

AUTİSM SPECTRUM DİSORDER MANAGEMENT PRACTİCES AND LEVEL OF
KNOWLEDGE AMONG GENERAL PEDIATRICIANS

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AUTISM SPECTRUM DISORDER MANAGEMENT PRACTICES AND LEVEL OF KNOWLEDGE AMONG GENERAL PEDIATRICIANS

Abstract:

Objectives: Early diagnosis of Autistic Spectrum Disorder (ASD) is challenging and may be delayed up to preschool years since there is no pathognomonic sign or laboratory test to detect. For early diagnosis and treatment, pediatricians should be aware of the psychological disorders and medical issues that children with ASD encounter. **Pediatricians play an important role in the early recognition of ASDs, because they are usually the first point of contact for children with ASDs.**

Methods: This study focuses on the role of pediatricians' awareness of autism and its effects on the life events of the autistic children. The study involved 270 volunteer pediatricians, from state and university hospitals.

Results: Pervasive disorders that the participants were most commonly aware of were lack of attention to social stimuli, fewer smiles, and not looking at the faces of others, not responding to their own name, delayed speech in the presence of hearing and gastrointestinal problems such as vomiting and eating .

Conclusions: The results of the present study show that pediatricians do not have the thorough knowledge of DSM-IV autism criteria and ASD. They have stated that they are not familiar with comprehensive evaluation techniques or are not comfortable with making the diagnosis of autism spectrum disorders, have inadequate knowledge about the effect of the disease on the rest of the patient life as an adult. They have also stated that having spending some time

in child and adult psychiatry clinics will make them feel more comfortable while approaching those patients.

ÇOCUK HEKİMLERİNİN OTİZM SPEKTRUM BOZUKLUĞU HAKKINDAKİ BİLGİ, TUTUM VE YÖNETİM PRATİKLERİ

AMAÇ: Otizme özgül rutin gelişimsel tanı araçları olmadığından tanı koymanın okul öncesi döneme kadar uzayabildiği görülmektedir. Erken tanı ve tedavi için hekimlerin otistik spektrum bozukluğu şüphesi uyandıran durumları iyi bilmesi ve bunları standart ölçme araçları ile değerlendirmesi gerekmektedir. **Günümüzde halen pediatristler Otizm spektrum bozukluğu olan hastaları ilk gören hekimler olduğu için erken tanıda önemli rol oynamaktadır.**

GEREÇ VE YÖNTEM: Bu çalışma pediatristlerin otistik spektrum bozukluğu ve yaşam olayları üzerine etkileri hakkındaki tutum ve davranışlarını değerlendirmek için tasarlanmıştır. Devlet ve üniversite hastanelerinde çalışan 270 gönüllü pediatrist ile anket yapılmıştır

BULGULAR: Katılımcılar sıklıkla yaygın gelişimsel bozukluk şüphesini sosyal stimulusların farkında olmayan, göz teması ve gülümsemesi az olan, ismi seslendiğinde cevap vermeyen, geç konuşan ve gastrointestinal problemleri olan hastalarda duyduklarını belirtmişlerdir.

SONUÇ: Bu çalışma pediatristlerin otizm spectrum bozuklukları ve DSM IV kriterleri hakkında yeterli bilgi sahibi olmadıklarını göstermiştir. Katılımcılar ASD hakkında tanı ve değerlendirme kriterlerini bilmedikleri, yaşam olayları üzerine etkisi hakkındaki soruları genel olarak düşük oranda doğru cevapladıkları ve örgün eğitime devam edebilme, evlilik gibi yaşam olaylarına bakış açısından ailelere yeterince objektif bilgi verecek düzeyde olmadıkları

görülmüştür. Bu hastalara uygun yaklaşım için çocuk psikiyatri kliniklerinde rotasyon yapılması gerekliliğini belirtmişlerdir.

