Regression in Autism from parents' perspective

[1]TCH. ASST. REBEKA STRNAD, MA, PROFESSOR OF SPECIAL AND REHABILITATION PEDAGOGY;
[1,2]ASSIST. PROF. PHD ERNA ŽGUR
[1]University of Ljubljana, Faculty of Education, Department of special and rehabilitation pedagogy, Kardeljeva ploščad 16, 1000 Ljubljana, Slovenia
[2]Institution of Higher Education for Physiotherapy FIZIOTERAPEVTIKA, Slovenska cesta 58, 1000 Ljubljana, Slovenia
Correspondence: rebeka.strnad@pef.uni-lj.si; erna.zgur@pef.uni-lj.si

ABSTRACT

Nowdays, autism affects 1 in 36 children. Approximately one-third of these children experience regression at least once in their lifetime. Regression can emerge at various stages of life and can affect different areas of functioning. For parents, both regression and the diagnosis of autism represent significant emotional challenges. In response, they turn to a range of coping strategies and seek support through both formal and informal networks. Through a multiple case study involving parents of children with autism, we found that in both instances, typical early development was followed by regression, which occurred around the age of two. In one case, a subsequent episode of regression occurred later on. Parents went through stages of grief during this time. During the period when regression took place, they reported an increased need for support, which they sought from associations, peer support groups, relatives, and other parents with similar experiences. They also actively searched for information, adjusted their expectations for their child, redefined life goals, and gradually moved from denial toward focusing on their child's abilities. The findings indicate that parents felt a lack of support from professionals within the healthcare and education systems. They expressed a desire for professionals across disciplines to provide more practical and realistic information and guidance, to work in closer collaboration, and to show greater empathy and understanding. This research highlights the importance of stronger cooperation between professionals in therapeutic and educational settings and the families of children with autism. **Keywords:** Autism, regression, parents of autistic children, coping, diagnosis, support, professionals

Regresija v avtizmu z vidika staršev

POVZETEK

V današnjem času ima avtizem 1 na 36 otrok. Pri približno tretjini otrok vsaj enkrat v življenju pride do regresije. Ta se lahko pojavi v različnih obdobjih življenja ter na različnih področjih delovanja. Za starša sta tako regresija, kot tudi diagnoza avtizma težki situaciji, s katerima se mora soočiti. Ob tem se starši poslužujejo različnih strategij ter oblik pomoči in podpore – tako formalnih kot tudi neformalnih. Z multiplo študijo primera staršev otroka z avtizmom smo ugotovili, da je v obeh primerih tipičnemu zgodnjemu razvoju sledila regresija, ki je nastopila okoli drugega leta starosti. V enem primeru je kasneje prišlo do ponovne regresije. Starši so ob tem prešli faze žalovanja. V obdobju, ko je do regresije prišlo, so starši potrebovali več pomoči in podpore, ki so jo iskali v društvih, podpornih skupinah, pri sorodnikih ter drugih starših s podobnimi izkušnjami. Ob tem so iskali čim več informacij, preoblikovali so svoja pročakovanja do otroka in cilje v življenju ter se, po začetnem zanikanju težav, osredotočili na otrokova močna področja. Z raziskavo smo ugotovili, da so starši pogrešali pomoč strokovnih delavcev znotraj zdravstvenega ter vzgojno-izobraževalnega sistema. Želeli bi si, da bi jim strokovni delavci iz različnih področij nudili več realnih in konkretnih informacij ter usmeritev, da bi med seboj delovali bolj povezano, da bi jih znali poslušati ter razumeti in upoštevati. Raziskava kaže potrebo po večjem sodelovanju med strokovnjaki iz rehabilitacijskega in izobraževalnega področja ter starši otrok z avtizmom. **Ključne besede**: Avtizem, regresija, starši otrok z avtizmom, soočanje, diagnoza, pomoč, strokovnjaki

INTRODUCTION

According to the Centers for Disease Control and Prevention, autism nowdays affects 1 in 36 children (1). It encompasses a broad spectrum of neurodevelopmental challenges, manifesting in areas of social communication and interaction, as well as the presence of repetitive and restricted patterns of behavior (2).

