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Everyday life of parents of Polish and Ukrainian children with autism spectrum disorders. Research report

Życie codzienne rodziców dzieci polskich i ukraińskich z zaburzeniami ze spektrum autyzmu. Doniesienie z badań

Abstract

Introduction. The birth of a child on the autism spectrum causes far-reaching changes in the life of the entire family. This is a problem for both Polish and Ukrainian families. The problems are many, starting from the child's diagnosis through various areas of everyday life.

Objectives. The aim of the research was to learn about the individual experiences in everyday life of parents of children with autism spectrum disorder of Polish and Ukrainian origin, to examine the parents' experiences during the course of pregnancy, childbirth, and early development, to making a diagnosis, determining the child's behaviour, and areas of everyday life that concern changes in the parents' lives.

Materials and methods. The article presents the results of qualitative research of an inter-

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pretive nature, conducted using an individual open interview. The research included parents (Polish and Ukrainian) of children with autism spectrum disorder (five Polish and five Ukrainian children).

Results. Based on the analysis of the statements of parents, most often mothers, three areas of experience were distinguished, reflecting the experiences that constitute the everyday life of parents of children on the autism spectrum. The first Area of Experience concerned the course of pregnancy, childbirth, and early developmental experiences, as well as everyday concerns about diagnosis. The second Area of Experience concerned child behaviour that constitutes the greatest problem in the everyday life of Polish and Ukrainian parents, and the Third Area of Experience concerned changes in everyday life and the significance of these changes.

Conclusion. All the children studied were diagnosed before the age of three or four. Most often, mothers take care of their child, who has been diagnosed with autism spectrum disorder. Despite anxiety and stress, they try to cope with this difficult situation. A significant problem in the lives of parents is the child's behaviour, most commonly aggression, auto-aggression, auto-stimulation, disturbed sleep, epilepsy, or uncontrolled escapes. In Ukrainian children, the above-mentioned behaviours have intensified. A change in everyday life is the organization of work at home. Almost all mothers are concerned for the future of their child. For Ukrainian mothers, an important change was leaving their country, parting with their husbands, family, and not knowing the Polish language.

Keywords: a child with autism spectrum disorder, parents, family, difficult behaviours, areas of parents' everyday experiences.

Abstrakt

Wprowadzenie. Przyjście na świat dziecka ze spektrum autyzmu powoduje daleko idące zmiany w życiu całej rodziny. Jest to problem zarówno rodzin polskich, jak i ukraińskich. Problemy dotyczą codzienności, począwszy od diagnozy dziecka, a na różnych obszarach dnia codziennego skończywszy.

Cel. Celem podjętych badań było poznanie indywidualnych wyzwań życia codziennego rodziców dzieci ze spektrum autyzmu polskiego i ukraińskiego pochodzenia, zbadanie doświadczeń rodziców – począwszy od etapu ciąży, porodu i wczesnych doświadczeń rozwojowych do momentu postawienia diagnozy, określenia zachowań dziecka, aż po pokazanie tych obszarów codzienności, które dotyczą zmian w życiu rodziców.

Materiały i metody. W artykule zaprezentowano wyniki badań jakościowych mających charakter interpretacyjny, przeprowadzonych za pomocą indywidualnego wywiadu otwartego. Badaniami objęto rodziców (polskich i ukraińskich) dzieci ze spektrum autyzmu (pięcioro dzieci polskich i pięcioro ukraińskich).

Wyniki. Na podstawie analizy wypowiedzi rodziców, najczęściej matek, wyodrębniono trzy obszary, odzwierciedlające doświadczenia składające się na codzienność życia ro-

dziców dzieci ze spektrum autyzmu. Pierwszy Obszar Doświadczeń dotyczył przebiegu ciąży, porodu i wczesnego etapu rozwojowego oraz niepokojów dotyczących diagnozy. Drugi Obszar Doświadczeń dotyczył zachowań dziecka, które stanowiły największy problem w życiu codziennym rodziców polskich i ukraińskich, a Trzeci Obszar Doświadczeń to zmiany dotyczące życia codziennego i znaczenie tych zmian.
Wnioski. Wszystkie badane dzieci zostały zdiagnozowane do trzeciego-czwartego roku życia. Dzieckiem, u którego zdiagnozowano spektrum autyzmu najczęściej opiekują się matki. Pomimo niepokoju i stresu starają radzić sobie z tą trudną sytuacją. Istotny problem w życiu rodziców stanowią zachowania dziecka, wśród których najczęściej spotykane to agresja, autoagresja, autostymulacje, zaburzony sen, epilepsja czy ucieczki niekontrolowane. U dzieci ukraińskich wymienione zachowania uległy znacznemu nasileniu. Zmianą w codziennym życiu jest organizacja pracy w domu. Prawie wszystkie matki boją się o przyszłość swojego dziecka. Dla matek ukraińskich ważną zmianą był wyjazd ze swojego kraju, rozstanie z mężem, rodziną, nieznajomość języka polskiego.

