Expression of Social Interaction of Parents Raising Children with Autism Spectrum Disorder

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Abstract. The article looks into the discourse of parents of children with autism spectrum disorder (ASD) in an online self-help support group, putting the main focus on the expression of social interaction. The research results revealed particular actualization of the collapse of social links and their re-establishment in the context of a family crisis upon learning the child’s diagnosis. For the stability of family relationships and social links with the surrounding environment, early assistance for the family and its environment is important, as well as clear definition of the actual situation and finding meaning when raising a child with ASD. The family’s adaptive response to ASD-caused challenges improves the quality of interaction with the environment, and helps normalize social interaction.

Keywords: autism spectrum disorder, social interaction, emotional crisis, social isolation, mutual support.

Introduction

Families with children with autism spectrum disorder (ASD) encounter various difficulties of their family functioning in various spheres: social connections, mobility, physical activity, nutrition, etc. These families experience continuous stress and anxiety (Johnson, Frenn, Feetham and Simpson, 2011). It affects not only parents but also other children in the family (Rao and Beidel, 2009). The stress level of parents in families with children with ASD is significantly higher than that of parents in families with
children with mental or behaviour disorders or chronic diseases. Research show that the stress the parents experience cannot be compensated by the child’s higher intellectual performance since the stress is directly linked to the child’s behavioural issues (Rao and Beidel, 2009; Johnson et al., 2011). The behavioural problems in children with ASD enhance significantly the stress experienced by their mothers (Estes, Munson, Dawson, Koehler, Zhou, and Abbott, 2009). Assistance to such families’ better quality functioning should be focused not as much on overcoming the symptoms of autism as on dealing the child’s behavioural issues (Johnson et al., 2011; Rao and Beidel, 2009; Estes et al., 2009). The stress that many families constantly experience is strongly enhanced by the decrease in possibilities to engage in favoured free-time activities, be involved in social life, and escape daily routine (Nealy, O’Hare, Powers, and Swick, 2012). Naturally, organizing free-time activities of a family raising a child with a disability depends not only on the family’s preferences but also on the possibilities and skills of the child with the development disorders (Mactavish and Schleien, 2004). Due to the nature of the ASD symptoms that is incomprehensible to many surrounding people, such families lose part of their connections with friends and relatives, leading them to feelings of isolation. In many cases, changes also occur in the intra-family relationships (between the husband and the wife, other children, or grandparents) (Nealy et al., 2012).

The emotional socialization of the parents is vital for the child’s long-term emotional development. Coaching provided by both parents for the children’s processes of emotional expression carries undisputed significance for the children’s emotional health (Bowie, Carrère, Cooke, Valdivia, McAllister, and Doohan, 2013). The quality of parenting is of crucial importance in overcoming depressive moods arising from the consequences of the child’s disability in the family. Its influence exceeds that of social or economic status of the family, or the child’s profile. The quality of marriage bears particular significance to mothers when dealing with difficulties rising from the child’s disability; whereas to the fathers external help and support are important (Kersh, Hedvat, Hauser-Cram, and Warfield, 2006). Research show that a great number of families (around two thirds) with children with disabilities take or have taken part in various self-help support groups. In most cases, these are people with better education and raising children with more complex disabilities. Their aim is to maintain contact with people with similar experiences. This shows that in serious cases, the support from official institutions is insufficient to families (Mandell, and Salzer, 2007). Parent support groups may be formed with the help of specialists, creating conditions for the parents to share examples of their own experiences. In such groups, parents not only discover other parents sharing the same experiences, receive pieces of advice and ideas but they also shift their role from support receivers to support providers. Once participants’ meetings in person are over, such parents often continue their activities of mutual support by joining other groups or creating such groups themselves (McCabe, 2008). Involvement in parent self-help support
groups alleviates negative feelings of social isolation arising from the incomprehension of surrounding people (Banach, Judice, Conway and Couse, 2010).

