

Sources of Parenting Stress Raising Children with Autism Spectrum Disorder: Subjective Experiences of Parents

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Abstract. Autism is a complex state of the individual's development manifesting itself in various different forms of behaviour, emotions, communication, etc. which create preconditions for the expression of different experiences. The article aims to reveal the subjective experiences of parents raising children with the autism spectrum disorder (hereinafter ASD) which are related to the sources of parenting stress they experience. A qualitative research approach was chosen to reveal the experiences of the subjects. The data were collected through a semi-structured interview, during which, open-ended questions were used so that not to limit the possible answers according to the assessment domains provided by the researchers. Qualitative content analysis using an open coding procedure was chosen for the analysis of the research data. By reconstructing the multi-layered context of social, cultural, and educational diversity of families raising children with ASD and analysing the subjective experiences of parents, the sources of the stress they experience are revealed. The study highlighted parents' internal-personal (parents' internal experiences) and external-social difficulties in relationship with society due to the personality and behavioural characteristics of children with ASD. The latter can be divided into micro (child's behaviour as a source of stress, challenges encountered in the child's daily life and changes in the environment) and meso (material challenges, negative societal attitude) spaces.

Keywords: sources of parenting stress, parenting stress, children with autism spectrum disorder (ASD), subjective experiences of parents.

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Introduction

Autism spectrum disorder (ASD) is considered a complex, lifelong developmental condition involving persistent challenges in social interaction, limited interests of the individual, and repetitive patterns of behaviour, interests, and activities (American Psychiatric Association, 2013). The autism spectrum manifests itself in many different forms; therefore, the range of challenges experienced in relation to the surrounding people and environment is very diverse and ambiguous, especially if we analyse this phenomenon from a sociological perspective. From a sociological-anthropological point of view, autism is seen as a biopsychosociocultural phenomenon; therefore, all aspects are considered significant in order to achieve a holistic understanding of it, as well as in evaluating other aspects and contexts to be associated with autism (Bartušienė, 2021).

Parents of children with ASD face a variety of challenges: from creating and following a strict and clear daily routine, removing physical and emotional barriers of the environment to searching for answers to existential questions. Bartušienė (2021), upon summarizing the results of scientific research and the subjective experiences of parents, notes that specialists in the field of autism constantly emphasize to parents their importance for the successful psychoneurological development of the child and the fact that only their efforts will determine who their child will be in the future: 'normal and independent', i.e., as similar as possible to a neurotypical person or not. Thus, in this context, parents, while facing external and internal barriers and social pressure, constantly experience various tensions and anxieties turning into constant stress.

The stress experienced by parents of children with ASD – parenting stress – and the sources of stress are the subject of extensive research (Miranda et al., 2019; Craig et al., 2016; Barroso et al., 2018; Spratt, Saylor, & Macias, 2007; Kiami & Goodgold, 2017, etc.). Scientific research shows that parents of children with ASD experience higher levels of stress than parents of typically developing – neurotypical – children (Miranda et al., 2019; Craig et al., 2016), or even compared to other parents raising children with other clinical features (Barroso et al., 2018). Some studies show that as many as 77 percent of mothers raising autistic children experience stress (Kiami & Goodgold, 2017). Considering the results of various studies on parenting stress, it has been observed that the developmental characteristics of children with ASD may affect parental stress differently. There are studies showing that IQ levels or emotional and behavioural problems are associated with higher levels of parental stress (Craig et al., 2016), and the combination of behavioural difficulties experienced by the child and disorders of cognitive development has the greatest influence on the stress experienced by the parents (Barroso et al., 2018; Spratt, Saylor, & Macias, 2007; Estes et al., 2009).

