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The Situation of Parents of Children with Autism in the Context of Refugeeism and War Trauma

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ABSTRACT

With the outbreak of the war in Ukraine, the lives of a huge number of families have irrevocably changed, forcing them to leave everything behind and flee their country. Juxtaposing this with the fact of raising a child for whom constancy and repetition are the most important framework for functioning, makes an already difficult experience much deeper and more traumatic. The aim of the article is to analyze the situation of parents of children with autism in the context of refugeeism and war trauma. As numerous studies show, these parents experience high stress and their well-being is reduced. Juxtaposing this with the perspective of war and refugeeism may be the basis for better listening to the needs of this group and reviewing the forms of support available in our country.

KEY WORDS: autism, family, refugeeism, war trauma, disability, stress

Introduction

In the 1980s, autism spectrum disorder (ASD) was reported to be 10–13 per 10,000 cases (Brysor et al., 1988). Autism is now said to be one of the most serious developmental disorders and occurs in more than 1 in 100 children (Wingate et al., 2014), and recent data from the United States indicate that it affects 1 in 36 people (Maenner et al., 2020). The continuous increase in the incidence of autism over the years does not allow us to remain indifferent to this problem, as it affects an increasing part of the population, and the difficulties associated with it are of an ongoing nature. The data on parents raising children diagnosed with autism spectrum disorder are also alarming. Studies clearly indicate that they experience a much higher level of stress

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than other parents of children with disabilities (e.g. Pozo & Sarriá, 2014; McStay et al., 2014). One of the characteristic features of children with autism is the pursuit of constancy and repetition, which is a tenuous basis for a sense of security in a complex and incomprehensible world. The outbreak of war is an event that changes your entire life in an instant, forcing you to make decisions that will have undeniable and often long-term consequences. It is precisely such decisions that many families fleeing Ukraine in search of safety have faced.

The article discusses the topic of stress related to the experience of war and migration, juxtaposing it with the difficult situation resulting from raising a child with autism. In order to better understand it, the symptoms of autism and the associated difficulties in functioning are briefly discussed. The situation of the parents was analyzed from the point of view of the characteristics related to the child himself as well as those related to the parent. A review of the actions taken in Poland towards this group of parents since the outbreak of the war was also carried out.

Stress related to the outbreak of war and migration

The invasion of Ukraine by the Russian Federation's troops, which began on February 24th 2022, triggered the largest migration of people since World War II. According to a UN report of March 16th 2022, 3.3 million people left Ukraine after just three weeks of war (Do Rzeczy, 2022). Between February 27th 2022 and November 7th 2023, almost 17 million refugees from Ukraine, mainly women and children, crossed the Ukrainian-Polish border (Turaleva, 2023). For some people, Poland was just a stopover on their journey, for others it was a destination where they settled in the short or long term. These data are highly variable because, on the one hand, there is still a high rate of migrant inflow, and on the other hand, some people decide to return to Ukraine. The scale of the phenomenon does not allow us to pass by it indifferently. When analysing the situation of people leaving their homes due to hostilities, it is worth first looking at the distinction between the notion of a refugee and a migrant. Refugeeism differs from the phenomenon of migration in two ways: its potentially temporary nature and the inability to treat the motives for leaving as purely voluntary activities (Shacknove, 1985). The subject of this article is the situation in Poland as a result of the consequences of Russia's armed attack on Ukraine. Civilians were forced to flee for fear of losing their lives as a result of hostilities. When analysing the fate of refugees, it is worth noticing that after experiencing the first trauma of war and escape, when arriving in a new place, other difficulties appear. Based on Maslow's theory of needs, the first challenges are to provide shelter and the basic necessities of survival, including employment. After providing a sense of security, the search for space for social relations and self-fulfilment in the new place begins. The transition from the problems

of existential experience to the difficulties of functioning in a new place is a part of the dynamics of the process whose subjects are refugees (Isański et al., 2022).

