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Children with Autistic Spectrum Disorder and Their Families

Zaburzenia spektrum autyzmu u dzieci – opieka rodziców

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Abstract

Background. The paper deals with the issue of families caring for a child with autism spectrum disorders (ASD). The authors present preliminary results of a survey regarding autism symptoms in children with autism and family´s experience with the approach of medical personnel during provision of health care.
Objectives. The aim was to find out how autism spectrum disorders manifest in their children and what attitude of health care workers children and their parents encountered.
Material and Methods. The survey on children with autism spectrum disorders, mainly focusing on cooperation between the health care workers and the parents, was conducted in February and March 2012. The survey probands were parents caring for children with ASD, namely four mothers and one father. One parent of the couple was interviewed only assuming the couple´s answers would be identical. A semi-structured interview was chosen as the most suitable method of survey.
Results. It was found that ASD symptoms in children differed and thus confirmed the diversity of manifestations of the condition and the difficulty of diagnosing it. The reported symptoms were a disorder of speech, delayed psychomotor development, walking on tiptoes, bouncing, hitting one´s head on the ground in distress, covering the ears, oversensitivity to noise, etc. The results of our investigation suggest that health care professionals lack relevant information about ASD and that they do not know how to deal with children with this condition.
Conclusions. We found, that the fact that the parents obtained relevant information from a doctor only in one of the five cases alarming. Based on the survey results we present a draft recommendation for the medical profession when treating children with autism spectrum disorders and dealing with their families (**Piel. Zdr. Publ. 2012, 2, 4, 265–270**).

Key words: child, autism, medical staff, parents, recommendation.

Streszczenie

Wprowadzenie. Praca dotyczy opieki rodzinnej nad dziećmi z zaburzeniami spektrum autyzmu (ASD). Autorzy przedstawili wstępne wyniki badań, które koncentrowały się na objawach dzieci z autyzmem i problemach dostępu rodzin do personelu medycznego podczas świadczenia opieki zdrowotnej.
Cel pracy. Określenie, czym charakteryzują się zaburzenia spektrum autyzmu u dzieci badanych rodziców, jaki jest dostęp do opieki zdrowotnej dla dzieci i ich rodziców.
Materiał i metody. Badanie koncentruje się na dzieciach z zaburzeniami spektrum autyzmu, głównie na współpracy pracowników służby zdrowia z rodzicami. Zostało przeprowadzone w lutym i marcu 2012 r. Respondentami byli rodzice, którzy opiekują się dziećmi z ASD. Były to cztery matki i jeden ojciec. Z powodu oczekiwanych reakcji rodziców przeprowadzono wywiad tylko z jednym z nich. Zalecaną metodą wydawał się wywiad semistrukturalny.
Wyniki. Stwierdzono, że objawy dzieci z ASD są różne. To potwierdza różnorodność objawów choroby i trudność diagnostyki. Jest to zaburzenie mowy, opóźniony rozwój psychoruchowy, chodzenie na palcach, skacz, bicie głową o ziemię w niebezpieczeństwie, zatkane uszy, wrażliwość na hałas itp. Wyniki badania pokazują, że pracownikom służby zdrowia brakuje informacji o chorobie ASD i nie wiedzą jakie mieć podejście do takich dzieci.
Wnioski. Tylko w jednym przypadku rodzice otrzymali od lekarza informacje o tym, jaka to choroba i jak pracować z dzieckiem – jest to alarmujące. Na podstawie przeprowadzonych badań i ich wyników przedstawiono projekt zaleceń dla pracowników służby zdrowia w stosunku do dzieci z zaburzeniami autystycznego spektrum oraz ich rodzin (**Piel. Zdr. Publ. 2012, 2, 4, 265–270**).

Słowa kluczowe: dzieci, autyzm, służba zdrowia, rodzice, zalecenia.