The sources of psychological stress mentioned by parents are quite often related to the evaluation of the child's neurological development by autism specialists, the feelings of moral guilt and shame due to insufficiently "good developmental results", constant

efforts to know and understand the child's neurological differences, to accept and come to terms with them, and combining "motherly intuition" with expert knowledge and expectations raised by the same experts to have time to teach children in the so-called sensitive period (Bartušienė, 2021). Other research has linked parenting stress to cognitive, social-behavioural, emotional, communication, and sensory challenges in a child with ASD (Giovagnoli et al., 2016; Bartušienė, 2021; Baroso et al., 2018), to the issues of the child's future, etc. Therefore, in this context, it is extremely important to pay attention to the emotional state of the parents, the parenting stress experienced by the parents, and the sources of this stress. A clearer identification and understanding of the sources of stressful situations would enable one to start looking more effectively for ways to provide opportunities for parents to help themselves and other parents how to reduce the barriers in the social environment and the social pressure on these parents to constantly "keep up, get it right, adapt, etc." in time, space and other dimensions.

The research problem can be characterized by a fundamental question: *What essential sources of stressful situations are identified by parents raising children with ASD?* Hence, the **research object** is the sources of stress in the aspect of subjective experiences of parents. The research aims to reveal the sources of stressful situations experienced by parents raising children with ASD in the aspect of subjective experiences of parents.

Research methodology, sample, ethics. A qualitative research approach was chosen to reveal the experiences of the subjects. The data were collected through a semi-structured *interview*¹, in the course of which, open-ended questions were used that did not limit the possible answers according to the assessment domains provided by the researchers. The latter were distinguished after analysing the scientific literature and conducted studies revealing the peculiarities of the stress experienced by adults in this situation and their coping capabilities (Frydenberg & Lewis, 1993; Folkman & Moskowitz, 2004; Valickas, Grakauskas, & Želvienė, 2010; Lazarus & Folkman, 1998).

Qualitative content analysis using an open coding procedure (Corbin & Strauss, 2014; Brinkmann & Kvale, 2005) was chosen for the analysis of the research data. The content of the responses, which formed the basis of the study, was split up according to the relevant diagnostic areas, divided into categories and subcategories, meaningful statements were selected. In the course of the research, the experiences and feelings of parents that they face when raising children with ASD were to be revealed. The expertise method was used for the validation of qualitative research data. The experts were presented with qualitative research tables with the intended diagnostic areas, categories characterizing them and illustrating statements. After analysing these, an opinion was expressed regarding the appropriateness and reliability of the data provided. The essential comments of the expert (naming and clarification of diagnostic areas, regrouping and highlighting of some illustrating statements) were taken into account

¹ The authors would like to thank R. Buividienė for her assistance in collecting the data for this study.

when analysing and interpreting the data. This made it possible to achieve a clearer and more detailed presentation of the research, more accurate presentation and analysis of empirical qualitative research data, quality of interpretation and presentation of results.

Informants – specifically, parents raising children with autistic disorder (N=17) – were selected through targeted convenience sampling from various cities and towns in Lithuania: Panevėžys, Kaunas, Utena, Vilnius, Klaipėda, Šiauliai, and Telšiai. By using this sampling method, researchers had the opportunity to interview everyone who agreed to participate in the study and get their opinions and experiences about the subject being studied (Bitinas, Rupšienė, & Žydzžiūnaitė, 2008; Žydzžiūnaitė & Sabaliauskas, 2017).

The research participants were informed in advance about the aim of the research, the course of the research, as well as the expected time and place. The qualitative semi-structured interview followed the principles of research ethics: respect for the individual and voluntariness. During the research, the privacy and anonymity of the research participants were respected, and all information received is considered confidential (Bitinas, Rupšienė, & Žydzžiūnaitė, 2008; Žydzžiūnaitė & Sabaliauskas, 2017).

Analysis of Research Results

During the study, an effort was made to find out what challenges those parents who raise children with autism spectrum disorders are facing and what causes the stress they are experiencing. The analysis of the research data made it possible to reveal the sources of stress experienced by parents raising autistic children, i.e., stressors based on their subjective experiences (see Table 1).

