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Original article

Specialty Care Programme for autism spectrum disorders in an urban population: A case-management model for health care delivery in an ASD population

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ABSTRACT

Subjects with autism spectrum disorders (ASD) have more medical needs and more difficulties accessing health care services than the general population. Their verbal and non-verbal communication difficulties and particular behaviors, along with lack of expertise on the part of physicians and failure of the services to make adjustments, make it difficult for them to obtain an appropriate health care.
Purpose: To describe a model for health care delivery in an ASD population.
Method: Review of relevant literature and a discussion process with stakeholders leading to the design of a service to meet the specialty health needs of subjects of all ages with ASD for a region with a population of 6,000,000.
Results: A service was designed centred around the concepts of case management, individualization, facilitation, accompaniment, continuous training and updating, and quality management. Five hundred and thirteen patients with ASD have been seen over a period of 18 months. The programme generated 1566 psychiatric visits and 1052 visits to other specialties (mainly Nutrition, Stomatology, Neurology, and Gastroenterology) in the same period.
Conclusion: Persons with ASD may benefit from adjustments of health care services in order to improve their access to adequate health care at the quality level of the rest of the population.

1. Introduction

Subjects with autism spectrum disorders (ASD) seem to have more medical needs and more difficulties in their relationships with healthcare providers than the general population [21,35,34]. Despite this, few reports on health care models specific to this particular population are available in the literature. The great difficulties families have in gaining access to medical resources and the great social and financial burden on both families and resources warrant programmes that endeavour to minimize the barriers between patients with ASD and the healthcare system that makes it difficult for them to obtain appropriate care.

Recent prevalence studies have indicated a great increase of ASD in the last 30 years [33]. Although the reasons for the rise are unclear and may include changes in diagnostic criteria, increased awareness of the condition among parents, medical professionals, and educators, variations in measurement, a true increase in the population, or a combination of these factors, the increased diagnoses of ASD have important implications for medical resources, in terms of cost, delivery, and organisation of care [29]. New data from the United States, collected by institutions participating in the Autism and Developmental Disabilities Monitoring Network, suggest that approximately 1 in 150 children in the communities studied have an ASD [33].

Many individuals with ASD are non-verbal or minimally verbal and cannot express pain or discomfort through speech. As a result, they may not communicate information about their symptoms as clearly as their typically developing peers. Even individuals with ASD who acquire verbal communication skills may have difficulty describing subjective experiences or symptoms [6]. In addition, sensory processing deficits may limit their ability to report pain or accurately identify the origin of their discomfort [3]. Furthermore, any physical disease is expected to affect the person who experiences it in several behavioural and cognitive ways. Pain and discomfort affect the level of alertness and attention and diminishes mental processing efficiency. This usually reduces cognitive and communication capacities, which in the population with ASD are already particularly limited. The threshold for disorganisation, confusion, frustration, aggressiveness, and perceptual distortions may lower. This, together with the restricted

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behavioural and communication repertoire of these persons make it likely that physical symptoms will translate into behavioural difficulties.

All the above-mentioned problems make the diagnosis and treatment of physical conditions in subjects with ASD difficult [10]. The differential diagnosis of behavioural changes in subjects with ASD always warrants a physical examination and sometimes a multidisciplinary consultation in order to rule out underlying medical conditions. However, most physicians are not trained to recognize medical problems in persons with ASD, who may manifest their physical symptoms in a different way than developmentally typical subjects. In fact, physicians have a self-perception of inadequate skills for dealing with persons with ASD [22].

2. Medical co-morbidities

Subjects with ASD may have associated physical problems (probably related to the aetiology of the autistic phenotype, such as metabolic or genetic conditions), but they also have more general medical problems [20], including functional ones as well as more intercurrent diseases than the general population. In fact, an increasing number of authors consider autism spectrum disorders a group of systemic disorders with cerebral impact, with a multifactorial aetiology and different pathological neurodevelopmental trajectories that may explain the extensive impact on the organism of the affected person [24,27]. Frequent medical co-morbidities include gastrointestinal symptoms or disorders, sleep problems, and epilepsy.

