



EXPERIENCE REPORT

6

Interview with a mother of autistic individual and her contribution to medical teaching: an experience report

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# Abstract

Autistic Spectrum Disorder (ASD) is a syndrome which affects 70 million people worldwide, 2 million of them only in Brazil, according to the World Health Organization. Given this, the bond between children with ASD in their socio-school environment is still complicated due to the lack of understanding of the subject by the individuals around them. Due to the population's lack of awareness on the subject, the perpetuation of stereotypes is remarkable and corroborates the presence of stigmas and prejudgments, jeopardizing even further the individual's socialization. The present report aimed to show the experience of medical students interviewing the mother of an autistic individual, and how this activity helped to understand the syndrome and how to deal with a patient with ASD. Therefore, the experience of interviewing the mother of an autistic person, through an online platform, brought questions to the personal and professional development of the students, as they were faced with a completely different reality. At the end of the interview, the prejudices, the difficulties of inclusion and accessibility that individuals with autism spectrum experience were highlighted, being essential a greater dedication and responsibility to improve their quality of life. In addition, it highlights the importance of this experience for the construction of the doctor-patient relationship among the students, as it promotes a more humanized Medicine, by making them see different points of view.

**Keywords:** Autism Spectrum Disorder. Education. Medical Education. Distance Social. Inclusion.

### Introduction

Autistic Spectrum Disorder (ASD) is a syndrome which affects 70 million people worldwide, 2 million of them only in Brazil, according to the World Health Organization (WHO). The ASD, due to its different degrees, makes each autistic person holder of individual characteristics, but some traits tend to be common among them, having different intensities in each case. Among such traits are the difficult of interaction with other people and in expressing oneself; speech troubles or the entire absence of it, repetitive movements may appear, problems with changes in the routine and in demonstrating affection to other individuals [1].

Therefore, this syndrome is classified as a global developmental disorder, affecting communication and social interaction, resulting in an atypical behavior of the individual within the society [1]. Given this, the bond between children with ASD in their socio-school environment is still complicated due to the lack of understanding of the subject by the individuals around them [2]. Due to the population's lack of awareness on the subject, the perpetuation of stereotypes is remarkable and corroborates the presence of stigmas and prejudgments, jeopardizing even further the individual's socialization [3,4]. In this context, the family responsible for an individual with ASD, especially the maternal figure, faces obstacles to meet one needs and access social rights [5].

Thus, the present report aimed to show the experience of medical students interviewing the mother of an autistic individual, and how this activity helped to understand the syndrome and how to deal with a patient with ASD.

#### **Experience report**

This report is about the experience of medical students, who had the opportunity to interview the mother of an autistic person, in order to unveil the daily challenges faced by both ones and how they relate to health professionals. The meeting took place remotely, during the COVID-19 pandemic, through Zoom, where the theoretical-practical classes of that semester at the college where the academics also took place. The interviewee started by introducing herself and explaining a little about how her and her son's routine was and then questions were made about several moments experienced by them, for example, how it was when she started to suspect the presence of this syndrome, how she felt when discovering the diagnosis and how the family dealt with this process. The period of denial/grief until facing the situation and discovering how to better deal with the disorder. There were also questions about the experiences the two had with medical care and how it was to deal with the lack of social inclusion, the prejudice experienced and the daily battle for their rights, and, as a result of, the need for a support network beyond family members, including doctors and teachers. As for medical care, the importance of the physician being patient and the office adapted to receive the patient with ASD was reported, since the patient is often agitated and wants to touch and pick up objects from the office. The physician must have empathy and gain the patient's trust to establish a better relationship and achieve better results. The answers given by the mother were emotional and opened the eyes of the students to understand the mother's side of an autistic boy in Brazil, who follows a path marked by care and dedication to her child, even in a challenging scenario that requires a lot of effort to reclaim their rights.

### **Reflection on the experience**

Given the experience of the medical students, it is necessary to reflect on the integration and access of autistic people in our society. It was clear that not only the autistic individual, but an entire support network such as family members, teachers, doctors, psychotherapists, among others, need to be aligned to face the adversities of social interaction and for a good human development. This scenario becomes even rougher as it is known that the minority of the families are able to provide the minimum conditions for the wellbeing and development of the patient. Therefore, there is a growing need to fight for public policies in which includes these individuals. In fact, it is necessary to remember the need to also invest in awareness for the population in order to develop a better communication and socialization skills, so that there is a strengthening and commitment for inclusion by government and social entities, in order to improve quality of these people's lives. Finally, this experience exposed the need for medical students to be in contact with the different realities they will face in their daily lives. If the knowledge dissemination among the population is important, the discussion and debate about patients with ASD among medical students is even more important, so that the care for these patients can be more humanized and capable of generating an effective improvement of the patient's life.

## Conclusion

The experience of interviewing the mother of an autistic person, through an online platform, brought questions to the personal and professional development of the students, as they were faced with a completely different reality. At the end of the interview, the prejudices, the difficulties of inclusion and accessibility that individuals with autism spectrum experience were highlighted, being essential a greater dedication and responsibility to improve their quality of life. In addition, it highlights the importance of this experience for the construction of the doctor-patient relationship among the students, as it promotes a more humanized Medicine, by making them see different points of view.

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### Data sharing statement

No additional data are available.

#### **Conflict of interest**

The authors declare no conflict of interest.

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