Słowa kluczowe: dziecko ze spektrum autyzmu, rodzice, rodzina, zachowania trudne, obszary doświadczeń codzienności rodziców.

Introduction

Autism spectrum disorder as one of the most serious child development disorders affects the whole family, “[...] it can be a frightening, exhausting and heartbreaking experience for parents and families of children with the disorder” (Heward, 2015, p. 9). The everyday life of the family is subordinated to the child and the family situation becomes difficult. Many factors contribute to this. Among them, difficulties related to communication with the child, the development of normal bonds between the child and other family members, the non-harmonious course of the child’s development, during which periods of improvement alternate with regression. Children on the autism spectrum present parents with particularly difficult challenges. The children’s behaviour often leads parents to exhaustion, confusion, “[...] helplessness in the face of difficulties in the child’s development. As a result of this helplessness, they often give up on their challenges” (Strząska, 2011, p. 30).

The lives of parents with a child on the autism spectrum from the moment of diagnosis are different from those of families with a healthy child or a child with developmental disorders other than autism.

The diagnosis of autism in a child involves a great deal of stress for the parents. In many cases, this stress is also accompanied by social and behavioural difficulties and feelings of guilt due to the attitudes of those around them, who attribute them to the parents' "inappropriate parenting" (Randall, Parker, 2010, p. 16).

Some parents feel angry, overwhelmed by feelings of helplessness and guilt, others go into shock, and still others go through periods of deep breakdown and depression (Randall, Parker, 2010, p. 31). According to research, two-thirds of mothers of children with autism manifest significantly elevated levels of stress, and parents themselves - when characterising their lives with a child with autism – use the term "stressful." The most stressful factors include the non-transient nature of the disorder and its impact on the future of the child and the family, the lack of understanding of the child's behaviour by those around them, and the lack of social support (Pisula, 2012).

The functioning of parents of a child on the autism spectrum can be varied. The variability also applies to the phases related to the child's disability. Various models and concepts of parental adaptation related to the acceptance of the child's disability can be found in the literature. The first of these, Simon Olshanky's concept (Błeszyński, 2005), called the chronic grief model, distinguishes 5 phases of parental reaction to an autism diagnosis:

mourning and protesting as an experience of not having your expectations and desires for

- your child fulfilled in your sense of helplessness,
- denial and denial of diagnosis,
- intrusive prospective fears,
- reworking and rethinking past behaviour,
- static, chronic sadness, while coping individually with the diagnosis.

Martha W. Bristor (1984) developed a model of the bereavement experience of parents of a child with autism, distinguishing 6 phases in it (after Pisula, 2012):

- In the first phase, the parent(s) experience the shock of finding out about the child's developmental disorder. Initially they do not understand what has happened, experience a sense of confusion, panic, blame themselves.
- In phase two, he/she begins to attempt to overcome the loss, using two coping strategies. The first strategy involves rejecting the diagnosis, seeking other professionals, gathering data that contradicts the diagnosis or developing the belief that the family's situation will not change despite the child's difficulties. The second strategy is to distance oneself from the object of worry, for example limiting oneself to caring and nursing activities.
- In phase three, an awareness of loss emerges and parents begin to seek information about the consequences of autism for the child and family. Emotional and/or physical exhaustion, neglect of health and appearance, and indifference to the environment may follow.

- The fourth phase is the feeling of loneliness. The unhappiness deepens, but a process of "wound healing" begins, leading to a gradual acceptance of reality.
- In phase five, known as the resolution and reformulation process, the parent becomes interested in the environment again and more optimistic about the future. However, the balance achieved is very fragile and can easily be lost under the influence of various events, such as the sight of healthy, playing children. Negative feelings occur much less frequently than in earlier phases.
- The sixth phase is overcoming the loss. The parent sees opportunities to overcome difficulties, enjoys life and believes that he or she will be up to the task of caring for the child.

The study of everyday life as a certain area of experience was initiated by Edmund Husserl, followed by Martin Heidegger or Alfred Schütz (Kaminska-Reyman, 2021). In spite of the difference between the authors, the following formulation seems to be common: "[...] it is in everyday life that the greatest tension of consciousness occurs, that is, everyday life affects consciousness in the most overwhelming, hurried and intense way. Its imposing presence cannot be ignored and can hardly even be weakened" (Berger, Luckman, 1983, p. 37).

