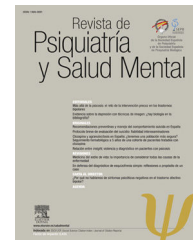




Revista de Psiquiatría y Salud Mental

www.elsevier.es/saludmental



BRIEF REPORT

Seeing the doctor without fear: www.doctortea.org for the desensitization for medical visits in Autism Spectrum Disorders[☆]



Leticia Boada^{*}, Mara Parellada

Servicio de Psiquiatría del Niño y del Adolescente, Hospital General Universitario Gregorio Marañón, Instituto de Investigación Sanitaria Gregorio Marañón (IISGM), Centro de Investigación Biomédica en Red de Salud Mental (CIBERSAM), Universidad Complutense de Madrid, Madrid, Spain

Received 22 July 2016; accepted 27 September 2016

Available online 10 March 2017

KEYWORDS

Phobia;
Systematic
desensitisation;
Disability;
Autism;
Anxiety

Abstract

Introduction: Doctor Tea is an online website designed to facilitate medical visits for those with autism spectrum disorder and other disabilities. People diagnosed with autism not only have greater medical needs than the general population, but also have particular characteristics that are often not accommodated by medical services. This lack of medical accommodation often creates a very complicated, and sometimes traumatic experience, when visiting medical facilities. Individuals with autism have great difficulty understanding social situations and contexts, such as medical tests or consultations, as well as difficulty in tolerating new situations and atypical sensory thresholds. Doctor Tea aims to reduce anxiety before medical consultations and procedures from a safe and well-known environment (school, home, etc.).

Material and method: The website, www.doctortea.org, provides information and materials (videos, cartoon, 3D animations, pictogram sequences, etc.) about the most frequent medical procedures and practices for patients with autism. The website also offers information to the doctors and families of patients with autism about the most common medical problems associated with autism.

Results: A total of 17,199 different users visited the website during 2015, with a total of 23,348 online visitors from more than 70 different countries since the website's release in November 2014.

Conclusions: The familiarisation with the medical procedures and its environment appears to decrease the anxiety in patients with disabilities during medical visits, as well as optimising the effectiveness of their medical visits and tests.

© 2016 SEP y SEPB. Published by Elsevier España, S.L.U. All rights reserved.

[☆] Please cite this article as: Boada L, Parellada M. Ir al médico sin miedo: www.doctortea.org para la habituación al entorno médico de pacientes con autismo. Rev Psiquiatr Salud Ment (Barc.). 2017;10:28–32.

^{*} Corresponding author.

E-mail address: lboada@iisgm.com (L. Boada).

PALABRAS CLAVE

Fobia;
Desensibilización
sistemática;
Discapacidad;
Autismo;
Ansiedad

Ir al médico sin miedo: www.doctortea.org para la habituación al entorno médico de pacientes con autismo

Resumen

Introducción: Doctor Tea es una página web diseñada para facilitar las visitas médicas de las personas con trastornos del espectro del autismo y/o con otras discapacidades. Las personas con autismo en muchas ocasiones no solo tienen mayores necesidades médicas que la población general, sino que presentan, además, unas características particulares que hacen que acceder a los servicios médicos se convierta en una experiencia muy complicada e incluso a veces traumática. Estas personas tienen grandes dificultades para comprender situaciones y contextos con implicación social como una prueba o consulta médica; dificultad para tolerar situaciones nuevas; y umbrales sensoriales atípicos. Doctor Tea tiene como objetivo reducir la ansiedad ante consultas, procedimientos y profesionales médicos desde un ambiente seguro y conocido (colegio, casa, etc.).

Material y método: La página www.doctortea.org proporciona información y materiales (videos, dibujos animados, animaciones 3D, secuencias de pictogramas, etc.) sobre las prácticas médicas más frecuentes a las que los pacientes con trastornos del espectro del autismo se tienen que enfrentar. También ofrece información a los médicos sobre las características de estos pacientes y a las familias sobre los problemas médicos más frecuentemente asociados.

Resultados: Durante el año 2015, 17.199 usuarios diferentes visitaron la web. Desde su lanzamiento en noviembre de 2014 el número de visitantes fue de 23.348 personas procedentes de más de 70 países diferentes.

Conclusiones: La familiarización con el entorno y los procedimientos médicos parece disminuir la ansiedad frente a los mismos y permite optimizar la eficacia de las visitas médicas y las pruebas complementarias que las personas con discapacidad necesitan.

