

GROWING UP WITH A BROTHER DIAGNOSED WITH AUTISM SPECTRUM DISORDER: THE SIBLINGS' PERSPECTIVE

SILVIJA HINEK¹, ANA TOKIĆ MILAKOVIĆ²

¹Dakovo Nursing Home, ²University of Zagreb, Faculty of Law, Department of Social Work,
contact: silvija.hinek@gmail.com

Primljeno: 3.12.2018.
Prihvaćeno: 5.6.2019.

Izvorni znanstveni rad
UDK: 376-056.36:616.896
616.896:316.362.1-055.71
<https://doi.org/10.31299/hrri.55.1.1>

Abstract: *The relationship between siblings is often the longest lasting relationship within an individual's life (Cicirelli, 1995). This relationship is especially important for individuals with developmental difficulties, since their siblings are usually those who undertake the role of caregivers, after the parents are no longer available to do so. However, recent research suggests that establishing a close relationship with a sibling diagnosed with autism spectrum disorder (ASD) may be considerably more challenging compared to siblings with other developmental difficulties (Tomeny et al., 2017). Although the siblings of individuals diagnosed with ASD have received a certain amount of attention in the last decade worldwide, this area is still under-researched in Croatia, and is insufficiently addressed in interventions aimed at helping families with children diagnosed with ASD. The aim of this study was to explore the experiences of siblings living with a brother with ASD and their perceptions of the received and needed support. Six semi-structured interviews with adult siblings of individuals with ASD were conducted and analysed using thematic analysis. Generally, most of the interviewed individuals show a relatively high level of acceptance and affection towards their brother and feel that they have adapted to the brother's condition. Although they mentioned some positive experiences and outcomes, they reported on many difficult aspects of growing up with their brother on the autism spectrum. None of them received any professional support during their growing up, and their opinions about the potential usefulness of programs targeted at siblings are divided.*

Key words: *siblings, autism spectrum disorder, support, qualitative study*

INTRODUCTION

The autism spectrum disorder (ASD) belongs to the category of neurodevelopmental disorders that manifest during early development years and is characterized by deficits that cause impairments in personal, social, academic and/or work functioning (American Psychiatric Association, 2013). Although symptoms differ from person to person and can range from mild to severe (Simpson, 2014), ASD is a complex condition affecting the individual's developmental path as a whole (including emotional, social and cognitive aspects) and impacting significantly the way individuals communicate with and relate to other people and the world around them. For this reason, ASD is not

only a difficulty for the affected individual, it is a challenge for the whole family, especially in developing mutual relationships.

Since the relationship between siblings is often the longest lasting relationship within an individual's life (Cicirelli, 1995), it is considered especially important for individuals with developmental difficulties because siblings are usually the ones who undertake the role of the caregiver, after the parents are no longer available. The quality of this relationship has also been shown to be of importance for the typically developing (TD) siblings of individuals with developmental difficulties, as their reports of positive, rewarding and close sibling relationships coincided with reporting the high level of general well-being and perceived benefits

of being a sibling to a brother/sister with disabilities (Hodapp & Urbano, 2007; Hodapp, Urbano, & Burke, 2010).

However, recent research suggests that establishing a high-quality, close relationship with a sibling diagnosed with ASD may be considerably challenging, even compared to siblings with other developmental difficulties (Tomeny, Elis, Rankin, & Barry, 2017). The reasons for this are the ASD sibling's challenging behaviors involving repetitive actions, aggressive behavior, impulsiveness (Hastings, 2003) as well as their scarce speech and communication (Kaminsky & Dewey, 2001). Other challenges may stem from the subordination of the TD child, in terms of the amount of time, attention and energy dedicated by the family to a child with ASD (Hesse, Danko, & Budd, 2013; Patelas, Hastings, Nash, Dowey, & Reilly, 2009), which might affect the TD sibling's successful adjustment (Hesse et al., 2013) and, subsequently, their readiness and capability to build a relationship with the sibling on the autism spectrum. Therefore, in studying and working with families, it is very important to capture the TD siblings' perspective of growing up with a brother or sister diagnosed with ASD, as well as the perceived influences on their own well-being.

Previous research on the siblings' perspectives documents both positive and negative experiences of growing up with siblings diagnosed with ASD. Positive experiences of growing up with a sibling on the autistic spectrum include the adaptation of TD brothers and sisters to the situation in the family, establishing cohesion as well as enjoying common activities and friendship with them (Patelas et al., 2009; Patelas, Hastings, Nash, Reilly, & Dowey, 2012). These siblings developed a deeper understanding of ASD and higher levels of gratefulness for their own health (Baron-Cohen & Bolton, 2000), better self-esteem and greater maturity compared to their peers (Ward, Tanner, Mandelco, Dyches, & Freeborn, 2016). Furthermore, fewer conflicts and less mutual competition among brothers and sisters were found in families with a child diagnosed with ASD (Ward et al., 2016). The positive aspects of growing up with a sibling with ASD also include developing a higher level of empathy (Baron-Cohen & Bolton, 2000; Benderix

& Sivberg, 2007; Corsano, Musetti, Guidotti, & Capelli, 2016), as well as learning about acceptance and tolerance toward others – living with a brother or sister with ASD can teach individuals to condemn other people less and to manage to accept them the way they are (Patelas et al., 2012).