The birth of a child is a great event for the whole family. Parents, especially, spend a significant amount of time preparing for its arrival and they do so in advance. They look forward to it, picture its appearance and plan its future. Naturally, when a child with a disorder is born, it affects the whole family. In the case of a child with autism spectrum disorders (henceforth as ASD), the parents might not even recognise that their child is not developing accordingly in the first months of its life. The children may seem a bit slower compared to their peers; therefore, the parents may not put much emphasis on it. However, the ones who must not miss these warning signs are health care professionals, particularly the child´s general practitioner and paediatricians. Sadly, it is they who sometimes convince the worried parents that everything is in order.

Autism spectrum disorders manifest themselves in early childhood. However, it depends on the type of disorder. Also, disorder diagnosis can be very difficult. The symptoms vary, may occur at different frequencies, intensity and a degrees of severity. Some of them may not occur at all. With age, the child's symptoms tend to change, grow in intensity and even disappear. ASD manifestations are very diverse. We would hardly find two individuals with autism manifesting the same symptoms. Despite the diversity, the disorder manifests itself primarily in three areas [1]. These were identified in the seventies for ASD diagnosing by Lorna Wing and were entitled the triad of impairments, i.e. difficulties in social behaviour, communication and imagination [4]. Therefore, the approach to such a child is interdisciplinary. Apart from parents, numerous experts (paediatricians, nurses, psychologists, psychiatrists, special pedagogues, etc.) are involved in the process of taking care of the child.

The actual diagnosis is complicated by the fact that autism may be combined with any other condition or disorder [4]. The right diagnosis is hence a result of an interdisciplinary cooperation. Psychiatric, psychological, neurological and genetic examinations should be a part of the diagnosis. Moreover, an early ASD diagnosis depends on several factors, e.g. when professional help is sought and the professional's ASD expertise, the degree of the child's disorder and the availability of a specialised facility diagnosing ASD [3]. In some cases, even during regular health examinations when the parents voice their concern over the child's developmental delay to the general practitioner, the diagnosis might still be delayed causing the parents to live in great uncertainty.

The family creates an intimate communion with close mutual relations and, therefore, such uncertainty may transfer from the parents onto other family members, especially children, naturally with consequences. Parents may feel unable to handle or raise their child. Sometimes those around them tend to point out the fact. Paradoxically enough, parents may feel relieved once the diagnosis is made as they now see that they are not a failure. Even though it is clear to them that the whole family will be affected, much more compromise, strength and bravery will be required. Health care professionals are to offer assistance in times like these. But do they? The paper attempts to provide the answer to this question.

The aim was to find out how autism spectrum disorders manifest in their children and what attitude of health care workers to children and themselves they encountered. A semi-structured interview was chosen as the most suitable method of survey.

Material and Methods

The paper presents results of a survey on children with autism spectrum disorders, mainly focusing on cooperation between the health care workers and the parents. The survey was conducted in February and March 2012. The survey respondents (probands) were parents who care for children with ASD, namely four mothers and one father. One parent of the couple was interviewed only assuming the couple´s answers would be identical.

Results

The primary aim of our survey was to determine how ASD symptoms manifest in children of the parents surveyed. It was found that ASD symptoms in children differed and thus confirmed the diversity of manifestations of the condition and the difficulty of diagnosing it. The reported symptoms were a disorder of speech, delayed psychomotor development, walking on tiptoes, bouncing, hitting one´s head on the ground in distress, covering the ears, oversensitivity to noise, etc. ASD symptoms are rather diverse and not always represented in all areas of the diagnostic triad. For children with autism, it is important that the diagnosis is made since an accurate diagnosis serves as the basis for any further effective professional intervention.

Our secondary objective was to determine the attitude of health care workers to children with ASD and their parents. The results of our investigation suggest that health care professionals lack relevant information about ASD and that they do not know how to deal with such children. Based on the findings, we would like to propose several recommendations to healthcare professionals to

follow when dealing with a child with ASD and their parents.

Discussion

The paper presents preliminary results of a survey carried out by interviewing parents of 5 children with ASD. Each interview contains basic information about the child (age, parturition, information about sibling and medical diagnoses), ASD symptoms in the child and the attitude of health care professionals to children and their parents. For ease of reference we titled the probands P1–P5.