Table 1.
Sources of parental stress – stressors

Category	Subcategories	Supporting statements
Internal experiences of parents	Lack of skills of understanding the child and adequate response	<... you can't understand the child... they can't tell what's wrong...> [R1]; <... you don't know, I don't know how to behave... in a situation...> [R5]; <... you don't know how to help...> [R1]; <... how to understand each other...> [R1]; <... not knowing how to act in a complicated situation...> [R12]; <... difficult to control...> [R5]; <... Inability to control the child...> [R15]; <... impossible to predict...> [R16]; <... doesn't know how to explain... or... ask someone else...> [R11];
	Fear of uncertainty and change	<... and...the tension... what the day will be like...> [R16]; <... when you lack respite and time for yourself...> [R5]; <... going out... to work... a challenge...> [R11]; <... you find a note...they leave... the classes will not take place...> [R4];

Category	Subcategories	Supporting statements
Child's behaviour as a source of stress	Undesirable emotional reactions and behaviour of the child	<... cries... screams... runs... > [R3]; <... through the brain when ... he wants to...> [R8]; <... unwanted behaviour of the child will appear...> [R11]; <... falls...> [R10]; <... cries... screams...> [R10]; <... can't sit for a while...> [R10]; <... may harm themselves or others...> [R15]; <... buzzing zzzzz is annoying...> [R8]; <... child...in the morning... crying... screaming...> [R16]; <... can't... what hurts, but cries...> [R16]; <... the most obvious differences in the situation with neurotypical children...> [R7]; <... a child ... whose mood changes...> [R15]; <... with emotions...> [R3]; <... when the child is stimulating...> [R5]; can get irritated, angry, stressed...> [R16];
	Lack of social skills of the child	<... attempts to ask to bring a thing ... > [R10]; <... for a child... to share toys... doesn't understand...> [R11]; <... doesn't know how to get involved... > [R3]; <... wait for his turn ... > [R11]; <... doesn't know how to explain... or... ask someone else... > [R11];
Challenges of the child's daily life and environment changes	Stress of having to constantly care for the child	<... can't leave... alone...> [R4]; <... to look after the child...> [R3]; <... Constantly monitor...> [R15], <... when you lack respite and time for yourself...> [R5];
	Child's nutrition challenges	<... food preparation...> [R16]; <... the ration is narrow...> [R16]; <... with food... > [R3]
	Unusual changes in the environment as sources of stress	<... every new, unfamiliar place... > [R14]; <... negative reactions of the child in an unfamiliar place... > [R14]; <... not the same colours... of the bus... > [R16]; <... new, unfamiliar place...> [R16]; <... calmly pass by some objects (strong attraction to water, for example, streams, river, fountains)...> [R15];
Material challenges	Searching for new sources of livelihood and threats of job loss	<... I had to give up my full time... job ... > [R16]; <... to look for new... forms of survival and sustenance... > [R4]; <... can't go to work...> [R4]; <... in matters of keeping your job... > [R4]; <... lack of finance... > [R5];
	Financial burden due to additional services	<... regarding the availability of therapies...> [R5]; <... be able to pay for the therapies...> [R5]; <... because therapies are very expensive... > [R17]; <... money... for the child's therapies...> [R17]; <... for collecting information, tests...> [R17]; <... for trips (to the osteopath and more than once)...> [R17];
Negative attitude of society	Fear of society due to lack of tolerance	<... when you get nasty comments from the environment...> [R1]; <... in playgrounds... > [R6]; <... tension... in society...> [R6]; <... the reaction of those around you... > [R8]; <...smoothing over situations... > [R8]; <... different behaviour of the child... > [R9]; <... people's intolerance... of the different person... > [R6]; <... condemnation...> [R6];

Category	Subcategories	Supporting statements
Negative attitude of society		<... putting into the frame...> [R6]; <... the reaction of those around you...> [R13]; <... public place...> [R13]; <... relatives...> [R13]; <... medical institutions...> [R13]; <... a longer period of time waiting to see specialists due to the child's unpredictable behaviour...> [R14]; <... stress when going out in public...> [R10]; <... especially when in a public place...> [R11]; <... children... are different, so it is difficult for others to understand... we encounter...> [R11]; <... stress... medical institutions...> [R16]; <... medical...> [R5]; <... medical institutions...> [R14];
	Dominant segregation culture in the educational institution	<... the fight... for...education...> [R5]; <... especially... school...> [R5]; <... general education nursery/ kindergarten...> [R16]; <... constant reproaches for the behaviour of the child...> [R16]; <... in kindergarten... the child... is different...> [R6]; <... if the child has special needs, then only special school, special therapists, etc...> [R6]; <... teachers want comfortable children...> [R6]; <... school...> [R13]; <... thoughts about future school...> [R6]