Boterberg et al. describe two models of autism onset: the early-onset model, where difficulties appear within the first 12 months of a child's development, and the regressive model, where early development is typical, followed by a loss of previously acquired skills (3) — aka. regression, or return to a lower developmental stage (4). Since some children experience difficulties in early development followed by regression, a third, mixed model is also considered (3, 5, 6). It is also important to distinguish regression from a general lack of skill acquisition, which suggests the possibility of even more subtypes and patterns in how autistic traits emerge (7-10).

Approximately one-third of individuals with autism experience regression at least once in their lifetime (6, 11). The mechanisms behind regression remain unknown. Some factors have been associated with the occurrence of regression, such as lower intellectual functioning, more pronounced autistic features, mitochondrial and metabolic disorders, co-occurring psychiatric conditions, and epilepsy. However, none of these associations have been conclusively proven (12 - 14). Regression most commonly occurs around the age of two but may also appear later (6). There are four identified subtypes of regression: language regression, language and/or social regression, mixed regression, and undefined subtype (10, 15, 16).

Upon receiving the diagnosis, parents typically go through stages of grief—shock and denial, anger, bargaining, sadness, and acceptance (17). The grieving process never truly ends for them, but resurfaces at different stages of the child's life, in varying intensities (18). During this time, emotional and social support becomes crucial (17). Parents of autistic child often show an increased need for both formal and informal support as well as information to better cope with daily challenges of raising an autistic child (19).

In Slovenia, support is provided through the Early Childhood Intervention (ECI) system and within the educational programs in which the child is enrolled. Parents may also access parental intervention programs such as EarlyBird Plus. As part of the ECI approach, a multidisciplinary team offers holistic medical-therapeutic, psychological, social, and educational) support—not only to the child with difficulties, but to the entire family (20). Professionals from different fields collaborate by sharing information and jointly designing an individualized support plan (21). A unified, multidisciplinary approach enables coordinated and complementary interventions that effectively and promptly influence the emergence and transformation of developmental functions. In such multidisciplinary teams, the collaborative work of a physiotherapist, occupational therapist, special education teacher and others is often essential. Their communication of key information regarding the child's progress helps relieve parents and supports them in better accepting their child's differences. This approach fosters more effective support across multiple areas of the child's life and enables more intensive and higher-quality intervention (22). Additionally, parents may find support through autism associations, peer support groups, and self-help communities. Information about the child's diagnosis, prognosis, and available forms of assistance is crucial, helping parents make informed decisions and remain active participants in the support process (23). When faced with difficult situations, such as a child's regression, parents employ a range of coping strategies. Lai and Oei identify four main categories: active avoidance, faith and spirituality, cognitive reframing, and problem-solving (24).

OBJECTIVE

The aim of the research was to investigate the circumstances of the phenomenon of regression, i.e., to determine in which areas parents noticed difficulties at the occurance of regression, how old their child was at that time, whether the child had already been diagnosed with autism, and whether any risk factors were present. We wanted to explore how the parents, involved in the study, coped with the regression, whether they went through stages of grief, and how they helped themselves during that period - what forms of help and strategies they used, and whether the need for these increased at the time of the onset of regression. Furthermore, we aimed to identify which strategies and types of help or support proved to be the most effective for included parents. Additionally, we were interested in the support parents received from professionals working with their child — who provided it, for how long, and whether the parents were satisfied with the assistance.

METHODOLOGY

We used a descriptive method of educational research. We conducted a qualitative multiple case study to examine the circumstances of regression in children with autism, how parents coped with it, what forms of support they used. The purpose of the research was to present parents' experiences as objectively as possible and to connect the information they provided with existing literature. A purposive sampling method was used, as specific individuals were selected in accordance with the research goals. The sample included three parents of two adolescents with autism — the mother (Mother 1) and father (Father 1) of a 24-year-old adolescent (Adolescent 1), and the mother (Mother 2) of an 18-year-old adolescent (Adolescent 2). To collect data, we used a semi-structured interview consisting of open-ended questions about the circumstances of the child's regression and the parents' experiences in coping with it.

