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The Knowledge and Awareness of Autism Spectrum Disorder within the Spanish Speaking Community

Thesis submitted in partial fulfillment of Honors

By

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Katrina Heil, Faculty Mentor
ABSTRACT

Based on past research of several different populations, it appears that there is a general lack of knowledge and awareness of Autism Spectrum Disorders (ASD’s). In order for people with autism to receive proper diagnosis, treatment, and have a high quality of life, it is important that everyone is aware and has a high level of knowledge of autism. This study sought to measure the level of awareness and knowledge of autism in the Spanish speaking community through a survey that addressed the characteristics and misconceptions of autism. The results showed that the majority of respondents correctly identified the characteristics of autism and correctly identified misconceptions as false. The results also showed that respondents had less knowledge of the misconceptions of autism than the characteristics of autism. This reveals that more information should be readily available about the misconceptions and characteristics of autism in order to ensure that those with autism are properly diagnosed, treated, and have a high quality of life.
INTRODUCTION

The group of developmental disabilities known as Autism Spectrum Disorders (ASD’s) is characterized by atypical development in behavior, socialization, and communication. Symptoms of this developmental disability typically appear in children by three years of age. The spectrum of disorders includes autistic disorder (i.e. autism), Asperger disorder, and pervasive developmental disorder – not otherwise specified (PDD-NOS). According to the Center for Disease Control in a 2008, it is estimated that an average of 1 in 88 children in the United States have an ASD (Baio, 2008). As the incidence of autism spectrum disorders (ASD’s) rise around the world, the exposure to these disorders also increases through relations with their peers, television, movies, newspapers, and various other media outlets. This exposure leads to awareness and knowledge, which may or may not be accurate depending on where this information originates. The purpose of this research is to examine the knowledge and awareness of ASD’s within the Spanish speaking community. The definition of Spanish speaking community for the purpose of this study is any person who is a native speaker of Spanish. There are few studies on the knowledge and awareness of ASDs, but even fewer that focus on a specific language community. This study is important because it will reveal the level of ASD awareness and knowledge among Spanish speakers, and may suggest that literature and information on the spectrum of disorders should be more readily available in Spanish.
HYPOTHESIS

The Spanish speaking community has a low level of knowledge of ASD’s.

LITERATURE REVIEW

Concerning ASD’s, there have been some studies measuring the level of knowledge within specific populations, but never within a specific language community. Several studies address the knowledge that Speech Language Pathologists (SLPs) have about the disorders. In a study by Schwartz and Drager, sixty-seven school-based SLPs from thirty-three different states completed a survey to test their knowledge about the disorder, and how comfortable they felt working with autistic clients. The results showed that “current professionals in the field have an unbalanced understanding of autism and have some insecurities regarding their abilities to provide effective services to these students” (Scharwtz & Drager, 2008). Another study by Cascella and Colella that focuses on the knowledge of speech pathologists showed that school speech pathologists from Connecticut were more confident in recognizing autistic behaviors, but were not confident in assessing or treating patients with autism (Cascella & Colella, 2004).

A 2001 study by Shah focused on the knowledge of autism in medical students. The study found that there was no difference in the level of knowledge between first year and fourth year medical students concerning the treatment and prognosis of patients with autism. Both groups of students had the same amount of knowledge about the symptoms and diagnosis of autism. This study notes that these discrepancies in the knowledge of
medical students needs to be addressed so that ASD’s can be more effectively diagnosed and treated (Shah, 2001).

Another study published in 2010 explores the knowledge of autism among middle school students. According to this study, 41.6 percent of students had heard of autism (Barger & Campbell, 2010). Based on this awareness of autism, the study concluded that the students with awareness of autism had a slightly better knowledge of autism than their peers who had never heard of autism. Overall, the students were varied in the level of knowledge that they had regarding the characteristics of autism. The study concludes that in order for autistic peers to participate successfully in an education system among their peers, there must be an increase in the level of knowledge of autism among students.

