FATHER'S EXPERIENCES IN CARING FOR TWINS WITH AUTISM AND ASSOCIATED DISORDERS

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The care of parents for children with special needs is an individual experience focused on finding a diagnosis and the reasons for the child's special needs, as well as determining which responses to the child's needs, emotions, and behavior are effective. In this article, we provide an overview of research in this field in the Slovenian context, complemented by a qualitative study, a case study of a father caring for twins with autism and associated disorders. For an in-depth analysis, we chose a narrative interview or autobiographical narrative of the father, supplemented by a review of documentation on redirecting children to appropriate educational programs and photographs, as well as memories. The case study provides guidelines for practitioners and education reformers, emphasizing the need to offer parents of children with special needs sufficient listening, information, support, and assistance, while raising awareness in the wider community and providing an environment for everyone to socialize, get to know each other, and make friends.

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IZKUŠNJE OČETA PRI SKRBI ZA DVOJČKA Z AVTIZMOM IN PRIDRUŽENIMI MOTNJAMI

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Ključne besede:
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individualizacija

Skrb staršev za otroke s posebnimi potrebami je individualna izkušnja, osredotočena na iskanje diagnoze in razloga otrokovih posebnih potreb ter ugotavljanje, kateri odzivi na otrokove potrebe, čustvovanje in vedenje so učinkoviti. V prispevku podajamo pregled raziskav na tem področju v slovenskem prostoru in jih dopolnjujemo s kvalitativno raziskavo, študijo primera očeta, ki skrbi za dvojčka z avtizmom in pridruženimi motnjami. Za poglobljeno analizo smo izbrali narativni intervju oziroma avtobiografsko pripoved očeta, ki jo dopolnjujemo s pregledom dokumentacije o usmerjanju otrok v ustrezne vzgojno-izobraževalne programe, fotografijami in spomini. Študija primera praktikom in snovalcem prenove vzgoje in izobraževanja podaja smernice, ki poudarjajo, da je treba starše otrok s posebnimi potrebami poslušati ter jim nuditi dovolj informacij, opore in pomoči, ostalo družbo pa ozaveščati o tej tematiki ter poskrbeti za okolje, kjer se lahko vsi družijo, spoznavajo in prijateljujejo.

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1 Introduction

The literature review shows that there are a few studies that, in general, indirectly investigate the area of parents of special needs children (SNC); these studies are mainly quantitative. In this paper, we will highlight segments that are relevant to our topic, breaking them down thematically into: (a) cooperation of parents of SNC with educational institutions, (b) parents of children with multiple disabilities, (c) associations for the empowerment of parents with SNC, (d) life changes of parents with SNC, and (e) parents' care for SNC who have autism.

a) Cooperation of parents with SNC with educational institutions

Cavnik (2019) pointed out that parents of SNC should be included in the help and support systems from an early stage, and therefore kindergarten educators should be adequately trained. Jereb (2020) adds that in kindergartens, there are more seminars for educators than for parents with SNC, which should be changed.

Korpar (2021) elaborated on certain challenges in kindergarten: some parents with SNC find it difficult to recognize the importance of cooperation with the educator, but this changes in a positive direction when it comes to the redirection process for SNC into an appropriate educational program (the process usually takes place during the transition from kindergarten to school).

Kovačič Purgaj (2018) proved that parents of SNC need more time for themselves during the early treatment of their children, support from other parents of SNC, services for SNC near home, more additional information about services that will be available in the future of SNC, meetings with experts, etc. Krivec (2016) noted that parents generally have positive attitudes toward the inclusion of SNC in regular sections of kindergarten. Kozel (2021) also noted similar positive attitudes about inclusion in school, emphasizing that parents with SNC have more positive attitudes than parents with typical children.

Based on research, Hartman (2022) estimated that inclusive pedagogues in elementary schools include parents in the team designing and evaluating individualized programs for SNC, while the results of Makoter (2020) showed that there is insufficient cooperation with parents for first-grade teachers and educators.

The field of parental cooperation is therefore divided into different areas and has different effects. Plešec (2021) added that in the future more attention will have to be paid to the design and implementation of individualized programs and professional work with children and parents than to the redirection process itself.