Introduction

The term autism spectrum disorders (ASD) has been used to include the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR)* (American Psychiatric Association, 2000) diagnostic categories autistic disorder, Asperger disorder, and pervasive developmental disorder—not otherwise specified (1). Pediatricians have an important role not only in early recognition and evaluation of autism spectrum disorders but also in chronic management of these disorders. Pervasive developmental disorders or autism spectrum disorders (ASD) range from a severe form, called autistic disorder, to a milder form, Asperger syndrome. If a child has symptoms of either of these but does not meet the specific criteria for either, the diagnosis is called pervasive developmental disorder not otherwise specified (PDD-NOS). Other rare, very severe disorders that are included in the autism spectrum disorders are Rett syndrome and childhood disintegrative disorder. All of these are characterized by varying degrees of impairment in communication skills, social interactions, and restricted, repetitive, and stereotype patterns of behavior (2). A revision of the diagnostic criteria of ASDs was proposed in the *Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5)* that was released in May 2013 (15). The autism spectrum describes a range of conditions classified as neurodevelopmental disorders in the fifth edition of the DSM. The new diagnostic criteria encompasses previous elements from the diagnosis of autistic disorder, Asperger disorder, childhood disintegrative disorder, and pervasive developmental disorder-not otherwise specified.

Prevalence of ASD is estimated to be between 6.5 to 6.6 per 1000 children (3,4). This range of prevalence indicates a need for earlier and more accurate screening for the symptoms

of ASD. The earlier it is diagnosed, the sooner the child can be helped through treatment interventions.

Because of the lack of autism specific routine developmental diagnostic tools, diagnosis may be delayed until just before preschool years. Recent reviews on autism have shown that in a study of 1300 families with autistic children, the age at diagnosis was around 6 years of age, but most of the families noticed some unusual behaviors in the 18th month and applied for medical help when the children were 2 years old (5,6). Hence, as suggested by the American Academy of Pediatrics, pediatricians have a great deal of role in diagnosis and treatment of the condition (7) . Since early intervention has a dramatic impact on reducing symptoms and increasing a child's ability to grow and learn new skills (8,9).

This study was conducted among pediatricians employed in various university and state hospitals of Ankara in order to evaluate the level of perception, attitude, and knowledge related to the diagnosis and management of autism and autism spectrum disorder through a questionnaire based on the DSM-IV diagnostic criteria (10).

Material and Methods

The study group comprised 270 pediatricians [141 (52.2%) from the university hospitals (UH) and 129 (47.7%) from the state hospitals (SH)]. The pediatricians were applied a four-step Likert type questionnaire comprising 40 questions based on DSM-IV diagnostic criteria, to evaluate their level of competence in the diagnosis and management of ASD. The questionnaire assessed the competence, attitude, and knowledge of the pediatric residents and included some questions related to common myths in public about the disorder. Pediatricians did not have any fellowship of pediatric departments.

The questions were generally related to DSM-IV criteria. Moreover, the issues concerning the differential diagnosis of ASD were also evaluated. The answers of “partially

agree” and “definitely disagree” were considered under the heading of “agree”, while the answers of “partially disagree” and “definitely disagree” were considered under the heading of “disagree”. The choice of “no opinion” was excluded from the statistical evaluation. Thus, more polarized and dichotomous data analysis was achieved.

The first part of the questionnaire consisted of the questions related to socio-demographic features, such as age, duration of residency, marital status, any experience with autistic patients, self-confidence in diagnosing autism, awareness of autism, and beliefs on receiving rotation in pediatric psychology department during residency. The second part included questions on suspected cases of ASD, general knowledge on ASD, knowledge on ASD subgroups and its effects on the major events of life such as schooling and marriage. The third part inquired the knowledge on the management of ASD, and the last part of the questionnaire was about the attitudes of the pediatricians towards the management of the disorder. Before the study, the participants were fully informed about the study and assured on the anonymity of their identity. The participation was completely voluntary.

For the statistical evaluation, SPSS 15.0 package program was used. The numerical values, age of the participants and the time of experience (the time spent practicing as a pediatrician) were expressed as mean \pm standard deviation (SD). Chi-square analysis was used in testing the differences between the answers of the participants regarding their institution (university or state hospital), and tenure of office. Furthermore, overall assessment of each division was carried out by using the independent t test ($p < .05$).