Reconstructing the multi-layered context of social, cultural, and educational diversity of these families, the analysis of the collected data allows a comprehensive look at the sources of stress of parents raising children with ASD based on the subjective experiences of the parents. Stress is a phenomenon that contains internal and external, physical and social variables that are unfavourable to the successful functioning of the personality. Generalized semantic units, singled out in the course of the study, specifically reveal the variety of the variables of stress sources (Frydenberg & Lewis, 1993; Folkman & Moskowitz, 2004; Lazarus & Folkman, 1998). Relatively, the sources of stress can be divided into *internal-personal* and *external-social* difficulties (Pikūnas & Palujanskienė, 2005).

The study highlighted parents' **internal-personal (parents' internal experiences)** and **external-social** difficulties in relationships with society due to the personality and behavioural characteristics of children with ASD. The latter can be divided into **micro (child's behaviour as a source of stress, challenges of the child's daily life and changes in the environment)** and **meso (material challenges, negative societal attitude)** spaces. The development of daily life and social interactions of these families keep presenting new 'surprises' to the families themselves and community members, requiring positive solutions in order to ensure successful social functioning. Such an interaction of **internal** and **external** variables in the social life and community activities of families can be perceived as an ecological system, multiple interaction where all interaction participants (families, children, professionals, community members) are

active and all variables are important because the success of social inclusion and the harmonious development of a diverse society depend on its success. The coherence of this system can be disturbed due to the **internal** experiences of the individual and the **external** relations with the social environment because both the person himself/herself and the social environment can have both shortages and surpluses. This discrepancy or disharmony disturbs the social balance, preventing change and development both for individuals and for society itself (Bronfenbrenner, 1992, 2001; Gevorgianienė et al., 2021; Lussi, 1995).

The research data reveal that family members associate a large part of the stressors with the **internal experiences** of the parents. Difficulties of this nature are undoubtedly of great importance to the social welfare of the family. This stress expression space highlights several contexts of the internal state of parents raising children with ASD, described by the following subcategories: **lack of skills of understanding the child and adequate response, fear of uncertainty and change**.

The experiences of the parents allow one to reconstruct the features of the social life of these families, the fears experienced, and the range of difficulties experienced creating obstacles to balanced functioning, social inclusion, well-being, and prosperity. The research participants stated that they constantly feel tension and stress [*<... you can't understand the child... they can't tell what's wrong...> (R1); <... you don't know, I don't know how to behave... in a situation...> (R5); <... you don't know how to help...> (R1); <... inability to control the child...> (R15); <... impossible to predict...> (R16); <... going out... to work... a challenge...> (R11)*], they feel as if they are on the battlefield, they are not always able to respond properly to the unexpectedness of the child's behaviour. Parents are likely to lose coherence on the physical, emotional, and spiritual levels, they seem to get into a 'vicious circle', in which it becomes very difficult to control themselves and maintain balance. Constant uncertainty and unforeseen situations lead to anxiety and stress, which are difficult to control and become dangerous to the individual's health, well-being and inner harmony (Mikulėnaitė & Ulevičiūtė, 2004; Keen, Webster, & Ridley, 2016).

Family members revealed that raising a child with a disability in the family disrupts the normal functioning and rhythm of the family, whereas events often begin to revolve solely around the child's needs and their satisfaction. Over time, the internal experiences of parents lead to stressful situations that cause fatigue, anxiety, and emotional health difficulties (Gevorgianienė et al., 2021). It becomes a constant emotional state of the parents (Estes, Olson et al., 2013).

