Knowledge about autism among Polish pediatricians

Wiedza na temat autyzmu badana u lekarzy pediatrów w Polsce

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Summary

Our current research concerns knowledge about autism among Polish pediatricians. A study was conducted in order to answer the question what is the level of knowledge of pediatricians on autism and whether it differs depending on the size of the city in which they work. The study involved a total of 50 physicians (25 from Warsaw and 25 from Włocławek). All the respondents specialized in the same field, that is, pediatrics. In the study, the Autism Questionnaire based on the research of Pisula (1) was used. The results showed that the pediatricians’ knowledge varies depending on the topic associated with autism. In case of some of the questions, the pediatricians showed high familiarity with the issue giving many good answers, but some areas proved to be problematic for them. We did not show any difference in the level of knowledge on autism among pediatricians from Warsaw and Włocławek. Both groups had almost the same number of correct answers in the questionnaire. Summing up the results of this research, one can conclude that the pediatricians’ knowledge about autism is incomplete. Undoubtedly, such situation may have a negative impact on the diagnostic process and, in the long run, on the future of an autistic child. Providing education to medical students and practicing doctors about the various aspects of autism would therefore be very useful, as their expertise will most likely lead to a better prognosis for autistic children.

Key words: autism, knowledge on autism, pediatricians, medical students

Streszczenie


Słowa kluczowe: autyzm, wiedza o autyzmie, lekarze pediatrzy, studenci medycyny

Autism is one of the most severe developmental disorders. Children with autism show deficits in communication and social behavior as well as present rigid patterns of activity and interests (2). Currently, autism is diagnosed more often than a few decades ago (3). There are therapeutic methods whose effectiveness is supported by numerous scientific studies (4). Early diagnosis of autism has an impact on the prognosis and functioning of the autistic children. The first group of professionals that the concerned parents report to are the pediatricians. It is important for pediatricians to have adequate knowledge of developmental disorders, as it can help in the timely and correct screening as well as diagnosis of autism. Moreover, having good understanding of various issues related to autism can help the primary care providers fulfill their management responsibilities (i.e., delivering high quality medical care, guiding parents to effective interventions and sources of accurate information) after the diagnosis has been made.
Despite the fact that nearly seventy years have passed since Kanner (5) first described autism, the disorder still has not been examined thoroughly (6). The American scientists from the Center for Autism Research at The Children's Hospital of Philadelphia and the Department of Medicine in Pennsylvania published an article in which they review state-of-the-art knowledge about autism. According to them, there has been much progress in understanding autism, the role of the early diagnosis and intensive therapy (7). Nevertheless, this knowledge often does not "filter down" to primary health care providers. Studies concerning the level of knowledge about autism among those professionals were carried out in the USA (8, 9), Pakistan (10), Nigeria and other African countries (11).

In Poland, Łęczycka (12) conducted a study in order to become acquainted with the state of knowledge about autism. A questionnaire that included 12 questions related to the subject in question was created. 390 people were surveyed. The respondents were the nursing students, students of psychology, medicine and educational pedagogy, nursery workers, special education school teachers, regular teachers and pediatricians (12). Of the respondents, nearly 62% heard about the term autism only on a theoretical level. 23.4% never met an autistic child. Less than a half, namely 47.2% of the respondents did not know how common such a disorder was. When asked about the time the first symptoms of autism emerge, only 31% of people knew the correct answer. The answers to the question about the cause of autism were varied. The majority of respondents considered that the cause was the damage to the central nervous system (21.7%). There were however responses indicating that the mother was to blame for the emergence of autism. 124 people did not reply to the question about the symptoms characteristic of the disorder. Little over 20% of the respondents pointed at the limited interactions with the social environment. Only a few took into consideration all symptoms. More than half of the respondents (57.2%) did not know whether children with autism were mentally handicapped, and even more of them, that is 69.2%, did not have any information about the disorders comorbid with autism. More than half of the respondents (57.7%) believed that there were methods to improve the functioning of people with autism. According to the respondents, the best place for the child's development was the family environment (41.8%). When it comes to treatment that would help a child in normal functioning, 62.8% of people did not give any answer. The others mentioned music therapy, physical therapy, Sherborne Developmental Movement Method, psychotherapy and pharmacology. The latter form was suggested by doctors and regular teachers.

