

Autism Awareness: An Overview

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ABSTRACT

Over viewing different studies inquiring autism awareness in the community, parents, educators, and health professionals reveal deficits in awareness. Overcoming the discrepancies in awareness is crucial in early recognition and cure of autism.

Keywords: Autism awareness; Community; Parents; Educators; Health professionals

INTRODUCTION

Autism disorder was first described in 1943 by the American child psychologist, Leo Kanner [1]. He reported 11 children whose behaviors were obviously different from those of others [1]. Kanner suspected that they had an inborn feature which had prevented their regular social contacts [1]. Autism disorder is sometimes referred to as early infantile autism, childhood or Kenner's autism [1]. Autism Spectrum Disorder is a neurodevelopmental disorder that is related with deficits in social interaction, and communication with restricted and repetitive behaviors [2]. In DSM-IV autistic disorder was under the category of pervasive developmental disorders together with Rett's disorder, Asperger's disorder, childhood disintegrative disorder and PDD-NOS [3]. In DSM-V all prior categories mentioned above were subsumed under the diagnosis of autism spectrum disorder [3].

Autism is a life-long neurodevelopmental condition interfering with the person's ability to communicate and relate to others [4]. It appears to be one of the fastest growing disabilities in children [5]. Frequency rates have been rising sharply and prevalences are estimated to be 1:88, and 1 in 50 amongst children [6]. Because of increasing prevalence, autism is broadly considered to be an emerging public health problem [7]. Signs begin to appear in early childhood [5,7-9].

There is great interest in lowering the age of recognition of autism [10]. Early identification is important because interventions to improve functioning may be more beneficial in younger children and optimize long term prognosis [5].

Adequate knowledge and awareness about childhood autism among healthcare workers can facilitate early diagnosis and this in turn allows early interventions [11].

Timely determination of autism might also depend on educators' knowledge and awareness about autism and their attitudes towards treatments [12-17].

Not all children with autism are mentally incapable; some of them can be smarter than normal children [18]. However, children with autism might end to have behavioral problems [18]. Some of the characteristics among these children can present severe problems for parents sometimes even isolating them from social life [18]. Studies on public awareness towards children with autism are essential in decreasing stigmatization of the children and their parents and create a sense of responsibility among citizens on autistic children and families [18].

To this end, the aim of this review is to overlook the current studies and discuss autism awareness in the community, parents, health professionals and educators.

MATERIALS AND METHODS

This review gives examples from different studies on autism awareness, discusses the positive and negative aspects, and also gives recommendations for awareness of autism.

RESULTS

Autism Awareness Concerning Community

When we examine the studies inquiring having heard the word 'autism' in communities' different percentages can be observed. In a study conducted on adults applying to a Family Health Center in Istanbul, Turkey, only 38.8% of the study participants were found to have heard the word 'autism' [19]; where as in a study performed in France, this percentage was reported as 100 percent [20]. In Wilson's study, around 69% of the parents had heard the word 'autism' [21]. It is reported by Sürmen that even having heard the word 'autism' has been statistically significantly effective in breaking prejudices against autism from many perspectives [19].

A study carried out in Northern Ireland in general public, found high levels of autism awareness, and more than half of the respondents reported to know someone with autism in their own family, friends or work colleagues [22].

Factors associated with lower autism awareness included being male [11,18,22-25] not completing higher education [19,22] being a young adult (aged 18-24) and not using the internet [22].

In the studies conducted in Malaysia and in Turkey, most of the characteristics of autism could be addressed by around half of the respondents; except for “Failure to develop friendship” and “Impairment of nonverbal behaviors like eye-contact, facial impressions, gestures etc.[18, 23].

Findings of Turkey, Boston, Nigeria and Karachi studies indicate ‘repetitive and stereotypical behaviours’ to be among the well-known characteristics of autism [5,11,23,24,26].