The reported prevalence of gastrointestinal symptoms in children with ASD has ranged from 9–70% or higher and the prevalence of gastrointestinal diseases [6] from 50–80% in the general population with ASD. The most common gastrointestinal symptoms and signs reported for persons with ASD are chronic constipation, abdominal pain with or without diarrhoea, and encopresis as a consequence of constipation. Other gastrointestinal abnormalities that have been described for individuals with ASD include among others gastroesophageal reflux disorder, abdominal bloating, and disaccharidase deficiencies, as well as pathologic findings such as inflammation of the gastrointestinal tract and abnormalities of the enteric nervous system [6]. Malabsorption and leaky gut syndrome have been hypothesized as causes for deficiencies of different nutrients. Non-severe chronic malabsorption may lead to caloric or protein malnutrition, which may go unnoticed in subjects who have difficulties expressing discomfort. In addition, children with ASD have a high potential to be obese, particularly in adolescence, where rates of 80 and 50% have been reported for risk of overweight and overweight, respectively, compared with 30.9% and 16.1%, respectively, in the general population [23,12].

Sleep problems are present in approximately 80% of children with ASD. They include atypical sleep architecture, longer sleep latency, more night-time awakenings, less sleep efficiency, longer phase I, shorter non-REM phase and slow waves, and others [31,44].

Epileptic problems are much more frequent and the age of onset has a different distribution compared with the general population. It has been stated that a third of subjects with ASD have developed epilepsy by the time they reach adolescence. Data vary and depend largely on the population studied. Epilepsy is more common in women, subjects with intellectual disability, and those with motor disturbances. Subclinical EEG abnormalities are also prevalent [16,45].

Food restrictions and fads are very common in subjects with ASD. They could be derived, in subjects with ASD, from food allergies or intolerances as well as from autistic features. Non-IgE-mediated allergic reactions to foods and food aversion all are issues to consider in ASD. In any case, they can lead to an imbalanced diet. Therefore, paediatricians and other primary care providers should be alert to potential nutritional problems in patients with ASD. Evaluation by a nutritionist who is familiar with nutrition support for individuals with ASD is recommended if caregivers raise concerns about the patient's diet or if the patient exhibits selectivity of intake or is on a self-restricted diet [6].

Other co-morbidities include ophthalmological, dermatological, and endocrinological problems. For example, astigmatism and binocular vision problems have been described as frequent in autistic children [14]; the incidence of atopic dermatitis and rhinitis is higher among adolescents with Asperger syndrome compared to healthy controls [36]; autistic children, and particularly lower-functioning children, have a greater incidence of ear infections than matched normal peers [30]. In addition, compared with controls, women with ASD have significantly more frequent testosterone-related disorders, such as hirsutism, irregular menstrual cycle, dysmenorrhea, polycystic ovary syndrome, and severe acne, and they are more likely to present associated behavioural issues than girls with other disabilities, such as Down's syndrome and cerebral palsy [26,7]. The high prevalence of medical issues is also evidenced by the elevated need for non-psychotropic medication found in a sample of 286 adolescents and adults with ASD: a total of 50% were taking non-psychotropic medication [18].

Care providers should be aware that problem behaviour in patients with ASD might be the primary or sole symptom of the underlying physical condition. Any pain or discomfort can present typically or atypically as nonphysical manifestations, including behavioural changes and/or problem behaviours. For example, Horvath and Perman (2002) reported disturbed sleep and night-time awakening in 52% of children with ASD who had gastrointestinal symptoms (vs. 7% of age-matched healthy siblings) and others [25] have reported unexplained irritability associated with reflux oesophagitis in children with ASD. Vocal and motor behaviours, self-injury and aggression, as well as overall changes in state of being (e.g. sleep disturbance or irritability) have also been reported as behavioural manifestations of abdominal pain or discomfort in persons with ASD [9]. Although the care of individuals who are non-verbal or have difficulties with communication or who display self-injurious or other problem behaviours presents special challenges, the approach to evaluation and diagnosis of possible underlying physical conditions should be no different from the standard of care for persons without ASD [6].