Summing up the results of the research, Łęczycka notes that knowledge about autism is incomplete and often varied. This fact also draws attention to little knowledge on fundamental issues, such as symptoms of autism or types of recommended therapies. According to the author, the state of knowledge of childcare workers as well as teachers in nursery and primary schools is particularly alarming. The study group also included pediatricians. Łęczycka claims that they are a specific group, because of the responsibility they bear. Parents turn to them first, therefore the doctors' knowledge should be complete and thorough so that they would be able to help parents recognize the symptoms and diagnose the disorder. The study shows that, unfortunately, their knowledge is insufficient to meet this challenge (12).

In subsequent years, research on the knowledge about autism was carried out by Pisula and colleagues (1, 13). In the first study (1), Pisula surveyed 93 psychology students. A questionnaire consisting of 18 questions was used. The questions pertained to a variety of issues related to autism (e.g., age of diagnosis, symptoms, etiology). The question concerning the incidence of autism gave rise to difficulties. As many as 71.2% of respondents did not know the correct answer. Most people knew the correct answer to the question about the first symptoms of autism (45.9%), indicating that they appeared prior to 3 years of age. More than a half, that is 55.7%, pointed out correctly that autism was more common in boys than girls. The answers about the causes of autism were somewhat varied. 41% of the respondents could not give the correct answer, 26.2% reported psychological reasons, another 18% – biological causes, and 10% stated that the causes of the disorder were unknown. In another question about the causes of autism, 34.4% of respondents blamed the mothers for their lack of love and emotional warmth. A little less, that is 32.8%, believed that the parents had some personality disorders that affected their child well-being. Most people (78.7%) answered that the main symptoms of autism were the social functioning difficulties, rigid patterns of behavior and interests (77%) as well as communication impediments (67.2%). About 44% of respondents did not know that mental retardation was a comorbid disorder linked with autism. As much as 27.9% of the respondents reported schizophrenia as a comorbid disorder with the disease in question. Less than a half, namely 44.3% of the students, claimed that it was possible to improve the functioning of the child, and a little less, that is 37.7%, believed that the chances were rather slim. A large number of people – 90% – considered that autism did not fade with age. In the questionnaire, there were also questions about therapy for children with autism. Most respondents (52.5%) suggested holding therapy, the others behavior modification (36%), non-directive therapy (23%) and the remaining 14.8% of people pointed to the Option Method as a treatment for autism. A large number of people (80.3%) pointed out that the home was the best place to work with the child, while only 32.8% suggested specialist health centers. Summing up the results, Pisula notes that in some areas connected with autism, such as the first and major symptoms of the disorder, the students achieved quite
satisfactory results, whereas in other domains, such as the causes of autism, their knowledge was definitely insufficient (14).

Pisula and Rola (13) conducted another study on the knowledge about autism. This time, they surveyed special education teachers, regular teachers and the third year students of special education. Among them, a few mentioned the triad of impairments characteristic of autism (14.3% of teachers in special education, 10% of students and 8.6% of regular teachers). The most frequent characteristic was connected with problems of social functioning. Most respondents stated that people with autism did not speak at all. As much as 72.5% of the students, 69.8% of regular teachers and more than 50% of teachers in special schools were deeply convinced of this fact. About 25% of all respondents claimed that autistic children were aggressive, hyperactive, and often eried. In the results described, one should pay attention to the question of the importance of psychogenic factors in the development of autism. As much as 50% of students felt that the cause was the lack of love and warmth on the part of mothers. The same response was also given by 41.9% of the regular school teachers and 28.6% of special education teachers. 32.5% of students also believed that autism may be traced to parents who have personality disorders. The teachers gave a similar answer (27.9% of regular school teachers and 23.8% of special education teachers, respectively). The answers concerning the therapeutic methods were quite varied, but the holding therapy was mentioned most often. Such an answer was given by 25% of students, 13.9% of regular school teachers and 11.9% of special education teachers (14).