According to Renata Stefańska-Klar (2011), everyday life on the autism spectrum has a temporal, spatial and cultural structure. The everydayness related to time is that related to the schedule of the day, week or year, typical events, typical disturbances, typical joys. Everyday life – is the shared experiences of the community of parents of children on the autism spectrum, from the course of pregnancy, birth and early developmental experiences, through to anxieties about diagnosis and the search for therapeutic and educational support for the child. The everyday life of the family – the everyday life of events in the family home, within and outside the family, on the street, on public transport, at school or at church. Everyday life in the institution the child attends – the everyday life of the programme, of therapy, of challenges, difficulties and hopes.

Jadwiga Kaminska-Reyman (2021) provides a description of the changes in areas of daily life for mothers of autistic children:

- in time – allocation of time (proportion of care and rest time, home activities, work; plans for the future (length of time perspective); past before the presence of the autistic child; events as reference points of the life course; structuring time (giving the organisation of time a certain structure);
- In living space – places of being (frequency, accessibility); choice of places (freedom, constraints); order/chaos in the environment; elements in the space (quantitative and qualitative framing); meaning of objects;
- in relationships with others – with the autistic child; with family members, with relatives; with others who are emotionally close; with others in a known

physical space (e.g. neighbours, teachers, doctors); with other strangers (people on the street, in transport, in institutions);
- in the subject – health; satisfaction of psychological needs; value hierarchy; activity; sense of control; self-image; satisfaction with particular areas of life.

Changes in particular areas of the life situation of mothers and families of autistic children are often interconnected, [...] it is the dynamics of the course of two processes: the process of changes occurring and the process of coping with them, and the state of the individual elements and the relations between them at a specific time (Kamińska-Reyman, 2021, p. 38).

J. Kaminska-Reyman (2021) investigated the everyday life of mothers of autistic children. The aim was "[...] to explore the individual experiences of mothers of autistic children regarding the changes in different areas of their everyday life resulting from the presence of a child with autism and the several years of coping process that is a continuous correlate of the child's autistic development" (p. 11).

This article is about Polish and Ukrainian families with children on the autism spectrum who are experiencing changes that are disrupting the existing internal and external order and are also causing further, often negative effects in their lives, which they have to cope with. A complicated situation is faced by Ukrainian families (often single mothers with children) who arrived in Poland after Russia's invasion of Ukraine. The war "[...] has fundamentally disrupted their sense of security and led to stress, the psychological consequences of which can be dangerous for the health prognosis of children with disabilities" (Shevchenko, 2022, p. 229). The war in the life of a child on the autism spectrum, which was already difficult, makes everything worse, the child loses what he or she has previously learned. The only thing parents can do is to try to create a new way of life and teach the child to function in it (Dawydenko, 2022).

The topic I have taken up is the result of many years of experience and interest in disability issues, in particular in supporting the development of children on the autism spectrum, but also in cooperating with and providing support to parents (from 2022 onwards also Ukrainian) with children with autism spectrum disorders. Lost Ukrainian mothers were in great distress looking for help, accommodation, an interpreter to help with paperwork, translate conversations with other people (often teachers). Teachers were from the beginning and continue to be a support for both Polish and Ukrainian families.

The aim of the research undertaken was to explore individual experiences in the everyday life of parents of children on the autism spectrum of Polish and Ukrainian origin, to establish the structure of the families studied, to examine the parents' experiences from the course of pregnancy, birth and early developmental experiences up to the point of diagnosis, and to identify the child's behaviour and areas of everyday life affected by changes in the parents' lives.

Test procedure

In relation to the theoretical assumptions indicated above, the research carried out aimed to present the areas of experience in the everyday life of parents with children on the autism spectrum of Polish and Ukrainian origin and to indicate which of them are of particular importance.

In planning the research process, I referred to the method of qualitative research, which is interpretive in nature "[...] its authors interpret what they see, hear and understand. These interpretations cannot be separated from personal experiences, biographies, contexts and prior views" (Creswell, 2013, p. 192). The research focused on the different experiences and changes in the daily lives of parents of children with autism spectrum disorders (Polish and Ukrainian).

In accordance with the research procedure, I formulated the following research problems:

- What are the experiences of parents of children on the autism spectrum, from the course of pregnancy, birth and early developmental experiences to the point of diagnosis?
- Is the child's behaviour a problem in parents' daily lives? Which ones are the biggest?
- What areas of daily life are affected by the changes, and which ones are of particular importance?