RESULTS:

The study included 270 pediatricians [141 (52.2%) from the university hospitals (UH) and 129 (47.7%) from the state hospitals (SH)]. The gender distribution of the participants was as follows: 158 (58.5%) female and 112 (41.5%) male. The mean age of the participants was 30.68 ± 6.51 years. The time spent practicing as a pediatrician in both hospitals was 7.14 ± 6.16 years. A hundred and thirty-three (49.3%) participants were unmarried; 137 (50.7%), married, and 83 (30.7%) had children. The most common reasons that pediatricians do not engage in general developmental screening were lack of time (85.2%). When the academic titles were compared for correct answers (residents, pediatricians) with t test, no statistically significant differences were detected between the two groups ($t=.736$, $SD=211.36$, $p>.00$).

The answers of the participants in self-evaluation of their own capability and knowledge on ASD have been provided in Table I. Accordingly, 188 participants (69.6%; UH: 67.4%; SH:71.6%) stated that they did not know the autism criteria listed in DSM-IV; 200 participants (91.1%; UH: 90.1%; SH:92.2%) felt that they were not furnished with sufficient knowledge, skill, and qualifications for diagnosis of ASD; 175 participants (64.8%; UH:54.6% ; SH:44.2%) reported that they did not follow any publications on ASD; 260 participants (96.3%; UH:96.5%; SH:96.1%) believed that during pediatric residency, they should have received education in Child and Adolescent Psychiatry department. There were significantly statistical differences of datas between the attenders of university hospital and state hospital according to correct answer ratios (Table II, III, IV) However, the reason of this difference was unclear. In our opinion, although both of hospitals have been pediatric neurology and child psychiatry clinic, the diagnosis of autizm could be effected by lack of experiences and presence of much more patients at state hospital clinics examined in a short span of time.

Following are the rates of participants stating that general developmental disorder should be suspected in (Table II): children who cried less, made less noise, and are introverted and obedient (84.4% of the participants); children who are hyperactive, show delayed speech development despite no loss of hearing, have difficulty in understanding the commands (72% of the participants); children who have concomitant motor coordination disorders and hyperactivity (67% the participants); children who had eating disorders and gastrointestinal system disorders in infancy and often vomited (61% the participants), and children experiencing difficulty in peer relations and complaining about not being able to join in the play (56% the participants).

The distribution of the rates of participants for the most common knowledge on autism based on their answers to the questions was as follows (Table III) : increased fondness towards the mother and/or father, or other primary caretakers (51.9%), markedly disordered social interaction within the wide spectrum of autism, (%90.7), hyperactivity as one of the primary symptoms (72.2%), autism not related with faulty attitudes of parents (84.8%), patients' lacking the ability to mimic (55.9%) , delayed speech not associated with deafness (89.3%), patients' lacking the ability to start a and carry out a conversation (60.0%), disordered sleep pattern (68.1%), presence of autistic characteristics in children with attention deficit hyperactivity disorder, but not at a diagnostic level (61.5%), and potential autistic behaviors in the presence of tuberous sclerosis (50.6%) and chronic lead exposure (66.7%). The least known information was the lack of autistic children in imagining and thus having no ability to set up creative games (22.2%), autism as an irreversible disorder affecting all of the areas of development (40.4%), the onset of symptoms before the age of three (44.4%), higher

chance of correct diagnosis after the age of three (47.8%), the risk of mental retardation (44.4%) and epilepsy coexistence (25.6%).

The answers to questions related to the treatment of the disorder (Table IV) revealed that 33.7 % of the participants had said that the condition had no cure; however, 79.6% of the participants were aware of antidepressant and antipsychotic drug use in symptomatic treatment, and 73.7% were aware that hyperbaric oxygen treatment was not used. According to 78.5%, patients should be have special education.

The answers to the questions on the effects of ASD on major life events showed that 102 (37.8%) participants were aware that there were no specialized primary schools in many country for autistic children. Individual evaluation of each of the questions revealed that 47% of the pediatrician stated that autistic patients cannot get married; 148 (54.1%) stated that 1-2 % of autistic patients can lead their lives independently; 170 (63%) stated that autistic patients cannot follow regular educational curricula (Table IV).

DISCUSSION:

Pediatricians play a crucial role in the evaluation and management of autism spectrum disorders. This role has grown in importance as the prevalence of autism has increased by 78% since 2002, according to the Centers for Disease Control and Prevention (11). Despite being such a common disease, lack of well-established diagnostic tools, apprehensive attitude and approach of the families often lead to delayed diagnosis (5,12). Accumulating information, increased pace of activities to develop public awareness, efforts to devise diagnostic tools of high sensitivity, and introduction of novel scales to the field have facilitated definitive diagnosis as early as three years of age in most autistic children .