The situation of children with ASD and their families has been analyzed in various aspects; however, the process of expressing social interaction remains an object for scientific exploration. This research aims at looking into the phenomenon of the social interaction of the family in the areas highlighted by the parents with children with ASD, and at understanding what processes determine the form of the family’s social interaction in various life situations.

The scientific problem of the research was based on the following question:

**Research question:** What is the process of the expression of the parents’ social interaction when the family has a child with Autism spectrum disorder?

**Method**

The expression of the social interaction in parents raising children with ASD has been selected as the research object. The scientific problem is analysed through the perspective of social phenomenon according to A. Schütz (1967), assuming that the social reality in question corresponds with the person’s deliberations conveyed in oral or written form. The language used allows to understand the meanings that “others” convey, and interpret them in given social context. The entries of parents with children with ASD in a thematic online self-help support group on the topics of autism serve as the context of the research. During the research, the group consisted of 3300 members. The data was analysed in stages, via the content analysis method. The first stage involved reading the parents’ entries in the thematic online self-help support group, and, following the logic of the research question, sampling the ones that reflected the expression of the families’ social relationships. Thus, 160 units of meaning were selected. During the second stage, the units of meaning were abstracted into dimensions. The third stage involved generalizing the units of meaning into topics, and analysing them with the aim of identifying the core components of the expression of the phenomenon, and interpreting them.

The discourse analysis highlighted three dimensions of the manifestation of the phenomenon, and seven topics that delineate the dimensions, illustrated by corresponding units of meaning.

**Research ethics.** Quotation right applicable to online group entries has been agreed upon with the authors of the entries. For the sake of research ethics, the title of the online group and the authors of the entries have been anonymized.
Result Analysis

The discourse analysis of the online self-help support group highlighted a dimension of the phenomenon manifestation, which reveals change in the family’s social links.

Dimension of change in social connections

There are three topics the parents refer to that reveal the phenomenon in question and which allow for identifying the trends in the manifestation of the phenomenon.

Initial emotional experiences of the parents. The research results show that emotionally the most difficult period for the family is suffering the foreboding of the child’s potential diagnosis, and immediately after learning it. This is the moment of extreme emotional load that the parents encounter, which causes tension and confused feelings that are hard to endure. The parents’ stories attest to deep sadness, pity towards the child, and search for help to calm down.

“Together with my husband, we spent the first month crying”, “...you look at the child and tears flow down your cheeks”, “how can we lead a normal life, how can we accept this piece of news in our minds?”, “...how did you accept the diagnosis?”

However, the sadness cannot be compared to mourning. During this period, the parents are proactive and strive to influence the problem. Firstly, they seek information. However, the symptoms of autism vary, making it complicated to find answers to specific questions that define their situation in the overall information pool. This, in turn, raises even greater tension and stress.

“I’ve read loads of information everywhere, my head is about to burst soon”, “There’s so much information, it felt like my brain was going to explode on to the walls”, “I’ve made an appointment to see a neurologist, to have a paid consultation because... all this reading is going to make my head burst, I cannot find peace.”

The research results show that the first period of time when the family’s suspicions emerge about the child’s potential development disorder and when they learn the diagnosis is a critical moment for the family’s further development. Assistance is necessary for a family experiencing strong emotional tension. In that period, information on the symptoms of autism and the genesis of the disorder, if read without appropriate context, may be interpreted imprecisely, thus merely increasing the anxiety. Therefore, it is of utmost importance for the family to receive intensive professional care in that period, which would help solve the issues of the child with the disability as well as those of the confused family.

Changes in familial relationships. In the absence of targeted assistance, the situation in the families take various turns. Strong parenthood leads to joint decisions, the family
deals with their initial emotions and continue to build the future together for themselves and their child.

“The diagnosis was like a cold shower, like an earthquake that changed our life... yet, we got over it, brought ourselves together, and we're moving on.”