© 2016 SEP y SEP. Publicado por Elsevier España, S.L.U. Todos los derechos reservados.

Introduction

Individuals with autism spectrum disorders (ASD) not only have greater medical needs than the rest of the population,¹⁻³ they also present some specific characteristics that make it possible that access to medical services could become a traumatic experience. Individuals with ASD: (1) have significant difficulties in understanding and in anticipating social situations and contexts such as those that occur in a medical test or visit to the doctor, where the doctor-patient interaction is essential for correct diagnosis and treatment of any disease; (2) can present a marked difficulty in recognising and expressing symptoms and, at times, their parents report that their pain threshold is above that of the general population,⁴ which means that their illnesses run the risk of getting worse before being detected; and (3) generally show a significant lack of flexibility and great rigidity when faced with adapting to new places and people, especially in situations that involve a certain amount of uncertainty and whose probability of unexpected changes is high (for example, in a hospital).

Children with ASD present a higher number of medical phobias when compared with children of their same mental age.⁵ They also present significantly greater levels of anxiety in relation to medical procedures than the general population.^{6,7}

To respond to these difficulties, a pioneering experience began in 2009 in the Community of Madrid: the creation of a comprehensive medical programme for medical services for

patients with ASD, set up in the Hospital General Universitario Gregorio Marañón.⁸ The main goal of this programme was to provide coordinated and specialised medical attention to the population with ASD in this community to cover their basic healthcare needs.⁹

From its opening in April 2009 through January 2016, 1910 patients were included in the AMI-ASD programme (with 79% being younger than 18 years old), a total of 17,845 consultations in Psychiatry and 8173 consultations in other specialties were handled, and a total of 3213 medical tests were performed. In the course of the activity of the AMI-ASD programme, the following factors became evident: (1) the advantage of having training before the visit and the medical tests, training centred on familiarisation with the clinical surroundings, and (2) the lack of easily available specific material for working on this prior desensitisation.

In our setting, there are some medical familiarisation experiences, above all in the educational environment. These attempt, through structured programmes based on desensitisation, to get their students used to the specifics of the healthcare setting (white coats, waiting times, diagnostic procedures, etc.). The programmes use "in vivo" elements, such as therapists disguised as doctors, and real medical devices. However, certain medical procedures and tests (such as a magnetic resonance scan, an orthopantomography or an electroencephalogram) are difficult to simulate, bearing in mind the lack of accessibility to these devices from an educational viewpoint.

Over the last decade, virtual reality has started to be used in systematic desensitisation procedures for the treatment of phobias, with considerable success.^{10–12} This use has been extended to individuals with autism,^{10,13} for whom it could be especially useful given the possibility that there might be better processing of visual information than auditory information.¹⁴ Both the results of previous studies^{11,15,16} and the day-to-day clinical practice seem to indicate that when there has been a prior anticipation, a specific training activity, a systematic desensitisation or a simple habituation to the procedures, patient anxiety is considerably reduced before, during and after such procedures.

Taking all of this into consideration, this programme was created to facilitate access to the medical setting, using a programme based on new technologies. The project was initially designed for patients with ASD. During the course of developing the project and in its diffusion through various forums, its usefulness became apparent for not only patients with autism, but also for other populations with other disabilities that share common characteristics of cognitive inflexibility and intolerance to changes. For that reason, these populations can benefit from the proposed methodology. The target population of the project was finally enlarged to the entire paediatric population. Healthcare professionals are another sector directly benefited, as it is foreseen that after using this material children with autism will come to consultations more calmly, a greater possibility of success in the examinations will be achieved and the time required for each consultation will be reduced.

Method

With the goal of making the performance of medical tests and seeing the doctor in the hospital more understandable

and less traumatic for patients with disabilities and, especially, those with autism, the website www.doctortea.org was designed. Specifically, the aims were: reduce the stress and anxiety generated in the patient before, during and after seeing the doctor; familiarise the healthcare professionals with the characteristics of the population with ASD and with the management of their disorder; and facilitate access by the families to medical information related to the health problems most prevalent in the population with ASD.

Procedure

Work groups were organised with personnel expert in medical services for patients with autism and professionals with experience in developing new technologies for autism. A set of professionals, medical procedures and healthcare spaces were chosen for the development of visual materials, bearing in mind the needs of the target population and the opportunity (Fig. 1). The material was designed and uploaded to a free, open access web platform (www.doctortea.org).