Summarizing both studies, Pisula points out that the knowledge of autism is not satisfactory, especially since the majority of respondents declared their interest in the subject of autism because of the job they do and the fields of study they chose. The main problem noticed by Pisula is that more than half of the respondents insisted on believing that the causes of autism were lack of love from the mother and other psychogenic factors. At the same time, the respondents suggested as the best method of treatment giving children love and warmth, which, in their opinion, the autistic children lacked. Such opinions will definitely affect the perception of autism as well as may hinder the cooperation between the parents of children with developmental disorders and the specialists (14).

In the year 2008 in the Lubuskie voivodship, a study concerning the needs of individuals with autism in the opinion of the medical community was carried out (15). It involved 71 physicians with specialization in: pediatrics, family medicine, neurology and psychiatry. Most of the respondents were female (68%). The age range was form 26 to over 60 years old. Less than half of the respondents (45%) declared that in their work they had contact with an autistic child. The survey included a question of how respondents assessed their own knowledge about autism. Only 1% of them stated that it was good. More than half of respondents (51%), deemed it as moderate and 48% as poor. Asked about the symptoms of autism, only one person identified correctly all of them. Most respondents indicated as a symptom of autism poor eye contact, whereas 43% suggested aggression toward people and objects and 28% indicated poor mobility. However at the same time, when asked to determine impairments in the main areas of functioning, 85% of respondents correctly indicated three of them: communication, behavior and social interactions. It is worth noting that the doctors also pointed to lack of relation with parents, showing no emotions, hindered intellectual development, hearing impairment and motor difficulties as symptoms of autism. Asked about the causes of autism, 95% of the respondents stated that the reasons were not known, and there were many theories related to this issue, especially to genetic and metabolic causes. A small percentage suggested as the source of autism emotional detachment of the mother. More than half of the physicians (55%) disagreed with the statement that autism was a mental illness, and 34% confirmed this thesis. The questionnaire also asked about the importance of pharmacology to cure or improve the functioning of people with autism. 40% of people opted for the pharmacological methods, stating they can cure and improve the functioning, while 49% disagreed with the idea, and 11% did not give any response at all. Asked about the sensory disturbances that occur in people with autism, 48% of people indicated hypersensitivity and 42% believed that all types of sensory disturbances may occur in autistic children. While 13% of respondents indicated that children with autism experience hyposensitivity, the same number of people did not know the answer to that question. The last question inquired about factors that would facilitate the doctors’ work with autistic people. A large number (80%) indicated greater availability of training and information.

Summarizing the results, a similar conclusion to the previous studies can be drawn, namely that the physicians’ knowledge about autism is varied and in some areas insufficient. Therefore, the authors suggest that the best way to improve the situation would be to start an active and bilateral cooperation between the institutions engaged in the promotion of knowledge about autism and autistic people and the medical environment.

Taking into consideration research results described above, a decision was made to examine the current state of knowledge on autism among pediatricians in Poland. This is a very important professional group, because most parents report to them if they see worrying symptoms in their child (9). Parents expect from the pediatrician to state whether the problem exists and give advice on how to proceed (16). Unfortunately, the symptoms are usually trivialized and the parents are reassured that their child will overcome the difficulties with age (17). The following hypotheses were proposed: 1) knowledge of pediatricians varies depending
on the topic associated with autism and 2) in a big city (Warsaw) knowledge of autism among pediatricians will be more complete than among a medium-sized city physicians (Wloclawek).