P1 – A mother of a 4.5-year old boy with a primary diagnosis of atypical autism, with affiliated diagnoses of hyperactivity, macrocephaly, hyperalbunemie, allergy to gluten and milk. There are no other children in the family. The boy was born of a physiological pregnancy by a ceasarean section. He appeared to be a healthy baby till 2.5 years, maybe just a little "slower".

According to the mother, at 2.5 years he gradually stopped using all the acquired words; therefore, she sought a doctor who provided the necessary examinations. In about 3 years the boy stopped responding to his name, he would run off, spin the wheel, cover his ears when he did not like something and wave his hands dismissively. He also used to display tantrums (he would lay on the ground kicking around). He refused to play or he did not know how to play. After the necessary examinations, the diagnosis of atypical autism and allergy to gluten and milk was confirmed. The mother states that certain autistic traits have been mitigated through a diet (a milk-free and gluten--free diet). The child is calmer, his interest in the surrounding has increased and his hyperactivity has been reduced due to the diet. The mother spent two weeks crying after hearing the possible diagnosis from a psychologist. She suffered primarily because of a lack of information about the condition. The psychologist was curt, with no signs of empathy and recommended only three Internet sources that were practically the only source of information for the parents. As for the visits to medical facilities, the boy's fear of the unknown makes him restless and angry. According to doctors he cannot be properly examined when alert, so most of the tests are carried out with short-term anesthesia. However, their visits to the paediatrician are handled well as the boy already knows the doctor. The mother has always been concerned about the long wait in the doctor´s waiting room where the boy is very restless and displays signs of the white coat syndrome. Some of the doctors and nurses fail to take it into account. The mother would prefer it if the medical staff had a different colour uniform than white and if they demonstrated the upcoming procedure on a doll or a stuffed toy for the boy to understand. Parents have come to terms with the diagnosis and they now rejoice at their son´s small victories.

P2 – A mother of a 5-year old daughter. The child has been diagnosed with atypical autism. The daughter´s other diagnoses are hyperactivity and moderate to severe mental retardation. The girl was born as a second child. Her older sister is 13 years old and has a nice relationship with the younger sister. The child was born in due course of a physiological pregnancy, the birth was without complications.

At 4 months, the girl did not lift up the head, which alarmed the mother who already had a comparison with the first child. The older one, although being born prematurely, lifted the head and laughed at this stage. Such activity was absent in the younger daughter. P2 reported her worries to the attending practitioner but was assured that everything is in order and that her daughter was a healthy baby. The mother refused to believe so and sought another practitioner who, after examination, suspected an autism disorder which was later confirmed. The mother describes the symptoms in her daughter as follows: "At 4 months she did not lift up the head, did not laugh, nor did she respond to her name. She seemed uninterested in playing. Later on she was not able to play, looked "through people" and banged her head against the ground. She likes looking at her hands, favourite books and magazines. She did not develop speaking and pointed to objects with a finger of another person." It took P2 a very long time to come to terms with her daughter´s diagnosis. She kept asking herself: "Why us?" The father refused to accept the situation and left the family. P2 was left alone with her two daughters. The younger girl is strongly fixated on her mother.

P2 got sufficient information on ASD from a child psychologist and a general physician including a contact for a facility working with children with similar conditions. P2 searched the Internet for more details about the condition. She reported that the biggest problem is having to wait in the doctor's waiting room and being in an unfamiliar environment. According to the mother, the medical personnel does not know the specifics of dealing with ASD children and many do not even know what autism is and how it manifests itself. Here is what she said: "It was a radiological examination. The nurse who worked in the X-ray room did not want to understand that Veronika would not stay still under the X-ray machine without running away or moving. When I tried to explain

this to her, she scolded me. Fortunately, another nurse, who understood the situation, intervened and after that the X-ray procedure went well, but I still did not feel comfortable". P2 would advise the health care workers to listen to the child's parents because they know their child best and know how to deal with them. She also expressed surprise over the fact that few health care professionals (nurses, doctors) know how autism manifests itself and how to approach children without aggravating their stress.