On the other hand, research also points to some negative aspects and outcomes of living with siblings with ASD. Some brothers and sisters have problems in emotional adaptation because they feel neglected by their parents which reflects on their quality of life (Baron-Cohen & Bolton, 2000) and some siblings point to social isolation and reduced free family and recreational time (Patelas et al., 2009). Research also shows that siblings experience fear of aggressive behavior (Ward et al., 2016), accompanied by feelings of embarrassment, frustration and disappointment (Angell, Meadan, & Stoner, 2012). Brothers and sisters of individuals with ASD report on less intimacy, nurturance and prosocial behavior compared to the siblings of individuals with Down syndrome, or TD siblings (Kaminsky & Dewey, 2001). Further challenges include coping with often unhelpful responses from the social environment, and explaining the condition of their sibling to others, which often led to feelings of shame, frustration and anger (Patelas et al., 2009). TD siblings often develop a sense of responsibility for their siblings with ASD (Benderix & Sivberg, 2007). In younger children, this manifests as feeling obliged to protect them from hurting themselves or others and occasionally providing parents with some respite, while older siblings develop a sense of responsibility for their sibling in the future, which is often accompanied by feelings of sadness (Benderix & Sivberg, 2007).

In sum, the current review of literature on the brothers' and sisters' experiences point to both positive and negative impacts of living with a sibling with ASD on the TD sibling's own development. Although siblings of individuals on the autism spectrum have received a certain amount of attention in the last decade worldwide, this area is still under-researched in Croatia, and has not been sufficiently addressed in interventions aimed at helping children with disabilities and their families (Wagner Jakab et al., 2006). Therefore, the aim of this study was to identify challenges in growing

up with a sibling diagnosed with ASD within the context of the Croatian support system, as well as the siblings' specific needs for support. This should assist in the development of successful programs aimed at facilitating positive relationships between siblings, cutting across the negative and promoting the positive aspects of their co-development. The research questions arising from this research objective are: 1. What are the adult siblings' experiences of living with a brother with ASD?, and 2. What are their perceptions of the received and needed support?

METHOD

Participants and procedure

The target population of this study were adult siblings of people diagnosed with ASD. Due to the specificity of the targeted population, a deliberate sampling was administered. Four men and two women in the age range from 21 to 44 years old participated in the study. The average age of the participants was 32 years. None of the participants were married, and one person cohabitated with a partner. All the participants lived in Zagreb and were employed. Five out of six participants rated their health status as excellent and only one as average. As for their educational status, three participants have completed high school education, one has a college education degree, one participant is currently a student and one has a university degree. Out of all the participants, apart from a brother with ASD, only one has another sibling, who is of typical development.

The participants were recruited through the Association for Autism Zagreb, to which an invitation for assistance in conducting the research was sent. Specifically, the association provided us with the contacts of the families whose members would meet the criteria of the targeted population of this research. Twelve parents were contacted altogether, out of whom eight agreed to provide the contact number of their TD children. Out of the eight contacted siblings, six agreed to participate in the study. Individual semi-structured interviews were conducted in their homes. Interviews lasted from about 20 to 70 minutes, with an average duration

of 40 minutes. Participants received a small gift as a token of gratitude for their participation.

Interview structure

The interview protocol consisted of three parts. In the first segment, the questions referred to the siblings' experience of growing up with a brother diagnosed with ASD, their everyday life, spending time together, the quality of the relationship, pleasant and unpleasant experiences and how having a brother with ASD influenced them. The second part of the protocol consisted of the questions concerning the support received so far, their perception of the need for support, and their suggestions for the possibly useful means of support to brothers and sisters of a sibling with ASD. The final part of the interview dealt with collecting socio-demographic data such as gender, age, education level, employment and marital status, the number of household members and an assessment of the participants' health status. Before the beginning of the interview, the interviewer (the first author of this paper) acquainted the participants with the purpose of the research, the planned topics of the interview, the estimated time of the interview, their right to stop the interview at any time, as well as the principle of confidentiality and anonymity of the data they provide. Furthermore, the participants provided their oral consent for the interview to be recorded.

Analysis

Each interview was transcribed verbatim. All transcripts were first read by the researchers in order to acquire a general impression about the accounts provided by the participants (Creswell, 2003). We processed the collected data using thematic analysis. The process of open coding was performed, after which the initial codes were grouped into subthemes and themes. In the process of coding the data, we used the constant comparative method (Strauss & Corbin, 1998) in cases where the data did not fit to the existing codes, new codes were developed. This iterative process resulted in consecutive refinements and improvements of the coding scheme. The researchers regularly discussed the codes and themes, agreeing upon the final solution.

