

Author's response to reviews

Title: The Importance of Physician Knowledge of Autism Spectrum Disorder:
Results of a Parent Survey

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Author's response to reviews: see over

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Dear Dr. da-Silva,

Thank you for the opportunity to revise our manuscript, “The importance of physician knowledge of Autism Spectrum Disorder: Results of a parent survey,” for possible publication in Biomed Central *Pediatrics*. We found the reviewer comments to be quite helpful in improving the presentation of the paper. We also made the formatting changes you requested. All of the Editor and Reviewer comments are addressed on a point-by-point basis below.

Editor’s Comments

1. **Ethics and consent.** As requested, we added ethics and informed consent details to the Methods section (see Design and Procedures, last paragraph, pp. 8-9). The addition reads as follows, “*This study was approved under Exempt status by the Human Subjects Committee of the Department of Psychology and the Institutional Review Board at Virginia Polytechnic Institute and University, in compliance with the Helsinki Declaration. A study description was provided online immediately preceding the survey. The description outlined the contents of the survey and stated that participation was completely voluntary, anonymous, and could be withdrawn at any time. Participants also were informed that they could skip questions, if desired. There was no compensation for participation. As permitted for Exempt status, submission of the survey served as informed consent.*”
2. **Manuscript formatting checklist.** We formatted the manuscript according to the checklist.

Reviewer's Comments

1. **Details about survey posting and notification to participants.** The reviewer requested additional information about how the families learned about the survey. As requested, we added the following information to the Methods in the Participants section (p. 6), “*Anyone who came across the survey was able to participate if they met the inclusion criteria (i.e., were a parent or caregiver of a person with ASD and currently resided in Virginia). In addition, administrators of the above-noted web sites sent email notices to their membership alerting caregivers to this survey. The email message directed caregivers to the agency’s web site to self-initiate the survey.*”
2. **Additional survey details.** The reviewer requested additional information about the items on the survey and how they were coded. We re-wrote the Methods, Design and Procedure section (pp. 7-8) to specify details about the survey items and the coding of items. We removed mention of the individual symptoms because we had no specific hypotheses about them, but mentioned that additional items were included in the survey that were not part of this paper. We also added a statement of the availability of the survey for readers. The survey description now reads as follows:

“The survey consisted of three sections that were provided in the same order for all participants. If the respondent had more than one child with ASD, they were asked to respond to items in reference to the oldest child. Additional items were included in the survey, but are not detailed here because we had no specific hypotheses about them in relation to age of diagnosis or information provided by professionals. A copy of the survey may be obtained from the second author or accessed at <http://www.psyc.vt.edu/centers/psc/clinics/autism/> (see Additional files 1).

The first section included general and demographic information (i.e., relationship to child, race/ethnicity, education, income, education, county of residence, etc.). County of residence was further

coded as 2 = rural, 1 = mixed, and 0 = urban, according to Virginia 2006 status codes (based on population density). Demographic information is presented in Table 1. The second section included questions specific to the child's ASD diagnosis (i.e., 3 = Autistic Disorder, 2 = Asperger's Disorder, 1 = Pervasive Developmental Disorder – Not Otherwise Specified), and age of initial diagnosis in months. Current ASD diagnosis was coded to reflect the spectrum from atypical to classic autism. This section also included questions related to the provider that initially diagnosed the child (i.e., 4 = Developmental Pediatrician, 3 = Psychologist, 2 = Neurologist, and 1 = Other/Psychiatrist/Primary Care Physician) and what information was provided by this diagnosing professional (i.e., Provided no additional information, Gave information about available resources, Gave literature about autism, Spent time talking about autism, Referred to an autism specialist, Referred to a support group, Advised on educational programs, Advised on medical programs). For analyses, the item on the provider was coded in order of increasing training that is specialized in early childhood development or ASD. That is, developmental pediatricians were considered to have the most early childhood/ASD training, and the others were considered to be about equal or varied in training. The item on information provided was coded as either 1 = 'no' (i.e., parent endorsed that the professional provided no additional information beyond the diagnosis) or 0 = 'yes' (i.e., if any of the listed forms of information were endorsed). Lastly, this section also asked respondents to report who/what helped them learn about ASD upon receiving the initial diagnosis (i.e., Healthcare Professionals, Education Professionals, Parent Resource Centers, Parents of children with Autism, Family member, Friends, Support Groups, Advocacy groups, Internet, Books, Magazines, and Videotapes, Conferences and Workshops, Did not seek further information, Other), and whether they were currently or previously in a parent support group or parent advocacy group for ASD.

