

# The Negative Consequences of Closed Access to Scientific Data and Other Barriers to Information Access – An Analysis of the Health Decisions of Parents Having Children with Autism Spectrum Disorder (ASD)

Ewa Dobrogowska-Schlebusch

Zakład Informacji Naukowej, Instytut Zdrowia Publicznego, Wydział Nauk o Zdrowiu, Uniwersytet Jagielloński Collegium Medicum, Kraków

*Address for correspondence:* Ewa Dobrogowska-Schlebusch, Instytut Zdrowia Publicznego, Grzegorzewska 20, 31-531 Kraków, ewa.dobrogowska-schlebusch@uj.edu.pl

## ■ Abstract

A diagnosis of autism can present a great challenge to the family with autistic children, especially to parents. Health information-seeking behaviour is described as one of many problem-solving and stress-coping strategies in literature. The information was found to have many important functions, e.g. it can contribute to the process of acceptance, it enables parents to access health care services, then to manage their child's difficult behaviour and it might help parents to respond more effectively to the range of life-changing events that may induce stress.

There are many barriers to meeting the information needs of parents having autistic children. Two different types of barriers to information access can be identified: "objective barriers" (problems communicating with health care professionals, healthcare professionals lack of skills and knowledge of managing children with autism, economic barriers to the access of information, information overload and a low level of health literacy) and "subjective barriers" (experience of social isolation and the parents' emotional state during diagnosis, which have the potential to make the families prone to misinformation). The main aim of this paper is to describe the negative consequences of barriers to the access of scientific research and evidence-based healthcare information (e.g.: spreading *anti-vaccine messages*). The problem will be discussed using the example of the information-seeking and health-related behaviour of parents with autistic children.

**Key words:** Autism Spectrum Disorder, access to information, information dissemination, information seeking behavior

**Słowa kluczowe:** spektrum autystyczne, dostęp do informacji, upowszechnienie informacji, zachowania informacyjne



Ministerstwo Nauki  
i Szkolnictwa Wyższego

Przygotowanie i edycja anglojęzycznych wersji publikacji finansowane w ramach umowy 914/P-DUN/2016 ze środków Ministra Nauki i Szkolnictwa Wyższego przeznaczonych na działalność upowszechniającą naukę.

## ■ Introduction

According to the International Statistical Classification of Diseases and Related Health Problems, autism belongs to the group of pervasive developmental disorders (F.84). The most characteristic irregularities of this disorder appear predominantly in three areas: communication, social interactions and behaviour (a stereotype area of interest and activity). Data from the Centers for Disease

Control and Prevention (2014) [1] indicate that nearly 1% of the world's population may suffer from autism; it is diagnosed in 1 out of 68 children in the United States. In Poland, the exact number of people suffering from autism is not known because there is no system for monitoring this disorder, especially in the adult population. It has been estimated that there are 347 thousand people with a range of autism spectrum disorders and 64 thousand people with child autism [2]. Autism is a developmental

disorder of indeterminate aetiology, displaying a number of symptoms which may impede an early diagnosis. Although it is one of the most frequently recognised developmental disorders, an effective method of treating autism is still unknown and there is a lack of consensus in the scientific world of how to support families who are raising children with the symptoms of autism [3].

Receiving a diagnosis of their child's autism is a very stressful experience for parents, primarily because the specialists who provide it are not able to give clear information about the causes of their child's disability, nor about the course of its development and the treatment methods that should be adopted. The parental stress may be intensified by a long waiting time for the diagnosis, by the manner in which it is communicated by a specialist (frequently with little empathy but emphasising the negative aspects of the child's functioning) and by the lack of any guidelines for proceeding with further treatment or support for the child's development. It is the parents who have to take responsibility for finding the necessary information [3, 4].

It is worth indicating that the relevant literature considers searching for information to be one of active, problem-oriented stress coping strategies (Transactional Model of Stress and Coping by Lazarus & Folkman as quoted by Pain [5]). Accessing information about the child's disease may fulfil many important functions, firstly it can facilitate parents' ability to accept a new situation, to obtain health care and nursing appropriate for the health needs of their child, or it can ease the problems of dealing with child's difficult behaviours [5] and other everyday stressful situations [6].

However, the parents of children with autism encounter many barriers to information access, both objective (problems in communicating with professionals, the general practitioners' lack of knowledge of ASD, limitations and costs associated with the access to credible sources of information, information overload, a low level of health competence, existence of the closed model of scientific communication) and subjective (the feeling of isolation and high level of stress, which impedes finding, correctly interpreting and applying the health information).

The aim of the paper is to discuss, on the basis of an analysis of the literature concerning information needs, the satisfaction of the diagnosis, the health decisions undertaken by the parents of children with autism and the negative consequences of the various barriers to information access.

The following issues are analysed in this paper:

1. What barriers to information access are encountered by parents of children with autism at different stages of the diagnostic process of their child and after receiving the diagnosis?
2. To what extent are the decisions of parents of children with autism, regarding the choice of an adequate method of treatment, their mitigating decisions and health awareness formed by the results of current scientific research? What factors may influence their health decisions?

## How to separate emotions from science – the barriers to information access encountered by the parents of children with autism

The literature indicates that there are at least four stages in the process of diagnosing children with Autism Spectrum Disorders: the period before receiving the diagnosis, receiving the diagnosis, the period after receiving the diagnosis and the period of accepting and adapting to the new situation [7]. To date, the research on health information needs and information behaviour of parents of children with autism was conducted during the last two stages of the diagnostic process, so there is limited information available about the process of searching for information before receiving the diagnosis. The research indicates that before receiving the diagnosis, parents have no prior knowledge of autism and their notion about this developmental disorder is frequently formed by the mass media or films like "Rain Man" directed by Berry Levinson [6]. Therefore, it would appear that the moment of the diagnosis should be the key moment for the health care provider to inform the parents about autism and the available support services for the child's development. This information should be suitably balanced between indicating the negative aspects of the developmental disorder (potential upbringing difficulties) and pointing to the programmes of early intervention [7], which may be of key significance for the further development of a child.