However, the mothers’ posts in the parents’ online self-help support group indicate that some families fail to endure the tension and relationships within the family grow warped or the family breaks up. In cases of family collapse, the mothers are most frequently the ones to suffer experiencing social exclusion or the husband’s withdrawal from the family.

“I felt very lonely with my child in the marriage”, “We broke up with the child’s father before the diagnosis”, “We were abandoned by the child’s true dad. He “heroically” escaped.”

A similarly important experience of the transformation of social links occurs outside of the family with the child with ASD. Numerous entries on the group speak of altered relationships with close people, terminated relationships with friends, as well as exclusion and isolation one goes through. In certain cases, significant changes occur even in the relationships with the parents of the child’s father. The grandparents fail to understand their grandchildren, feel embarrassed about them, or blame the parents for the child’s disability. In some cases, the relationships of the family raising the child with ASD with the parents of the spouses come to an end.

“My parents and my brother support me. There’s nobody else left. No relatives, no friends, no child’s father or his relatives”, “In our case, our connection with a great many of friends somehow “broke”. . . . Before the diagnosis, we were an outgoing, fun family. Now, there’s only one couple of friends left, who are our treasure’s godparents”, “I can feel communication has changed. They don’t understand the diagnosis itself, and they keep giving advice.”

The parents’ discourse in the online self-help support group clearly indicates the relevance of the need of social assistance not only to the family but also to the family’s immediate environment. The symptoms of autism, which affects the area of social interaction, impacts not only the relationship between the child and their parents but it also exceeds the family boundaries and causes significant disruptions to the relationships around it. A new social and psychological situation of the family, which is difficult to manage and to understand, triggers processes of segregation towards the family.

**Reasons to changed social links**

The discourse in the parents’ online self-help support group allows to analyse the reasons of the processes of segregation. The initiative to withdraw from others might come not only from the surrounding people but also from the parents raising the child with ASD. When parents face difficulty in coming to terms with the reality and accepting their child’s differences when comparing their abilities with those of ordinary children, it is easier to distance yourself and at least temporarily reduce the sense of contrast.
“I myself don’t want to talk to other mothers. It hurts me to see how much healthy children can do and compare it to mine, I don’t know how to listen without envy to other mothers’ praises of what great achievers their children are, etc.”

In other, more frequent, cases, the processes of segregation derive from the reactions of surrounding people to inadequate behaviours of the child with ASD in situations that require flexibility in social interaction. The child’s disturbing behaviour that is also difficult to control confuses surrounding people. Unable to find an appropriate manner to react in such situations, they withdraw. Thus, uncomfortable situations are avoided, yet the family remains in isolation.

“It’s been two years since everyone found out and simply withdrew; we have no contact. The child screams. We can’t visit anyone and nobody can even come over to us because the child’s scream is never-ending, I can’t even put a kettle on for some tea; and it’s also unpleasant to everyone, it grates on the ear.”

Aligning the needs of the family and those of the public, gradually responding to the obligation for the child and the friends to understand incomprehensible situations, to learn to act in them, to adapt, and accept challenges may help the family to preserve their connections, and the child to acquire skills of participating in a community.

“There was a time when we refrained from spending time with most of people because there was a big regress. I had neither a desire, nor strength to cause my child to scream. But when he got older, we started to go out to meet people. Not a single one of our friends turned away. They all simply understood we have a different child. If someone asked, we would tell the story, if they did not, we would simply spend time together.”

The preparedness of society to accept, understand, and react adequately to the behaviour of a child with ASD is a factor of great importance for the family’s choice to either be in open society or remain in isolation. Inappropriate reactions of surrounding people to the child behaving inadequately doubles the emotional tension to the parents. The necessity to control the child’s behaviour in public and respond to the reactions of the surrounding people may become a reason for avoiding public appearances.