For a person with an ASD who presents for treatment of a problem behaviour, the care provider should consider the possibility of a medical comorbid condition accompanied by pain or discomfort, particularly if the behavioural change is unexplained or sudden. The behavioural treatment should not substitute for medical diagnosis and should be developed, implemented, and changed as needed in cooperation with the medical caregivers responsible for diagnosis [6]. The high resource use, including outpatient physician visits, number of medications prescribed, time spent with physicians, and the high associated costs (both for the health care system and the family), together with the patient well-being, makes it reasonable that coordinated care be implemented [34].

There are initiatives in different countries, but particularly in the United States (US), such as one led by the Autism Treatment Network, with the goal to develop protocols and assess the treatment of co-morbid physical conditions in ASD disorders [3]. However, the huge differences in health care delivery between the US and many European countries make it difficult to extrapolate the organisation of health care programmes from US experience to Europe. For instance, in a recent study that evaluates the access to specialty care in New Jersey, children with autism frequently had a private insurance plan, and they were more frequently visited by specialists after the initiative of parents or school personnel that after a primary care physician referral [41].

3. Access to care

Despite their increased physician and hospital needs compared with children in general, and their use of health resources more frequently than children in the general population [34], studies have identified difficulties for children with ASD in gaining access to needed resources, and dissatisfaction with care [29,32,37,47,50]. Health needs of subjects with ASD are generally considered to be unsatisfactorily met [28,19]. Even when compared with other children with special health care needs but without emotional, developmental, or behavioural problems, children with autism spectrum disorder are more likely to have unmet needs for important components of health care. They have more difficulties obtaining care, and specialty care in particular [29,32]. The Autism Europe position paper on care for persons with autism spectrum disorders (2010) posits that ''People with autism must also have access to the ordinary healthcare services and receive the care that is appropriate to their health needs, in accordance with the same standards afforded to other persons''.

ASD, therefore, represents a challenge to current health care systems, which need reforms or adjustments to provide quality care for this population. In this paper, we provide a description of the programme set up for Comprehensive Medical Care for Autism Spectrum Disorders (AMITEA) at a General University Hospital in Madrid, Spain in April 2009 to attend to the specialty medical needs of individuals with autism spectrum disorders. We then describe the key aspects of the programme and report on the activity conducted over the first 18 months of operation. We end by discussing the activity developed and the key elements that the attending physicians value for the experienced gained along the way in the first steps of this pilot programme.

4. Materials and methods

To develop the AMITEA programme, we first reviewed the relevant literature, including national and international reports and guidelines on the health of subjects with ASD, the need for adjusting programmes that provide health care for this population, and existing health resources for them [28,54,8,11,15,38,43,46,2,48]. After the review, face-to-face meetings were held and an ongoing discussion process was undertaken with the representatives of family associations (among others, with the Director for Medical Affairs for the Autonomous Community of Madrid Autism Federation), with the heads of target specialties (Neurologist, Neuropaediatrician, Ophthalmologist, Otolaryngologist, Stomatologist and Nutritionist), service providers (Health Minister and Health Counselors of the Autonomous Community of Madrid) and hospital managers (Medical Directors of Hospital General Universitario Gregorio Marañón) in order to design the most appropriate programme in our context. We also contacted the two programmes that were then providing partial health services adapted to the autistic population in Spain (the Special Patients Programme at the Hospital de Alicante for emergency care of patients with ASD, and the Stomatology Programme for the Disabled at Hospital Gregorio Marañón, Madrid).

5. Context

Although ASD have been present with different names for more than thirty years in the classifications of mental disorders, the general view in our context has been to consider them a disability ''rather than'' a disorder. Therefore, educational and social systems have been the main providers of services for these persons. However, it is increasingly recognized that these persons are patients (persons in need of health care) for more of the time in their lives than the general population. Furthermore, it is now clear that ASD represent a group of conditions characterised by deviant neurodevelopment with multiple possible biological causes. In addition and because of this, persons with ASD present different levels of disability, depending on multiples variables.