However, it is a primary health care provider who becomes the first barrier to information access for the parents of children with autism. Research, conducted with the participation of parents or carers of children with ASD, related to: the general difficulties associated with caring for autistic children [8], satisfaction with the diagnosis [7, 9] communication with doctors during the diagnosis [4], or the information needs of the carers of children with autism [6], indicates that parents are not satisfied with their interaction with the doctor giving the diagnosis. They are especially dissatisfied with the range and quality of the information obtained and the lack of the doctor's knowledge about autism [4, 9]. Parents report that physicians limit their role to disclosing the diagnosis, at best they give parents an information leaflet about autism without explaining the nature of this developmental disorder, or where, and how they can use the services of educational and therapeutic support for their child. They do not provide any guidelines for coping with child with ASD. This forces parents to take over the responsibility for finding the relevant information [4, 6]. The results of the survey conducted with 146 carers of children with autism in 2007 by Rhodes et al. [10] indicate that only in 40% of cases the specialist disclosing the diagnosis of autism gave additional information about the disorder. Only 6% of doctors referred carers to an autism specialist, 18% of doctors gave no further information about autism, or the availability of support services. Moreover, parents are usually dissatisfied with the mode of disclosing the diagnosis by doctors, who tend to visualise the child's future negatively by using technical and explicit language [7, 11].

Doctors inability to convey the information regarding the methods of treating autism and the available support services may result from the nature of the disorder itself, rather than from the doctors' lack of knowledge. The Autism Spectrum Disorder (ASD) is one of the most complex developmental disorders with unknown aetiology. There is currently no known 'cure' for autism, therefore and there is no-one who can ascertain parents about the future of their child, or advise them on what kind of therapy should be chosen [12]. According to Mansell and Morris [7], during the diagnosis parents are not given any information about the causes of autism because the answer to that question simply doesn't exist. The diagnosis of autism poses a great challenge for a family doctor, because the Autism Spectrum Disorder (ASD) have a very wide range of symptoms, from mild developmental anomalies to very serious behavioural disorders. Delays in speech development and behavioural disorders are frequently evident with small children between one and three years of age and are not necessarily the symptoms of autism. Therefore, physicians are wary of giving a wrong diagnosis and inducing unnecessary stress on parents whose children may just be developing more slowly [9]. The reasons for a delay in diagnosis may also be the physician's concern about the strong emotional reaction of parents on receiving the diagnosis of autism, or the hope that child's symptoms of autism may soon disappear [10].

However, parents of children with autism expect doctors and other specialists treating autism (special pedagogues, speech therapists, teachers) to be credible sources of information about the nature of this developmental disorder and the available support services of educational and health care [8]. The survey conducted by Derguy et al. [13] with a group of 141 parents (including 57 parents of children with autism), which aimed at investigating the priority needs of parents having children with ASD, indicated that information needs are the most important requirement (highlighted by 89.5% of parents having children with ASD). These needs were more important than psychological (73.5%), material (71.0%) or educational needs (58.8%).

The information needs, most frequently listed by parents as essential following the diagnosis, include information about the aetiology of autism, the available therapies, the possibilities of early support for the child's development, the systems of social support, guidelines for further action, the methods of coping with the diagnosis, the possibilities of financial support, the problems of parenting an autistic child, the child's future ("what will happen when we are not here") and explaining the children's problems to others [4, 6, 8]. The results of the research by Brogan and Knussen [14] indicated that parents' satisfaction with the diagnosis was increased by aspects such as, the way the diagnosis was communicated, the quality of the information received (parents were more satisfied if the information given orally by a doctor was reinforced with written information), the possibility of asking a specialist additional questions and a doctor's serious consideration of parents' early suspi-

cion of their child's disability. The satisfaction with the diagnosis increased when it was presented in a more definite manner [14], it had a coherent structure and it was given relatively quickly by doctors having appropriate knowledge of autism and the appropriate interpersonal skills [4]. According to Abbot et al. the shock induced by hearing the diagnosis could make understanding of the information by parents very difficult, which is why they appreciated the doctors who devoted time to them, who understood their emotional state and enabled them to ask questions [15]. The research by Osborne and Reed [4], who conducted 15 focus groups with parents of children with autism at various ages, indicated that the perceptions of the parents of what they feel would be of benefit to them changed with the passage of time after the diagnosis. The parents of younger children thought that they should be given the maximum possible amount of information about autism during the diagnosis, especially how the disorder may develop in their child, even though, at that moment, they were not able to absorb and remember this information. The parents of older, school-aged children thought that the information about the available support services should be given to them gradually and they wanted more specific information, e.g. about the programmes of early intervention.

The problems in communicating with doctors and other specialists working with children with ASD do not occur only during the diagnosis. Parents are relatively satisfied with the contacts with school teachers [4], however, they frequently indicate the lack of collaboration between the systems of health care, education services and social care following the diagnosis; they also mention the reluctance of these service providers to exchange information [4, 6]. According to parents, this problem could be solved by establishing a liaison service to forward information ("liaison worker", "key worker", "passer-on of information"), who would also act as a point of contact for the parents to guide them through the system supporting people with autism, simultaneously coordinating the work of the individual services [4].