METHOD

Respondents

Pediatricians participated in the study, which was conducted in two Polish cities, namely in Wloclawek, which represented a medium-sized city, and in Warsaw, which represented a very large city. A total of 50 physicians participated: 25 people from Wloclawek and 25 people from Warsaw. The study included a total of 41 women (21 from Wloclawek, 20 from Warsaw) and 9 men (4 of Wloclawek, 5 of Warsaw). All the surveyed specialized in one field, that is pediatricians. The medical practice as pediatricians for women from Warsaw ranged from 7 years to 28 (M = 21.8, SD = 4.96), for men from 20 to 30 years (M = 25.4, SD = 4.15), whereas in Wloclawek it ranged from 8 years to 48 years (M = 26.04, SD = 9.32) for women and for men, the number was between 25 and 31 years (M = 27.5, SD = 2.64). The study was conducted between February and April 2012. The average amount of time per one survey was about 15 minutes. The experimenters met individually with each participant at their place of work.

MATERIALS

In the study, the “Questionnaire on the knowledge of autism” was used (it is available on request from the author for correspondence). This questionnaire is a modified version of a survey used in Pisula’s research (1). It consists of 11 groups of questions. For each question, one chooses either “yes” or “no”, depending on the answer one considers to be correct. The questions refer to the key issues in autism (e.g., the factors that contribute to the development of autism, diagnostic criteria, comorbid disorders, prognosis for the people affected by autism, effective methods of intervention, the incidence of autism, the characteristic behavior of people with autism, the diagnosing methods).

PROCEDURE

The respondents were informed that the study involved assessing the level of knowledge about autism. They were also informed about the anonymity of the research and the possibility of withdrawal from participation at any time without any consequences. They were told there was no time limit to fill out the questionnaire. Once we obtained the oral consent of the person tested, the respondents were given the questionnaire. They were asked to complete the questionnaire by circling one of the options – “yes” or “no” – next to a given statement. Completing the questionnaire took about 15 minutes. The testing procedure looked the same in both cities (Wloclawek, Warsaw).

RESULTS

In order to verify the first hypothesis, the frequency analysis was used. The following results, shown in percentages, are the correct answers given by the respondents.

In the first question of the survey (the factors contributing to the development of autism), there were three correct answers (i.e., pregnancy and childbirth complications, genetic factors, neurobiological disorder). Most of the respondents, that is 98%, indicated neurobiological disorders. 86% were in favor of the genetic factors, while 60% opted for the pregnancy and childbirth complications. 36% of the respondents linked autism with the personality disorders of the parents. 18% of respondents said that parenting mistakes and lack of love on parents’ part were the factors that contribute to the development of autism. The average percentage of correct answers to this question was 78.7%.

In the next question concerning the diagnostic criteria for autism, one was to circle four answers (i.e. impaired social interaction, delayed speech development, or lack there of, limited interests, and rigid patterns of behavior). All respondents indicated correctly that the diagnostic criteria include abnormal social interactions (100%). 94% indicated limited interests and rigid patterns of behavior. The delayed development of speech or lack of it were marked correctly by 90% of the respondents. As many as 84% of people felt that sensory sensitivity was one of the diagnostic criteria for autism. On the other hand, more than half of the respondents (62%) found that children with autism were aggressive. Half of the respondents (50%) pointed to the difficulties in auditory analysis. Another 48%, marked mental retardation. 34% of those questions marked the impaired motor development and 8% suggested visual impairment. The average of the correct answers to this question was 69.3%.

In the next set of questions (the age of the onset of symptoms), the correct response (i.e., before the age of three) was given by only 36% of respondents. Most people found the onset of symptoms was of no importance for diagnosis (54%). 30% of people indicated that one can diagnose autism only if symptoms occurred before the age of two, while 14% responded that in order for the diagnosis of autism to be given, symptoms have to be visible by the end of the first year. The average percentage of correct answers to this question was 59.5%.