Because there are no autism specific routine developmental diagnostic tools, the diagnosis may be delayed to preschool age. Review of recent literature indicated that in 1300 families, the mean age of autism diagnosis was around 6 years of age. However, the parents seem to notice the deviation of their children as early as 18 months of age and apply for medical help at around the age of 2 (13). This has clearly shown the need for the role and awareness of pediatricians in the diagnosis and treatment of autism spectrum disorders in recent years. In our study, the majority of the participants stated that they did not have the sufficient knowledge, experience, and qualifications to diagnose autism (74.1%), did not know the diagnostic criteria for autism as described in DSM-IV (69.6%), and were not provided with any training on autism related issues (91.1%). In our country, the rate of follow-up for healthy children has increased in recent years and thus, the roles of the physicians in early diagnosis and informing the families of autistic children on the effects of this disease on life event have also increased.

Physicians should be well aware of the autism suspected conditions and evaluate these conditions with standard scales. In our study, it was noted that they were able to notice

the early signs of autism, but did not evaluate them with standard measurement tools and did not adequately use the developmental screening tests. Of the participants, 84.8% suspected autism in infants that cried less than usual, made less noise than usual, mostly introverted, and did not bother the family, while 72% suspected autism in hyperactive infants with delayed speech despite no loss of hearing or in those who had trouble in understanding the commands.

For diagnosis of autism, a patient must have three conditions: poor communication and social development, repetitive behaviors, and limited interest. The onset of these disorders is before 30 months of age (14). As was deduced from the answers to the questions on general knowledge of autism, 90.7% of the participants knew the general definition of autism. However, 40.4 % did not agree that autism affected all the developmental areas and was an irreversible disease.

More than half of the participants have provided correct answers to the questions on whether the primary characteristic of autistic patients was increased fondness to mother or father or another primary caretaker (51.9%); whether the disease was associated with wrong attitudes of the parents (84.8%); whether the patients had an ability to mimic (55.9%); whether delayed speech was related to hearing loss (89.3%); whether they had the ability to start speaking and continue speaking(60.0%); whether they had sleeping disorders (68.1%); whether autistic behaviors could develop due to tuberous sclerosis (50.6%) and chronic lead exposure (66.7%). These rates indicate that the participants were aware of the characteristics described by general definition.

In 2015, Kim SK et al reported that ASD should be kept in mind when pediatric patients presented with developmental delays, particularly who have delay in expressive language referred to the pediatric clinics. They recommended that prompt diagnosis and

appropriate behavioral therapy for patients with ASD could improve their clinics and provide well prognosis. Thus pediatricians must be on the alert for the signs and symptoms of ASD and treat patients with ASD at an early stage.

Sundhinarase et al (17) showed that the parents of patients who suffered from ASD's symptoms could affect the diagnostic process and these interviews led the pediatricians to make the diagnosis of ASD according to parents concerns. An open communication between pediatricians and parents is able to provide a healthier relationship and prevent misunderstandings. Pediatricians must inform parents about the symptoms of autism, diagnostic process and then eligible therapy. By strengthening the relationship and communication between pediatricians and parents, earlier interventions can be initiated and ultimately lead to better outcomes for children with ASD.

Evaluation of Table III showed that both groups provided correct answers at low rates to the same questions. The questions, the correct answers of which were the least known, were whether autistic children lacked imaginary creative play due to lack of imagination (22.2%); whether autism was a disease that affected all the developmental areas and was irreversible (40.4%); whether the onset of autism signs was before three years of age (44.4%); whether the diagnosis of autism could be established correctly after three years of age (47.8%); and whether there was a risk of coexisting mental retardation (44.4%) and epilepsy (25.6%). The lack of information on the age of onset and the age of diagnosis suggests that as was stated by the participants in the answers to the general evaluation questions, they do not use their limited theoretical knowledge in practice and do not follow-up autistic children. To put their theoretical knowledge into practice, pediatricians should have rotations in child psychiatry clinics.