A study of the knowledge of autism among general practitioners in Karachi, Pakistan found that only 44.6 percent of the general practitioners surveyed had heard of autism (Assassi, Ibrahim, & Rahbar, 2010). Like other studies, this study measured the awareness of autism in relation to the knowledge of autism among its participants. This particular study excludes the answers of those practitioners who claimed no awareness of autism. Among the practitioners that were aware of autism, the study concludes that there are “knowledge deficits concerning autism etiology and diagnosis” (Assassi, Ibrahim, & Rahbar, 2010). The study concludes that in order for autism disorders to be properly diagnosed and treated, both private and public medical schools in Pakistan should develop a more robust curriculum on the subject of autism.
RATIONALE

Based on existing studies, it appears that there is a lack of knowledge of autism among several different populations. For proper diagnosis, treatment, and overall quality of life for those with autism, the population around them must have a clear understanding of their condition. By studying the level of knowledge that Spanish speakers have, it may be possible to improve the diagnosis, treatment, and quality of life of those with autism by providing information about the spectrum of disorders in Spanish.

METHODS AND MATERIALS

In order to gather the data required for this study, a survey was available to test subjects via the online survey service SurveyMonkey. The survey was sent to a random population of people in the Spanish speaking community. This survey consisted of questions in Spanish based on demographics, awareness of autism, and knowledge of autism. The questions address the characteristics of autism as well as common misconceptions about autism. The questions regarding the characteristics and misconceptions of autism were structured as statements in which the participants must respond with a “yes”, “no”, or “I don’t know” answer, in order to indicate whether they believed the statement to be a characteristic of autism. For each answer that is correct, the respondent received one point. For an incorrect answer, or a response of “I don’t know”, the respondent received zero points. These points were divided by the twenty total points in order to calculate the percentage of correct answers. In order to measure the overall knowledge of the entire respondent group, the mean of the number of correct responses will represent the entire group.
RESULTS

There were thirty-three respondents to the online survey. However, not all thirty-three respondents answered every question. 27.3 percent of the respondents were male while 72.7 percent were female. The age of respondents ranged from age 17 to 63 with the median age being 29. Out of 30 respondents 100 percent claimed they had heard of the term “autism”. The majority, 75.8 percent, of respondents stated they had heard of, or learned about autism through television. Other top responses included the Internet at 57.6 percent, friends at 54.5 percent, magazines at 51.5 percent, and school at 48.5 percent. Overall, the respondents’ mean number of correct answers was 12.53 out of 20 possible correct answers, which produces an average of 61.5 percent of correct answers from respondents. Respondents scored 70.7 percent on questions relating to the characteristics of autism, while they scored 54.8 percent on questions that addressed common misconceptions associated with autism.
**Table 1 Survey Results by Question**

Correct responses are underlined.

<table>
<thead>
<tr>
<th>Question</th>
<th>Results</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Question 1</td>
<td>Yes (97.2%) No (2.8%)</td>
<td></td>
<td></td>
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<tr>
<td>Question 2</td>
<td>Male (27.3%) Female (72.7%)</td>
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<td></td>
</tr>
<tr>
<td>Question 3</td>
<td>Age Range Median Age</td>
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<td></td>
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<tr>
<td></td>
<td>17-63 29</td>
<td></td>
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<tr>
<td>Question 4</td>
<td>Yes (100%) No (0%)</td>
<td></td>
<td></td>
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<tr>
<td>Question 5</td>
<td>See Figure I don't know (0%)</td>
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<td></td>
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<tr>
<td>Question 6</td>
<td>Yes (100%) No (0%) I don’t know (0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question 7</td>
<td>Yes (76.7) No (16.7) I don’t know (6.7%)</td>
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<tr>
<td>Question 8</td>
<td>Yes (56.7) No (30%) I don’t know (13.3%)</td>
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<tr>
<td>Question 9</td>
<td>Yes (16.7%) No (63.3%) I don’t know (20%)</td>
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<td></td>
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<tr>
<td>Question 10</td>
<td>Yes (73.3%) No (16.7%) I don’t know (10%)</td>
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<td></td>
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<tr>
<td>Question 11</td>
<td>Yes (16.7%) No (60%) I don’t know (23.3%)</td>
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<tr>
<td>Question 12</td>
<td>Yes (10%) No (56.7%) I don’t know (33.3%)</td>
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<td></td>
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<tr>
<td>Question 13</td>
<td>Yes (63.3%) No (13.3%) I don’t know (23.3%)</td>
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<td></td>
</tr>
<tr>
<td>Question</td>
<td>Yes (%)</td>
<td>No (%)</td>
<td>I don’t know (%)</td>
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<td>56.7%</td>
<td>26.7%</td>
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<tr>
<td>25</td>
<td>36.7%</td>
<td>10%</td>
<td>40%</td>
</tr>
</tbody>
</table>
Figure 1