Topolovec and Schmidt (2015) noted that after being transferred from a regular primary school to an adapted program with a lower educational standard, children with disabilities feel better because the program is more suitable for them. The disadvantage is that these schools are geographically scattered and SNC have fewer opportunities to socialize with their peers.

b) Parents of children with multiple disabilities

Zadravec (2021) explained that parents who have a child with multiple disorders experience more stress and that, in general, SNC parents, compared to parents who have typical children, express lower values of mental well-being, except autonomy. At the end of the research, the author (Ibid.) suggested that a regression analysis should be carried out, which could be used to determine the factors that influence the stress and mental well-being of parents of SNC.

c) Associations for the empowerment of parents with SNC

Gašparić (2021) wrote about the organizations, associations, and institutes in Slovenia that empower parents of children with disabilities, for example, the Školjke Maribor Society, SNOP Society, Bodi zdrav Association, Sožitje. These associations mostly operate in specific fields and focus on larger cities such as Ljubljana and Maribor.

d) Life changes of parents with SNC

The involvement of both parents and relatives is crucial for the development of a child with autism. This collaboration is essential as the child requires assistance with activities such as eating, drinking, toileting, personal hygiene, and other basic life activities (Horvat, 2009). The majority of parents of children with disabilities completely adapt their lives to meet the needs of their children, affecting their employment and daily tasks (Kolarič, 2009).

Parents of children with autism are overwhelmed with work, childcare, and family responsibilities, lacking sufficient knowledge about their child's diagnosis and receiving inadequate support from professionals. The introduction of free therapies for children, accessible in their home environment, along with companions or potentially volunteers, and in the future, personal assistants, were suggested. Improved awareness and acceptance of autism within society would also contribute significantly, requiring efforts to raise public awareness (Gostenčnik, 2021).

e) Parents' care for SNC who have autism

Children with autism can form attachments to their parents, although to a lesser extent than their typically developing peers. Parental sensitivity acts as a protective factor, preventing the development of insecure attachment in these children (Cugmas, 2018). Šnopl (2009) emphasized that the experiences of parents with a child with autism are unique to each family, but it is still noticeable that these parents often require more assistance from professionals and others. However, they are generally satisfied with the work of professional services. The most effective way to assist a child with autism is to identify the diagnosis early and initiate effective intervention with a quality educational plan (Ibid.).

The research problem presented in this article is based on the research question of exploring the experiences of a father, caring for twins, both of whom have autism and associated disorders. Making a narrative interview or autobiographical narrative story from the father allows for a broad coverage of this thematic area. The research aims to capture, in addition to the father's experiences, any feelings, thoughts, memories, and other aspects occurring in such a life experience that observers and researchers might not have considered (Ličen, 2013). Theoretical foundations will assist in the analysis and interpretation of the interview. The purpose of this qualitative research is to complement the results of other studies by delving into an atypical case and highlighting potential atypical life patterns.

2 Materials and Methods

2.1 Instrument

We conducted qualitative research using the biographical method. As a data collection instrument, we have made an autobiographical narrative interview with the father of twins with autism and other additional disorders.

The autobiographical interview allows for a retrospective view or focus on the life history of the interviewee. In the pre-phase, we familiarize ourselves with the interviewee, establish trust, explain the significance and purpose of the interview, and ensure anonymity. In the initial phase, we introduce the central theme of the conversation to the interviewee and pose an initial question that encourages the narration of their life story. The central phase is where the interviewee is listened to attentively and actively; only after they independently conclude their narrative, the questioning phase follows. In this phase, the researcher asks questions related to the heard narrative. In the concluding phase, we signal the end of the interview to the interviewee, followed by an informal conversation if desired (Rapuš Pavel, 2022). Nölke (1999) emphasized the crucial importance of granting the interviewee as much freedom in narration as possible in this method. This allows for obtaining an authentic narrative, where the interviewee confesses themes that are genuinely important to them. Ličen (2013) concludes that the 'narrative method, as a research method, is suitable for exploring experiences and memories and the formation of meanings in individuals and groups (ibid, p. 36).

To complement the autobiographical narrative with additional sources, we included a review of documentation related to the redirection of children to a specific adapted educational programme. In this review, we listed all the disorders with which the children are identified and added any potential divergent information contained in the documentation. The interviewee also contributed photographs as a source of data, depicting environments where they had engaged with the children.

2.2 Sample

We interviewed the father of twins, both of whom have autism and associated disorders; they were 15 years old at the time. We selected an atypical case, as we did not find an in-depth study in the literature on parents with twins with special needs.