The period after the autism diagnosis is the time when parents search most intensively for information [7, 16, 17]. Searching for information is recognised as one of active, problem-oriented stress coping strategies (Transactional Model of Stress and Coping by Lazarus & Folkman as quoted by Pain [5]). Acquiring information about children's diseases or disabilities by their parents may satisfy many significant requirements. Primarily, it may facilitate adapting to a new life situation and accepting the child's disability, access to health and nursing care appropriate for the child's wellbeing. Moreover, it may provide a sense of control, enable planning for the future, facilitate coping with various difficult everyday situations, e.g. educational problems and the child's difficult behaviour [5]. It could also enable parents to take an active role in making health decisions [6, 16]. Parents may be motivated to search for information in order to control the activities of professionals, or to acquire skills to communicate about the child's developmental disorder with others, including with the child [18]. The search

for information results from parents' dissatisfaction with the health service and other professionals specialising in autism therapy [6]. Furthermore, it results from the difficulty of accepting the diagnosis and the information about the impossibility of curing autism. Parents search for information in the hope of finding an effective method of treating autism, which will prove that "science is wrong" [8]. Although parents search enthusiastically and intensively for information about the problems of their child and frequently become experts in autism, knowing more about the developmental disorder than specialists in autism, they soon realise that finding valuable and credible information is not easy [6, 17]. The research relating to information needs and the behaviour of parents of children with ASD, or to their health decisions, reveals the difficulties which parents encounter in locating adequate information and putting it into practice in a manner which is beneficial for their child's current developmental situation [6]. Additionally, it emphasises the problems of information overload and the searching process itself, which overwhelms parents. Moreover, the barrier deterring the correct perception and interpretation of the information is the parents' emotional state immediately after the diagnosis [16], which may be compared to condition of grieving [19], increased by a feeling of helplessness, permanent stress and exhaustion.

The research by Pain [5] indicated that parents have mixed feelings about the benefits of searching for and finding information. The knowledge provides them with feeling of control of their own life by facilitating access to various health and educational services, or coping with the problems of bringing up their children. However, gaining knowledge may increase the fear, especially, if the sources of information used are contradictory and produce a dark vision of their child's future [4, 6].

Research [7, 12, 16, 17] indicated that parents of children with autism use many sources of information, including personal sources (doctors, teachers working with autistic children, speech therapists, special pedagogues, psychologists, physiotherapists, other parents with autistic children), written sources (books, magazines, newsletters about autism) and electronic sources (Internet, email letters, social networks). However, after a diagnosis, the predominant sources of information used by parents tend to be informal. The on-line survey conveyed by Mackintosh et al. [12] revealed, for example, that parents obtained their knowledge of autism from seven different information sources, 88% from books about autism, 86% from on-line sources, but only 44% from scientific journals. Of the personal sources of information, specialists in early intervention, psychologists, therapists and speech therapists were most appreciated by parents (57% of parents cited them as a source of information), 49% consulted with teachers, 48% with doctors and 17% with family members. Similar results were reported in the research undertaken by Rhodes et al. [10]. The authors conducted an online survey in Virginia, USA, with 146 parents of children with autism. The parents indicated that the most frequently used sources of information after the diagnosis were the mass media (71–73% e.g. In-

ternet), conferences/workshops (42%) and other parents (42%). Only 15–20% of the interviewed parents admitted receiving their information about autism from specialists. An important form of self-education for parents having autistic children is participating in conferences, seminars and support groups [17] as they provide an opportunity to meet with other parents [6]. It has been indicated that the parents of other autistic children and self-support groups become one of the most significant sources of information and social support [6, 8, 12, 16]. This may result from the fact that other parents of children with autism are most experienced in using the various support services and know their limitations [5]. In the face of professionals lacking adequate knowledge, the parents start acting as experts in autism. Parents can compare their feelings with the experience of other parents and learn from their failures and successes. They can be relieved and psychologically comforted by observing others in a similar, or even worse, situation [20]. This effect is called "walking in the same shoes factor" by Mackintosh et al. [12]. Although support groups and foundations may supply parents with much valuable information, it is assumed that this information may be largely shaped and distorted by the private perspective of people involved in the self-support groups, which may mean that this information is somewhat unbalanced [16].

The Internet is also an important source of information about autism for parents [10, 12, 16, 17]. However, the sources of information chosen by the parents frequently become the sources of disinformation. In 2012 Stephenson et al. [21] conducted research on the quality of information about educational and therapeutic interventions, which were available on-line in the services of the National Society for Autism. This information was compared with the ranking list prepared after a systematic survey of literature of the most effective interventions and therapies used in the treatment of autism. The research revealed that the institutions which were responsible for spreading the latest credible information about particular therapies and the educational interventions used to treat autism were ineffective. They frequently directed parents to methods which are unsupported by scientific evidence, or to commercial providers of health services. Frequently, contradictory information about the effectiveness of particular methods to treat autism was given within one service. In 2005 Metz et al. [22] conducted a very interesting experiment relating to on-line information about autism. After writing the key words "autism" and "treatment" into Google, the authors found over 65 recommended therapies as being effective for treating autism. They included: technology "ADAM" ("Aphysical Dimensional Access Manager"), which advocates unlocking autism by means of a technique similar to telepathy (using the Internet for this), stem cells of a sheep, fish oil, thyme and others.

There is another problem related to using the Internet as a source of information about health, which is the parents' vulnerability to various on-line fraudsters. This refers to web sites which exploit parents' gullibility and their desire to find 'a medicine for autism' as soon as

possible, and which try to sell them various products, by using the language of a religious or scientific discourse and quoting the opinions of pseudo-experts [6, 16]. Parents' vulnerability to disinformation was reported in the research on the information needs of parents with autistic children by O'Reilly et al. [16]. The research indicated that just after receiving a diagnosis, parents have a great need for information relevant to their child's disability. However, their emotional state frequently prevents them from "separating emotion from science" making them vulnerable to various sources of disinformation about autism. In consequence, they may take many wrong decisions, e.g. spending money participating in conferences of doubtful scientific quality. According to O'Reilly et al., this vulnerability of parents to disinformation is not solely conditioned by their emotional state after the diagnosis, or by the stress caused by the everyday care of their children. It may be significantly influenced by other factors, e.g. their low health literacy (inability to find appropriate health information, its evaluation and its practical application).