“And if you happen to meet me on the street, in a shop, a café, outside, or in the school with a weirdo whom I often hold by hand, who tosses around when queueing, who occasionally shouts out strange things, begins to sway or gets an anger attack; please, be so kind and don’t moralize or comment.”

The analysis of the change in social interaction of families with children with ASD shows that social support should not be restricted to the family and its immediate environment. Raising public awareness on the forms of manifestation of the symptoms of autism and their effect on interpersonal relationships might bring strong decrease in the likelihood of the collapse of the families’ social connections. On the other hand, the one-sidedness of the child’s interaction and his or her disturbing reactions to surrounding people make an important target for support and assistance to the family.
Dimension of mutual support

The analysis of the discourse of parents raising children with ASD, which reflects the family’s social life, reveals targets for mutual support that would provide help in accepting the new situation in the family and normalize the quality of life in it. Two topics clearly emerge in the discourse.

**Definition of a new reality.** Research data shows that parents with more experience put effort to describe to those with less experience, in a subtle and encouraging yet realistic manner, the actual situation that they must accept in order to see their social lives return to normal. The discourse refers to acknowledging the disturbing reality, along with a belief in progress and hope.

“The easiest thing is to say “Don’t be afraid”, but I’m actually telling you “Do not be afraid.” As the child grows, the situation changes. Sometimes we imagine a gloomy future and we later see things evolve in a completely different way”, “I wish you lots of patience. Sooner or later, time will still come when the child will be able to take care of toilet issues himself.”

Other entries in the mutual support discourse provide an encouraging vision of an actual future, without overstepping the boundaries of reality.

“No one grows out of autism. The person remains, in a way, different anyway”, “Your little one is unique. And life with the diagnosis is not as scary as it seems.”

**Providing existential meaning to the situation.** The research findings show that emotional mutual support among parents reaches down to the meaning of life. Discovering the value of a complex life and believing in it makes it easier to accept the reality, respond to it in an adequate manner, and not to attempt to overtake time, but rather to find solutions to current challenges.

“Children come to our lives not as a punishment but in order for us to find the meaning of life through hard sacrifices of our time and effort to such special children. The parents’ love and hope are omnipotent”, “Don’t look for symptoms while he is little!!! Love him, raise him. There’s a season for everything.”

Mutual support in overcoming emotional crisis, coming to grips with the new situation, and joining a group of people sharing the same fate helps escape the feeling of desperation and foresee steps towards further life of good quality. The greatest loss for the family during the period of emotional crisis is the collapse of social connections. However, the results of the research show that the parents are capable of seeking the elimination of the consequences of the collapse.

**Dimension of restoration of social connections**

The number of entries in the online self-help support group shows that normalizing the family condition is a topic that enjoys great relevance in the mutual support discourse.
It is mostly emphasized by women. They care about the family’s life quality, overcoming their own solitude, and the future of their child with ASD.

**Need of family rebuild.** The research results show that having experienced a break-up of a family, expectations to have a full family remain, nevertheless, present. The discourse content reveals various deliberations of women on the issue; even in cases where the woman denies the need for a full family, the expectation remains.

“I am single; although, if I wished, I could have my other half. But I don’t need it, . . . at least for now, . . . because I have things to keep me busy. There’s a lot of work with my son.”

The research results allow to state that the women find it difficult to make the decision to look for and start a new relationship. Their previous experiences and the otherness of the children they raise constitute an obstacle for planning the future of the family freely. However, the online self-help support group serves as a place to openly share feelings, thoughts, and personal success stories in order to encourage women not to remain in social isolation and solitude.

“I felt ashamed even to think about looking for another man. At the time, not only did I have an autistic son but also two daughters. Three in total. Almost forty years old. Yet, I decided to look for another husband. At first, I did not believe it would take me anywhere. I thought I’d at least have some pen-pals. That’s at least something to lift up the heart. And I saw there actually were men available. I found a suitable one and now it’s almost two years that we’ve been married.”