Question Five Results

[Bar chart showing the number of respondents for various sources, with 'Television' having the highest at 25, followed by 'School' at 17, 'Magazine' at 19, and others with varying numbers.]
DISCUSSION

In order for people with autism to have proper diagnosis, treatment, and quality of life, it is imperative that the people around them have a high level of knowledge and awareness of autism. According to this study, the people surveyed within the Spanish speaking community are aware of autism, since all respondents answered they had heard of the term. Overall, the majority of respondents correctly identified the characteristics of autism and noted that the misconceptions were false. However, respondents answered 37.4 percent of questions incorrectly, or indicated that they were unsure of the answer. While this is the minority of responses, it is important for 100 percent of respondents to answer all questions correctly in order to ensure that those with autism are properly diagnosed, treated, and have a high quality of life. Based on the percentage of correct answers based on question type, it appears that respondents answered more questions concerning the misconceptions of autism incorrectly than questions concerning the characteristics of autism. Therefore, more information should be readily available in Spanish addressing these misconceptions, as well as the characteristics of autism. In addition, because the survey was given via the Internet, it is possible that the respondent group has a higher level of knowledge and awareness of autism because of their access to and familiarity with the Internet. It seems that the most effective means of distributing this information would be through television, Internet, magazines, and school, since these are the top means in which respondents indicated they had heard of autism.
APPENDIX: Survey of the Knowledge of Autism
1) Is Spanish your native language?
   Yes
   No

2) Gender
   Male
   Female

3) Age:

4) Have you heard the term “autism”?
   Yes
   No

5) In which of the following settings have you heard the term or received information about Autism?
   Check all that apply.
   Physician
   Family Member
   Friend
   Counselor
   Teacher
   Medical pamphlet
   Magazine
   Internet
   Television
   Radio
   Newspaper
   School
   Other (please list)
Characteristics of Autism
Based on YOUR understanding of autism, answer “yes” if you believe that the statement is a characteristic of Autism, “no” if you believe that the statement is NOT a characteristic of Autism, or “I don’t know”, if you are not sure whether the statement is or is not a characteristic of Autism. Please do not consult any outside sources including books, the Internet, pamphlets, etc. when completing this survey.

6) A person with autism has difficulty interacting socially with others.
   Yes
   No
   I don’t know

7) A person with autism may avoid making eye contact.
   Yes
   No
   I don’t know

8) A person with autism has an emotional or psychological disorder.
   Yes
   No
   I don’t know

9) A person with autism does not want friends.
   Yes
   No
   I don’t know

10) A person with autism may exhibit ritualistic or repetitive behavior.
    Yes
    No
    I don’t know

11) A person with autism can be cured or will eventually grow out of it.
    Yes
    No
    I don’t know

12) A person with autism may be self-injurious.
    Yes
    No
    I don’t know
13) A person with autism may have very limited interests. (i.e. preoccupation with one toy, movie, game, etc)
   Yes
   No
   I don’t know

14) A person with autism cannot show affection.
   Yes
   No
   I don’t know

15) A person with autism may not speak at all.
   Yes
   No
   I don’t know

16) A person with autism may thrive on routines and organization.
   Yes
   No
   I don’t know

17) A person with autism may not have normal sleeping patterns.
   Yes
   No
   I don’t know

18) Autism is caused by poor parenting.
   Yes
   No
   I don’t know

19) Autism is associated with mental retardation.
   Yes
   No
   I don’t know

20) Autism is very rare.
   Yes
   No
   I don’t know
21) All people diagnosed with autism exhibit the same characteristics.
   Yes
   No
   I don’t know

22) All people with autism are hidden geniuses, or have hidden special abilities.
   Yes
   No
   I don’t know

23) Scientists and medical professionals know the cause of autism.
   Yes
   No
   I don’t know

24) Characteristics of autism are revealed before a child is three years old.
   Yes
   I don’t know

25) Asperger Syndrome is a type of autism.
   Yes
   No
   I don’t know
REFERENCES