The next question was about the disorder, disease or phenomenon, which at least half of the people with autism suffer from. There was only one correct answer to this question (i.e., mental retardation). 82% of the respondents answered the question correctly. Most people identified the Savant Syndrome (84%). 22% linked left-handedness to autism. Next, 14% pointed to epilepsy and 12% to the Fragile X Syndrome. The remaining 8% circled Down’s Syndrome and, the least, 4%, excess weight. The average percentage of correct answers to the question was 78.2%.
In the section devoted to relation of autism to gender and social status, 68% of respondents answered correctly that autism was more common in boys than in girls. 64% of the respondents marked incorrectly that autism was more common in well-developed countries. The remaining 28% felt that there was no difference between boys and girls in the incidence of autism. The average percentage of correct answers to this question was 58.6%.

When it comes to the questions focusing on the prognosis for autistic children, 90% of the pediatricians recognized correctly that children with autism would need life-long help of others if they did not receive intensive therapy. Some respondents felt that children with autism could be completely cured (22%). 78% disagreed. Much more than a half, that is 70% of people, said that about 50% of children receiving early and intensive behavioral therapy would be able to function independently in regular schools. However, 66% believed that children with autism had a small chance of functioning well in society. The average percentage of correct answers to this question was 76.6%.

The vast majority of respondents found behavioral therapy as an effective method of intervention for people with autism (92%). 78% of doctors marked the TEACCH model as effective therapy method. Those were the only correct answers. Another 62% pointed out incorrectly to auditory integration training and diet (48%). The average percentage of correct answers to this question was 65.1%.

The responses about the incidence of autism were quite varied. Only 20% gave the correct answer by selecting the number of 10-15 people per 10,000. The largest number of the respondents (44%) marked 2-6 per 10,000 people, while 32% estimated 1 per 10,000. 4% of pediatricians claimed that more than 30 children in 10,000 have autism. The average percentage of correct answers to this question was 59.6%.

The vast majority of those surveyed characterized well the behavior of autistic children. Most of them, that is 98%, said that the relations of autistic children with their peers were insufficient. 96% said they children with autism did not feel the need to share with others their joys, interests and achievements. According to 94% of the respondents, it was also characteristic that they had difficulty recognizing the mental states of others as well as explaining and predicting their behavior. 92% of the respondents pointed out to the stereotypical and repetitive motor manners. 52% of the respondents marked wrongly the reduced energy in carrying out tasks and 28% of people suggested eating disorders as characteristic of autism. The average percentage of correct answers to this question was 84.2%.

Asked about the possibility of mistaking early diagnosed autism with other disorders, 78% of the respondents pointed out correctly to mental retardation. A similar proportion of respondents (76%) indicated Asperger’s syndrome, thus giving an incorrect answer. 34% of the respondents marked correctly the Rett syndrome. The average percentage of correct answers to this question was 45.3%.

The question about diagnosing the children with autism was answered correctly by the majority of respondents, who pointed to a structured interview with the parents (94%) as one of the elements of the diagnostic process. 88% also gave the correct answer indicating that a child was observed in different situations during diagnosis. 70% marked incorrectly that the diagnosis of autism was based on the test of autism and the Wechsler intelligence test (52%). The average percentage of correct answers to this question was 64.6%.

Additionally, the average of correct answers to each set of the questions was calculated in percentage. In table 1, the values are ranked from the largest to the smallest.

Table 1. The average of correct answers ranked from the largest to the smallest percentage.