Dosreis et al (4) reported that lack of familiarity with screening tools (62 %), referred to a specialist (47%), lack of enough time (32%) were the main reasons for not screening for ADS. The results of this study were similar to ours. They recommended that the familiarity with screening tools, enough time for interviewing and resources, appropriate education about ASD can cause pediatricians to be acquainted with diagnosis of the disease.

Of children with autism diagnosis, 70% have mental problems. While 10-15% have normal or above normal intelligence and 25-35% have mild or borderline mental disability, 50% have severe mental disability. The question on this issue was correctly answered by 44.4% of the participants.

The answers to the questions on ASD provided by the participants in our study revealed that the participants generally did not know the subgroups, and the majority did not know Rett syndrome and disintegrative disorder in childhood. (Table III). It is thought-provoking that pediatricians who follow-up healthy children and act as a first step consultant to parents do not know these disorders progressing with developmental retardation, terminated growth of the head circumference, and severe retardation in linguistic and communication skills of otherwise normal 2-3-year old children.

The generally accepted treatment of autism is special education and cognitive behavioral treatment methods that aim at overcoming the fundamental developmental disorders of the autistic child. There is no definitive drug therapy. A very low rate of participants answered correctly to the questions on this issue (33.7%). Special education that starts at an early age increases the quality of life. Lack of information of the participants on this issue might be because of lack of sufficient education. As in many countries of the world, physicians contribute to delayed diagnosis and are not able to provide sufficient information to families.

The most important question for families with autistic children is what is in store for them and how their children will be in the future. It is highly difficult to consider the state of the autistic child in an early age and then determine the point that the child might arrive in the future. Families primarily want to know whether their children will be able to speak, go to school, and what kind of difficulties they will encounter in school. A low rate of participants answered correctly to the question on the effects of autism on life events. It is clear that they were not qualified to provide objective information for the families on the life events such as chances of their children to attend normal education schools and marriage.

Conclusion:

Autism and subgroups of pervasive developmental disorders put a huge burden on the society with their social and economic costs and significant effects on the life quality of the families. To increase the life quality of autistic patients and diagnose early, increasing the number of associated occupational groups and supporting their efforts and increasing the awareness, skills, and qualifications of pediatricians on this disease have gained importance. In addition, pediatricians should listen carefully to parents when discussing their child's development.

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Table I: The ideas of the participants on the level of education and information they have received on the subject

n=270	YES		NO	
	n	%	n	%
I have relatives followed-up with a diagnosis of autism	15	5.6	255	94.4
I examined an autistic patient throughout healthy child training.	65	24.1	205	75.9
I examined an autistic patient throughout child neurology training.	110	40.7	160	59.3
I know the diagnostic criteria for autism listed in DSM-IV	82	30.4	188	69.6
I believe I possess the knowledge and skills to diagnose autism.	24	8.9	246	91.1
Reading periodicals, books, articles on autism	95	35.2	175	64.8
I believe during pediatrics education, there should be rotations in the Child and Adolescent Psychiatry Departments	260	96.3	10	3.7

Table II: Suspected autism cases

Children should be screened for autism	<i>Number of correct answer (%)</i>			
	Total correct	University H	State H	P
Children with disordered eating, frequent vomiting, and gastrointestinal problems in infancy	159(58.9)	86(61.0)	73(56.6)	p>0.05
Children with problems in communication with peers within the first three years of age, and lack of skills to set up games or participate in an ongoing game and learn its rules.	219(81.1)	118(83.7)	101(78.3)	p>0.05
Cases with concomitant motor coordination disorders and hyperactivity	212(78.5)	119(84.4)	93(72.1)	p<0.05
Babies producing little voice and not crying when left alone	229(84.8)	120(85.1)	109(84.5)	p>0.05
A child with hyperactivity, delayed speech, and difficulty receiving directions at the age of three	209(77.4)	114(80.9)	95(73.6)	p>0.05

Table III: Answers of the residents to the questions on their knowledge of autism and autism spectrum disorders