Spain has a health care system that is predominantly funded through general taxation and it is intended to provide universal access (available to all, irrespective of their ability to pay). It is considered an inalienable social value and, in order to achieve greater social equity and satisfaction, the system needs to attend to the particularities associated with specific population groups, such as persons with disabilities [13]. Governance of the health care system is fully decentralised to seventeen Autonomous Communities. One of them is the Community of Madrid, with around 6,000,000 inhabitants.

The first ASD family associations were established in Spain in 1977 and services for ASD have evolved greatly since, particularly to attend the educational and social needs of this population. However, health services have not traditionally paid special attention to these individuals and their needs for adjustments in the system. After the literature review and the multiple meetings with the stakeholders involved, we did not find any programme in our country targeting the range of special health needs of persons with ASD.

Given the low satisfaction of the families with the health care received by their relatives with ASD [4], ten years ago, the family associations, most of them organised under the ''Federación Autismo Madrid'', started to lobby the local government of the Community of Madrid to set up a centralised service to assist persons with ASD, throughout their lives, with all the specialty medical needs they might have. Working groups met and a report was published in 2001 that included the medical needs of patients with ASD [4].

After the consulting process that led to the design of this pilot programme, difficulties for patients with ASD in obtaining the proper health care could be summarized as follows: persons with ASD may not express pain, even if they have language skills; persons with ASD have difficulties identifying the origin of their discomfort; persons with ASD have difficulties going outside their usual environment; persons with ASD have difficulties with social interaction that interfere with a standard doctor-patient relationship, and persons with ASD may have problems to understand the final purpose/objective of a medical exploration/visit, the concept of health, being healthy, getting better, etc.

Difficulties of health services in providing adequate care for persons with ASD can be summarized as: low prevalence of ASD precludes professionals from having sufficient experience in managing patients with ASD; health services have to deal with cumbersome bureaucracy, and long waiting times and overstimulating settings are inherent parts of public health care systems and barriers for the ASD population.

The final consensus after all the working meetings was that, given the severity of the clinical picture, the high frequency of associated organic and mental health problems, and the difficulties this population has expressing their needs and understanding the outside world, subjects with ASD require preferential and specific health management.

Therefore, based on the family representatives' perception of unmet needs, the principles of universal, free, and equitable health care that characterises Spanish National Health System, the regional government of Madrid decided to take action and a programme was set up on April 2009 at a tertiary hospital in Madrid, Hospital General Universitario Gregorio Marañón. A series of meetings were then held to decide how best to organise the programme. The principles to be followed were to provide specialty care for all persons with ASD in a community of six million people, irrespective of age, with the National Health System as the provider through the Regional Health Department.

There is no direct data on the prevalence of ASD in the Community of Madrid. Possibly the best approximation comes from a study conducted in 2001 with an epidemiological methodology of indirect estimation. It found that, based on a population of 4,750,945 inhabitants, there would be 1795 persons with Kanner's autism under 29 years of age [4]. However, according to that study, only 562 subjects (under the age of 38) were registered in any known database (mainly family associations). The report also mentioned that 70% of the registered cases were under 20 years of age, 40% of the cases had a diagnosis of Kanner's autism; 77% had mental retardation; 40% had a known organic disease (37% viral infections, 23% central nervous system diseases, 20% epileptic seizures, 7% chromosomal abnormalities, and 28% other organic disorders). In addition, 41.5% had significant associated problems, such as visual problems (35%), nutritional problems (26%), auditory problems (18%), sleeping problems (11%), anxiety (11%), or phobias (11%). Almost half the patients (49.58%) had severe behavioural problems [4].

A pilot service was then designed to attend the health needs regarding medical specialties of subjects with ASD of all ages in the whole community of Madrid, facilitating their access to health care and position it at the level of the health care of the rest of the population.

During the period covered by this report, following a policy of continuous quality improvement, the professionals working in the programme (three part-time psychiatrists, one psychologist, and one nurse or case manager) have had fortnightly working meetings to establish a consensus on the patient management and specialty referrals in the target population.