We believe that such a case is even more complex than other typical cases, and thus, we are examining it separately and in-depth. We ensured the interviewee's data anonymity by not recording other details about him, except for his employment, which was related to caring for children with special needs. To preserve his anonymity, we omitted certain sensitive details from the story that could reveal his identity. However, we retained his story to a degree that still enabled the analysis.

2.3 Research plan

Based on the research problem, we contacted the interviewee, and inquired about the possibility of participating in our autobiographical interview. We explained the purpose and significance of the research for understanding the experiences of parents facing the more complex challenge of caring for SNC. We assured him of the anonymity of his identity and the protection of sensitive personal data. We offered an informal conversation after the interview, allowing him to gain feedback on his story, and to obtain any information he might need given his life situation. The interview was conducted via a video call to capture the interviewee's nonverbal communication and to provide active empathetic listening. While conducting the interview, we adhered to the phased approach outlined by Rapuš Pavel (2022). We recorded the video call for easier processing (with the interviewee's consent). The acquired data were subjected to hermeneutic-analytical analysis, wherein we attempted to interpret life paths, behavioral patterns, processes of growth and change on the continuum of past, present, and future, etc. (Rapuš Pavel, 2022). We largely relied on Nölke's (1999) explanation, that autobiographical analysis allows for the discovery of new patterns and themes in an individual's life that could not be predicted within predetermined categories. We also followed the guidance of Pajnik and Bajt (2009), who stated that interview analysis is initially divided into thematic segments, emphasizing what is important to the interviewee in the past, and how it influences their future, strictly adhering to the interviewee's narrative. Such an approach serves as a model for social-pedagogical interventions based on a good understanding of an individual's life situation. In the results of hermeneutic interpretation or autobiographical analysis, we strived to maintain the father's vocabulary as much as possible to preserve the authenticity of his experiences. Only when necessary for interpreting and explaining the story, we added a minimal number of words or a clarify term in parentheses – the latter is indicated with the abbreviation a.n. (i.e. author's note).

After the interview, we asked the interviewee for the children's documentation, through which they were directed to appropriate educational programs, and for any photographs that could reveal the places or attractions they visited with the children.

3 Results

In the results section, we present the hermeneutic analysis of the autobiographical narrative of the father of twins with special needs, supplemented by data from two sources: the documentation of redirecting the children to an appropriate educational program, and photographs, capturing memories of trips or others interesting family involvement in society.

3.1 Hermeneutic interpretation

Hermeneutically, the autobiographical narrative is interpreted by dissecting it into thematic sections in chronological order. The interviewee in our case study generally followed chronological order in the story itself; only towards the end, he returned to the description of the behavior and characteristics of the children, resulting in more entries in this segment. In Table 1, we assigned overarching thematic categories to all parts of the autobiographical narrative and numbered them accordingly.

Table 1: **Father's experiences, categorized by theme**

1. Birth of twins and recognition of challenges
“Premature birth of twin boys; one born with 600g, the other with 800g birth weight. Extended period in the incubator after birth. Developmental delay emerged, resulting in incessant crying, screaming, episodes of shaking, impaired walking, and prolonged diaper use (one even until the age of 11). The situation worsened after initial vaccination: swollen eyelids and vomiting occur following their first mandatory vaccination.”
2. Monitoring children's development in the developmental clinic
“In the developmental clinic, efforts were made to teach the boys to walk, but they resisted with strange behavior– screaming, vomiting, refusing to cooperate.”
3. Kindergarten and observations of challenges
“Children enrolled in a regular kindergarten at the age of 4. Observations indicated that they behave differently and had additional care needs. They often cried uncontrollably, showing no interest in toys, and disliking physical contact.”
4. Caring for the child at home and establishing diagnosis in institutions
“The boys were attached to us, but they expressed it differently. They didn't reciprocate emotions and were rarely engaged in play. They required comfort 24 hours a day. We sought a diagnosis from two institutions and discovered a suspicion of autism, with one boy in a more severe form and the other in a milder form. We also underwent genetic testing, but no findings were revealed. This recent year they are waiting for further tests.”

