinner only once, and that was because someone accepted to take care of our child, not because we couldn't afford it, but because we really don't have anyone to leave our child with."

These kinds of challenges are widespread in Bosnian society. For most individuals, it can be difficult to balance the responsibilities of being a parent and a partner. This can be particularly challenging when additional time and effort are needed in the parenting role as in the case of parents of children with autism (Brobst et al., 2009). However, it is important to have support from the spouse /partner, and many reports stress that aspect. Some examples of this:

“My husband and I share the same responsibilities, I do not have the problem that my husband left me, as there are many such cases.” Similarly, one other mother also wrote:

"My husband is the most responsible for our child's progress besides kindergarten and school. He (the child) has gained discipline and a sense of order from his father, which is very important for children on the autism spectrum because they tend to be hyperactive. My husband has managed to impose a rhythm, some forms of behavior, and a sense of order. He probably has more sensitivity, breadth, spirit, and a sense of humor."

Other studies have also emphasized the significance of sharing the workload with one's spouse and dividing responsibilities (Brown et al., 2021; Kuhaneck et al., 2010). It is important to note that research has indicated that spousal relationships are multifaceted and tend to change over time. Some families report a better relationship between each other, but on the other hand, some also reported fighting more, lack of spousal support, and a feeling of distance from their spouse (Hobart, 2008).

Child’s future

The last theme we identified concerns the future and uncertainty regarding their child. Parents ask themselves what will happen to their children when they (parents) are gone. This is best reflected in the concerns of one mother who wrote: “The problem is also that we are getting older, losing strength, while our children are getting stronger. We are not able to take care of them as we did before. The day will come when death strikes us and we will have no one to leave our children to.”

The implications of this statement are related to the challenges and fears faced by ageing parents of children with disabilities. The parents may be concerned about their ability to continue providing care and support for their children as they age and become less physically capable. They may also be worried about their children's future after their own passing, as they may not have anyone to care for them or ensure their well-being. This highlights the need for greater support and resources for ageing parents of children with disabilities, as well as planning for the long-term care of these individuals.

Concerns about their children’s future after the parents are gone is a universal topic in parental narratives. Previous studies have found that death concerns of parents with autism are related to their psychological well-being (Cox et al., 2015). Thus, it would be extremely important to have local support systems in place so that parents are aware of them. That, in turn, would certainly alleviate some of the parental anxiety regarding their children’s future.

Strengths of this study

We believe that this approach in analyzing parents’ experiences is very valuable in providing us with the experiences of parents. Also, involving parents of children with autism in research and having them as authors of papers can help ensure that research is relevant, meaningful, and inclusive, and can contribute to a more accurate and comprehensive understanding of autism and its impact on families. Parents of children with autism have first-hand experience and insight into the challenges and issues that their children and families face. This can provide a unique perspective that may not be captured by researchers or professionals who do not have this experience. Additionally, by being authors of papers related to autism, we believe that parents can contribute to raising awareness and understanding of autism and its impact on families.

Limitations

There are several limitations in this study that need to be acknowledged. Firstly, the sample of parents featured in these texts may not be representative of the entire population of parents with children with autism in Bosnia and Herzegovina. Access to media and the ability to share experiences via an article may not be available to every parent. Secondly, different individuals may interpret the content in various ways, resulting in multiple themes in a single piece of content, as is typical with this type of study. Furthermore, the number of media articles covering parental experiences was limited, with only 20 articles identified for analysis. As this was a written material analysis, we could not ask follow-up questions that would provide a better understanding of parental challenges. Content analysis of written material is typically limited to the information that is explicitly stated in the text and does not capture non-verbal cues or other contextual information that may be important in understanding the text. This can limit the depth and nuance of the analysis and may not provide a complete understanding of the phenomenon being studied. Future studies should complement the written material with interviews with parents as it would provide a more comprehensive picture of parental challenges in Bosnia and Herzegovina.

4. Conclusions

The main identified themes in media articles written by parents were support, education, spousal relationships, and the child's future. These themes are often interconnected and highlight the complex and multifaceted experiences of parents of children with autism. The findings underscore the importance of providing comprehensive support to parents, increasing awareness of their needs and challenges, and advocating for policies and interventions that address these issues.

Conflicts of interests

The authors declare no conflict of interests.

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