In this article, I used an individual qualitative open-ended interview (Creswell, 2013, p. 197). An interview is a conversation, it provides the opportunity to freely formulate questions and to change their order and pose follow-up questions (Krajewski, 2006). The questions were pre-planned by me, during some individual meetings the order was changed. This happened especially in interviews with Ukrainian mothers when there was a problem with understanding the question. The interpreter took longer to prepare the translation and the question was revisited. The method of recording the respondents' statements was consent to recording "[...] recording [...] the course of the interview is possible, and sometimes highly advisable, but always on the condition that the interviewees are informed about it and obtain their consent to it" (Lobocki, 2006, p. 285).

The surveys were conducted during the 2023/2024 school year, on a date set by the parent. The place where they were conducted was most often a school in the Silesian Voivodeship, in two cases the home of a child who had individual teaching. Ten mothers and two fathers (from Poland) participated in the study. Ten children on the autism spectrum with moderate or severe intellectual disabilities, sometimes with couplings, and five Polish and five Ukrainian children were selected. Due to the situation in Ukraine, the names of the children and parents, the children's places of birth, and the addresses of the institutions the children attend were omitted. The children were aged 10 and 11, diagnosed, their mothers already had a lot of experience in care and could tell what their daily life was like. The fathers, due to their professional work, looked after the children sporadically. The mothers of the Ukrainian children were interviewed with the help of an interpreter who spoke Ukrainian and Polish.

In order to show a complete picture of the daily life of parents of Polish and Ukrainian children with autism spectrum disorders, it is necessary to present the family structure: gender of the child, age of the child on the autism spectrum, country of birth of the child, siblings, full or single parent family and parents' education (Table 1).

Table 1

Structure of surveyed families with a child on the autism spectrum

No.	Sex of the child	Age of child	Country of birth of the child	Siblings	Family	Mother's education	Father's education
1	D	10	P	no	single mother	higher	higher
2	C	10	P	younger brother (autism spectrum)	single mother	Medium	
3	C	10	P	younger brother (autism spectrum)	full	higher	higher
4	C	10	P	1 older brother 2 younger brothers	full	professional	professional
5	C	11	P	no	full	Medium	professional
6	D	10	U	big sister	full	professional	professional
7	D	11	U	little brother	full	professional	professional
8	C	10	U	no	single mother	Medium	
9	C	10	U	Younger brother (disabled)	full	higher	higher
10	C	11	U	big brother (autism spectrum)	full	higher	higher

Note: D – girl; C – boy; P – Poland; U – Ukraine.

Source: compiled from the results of Author's own research.

There were five children in the Polish family group studied, including one girl aged 10 and four boys (three aged 10 and one aged 11). In the Ukrainian group, there were two girls (aged 10 and 11) and three boys (two aged 10 and one aged 11).

In the group of Polish families, two children have no siblings; one has one older and two younger brothers; while two children have a younger brother on the autism spectrum. In the group of Ukrainian families, one boy has no siblings; one girl has an older sister, one has a younger brother; two boys have siblings with disabilities (including one on the autism spectrum).

There are two single mothers and three full families in Polish families. One Polish mother has a vocational education, two a secondary education and two a tertiary education. Two fathers have vocational education, two have higher education, one person did not specify education. In Ukrainian families, one mother is raising a child alone. Two mothers have vocational education, two higher and one secondary education. Two fathers have vocational education, two have higher education, one person did not specify education.

Findings

The analysis of the empirical material of the research conducted, i.e., the analysis of the statements of the respondents, made it possible to answer the problem questions. The results of the qualitative research were presented in the form of areas of parents' experiences, which make up the everyday life of parents of children on the autism spectrum. For the purposes of this paper, only selected statements of respondents were presented[*].

First Area of Experience. Course of pregnancy, birth and early developmental experiences up to diagnosis

The analysis of the mothers' statements shows that in both Polish and Ukrainian families there are some mothers whose pregnancies and births went well (in three Polish mothers and in four Ukrainian mothers), in some the pregnancy was at risk (in two Polish mothers and one Ukrainian mother), and the mothers were hospitalised in a pregnancy pathology unit. One of the Polish mothers gave birth in the car, the birth was delivered by the child's father. Mothers with a normal course of pregnancy indicated factors that could have triggered their child's autism spectrum (prematurity, vaccination or English classes). Two Polish children received rehabilitation and speech therapy support immediately after leaving hospital. Three Polish children received rehabilitation, speech therapy and therapeutic assistance from the moment the parents observed their child's

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[*] The order of the mothers' statements (Mother 1, Mother 2, etc.) follows from Table 1.

abnormal development (the child in infancy did not smile at those closest to him or her, often cried, bent his or her body, plugged his or her ears and did not communicate). None of the Ukrainian mothers reported that their child received rehabilitation or speech therapy help immediately after leaving the hospital. One Ukrainian mother reported that she noticed problems at nine months of her child's life (this was the first epileptic seizure), the other mothers noticed problems in their children when they reached the age of two to three years (behavioural problems, speech problems, aggression, self-aggression).