6. Results

6.1. Comprehensive Medical Programme for Autism Spectrum Disorders (AMITEA).

The specific objectives set for the programme were: to make the differential diagnosis of medical and behavioural conditions, including the medical correlates of any condition potentially associated with a behavioural change; to follow all psychiatric conditions; to deal with problems of daily living: nutrition, sleep, habits, etc.; to centralise all possible medical and nursing procedures; to refer, coordinate, and follow-up on all medical specialty needs.

6.2. Organisation of the Programme

Any patient with an ASD can be referred to AMITEA by any physician in the public health care system via fax. The case manager and the clinical manager then evaluate each referral and set an appointment depending on the urgency of the case. The case manager also gathers all available past medical reports from the family, primary care physician and residential or day care centres the patient might be attending. A psychiatrist is the physician that first assesses the case, gathering the following information: developmental history; health habits (hygiene, sleep, nutrition); general medical history; psychiatric/behavioural history, and features related to the ASD that may influence the patient's relationship with the health care system. These include previous experiences with health visits, fears (such as "white coat" anxiety or fear of blood tests), sensory difficulties (such as low or high pain sensitivity, hyperaesthesia), significant people who may put the patient at ease at difficult moments, and common reactions in new, stressful, or uncertain situations. After the initial assessment is conducted, the patient is referred for general follow-up in the AMITEA Programme, psychiatric follow-up or different specialists to address particular needs. The process that leads to patient visits with other specialist and the resulting examinations and follow-up visits is all facilitated by the case manager who organises and coordinates all appointments and their sequence, rationalizing times and spaces to minimise the patient exposure to long waits, multiple visits, multiple days in the hospital, and difficult and avoidable situations. The case manager also informs the receiving service of the characteristics of the patient to be assisted and accompanies the patient and family whenever needed. Some of the specialties are in very high demand or particularly difficult for patients to attend. In these cases, protocols are designed to overcome the specific difficulties or characteristics related to the specialty. Examples of this are providing anaesthesia for minor procedures, the availability of instruments for assessing visual acuity in uncooperative patients, or the possibility of having educators or relatives present at any medical procedure. Coordination with Primary Care physicians is also undertaken when appropriate.

The case manager also gathers information on the previous experience of the subject and the family with medical services, and the stress and the satisfaction they have with the care received. This information is obtained again one year later in order to comply with a policy of continuous improvement and quality management in the Psychiatry Department to which the programme belongs [53].

The programme characteristics and key elements of AMITEA are shown in Table 1, and a diagramme of the programme is presented

Table 1
Key elements in the organization and management of the AMI-TEA program.

Key elements	Procedures
Facilitation	Easy access[a], Multi-appointment system[b], telephone appointments, anticipation. Avoidance of duplication of effort. Efficient use of time
Coordination	Information, referral, training
Escort/Accompaniment	To all medical procedures, by nurses and significant persons
Case management	Case manager, individual-based
Professionalization	Evidence-based or experts' consensus practice, information, continuous training of attending professionals. ASD-based and individual-based protocols
Training	Internal and external courses. Up-dating. Staff training
Information	Courses, leaflets, client-based
Priority	Positive discrimination
Continuity of care	All ages
Minimization of variables	Centralization of medical/nursing procedures, one specialist per specialty, minimal settings and persons involved.
Anticipation	Information, desensitization, anesthesia for minor procedures when needed
ASD appropriate	Facilitative communication systems. Friendly environment: predictive, structured, visual

[a] There are multiple paths to enter the program (referral by any doctor in the public sector).
[b] As many medical visits and/or medical procedures scheduled in the minimum possible number of days.

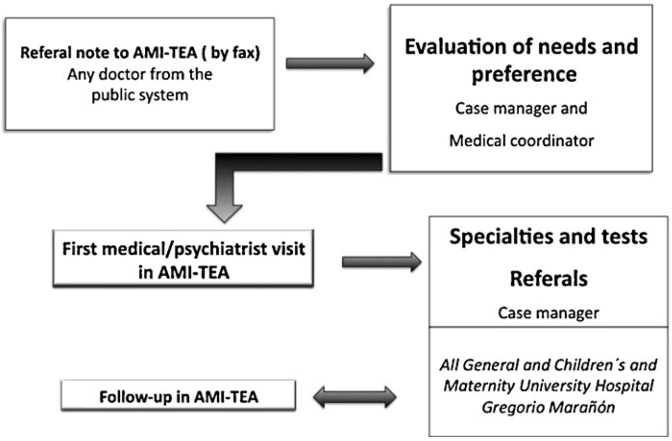

Fig. 1. Organization of AMI-TEA.

in Fig. 1. The characteristics of inadequate health care in subjects with ASD and mechanisms of the AMITEA programme to overcome them are shown in Table 2.