RQ1: *What were the circumstances surrounding the onset of regression of already acquired skills or behaviors of the child? In which areas of development did regression occur? Were there factors present associated with an increased possibility of regression?*

RQ2*: Did parents go through stages of grief upon the occurrence of regression? Did the grieving differ from coping with the diagnosis?*

RQ3: *Did parents seek causes of the regression upon learning about it? To what did they attribute the regression? To what did professionals attribute the regression?*

RQ4: *Did they need additional help upon learning about the regression? What kind? Which forms of help and strategies they recignised as effective in their opinion?*

RQ5: *Did parents receive adequate help and support from the professionals who treated the child during the time when regression occurred? How long was the help needed? Who provided it?*

RESULTS

The research confirmed that regression in both adolescents occurred around the age of two. In Adolescent 1, a second regression occurred at the age of 18. In both cases, the autism diagnosis followed the regression, which was also the reason for seeking professional help. Upon the second regression of Adolescent 1, the parents once again sought help and answers from professionals. Early development in both adolescents was typical, followed by regression, placing them within so-called regressive model of autism. The first regression in Adolescent 1 was marked by a gradual loss of language (cessation of functional speech, reduced speech, echolalia) and social skills (loss of gestures, lack of response when called, etc.), gradually intensifying approximately one year. Preschool teachers were the first to notice it. Gradual, slow regression is more common and is often first detected by professionals (16). The second regression in the same adolescent brought a sudden deterioration in behavioral profile and adaptive functioning, categorizing it as a mixed subtype. In Adolescent 2, the regression was rapid and highly noticeable, involving loss of speech, nonverbal communication, changes in play and imagination — which also suggests a mixed subtype. A rapid onset of regression is common in the loss of language skills. In line with the findings of Gadow et al. who note that regression more frequently occurs in individuals with both autism and significantly lower intellectual abilities or more pronounced autistic traits, these were confirmed in both cases (12). Other potential factors mentioned in the literature (e.g., epilepsy, mitochondrial and metabolic disorders) were not present, except for the onset of obsessive-compulsive disorder in Adolescent 1 during the second regression, which aligns with findings that psychiatric comorbidities can exacerbate behavioral challenges (14).

Coping with regression and the diagnosis of autism coincided for all parents, meaning they experienced the process of accepting the regression and the diagnosis simultaneously. All parents reported emotions that can be attributed to the stages or process of grief upon facing regression and the diagnosis of autism (18). During the second regression of Adolescent 1, both parents experienced similar emotions. The only observed difference between coping with the initial regression (and at the same time diagnosis) was the speed of the grieving process, as the parents reported reaching the stage of acceptance more quickly.

Two of the three parents south the causes of their child's regression. Mother 1 linked the second regression to obsessive-compulsive disorder, while Mother 2 initially suspected deafness, then vaccines. She reported that this explanation calmed her down, as she did not blame herself or her actions for the regression. Some professionals attributed the cause of regression to the parents, which made them uncomfortable — a point mentioned by both Mother 1 and Father 1. Mother 2 stated that professionals initially interpreted the regression as a psychological response to the birth of a sibling but later acknowledged autism as the cause.

During the regression, parents actively sought information and attended seminars. They reported that having access to information (online resources, seminars, courses …) was the most helpful at the beginning, as they understood the situation better, understood the diagnosis better, and found it easier to decide on how to procced. They valued the support of associations, support groups, family, and friends. All parents highlighted that one of the most important aspects of support was socializing and connecting with other families facing similar challenges. Systemic support (help within early intervention centers, programs of interventions for parents, or help within educational institutions) was insufficient. It is important to note that at the time of the first regressions, the Early Childhood Intervention as defined by *Zakon o celostni zgodnji obravnavi predšolskih otrok s posebnimi potrebami (*the Act on Comprehensive Early Intervention for Preschool Children with Special Needs) had not yet been fully implemented (25). At first, the parents denied the situation, then gradually reshaped their expectations, accepted the condition, and adjusted their priorities. They adopted strategies of seeking information and focusing on the child’s strengths.

In Slovenia, both the educational and healthcare systems offer support not only to children with special needs but also to their parents. However, the parents unanimously agreed that systemic support was insufficient, which they attributed to the rarity of regression (at the time of their children’s first regression, the phenomenon of regression was rarely discussed and poorly researched) and the system that restricts professionals.