The approach of the informants allows to reconstruct the features of the **external micro-social** life of these families, the fears and stress experienced. This reveals several diagnostic contexts that highlight several subcategories. The data provided by the research participants allow to reveal the **external stressors of the micro-environment**, arising from the **child's own behaviour, which becomes a source of stress**. Parents also talk about **undesirable emotional reactions and behaviour of**

the child [*<... cries... screams... runs... > (R3); <... can't sit for a while...> (R10); <... may harm themselves or others...> (R15); <... falls...> (R10)*], **lack of social skills of the child** [*<... doesn't know how to get involved... > (R3); <... wait for his turn... > (R11); <... doesn't know how to explain... or... ask someone else... > (R11)*].

Great social tensions and challenges for families also arise from **changes in the child's daily life and environment**: due to **the need for constant care of the child** [*<... can't leave... alone...> (R4); <... constantly monitor...> (R15)*], **nutrition** [*<... food preparation...> (R16); <... the ration is narrow...> (R16)*] and **unusual changes in the environment** [*<... negative reactions of the child in an unfamiliar place... > (R14); <... not the same colours... of the bus... > (R16); <... calmly pass by some objects... strong attraction to water, for example, streams, river, fountains...> (R15)*]. The latter **external** stressors are also associated with the **micro environment** of these families, its minimal changes, which cause unpredictable behaviour of these children.

Often simple and mundane everyday life situations (eating, shopping, walking or similar) do not cause stress and anxiety for ordinary families. It often becomes a challenge for the children of these families: parents going to work, hurrying, riding the bus, its new colour, sound, change of route, agenda or food ration cause tension and overreaction. Such changes in the environment are difficult for children with ASD, they have difficulty adapting to it, and therefore it can provoke anxiety and inappropriate behaviour, which is not directed at a specific person, but which arises from the specifics of the disorder, and it causes **stressful situations** for parents (Mikulėnaitė & Ulevičiūtė, 2004).

The authors note that *autism* is one of the most challenging disorders, with characteristic features such as the child's unpredictable behaviour, impaired social communication, atypical and strange behaviour, and problems with imagination and time perception.

The analysis of the subjective experiences of the parents allowed us to reconstruct another context of **external (meso)** sources of stress, related to several spaces: **negative attitude of society** towards these families and **material challenges**.

Upon analysing the **negative attitude of society** towards children with ASD, it becomes clear that families feel **fear of society due to lack of tolerance** [*<... when you get nasty comments from the environment...> (R1); <... tension... in society...> (R6); <... people's intolerance... of the different person... > (R6); <... condemnation...> (R6); <... stress when going out in public...> (R10); <... stress... medical institutions...> (R16)*].

The analysis of the research data made it also possible to distinguish the **subcategory** of stressors related to the **segregation culture in the educational institution** [*<... the fight... for...education...> (R5); <... if the child has special needs, then only special school, special therapists, etc... > (R6); <... teachers want comfortable children... > (R6)*].

In families raising children with ASD, difficulties in **material** well-being also become evident, as the **search for new sources of livelihood** becomes important, the **threat of job loss** appears [*<... I had to give up my full time... job ... > (R16); <... to look for new...*

forms of survival and sustenance... > (R4); <... can't go to work...> (R4)]. These children also need additional social, medical, and health services, which are often expensive and become an additional **financial burden** for the parents **due to the services** [*<... because therapies are very expensive... > (R17); <... for collecting information, tests...> (R17); <... for trips (to the osteopath and more than once...> (R17)].* Families raising children with ASD have to constantly take care of them, they cannot leave them alone, as a result they have to give up part of their work, or end their working relationship altogether and devote themselves to childcare. This often results in a decrease in income, parents suffer financial losses, which are urgent and necessary for the children's health, social, educational support and services. The latter, according to the parents, often become expensive, and difficult to afford.