RESULTS

The experience of living with a brother diagnosed with autism spectrum disorder

The first research question referred to the description of the individual experiences of the TD siblings about growing up with a brother diagnosed with ASD. The questions touched upon their growing up, everyday lives, mutual relationship, positive and negative experiences, and reactions from the social environment. We extracted nine themes (with related subthemes): the sibling's role in the brothers' life, the acceptance of the brothers' condition, the feelings related to having a brother with ASD, interaction-related difficulties, the relationship with the brother, the relations with the social environment, parental double standards, positive experiences and perceived influences on their own personalities.

The sibling's role in the brother's life. While describing their everyday lives with their brother who is on the autism spectrum, most siblings named their parents as the main caregivers to their brother with ASD. However they also reported **"stepping in" as a caregiver** – providing help with taking care of their brother when the parents are prevented (*"... the mother is the caregiver, today, and she has always been... Once, when mom went to the hospital to have surgery, and was absent for a few days, I devoted myself to my brother and took complete care of him 24/7. That week I didn't go to school... giving him a bath, helping him shower..."* (P2)). In addition, aware of the parents' mortality, several brothers and sisters shared their **thoughts about the future** and being preoccupied with the increased responsibility for their brother in the future (*...one day my folks won't be here... mom has already gone, it's dad's turn now... think what my life will be like if I have a wife... children...? Will he live with me or somewhere else? Could I bear that he is somewhere else? ...I started thinking about it in secondary school... you know that this is waiting for you...* (P4)).

Acceptance of the brother's condition. All participants reported that living with a brother who has ASD is "normal" to them and display a high level of acceptance. They provide several rationales for this acceptance: some participants stated that

their **brother was "always like that"** (*...my brother has always been here... as far as I can remember, so it was a normal situation for me. Always.* (P4)), or they **adjusted as they were growing up** (*There were phases... when you're asking yourself – Why did it happen... to me? Why is he like that? Especially when you are younger and don't understand all that. I remember, then I thought – ok, now my brother is going to the hospital, then he will come back healthy... Until you realize, until you get informed and involved, as you get older you understand what it is, that it's a condition... Yes, I've accepted it, completely, completely, without shame, hesitation, completely, at all... it is all normal now... If I go somewhere, my brother goes with me...* (P2)). Also, the participants report that **what seems abnormal to others is normal inside their home** (*...things we go through every day, well, it's abnormal for most of people. These are not normal conditions, but you live like that, it becomes normal to you...* (P5)).

Feelings related to having a brother with ASD. The fact of being the brother or the sister of someone with ASD evoked both pleasant and unpleasant feelings in the participants. The pleasant feelings included **love and cuddling, happiness, not being difficult** (to take care of the brother), **not being embarrassed**, and **having fun**. They more frequently mention unpleasant feelings in their accounts, such as **hardship, embarrassment, annoyance, anger and frustration, sadness, fear/ anxiety/tension, helplessness and exhaustion**. Interestingly, in several instances the same participants stated it was not a problem nor difficult to have a brother with ASD whereas in another context they would acknowledge how difficult it was for them.

Interaction-related difficulties. All the participants spent a considerable amount of time narrating and providing examples of the difficulties in social interaction that their brother had. Among these, they mentioned **communication problems** stemming from low verbal abilities, problems understanding others and being understood, as well as the deficits in social communication (*Essentially, he has low verbal abilities. And there were problems of... understanding and communication* (P6)). They also talked about their **exposure to chal-**

allenging behaviors like angry outbursts, yelling or screaming (...he has outbursts, aggressive horribly. And you really don't know when it will happen, just all of a sudden... (P1)).

Relationship with the brother. Some participants describe the relationship with their brother as an **“unusual” relationship** that is manifested through the lack of (or no) interaction (...we don't discuss anything like two brothers, nor did we play together when we were little...He has got his own world, and I have got mine. And that's it. There is no normal relationship, no. (P5)), lack of reciprocity (...you do everything, and get nothing... (P4)) and lack of stability (If he is in his good phase, I also somehow have a different attitude towards him, and if he is at some of his other stages... (P2)). Furthermore, some participants feel the **attachment** in the relationship with their brother (...I'm pretty attached to him...And I simply like that he is always somewhere near. (P1)). Many participants describe the relationship through their **joint activities** which involve taking a walk, going to the cinema, playing computer games, having a meal/drink together outside (Our relationship was that we mostly played computer games... (P3)). One participant (P5) quotes that he had no shared activities with his brother. Finally, one participant stated that she had an **authoritative relationship** with her brother (I, as a sister, did not really give it up to him...you know, like brother and sister...Let's say unlike parenthood...So, a parent will probably give it up to you earlier than your brother or sister. So he always had some kind of better contact with me than with our parents. It's different. Because they like authority, actually... (P6)).