DISCUSSION

The study addressed key research questions concerning developmental regression in two adolescents diagnosed with autism. In both cases, regression occurred around the age of two, consistent with the findings of Macedoni-Lukšič, who also highlights the possibility of regression during adulthood—an observation confirmed in our study through a secondary regression in one participant (11). In both cases, the onset of regression was the trigger for seeking professional support, ultimately leading to a diagnosis of autism. This aligns with prior research indicating that regression often precedes diagnosis (15). Given the typical early development followed by a notable regression, both cases correspond to the regressive model of autism (6). In Adolescent 1, the initial regression was characterized by a gradual decline in language and social skills (suggesting a language and/or social subtype), while the second regression, occurring in late adolescence, primarily affected behavioral domain and adaptive skills, indicating a mixed subtype. In the case of Adolescent 2, regression involved a rapid loss of language, imaginative play, and nonverbal communication, which also places this case within the mixed subtype category (10, 16). Our findings confirmed associations between regression and significantly lower intellectual functioning, more pronounced autistic traits, and the presence of psychiatric comorbidities — corroborating existing literature (12, 14). No connections were identified with other medical conditions frequently mentioned in the literature, such as epilepsy, mitochondrial disorders, or metabolic dysfunctions (12, 26).

The second research question explored whether parents experienced stages of grief in response to their child’s regression and whether these experiences differed from those following the initial autism diagnosis. All parents reported emotions corresponding to stages of grief, which experts deem crucial for family adaptation and the reestablishment of family dynamics (18). Notably, the parents of Adolescent 1 reported reaching the acceptance stage more rapidly during the second regression than during the initial regression that coincided with diagnostic period.

The third research question focused on parents' initial reactions and their search for explanations regarding the onset of regression. Mother 1 attributed the second regression to the development of a psychiatric disorder. Mother 2 initially suspected hearing loss and later attributed the regression to vaccinations—a common reaction, as many parents seek external triggers for such events (27). In some cases, professionals also directed blame toward parents themselves (28), which was confirmed by two participants.

All parents reported an increased need for support during the regression period. They actively sought information through various sources and attended seminars, which they found crucial in understanding the situation and making informed decisions (23). All participants also engaged with autism associations and support groups, where socialization and connection with families experiencing similar challenges played a central role (23, 29). Formal support — such as that provided through early intervention centers, educational institutions, or parent-focused interventions — was reported to be insufficient. Initially, parents tended to deny the severity of the situation, which, although potentially less adaptive, may serve as a temporary coping mechanism that provides time for emotional adjustment (24, 30). Father 1 also reported emotional suppression during this period. Eventually, all parents restructured their expectations, accepted the situation, and redefined their life priorities. They adopted coping strategies such as seeking information and focusing on their child's strengths. Literature identifies information-seeking as one of the more effective strategies for managing stress and uncertainty (24). However, coping strategies cannot be universally labeled as effective or ineffective, as their success largely depends on individual and contextual variables.

The final research question examined the nature of the support parents received from professionals working with their child, the duration of this support, and the providers involved. All parents agreed that the professional support received during the regression period was insufficient, despite national legislation—specifically *Zakon o celostni zgodnji obravnavi predšolskih otrok s posebnimi potrebami* (the Act on Comprehensive Early Intervention for Preschool Children with Special Needs) —which calls for a multidisciplinary approach involving both children and their families (25). Participants expressed a strong desire for a more comprehensive and family-centered approach that would consider broader contextual factors such as parental education and socioeconomic status (19), while also focusing on family strengths and successes (31). Compared to the time when the parents in our study experienced their children's regression, the current Early Childhood Intervention Sstem in Slovenia has evolved to include a broader social context, with a shift from deficit-oriented practices to family-focused support. Within this model, multidisciplinary teams collaborate regularly, integrating specialized knowledge and jointly planning interventions. This contributes not only to the strengthening of the child's developmental competencies but also to empowering parents in their caregiving role. Through this model, families receive multidimensional support—medical-therapeutic, psychological, social, and educational (32).