Almost all children, both Polish and Ukrainian, were diagnosed by the age of three, one Ukrainian child at the age of four. Several mothers, mostly Polish, experienced high anxiety, stress and some were being treated for depression. Only one Ukrainian mother reported that she was being treated for depression.

(Mother 1)*: The pregnancy was at risk, I was lying in pregnancy pathology, I felt unwell, but despite this it didn't even occur to me that there might be something wrong with the baby. After the birth, the doctors immediately saved the baby, then after leaving the hospital with my daughter I had to attend rehabilitation and speech therapy. She didn't speak, always made only one sound iiii, put everything in her mouth, threw objects, kicked everyone who was around. When I started reading books on autism my husband and were in shock, we searched for different therapies for our daughter.

(Mother 2): Pregnancy was at risk, delivery by caesarean section, without complications. The boy received 3 points on the Apgar Scale, the child stayed in hospital. His development was abnormal, he cried a lot; when he was about 15 months old, he started plugging his ears when there was a noise nearby or when someone shouted; later this was joined by banging his head against the wall or the floor. He was a late talker, actually repeating words he heard. When he was fed and able to put food in his mouth by himself, unattended, he would stuff whole sandwiches, fruit, potatoes and other foods into his mouth. He would cuddle with his grandmother and me.

(Mother 3): Pregnancy was normal, delivered in a car during the drive to hospital. Son developed normally until 2 years 7 months. We enrolled our son for English and in the third class he started to withdraw, i.e., he walked into the corner of the room where the class was held, within a week he stopped talking, at home he started smearing stool on the walls, there was hyperactivity. Probably the worst part for us was the beginning when we found out about our sons' diagnoses. My husband and I both became depressed, once me and my husband had worse days (very bad days), supporting each other and we still support each other today.

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* The mothers' statements were quoted in the original transcript and were not subject to editing.

(Father 3): We waited a long time for our first child, I dreamt that we would travel the world and Poland together, that he would finish his studies and it happened otherwise. I have worse and better days, but I always support my wife.

(Mother 4): Course of pregnancy normal, son scored 10 on the Apgar scale. After the baby was vaccinated around 5–6 months, the son developed a temperature of 40°C in the evening, limpness of the body, and was taken to hospital. From then on, the child's development was abnormal. He did not make eye contact, did not play with anything, did not understand speech, rarely made sounds, was not interested in toys. When he started to walk, he was constantly running on tiptoe, running away from the room, not sensing danger. He grabbed objects mainly that he could put in his mouth (all foods, toys, sticks, pebbles, earth, etc.). Autism was diagnosed at 2 years old, but he has participated in rehabilitation and speech therapy classes since he was 7 months old. I love my son very much and although I had no support in my husband who was constantly working, I never had any problems with my son having autism.

(Mother 5): Pregnancy went well, natural delivery, son received 9 points on the Apgar scale. I noticed that the child in infancy was not smiling at those closest to him, was bending his body, was crying very often. He drooled a lot and did not speak, despite being small he would hit me, pull my hair, drop and break my glasses. At the age of 3 he was diagnosed with atypical autism, cryptogenic symptomatic epilepsy, motor clumsiness syndrome. I experienced shock, rebellion, I was ashamed of my son's behaviour, for walks I would go to the park or we would go to the woods so no one would see us.

(Father 5): My wife has had a hard time with the fact that my son has autism, I am lighter because I work a lot. In addition, I love riding my bike.

(Mother 6): When I was pregnant I had to lie in hospital, after the birth, the child lay in hospital for 1 month. In Ukraine she was diagnosed psychologically, diagnosed with mental retardation, also treated with a neurologist. At the age of 3, she was diagnosed with autism. Until the age of 4 she did not attend any therapies, I had to take care of my daughter all day long, there were problems with falling asleep, she would wake up at night, then she had to be rocked to fall asleep again. She didn't speak, only made sounds. Problems with eating, I had to grind, the day was subordinated to my daughter, I had little time for my other daughter. My husband helped me little because he worked hard and came home late.