5. Difference between mild and severe forms of autism
“The boy with a milder form of autism strives to compensate for everything (a. n.: he can follow guidance, learn, and adapt), he has a sense of creativity, and can be independent, although trust is challenging. Once, he left home and spent a weekend somewhere - we were worried and searched for him, but he found it amusing. He would like to take a driving test but he has struggled with online theory attempts. He enjoys watching horror movies on TV and follows Messi, aspiring to reach him. He believes that America has better cars, and expresses a desire to go there. The other boy, with a more severe form of autism, is afraid of even a tiny insect. We wish he could communicate basic needs. He takes food on his own. He has distinct preferences - for instance, he asks his father when he needs a drink can to be opened, and asks his mom when he wants a food can to be opened; if we swap roles, he refuses to eat/drink. He had a period of intense interest in cans around the ages of 4 to 7; then, he was fascinated by CDs, colorful and shiny objects. He also likes glow sticks, and we have agreed that he can use two per day. He enjoys blowing bubbles, which he demonstrates when visitors come. He's pleased to gain attention and applause for it. This boy generally struggles more with emotions - calming, comforting, and falling asleep are challenging. It's necessary to know the right techniques for him. For instance, if we are in a store, he might suddenly stop, tilt his head back, and start screaming - they need to take him outside and apply slight pressure to a specific point on his wrist and palms to calm him down. He drinks water, waits for five minutes, and is like a new person. Similarly, in the evening - before he sleeps, massaging a specific point on his feet helps him relax and fall asleep. If this is not done, he comes to seek comfort at night. On TV, he watches very simple, funny, and non-violent things. He doesn't eat with us but joins the table when we finish.”
6. Integration in school and observing challenges
“Children immediately enrolled in a special school; the boy with a more severe form of autism attended an OVI (Special Education Program), and the boy with a milder form of autism was in a program (a. n.: adapted educational program with a lower educational standard). They had a difficult time adjusting to school. It took them both between one month and one year to get used to the new environment. During this time, they showed disinterest and rudeness. Even later, there were adaptation difficulties, such as withdrawing, and crying. During lessons, neither of them showed interest in reading and drawing. Everything had to be done through play, with frequent breaks. In such work, planning is challenging (a. n.: success has its ups and downs, and it's unpredictable what the child will excel at and what not).”
7. Contacts with relatives and parental feelings in this regard
“Some relatives did not understand the children's different behavior and distanced themselves from the family. For us this was not a problem. You love your child; he or she is yours.”
8. Puberty and behavior in school during this period
“During puberty, children became even more prone to crying, withdrawing into themselves, and disliking each other. Their behavior worsened at school – it became somewhat aggressive and peculiar (e. g., licking doorknobs).”
9. Parents' response to deterioration in behavior
“A pediatric psychiatrist, in collaboration with a clinical psychologist, determined that the boys have attention deficit hyperactivity disorder (ADHD). She prescribed medication for them, but was cautious, advising that they take only the necessary dosage to calm down and focus, as an excessive dose could lead to drowsiness.”
10. Inclusion in another program for one of the boys and observations of both in this program
“Both boys are in OVI (a.n.: a special education program) for two years. It's different here because they protect each other. The boy with milder autism protects his brother with more severe autism - he quickly rushes to him if needed. Both boys now understand things and

events a bit better. Although there are significant variations. The boy with more severe autism had a strong aversion to going to school for some time. We tried to make him think he wasn't going to school but, for example, to a store. He resented this a lot, and it took half a year before he forgot about it. He doesn't forget what you promise him. For instance, if you tell him that he'll get bubbles later, he comes to you and says, "bubbles," to remind you.”
11. Feelings of parents regarding the distinctive behavior of children
“When you live with them, you give a part of yourself – you are a parent, a child, a caregiver. The child gets attached, comes to you, and waits to hear what the teacher (a. n.: the child often sees parents in the role of a teacher) will say. You have to listen to the child. They are very observant to see if you are truly with them, as they might lose trust otherwise. Children quickly sense your emotions; if you're sad, for instance, they come to comfort you and then genuinely smile. Children find it challenging to accept scolding and yelling – in such cases, they get scared, wet the bed, and give you a nasty look. But if you say nicely that they should do better next time, they tend to adhere to it more. It's crucial to know this because otherwise, you won't get anywhere – once they have a habit, they believe they are right. You have to accept the situation as it is. The child psychiatrist believes that time for improvement should slowly stop, allowing them to continue progressing in their development. They will reach their maximum potential. The boy with fewer problems shows signs of facial hair, while the other, with more challenges, does not. The latter generally communicates less – for example, if something hurts, he won't say it directly, and we have to guess. However, this doesn't stop us because they are sweethearts. They don't hide anything. They show what they have done or try to prevent something from going wrong. You just have to be there for them.”
12. Thoughts about the future
“At first, we thought they would stay in school until the age of 18, and then they would go to workshops (a.n.: special centers, where special needs children can work). Now we believe they will stay in school until the age of 26 because it benefits them – they work on self-esteem, practical exercises, and manual skills.”
13. Free time
“Usually, we all go to the store together. They wander around, look at cans if they are of different colors, etc. If mom stays home, they strictly stick to me, and there are no problems. We plan ahead, and if one of them causes trouble, he stays home next time. If they go with just mom, one is lively, and the other one cries.”
14. Parents employment
“I took a job as a family assistant. I had to leave the job market because I needed to be with the children 24 hours a day so that they have not been deprived of anything. Their mother has a disability status, so she cannot take care of them on her own.”