CONCLUSION

The aim of this study was to explore the circumstances surrounding the occurrence of regression in two individuals diagnosed with autism and to examine how their parents responded to this developmental change. Study confirmed the presence of several risk factors commonly cited in literature as being associated with regression. In both cases, regression occurred around the age of two and affected multiple developmental domains simultaneously. This multifaceted regression prompted the parents to seek professional assistance, which subsequently led to a diagnostic assessment and the confirmation of an autism diagnosis. Parents employed similar coping strategies in both cases. They actively sought information, became involved in autism-related associations and support groups, and redefined their expectations and perceptions of their child's developmental trajectory. However, they also reported a lack of adequate support within public systems, even though such support is formally provided for under Slovenian legislation. Encountering regression in one's child is, undoubtedly, a traumatic experience for parents. For this reason, it is essential that appropriate support is made available to them across existing systems—healthcare, social services, educational institutions, and non-governmental organizations. Such support not only helps parents to better cope with the situation but also empowers them to engage more confidently in supporting their child’s development. It is important to acknowledge that each parent responds in their own unique way. There is no single 'correct' path to coping, and it is therefore crucial to offer a range of support options, allowing each individual to find the approach that best suits their needs.

LITERATURE

1. Centers for Disease Control and Prevention. Prevalence of Autism spectrum disorder [spletna stran na Internetu]. Pridobljeno 18. 3. 2025 s spletne strani: https://www.cdc.gov/autism/data-research/index.html
2. Okoye C, Obialo-Ibeawuchi CM, Obajeun OA, Sarwar S, Tawfik C, Waleed MS, et al. Early diagnosis of autism spectrum disorder: a review and analysis of the risks and benefits. Cureus. 2023; 15(8).
3. Boterberg S, Van Coster R, Roeyers H. Characteristics, early development and outcome of parent-reported regression in autism spectrum disorder. J Autism Dev Disord. 2019; 49(11): 4603–25.
4. Regresija. V: Slovar slovenskega knjižnega jezika [spletna stran na Internetu]. 2. dopolnjena in deloma prenovljena izd. Ljubljana: ZRC SAZU; 2025. Pridobljeno s: https://fran.si/iskanje?View=1&Query=regresija
5. Ozonoff S, Williams BJ, Landa R. Parental report of the early development of children with regressive autism: The delays-plus-regression phenotype. Autism. 2005; 9(5): 461–86.
6. Barger BD, Campbell JM, McDonough JD. Prevalence and onset of regression within autism spectrum disorders: A meta-analytic review. J Autism Dev Disord. 2013; 43(8): 817–28.
7. Boterberg S, Charman T, Marschik PB, Bölte S, Roeyers H. Regression in autism spectrum disorder: A critical overview of retrospective findings and recommendations for future research. Neurosci Biobehav Rev. 2019; 102: 24–55.
8. Kalb LG, Landa R, Law PA. Onset patterns prior to 36 months in autism spectrum disorders. J Autism Dev Disord. 2010; 40(11): 1389–402.
9. Ozonoff S, Iosif AM, Young GS, Hepburn S, Thompson M, Colombi C, et al. Onset patterns in autism: correspondence between home video and parent report. J Am Acad Child Adolesc Psychiatry. 2011; 50(8): 796–806.
10. Thurm A, Powell EM, Neul JL, Wagner A, Zwaigenbaum L. Loss of Skills and Onset Patterns in Neurodevelopmental Disorders: Understanding the Neurobiological Mechanisms. Autism Res. 2018; 11(2): 212–22.
11. Macedoni-Lukšič M. Spekter avtistične motnje. In: Kržišnik C, Battelino T, editors. Izbrana poglavja iz pediatrije. Ljubljana: Univerza v Ljubljani, Medicinska fakulteta, Katedra za pediatrijo; 2006. p. 115–26.
12. Gadow KD, Perlman G, Weber RJ. Parent-reported developmental regression in autism: Epilepsy, IQ, Schizophrenia spectrum symptoms, and special education. J Autism Dev Disord. 2017; 47(1): 918–26.
13. Shoffner J, Hyams L, Langley GN, Cossette S, Mylacraine L, Dale J, et al. Fever plus mitochondrial disease could be risk factors for autistic regression. J Child Neurol. 2010; 25(4): 429–34.
14. Rosen TE, Mazefsky CA, Vasa RA, Lerner MD. Co-occurring psychiatric conditions in autism spectrum disorder. Int Rev Psychiatry. 2018; 30(1): 40–61.
15. Davidovitch M, Glick L, Holtzman G, Tirosh E, Safir MP. Developmental regression in autism: Maternal perception. J Autism Dev Disord. 2000; 30(2): 113–9.
16. Goldberg WA, Osann K, Filipek PA, Laulhere T, Jarvis K, Modahl C, et al. Language and other regression: Assessment and timing. J Autism Dev Disord. 2003; 33: 607–16.
17. Dodič D. Kako sprejmemo “drugačnega” otroka v družini in okolici?. Ljubljana: Corason; 2016.
18. Görgner J. Rojstvo otrok s posebnimi potrebami in pot k osamosvojitvi v starosti njihovih staršev. Kakovostna starost. 2017; 20(3): 3–14.