From a psychological point of view, the experience of war meets all the criteria for a psychological crisis. This is an emergency situation that requires different ways of coping than those used so far. In many cases, it can pose a direct threat to life and health. Additionally, stress is exacerbated by loneliness and lack of loved ones (Jain et al., 2022). As Charlson et al. (2019) emphasizes, the lack of appropriate support can result in the inability to cope with the trauma of war and the development of serious mental health disorders. Studies show that 22% of people experiencing war in the following years may suffer from PTSD, depressive disorders, anxiety disorders, bipolar disorder or schizophrenia.

The awareness of the complexity of the refugee situation sheds much more light on their needs, and the situation is further complicated by the fact that the majority of people fleeing the war are women with children. As Zabłocka-Żytka and Lavdas (2022) emphasize, families consisting of people with chronic illnesses, both mental and somatic, who had to interrupt treatment in Ukraine due to hostilities, are in an extremely difficult situation. These patients need systematic therapy or access to medication, and this help is not always available immediately. Cerimović (2023) adds that special attention should be given to families with children with disabilities or developmental difficulties. In their case, the effects of war are multiplied.

The situation of parents of children with autism in the context of refugeeism and war trauma

A child's disability and its impact on the situation of refugee parents

The term "autism" in reference to disorders observed in children was introduced by Kanner (1943). The word autism is derived from the Greek word autos- alone. Three areas have been identified, in which disorders characteristic of autism, called the autistic triad, are revealed. These include a limited ability to form relationships with other people and participate in social interactions, impaired communication skills and schematism, a limited repertoire of activities and interests combined with a lack of imagination. A characteristic feature of autism is the combined occurrence of disorders in all three spheres.

Despite fairly precise diagnostic criteria, practitioners working with autism agree that it is a highly differentiated and multiform disorder, which means that there are no two children with autism who are the same. Each of them has an individual set of symptoms, often completely opposite.

In order to better understand the situation of families raising children with autism spectrum disorders, it is worth taking a closer look at the symptoms of this disorder. The most visible symptom of autism is impairment of social contacts. Children have problems with associating facts and correctly interpreting social situations. Characteristic difficulties also apply to the play of children with ASD. From an early age, they are able to deal with objects much longer than they do with interactions with other people. Their play is repetitive and based on schematic action.

Another extremely important symptom of autism is communication problems. Both the development of language and the communicative competence itself depend on the degree of severity of their autistic traits and intellectual level. The age at which children were provided with therapeutic assistance is also important in this respect. Children who develop symptoms of autism early, develop communication problems as early as infancy. They are not interested in the spoken word and often also in other sounds. Some of them will never speak, and many will never develop semantic language. Children whose autistic traits began to manifest later, develop speech slightly different. They often use words or simple sentences. The appearance of the first symptoms of autism is often associated with speech regression. A child's speech is shortened, often taking the form of single words to satisfy a current need. At the same time, the disappearance of forms of non-verbal communication is progressing.

Schematism in action is another noticeable symptom of autism. It can take many forms, from simple movement stereotypies to narrow, persistent interests. A manifestation of this rigidity may be, for example, a strong need to follow a specific schedule, ways of performing a specific task, or the unchanging location of objects in the person's environment. It is assumed that at the root of limited behavioural patterns lie problems in the reception and processing of sensory impressions (Cunningham & Schreibman, 2008).

Learning more about autism helps to better interpret individual behaviors. Many of them are related to sensory integration disorders. This is confirmed not only by numerous research reports (Robertson & Barron-Cohen, 2017; Shon et al., 2019) but also statements by adults with ASD (Williams, 2005; Grandin, 2019). Sensory disorders cause stimuli to flow to the child in an altered way, they are too strong or too weak, and chaotic. The brain has a problem with extinguishing less important information, as a result of which many stimuli reach the child with equal force (Pisula, 2012a).

When it comes to the prevalence of autism spectrum disorder, current reports from the United States provided by the Centers for Disease Control and Prevention – a US government agency conducting activities related to health promotion, already indicate 1 case of autism in 36 people (Maenner et al., 2020). There is no complete epidemiological data on the prevalence of autism in Europe or Poland, but it is undeniable that over the last decades we have been dealing with a steady increase in the

number of ASD diagnoses. Given these reports, it is not surprising that among the refugees there are also families raising children with this disability. According to Pisula, Winczura and Banasiak (2023), their number is difficult to estimate due to the fact that there are no such records either at the local or central level. In addition, it should be remembered that the total number of migrants staying in Poland at any given time is also very variable, as has been already discussed.