In Table 2, we add questions and answers based on the interviewee's narrative, providing additional clarification of his experiences, emotions, and memories.

Table 2: Additional questions for the interviewee, based on his narrative

In your narrative, you mentioned several institutions in which you were involved with your children. Were there any others that you might not have mentioned in the narrative? "In addition to kindergarten, school, developmental clinic, and child psychiatric clinic, for a while, the Social Center also visited our home, providing lay assistance at home. Not anymore now, as the children refused, and they saw, that we handle them as they are."
You mentioned free time spent together with the children, such as going to the store. Do you have other experiences of integrating into the community, for example, involvement in associations? "We also got involved in the municipality when there were workshops held there. Then, we joined a society for people with disabilities. In this case, too, there were occasions of significant resistance from the children, so we stopped. However, we still visit a center where they sell second-hand items. The children enjoy this a lot because these items can be disassembled, repaired, glued, assembled, etc. In general, it is difficult to include children in activities because, on the one hand, they resist, and on the other hand, some organizations do not accept such autistic children for vacations. Once we had everything arranged, but this diagnosis prevented their inclusion."
You mentioned that you are available to the children 24 hours a day, understanding, observing, trying to handle them correctly, accepting them, etc. Do you ever take vacations, free time, or time for yourself? "Actually, no. Only once, when they were in the hospital, I had time for a movie, which I usually can't watch with them. Otherwise, I don't go to therapies or other types of breaks where I could be alone. Of course, you need to be mindful of exhaustion, but I draw energy from faith, and I don't need anything else. In the evening, I have my meditation, which means a lot to me, and I calm down and gather new strength. However, it can be different for other parents. They don't have the energy to take their children out because it's too tiring. Here, it's important to understand that children are deprived if you don't take them out, and you have to accept that. When you manage to do that, you see that it's love and a mission. You have to persevere and recharge your energy. You can't rely on everything, not even on professionals, because there hasn't been enough help here, and it's still a taboo subject. They give you certain guidelines, then you have to continue searching on your own, how you will react, and what the child likes and doesn't like. You can insist on some things and do them, but not everything."
You mentioned that the children were immediately enrolled in a special school. Did you find this okay, or have you ever wished that they could attend a regular school like other children? "On one hand, we found it okay because it's a school that knows how to handle these children. On the other hand, there are no other children for our kids to see or interact with. They might have encountered other children in some places, but in those situations, they fear each other. Even adults are afraid of our children. Therefore, we wished that these programs could sometimes be part of regular primary schools – this way, the children would be under the same roof as others and could get used to each other, like seeing each other during breaks, on the playground, on the bus, etc. It doesn't seem right to us that these children remain unknown, that people wonder about them, are frightened, and don't know how to interact with them."

Table 3 complements the autobiographical narrative with a precise definition of disorders identified for both boys based on the documentation regarding their enrollment in the educational program (considering the most current or latest documentation). The remaining part of the documentation, observations about the child, does not differ from the information in the autobiographical narrative.

Table 3: Precise definition of disorders identified for both boys based on the documentation regarding their enrollment in the educational program

Boy 1	A child with a moderate intellectual disability Long-term illness A child with autistic disorders (A child with moderate limitations in social communication and social interaction; A child with moderate weaknesses in behavior, interests, and activities)
Boy 2	A child with multiple disorders, namely as a child with a moderate intellectual disability and as a child with an autistic disorder.

In the narrative, the father mentioned that Boy 2 has a more severe form of autism, while Boy 1 has a milder form. Boy 1 has newer documentation where the definition is more detailed. The definition also includes attention deficit hyperactivity disorder under the category of long-term illness.

Table 4 contains documentation of the environment, where the family was involved, based on photographs.

Table 4: Environment, where the family was integrated, based on photographs

Choosing a toy at the reuse center.
Train ride.
Buying food and drinks in a store.
Dismantling practical products.

