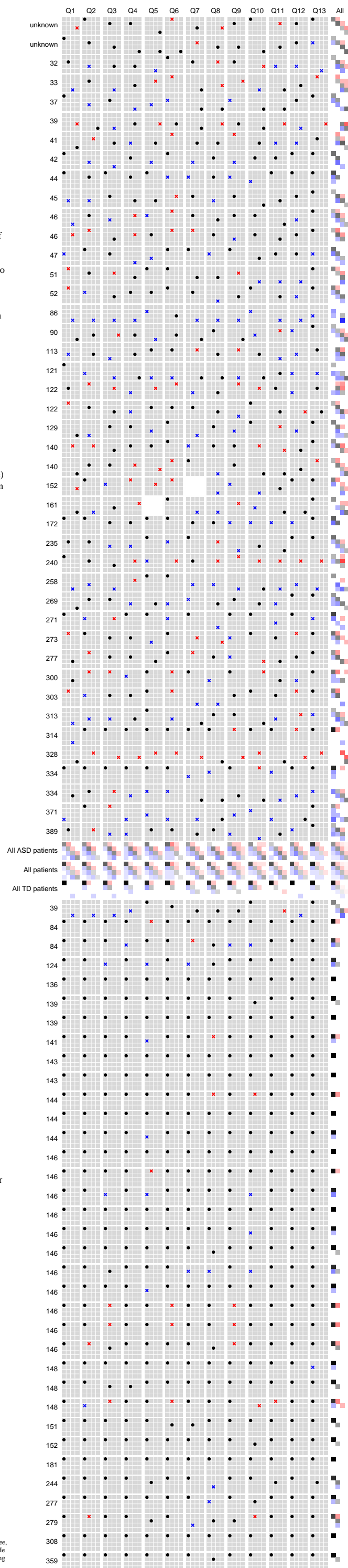


Parental Concerns Questionnaire in Autistic and Typical Children

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Note the highly variable nature of the responses here in the patients who display Autism Spectrum disorders. Illness is not defined so much by differences in mean but by differences in variability. Contrast this with the Typically Developed patients on the bottom portion of the plot.

Two missing data points are evidenced by the lack of the grey boxes. Couple this with the two unknown time differences (above) and the absence of missing data in the Typically Developed patients and one begins to wonder about randomness of missing data. Are data really missing at random or are there aspects of caring for an autistic child that render data collection much more difficult?

The comfortable structure of the Typically Developed patients is obvious here in the lower area of the plot. The patients here are generating not only consistent scores across time (evidenced by the black instead of red or blue) but also consistent 'no problem' scores. The consistency is further borne out in the clustered time differences.

This graphic shows the responses of 78 children's parents to the Parental Concerns Questionnaire at two time points. The Parental Concerns Questionnaire is composed of 13 questions, each question having 4 possible answers from 1 ('no problem') to 4 ('severe problem'). The questions each cover a specific area of child behavior: 1 – Language use and understanding, 2 – Compulsive behaviors, 3 – Anxiety, 4 – Sensory issues, 5 – Sleep disturbance, 6 – Aggression, 7 – Hyperactivity, 8 – Attention span, 9 – Mood swings, 10 – Eating habits, 11 – Social interactions, 12 – Self-stimulatory and repetitive behaviors, 13 – Self-injurious behaviors. At each of the two time points, parents were to describe the extent of the problem within the past month.

Each row shows the responses for one child (patient), with each column showing the response to one question. The grey square therein is further divided into four subrows and four subcolumns corresponding to response at the first time point (the subrows) and the response on the second time point (the subcolumns). A response of '1' at the first time point and '1' at the second time point is in the upper-left corner of the grey box; (4,4) is in the lower-right corner. Responses that show no change between time points for a patient are shown with black dot. Changes are shown with an 'x', increases in severity in red, decreases in blue. Therefore, a worsening from a '3' at the first time point to a '4' at the second time point on question 1 (as in the first patient, far left, top row) is a red 'x' in the third subrow and fourth subcolumn. Each patient is summarized at the far right of that row with a grid of shaded boxes corresponding to the responses on the individual items. The intensity of the shading shows the percentage of responses in that cell, with white showing 0% and the darkest color showing 100%. As such, the summary distribution shows the overall consistency of responses across all the questions and across the two time points within a patient.

The patients are divided into two groups. The patients in the top portion of the plot display Autism Spectrum disorders (ASD) while the patients in the bottom portion of the plot are Typically Developed children (TD). Each of these groups is summarized for each question and for all the questions on the appropriate rows in near the center of the plot. The entire group of 78 patients is also presented ('All patients').

Although the original design sought to collect readings approximately 20 weeks apart, ie, 140 days, not all of the patients had the same amount of time between the two time points when responses were garnered. To display any effect of these differing time lags, patients are sorted within each group in order of the time between the two readings. These differences (in days) are shown on the left margin of each row. Two patients in the ASD group had unknown time differences and are labeled as such.

A number of conclusions are available from the graphic. A simple cursory view of the plot shows the dramatic differences between the ASD patients and the TD patients. The variability between the time points (as evidenced by the numerous reds and blues) in the ASD patients in the top portion of the plot provides a stark contrast to the even and perhaps even rigid consistency of the TD patients on the bottom. This drastic difference is evident on the individual questions and in the summaries across the questions within each patient. The TD children live in a completely different world from the world of the ASD children; almost all of the TD children present a score of '1' at each time point for each question.

Two ASD patients have missing data, one on question 5 and one on question 7. Also, two ASD patients have missing time lag differences.

The summaries across the questions for the two groups show differences as well. Note, for example, the differences in the distributions for the ASD patients between questions 4 (Sensory issues) and 5 (Sleep disturbance). The question 4 distribution carries most of its mass near the center (responses of 2 and 3, 'mild' and 'moderate' problem), while the question 5 distribution carries much more of its mass near '1'. Question 6 (Aggression) shows a more balanced distribution while question 10 (Eating habits) is more stable but has mass at both the '1' and '4' extremes, an 'all-or-none' kind of situation.

The investigators were interested in the reliability of this instrument over time; hence, the two readings at two time points. The distribution of time lags, however, points to what may be a fatal flaw in the data's ability to answer that question. Note the smooth and relatively even distribution of times for the ASD patients — barring the 'unknowns', only 4 time differences (46, 122, 140, and 334 days) show more than one patient with the same time between readings. On the other hand, the TD patients on the bottom have 25 of 35 patients between 136 and 152 days, including 11 on 146 days. The ASD patients only have 3 of 43 patients with documented differences in that same time frame. Why is there this difference between the patient groups and how might this influence the reliability of the instrument?

A few patient anomalies exist as well. The first patient in the TD group, with a time difference of 39 days, has a pattern of responses that is much more consistent with the ASD patients than with the TD patients. In contrast, two patients in the ASD group, those with 314 and 334 days, have a pattern of responses that more closely resembles the TD group. Could these patients be mis-classified?

This plot demonstrates the dramatic differences that parents of children with Autism Spectrum disorders face relative to parents of Typically Developed children. Unfortunately, due to how these differences present themselves in the time lags between visits, the primary question of 'Can this tool be used reliably to assess changes in autism patients?' cannot be answered. The tool is highly reliable at all time points in Typically Developed children (who essentially have no symptoms) but it shows little consistency in children with Autism Spectrum disorders. It does not appear that this lack of consistency changes with the passage of time.