There is a lack of research in the literature on refugees raising children with autism spectrum disorders. However, there is no doubt that their situation is particularly difficult (Pisula et al., 2023). An analysis of the situation of these families certainly requires a multidimensional view. They are experiencing the same burdens as other families fleeing in fear for their own lives and the lives of their loved ones. Many of these people have had traumatic experiences related to the loss of loved ones and fear for their own lives. Families arriving from the areas where hostilities were taking place, hid in shelters or cellars before deciding to flee, experienced hunger, cold and lack of sleep. Often, the places where they hid were overcrowded (Shevchenko, 2022). The very moment of leaving the country could also be a difficult experience in many cases (a journey lasting many days in difficult conditions, long waiting periods, uncertainty and fear). After crossing the borders of Ukraine, the feeling of relief was often intertwined with the pain at the loss of their lives, longing for people who had to stay in the country (Davydenko, 2022).

The situation of families of children with autism fleeing the war is undoubtedly aggravated by the child's diagnosis and limitations. These children show great difficulty in adapting to new situations. They are also characterized by a reduced tolerance of uncertainty. A lack of understanding of the surrounding world and difficulties in correctly predicting possible outcomes and consequences repeatedly translate into increased levels of anxiety (Hollocks et al., 2018). Combining this with additional stressful events related to war and migration, they can lead to serious mental health crises. In order to function better in the environment, people with autism need predictability of events, a fixed daily order, which is difficult to achieve in the face of war. An additional obstacle is the difficulty in understanding social situations and regulating emotions. These people receive limited support, and separation from loved ones can further increase their uncertainty about the world around them (Camm-Crosbie et al., 2019). Numerous changes and increased levels of stress can further increase the already high sensory sensitivity of children, which, when exposed to a large number of stimuli (noise, overcrowding, staying in tight spaces), can affect sleep problems and further deteriorate their functioning, causing difficult behaviours such as yelling or aggression/self-aggression (Lane et al., 2022). This, in turn, can lead to stigmatization of the child and their parents by those around them, increasing their isolation and reducing their ability to benefit from social support (Swaab et al., 2021). Thus, it can

be seen that autism spectrum disorder is a special type of disability, the symptoms of which significantly hinder coping with new, traumatic situations, such as the experience of war. In the light of these facts, further analysis of the situation of these families seems to be particularly justified.

Stress of parents of children with autism in the context of war and refugeeism

Everly and Lating (2002) defined parental stress as a complex construct involving behavioural, cognitive, and affective components, a combination of child and parent characteristics, as well as components of the family situation, as they relate to a person's assessment of fulfilling the role of parent. The stress of parents of children with autism has been the subject of numerous studies over the years. It is clear from the results that they experience stronger stress on a daily basis, not only in relation to parents of healthy children, but also towards parents of children with other disabilities (e.g. Eisenhower et al., 2005; McStay at al., 2014). The mere appearance of a child into the world does not foreshadow any difficulties that may arise. Mothers often declare that the pregnancy period passed without any complications, the test results were good. The birth itself was also often unremarkable, and the baby received maximum points on the Apgar scale. Also, the first year of life often passed without any alarming symptoms. Over time, they begin to notice that their child is different from their peers (Szmania, 2014). The process of searching for the causes of a child's difficulties is often a tedious and stressful period, especially when we are talking about a disability that specialists have only been aware of for several decades (Deschamps et al., 2020). Despite the passage of decades, many parents still face the fact that giving their child a diagnosis requires not only a lot of time, but also a lot of funds. A prolonged period of time in which the child remains without the identified causes of his or her problems is an additional source of stress and a sense of irretrievable time passing (Yanes et al., 2016).