When encouraging to build a new relationship with another man, the women firstly emphasize the necessity of having confidence in oneself, in one’s unchanged status as a woman, and in one’s right to personal happiness. They encourage pro-activity and focus of the woman herself in changing her situation.

“If you want a relationship, simply stay open to one. . . . You have a choice among men, just like any other woman. And, just like any other woman, if you wish to have a relationship, you simply must look for acquaintances and seek romantic interaction.”

The content of the discourse in this self-help support group reflects a great number of cases of fathers withdrawing from the family during the difficult period of crisis; however, numerous success stories are also shared here of another man arriving to the family and successfully performing the role of the father of the family. The women use their own life examples as an encouragement not to be afraid of new relationships.

“Now, a new boyfriend has been raising my autistic daughter for over three years. He gladly helps me with all the therapies, he joins in to her education, and says “If this is what all our other children will be, autistic, let them be so.” So, don’t be afraid – there are all sorts of people.”
These stories confirm the sensitivity and vulnerability of the family crisis period when problems stemming from the child with ASD first occur in the family. Later, once the family adapts to the altered conditions, the symptoms of autism have smaller impact on the social functioning of the family.

**Family planning.** The content of the discourse in the parents’ self-help support group reveals that the experience of raising a child with ASD in the family has a great influence on its further planning. The families are aware of the possibility to have more children with the same problem. Such awareness becomes an actual obstacle in planning a larger family.

“When I was expecting our second baby, I did not yet know our son was autistic. We thought his speech was simply lagging behind. Had I known it, I would not have dared to have the second child. But now I’m happy we found it out only later. We have a wonderful daughter who loves her brother.”

In other cases, on the contrary, projecting the future of the child with ASD serves as a stimulus for having more children. These are cases when, by planning to have more children, the parents are arranging for care provided to their child with the disability by his or her relatives in the far future when the parents will no longer be capable of looking after the child themselves.

“Time came when we felt selfish: our son is autistic, so all our strength and time goes to him. We decided that as our son grows, he’ll need someone close to him, a friend – we are growing old…So we planned a “caboose” baby. And here you are, there’s a little “happiness” running around the house. The brothers sense each other very well, they have a strong connection. Sometimes with my husband we discuss about the third child but again, fear takes molehills for mountains.”

The content of the discourse in the self-help support group also reveals cases when families welcome several babies with ASD. The discourse analysis shows that the experience acquired and full knowledge of ASD symptoms as well as the ability to adapt to different needs allows accepting the children’s otherness as a natural phenomenon and render the family life normal.

“My eldest one has ASD. When the older one was 16, we decided to have more children. We knew the probability has high, yet we made the decision – come what may. We’re not that afraid of autism in fact; we raised one, we’ll raise another one too. The baby was born with ASD. Two years later, we welcomed one more son, with the same problem again. But we’re a truly happy family, we already know everything, we know how to raise these children.”

The content and context of the discourse in the online self-help support group shows that once the emotional tension fades, families begin to gradually restore their balance, liberate themselves from social isolation, and the experiences of a happy life return.
Discussion