The research indicated that parents of children with autism may find it difficult to distinguish between the methods of treating autism, which are based on scientific evidence, and those which are potentially harmful to health [8]. This is because they do not fully understand what the 'effectiveness' of a treatment method means [16]. When choosing therapeutic or educational interventions, which are appropriate for their child, parents may consider a number of factors (e.g. cultural aspects, availability of services) rather than whether the effectiveness of a given method of treatment has been proven by scientific research [23]. The reason why parents do not use scientific sources of information may be the lack of time for studying them, their health competences [16, 21] or limited availability of such sources of information [12] resulting from the closed model of scientific communication prevalent in many countries.

The barriers to information access encountered by parents of children with autism may also depend on their social and economic situation. An on-line survey conducted by Mackintosh et al. [12] with a group of 498 parents of children with autism from many countries (USA, Canada, Australia, New Zealand, Ireland, England) revealed that parents with a lower income used personal sources of information (parents of other children with autism) and written sources of information (medical journals), much less than parents from more affluent classes. They had less opportunity to participate in group meetings (conferences, workshops), which the authors suggest, is related to the cost involved in accessing these sources of information (e.g. paying a conference fee, accommodation, travel costs). According to the authors, single parents also were in a more difficult situation because they could not participate in meetings with other parents (even free meetings), being constrained by family limitations and the high cost of caring for children.

## **The vaccine which reputedly induced autism — the influence of the media in forming health awareness in the parents of autistic children**

There has not been enough research conducted which would address the link between the barriers to information access encountered by parents of children with autism and the decisions made by them about the choice of the most suitable treatment method for their child or the parents' preventive behaviour. However, reports about health or prevention choices, which are most frequently made by parents of children with autism, conclude that their decisions are little influenced by the results of current scientific research.

One of the most illogical scientifically examples, which could bring catastrophic results of health choices taken by parents of children with autism, is the decision to stop or delay vaccine for children with autism or their younger siblings. In 2002 Bazzano et al. [24] conducted a cross-sectional telephone survey with 197 parents or legal guardians of children with autism spectrum disorder, who used the services offered by Westside Regional Centre (WRC) in Los Angeles. More than half of those surveyed decided to change or discontinue their child's vaccine schedule after receiving the diagnosis of autism. Similar conclusions were presented in the research paper by Abu Kuwaik et al. [25]. These authors investigated the vaccination history of the younger siblings of autistic children who were treated in three health centres in Canada. The research group consisted of 261 parents: 98 of their children were the younger siblings of children with ASD, 98 were older siblings of autistic children, while 65 children did not have siblings with autism and constituted the control group. It was revealed that in the group of 'younger siblings', the use of vaccines was delayed for 48% of the children, and vaccines were not used at all for 12.2% of the children; in the group of 'older siblings', vaccines use was delayed in 16.3% and only one child was not vaccinated at all. However, in the control group all children were fully vaccinated, with vaccines being delayed for only 9.2%. Additionally, the on-line survey, conducted by Rebecca Rosenberg et al. [26], with almost 500 parents of children with autism, indicated that almost 20% of respondents delayed or resigned from vaccinating their younger children because they were convinced that the vaccine played a significant role in the appearance of autism in their older children.

The 'anti-vaccination' behaviour of parents having children with autism results from the fear of the combined vaccine against measles, mumps and rubella (MMR), which spread in UK after the publication of an article by Wakefield et al. [27]. In the article, which was published in the prestigious "The Lancet" medical journal, Wakefield et al. described cases of 12 children with the symptoms of bowel inflammation and developmental regression, whose parents had consulted a gastroenterology specialist in London. In two thirds of the cases the parents of these children were convinced that their children's developmental regression occurred soon after their

inoculation with the MMR vaccine. This was used by the authors to hypothesise that there may be a relationship between the use of the MMR vaccine and the increase in children developing autism. The article by Wakefield et al. proposed only a hypothesis arising from the research, however, it caused great interest in the British press. Many press articles were published about “the research that proved the relationship between the use of vaccines and autism”. The spread of the gossip about the MMR vaccine causing autism was intensified by the transmission of a CBS programme called “60 Minutes”, in which Wakefield stated, that if he had to vaccinate his children, he would not use the combined vaccine, but would use separate vaccines against measles, mumps and rubella. It has been estimated that the media publicity caused a reduction in the use of the preventative vaccination in Great Britain from 94% to 75%, with a simultaneous increase in children contracting mumps [28].

The scientific limitations of Wakefield et al.’s publication were soon discovered by other scientists (the small number of cases, the lack of a control group and relying on parents’ memories and convictions). Moreover, the whole series of reliable scientific research conducted in the following period did not identify any relationship between MMR vaccine and autism (information about them is included in the publication of Offit and Coffin [28]). The investigation conducted by a British journalist, Brian Deer, proved that Wakefield committed scientific fraud (including: falsifying patients’ history, treating children unethically, having a conflict of interests and cooperating with other vaccine producing pharmaceutical companies), which led to the trial of the scientist and later being struck off the medical register by the General Medical Council [29]. In 2010 the publication of Wakefield et al. was retracted by “The Lancet”. The official reason for withdrawing the publication was the lack of an agreement to conduct the research by a local bioethical commission and falsification of the research results [30]. Despite all the measures taken, the vaccination panic was impossible to control. This was confirmed by many studies undertaken with parents of children with autism who frequently claimed that the MMR vaccine was one of the causes of their children’s disability (as quoted by Hebert & Koulougliot [31]).