Coming to terms with the diagnosis is a long-term process and is similar to the situation of people who have to deal with the death of a loved one. According to the Bristor (1984) model, the period of "mourning" consists of six phases. The first is the shock phase, in which the parent does not fully understand what actually happened. He feels lost and often blames himself. In the second phase, he tries to overcome the feeling of loss in two ways: he rejects the diagnosis and gathers information that contradicts it, he looks for other specialists in order to maintain the current state of affairs, or he isolates himself from the object of his worry by limiting his relationship with the child to caring activities. The third phase brings a greater awareness of loss. The parent tries to estimate what the diagnosis of autism will change in the life of the child and the family. During this phase, he may experience physical exhaustion, which takes

a toll on his health and appearance. Concentrating on one's own tragedy intensifies the feeling of loneliness. In the fourth phase, the parent continues to feel severe pain from the loss and loneliness. In this phase, however, the process of gradual acceptance of reality begins. Phase five is the time when the parent gains more confidence in his abilities, begins to take a new interest in the surroundings and is more optimistic about the future. However, this is not yet the end of the grieving process, as the balance achieved is very fragile. It can be disturbed by various, often trivial events, such as the sight of healthy children playing. Only the sixth stage brings the parent a sense of greater peace. He begins to see the possibilities of overcoming difficulties and enjoys life again.

The course of the process of "mourning" of parents of children with autism may differ in relation to parents of children with other disabilities, at least due to the long time that elapses from the appearance of the first symptoms of the disorder to obtaining a medical diagnosis (Gentles et al., 2020). This is a due to the huge variation between children within the same diagnosis, which makes it difficult to make an unambiguous prognosis, and coming to terms with the future seems to be more difficult due to its unpredictability (Pisula, 2012b).

A strong source of stress is also a great fear for the future of children. This applies to all parents of children with disabilities (Watson et al., 2013). They are afraid of what will happen to their children when they are gone. Predictions about the future of children with autism are extremely difficult, which is why this issue is particularly burdensome for parents of children with autism (Liebermann et al., 2018). In the face of the experience of war, this fear is much more justified and its intensity is significantly higher.

Factors influencing parents' stress levels are often cited by researchers as difficult behaviours and problems in communication and social relationships (Al-Oran & Khuan, 2021). In addition to the characteristics of the child, it is also worth looking at the characteristics of the parents and the experiences directly related to them. These parents, like their children, have experienced trauma. Research conducted by Eltanamly et al. (2021) shows that parents showed less warmth and strictness towards their children in connection with war events, which partially mediated the relationship between the experience of war and symptoms of post-traumatic stress, depression and anxiety, social problems, and the child's presentation of challenging behaviours. This is confirmed by Slone and Shoshani (2017), who show that a warm and empathetic approach of the parent, especially the mother, is conducive to better adaptation of children in the situation of war trauma. Thus, we can see here the mechanism of a vicious circle, in which the stress of parents could translate into their attitudes towards their children, thus increasing adaptation difficulties, which in turn again led to an increase in the perceived stress. Fear for the child and the effects of war and migration on the child could also be a factor intensifying parental stress. The awareness of the needs of chil-

dren with autism and their striving for predictability and constancy in the face of the unpredictability they will have to face could have been the basis for the growing fear of the child's loss of skills and developmental regression in parents. Another factor that may have contributed to this phenomenon was the discontinuation of the child's therapy in Ukraine. According to the research of Pisula et al. (2023), many families raising children with autism, came to Poland in connection with the war operations in their country, without any documentation confirming the diagnosis or even information about the previous forms of support for the child and its needs, or with the certificates which were inconsistent with modern classification systems. This significantly hindered the organization of help for children from Ukraine and extended the time that passed until the necessary therapy was implemented.

In the face of experienced stress, social support is a factor that reduces it. The benefits of social support in aid of children with autism are well documented scientifically (e.g., Robinson et al., 2016; Robinson & Weiss, 2020). Social support should be understood as social resources that people perceive as available, or that are actually provided to them by non-professionals, both in the context of formal support groups and informal helping relationships (Cohen et al., 2000). Perceived social support constitutes the belief that support is appropriate or available when needed, reflecting how an individual perceives the support offered to him rather than the support actually provided to him (Thoits, 1982). It appears that perceived support can help improve a person's well-being regardless of the stressors he experiences and may be particularly important in the context of chronic and acute negative life events (Cohen, 1988).