6.3. *Activity (April 2009-September 2010)*

AMITEA saw 513 different subjects in the reporting period (18 months). One-fifth were women (19.7%) and the rest were men. Psychiatric comorbidity in a sub-sample of 50 consecutive new patients consisted of 66% of patients with mental retardation and 52% with a comorbid psychiatric condition (26% with conduct disorders, 20% with attention-deficit hyperactivity disorder, 4% with an emotional disorder and 2% with obsessive-compulsive disorder). The oldest patient was 52 years old and 68% of patients were under 15 years of age. The programme generated 1,566 psychiatric visits, 1,052 visits to other specialties, and 354 medical tests. As regards to non-psychiatric medical visits, one-third (33%) were for children or adolescents (up to 15 years of age) and two - thirds for adults. Fig. 2 shows the distribution of specialties that subjects with ASD were referred to and Fig. 3 shows the medical tests that were performed.

The specialties in highest demand for children and adolescents were, in decreasing order, Neuropaediatrics, Nutrition, Stomatology, Ophthalmology, Traumatology, Dermatology, and Gastroenterology, while the specialties most required by adults were Nutrition, Stomatology, Neurology, and Gastroenterology. The number of referrals for each subject ranged from 1 to 21.

Table 2
Barriers for patients with ASD to receive appropriate medical care and mechanisms to overcome them from AMI-TEA program.

Barriers for subjects with ASD	Key elements in AMI-TEA
Communication	Accompaniment (family or educators/AMI-TEA nurse) Augmentative and Alternative Communication Systems Information/Training/Professionalization of attending doctors
Social interaction	Priority Information/Training/Professionalization of attending doctors
Sensory problems	Adjustment of spaces and schedules
Rigidity	Multi-appointment system Continuity of care Centralized nursing procedures Minimizing new variables Family and patient-based care Anticipation
Stereotyped behaviours	Information/Training/Professionalization of attending doctors Individualization of protocols for ASD and for individuals

7. Discussion

The results of this review and description of a model of care for subjects with ASD in an urban population in Spain reflect the health care situation of patients with ASD in the Community of Madrid, which is, to our knowledge, very much the same in the rest of Spain and probably not very different from other European countries with public health care systems.

The age distribution does not parallel the expected population distribution of subjects with ASD. Although there are no data to directly compare the age distribution of the population seen in AMITEA with the age distribution of subjects with ASD in the general population, the age distribution of patients in primary care is much older than AMITEA patients, and this is even more true of those who are referred to specialists [17]. Taking into account that life expectancy for ASD is reported to be only 5–10 years lower than in the general population [21,42], it would be expected that the population of patients with ASD is older than the population seen in this pilot programme. This probably reflects the paucity of ASD diagnoses in subjects over 30 years of age, and the fact that parents of subjects with autism traditionally consulted private physicians or those attending the Residential or Day Centres.

Adult patients were most frequently referred to nutrition, stomatology, neurology, and gastroenterology specialists. Children