Further evidence for the influence of the media on the development of health awareness, not only with parents of autistic children, but also with doctors, is the use of secretin, the hormone released by the glands of the duodenum mucous membrane and small intestine, as a method of treating autism. Using secretin as a medicine for autism became popular after the publication of an article by Horvath et al. [32], which described three cases of autistic children having disorders in their digestive system. As a result of applying an injection of secretin for diagnostic purposes (endoscopy), the symptoms of gastric disorders were abated as were the symptoms of autism in the sphere of social-communication. After the mass media publicity about Horvath’s discovery, thousands of children with autism received injections of secretin, which led to major problems in purchasing the hormone.

From the scientific point of view, Horvath et al.’s article is of little value (the case study is at the bottom of the hierarchy of scientific proof). Moreover, the whole series of well-designed clinical research (presented in the articles by Levy and Hyman [33] and Metz et al. [22], Matson et al. [23]) and a systematic review of the research undertaken by Cochrane Collaboration [34] revealed that secretin is not effective in treating the autistic symptoms such as problems with social interaction, communication, or for the reduction of compulsive and routine behaviour. However, in practice doctors still prescribe secretin following a clear demand by the parents of children with autism [22].

### “When there is no cure, there are 1000 treatments”

‘When there is no cure, there are 1000 treatments’ (Daniel Cohen) – it is not surprising, that this quotation is placed at the beginning of an article by Goin-Kochel et al. [35] about the treatments which the parents choose for their children with ASD. Autism belongs to the group of developmental disorders for which, to date, no effective medicines have been found. For the various people suffering from this disorder, autism may have a different course and degree of intensity. However, cases of total “recovery from the disease” have very rarely been reported [31].

The research has shown that the most effective methods for supporting children with autism are: methods combining special pedagogy and educational support programmes, communication training (speech therapy), early intensive behavioural therapy and social skills training [23, 36]. There is no scientific evidence for the effectiveness of alternative medicine in the treatment of autism [22, 37, 38]. However, according to some studies, the parents of children with autism frequently choose non-conventional medicine as a treatment for their children [37–42]. It has been estimated that from 32% to 92% of parents of children with autism choose to use non-conventional methods of treatment [23]. The most important reasons for using alternative medicine are: the parents’ dissatisfaction with conventional methods of treatment, or their ineffectiveness; the lack of consensus about the most effective method of treatment; the lack of access to physiotherapy programme; a preference for non-invasive treatments [23, 37]; the fear of side-effects caused by traditional treatments and the parents’ personal health convictions [36], e.g. about the aetiology of the disease [43]. Choosing non-conventional treatments may also be related to the willingness of alternative medicine specialists to devote more time to parents comparing to the traditional medical specialists [36, 37]. Hanson et al. [41] indicate that the use of alternative medicine may be related to parents’ preference for treating their children with natural methods rather than “artificial” or “industrial” products for fear of the safety of pharmaceutical treatment, the low cost of non-conventional treatments (e.g. vitamins) and their availability without a prescription. Additionally, Hanson et al. indicate that the choice of these treatments may relate to the parents’ system of

values, because the research results reveal that people with a higher level of spirituality, or are more religious, tend to select non-conventional treatments.

The survey conducted by Miller et al. [44] with 400 parents of children with autism in the USA shows that these parents tend to use untested, pseudo-scientific methods to support their children's development regardless of their education level, wealth and the time of the diagnosis. When taking health decisions, parents rely on recommendations and word-of-mouth (e.g. information heard during workshops, or from other parents of children with autism) more frequently than the information from scientific sources. Although in the cited research, parents indicated that autism specialists (such as psychologists, speech therapists, physiotherapists, doctors, special pedagogues) are a valuable source of information, the research results revealed that those specialists frequently recommended parents to use scientifically unjustified treatments. Physiotherapists, speech therapists and occupational therapist especially recommended parents to use treatments not supported scientifically. Five treatments are most frequently recommended by these specialists, which include for e.g. Auditory Integration Training or the Tomatis method, although research indicates that these methods may be potentially harmful for children and sensory integration therapy, for which there is limited or mixed evidence of its effectiveness.

Another study, showing that the results of scientific research are not necessarily a decisive factor for the health choices of parents of children with ASD, was an on-line survey to investigate the treatments currently used by families of children with the autism spectrum disorder [40]. The survey, which was distributed by means of web sites devoted to autism and distribution lists in Canada and the USA, was answered by 970 parents of children with autism. 63% of those parents did not use the Applied Behaviour Analysis treatment (ABA), which according to the authors is the best supported scientifically method and 23% did not use any treatment for their children. However, among the methods most frequently chosen by parents were scientifically unsupported treatment methods, such as pharmaceuticals, alternative diets and psychological treatment. According to the authors, the parents' health care decisions are influenced by many factors, such as their conviction about the aetiology of the disease, their parenting style, their lifestyle, the mass media and information from other parents. The choice of treatment may also be influenced by the availability of health care and the educational services (parents frequently have a limited choice of treatments, so they choose those which are currently available), their social-economic status or how they perceive the effectiveness of a given treatment. Parents' opinions on the effectiveness of a given method are formed by their perception of the child's progress after the application of a given intervention, not by the scientific results presented in literature.