Relations with the social environment. In their narratives about the experience of living with their brother on the autism spectrum many participants mentioned and described some **inconveniences in public** they experienced with their sibling, related to their brother's awkward behavior in public. Regarding other people's reactions and their (mis) understanding, they provided both pleasant and unpleasant examples (...a kid is eating ice-cream or cake or something, and he comes and takes it from him. Of course, the kid starts to scream... his parents...some of them just say (exclaimed) “aaaa” and ...they practically run away, but

some parents are great ...and say: “you see, you could have offered him some, see we are not all the same...”. And...they leave us in some normal way. (P4)). Another subtheme concerning the relations with the social environment that featured in the siblings' accounts are **difficulties in explaining their brother's condition to others** (...I wasn't embarrassed because he was like that, but, I didn't want to answer all those questions, firstly, because it would take too much time, secondly, because it's really not important to those people who belong to a wider circle of your acquaintances (P4)). Several participants also pointed to the high level of their **friends' acceptance** of their brother with ASD (...with my friends...he is a favorite in company and accepted (P2)).

Parental “double standards”. Most participants acknowledged that the parents gave more attention, time and other resources to their brother with ASD than they themselves had a chance to receive. However, the siblings generally show a lot of understanding for these “double standards” (...my mother told me once that they wanted me to go to music school, but they simply couldn't...organize it...one car, they drove him to school.... When my mother told me...: “Maybe we didn't take enough care of you”. Then I said: “you said this now and never again! ...you did all you could do.” (P4)).

Positive experiences. When asked about the potential positive aspects of growing up with their brother on the autism spectrum, some participants recalled many **funny situations** like pranks and funny misunderstandings (...When there was a football match... we would score a goal and everybody is happy. For some time he rejoiced with us, but he would also rejoice when the opposing team scored a goal... (P3)). They also listed some of the **brother's positive traits** like honesty, willingness to share, meticulousness etc. (Many things. They are usually very sincere, autists don't lie. (P6)). **Cuddling** was also mentioned in several cases as a positive experience with the brother (He's a big cuddler...likes listening to music and, I don't know, we listen to music together and we give each other kisses (laughter) (P1)). One participant mentioned **being given more freedom by the parents** as a positive side effect of growing up with a challenging sibling (I have a feeling that there was more

freedom...I remember the parents of that time... they thought they knew best, but, actually, they made a mistake because they just pressured the kid at the age when they didn't need to cling to him. I. e. he must be clung to in a smarter way. And my folks had no time for that, so I was lucky. (P4)).

Perceived influence on their personality.

Most participants agreed that growing up with a brother with ASD had some implications on developing their own personality traits. Some participants outlined **becoming more responsible** earlier than their peers (*I became responsible at an early age. I can really say that...Because living with him teaches you that you must be a certain way. I have never done anything irresponsible, especially not to him (P2)*). Several participants reported increased **understanding/empathy for other people** (*... It's written (on the car) that it's driving school and....there is someone who drives his third lesson, and...he doesn't know how to squeeze the gas pedal and the brakes, his car turns off...and now the guy behind him, naturally, starts to honk the horn. I think that one must understand that someone doesn't know all that, he is only in the process of learning...so you must have understanding, just as my brother can't do some things, that driving school student can't do that at that moment (P4)*), or inclination towards **prosocial behavior** (*I have no problem approaching anybody who needs my help (P2)*). One sibling highlighted that his brother's condition **motivated him for success** (*...you see him and when you understand his condition, you want to improve your life for yourself. You don't expect some things to be done for you. ...no matter how strange it sounds, it is actually motivating. (P5)*). Only one participant declares that he perceives **no influence of his brother's ASD on his own life** (*Well... It didn't change me because practically all my life I have known that it is so ... but it changed my folks a lot, because when this tragedy happened in the family, you just can't stay normal ... you can't stay unchanged (S03)*).

Perceptions of the received and needed support

The second research question referred to the perceptions of the received and needed support. The questions touched upon the participants'

perceptions of the support provided to the whole family, as well as the specific support provided to them as siblings of individuals with special needs. Furthermore, they evaluated their need for support so far and their recommendations for the potentially useful types of support were prompted. We extracted 3 themes with subthemes: received support, the perceived need for support and suggestions for the types of support.

Received support. When asked about the support they received regarding their brother's condition, the participants pointed to the **informational and emotional support from their parents** (*...she (mom) would simply give us instructions. Look, like this, like this, like this. Look, not that way, but this way with him. (P5); I was also happy, because I knew that I always had their (the parents') support... (P2)*). They also mentioned **support from the extended family** (*Everyone gives their best... not only mom and dad, but also grandmother and grandfather and aunt and uncle (P3)*) and **support from friends** (*Me and my brother would be out somewhere and it starts to rain, nobody can come and get us, I call my friend to come to pick us up and so... (P2)*). It is worth noting that no participants can recall **any formal support** targeted at siblings of individuals with ASD. (*No...nothing... (P2)*) and some of them subsequently critique the system and the experts (*I attack the experts here... There are good experts, but there are more bad ones than good ones. (P6)*).

Perceived need for support targeted at the siblings. The participants' opinions about the potential usefulness of programs targeted at siblings of persons with ASD are somewhat divided. Thus, four participants perceive **no need for specific support** (*I have no feeling that it would help me very much...let's talk about that, no, no, no way. But, I am probably not the kind of person who would benefit from something like that, I have no need for that. (P4)*), and only two participants saw the **benefit in support provision** (*I think that we'd better talk....Yes, the brothers and sisters are, let's say, neglected a little...in these hard situations. Especially, when he was hospitalized...Then...in puberty...I was a girl then, too.... I kept something for myself, and that suffocated me, squeezed me... (P6)*).