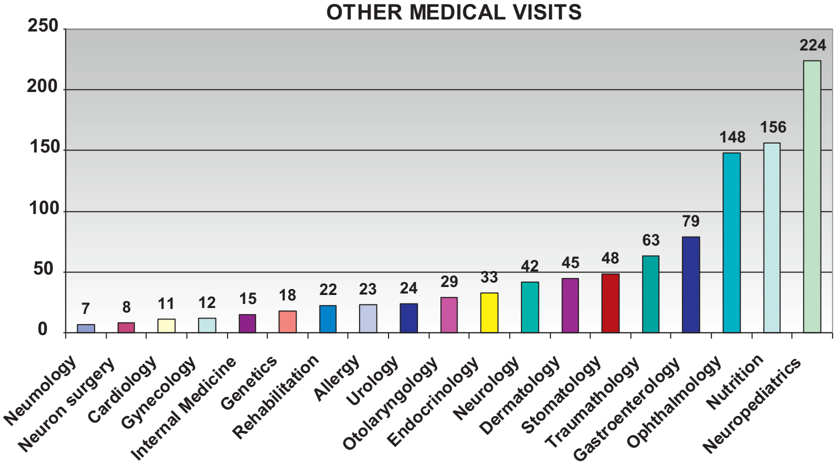

Fig. 2. Specialists visits referred by the AMI-TEA program over 18 months of running.

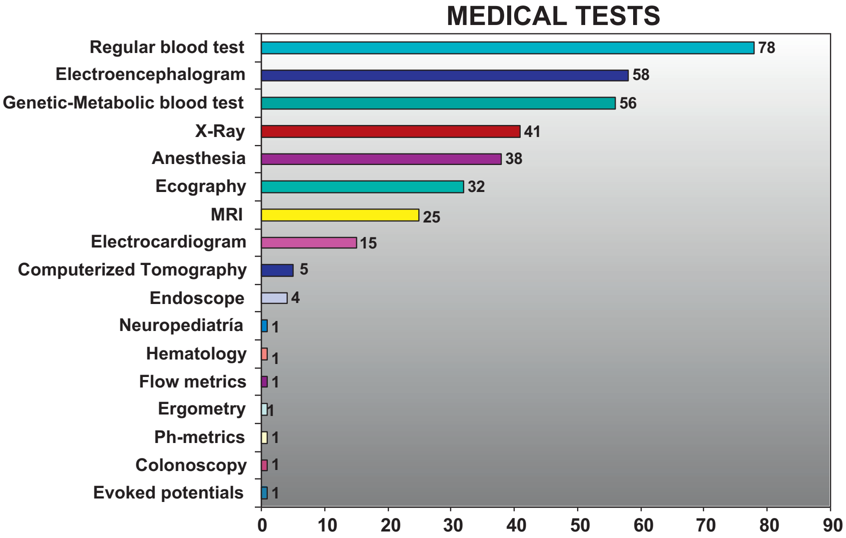

Fig. 3. Medical tests conducted for patients in the AMI-TEA program.

and adolescents were mainly referred to neuropaediatrics, nutrition, stomatology, ophthalmology, traumatology, dermatology, and gastroenterology specialists. This distribution probably reflects not only the health needs of these patients, but also previously unmet needs and the availability and sensitivity of the different departments and professionals. In the case of adults, many patients have needed nutritional referral for overweight and for ingestion of multiple over-the-counter supplements that needed to be rationalized and that conflict with the real nutritional needs of the patient. Stomatology was needed for the care of chronic conditions with the subjective (or real) perception of the families that dental care complications in subjects with ASD (with more sedation needed for minor procedures and difficulties in evaluation) could not be overcome by a regular provider. Neurology referrals were mainly due to lack of appropriate follow-up for epilepsy, with fewer than recommended medication adjustments and blood tests.

In children, the high percentage of neuropaediatric referrals responds to the problem of children not having the complete medical differential diagnosis recommended for ASD and for treatment of epilepsy. Nutritional consultations have been mainly for assessing the effect of dietary restriction and nutritional fads, and the ingestion of supplements, together with overweight and risk of metabolic complications. Ophthalmology referrals are mainly due to a protocol established for assessing all children at least once in their childhood, even when there is no suspicion of a visual problem.