An interesting insight into the factors motivating parents of children with autism to choose pseudo-scientific or esoteric treatments, called by the authors "fad treatments", is given in an article by Metz et al. [22]. The first

group of reasons for choosing fad treatments may be the lack of access to programmes providing early support for child development, the need to find prompt help for the child, the desire to be free from the feeling of guilt for not taking appropriate action. These may force parents to choose treatments which look reliable (although they may not necessarily be so) and give them hope. The second group includes the parents' lack of knowledge about autism, understanding the concept of evidence based medicine, the lack of appropriate scientific competence, or the ability to evaluate the quality of the various sources of information. The parents of children with autism tend to learn as much as possible about the disability of their children and the availability of possible therapies. However, it is not known if the parents' process of acquiring knowledge is systematic and whether they have the ability to understand it. The parents of children with autism frequently rely on secondary sources of information, which tend to have a summary character, but they do not provide parents with the insight to the process of reaching scientific conclusions. Finally, parental choices of fad treatments may be ascribed to the health care system. Doctors have little knowledge of autism and may frequently communicate contradictory information about the developmental disorder, which may often result from their financial relationships with commercial institutions.

Metz's hypothesis that medical doctors could be the potential source of disinformation on the effectiveness of autism treatments is supported by research conducted by Rahbar et al. [45] on 348 general practitioners in Karachi, Pakistan. The aim of the cross-sectional survey was to investigate knowledge and attitude of GPs in Karachi regarding autism. The survey revealed that less than half of the physicians interviewed (44.6%) had heard of autism, 53.4% had learnt about autism from the media and less than 20% had encountered the problem during their clinical practice. Moreover, even those doctors who had heard about autism had false concepts about its aetiology and symptoms. They marked the wrong statements in the survey e.g. the cause of autism is parents' emotional frigidity (theory from 1943), autism is a prediction of schizophrenia, the occurrence of autism may be prevented. The survey showed that doctors less than thirty years of age, who had graduated from medical studies within the previous five years, had a better knowledge of autism. In the group of doctors who had knowledge of autism, only 45.5% declared that their medical school was their source of information about this developmental disorder, 12.8% declared that their source of information was participation in symposia and seminars. Another survey conducted with 191 doctors in New South Wales in Australia [46] also revealed that family doctors may lack sufficient knowledge about autism. However, almost 60% of the surveyed doctors were correct in knowing that the programmes of early developmental support are based on scientific evidence. Nevertheless, 8% of doctors indicated that children with a suspicion of autism should not be vaccinated with the combined MMR vaccine. The analysis of doctors' comments displayed that their sources of knowledge about autism were primarily through

their interactions with the parents of children with autism and members of diagnostic teams, basic health care articles on autism, participation in special courses, and even web sites about autism prepared by schools, or for programmes offering early support interventions for children with ASD.

Reaching for untested and scientifically unsupported methods of treating autism by family doctors and other autism treatment professionals may be caused by various factors. These may include: a low level of social awareness of autism; gaps in the system of medical education [45, 47]; the low level of research infrastructure in many centres; the lack of knowledge of current research on autism, or effective interventions in the treatment of the disability [21]; reliance on clinical practice experience and interactions with patients, rather than medical literature, when taking decisions about treatments for patients. Another factor accounting for physicians' lack of knowledge about autism may be the closed system of scientific communication existing in many countries, however, this relationship has not yet been studied. As stated by Emanuel Kulczycki [48], in the closed model of scientific communication, access to knowledge and scientific materials is possible only by paid subscriptions. This model doubly enforces the limitations. To get access to a given journal, academic institutions (libraries) must pay for access to the publisher's database. The chosen licence enforces additional limitations, e.g. allowing access to the data base only from licensed computers on the premises of the institution which purchased the subscription. In this manner, only students and researchers employed by the institution have access to the scientific material [48]. When free access to scientific knowledge is the privilege of the very few clinical doctors who work in large academic centres, it is not surprising that the primary health care physicians working in hospitals and clinics, far away from universities or centres specialising in autism treatment, may have problems recognising the symptoms of autism, making the appropriate diagnosis and supporting parents in selecting a suitable method of treatment. As stated earlier, the lack of appropriate knowledge of autism, especially among primary health care physicians, may have many negative consequences. Primarily, it may impede the early diagnosis of autism and the introduction of early educational interventions, which are key matters in treating a developmental disorder such as autism. As a result, parents searching for various possible treatments frequently choose non-conventional treatment methods, not scientifically supported, which may have negative effects on the health and development of the child.

## Conclusions

The decisions taken by parents of children with autism about the methods of treatment, which are most suitable for their children, may be influenced by various factors. However, the significance of the access to adequate, current and reliable information about autism in health decisions must be remembered. The parents of children with autism face many barriers in accessing information

at every stage of the diagnosing process and following the diagnosis. These barriers range from the professional incompetence of the primary health care providers, limitations resulting from the degree of the parents' health literacy (including health information literacy), their emotional state and stress, especially after receiving their child's diagnosis, to accessing various, frequently contradictory, sources of information about autism (Internet, mass media, word of mouth, the opinions of other parents of children with autism). Another set of barriers to information are limitations of a social and economic nature such as low income, single parenthood or geographical constraints by living far away from specialist centres of scientific knowledge.

It is very important that, during and after the process of diagnosis, doctors and other professionals specialising in autism provide parents with current, scientifically supported information about the suspected aetiology of autism, the available and effective treatments and indicate the other forms of support available for the children and their parents. The lack of access to reliable information, as discussed in the paper, may result in parents taking risky health decisions, such as resigning from further vaccinations for their children, choosing ineffective, expensive and harmful methods of treatment, or applying various treatments at the same time, which in some cases may lead to the regression of autism. Searching for information is one of the important strategies of coping with stress during the diagnostic process, and subsequently coping with the problems of raising a child with autism. However, during the process of information seeking, parents should be provided with appropriate support by the specialists. As proposed in the publication by: Osborne and Reed [4] this may be done by establishing a service of "a liaison worker" for information, which would facilitate the mutual exchange of information between the various centres specialising in autism treatment and provide information support for parents. This function could be partially undertaken by libraries and information centres, especially those located in the medical and educational centres. It is equally important to disseminate current scientific achievements adequately through the mass media; e.g. the research proving the lack of a relationship between the combined MMR vaccine and autism; in a form which is fully understandable by an average user of health care.