Perceived support is consistently associated with parental well-being, including lower levels of stress (Tak & McCubbin, 2002), depressive symptoms (Rueger et al., 2016), and increased self-confidence (Freeman & Rees, 2010). This pattern can also be seen in parents of individuals with autism, with perceived support associated with fewer mental health problems and greater life satisfaction and overall well-being, in both mothers and fathers (Benson & Karlof, 2009). Among the factors that negatively affect the perception of social support, researchers often mention difficult behaviors presented by the child. In the face of war trauma, the risk of the child presenting difficult behaviours increases, which in turn can have a negative impact on the parent's perceived social support. A sense of stigma and the stressful nature of social relationships are also factors influencing the use of social support (Gray, 2006). Autism spectrum disorder is a special type of disability that is often invisible at first contact. As a result, these children are often judged as naughty and their parents are credited with a lack of parenting competence. This negatively affects parents' self-esteem and their ability to reach out for support. In the face of trauma, this is especially important, often leaving these parents on their own. An additional burden, which cannot be omitted,

is the fact that most of the refugees coming to Poland are women with children. They therefore have to deal with the difficulties that arise alone.

Forms of assistance offered to children with autism and their parents coming from Ukraine to Poland

According to the research of Pisula et al. (2023), the main needs of families with children with autism coming to Poland in the face of the war in Ukraine include:

- deepening the diagnosis of the child's developmental difficulties and a possible medical diagnosis (many families did not have a clear diagnosis or the child's entire documentation remained in Ukraine),
- learning the Polish language, and in the case of children who do not use verbal speech, support in alternative communication,
- integration activities with other children,
- support for entire families by providing housing and assistance in finding a job and legal advice,
- psychoeducation of parents in the field of better understanding autism spectrum disorder and better coping with various situations related to care and upbringing,
- psychological help for families related to the experience of war trauma.

The Polish community has responded quickly and decisively to the needs of refugees from Ukraine coming to our country. To a large extent, these were grassroots initiatives, in which people offered accommodation to Ukrainians and support in finding jobs. Numerous institutions provided free services to refugees, such as legal advice, medical services and specialist consultations. Over time, the aid offered became more organized and coordinated on behalf of the state. In counselling and guidance centres, children received a diagnosis of developmental difficulties and assistance in preparing the necessary documentation to improve the use of available forms of support and special education. Children were also offered numerous classes with specialists: a psychologist, speech therapist, pedagogue or sensory integration therapist. These families were often given priority, thus reducing the time they would normally have to wait to receive assistance. Parents had the opportunity to take advantage of consultations, during which they learned about possible forms of help, available social benefits and ways of obtaining them. In many facilities, a Ukrainian-speaking specialist or an interpreter was available to assist in the communication process. Families often also received help in finding jobs and housing, financial support, or help in buying medicines, food and other necessities. Parents were offered educational support to learn more about their child's disorders and help in working on challenging behaviours.

They were much less likely to have the opportunity to receive psychiatric help, and therapeutic support was usually ad hoc. According to a study by Pisula et al. (2023), only in one of the surveyed centres in the country, the opportunity to participate in a support group was offered to the parents. An analysis of the assistance provided from the point of view of their comprehensiveness and synchronisation brings conclusions that these families received intensive assistance in diagnosing the child and obtaining appropriate documents enabling them to complete their education in specialist institutions as soon as possible. Unfortunately, this was not tantamount to providing children with places in such institutions. Despite the increase in the limits of children in groups, over time the number of available places for children in the institutions turned out to be insufficient (Rozporządzenie…, 2022).

From the point of view of parents' experience, in many cases, when they came to Poland, they only knew that their children were not developing properly, but the final diagnosis had not been made yet. Diagnostic processes carried out in an accelerated manner in Poland aimed at verifying the child's development as quickly as possible in order to provide him or her with specialist care. Parents of these children (usually alone) have therefore had to confront the challenges of being a refugee on the one hand and receiving a diagnosis of autism on the other, which is itself a strong stressor, forever changing the life of the family (Reed & Osborne, 2019). From the point of view of the discussed impact of stress on the parent's condition and his or her process of coping and responding to the child's needs, this is of particular importance.