4 Discussion

The literature review provides a framework for understanding the father's role in raising twins with autism and associated challenges. It is evident that the literature addresses topics that frequently arise as issues in raising children with special needs, such as parental collaboration with preschools/school (e. g., Cavnik, 2019), how parents cope with challenges when having children with multiple disorders (e. g., Zadravec, 2021), which associations/organizations they can turn to (e. g., Gašparić, 2021), how their lives have changed (e. g., Horvat, 2009), and what is specific to parents of children with autism (e. g., Cugmas, 2018). From the results of hermeneutic analysis, we observed a detailed description of the story from the birth of the twins to present, when they are 15 years old. It covers various phases of life: the birth of the twins and observation of difficulties, monitoring child development in developmental clinics, kindergarten and observation of issues, caring for the child at home and determining diagnoses in institutions, the difference between milder and more severe forms of autism, inclusion in school and observation of challenges, family interactions, puberty and behavior during this period, parental interventions when behavior worsens, the inclusion of the second child in a special education program, parents' feelings about the children's distinctive behavior, thoughts about the future, free time, and parental employment.

The interviewee was consistently optimistic throughout the narrative and eager to share as much information as possible that could be beneficial to the wider public. Certain themes could be identified as reoccurring life patterns. For example, the challenges of the children and parents' responses to them appeared either directly or indirectly in every phase. Reconstructing such patterns highlights the importance of developmental and other issues in adapting the entire lives of parents to their children (Kolarič, 2009). Through analysis, we can vividly understand what this means—constantly searching for the underlying problem and also identifying the causes. The father mentioned that while it is not known for genetics to influence the development of autism, he is now involved in such research for the second time.

It seems that the cause of the children's diagnoses is in a subordinate position to their actual behavioral characteristics. In the actual conversation, the father focused approximately six times on descriptions of the children's behavior – most notably on their crying, screaming, and unpredictability.

In the father's story, a behavioral pattern of the children repeats, where they resist changes and find it difficult to adapt, requiring additional energy from the parents. The father values greatly the fact that he could leave the job market and get employed as a family assistant, especially because his wife, the mother of the twins, wouldn't be able to manage such care on her own due to her disability. He emphasized that such a life is a mission.

The father pointed out that his work is meaningful because he is giving himself for the lives of others. From the literature, we found that other parents have also adapted their lives to their children's special needs, but the authors emphasize more overwhelm and burnout (e. g., Gostenčnik, 2021) than our interviewee. Even from the photos, it is evident that the children enjoy engaging with their surroundings and effectively respond to the environment despite the challenging adaptation.

Some authors, for example, Kovačič Purgaj (2018), report that Parents emphasized the need for more support from the environment, either professional or other, such as parents of children with special needs. However, our interviewee differs in this aspect, as he believes that while professionals can provide guidance, the real work on specific approaches and methods to calm the child must be done by the parents themselves.

Regarding the question of inclusion, we obtained similar data like Topolovec and Schmidt (2015). The interviewee thought it would be better if special and adapted programs for children with special needs were integrated under the same roof as regular elementary school programs.

The answer to what exactly helps our interviewee overcome the stresses and challenges of everyday life is revealed in the narrative, where he expressed the importance of faith or evening meditation. This aligns with the findings of Zadravec (2021), who explored factors influencing the mental well-being of parents in her research. One might expect that the father, caring for the twins and his wife with disability, would be highly burdened and possibly pessimistic. However, quite the opposite is true, demonstrating a high degree of resilience and strength. It was crucial for him that autism was diagnosed early, allowing for timely support and assistance in the developmental clinic (Šnopl, 2009).

The definitions of children's diagnoses (Table 3), extracted from the documentation, indicate that the challenges are highly complex, and the way the father describes caring for the children, is even more encouraging from this perspective. The photographs depicting their involvement in the environment (Table 4) further confirm that life with such significant challenges can be beautiful – if it is filled with love, as our interviewee expressed.

5 Conclusion

In a nutshell, the result of the study is the father's experience in caring for twins with autism and associated issues, including the below highlights, values, attitudes, or guidelines.