Suggestions for the types of support. Finally, participants provided some suggestions concerning the possible means of support that might be useful to the siblings of individuals with ASD, based on their own experience. They suggested that it is important to have **someone to talk to** outside of the family (*I also had moments, although I'm open and I didn't hide anything from mom, but...I would keep some things for me, and it would stifle me...I think it would be much better if we could have...someone to talk to us...(P2)*), and others saw the benefits of being in **contact with other typically developing siblings who have siblings with ASD** (*Within the association, maybe it would be better...to talk...to come in contact with other brothers and sisters...(P6)*), participating in **working groups** (*...I think it would be much better if we could have some working groups...(P2)*), and **getting appropriate explanations about their brother's condition** (*...the approach to the child is very important...how do you, for example, explain to a 10 or 11-year-old child what it (autism) is...(P6)*).

DISCUSSION

The findings of this study offer insight into the experiences of a small sample of adults who have a brother diagnosed with ASD. Consistent with the review of literature presented in the introduction section, siblings in our sample outlined both positive and negative aspects of growing up with their brother. By doing so, all the participants reported that living with a brother who has ASD is “normal” to them and almost all of them exhibited a high level of general acceptance, regardless of the different unpleasant feelings they often faced (frustration, anxiety, anger, sadness etc.).

The siblings mostly perceive their role in their brothers' lives as very important in terms of occasionally helping the parents in their caregiving role, and are very preoccupied with their role in their brother's life in the future, when the parents will no longer be available as caregivers. Similar worries have already been documented in previous research (Angell et al., 2012; Benderix & Sivberg, 2007; Patelas et al., 2012). Because of their sense of responsibility for their brother, they often delay their own plans to be able to take care for their brother (Corsano et al., 2012).

Furthermore, all the participants talked about the difficulties of social interaction with their brother. Among these, they mentioned communication problems stemming from low verbal abilities, problems in understanding and the deficits in social communication. They also talked about their exposure to challenging behaviors such as angry outbursts, yelling or screaming. All of these represent challenges for establishing a sibling relationship (Hastings, 2003), and may explain why relationships with siblings who have ASD are averagely lower in quality compared to being the sibling of people with other disabilities (see Tomeny et al., 2017, for a review). Thus, in previous research, TD siblings identified the challenging behaviors as the most negative aspect of coexistence with a brother or sister with ASD (Angell et al., 2012), and pointed to aggressive behavior as one of the most stressful experiences in growing up with a brother or sister with ASD (Patelas et al., 2012). Also, in previous studies, communication problems (Ward et al., 2016) and the inability to conduct mutual conversations (Moysen & Roeyers, 2011) were identified as the main difficulties in establishing sibling relationships.

Accordingly, in our study, some participants describe the relationship with their brother as an “unusual” relationship that is manifested through the lack of (or no) interaction but most of them feel the attachment in the relationship with their brother nevertheless. Many participants describe the relationship through their joint activities which involve taking a walk, going to the cinema, playing computer games, having a meal/drink together outside. In previous research, some brothers and sisters reported that they had a close and warm relationship with their brothers and sisters with ASD (Kaminsky & Dewey, 2001), while others were not close to each other (Hodapp & Urbano, 2007). Tomeny et al. (2017) showed that TD brothers and sisters of children with ASD have less positive attitudes towards their relationship with their siblings compared to the siblings of children with Down syndrome.

Another challenge mentioned by our participants were the relations with the social environment. They described numerous inconveniences experienced due to their brother's awkward behav-

iors in public. Similarly, previous research reported on prejudices and being misunderstood by their surroundings, as well as the people's ignorance about the ASD (Patelas et al., 2009). Opperman and Alant (2003) found that TD brothers and sisters believed their surroundings did not accept their siblings with ASD without prejudice and did not actually know how to behave in their company (Opperman & Alant, 2003). Also, staring at individuals with ASD had been reported in earlier research (Moyson & Roeyers, 2012). However, the participants in our sample described both pleasant and unpleasant examples of other people's reactions to their sibling with ASD. Together with some negative aspects concerning the relations with the social environment, several participants mentioned the perception of the acceptance of their brother with ASD by their friends, as well as some positive reactions from the observers. Another subtheme concerning the relations with the social environment in our study concerned the difficulties in making decisions who to explain the brother's condition to and how much detail to go into. Similarly, Patelas et al. (2012) found that many siblings refrain from explaining to their friends that they have a brother or sister with ASD. Since a child with ASD requires a lot of time and effort from the parents, it is not surprising that, in previous research, their siblings indicated that they received less attention from the parents compared to their sibling with ASD (Angell et al., 2012; Patelas et al., 2009; Ward et al., 2016). Moreover, Fleary and Heffer (2013) reported that the brothers and sisters felt jealous of their sibling with ASD because of that, and some even felt indignant about it (Meyer, Ingersoll & Hambrick, 2011). Hesse et al. (2013) reported that the lack of parental attention can be associated with poorer social adaptation of TD siblings, and Wigston, Falkmer, Vaz, Parsons, and Falkmer (2017) found that the brothers and sisters of children with ASD participated in fewer extracurricular activities than the siblings of TD children (Wigston et al., 2017). Interestingly, although the participants in our study also confirmed the previous findings about parental double standards, in most cases they also justified the fact that they received considerably less attention and available resources from the parents, because of their awareness of the needs their brother with ASD had. This was not mentioned in