AUTISM IS/ CHILDREN WITH AUTISM	Number of correct answer (%)			
	Total correct	University H	State H	<i>P</i>
Is a spectrum disorder in which disordered social interaction is marked.	245(90.7)	130(92.2)	115(89.1)	p>0.05
One of the primary symptoms of hyperactivity	195(72.2)	102(72.3)	93(72.1)	p>0.05
No connection with the mother, father, or a primary caretaker is observed.	140(51.9)	75(53.2)	65(50.4)	p>0.05
It is a psychological disorder stemming from wrong attitudes of the parents	229(84.8)	117(83.0)	112(86.6)	p>0.05
The diagnosis is made after 36 months of age	129(47.8)	62(44.0)	67(51.9)	p>0.05
70% have mental retardation	120(44.4)	81(57.4)	39(30.2)	p<0.05
They have no ability to imitate	151(55.9)	80(56.7)	71(55)	p>0.05
The symptoms start after 3 years of age	120(44.4)	68(48.2)	52(40.3)	p>0.05
80% are geniuses	109(40.4)	62(43.9)	47(36.4)	p>0.05
70% are deaf, so they cannot speak	241(89.3)	125(88.7)	116(89.9)	p>0.05
They can play imaginary games	60(22.2)	40(28.4)	20(15.5)	p<0.05
Their fine and rough motor development is retarded	133(49.2)	70(49.6)	63(48.8)	p>0.05
It affects all the areas of development and is an irreversible disease	109(40.4)	61(43.3)	48(37.2)	p>0.05
Chronic lead exposure is the reason for the onset of the autistic symptoms	180(66.7)	102(72.3)	78(60.5)	p<0.05
They cannot initiate and continue a conversation	162(60.0)	80(56.7)	82(63.6)	p>0.05
Children with tuberousclerosis suffer from autism	134(50.6)	76(53.9)	58(47.0)	p>0.05
Children with hyperactivity attention deficit disorder have autistic characteristics, but these are not at a diagnostic level.	166(61.5)	87(61.7)	79(61.2)	p>0.05
20-30% have the risk of epilepsy development	69(25.6)	45(31.9)	24(18.6)	p<0.05
They have disordered sleep patterns	184(68.1)	104(73.8)	80(62.0)	p<0.05
AUTISM SPECTRUM DISORDERS				
Responsive connection disorder is a subgroup	81(30.0)	41(29.1)	40(31.0)	p>0.05
Specific phobias are important clues in differential diagnosis of Asperger disorder	155(57.4)	96(68.1)	59(45.7)	p<0.05
Those with a diagnosis of Asperger disorder are autistic individuals with high functionality	142(52.6)	81(57.4)	61(47.3)	p>0.05
Childhood degenerative disorder is the most common	112(41.5)	67(47.5)	45(34.9)	p<0.05
Childhood degenerative disorder is seen in individuals with risk factors such as a febrile disease, and migration	90(33.3)	46(32.6)	44(34.1)	p>0.05
In those with Asperger disorder, verbal communication disorder is noteworthy	155(57.4)	92(65.2)	63(48.8)	p<0.05
Major depression often accompanies Asperger disorder	159(58.9)	96(68.1)	63(48.8)	p<0.05
In Rett disorder and childhood degenerative disorder, the development in the first 3 years of life is normal.	74(27.4)	42(32.6)	32(22.7)	p<0.05

Table IV: Answers of the residents to questions about treatment and management and life events on autism and autism spectrum disorders

	The number of total correct answer (%)	University H Number of correct answer (%)	State H Number of correct answer (%)	p
TREATMENT AND MANAGEMENT				
There is no treatment	91(33.7)	52(36.9)	39(30.2)	p>0.05
There is no drug therapy. To control hyperactivity, low doses of antidepressants and antipsychotics can be tried.	215(79.6)	119(84.4)	96(74.4)	p<0.05
Hyperbaric oxygen treatment is an effective method in the treatment of autism	199(73.7)	109(77.3)	90(69.8)	p>0.05
It is important to provide a regular special education	212(78.5)	119(84.4)	93(72.1)	p>0.05
EFFECTS ON THE LIFE EVENTS				
Those with general developmental disorder diagnosis cannot get married	127(47.0)	65(46.1)	62(48.1)	p>0.05
1-2% can lead independent lives	148(54.8)	80(56.7)	68(52.7)	p>0.05
They cannot attend normal education	170(63.0)	94(66.7)	76(58.9)	p>0.05
There are specialty primary schools for autistic children	102(37.8)	62(44.0)	40(31.0)	p<0.05

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