19. Rehberger T. Vloga družine v zgodnji obravnavi otrok z avtizmom. Socialna pedagogika. 2018;22(3-4):229–54.
20. Žgur E. Analysis of preschool children placement state in Slovenia. In: Blažević I, Radetić Paić M, Benassi L, editors. Developmental determinants of preschool and school aged children. Pula: Juraj Dobrila University of Pula, Faculty of Educational Sciences; 2018. p. 87–103.
21. Globačnik B. Zgodnja obravnava. Ljubljana: Zavod Republike Slovenije za šolstvo; 2012.
22. Žgur E. Center za izobraževanje, rehabilitacijo in usposabljanje Vipava. In: Šoln Vrinc P, Jakič Brezočnik M, Švalj K, editors. Zgodnja obravnava: Izhodišča za sistemsko ureditev. Ljubljana: Ministrstvo za izobraževanje, znanost in šport, Sektor za izobraževanje otrok s posebnimi potrebami; 2016. p. 36–7.
23. Restoux P. Življenje z drugačnim otrokom. Radovljica: Didakta; 2010.
24. Lai WW, Oei TPS. Coping in Parents and Caregivers of Children with Autism Spectrum Disorders (ASD): a Review. J Autism Dev Disord. 2014; 1(3): 207–24.
25. Zakon o celostni zgodnji obravnavi predšolskih otrok s posebnimi potrebami (ZOPOPP) [spletna stran na Internetu]. Uradni list RS, št. 41/17; 2017. Pridobljeno s: http://www.pisrs.si/Pis.web/pregledPredpisa?id=ZAKO7681#
26. Macedoni-Lukšič M. Epilepsija in avtizem. In: Kržišnik C, Battelino T, editors. Izbrana poglavja iz pediatrije. Ljubljana: Univerza v Ljubljani, Medicinska fakulteta, Katedra za pediatrijo; 2012. p. 116–20.
27. Goin-Kochel RP, Fombonne E, Mire SS, Minard CG, Sahni LC, Cunningham RM, Boom JA. Beliefs about causes of autism and vaccine hesitancy among parents of children with autism spectrum disorder. Vaccine. 2021; 39(40): 6327–33.
28. Moreno S. A parent view of more able people with autism. In: Schopler E, Mesibov GB, editors. High-functioning individuals with autism. Chapel Hill: University of North Carolina School of Medicine; 1992. p. 91–103.
29. Schmidt I, Schmidt J, Schmidt M. Drama je biti starš vesoljca. Maribor: Založba Pivec; 2017.
30. Luther EH, Canham DL, Young Cureton V. Coping and Social Support for Parents of Children With Autism. J Sch Nurs. 2005; 21(1): 40–7.
31. Novljan E. Sodelovanje s starši otrok s posebnimi potrebami pri zgodnji obravnavi. Ljubljana: Zveza Sožitje; 2004.
32. Žgur E. Vidik razvojne utemeljenosti zgodnje obravnave rizičnih otrok v predšolskem obdobju – izzivi SRP [Plenarno vabljeno predavanje]. Strokovni posvet Zgodaj ni prepozno – Uresničevanje zakona o celostni zgodnji obravnavi otrok s posebnimi potrebami in otrok z rizičnimi dejavniki; 2023 Sep 28; Bukovica: Dvorana Angela Mlečnika.