previous research, and a possible explanation for these somewhat novel results may be in the age group of our participants. Previous research mostly involved children and adolescents (aged between 5 and 18 years), while the average age of the participants in this study was 32 years. It is possible that their maturation led to greater understanding and justification of their parents' actions.

Regarding the positive experiences of growing up with a brother with ASD, the results of this study are similar to those reported in previous research. Some participants recalled various funny situations involving their brother, as well as the brother's positive traits. Cuddling was also mentioned in several cases as a positive experience with their brother and one participant mentioned having more freedom from the parents as a positive 'side effect' of growing up with a challenging sibling. Similarly, in previous studies, the participants pointed to the positive qualities of their brothers and sisters, such as sharing a sense of humor, funny situations and enjoying the moments spent together (Burke, 2004; Patelas et al., 2009; Ward et al., 2016).

All the participants (except for one) agreed that growing up with a brother with ASD had some influence on the development of their own personality, and they predominantly talked about positive impacts. This included developing a sense of responsibility earlier than their peers, increased empathy for others and an inclination towards prosocial behavior. Similarly, Angell et al. (2012) found TD siblings to cite a sense of responsibility as the dominant sense in their relationship. However, Benderix and Sivberg (2007) found that many brothers and sisters felt obliged to protect their sibling with ASD, and this sense of responsibility increased with age, resulting in worry and thoughts about their future. The development of empathy, patience, sensitivity for others and caregiving potential have also been mentioned as the perceived benefits of being a sibling of a person with ASD in previous research (Angell et al., 2012; Ward et al., 2016).

The second research question tapped into the siblings' perception of received and needed support. Concerning the received support, the participants pointed to the informational and emotional support from their parents, support from the

extended family and support from friends. The aforementioned can be ascribed to the fact that the support system is still scarce in Croatia, leading to the family members relying on each other's support (Wagner Jakab et al. 2006). However, it is quite an unexpected finding that none of the participants received any professional support while growing up, and that the opinions about the potential provision of such support are divided. While the majority of our participants decline a need for specific support targeted at siblings of individuals with ASD, two participants identified potential benefits of such support and made suggestions concerning the possible means of support that might be useful for siblings of individuals with ASD. These were: talking with someone outside family, being in contact with other TD siblings who have siblings with ASD, participating in working groups and getting the appropriate explanations about the brother's condition.

Somewhat contrary to our results, previous research provided some evidence of the benefits of both informal and formal support to the typical siblings' development and coping with their siblings' ASD. Thus, in the study conducted by Angell et al. (2012), the participants expressed that they benefited from conversations with others who understood their situation, implementing the learned techniques to interact with their siblings with ASD, as well as that they saw benefits from educating others about ASD (Angell et al., 2012). Ling-Ling, Davenport, and Schmiege, (2012) point to the importance of open communication, sense of expression, the use of different support networks, and educating the brothers and sisters, as well as their parents, in the everyday challenges of living with people on the autism spectrum. Sibling support groups provide potentially helpful environment for coping with the situation of having a sibling with ASD. In such groups they are given the opportunity to discuss their experiences, express their feelings, solve problems, learn about autism in a supportive environment, and equally important, to have some fun. Thus, the results of an interventional study indicated that the siblings' notions and knowledge of autism improved significantly by participating in a sibling support group (Smith & Perry, 2004). Kaminsky and Dewey (2002) found

the social support from family members, friends, neighbors and professionals to be very important for the acceptance and life quality of the siblings of individuals with ASD (Kaminsky and Dewey, 2002). In the research conducted by Patelas et al. (2009), the participants reported that with the help of the parents, friends or peers they managed to overcome all the challenges they encountered in coexisting with their siblings with ASD (Patelas et al., 2009). They also mentioned the benefits of the respite service support (Patelas et al., 2009). Families need a support system to help them face and adapt to the challenges of caring for children with ASD. The quality of the services available to the families directly contributes to the parents' optimism, and early intervention services help foster hope, which is an important element of coping and adaptation of the whole family (Hall, 2012).

In line with our results, Lock and Finstein (2017) found that parents of individuals with ASD were eager for their TD offspring to participate in the support groups, while the TD siblings themselves expressed less interest. It seems that it may be very difficult for people who had no support to identify the benefits it could have provided, which is important for the support system creators to bear on mind. Educating and motivating the siblings for the participation might be a crucial part of the intervention.