Following the idea by A. Schütz (1967) that the core source of meaning of the phenomenon lies in the deepest layers of experience that are still, however, accessible for reflection, it can be claimed that the parents’ discourse reveals a clear impact the ASD has on the evolution of the family’s social connections. The appearance of a child with ASD in the family causes extreme emotional tension to the parents that is difficult to overcome. It can be compared to experiencing a catastrophe and affects the family’s future functioning. The research findings reveal a particularly high level of tension at the moment of the first suspicion and upon learning the diagnosis, and the results of research by Johnson et al. (2011) show the trend of a prolonged emotional tension of the kind. The results of the analysis of the parents’ discourse in the online self-help support group reveal that the tension in the family and its environment stems from the peculiar behaviour of the child and his or her reaction to the environment, which express the need to distance themselves from external environment and maintain the smallest possible number of social connections. At the beginning of life with the child, the reactions of the members of the family and its immediate environment seemingly repeat the reactions of the child with ASD, namely, distancing and isolation. The most difficult consequence of the phenomenon is the decision of the child’s father to abandon the family. Considering the correspondence of this finding of the research and the conclusion of the research by Kersh et al. (2006) that external assistance and support are of great importance to the father, a particular need for initial social support to the family gains relevance, which should be targeted more to overcoming the emotional crisis in the family than to dealing with the symptoms of autism. Based on the findings of the research by Kersh et al. (2006), it is likely that once the father of the child overcomes the emotional crisis with the help of external assistance, the mother would profit from the preserved strong connection with her husband. The results of the research indicate the collapse of the family’s links with its environment. The findings of the research by Nealy et al. (2012) confirm the phenomenon. As a result, the phenomenon of a family raising a child with ASD generates the need for social support assuming the direction from the family members towards the social environment surrounding the family. The content of the discourse of the parents’ self-help support group reveals that the ability of the family to discover new existential meanings of a complicated situation allows to accept the reality more easily, and act within it. The state of the family and its calm stance helps to preserve social connections with the environment. The phenomenon of a newly restored family is of interest, when a new man arrives at the family, assumes the role of the father, and successfully provides care to the child with ASD. This phenomenon allows for a presumption that a man that did not experience the initial emotional crisis, accepts ASD-caused challenges more easily, assigning priority to other aspects of life in a family.
In the online self-help support group, entries by the women prevail. They accept the situation of the family, and share their experiences with others, thus helping both themselves and other families sharing the same fate.

Limitations

Taking into account the fact that this research looks into the social experience of parents in the cultural context of one country, the findings cannot be generalized to provide conclusions regarding the experience of families raising children with ASD in other cultural contexts. The results of the research call for more profound research into the experiences of mothers and their adaptation to the new situation as well as into the phenomenon of the successful participation of a step-father of the child with ASD in the family life.

Conclusions

The findings of the research show that families of children with ASD assign particular relevance to the emotional crisis that occurs once the ASD diagnosis is suspected and then confirmed. At that critical period, intensive support to the family and its surroundings is necessary in order to facilitate the adaptation to new conditions, preserve social connections within and outside the family. The collapse of social connections results not as much from the inability to control the child’s maladaptive behaviour in situations that call for social flexibility, as it does from the difficulties for adults to comprehend and respond in a flexible manner to such situations.

The clear definition and assigning meaning to the actual situation when raising a child with ASD is of great importance for the stability of familial relationships and social connections with the environment. The family’s adaptive response to ASD-driven challenges improves the quality of interaction with the environment, and helps to normalize social interaction, and in some cases to seek to expand the family.

References


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**Tėvų, auginančių autizmo spektro sutrikimą turinčių vaiką, socialinės sąveikos raiška**

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**Santrauka**

Straipsnyje analizuojamas tėvų, auginančių autizmo spektro sutrikimą (ASS) turinčius vaikus, diskursas internetinėje tarpusavio paramos grupėje dėl socialinių ryšių raiškos. Šeimos, auginančios vaikus, turinčius šį sutrikimą, patiria šeimos funkcionavimo sunkumų įvairiose srityse: socialinių ryšių, mobilumo, fizinio aktyvumo, maitinimosi ir kitose. Šioms šeimoms būdingas nuolat išgyvenamas stresas ir nerimas (Johnson, Frenn, Feetham, Simpson, 2011). Tai
paliečia ne tik tėvus, bet ir kitus šeimos vaikus. Tėvų emocinė socializacija yra gyvybiškai svarbi ilgalaikei vaiko emocinei raidai. Abiejų tėvų vadovavimas vaikų emocinės raiškos procesams turi nenuginičjamos reikšmės vaikų emocinei sveikatai (Bowie ir kt., 2013).