- Early detection of children's special needs is crucial. Experts can provide diagnoses and guidance, but parents regulate care, respond to maladaptive behavior, manage sensitivity to environmental stimuli, etc., which are characteristic of these children, the latter requiring concentration, calmness, patience, courage, and perseverance to integrate children into society.
- Despite limitations in certain activities for children with autism (e. g., not being able to go to the seaside with a group of other children), individual experiences should be facilitated to the extent each child can handle.
- Autism manifests in milder and more severe forms, so it is necessary to understand each child individually; it can coexist with other disorders (in our case study, alongside attention and hyperactivity disorder and mental disorder); its impact can also vary across different life stages (in our case study, behavior worsened during puberty).
- Living with special needs children is unpredictable because certain achievements, that have been reached, are relative. A particular stimulus can again threaten the child to such an extent, that recovery may take a long time.
- Children with autism need to be provided with support, withdrawal, time for rest and calming. We cannot expect them to be like others and they need to be accepted as they are.
- Being a parent to a child with special needs means a mission and self-sacrifice. Acceptance of this situation is a better solution than fighting against it, denying the problem, escaping into other issues, etc. The parents need to support each other in this, even though both may not be able to participate equally in every aspect with the child. They must do their best in their capacities.

The limitation of the study is that the results cannot be generalized because it is a case study. The contribution to the scientific field is that this method complements other data with specific insights from experiences, memories, and first-person narratives. Such a case study can be replicated in other atypical cases of parents caring for children with special needs, which can collectively provide more opportunities to understand their situations. All of this forms the basis for practices to meet the needs of these families and for professionals, involved in the reform of the national education programs, to consider individualization in all approaches for children, youth, and their families with additional needs and abilities.

References

Cavnik, A. (2019). *Sodelovanje z družino ključni dejavnik uspeha zgodnje obravnave otroka s posebnimi potrebami* [*Collaboration with the family is a key factor in the success of early intervention for a child with special need*] [Magistrsko delo, Univerza v Mariboru]. Digitalna knjižnica Univerze v Mariboru. https://dk.um.si/IzpisGradiva.php?lang=slv&id=75579

Cugmas, Z. (2018). Navezanost na starše pri otrocih z motnjami avtističnega spektra (MAS) [Attachment to Parents in Children with Autism Spectrum Disorders (ASD)]. *Pedagoška obzorja, 33*(2), 52–63.

Gašparić, L. (2021). *Strokovna in interesna združenja za otroke z motnjo avtističnega spektra* [*Professional and Interest Associations for Children with Autism Spectrum Disorder*] [Magistrsko delo, Univerza v Mariboru]. Digitalna knjižnica Univerze v Mariboru. https://dk.um.si/IzpisGradiva.php?lang=slv&id=78338

Gostenčnik, J. (2021). *Spremembe življenjskih vzorcev družine z otrokom z avtizmom* [*Changes in Family Life Patterns with a Child with Autism*] [Magistrsko delo, Univerza v Ljubljani]. Fakulteta za socialno delo, Univerza v Ljubljani. https://repozitorij.uni-lj.si/IzpisGradiva.php?lang=slv&id=124406

Hartman, T. (2022). *Načrtovanje dela inkluzivnih pedagogov z otroki s posebnimi potrebami* [*Planning the Work of Inclusive Educators with Children with Special Needs*] [Magistrsko delo, Univerza v Mariboru]. Digitalna knjižnica Univerze v Mariboru. https://dk.um.si/IzpisGradiva.php?lang=slv&id=81429

Horvat, A. (2009). *Otrok s posebnimi potrebami (avtizem)* [*Child with Special Needs (Autism)*] [Diplomsko delo, Univerza v Mariboru]. Digitalna knjižnica Univerze v Mariboru. https://dk.um.si/IzpisGradiva.php?lang=slv&id=12087

Jereb, S. (2020). *Stališča vzgojiteljev in staršev do zgodnje obravnave otrok* [*Attitudes of educators and parents towards early intervention for children*] [Magistrsko delo, Univerza v Mariboru]. Digitalna knjižnica Univerze v Mariboru. https://dk.um.si/IzpisGradiva.php?lang=slv&id=78172

Kolarič, J. (2009). *Življenje družin z otroki z motnjami v duševnem razvoju, vključenimi v Dnevni center Maribor - Organizacijska enota ZUDV Dornava* [*Life of families with children with intellectual disabilities involved in the Daily Center Maribor - Organizational unit ZUDV Dornava*] [Diplomsko delo, Univerza v Mariboru]. Digitalna knjižnica Univerze v Mariboru. https://dk.um.si/IzpisGradiva.php?lang=slv&id=10605