The study by Pisula et al. (2023) also sought answers to the causes of difficulties in helping parents of children with autism arriving from Ukraine. The main difficulties were communication barriers and the lack of access to diagnostic tools in Ukrainian, especially in the initial period. In the context of several months since the outbreak of the war, translations of some tests into Ukrainian have appeared (Pracownia…, 2024. Another problem was the lack of existing documentation of children, which would allow for better differentiation between the child's symptoms resulting from his or her disability and which are the result of war trauma. Many of the reported difficulties were also related to the inefficiency of the Polish health care system, especially in access to child psychiatrists, which Polish society has been struggling with for years (Wciórka, 2024). Specialists also complained about the low level of awareness and knowledge of parents about autism spectrum disorder, which translates into concerns related to psychological diagnosis and initiating administrative procedures related to, for example, obtaining a disability certificate. The attitude of parents was often characterized by distrust, fear, and lack of motivation (Pisula et al., 2023). The source of this attitude may have been difficulties related to adapting to a new situation and a sense of being overwhelmed by the number of difficult experiences (Lim et al., 2021). In the light of these data, it seems necessary to increase the number of actions taken for

the benefit of parents of children with autism, including ensuring access to long-term psychological and psychiatric help. It is also necessary to take action to increase access to social support, both individually and in groups. From the point of view of the long-term nature of the impact of stressors (almost two years of hostilities), the aid activities carried out should be systematic and long-term.

Conclusion

This article discusses the situation of parents raising children with autism spectrum disorder coming to Poland in connection with the war in Ukraine. The most important characteristics related to the functioning of a child with autism and the impact of these features on the stress and emotions of their parents are presented. Raising a child with abnormal development makes it significantly more difficult to meet everyday life challenges and fulfill the role of a parent. In the case of families of children with autism, the situation is further complicated by the child's difficult behaviours and communication problems, which are often the cause of negative social evaluation, reducing the social support perceived by parents. Another important factor determining the situation of parents is the ongoing hostilities in Ukraine, which have forced many families to flee their homeland and seek help abroad, including Poland. The situation we have been dealing with since February 24th 2022 is an unprecedented event in our country. In the face of the enormity of refugees, Polish society has united by engaging in grassroots initiatives aimed at providing support to those in need. Poles offered not only financial or material help, but were also ready to invite migrants to their homes, treating them as new members of the family. At the national level, too, there have been many forms of assistance to families fleeing the war. Numerous legal regulations provided tools to offer support to refugees on various levels, such as the possibility of admitting Ukrainian children to schools and kindergartens. The state also offered financial support and access to various forms of assistance on an equal conditions with Polish citizens. In the light of this broadly understood help, it is worth looking at the extent to which it responded to the needs of families of children with autism coming to Poland. Many times, they did not have any documentation regarding the child's development and needs. Sometimes because it stayed in institutions providing help to the child in Ukraine, and sometimes because these activities were not completed. Parents coming to Poland needed their children to be covered by diagnostic activities, giving them a pass to provide them with support. The assistance they received in this regard in Ukraine was at a lower level than what we are currently observing in our country. This resulted in a low level of knowledge of the parents and their distrust of the diagnosis and its irrevocability. Specialists in Poland offered not only support in the field of diag-

nosis and possible forms of therapy, but also the possibility of consultations. However, many aid activities were of an ad hoc nature and a small number of activities aimed at the parents themselves. In the face of the war trauma, the necessity of separation from their loved ones, and in comparison with the child's developmental problems, of which they were often not fully aware, their situation was particularly difficult. An analysis of the system of assistance for families of children with autism in Poland brings similar conclusions many times, showing that these difficulties apply not only to refugees from Ukraine. In our country, there is still too little attention paid to the needs of this group of parents or these activities are not comprehensive and long-term. It is also impossible not to mention the problem of access to psychiatric care, which has been publicized for years, and which is of particular importance in this area.

To sum up, in the face of the outbreak of the war in Ukraine, Poles have shown great commitment and a sense of responsibility for their neighbours. They have provided and continue to provide refugees with a wide range of assistance. Among those supported, there are many families in a particularly difficult situation. Parents of children with autism are certainly one of them. A deeper analysis of their needs indicates a further need to provide support and adapt them to current needs, with particular emphasis on helping the parents themselves, who play the most important role in this process.

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