(Mother 7): Difficult pregnancy, daughter born at 42 weeks gestation by caesarean section. I had little amniotic fluid and the baby suffered from hypoxia. My daughter developed normally until she was 9 months old and during this period the first epileptic seizure appeared. Since the first epileptic seizures occurred, I lived in constant stress, from seizure to seizure, she was not treated, she cried often and did not sleep at night.

(Mother 8): Normal pregnancy, natural childbirth. When my son turned 2 years old, I noticed that something disturbing was happening with the child. He was deviating from his peers, he was not speaking, he was very aggressive, auto-aggressive and hyperactive. For no reason at all, he was hitting everyone who was nearby and throwing objects. At the age of 4, he was diagnosed with atypical autism, hyperactivity and aphasia. Doctors changed the medication frequently, but it did not work. My son required full-day care, and as I was raising a child alone it was very difficult for me. I couldn't go to work, I devoted the whole day to my child. I was very tired.

(Mother 9): The pregnancy went smoothly, but the foetus was lying low and there was a risk of prematurity. Premature birth, after leaving the hospital I noticed that my son was not developing well. My son has been sleeping very badly from birth until now, he can't fall asleep on his own, we have to rock him to sleep and be with him all night. We take turns doing this with my husband. The son does not speak and does not understand everything.

(Mother 10): Pregnancy normal, son developed normally until he was 2 years old. I noticed that when he started to walk around 1 year old, he was very mobile, putting different objects in his mouth, getting angry often and biting his hands. He started to speak quite early, but could not communicate his needs, was disturbed by some sounds, would plug his ears and squeak. Sometimes my husband and I could not cope emotionally.

Second Area of Experience. Child behaviour posing the greatest problem in the everyday life of Polish and Ukrainian parents

The child behaviours most often mentioned by parents as the biggest problem in everyday life are aggression and self-aggression. Physical aggression refers to hitting the mother or others, kicking, hitting, breaking glasses, etc., verbal aggression (swearing) occurs in the Ukrainian girl and is related to not understanding the Polish language. Self-aggression: hitting oneself on the head, scratching oneself, pinching, tearing wounds, biting hands, etc. Among other behaviours mentioned by mothers were self-stimulation, stereotypical activities, disturbed sleep, epilepsy or uncontrolled escapes.

Lack of communication with the child is a problem mentioned by all Polish and Ukrainian mothers and fathers of both nationalities. Children do not understand questions addressed to them, they do not understand commands. Children often have echolalia or make sounds without the purpose of communicating. They respond poorly or not at all to attempts at communication. This poses a huge barrier to contact with the child.

(Mother 1): All the behaviours I mentioned earlier are occurring and have even increased. The worst behaviours are when my daughter kicks everything, drops things, pulls things off the table and whatever is within reach. She also has gastrointestinal problems and as a result I have to prepare proper meals, which takes me quite a long time.

(Mother 2): The worst behaviours for me in my son are hitting himself on the head, scratching himself, pinching himself, tearing wounds. When these behaviours occur we immediately start, me or my mother, singing a song and my son stops and becomes cheerful and gentle. But he is also often stubborn, for example when he wants to leave the house to go into the garden.

(Mother 3): The behaviour that annoys me is homework behaviour. I don't do anything for my son so he does his homework for a very long time, he interrupts, he gets upset, it annoys me a lot.

(Mother 4): The biggest problem with my son's behaviour is his constant running away, the door in the flat has to be closed because one moment and my son is gone. Also, when we walk down the street he has to be held firmly by the hand because he can break free and run, for example under a car. Another problem is putting everything in his mouth, no matter if it is edible or not. I, for example, often bake a cake, a moment's inattention and flour, fat, eggs, whatever is in my son's mouth, on the wall, on the floor; if we drink coffee, tea, we have to be careful because our son will spill it. And I could give many such examples.

(Mother 5): My son's behaviours that are sometimes unacceptable are: hitting me, kicking me, destroying my glasses, hitting the windows or the wall. In the car he has destroyed the door handles, he jumps when the car stops, e.g., at traffic lights, then he jumps and shouts.

(Father 5): The wife was and still is overprotective, which is probably why the son is beating her.

(Mother 6): Behaviours that create problems on a daily basis are lack of speech, stubbornness, putting objects and food in his mouth, flapping objects. He likes to put shoes in his mouth and sometimes undresses.

(Mother 7): The trip to Poland and the change of residence have increased aggressive behaviour in the daughter, the daughter tugs on others, pulls hair, pinches, and swears more often, she is more nervous, is under constant stress, asks about her dad and grandmother who stayed in Ukraine.