The final section surveyed parents' opinions regarding the status of autism-related outpatient services in their local area. Parents were asked to identify which services they had used or were currently using and then evaluate the services using a scale from 1-5 with 5 being the highest. Respondents were presented with a range of potential biomedical, behavioral, and educational services. Ratings were based on the availability and ease of locating the service in their area (within a forty mile radius), their satisfaction with the quality of the services, and the perceived need for such services in their area."

- 3. Clarification of analyses.** The reviewer correctly notes that we neglected to mention the coding of age of diagnosis in the Methods section. We have now clarified all coding (see Reviewer Comment #2 above). The reviewer then questions the use of linear regression for categorical outcome measures, and how the demographic and symptom information was used in the regression analyses. Lastly, the reviewer requested that the regression findings be noted in a table with the point estimates and p-values. To address these issues, the Results section was clarified by creating subsections that addressed each hypothesis and corresponding set of analyses. The first subsection addressed the analyses relating to age of diagnosis. The information on the multiple regression was clarified (see Results, Age of Diagnosis, pp. 9-10), and a table with point estimate and significance values was added (see Table 2, p. 23). We also added oneway analyses of variance to compare group means for provider type and diagnosis, and thus further confirm the regression findings. The second subsection addressed the analyses relating to the information provided. The reviewer correctly noted that the outcome variable was categorical, and so a linear regression was not the most appropriate analysis. Therefore, we re-conducted the analysis using the appropriate logistic regression (see Results, Information Provided by Diagnosing Professional, pp. 10-11). Point estimates and significance values were also added in Table 4 (p. 24). All demographic variables were entered simultaneously, as none were expected to be more highly associated than any other. Individual symptoms were not used in our analyses because we had no specific hypotheses regarding the different symptoms. Instead, we added the child's current diagnosis (Autism, Asperger's Disorder, or PDD-NOS) as a proxy for

their profile on the autism spectrum. Lastly, we added a Pearson chi-square analysis to further evaluate the proportions of professionals who provided information.

4. **Tighten Discussion section.** The reviewer notes that the Discussion section would benefit by tightening our conclusions based on our findings. For example, he notes that we underscore the importance of pediatric referral, despite the fact that we collected no information about whether and when referrals from primary care were made. He also noted that age of diagnosis could be delayed because of long waitlists for specialists or parents not following up on referrals, to name two possibilities. Lastly, he noted that we point to a lack of resources in rural areas, but we had no significant findings associated with rural status.

We attempted to address these points by acknowledging them in the Discussion. The reviewer is correct that we do not know if referrals from primary care were made prior to seeing the professional who made the initial diagnosis, or how they were handled by caregivers. We therefore deleted most of our Discussion related to this issue, and simply added the following statement when discussing the implications of our findings for screening (p. 17, first 2 sentences): *“While there may be multiple reasons for the delay in diagnosis (e.g., long wait-lists for specialists, lack of specialists in local areas, delay in follow-through after a referral is made to a specialist), one potential problem could be delays in detection by primary care physicians. Therefore, another possible implication involves the physician’s ability to make earlier referrals and/or diagnoses by using reliable ASD screening and diagnostic tools.”*

We also streamlined the Discussion section to better reflect the conclusions based on our findings, rather than simply reviewing the state of the literature. We summarized and reviewed the study findings on pp. 12-14. We also clarified that our findings did not replicate other studies showing older age of diagnosis in rural areas. However, we added additional information, based on our findings, that children from rural areas were diagnosed about 8 months later than other areas and were less likely to receive additional information from their providers. We further cautioned that these values were not statistically significant, but worthy of further research attention (Discussion, p. 15 last paragraph, continued on top of p. 16).

5. **General comments.** As suggested, we attempted to streamline the Background and Discussion sections. We shortened the Discussion by 3 pages, and made language corrections throughout the paper as needed.

Thank you again. My co-authors and I are hopeful that we have addressed the comments in a satisfactory way. I look forward to hearing your response.

Sincerely,

Angela Scarpa, Ph.D.