P3 – A mother of a 5-year old daughter diagnosed with infantile autism. The child's other diagnoses are hyperkinetic disorder (Attention Deficit Hyperactivity Disorder – ADHD) associated with hyperactivity and pulmonary artery stenosis. The girl often suffers from laryngitis, tonsillitis, sinusitis, and her autistic symptoms always become more prominent during an illness. She has an older brother and their sibling relationship is good. The mother observed that from about 18 months of age the daughter did not develop the same way as other children. She pointed it out to the attending physician, who did not share her concerns. At the age of 2.5 years, the differences between her daughter and other children became more pronounced, in other words she acted strangely. Mother's friend who works in the social sphere confirmed the fact and was the first person to voice the suspicion that it could be autism, which was later confirmed. In this case autism was detected in all three areas of the diagnostic triad.

The mother describes the symptoms as follows: "She loves to carry strings in her hands or some other small objects, walks on tiptoes, always bounces, and rocks from side to side when thinking. She uses her own language that only I understand. Sometimes it takes even me quite a long time to figure out what she wants to communicate, but she often only speak to herself. She repeats words beautifully but does not understand their meaning. Furthermore, the daughter demonstrates a lower self-preservation instinct and a reduced pain threshold. She also likes to run around naked. She points to objects with my hand. Is fascinated by the movement of certain things, i.e. she opens and closes things and watches the movement with great interest. She tends to be hypersensitive to various sounds and dislikes areas where there are many people, but paradoxically enough she enjoys visiting supermarkets. She likes rituals". To confirm the diagnosis the girl underwent psychological, neurological, phoniatric, genetic and psychiatric examinations. P3 thought the diagnosis took too long as she had known from the very beginning that her daughter was not okay. She felt a great need to learn how to work with her daughter in order for her to develop. The mother is optimistic and confident that they will manage with the help of family and close friends. In her own words, the attitude of health care workers was satisfactory. However, she received very little information about the condition from them. She obtained some of the information from the aforementioned friend but most of the information was found on the internet and in books. Her daughter hates noise, does not like the applying patches, responds better to female doctors, which was also the reason for the change of a psychiatrist. P3 encounters mostly a willing attitude when visiting doctors and reported that they never refused to treat her child. Before visiting a medical facility, the mother contacts the doctor to agree on a specific time and explains the importance of compliance with the agreed time. At home she "rehearses" the expected course of examination with her daughter. The daughter responds well to the system of rewards, so she always buys a small gift for her, such as a magnet on the fridge. P3 appreciates it when the doctor accepts her suggestions.

P4 – A 5-year old boy's mother. He was diagnosed with infantile autism. There is also a daughter, aged 18 in the family. Her relationship with the brother is a very nice one. She helps her mother take care of him.

The suspicion that something is not right with the boy arose around the third year of age. He did not want to talk and used to have extreme outbursts of anger. Later, after his diagnosis, they also noticed him walking on tiptoes. The diagnosis took several months, during which the boy underwent a neurological examination, which included an MRI and EEG, a metabolic and psychological examination, as well as an examination by a speech therapist. The final diagnosis of autism was provided by a psychologist who also informed the mother. P4 searched for information about autism mostly on her own account, on the Internet, in a specialised pre-school, which her son attends and from a friend who has a child with the same condition.

The son's general practitioner provided her with insufficient information, which upset the mother. The mother is rather displeased with the doctor's attitude, as the doctor does not seem to comply with her son's disorder. Based on her experience P4 is considering changing practitioners. The biggest issue when visiting a medical facility is the boy's fear of unfamiliar environments and the fear of pain. Regarding other health care professionals and their attitude, P4 replied that they differ. Some health care professionals are patient and explain everything for her son to understand the procedure. On the other hand, most doctors and nurses focus on their performance and disregard the patient. She believes that health care

professionals do not know how to approach a child with autism, and worst of all, they do not accept the advice of parents.

P5 – A father of a 4-year old son diagnosed with infantile autism. The boy was born as a third child and has two older sisters, aged 6 and 7. The relationship among children is a regular sibling-like relationship, according to P5. The father did not wish to comment on autism symptoms in his son. He was more communicative when asked about the behaviour of health care professionals. P5 reported that the doctor provided hardly any information. They found out most information online, in books or from parents of children with the similar condition. Surprisingly, the father said that the neighbourhood sees his son as an object and "not as a human being". When asked about what he fears most when visiting a medical facility, P5 clearly stated that they fear everything, e.g. that the doctor will not be able to keep the time of the appointment, that the waiting room will be full of people and that the doctor will ask his child to perform certain activities, which he will be unlikely to carry out.