(Mother 8): The son is very aggressive and self-aggressive. Unfortunately, he throws everything that is within his reach, he beats himself, me, his grandmother. It is very hard for me.

(Mother 9): From birth until now he sleeps very badly, he can’t fall asleep on his own, we have to rock him to sleep and be with him all night. We take turns doing this with my husband. My son doesn’t speak and doesn’t understand everything. Neither I nor my husband have been ashamed or made a tragedy out of the fact that our son has autism. We didn’t have any mental breakdowns – we accepted the situation straight away.

(Mother 10): My son’s hyperactivity continues, the hand biting has increased even more, which is very worrying. Problems with eating have joined in. If something is not to his son’s taste he has a vomiting reflex.

Third Area of Experience. Changes in daily life and the meaning of these changes

The most frequently mentioned – by both Polish and Ukrainian mothers – change that relates to daily life is giving up work. Only one mother from Poland and one from Ukraine work, one mother from Poland works casually. An important experience is the help of others, e.g. husband, grandparents, sister. Some mothers are left with everything on their own, they have no support from their family, more often they get it from teachers. A change for Ukrainian mothers is leaving their country because of Russia’s invasion of Ukraine, separation from husband, family, lack of knowledge of the Polish language, three mothers would very much like to return to Ukraine after the war is over. Another experience is the organisation of work at home. The rhythm of the day has to be adapted to the rhythm of the child (his sleeping, wakefulness, going for a walk, to kindergarten or school). The time spent constantly in the company of the child means that some mothers have no free time for themselves. On the other hand, some Polish mothers, especially those who belong to a support group, organise outings with their girlfriends or even trips of several days. And the last experience is the mothers’ concern for the future of their children. Most of the mothers surveyed are worried about the fate of their children.

(Mother 1): I don’t work at the moment, I rest when my daughter is at school. The worst are holidays and winter holidays. With my husband we even used to go abroad with our daughter, unfortunately now I don't go anywhere myself with my daughter, but I live at home, we have quite a big garden; my daughter loves the pool in summer, she has a nest swing, so we have to survive the holidays somehow. It's more of a problem in winter, but it's only 2 weeks. I rarely meet up with friends, and even with my daughter I don't go out anywhere except to the doctor. I can't count on the help of my parents and in-laws. Often, I am helped by a teacher or a teacher's aide from school. I'm worried about the future – when my daughter will finish school.

(Mother 2): Since the birth of my child my mum has helped me with the care, my husband initially worked abroad, then with two sons with autism he left me. In fact, everything at home is taken care of by my mother. I work, it's a break from all the problems for me. I have my day organised in such a way that when I get up I have to prepare breakfast, wash my son, get him dressed, get him ready to go to the bus and I go to work. I pick up my son from his grandmother, who looks after him until I arrive. I also pay for a babysitter when I want to go out with my friends to a café or cinema. I often think about what will happen next, how I will manage, as my mother increasingly needs help herself.

(Mother 3): I have my day organised, written on a board. I belong to a support group, from which we formed our own group, with whom we meet and go to cafes, go to spas. A big problem for us was and still is that our sons won't graduate, won't start families, will require constant support.

(Mother 4): I have four sons. But I manage without any problem. My husband works, he doesn't really help me with anything. I earn extra money when I have the opportunity. I also take care of the house and the children, my mum used to help me, now she's gone, but I can count on a friend or a cousin. In the morning, when everyone is still asleep, I go out to buy bread, make breakfast for the whole bunch. I take my son to the bus, then quickly dinner, laundry, quick cleaning. It's no problem for me that my son has autism. I love all my sons equally. I don't think about the future, maybe because I have 4 sons and I don't have time to think about what will happen next week. I live today, even if we have to go on holiday we go at the last minute, we buy a small house fenced in so my son doesn't run away. My dream is just for everyone to be healthy and for me to have the strength to look after my son.

(Mother 5): I am a nurse by training, but I have not taken a job since my son was born. My son is an only child, I was always overprotective, I couldn't cope with the fact that he is disabled and has autism. I protected him from the whole world at first. I often cried, I was sad, and I was angry. I had a big problem with myself. Since I started to belong to a support group everything has changed. Before, I wouldn't leave my son with my husband. Now he stays with my husband, he functions much better, and I can go to a café or go out with friends. Every year we go to Croatia and then we take my mum, who helps us to look after our son, then we can go out somewhere alone. My biggest fear is for my son's future. We will find a day centre, I can't imagine having to look after him all day.