<table>
<thead>
<tr>
<th>Issue</th>
<th>Average</th>
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<tbody>
<tr>
<td>1. Behavior characteristic of people with autism</td>
<td>84.2%</td>
</tr>
<tr>
<td>2. Factors contributing to the development of autism</td>
<td>78.7%</td>
</tr>
<tr>
<td>3. Disorders/diseases/phenomena comorbid with autism</td>
<td>78.2%</td>
</tr>
<tr>
<td>4. Prognosis for autistic children</td>
<td>76.6%</td>
</tr>
<tr>
<td>5. Diagnostic criteria for autism (according to ICD-10 or DSM-IVTR)</td>
<td>69.3%</td>
</tr>
<tr>
<td>6. Effective methods of intervention in working with autistic people</td>
<td>65.1%</td>
</tr>
<tr>
<td>7. The basis on which autism was diagnosed</td>
<td>64.6%</td>
</tr>
<tr>
<td>8. The incidence of autism</td>
<td>59.6%</td>
</tr>
<tr>
<td>9. When it is possible to diagnose autism</td>
<td>59.5%</td>
</tr>
<tr>
<td>10. Characteristics of autism</td>
<td>58.6%</td>
</tr>
<tr>
<td>11. Differentiating autism from other disorders</td>
<td>45.3%</td>
</tr>
</tbody>
</table>

We conducted the analysis of variance with the repeated measures and the dependent variable accepted three values: the highest (84.2%), medium (65.1%) and the lowest (45.3%). The obtained result was the analysis of variance F (2, 96) = 49.33, p < 0.001.

The following analysis was conducted to compare the measurements with each other, using post hoc tests with Bonferroni correction and the degree of statistical difference was found between the measurements. The level of knowledge of the characteristic behavior of autism (M = 84.2%, SD = 14.20) was significantly higher (p < 0.001) than the level of knowledge related to the effective methods of intervention (M = 65.1%, SD = 23.01). The level of knowledge about the effective methods of intervention (M = 65.1%, SD = 23.01) was also significantly higher (p < 0.01) than the one related to differentiating autism from other disorders (M = 45.3%, SD = 22.25). The above results support the hypothesis of the varied knowledge of pediatricians, depending on a given issue related to autism.

In order to verify the second hypothesis, the analysis using the Mann-Whitney U test for independent samples, was conducted. The pediatricians from Warsaw had a similar number of correct answers (M = 38.68,
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physicians reported low self-perceived competency in providing care for children with ASDs and a desire for education (18). Thus, a common and undesired situation is such that pediatricians trivialize the disorder due to lack of knowledge. Another very important aspect of the pediatricians’ work is to guide “families to empirically supported educational and habilitative practices and help them evaluate the appropriateness of educational services being offered” (19, p. 1). This can also be a challenge if doctors lack knowledge about certain characteristics and empirically supported treatments for autism spectrum disorders (ASDs). As Skellern et al., (20) showed in a survey of families of individuals diagnosed with ASD, about 33% of physicians spontaneously discussed non-traditional therapies for autism, which did not have strong empirical support.

Conclusions from previous and current research are straightforward: pediatricians across the world do not have complete knowledge on autism and should be continually educating themselves on the disorder, which is more and more commonly diagnosed. It may be necessary to introduce more information on developmental disabilities during the course of studies for medical students and then more thorough educational opportunities for doctors who choose to specialize in pediatrics or have other specializations which are also conducive to coming across a child with autism (e.g., family medicine). In order to help interested doctors, we list below a number of organizations which provide trainings and workshops on autism, developmental disabilities and effective therapeutic interventions for children with autism (tab. 3).

Table 3. List of organizations which offer workshops related to developmental disabilities and behavioral therapy (based on: Suchowierska, Ostaszewski, Bąbel, 2012).

In Poland a number of workshops devoted to behavioral therapy is offered by institutions/clinics which provide services for children with autism and related disabilities as well as non-governmental organizations which promote applied behavior analysis. Below we enlist some of them.

- Polskie Towarzystwo Terapii Behawioralnej: www.pstb.org
- Polskie Towarzystwo Psychologii Behawioralnej: www.ptpb.pl
- Stowarzyszenie Pomocy Osobom Autystycznym: www.spoa.org.pl
- „Krok po Kroku” – Fundacja na Rzecz Dzieci z Zaburzeniami Rozwoju i Ich Rodzin: www.krokpoYRO.org
- Fundacja – Instytut Wspomagania Rozwoju Dziecka w ramach Niepublicznego Ośrodka Doskonalenia Nauczycieli: www.iwrd.pl

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