Equally important is the appropriate education of doctors and other specialists. They should be provided with evidence-based information related to autism treatment. This may be achieved by introducing appropriate changes into educational programmes (medical studies, pedagogy, speech therapy, physiotherapy studies and others). Doctors' knowledge may also be improved by expanding the concept of "Open Access", which is an open model of scientific communication enabling free access to the most current and credible research papers on the subject of autism.



## References

1. ASD. *Data and Statistics*, 2014, <http://www.cdc.gov/ncbddd/autism/data.html>; accessed: 24.03.2015.
2. *Autyzm – Sytuacja dorosłych. Raport 2013*, Fundacja SY-NAPSIS, Warszawa 2014.
3. Mulligan J., Steel L., Macculloch R., Nicholas D., *Evaluation of an information resource for parents of children with Autism Spectrum Disorder*, "Autism. Int. J. Res. Pract." 2010; 14 (2): 113–126.
4. Osborne L.A., Reed P., *Parents' perceptions of communication with professionals during the diagnosis of autism*, "Autism" 2008; 12 (3): 309–324.
5. Pain H., *Coping with a child with disabilities from the parents' perspective: the function of information*, "Child Care Health Dev." 1999; 25 (4): 299–312.
6. Murphy T., Tierney K., *Parents of Children with Autistic Spectrum Disorders (ASD): A Survey of Information Needs*, [http://www.ncse.ie/uploads/1/parents\\_of\\_children\\_with\\_asd.pdf](http://www.ncse.ie/uploads/1/parents_of_children_with_asd.pdf); accessed: 24.03.2016.
7. Mansell W., Morris K., *A survey of parents' reactions to the diagnosis of an Autistic Spectrum Disorder by a local service: access to information and use of services*, "Autism Int. J. Res. Pract." 2004; 8 (4): 387–407.
8. Hall H.R., Graff J.C., *Parenting challenges in families of children with autism: a pilot study*, "Issues Compr. Pediatr. Nurs." 2010; 33 (4): 187–204.
9. Goin-Kochel R.P., *How many doctors does it take to make an Autism Spectrum Diagnosis?*, "Autism" 2006; 10 (5): 439–451.
10. Rhoades R.A., Scarpa A., Salley B., *The importance of physician knowledge of Autism Spectrum Disorder: results of a parent survey*, "BMC Pediatr." 2007; 7: 37.
11. Nissenbaum M.S., *The interpretative conference: sharing a diagnosis of autism with families*, "Focus Autism Dev. Disabil." 2002; 17: 30–43.
12. Mackintosh V.H., Myers B.J., Goin-Kochel R.P., *Sources of information and support used by parents of children with Autism Spectrum Disorders*, "J. Dev. Disabil." 2005; 12 (1): 41–51.
13. Derguy C., *Having a child with autism: What kind of needs and support expectations for parents?*, "Eur. Psychiatry" 2013; 28 (suppl. 1).
14. Brogan C.A., Knussen C., *The disclosure of a diagnosis of an Autistic Spectrum Disorder: determinants of satisfaction in a sample of Scottish parents*, "Autism" 2003; 7 (1): 31–46.
15. Abbott M., Bernard P., Forge J., *Communicating a diagnosis of Autism Spectrum Disorder – a qualitative study of parents' experiences*, "Clin. Child Psychol. Psychiatry" 2013; 18 (3): 370–382.
16. O'Reilly M., Karim K., Lester J.N., *Separating "emotion" from "the science": exploring the perceived value of information for parents and families of children with Autistic Spectrum Disorder*, "Clin. Child Psychol. Psychiatry" 2015; 20 (3): 500–514.
17. Stoner J.B., Bock S.J., Thompson J.R., Angell M.E., Heyl B.S., Crowley E.P., *Welcome to our world: parents' perceptions of interactions between parents of young children with ASD and education professionals*, "Focus Autism Dev. Disabil." 2005; 20 (1): 39–51.
18. Starke M., Moller A., *Parents' needs for knowledge concerning the medical diagnosis of their children*, "J. Child Health Care Prof. Work Child Hosp. Community" 2002; 6 (4): 245–257.
19. Benderix Y., Nordstrom B., Sivberg B., *Parents' experience of having a child with autism and learning disabilities living in a group home: a case study*, "Autism Int. J. Res. Pract." 2006; 10 (6): 629–641.
20. Ludlow A., Skelly C., Rohleder P., *Challenges faced by parents of children diagnosed with autism spectrum disorder*, "J. Health Psychol." 2012; 17 (5): 702–711.
21. Stephenson J., Carter M., Kemp C., *Quality of the information on educational and therapy interventions provided on the web sites of national autism associations*, "Res. Autism Spectr. Disord." 2012; 6 (1): 11–18.
22. Metz B., Mulick J.A., Butter E.M., *Autism: A late-20th-century fad magnet*, in: J.W. Jacobson, R.M. Foxx, J.A. Mulick (eds), *Controversial Therapies for Developmental Disabilities Fad, Fashion, and Science in Professional Practice*, Lawrence Erlbaum, Mahwah, NJ 2005: 237–263.
23. Matson J.L., Adams H.L., Williams L.W., Rieske R.D., *Why are there so many unsubstantiated treatments in autism?*, "Res. Autism Spectr. Disord." 2013; 7 (3): 466–474.
24. Bazzano A., Zeldin A., Schuster E., Barrett C., Lehrer D., *Vaccine-related beliefs and practices of parents of children with Autism Spectrum Disorders*, "Am. J. Intellect. Dev. Disabil." 2012; 117 (3): 233–242.
25. Abu Kuwaik G., Roberts W., Zwaigenbaum L., Bryson S., Smith I.M., Szatmari P. et al., *Immunization uptake in younger siblings of children with Autism Spectrum Disorder*, "Autism Int. J. Res. Pract." 2014; 18 (2): 148–155.
26. Rosenberg R.E., Law J.K., Anderson C., Samango-Sprouse C., Law P.A., *Survey of vaccine beliefs and practices among families affected by Autism Spectrum Disorders*, "Clin. Pediatr. (Phila.)" 2013; 52 (9): 871–874.
27. Wakefield A.J., Murch S.H., Anthony A., Linnell J., Casson D.M., Malik M. et al., *Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children*, "Lancet" 1998; 351 (9103): 637–641.
28. Offit P.A., Coffin S.E., *Communicating science to the public: MMR vaccine and autism*, "Vaccine" 2003; 22 (1): 1–6.
29. Godlee F., Smith J., Marcovitch H., *Artykuł Wakefielda wiążący szczepionkę MMR z autyzmem był oszustwem*. 2011, <http://pediatria.mp.pl/szczepieniaochronne/show.html?id=59132>; accessed: 24.03.2015.
30. The Editors of the Lancet, *Retraction – Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children*, "The Lancet" 2010; 375 (9713): 445.
31. Hebert E.B., Koulouglioti C., *Parental beliefs about cause and course of their child's autism and outcomes of their beliefs: a review of the literature*, "Issues Compr. Pediatr. Nurs." 2010; 33 (3): 149–163.
32. Horvath K., Stefanatos G., Sokolski K.N., Wachtel R., Nabors L., Tildon J.T., *Improved social and language skills after secretin administration in patients with Autistic Spectrum Disorders*, "J. Assoc. Acad. Minor Physicians Off. Publ. Assoc. Acad. Minor Physicians" 1998; 9 (1): 9–15.
33. Levy S.E., Hyman S.L., *Novel treatments for Autistic Spectrum Disorders*, "Ment. Retard Dev. Disabil. Res. Rev." 2005; 11 (2): 131–142.