(Mother 6): We had to leave Ukraine, we ended up in Katowice. Here my daughter attends a special school. In Poland, my older daughter helps me, my husband stayed in Ukraine; I have trouble understanding Polish so my daughter translates and communicates with the school my younger daughter attends. In the morning, I have to get my daughter ready for school and I go to work, and when my daughter returns, I am so tired that I only do the most necessary things, i.e. dinner, laundry, cleaning, rarely a walk (usually only on Sundays). I dream of returning to Ukraine, there I have a husband, a family I could always count on.

(Mother 7): We have poor housing conditions: a tiny room in a dormitory, a shared kitchen. When my daughter went to school, I had a moment for myself and my son. Unfortunately, now that she is on individual tuition, again I can hardly go out anywhere by myself. I have a little help from my sister who works, my husband stayed in Ukraine. I also get help from the teachers, when they come to class, I can do the shopping. I see my future in Ukraine, I can't find my way back to Poland. It's good that I'm here with my sister, the two of us are better together.

(Mother 8): My mother and I take care of our son together. If I were alone, I wouldn't be able to cope in Poland. I have a problem with the Polish language, because of my son's condition I cannot work. The ladies who come to the classes offer us to go out and then my mother and I usually go alone to a bench somewhere and we can talk calmly (about our future, Ukraine, returning to Ukraine).

(Mother 9): There is also my mother in Poland who helps us a lot. I don't know if we will go back to Ukraine because here we have quite good conditions, the boys are driven to school, my husband has a job and I am applying for a job at university.

(Mother 10): In Poland, my husband and I work and have good housing and living conditions. We have help from an employed person to look after our sons. Unfortunately, I am being treated for depression. I often have thoughts about our future, including that of my sons. I have no one to talk to about it. I miss my parents, my family, my friends who we used to hang out with.

Conclusion

Having a child with an autism spectrum disorder is a great challenge for the whole family, but the greatest and particularly acute one is for the mothers, because "[...] it is on their shoulders, after all, that the whole problem of care and upbringing in these completely changed conditions falls" (Sekułowicz, 2000, p. 70). The incomprehensible and difficult-to-predict behaviour of a child on the autism spectrum means that the course of his or her mother's life is marked by ever-emerging changes in her everyday life (Kaminska-Reyman, 2021).

The research procedure was determined by the successive steps of the interpretative qualitative research method: from the individual interviews with the parents (ten mothers and two fathers), which allowed access to their subjective experiences of changes in daily life, to the way they cope with them.

On the basis of the Three Areas of Experience study carried out, the following conclusions can be drawn from the discussion of the statements made by the people interviewed:

- Polish children with problems shortly after birth received rehabilitation and speech therapy right after leaving hospital or as soon as the parents observed worrying symptoms.
- Almost all children, both Polish and Ukrainian, were diagnosed by the age of three-four.
- A child diagnosed with an autism spectrum disorder is usually cared for by his or her mother (in Polish and Ukrainian families). Despite anxiety and stress, they try to cope with this difficult situation. Not all mothers have support in their husbands and families. Only some can count on the help of their husband, mother or sister to care for their child around the clock.
- A significant problem in the lives of parents, both Polish and Ukrainian, is child behaviour. Most frequently mentioned by respondents: aggression, self-aggression, self-stimulation, disturbed sleep, epilepsy or uncontrolled escapes. In Ukrainian children, the aforementioned behaviours increased even more after their departure from Ukraine. These behaviours are unfortunately not dealt with by parents.
- Lack of communication with the child is a problem mentioned by all Polish and Ukrainian mothers and all fathers. Children do not understand questions addressed to them, they do not understand commands.
- Due to the need for round-the-clock childcare, when asked about the biggest change in their lives, both Polish and Ukrainian mothers mention giving up work. A change in daily life is also a change in the organisation of work

at home. According to the mothers' statements, the rhythm of the day is adapted to the rhythm of the child, its sleep, wakefulness or going for a walk.

– The time spent constantly in the presence of the child leads to some mothers having no free time for themselves, only a few mothers who belong to a support group organise their free time. Almost all mothers are afraid for their child's future. For the Ukrainian mothers, an important change was leaving their country, separating from their husband, their family, not knowing the Polish language.

In conclusion, it can be said that "[...]someone who has not experienced the everyday life of autism, has not experienced a single day in direct contact with an autistic person, that person cannot say that he knows anything about autism. He knows nothing" (Stefańska-Klar, 2011, p. 8). The research conducted, individual interviews with parents, especially mothers, brought me even closer to understanding various aspects of the situation from their everyday life, their problems, anxiety, and fear. I hope that the results of this research will inspire further research into the situation of families of children on the autism spectrum.

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