Autism Awareness Concerning Parents

Several studies show that early diagnosis of childhood autism enables prompt initiation of appropriate therapy, early behavioral and social intervention aiding in their development and improving their communication and social skills [12-17]. Most of the time after behavioral and social training conducted at early ages, the symptoms might be easy to manipulate [13,15,16,27,28]. Early and intensive intellectual, behavioral and social intervention programmes in young children with autism are largely recommended in the cure of autism [17,29]. However, the length of time from parents’ first notice of symptoms to the time of diagnosis is relatively long, leading to delayed diagnosis and intervention [12,30]. One of the reasons for the parents’ consulting appropriate health authorities for timely diagnosis can be because of insufficient public awareness of autism or because of the embarrassment of possible stigmatization of children having autism in the community [18,31,32]. Furthermore, the parents of children having autism, frequently encounter hostile or insensitive reactions from the public when their children behave inappropriately [32,33]. The parents might be subjected to stigma due to the public’s misconception of their lack of control or discipline over their children having autism [32,33]. Stigmatizing public reactions can have an impact on the individual’s sense of full participation in social life [31]. Therefore, decreasing discrimination and stigmatization and creating a sense responsibility among citizens for children and their families and increasing public awareness towards children with autism can be very important in the early diagnosis and treatment of autism [18] since the most important treatments of autism can be accomplished in social settings. To this end, the diagnosis experiences of parents of children having autism, their feelings and social interactions before, during and after diagnosis, their perceptions of social stigma and their ways of coping are essential reasons for policies to establish complete autism awareness in parents.

Autism Awareness Concerning Educators

Outside of parents, educators are most likely to spend long time and close relations with children having autism in the early years of life [13,14]. Early recognition can depend on educators’ awareness about autism and their attitudes towards treatment [12-17]. The educator’s ability to pick out a child with autism in class is helpful on the long term [14]. The Illinois Wesleyan University

greatly emphasizes the role of educator training in not only identification but also management of Autism Spectrum Disorders [14]. Furthermore educators must be able to not only identify children with developmental problems but also refer them to appropriate health authorities [15]; from thereon they can take a role in family support services [12].

In several awareness studies the characteristics of childhood autism to be best known were found to be “social interaction difficulties and lack of social responsiveness” [5,6,15,16,28,34-36]. “Making friends” being a challenging issue for the children having autism is reported to a high extent by the participants in Dillenburger’s study [6]. In a review article reported by Gray, the early features of autism were reported as “lack of interest in other children”, lack of seeking to share own environment”, “failure to develop peer relations”, “failure to join in activities of others”, and “lack of social play” [35]. In the London study, it is reported that children with autism actually seek friendships with others, but they do not have the skills to maintain them [37]. In Durand’s study the elementary school teachers characterized autism as a social communication problem [20]. In Wang’s study conducted on caregivers of children having autism in China, poor ability to communicate was the best known characteristic of childhood autism [12]. A child with autism having difficulty in communicating and in social interactions was mentioned as the top ranking characteristic of autism by primary school teachers in Pakistan in Arif’s study [14]. Similar results appeared in Lian’s study conducted on pre-school teachers in Singapore [15] and on Liu’s study also carried out on pre-school teachers in China [13].

Children having autism are most of the time reported to have difficulty with not only verbal but also with nonverbal communication such as lack of eye-contact, lack of gesture, lack of facial expression, lack of social responsiveness, disliking social touch with almost no social smile [5,15,28,35,36,38,39]. In a Turkish study carried out in elementary school teachers, around half of the respondents mentioned that children with autism have difficulty maintaining eye-contact [26]; additionally Yasar’s study conducted on College of Education Students in Ankara and Trabzon in Turkey, similar findings were reported [27]. Poor eye-contact, gesture, and social responsiveness emerged in similar ratios in the cited articles [12-15].

As far as the strengths of a child having autism was concerned “Likes sports, music, arts, math etc” were mentioned by less than half of educators in Wang’s study conducted on caregivers of children having autism in China [12]. It is commented by Yasar that not only families but also teachers must be aware of these strengths for the social and intellectual development of children with autism and for them to be better accepted by the community [27].