Korpar, M. (2021). *Komunikacija med vzgojitelji in starši otrok s posebnimi potrebami v rednih oddelkih vrtcev v Mariboru in okolici* [*Communication between educators and parents of children with special needs in regular kindergarten classes in Maribor and the surrounding area*] [Magistrsko delo, Univerza v Mariboru]. Digitalna knjižnica Univerze v Mariboru. https://dk.um.si/IzpisGradiva.php?lang=slv&id=79396

Kovačič Purgaj, V. (2018). *Študija zadovoljitve potreb družin otroka s posebnimi potrebami* [*Study of satisfaction with the needs of families of children with special needs*] [Magistrsko delo, Univerza v Mariboru]. Digitalna knjižnica Univerze v Mariboru. https://dk.um.si/IzpisGradiva.php?lang=slv&id=70168

Kozel, S. (2021). *Stališča staršev predšolskih in osnovnošolskih otrok do inkluzije v vzgoji in izobraževanju* [*Opinions of parents of preschool and elementary school children about inclusion in education and upbringing*] [Magistrsko delo, Univerza v Mariboru]. Digitalna knjižnica Univerze v Mariboru. https://dk.um.si/IzpisGradiva.php?lang=slv&id=80988

Krivec, K. (2016). *Stališča staršev predšolskih otrok do vključevanja otrok s posebnimi potrebami v redne oddelke vrtca* [*Opinions of parents of preschool children about the inclusion of children with special needs in regular kindergarten groups*] [Magistrsko delo, Univerza v Mariboru]. Digitalna knjižnica Univerze v Mariboru. https://dk.um.si/IzpisGradiva.php?lang=slv&id=60698

Ličen, N. (2013). Paradoksi narativne metode pri raziskovanju učenja in situ [The Paradoxes of Narrative Method on Learning in Situ]. *Andragoška spoznanja, 19*(3), 31–45.

Makoter, S. (2020). *Primernost poučevanja otrok s posebnimi potrebami v rednih oddelkih po ocenah učiteljev in vzgojiteljev v prvem razredu* [*Appropriateness of Teaching Children with Special Needs in Regular Classrooms: Teachers' and Educators' Assessments in the First Grade*] [Diplomsko delo, Univerza v Mariboru]. Digitalna knjižnica Univerze v Mariboru. https://dk.um.si/IzpisGradiva.php?lang=slv&id=76184

Nölke, E. (1999). Rekonstruktivna hermenevtična analiza biografij v socialnopedagoškem delu [Reconstructive Hermeneutic Analysis of Biographies in Social Pedagogical Work]. *Socialna pedagogika, 3*(4), 425–444.

Pajnik, M. in Bajt, V. (2009). Biografski narativni intervju: Aplikacija na študije migracij [*Biographical Narrative Interview: Application to Migration Studies*]. *Dve Domovini*, (30). 69–89.

Plešec, N. (2021). Sodelovanje šolske svetovalne službe s starši otrok s posebnimi potrebami [Collaboration of the school counseling service with parents of children with special needs]. *Socialno delo, 60*(4), 347–358.

Rapuš Pavel, J. (2022). Biografski pristop pri socialnopedagoškem delu [Biographical approach in social pedagogical work]. In D., Zorc Maver (ur.). *Inovativno učenje in poučevanje za kakovostne kariere diplomantov in odlično visoko šolstvo*, (pp. 201–217). Univerza v Ljubljani, Pedagoška fakulteta. Prva e-izdaja. DOI: 10.51746/9789617128222

Šnopl, V. (2009). *Mnenja staršev o podpori, obravnavi in izobraževanju otrok z avtizmom* [*Parental opinions on support, treatment, and education of children with autism*]. [Diplomsko delo, Univerza v Mariboru]. Digitalna knjižnica Univerze v Mariboru. https://dk.um.si/Dokument.php?id=9387&lang=slv

Topolovec, U. in Schmidt, M. (2015). Šolanje osnovnošolcev s posebnimi potrebami [Education of elementary school students with special needs]. *Pedagoška obzorja, 3*(3/4). 3–18.

Zadravec, M. (2021). *Psihološko blagostanje, stres in vključenost v šolanje staršev otrok s posebnimi potrebami* [*Psychological well-being, stress, and involvement in schooling of parents of children with special needs*] [Magistrsko delo, Univerza v Mariboru]. Digitalna knjižnica Univerze v Mariboru. https://dk.um.si/IzpisGradiva.php?lang=slv&id=78733