34. Williams K., Wray J.A., Wheeler D.M., *Intravenous secretin for Autism Spectrum Disorders (ASD)*, "Cochrane Database Syst. Rev." 2012; 4 (Journal Article): CD003495.
35. Goin-Kochel R.P., Myers B.J., Mackintosh V.H., *Parental reports on the use of treatments and therapies for children with Autism Spectrum Disorders*, "Res. Autism Spectr. Disord." 2007; 1 (3): 195–209.
36. Levy S.E., Hyman S.L., *Complementary and alternative medicine treatments for children with Autism Spectrum Disorders*, "Child Adolesc. Psychiatr. Clin. N. Am." 2008; 17 (4): 803–20, ix.
37. Al Anbar N.N., Dardennes R.M., Prado-Netto A., Kaye K., Contejean Y., *Treatment choices in Autism Spectrum Disorder: the role of parental illness perceptions*, "Res. Dev. Disabil." 2010; 31 (3): 817–828.
38. Whitehouse A.J., *Complementary and alternative medicine for Autism Spectrum Disorders: rationale, safety and efficacy*, "J. Pediatr. Child Health" 2013; 49 (9): E438–442: quiz E442.
39. Green V.A., Pituch K.A., Itchon J., Choi A., O'Reilly M., Sigafos J., *Internet survey of treatments used by parents of children with autism*, "Res. Dev. Disabil." 2006; 27 (1): 70–84.
40. Bowker A., D'Angelo N.M., Hicks R., Wells K., *Treatments for autism: parental choices and perceptions of change*, "J. Autism Dev. Disord." 2011; 41 (10): 1373–1382.
41. Hanson E., Kalish L.A., Bunce E., Curtis C., McDaniel S., Ware J. et al., *Use of complementary and alternative medicine among children diagnosed with Autism Spectrum Disorder*, "J. Autism Dev. Disord." 2007; 37 (4): 628–636.
42. Wong H.H., Smith R.G., *Patterns of complementary and alternative medical therapy use in children diagnosed with Autism Spectrum Disorders*, "J. Autism Dev. Disord." 2006; 36 (7): 901–909.
43. Mandell D.S., Novak M., *The role of culture in families' treatment decisions for children with Autism Spectrum Disorders*, "Ment. Retard Dev. Disabil. Res. Rev." 2005; 11 (2): 110–115.
44. Miller V.A., Schreck K.A., Mulick J.A., Butter E., *Factors related to parents' choices of treatments for their children with Autism Spectrum Disorders*, "Res. Autism Spectr. Disord." 2012; 6 (1): 87–95.
45. Rahbar M.H., Ibrahim K., Assassi P., *Knowledge and attitude of general practitioners regarding autism in Karachi, Pakistan*, "J. Autism Dev. Disord." 2011; 41 (4): 465–474.
46. Garg P., Lillystone D., Dossetor D., Kefford C., Chong S., *An exploratory survey for understanding perceptions, knowledge and educational needs of general practitioners (GPs) regarding autistic disorders in New South Wales (NSW), Australia*, "J. Clin. Diagn. Res. JCDR" 2014; 8 (7): PC01–09.
47. Shah K., *Research in brief: what do medical students know about autism?*, "Autism Int. J. Res. Pract." 2001; 5 (2): 127–133.
48. Kulczycki E., *Otwarte czasopismo. Zakładanie czasopism naukowych oraz transformacja czasopism zamkniętych*, Stowarzyszenie EBIB, Toruń 2013.