The analysis of parents' experiences revealed society's limited readiness to accept different children. Members of society often retort or even condemn parents for their child's misbehaviour, "gaps in upbringing", thus causing negative emotions, mistrust, and stress to the family members. In the postmodern multi-layered society, in which we now live, different philosophical attitudes, value systems, and cultures coexist. Such eclecticism presupposes a new approach to human being, leads to new combinations, where the boundaries between particularity and universality, individuality and sociality are disappearing, where the process or action becomes more important than the result, where being in uncertainty becomes important, and momentary experience is valuable. In her works, Bartušienė (2021) changes the term 'autism' with the concept of neurological diversity, which is close to the idea of neurodiversity proposed by Singer which can be expressed as a fact of human biodiversity, as an infinite variation of human cognitive abilities, in which each person has different neurological characteristics which have a significant impact on a person's thinking, communication, learning, creating social connections with other people and experiencing the physical environment. On the other hand, the context of the opinions of parents raising children with ASD highlights quite clear boundaries between position and opposition, norm and specialness, difference and similarity. Members of society do not tend to destroy these boundaries, and there remains a desire to separate different members of society, to limit communication with them (Bitinas, 2000; Duoblienė, 2006).

The analysis of the subjective experiences of family members also highlighted the negative attitude and a **segregation culture towards children with ASD in educational institutions**.

As the parents notice, educational institutions are not open to the arrival of other students in the community, regardless of the educational transformation aspirations of the EU countries, including Lithuania, to create a postmodern inclusive education system, encompassing the diversity of all groups of students, based on values that acknowledge differences, the activeness, cooperation, and continuous improvement of the participants in the educational process, positive attitude towards students, high personalized expectations for each student (Conception of Good School, 2015; Education Development Program

2021-2030). It should be noted that postmodern education is a philosophy with a system of views, theory, methodology, and practice of the educational process, which, by the way, is on the way to development and requires not only clear political and legal regulation (likely to be achieved faster), but also a change in values, beliefs, educational culture, practice, training of specialists (which is a slower process). The slowness of this process is complicated not only by the heritage of ideological education, but also by the complexity of the process of value and spiritual changes, as well as susceptibility to the time and quality of deconstruction (Bitinas, 2000; Duoblienė, 2011).

Conclusions

Autism and its spectrum disorders are classified as a group of complicated complex disorders, with characteristic personality and behavioural features and difficulties in social relations with other people. This often complicates the process of successful inclusion of children with ASD into communities and educational institutions and causes a lot of anxiety and stress for family members. Autism is a lifelong neurological condition, characterized by a specific developmental process that is usually difficult to predict and control, as well as unique sensorics, communication, teaching/learning methods and relationships with the environment and other people.

By reconstructing the multi-layered context of social, cultural, and educational diversity of families raising children with ASD and analysing the subjective experiences of parents, the sources of the stress they experience are revealed. The analysis of the subjective experience of the parents revealed that the variables of stressful situations experienced by them can be relatively described as *internal-personal* and *external-social*. The success of the functioning of the ecosystem of the families and community, paving the way for the welfare of these families, depends on the harmony of multiple interaction of these variables.

The stress experienced by parents, the constant tension due to the unpredictable behaviour of children and frequent aggressiveness cause *internal-personal* difficulties. Family members feel tired, they feel tension and stress, and they are not always able to respond properly to the unexpected behaviour of the child. Parents are likely to lose harmony on physical, emotional, spiritual levels, as it becomes difficult to control themselves and maintain balance. Constant uncertainty and unforeseen situations lead to anxiety that is difficult to control, eventually turning into stress, which can become dangerous for a person's health, well-being, and inner harmony.

External-social difficulties disrupt the smooth social interactions of families and communities. Due to the lack of tolerance for the otherness of the surrounding people and the manifestations of the segregation culture, such families become not always desirable in communities, as well as in medical and educational institutions.

The stress experienced by parents raising children with ASD disturbs the harmony of the ecosystem, and complicates the process of social inclusion of these individuals.

The analysis of the subjective experiences of parents allows one to make the following statement that, regardless of the legal basis in the country, which is managed in a postmodern way in favour of social inclusion, the attitude and values of society and the communities of educational institutions, the change of the educational process remain rather rigid. In our society, which is becoming postmodern, the educational culture of educational institutions remains quite conservative, slowly moving in the direction of respect for otherness, for each child and personalized assistance, in no way reducing stressful situations for families raising autistic children.

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