In Yasar’s study conducted on College of Education students in Turkey, majority of the students indicated that they did not know any individual with autism and that they have never experienced teaching a child having autism [27].

In severe forms of autism, aggressive behaviors might be seen [40]. However those problematic behaviors occur not frequently and generally after behavioral and social training given at early ages, they might be often easy to handle [13,15,16,27,28].

In McConkey's study, the most difficult problems the educators found hard to manipulate was temper tantrums [16]. In countries where children widely start pre-school at early ages like in Sweden, Early Intensive Behavioral Intervention (**EIBI**) programmes in small children with autism are to a large extent delivered by regular pre-school staff [29]. These EIBI methods are also being recommended by other researchers [13,15,16,27,28].

It is emphasized that children with autism are also at risk of being ignored or harmed in class, for instance they are more likely to be bullied [22,41,42]. In Humprey's study the participants mentioned that the benefits mainstream pupils without autism would earn from a child with autism integrated into class was expanded understanding and tolerance of individuals different to themselves [41]. McConkey also indicated that not only children having autism would benefit from being included in class as a mainstream student but also their normally developing peers [16].

Majority of the educators pronounced that they felt uncertain in being able to meet the demands of children having autism in their class in Liu's, Humprey's and McConkey's studies [13,16,41]; whereas in Sweden, pre-school teachers felt more confident about their approach to the children having autism [29]. In Yasar's study conducted on College of Education students in Turkey, participants declared that they possess basic knowledge about autism, but that they needed more inclusive knowledge on autism [27].

Autism Awareness Concerning Health Professionals

Sufficient awareness about autism among health professionals facilitates early diagnosis [10,11]. Whether the health professional offers further information needed to families/caregivers about autism or not, greatly affect the overall prognosis of these children [11]. However, autism is often not diagnosed until age of 3-4 years and medical providers may lack training to present parents evidence-based treatment interventions [43]; this in turn results in parents' deviating to other sources of knowledge that may not be so correct [43]. In a Nigerian study, it is reported that health professionals believed that etiology of autism can be natural, supernatural and preternatural [44].

Children with autism can be recognized by a variety of health professionals [10,11,24,25,44-50]. Multidisciplinary health teams include child psychiatrists, child neurologists, primary care physicians, family practitioners, pediatricians, Otorhinolaryngologists, psychologists, nurses, pharmacists, audiometricians, nurses and other medical specialists [10,11,24,25,44-50].

Not only graduates but also undergraduate medical, nursing, pharmacy, psychology and nursing students being a candidate of such multidisciplinary teams are expected to be familiar with autism better than the community [23-25, 47].

In a study carried out on first grade medical and nursing students in Turkey, majority of the participants were found to be aware of autism [23]. Deficits in education and awareness of autism among medical students were reported in Karachi study [24]. In the Istanbul study, nursing students were found to be more aware on autism than medical students presenting a higher percentage [23]. In the Nigeria study, medical students were found to be equipped with relatively more knowledge about childhood autism than nursing students [51]. This was commented to be due to the longer exposure in Pediatrics of the medical students [51].

In a study carried out among pharmacy students by the University of Mississippi and among pharmacists by the University of Marmara, majority of the participants were found to be aware that individuals with autism have impairments in social and communication domains [48,49]. In the United Kingdom, autism was detected to be a topic that was the least frequently taught in the mental health curricula of Pharmacy Schools [50].

Given that impairments associated with autism appear before age of 36 months, primary care physicians, family practitioners and pediatricians can be the first healthcare providers who might come up with the child through routine wellness checks [11,45]. In several countries family practitioners and pediatricians are the initial line of contact between the parents and the health care system [52]. It is indicated that the family member usually expresses his//her initial concern about peculiarities in the development of his/her child initially to pediatricians and family practitioners [53-55].