The population with ASD usually has learning processes initially based on the specific and the literal, then going later to learning from more abstract stimuli and situations,^{17,18} generalising what has been learned and consequently making their behaviour more flexible. There is also great heterogeneity in the intellectual level and in the language of these patients.^{19,20} Because of these factors, the project is offered in content of varying levels of complexity. The same content is shown in different presentation formats: cartoons, videos, 3D animations and real material from the hospital when the project originated (Hospital General Universitario Gregorio Marañón) and another 10 hospitals

TESTS	SPACES	PROFESSIONAL	INSTRUMENTS	GAMES
<i>(videos, cartoons, pictogram sequences, 3D animations)</i>	<i>(videos and 3D animations)</i>	<i>(videos and cartoons)</i>	<i>(tri-dimensional rotation)</i>	
Electroencephalogram	Doctor's office	Psychiatrist	Depressor	Find the differences
Magnetic resonance	Magnetic resonance room	Neuropaediatrician	Magnetic resonance machine	Colour
Oral medicine	Oral medicine consultation	Oral medicine specialist	Orthopantomography	Join the dots
Orthopantomography	Orthopantomography	Nurse	EEG cap	Labyrinths
Blood analysis	Nursing consultation	Neurologist	Electrodes	Memory
Ophthalmology	Ophthalmology consultation	Ophthalmologist	Apparatus for evaluating vision	Puzzle
	Halls	Traumatologist	Sphygmomanometer	
	Admissions waiting room	Internist		
	Hospital outside views	Psychologist		

Figure 1 Material available at www.doctortea.org.

and healthcare centres at the national level. In addition to desensitisation material for patients, the website offers informative reference material for both families and professionals. This material attempts to answer frequent questions related to the health of the patient with ASD (for example, what are the health problems and illnesses most common in autism, how to prepare for a visit to the dentist, how a trip to the Emergency Room can be facilitated, etc.).

Results

During 2015, 17,199 different users visited the website, representing an average of 1433 web users a month. Since its launch in November 2014, the number of different visitors (accumulated) was 23,348 people. Of the users that know the website and enter for the first time, 83.5% return to it. Visitors from more than 70 different countries have accessed the website, the 10 with the most visits being Spain, Argentina, Russia, the United States, Mexico, Chile, China, Peru, Venezuela and France.

Other qualitative outcomes include the interest of foreign institutions in translating the materials to other languages and the invitation to multiple scientific forums, family associations and professional associations to present the project.

Conclusions and discussion

The website Doctor Tea (www.doctortea.org) was developed within the AML-ASD programme for comprehensive medical treatment for individuals with autism, after recognising the difficulties that these individuals have for access to medical services and the performance of medical tests. Working to facilitate medical access is especially relevant in the individuals with autism, given that these patients present greater difficulties than the general population in the processes required for access to appropriate medical treatment (tolerance for waiting, uncertainty and novelty, exposition to incomprehensible processes and social relations with strangers).

Doctor Tea was developed as a free, open access tool, which makes familiarisation with medical settings and procedures possible, and which seems to reduce anxiety in these situations and to allow optimisation of the efficacy of seeing the doctor and of the complementary medical tests needed. As far as we know, there is no other device or programme that permits the possibility of carrying out personalised familiarisation or desensitisation to the reference healthcare devices, from the patient's own home or from the school, for such an amount of tests or real settings that are so complete. In addition, the extra advantages of being able to use them with other related populations (children and adolescents, individuals with other disabilities, etc.) increase the potential usefulness of the tool.

Ethical responsibilities

Protection of human and animal subjects. The authors declare that no experiments on human beings or on animals have been performed for this research.

Confidentiality of data. The authors declare that no patient data appear in this article.

Right to privacy and informed consent. The authors declare that no patient data appear in this article.

Funding

Fundación Orange.

Conflict of interests

The authors have no conflicts of interest to declare.

Acknowledgements

Our thanks to the *Fundación Orange* for funding the project, and especially to Manuel Gimeno, Verónica Pensosi and Blanca Villamia for their work and enthusiasm in the project. To the Research Foundation of the Hospital Universitario Gregorio Marañón for project management, and to all those associations of relatives of individuals with autism, hospitals, healthcare centres and participating professionals, as without their selfless participation, this project would not have been possible. To José Romo, Carmen Moreno, Cloe Llorente, M. Luisa Dorado and María Mayoral for their encouragement in the initial phases of the project.