P5's experience with health care workers in general is very negative. It seems to him that it is the first time they have come in touch with a child with ASD and that they do not know how to deal with his son. According to him, they are not able to organise their work effectively which leads to delay of the examination and subsequently to problems. During long waits in the waiting room the child with autism shows his frustration in an unexpected way, e.g. by shouting. Then the health care professionals ask the parents to calm the child down, which is often impossible and the only solution is to leave. According to P5, health care professionals do not have enough medical information about ASD and he expresses great surprise that this kind of knowledge is not taught during their studies. As an exceptional experience, he describes a situation when a nurse in the neurologist's office managed to keep their son occupied the whole time the parents were speaking to the doctor.

Ten Commandments for health care professionals, supporting specific approach to children with ASD:

1. Set an appointment with an ASD patient for a fixed time (preferably at the end of your working hours when there are no longer many other children in the waiting room). Keep the set time. In the event of an unscheduled appointment, examine the child with priority. Do not keep an ASD patient waiting for long.

2. Explain the procedure to the child's parents (caregivers) in advance so that they can prepare the child for the visit, e.g. by using communication cards or demonstrating the procedure in role-playing. It is also possible to use photos of the staff, the waiting room, the surgery and the equipment the doctor is likely to use.

3. Suggest a process of gradual familiarisation of the child with the environment and personnel. When you first visit the surgery, the child becomes familiar with the waiting room. On your next visit the child meets the staff and the equipment and on the next visit it can be examined and treated (very individual).

4. Cooperate with the child's parents (caregivers), obtain information to facilitate the examination of the child. Take their advice even if it seems insignificant to you.

5. It should be commonplace that parents (caregivers) are present at the examination. Parents (caregivers) represent the only certainty for children with ASD in an unfamiliar environment. Their presence also soothes them.

6. Take your time. Prior to the examination show the child what kind of examination you are going to perform (using a demo toy, communication cards, etc.). Try to draw the child´s attention (check with parents or caregivers to see what the child likes or finds interesting).

7. Keep in mind that narcosis is not always necessary for successful treatment. Consider its necessity.

8. Work calmly, quietly eliminate noise and sharp light which could alarm the child. Speak in a calm tone of voice and in simple sentences.

9. Do not insist on the child´s presence in counselling centers, unless it is necessary.

10. Be tolerant to the children and their parents (caregivers). Keep in mind that despite the effort of all parties involved, the child may still react negatively to the examination. Try not to blame anyone for it [2].

Conclusions

The authors are aware of the fact that the survey results cannot be generalised. However, we find the fact that the parents obtained relevant information from a doctor only in one of the five cases alarming. Therefore, we appeal to medical professionals to treat children with ASD and their parents as true professionals. In practice, this means that they become more supportive of families caring for children with ASD. They are to understand the children´s special needs. They should be able to help or refer the parents to a specialised facility for assistance and advice. In any case, it is necessary to strengthen the parents´ confidence and approach them and their children with respect. We are not only experts in our own field. First of all, we are people with hearts in the right place.

Reference

[1] **Bartoňová M.:** Co víme o autismu. Asociace pomáhající lidem s autismem APLA – JM o. s. 10.03.2012 http://www.apla-jm.cz/index.php?ID=16.
[2] **Kalášková M.:** Specifika ošetřovatelské péče u dítěte s poruchou autistického spektra. Bakalářská práce. Univerzita Tomáše Bati ve Zlíně, Fakulta humanitních studií. Zlín 2011, s. 58.
[3] **Masopustová Z., Lacinová L.:** Raná diagnostika dětského autismu. Pediatrie pro praxi 2006, 4, 207–209; http://www.pediatriepropraxi.cz/pdfs/ped/2006/04/06.pdf.
[4] **Thorová K.:** Poruchy autistického spektra. Portál, Praha 2006.

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