Reviewer's report

Title: Traditional and non-traditional seizures treatments for autism: an on-line survey.

Version: 2 Date: 20 October 2010

Reviewer: Barbara Myers

Reviewer's report:

Review—Traditional and non-traditional seizure treatments for autism: An on-line survey

This on-line questionnaire study raises important questions about treatment for seizures in individuals in the autism spectrum, including the efficacy of treatments both for the seizures themselves and for other behavioral factors. The study included about 1000 participants who reported on individuals with ASD. We currently have little information on the relative effectiveness of treatments for epilepsy, and so this is a much-needed addition.

Major Compulsory Revisions

1. The participants (the caretakers who responded) are not described. The reader needs to know the relationship of the respondent to the person with ASD. Please report the number/percentage who are mothers, fathers, other family members, hired caregivers, etc. In particular, the term “caretakers” brings to mind matrons in group homes, though I doubt that many of the individuals were living in out of home settings. The demographics of the participants are noticeably absent.

2. In the same way, the demographics of the target individuals with ASD need to be reported, including the age range, the ethnicity, etc. Table 1 eventually shows what appears to be the mean and s.d. of the age of the individuals with ASD (though this is not clearly labeled as such).

3. The authors need to make clear at multiple points that treatment efficacy is the perception of the caregivers and that this was not assessed by the researchers or reported by professionals. It is clear to me that this is what the paper is reporting, and they do say so, but it needs to be at every turn—“perception of change” rather than “improvements.”

4. In the introduction, references are needed for a number of points. For example, p. 4, 1st paragraph, “Finally, individuals with ASD can be very sensitive to medication side effects [reference needed for this], so older AEDs which tend to have higher rates of side effects [reference needed for this] might be less appropriate for individuals with ASD.”

Next paragraph—“There is reason to believe that some non-traditional
treatments may help with the frequency and severity of seizures [reference needed].”

Note, I am not questioning these points but rather ask that they be backed up with references to the literature. If no such references exist, then the points should be made in a more hypothetical way rather than as assertions of known truth.

5. I am very much concerned about the methodology for the questionnaires. Apparently, there was a separate questionnaire for caretakers of individuals with and without seizures. Why are they separate, and in what ways are they different? Does this mean that participants had to make the decision at the onset, at the point of clicking one or the other link, as to whether their family member was in the seizure group? I can picture this being a fuzzy question for the participant. (Hm, we thought maybe he had seizures when he was two, but it was never really confirmed. Or, he had seizures when he was younger but hasn’t had any since puberty. Or other scenarios of uncertainty.)

What questions do the participants in the non-epilepsy sample answer (and not answer)?

6. Page 9, the authors report that responders to the ARI advertisement used certain treatments more often than the responders to the non-ARI support group ads. How did you know? Did people report on the questionnaire where they saw the ad? What are samples of the “other” sources that advertised the study; were they mainline autism organizations or specialty subgroups of some kind? Were different questionnaires used? Importantly, how many came from each source? This should have been reported in the Methods.

7. The 733 participants who reported on the individuals’ seizures had to report on the seizure type. Were they given a checklist? Did they volunteer the type? Could they affirm several types, or just one? How confident can we be that they knew all those labels? Do families really know if their child had each of those types of seizures—do their doctors tell them, and does it make sense to them? I do not mean to question the truth of the parents’ reporting or their ability to understand, but I wonder whether doctors routinely tell parents their child had “subclinical epileptiform discharge” and whether the parent remembers that term years later. Reporting to the readers on what the parents had to answer would help here.

8. I have similar questions about the treatments. Did the participants volunteer the names of medications used, or were these provided as a checklist? Did the “control” group have the same opportunity to report on the medications? These families may have been using these same medications for other symptoms.

Similarly, were the non-traditional treatments provided as a checklist? Did both groups of respondents respond to this list? All of this should be made clear in the description of the measure and the procedure.

Did you ask questions about “tried it” versus “using now?” Did you ask if they had discontinued a treatment?
Your reported list does not include some of the behavioral treatments that are most commonly used (e.g., speech therapy, sensory integration therapy, EIBI, etc.). Did you ask about these?

9. Families are most often using multiple treatments at the same time. You need to assert this early and often! This makes it very hard to ascertain what a specific treatment is doing. There is not way to change this reality—we cannot ask families to do just one thing for 6 months—but it needs to be stated.

In particular, I am guessing that many (most?) families were using both traditional and non-traditional treatments at the same time. If so, and if they perceive a change in their child’s symptoms, how can they say which treatment was responsible? There needs to be cautionary statements about this.

10. We need a more complete explanation of Ward’s technique for cluster analysis, as this procedure is not well known. Do the clusters relate to what people used the same treatment? Or to the relationship between the treatment and some outcome?

11. What post hoc test is used (e.g., Scheffe, etc.)?

12. I find the adjustment of p value to p < .01 to be insufficient. For accuracy, you should use Bonferoni corrections and then report p values in light of that correction. This could at least be used for the contrasts within one little set of analyses.

13. The tables are not properly prepared. They cannot be published in this form.

14. Tables S7 and S8 are totally un-interpretable. I cannot even tell what they are trying to report. They are barely mentioned in the text, so there is no help there.

15. The figure (the one with 6 figures on it) is hard to understand. After studying it for a while, I figured it out, but . . . . It would help to not have them smushed onto one page and for each to have its own title. As there is no page limit, these should be prepared as individual figures with titles.

16. The authors say that a limitation of the study is the potential bias of the responders (p. 14) as individuals who use non-traditional therapies tend to be critical of traditional drug treatments. I would like for them to expand on the “potential bias” of the participants due to the study’s association with ARI. ARI (and the whole DAN movement) promote a version of ASD that is not universally accepted, to say the least. Something needs to be said about the source of the study.

Minor Essential Revisions

1. The authors provide a key for some of their abbreviations, but there are still many abbreviations that are not “translated” for the reader. These should be explained either in the text or the key.
2. In the Discussion, p. 13, please mention that the KD can be dangerous. This is likely true of some of the other treatments as well. This may be more than minor.

3. The references are inconsistently prepared. Some (many) lack dates. Some have unusual formatting. This must be cleaned up.

Discretionary Revisions

1. Table 1 lists ages for “seizure onset—resolved,” “seizure resolved—resolved,” and “seizure onset—ongoing.” There is no explanation for this, and the issues of resolved and ongoing are not addressed in the paper or in analyses. Is this important to the study?

2. Very little is reported about side effects. I would recommend either expanding this treatment considerably or leaving it for another paper. As is, it is un-interpretable.

Commentary

I am grateful that the authors conducted this study. I am obviously suggesting substantial work on the manuscript. It is a valuable study and the manuscript needs to be improved so that the field can know about its findings.

Level of interest: An article of importance in its field

Quality of written English: Acceptable

Statistical review: Yes, but I do not feel adequately qualified to assess the statistics.

Declaration of competing interests:

I declare that I have no competing interests.