However early identification of childhood autism is very often challenging in the context of primary care visits, because there is no pathognomonic sign or laboratory test to detect it [30]. Thus the physician must identify the child having autism on the presence or absence of a constellation of symptoms [30]. Early identification is also determined by listening carefully to parents' concerns about their child's development and behavior [30].

The primary care physicians, family practitioners and pediatricians possess key positions to also consult, provide support and guide the families to appropriate health authorities [5].

Since children with autism have impaired or delayed speech and might frequently appear as if having hearing problems [56] physicians working in the discipline of Otorhinolaryngology can also be considered as a first contact health discipline for autism [56].

In a study conducted in Lahore, Pakistan "social interaction difficulties and lack of social responsiveness" were mentioned to be the leading characteristics necessary for the diagnosis of childhood autism among physicians [34]. Additionally similar findings manifested in potential first contact health professionals in a study from New York [5].

In India pediatricians marked "lack of eye-contact" and "lack of social responsiveness" as the top two features necessary for diagnosis of childhood autism [57].

“Need for sameness and resistance to change in routines” and also “repetitive and stereotypical behaviors” were less known in the Lahore and India studies [34,57]; as compared to the New York study [5].

In a study carried out in U.S.A., health specialists and primary health care providers tend not to support that children with autism share social attachments or affectionate behaviors to individuals around them [46].

Difficulty maintaining social relationships, deficits in nonverbal communication and lack of eye-contact were indicated as important items for the diagnosis of autism by the first-contact health providers [5]. In the first-contact health professional study, the majority of the respondents were not aware that seizures occur more commonly among individuals with autism [5].

Symptoms of communication impairments emerged as a knowledge gap about childhood autism among the health care workers in Nigeria [11].

In the Kaduna State study in Nigeria, the pediatricians were found to be more knowledgeable on childhood autism than general practitioners [58].

In the studies carried out in Singapore and in Pakistan, general practitioners were found to be lacking in knowledge about autism [52,59].

Sabuncuoğlu presented lack of knowledge about childhood autism among Family Medicine residents in Turkey [60].

In Florida, primary health care workers indicated that they felt uncomfortable in determining children having autism [46]; besides some outdated beliefs and misconceptions regarding childhood autism are reported to exist among health workers in some studies [5,34,46].

In Goldik’s study, the pediatricians and primary care physicians presented a lack of self-perceived competency on childhood autism [61].

In some studies examining parental concerns, because of misdiagnosis and the physicians’ dismissing these concerns, parents indicate to lose trust in the physicians [62,63] In a study conducted in UK, several parents had been reported to be prematurely reassured by their health provider that there was nothing wrong about their child [55].

In the Latino study, parents explained the diagnostic process as being prolonged, unsuitable, confusing and distressing for the child [62]. These factors resulted in parents’ to normalize their child’s early behaviors, denying that a problem existed and losing trust in the medical system [62].

It is recommended by Harrington that the physicians should inquire about parents’ beliefs, learn what treatments the children are receiving, conduct screening at the 18 month visit and make referrals for further evaluation as soon as a child begins to exhibit signs suggestive of autism [63].

De Ocampo et al. also advises that a primary care physician should be knowledgeable about the medical conditions a child with autism might encounter such as seizures, sleep problems, chronic constipation and preventive dental care [54]; furthermore a close collaboration between the community, the family, the educator, the health specialist and the primary care physician should be established [54].

CONCLUSION

As social awareness increases people will transit from distinguishing autism from the mentally ill or dangerous, to special-needs individuals [18]. As public awareness increases negative views about autism is reduced [18]. Most of the time education can prevent prejudice against individuals with autism in the community [19]. One of the proper approaches may be to emphasize with autistic individuals, and their families, and contribute to their social development [19,64]. A study which integrates groups with and without autism in sportive, cultural, and art activities were observedly beneficial for both groups, and also contributed to alleviation of social, and communicative difficulties [19, 64]. Indeed treatment of individuals with autism will be possible by integrating them into the society [19,64].

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