Limitations and directions for future research

The targeted population of this research were adult siblings of people diagnosed with ASD. The limitation of the applied strategy of sampling is that all the participants are associated with the Association for Autism - Zagreb, which means that their parents and siblings with ASD do receive some kind of support from the mentioned organization. Future research should examine the experiences of siblings whose family members may not have any type of support. Furthermore, the potential limitation might be that this population is not often involved in research. As the research on this topic in Croatia is still rather scarce, all participants stated that they never participated in anything similar and that this was the first time anyone had asked about their experience of living with a family member diagnosed with ASD. This might have

resulted in selective responses of the individuals who are better adapted to the invitation to participate in the study. It is also important to outline that due to the small number of respondents and the use of qualitative research, the generalization of the findings is rather limited. Another limitation stems from the retrospective nature of collecting the data – our participants were adults who reflected on their memories that might have changed over time. The avenue for future research might be to carry out a longitudinal research in order to collect and understand the experiences and needs of TD siblings of persons with ASD at different stages in their life. Specifically, there might be differences in experiences between siblings of different age,

differences depending on the order of birth, and the overall experience might depend on the number of years coping with their brother's disorder. Finally, future studies should investigate the reasons why some siblings, in spite of the immense life challenges they face, believe that TD brothers and sisters would not benefit from professional help and support during their upbringing; and whether this has something to do with their age and stage of development, their negative experiences and general distrust of the support system in Croatia; or whether the concept of professional support in question was too abstract for the participants to see the potential benefit of it.

REFERENCES

- American psychiatric association (2013): Diagnostic and statistical manual of mental disorders, (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Angell, M. E., Meadan, H., & Stoner J. B. (2012): Experiences of siblings of individuals with autism spectrum disorders, *Autism Research and Treatment*, 2012, 1-11.
- Baron-Cohen, S., & Bolton, P. (2000): *Autism: the facts*. New York: Oxford University Press.
- Benderix, Y., & Sivberg, B. (2007): Siblings' experience of having a brother or sister with autism and mental retardation: a case study of 14 siblings from five families, *Journal of Pediatric Nursing*, 22, 5, 410-418.
- Braun, V., & Clarke, V. (2006): Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3, 2, 77-101.
- Burke, P. (2004): *Brothers and sisters of disabled children*. London: Jessica Kingsley Publishers.
- Cicirelli, V.G. (1995): *Siblings' relationship across the life span*. New York: Plenum Press.
- Corsano, P., Musetti, A., Guidotti L., & Capelli F. (2016): Typically developing adolescents' experience of growing up with a brother with an autism spectrum disorder, *Journal of Intellectual and Developmental Disability* 42, 2, 151-161.
- Creswell, J. W. (2003): *Research design: Qualitative, quantitative and mixed method approaches*. London: Sage Publications.
- Dunn, J., & Kendrick, C. (1982): *Siblings: love, envy and understanding*. Cambridge: Harvard University Press.
- Fleary, A. S., & Heffer, W. R., (2013): Impact of growing up with a chronically ill sibling on well siblings' late adolescent functioning, *ISRN Family Medicine*, 1-8.
- Hall, H. R. (2012): Families of children with autism: behaviors of children, community support and coping, *Issues in Comprehensive Pediatric Nursing*, 35, 2, 111-132.
- Hastings, R.P. (2003): Brief report: Behavioral adjustment of siblings of children with autism, *Journal of Autism and Developmental Disorders*, 33, 1, 99-104.
- Hesse, T. L., Danko, C. M., & Budd, K. S. (2013): Siblings of children with autism: Predictors of adjustment, *Research in Autism Spectrum Disorder*, 7, 11, 1323-1331.
- Hodapp R. M., & Urbano R. C. (2007): Adult siblings of individuals with Down syndrome versus with autism: findings from a large-scale US survey, *Journal of Intellectual Disability Research*, 51, 12, 1018-1029.
- Hodapp R. M., Urbano R. C., & Burke, M. M. (2010): Adult female and male siblings of persons with disabilities: Findings from a national survey, *Journal of Intellectual and Developmental Disability* 48, 1, 52-62.
- Joffe, H., & Yardley, L. (2004): Content and thematic analysis. In Marks, D.F., & Yardley, L. (Eds.), *Research Methods for Clinical and Health Psychology* (pp. 56-68). London: SAGE Publications.
- Kaminsky, L., & Dewey, D. (2001): Sibling relationships of children with autism, *Journal of Autism and Developmental Disorders*, 31, 399-410.
- Ling-Ling, T., Davenport, R., & Schmiege, C. (2012): Supporting siblings of children with autism spectrum disorders, *Early Childhood Education Journal*, 40, 47-54.
- Lock, R. H., & Finstein, R. (2009). Examining the Need for Autism Sibling Support Groups in Rural Areas. *Rural Special Education Quarterly*, 28, 4, 21-30.
- Lovell, B., & Wetherell, M. A. (2016): The psychophysiological impact of childhood autism spectrum disorder on siblings, *Research in Developmental Disabilities*, 49-50, 226-234.
- Meyer, K. A., Ingersoll, B., & Hambrick, D. Z. (2011): Factors influencing adjustment in siblings' of children with autism spectrum disorders, *Research in Autism Spectrum Disorders*, 5, 4, 1413-1420.
- Moyson, T., & Roeyers, H. (2011): The quality of life of siblings of children with autism spectrum disorder, *Exceptional Children*, 78, 1, 41-55.
- Moyson, T., & Roeyers, H. (2012): „The overall quality of my life as a sibling is all right, but of course, it could always be better“. Quality of life of siblings of children with intellectual disability: the siblings' perspective, *Journal of Intellectual Disability Research*, 56, 1, 87-101.