References

1. Gurney JG, McPheeters ML, Davis MM. Parental report of health conditions and health care use among children with and without autism: National Survey of Children's Health. *Arch Pediatr Adolesc Med.* 2008;180:825–30.
2. Catala-Lopez F, Genova-Maleras R, Alvarez-Martin E, Fernandez de Larrea-Baz N, Morant-Ginestar C. Burden of disease in adolescents and young people in Spain. *Rev Psiquiatr Salud Ment (Barc).* 2013;6:80–5.
3. Lara E, Garin N, Ferrari AJ, Tyrovolas S, Olaya B, Sanchez-Riera L, et al. The Spanish Burden of Disease 2010: neurological, mental and substance use disorders. *Rev Psiquiatr Salud Ment (Barc).* 2015;8:207–17.
4. Bandstra NF, Johnson SA, Filliter JH, Chambers CT. Self-reported and parent-reported pain for common painful events in high-functioning children and adolescents with autism spectrum disorder. *Clin J Pain.* 2012;28:715–21.
5. Evans DW, Canavera K, Kleinpeter FL, Maccubbin E, Taga K. The fears, phobias and anxieties of children with autism spectrum disorders and Down syndrome: comparisons with developmentally and chronologically age matched children. *Child Psychiatry Hum Dev.* 2005;36:3–26.
6. MacNeil BM, Lopes VA, Minnes PM. Anxiety in children and adolescents with autism spectrum disorders. *Res Autism Spectr Disord.* 2009;3:1–21.
7. Maj M. The need to protect and promote physical health in persons with severe mental illness. *Rev Psiquiatr Salud Ment (Barc).* 2009;2:1–4.
8. Parellada M, Boada L, Moreno C, Llorente C, Romo J, Muela C, et al. Specialty Care Programme for autism spectrum disorders in an urban population: a case-management model for health care delivery in an ASD population. *Eur Psychiatry.* 2013;28:102–9.

9. Lolas-Stepke F. Trends and clinical need of ethical principles. *Rev Psiquiatr Salud Ment (Barc)*. 2015;8:1–2.
10. Maskey M, Lowry J, Rodgers J, McConachie H, Parr JR. Reducing specific phobia/fear in young people with autism spectrum disorders (ASDs) through a virtual reality environment intervention. *PLOS ONE*. 2014;9:e100374.
11. Shabani DB, Fisher WW. Stimulus fading and differential reinforcement for the treatment of needle phobia in a youth with autism. *J Appl Behav Anal*. 2006;39:449–52.
12. Olasov Rothbaum B, Garcia-Palacios A, Rothbaum AO. Treating anxiety disorders with virtual reality exposure therapy. *Rev Psiquiatr Salud Ment (Barc)*. 2012;5:67–70.
13. Bellani M, Fornasari L, Chittaro L, Brambilla P. Virtual reality in autism: state of the art. *Epidemiol Psychiatr Sci*. 2011;20:235–8.
14. Mottron L, Dawson M, Soulières I, Hubert B, Burack J. Enhanced perceptual functioning in autism: an update, and eight principles of autistic perception. *J Autism Dev Disord*. 2006;36:27–43.
15. Wolff JJ, Symons FJ. An evaluation of multi-component exposure treatment of needle phobia in an adult with autism and intellectual disability. *J Appl Res Intellect Disabil*. 2013;26:344–8.
16. Ricciardi JN, Luiselli JK, Camare M. Shaping approach responses as intervention for specific phobia in a child with autism. *J Appl Behav Anal*. 2006;39:445–8.
17. Church BA, Rice CL, Dovgopoly A, Lopata CJ, Thomeer ML, Nelson A, et al. Learning: plasticity, and atypical generalization in children with autism. *Psychon Bull Rev*. 2015;22:1342–8.
18. Mercado E, Church BA. Brief report: simulations suggest heterogeneous category learning and generalization in children with autism is a result of idiosyncratic perceptual transformations. *J Autism Dev Disord*. 2016;46:2806–12.
19. Howe YJ, O'Rourke JA, Yatchmink Y, Viscidi EW, Jones RN, Morrow EM. Female autism phenotypes investigated at different levels of language and developmental abilities. *J Autism Dev Disord*. 2015;45:3537–49.
20. Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators; Centers for Disease Control and Prevention (CDC). Prevalence of autism spectrum disorder among children aged 8 years – autism and developmental disabilities monitoring network: 11 sites, United States, 2010. *MMWR Surveill Summ*. 2014;63:1–21.