The high number of specialty referrals warrants a rigorous study of the medical needs of the population with ASD in community samples, with detailed descriptions of the impact of encountered problems on the lives of patients and their families. The aim of the programme is to coordinate medical care for patients' health and behavioural problems. Recognition that problem behaviours might indicate an underlying medical condition would facilitate diagnosis and treatment and ultimately improve the quality of life for many persons with ASD [6]. Education of caregivers and health care providers is necessary to impart knowledge of how to recognize typical and atypical signs and symptoms of systemic disorders in individuals with ASD. Data are needed in order to guide medical examinations in these subjects. Strong partnerships between mental health and other medical specialists seem necessary in order to provide adequate health care for persons with ASD. In fact, in addition to the reported high medical comorbidity and its particularities, psychiatric comorbidity has been described as more the norm than the exception. In the preliminary data presented for a subset of the treated population, we have shown that 52% of the patients had a comorbid psychiatric condition. Other studies have shown very high co-morbidities also, such as 63% comorbid main psychiatric disorders in a population-based study of ASD children 10–14 years of age [52] and almost 53% comorbidity in a clinical sample derived from a service for adults with ASD (mean age 32.6 years) [40]. In addition, it has been reported that 35% of children with ASD use at least one psychotropic medication [49].

Politically, an intellectual or other type of disability should not be a determinant of quality of specialty care in countries with public health systems. Resources need to be accessible environments not only to eliminate physical barriers but also for elimination of communication, social, and environmental barriers [1].

In the care of persons with ASD, two approaches are appropriate. In addition to standard medical knowledge, a functional approach is warranted, in which mild or isolated symptoms or signs can be understood in the context of the underlying physiological mechanisms involved. Mild physiological disturbances may produce suboptimal functioning that can have an important functional impact. For example, the presence of pain can result in the child's perception that simple daily tasks and routines are much more aversive than would be the case if the child was healthy and free of discomfort. As a consequence, these tasks and routines now might trigger bouts of severe problem behaviour as the child attempts to escape from the now aversive situation.

The data in this report underscore the importance of finding new ways to coordinate the care of children in special populations and high demands on mental health and general medicine resources. The particularities of the resources should necessarily be country-, region-, and context-specific, but it seems clear that some kind of programme is necessary to facilitate access to health care and to break the communication and behavioural barriers that prevent persons with ASD from getting the same health care as the rest of the population. The literature is very limited in descriptions of service models to deal with the complexity of medical care in special populations, particularly with reference to specialized care. The "medical home" model is an exception and some research has been conducted on this model of service delivery for primary care, mainly in the United States. The problem is that research-based interventions or methods are very scarce, health needs of a child with ASD may be concurrently served in multiple settings and that care is not coordinated or optimal [5,39,51].

In the belief that any pilot programme needs to be tested for effectiveness, we have set up an evaluation project. This includes a baseline and one-year evaluation of 100 new patients in 4 aspects: health status, access to services, satisfaction with health services and expenditures on health care. A preliminary analysis of the first 70 patients included in the evaluation shows that 40% of the parents have a perceived health score of less than 75% on the visual analogue scale of the EuroQol [55]. The mean score on this scale is 76.06 (SD 21.73). This scale scores the self-perceived health of the population on a scale of 0 to 100, and it was completed by the parents or legal guardian of the patient. There is very little data to compare these results with, but a recent study has shown that the mean score in a sample of almost one thousand healthy Spanish children was 83.8 (SD 13.7) [55].

The programme and the data presented in this report do not permit to extract conclusions about incidence and types of disease in the ASD population. The sample is a clinical one and the fact that this report covers the first 18 months of a specific programme in the absence of any such prior programme determines the results greatly. The objective of the report is, however, to present a possible model of intervention for sensibly and appropriately attending to the medical specialty needs of persons with ASD. In interpreting the results, it is necessary to take into account the context, as this type of programme needs to be designed very specifically around the particular needs of the population it will serve.

8. Conclusion

Persons with ASD have more medical needs than the general population and their singular characteristics constitute a barrier to adequate health care at the same level as the care received by the reference population of persons without ASD. Persons with autism require more frequent medical visits, more frequent diagnostic assessments in order to properly diagnose underlying conditions, more training of health care professionals and mechanisms to overcome the communication barriers that are a feature of ASD. Our programme is one clinical initiative for meeting the needs of a population with high health care demands in a facilitative and coordinated way.

Disclosure of interest

The authors declare that they have no conflicts of interest concerning this article.

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