- Opperman, S., & Alant, E. (2003): The coping responses of the adolescent siblings of children with severe disabilities, *Disability and Rehabilitation*, 25, 441–454.
- Patelas, M. A., Hastings, R. P., Nash, S., Dowey, A., & Reilly, D. (2009): “I like that he always shows who he is”: The perceptions and experiences of siblings with a brother with autism spectrum disorder, *International Journal of Disability, Development and Education*, 56, 4, 381-399.
- Patelas, M. A., Hastings, R. P., Nash, S., Reilly, D., & Dowey, A. (2012): The perceptions and experiences of adolescent siblings who have a brother with autism spectrum disorder, *Journal of Intellectual and Developmental Disability*, 37, 4, 303-314.
- Powell, T. H., & Gallagher P.A. (1993): *Brothers and Sisters: A Special Part of Exceptional Families*. USA: Brookes, Baltimore.
- Shivers, C. M., & Plavnick, J. B. (2015): Sibling involvement in interventions for individuals with autism spectrum disorders: a systematic review, *Journal of Autism and Developmental Disorders*, 45, 3, 685–696.
- Simpson, S. (2014): *Autism, Nursing standard*, 28, 28, 19-19.
- Smith, T., & Perry, A. (2004). A sibling support group for brothers and sisters of children with autism. *Journal on Developmental Disabilities*, 11, 77- 88.
- Strauss, A., & Corbin, J. (1998): *Basics of qualitative research: Grounded theory, procedures and techniques* (2th ed.). London: Sage Publications.
- Tomeny, T. S., Elis, B. M., Rankin, J. A., & Barry, T. D. (2017): Sibling relationship quality and psychosocial outcomes among adult siblings of individuals with autism spectrum disorder and individuals with intellectual disability without autism, *Research in Developmental Disabilities* 62, 104-114.
- Wagner Jakab, A., Cvitković, D. & Hojanić, R. (2006). Some features of relation between siblings and people with special needs. *Croatian Review of Rehabilitation Research*, 42, 1, 77-86.
- Ward, B., Tanner, B. S., Mandleco, B., Dyches, T. T., & Freeborn, D. (2016): Sibling experiences: Living with young persons with autism spectrum disorders, *Pediatric Nursing*, 4, 2, 69-76.
- Wigston, C., Falkmer, M., Vaz, S., Parsons, R., & Falkmer, T. (2017): Participation in extracurricular activities for children with and without siblings with autism spectrum disorder, *Developmental Neurorehabilitation*, 20, 1, 25-39.

ODRASTANJE S BRATOM S POREMEĆAJEM IZ AUTISTIČNOG SPEKTRA: PERSPEKTIVA BRAĆE I SESTARA

Sažetak: Odnos između braće i sestara često je najdugotrajniji međuljudski odnos (Cicirelli, 1995). Ovaj odnos posebno je značajan za osobe s teškoćama u razvoju, jer njihova braća i sestre često preuzimaju ulogu skrbnika nakon što roditelji više nisu u mogućnosti obnašati tu ulogu. Međutim, novija istraživanja impliciraju da uspostavljanje bliskog odnosa s bratom ili sestrom s poremećajem iz autističnog spektra može biti značajno složenije i teže u usporedbi s braćom i sestrama s drugim teškoćama u razvoju (Tomeny et al., 2017). Iako je problematika braće i sestara osoba s poremećajem iz autističnog spektra predmet istraživanja u svijetu, u Hrvatskoj je još uvijek nedovoljno istražena, naročito s obzirom na implikacije takvih istraživanja u intervencijama usmjerenim obiteljima djece s poremećajem iz autističnog spektra. Cilj je ovog rada istražiti iskustva braće i sestara brata s poremećajem iz autističnog spektra te njihovu percepciju dobivene i potrebne podrške. Kvalitativnom tematskom analizom analizirano je šest polustrukturiranih intervjua s odraslom braćom i sestrama osoba s poremećajem iz autističnog spektra. Većina intervjuiranih sudionika pokazala je relativno visoku razinu prihvaćanja i privrženosti prema svojoj braći, te su smatrali da su se prilagodili načinu funkcioniranja svoje braće. Unatoč nekim pozitivnim iskustvima i ishodima, uputili su na brojne izazovne i teške aspekte odrastanja s bratom s poremećajem iz autističnog spektra. Nijedan sudionik nije bio uključen u programe formalne podrške tijekom odrastanja, a njihova mišljenja o potencijalnoj koristi programa namijenjenih braći i sestrama su podijeljena.

Ključne riječi: braća i sestre, poremećaj iz autističnog spektra, podrška, kvalitativno istraživanja