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Effects of written disclosure on psychophysiological stress among parents of children with autism: A randomized controlled pilot study

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ABSTRACT

Background: In comparison to parents of typically functioning children or parents of children with other developmental disabilities (i.e. Down’s syndrome or cerebral palsy), parents or caregivers of children with an autism spectrum disorder (ASD) sustain a greater incidence of depression, anxiety, and emotional distress. It is imperative to identify effective methods that target improvement to caregiver mental health.

Method: A randomized controlled pilot study was conducted to investigate the effect of a written disclosure intervention (expressive writing about traumatic events versus neutral events) on the psychophysiological stress of 71 parents (age 23–62) caring for a child with ASD. Self-reported measures of stress (parenting stress, caregiver burden, and global stress) and a stress biomarker (cortisol awakening response) were evaluated at baseline and 6-month follow-up. Adjusting for baseline values, we performed a univariate analysis of covariance to test directional hypotheses that parents in the treatment group would show a reduction in subjective stress and improvement in physiological stress over time.

Results: As expected, treatment group parents displayed healthier cortisol activity and reported less global stress compared to controls. Whereas within group analyses indicated all parents experienced improvement in parenting stress and caregiver burden over time, there was no significant treatment effect for these caregiving-specific stress measures.

Conclusions: Within this pilot study, written disclosure appeared beneficial to caregiver psychophysiological stress. However, due to the provision of substantial participant adherence support, we refrain from suggesting feasibility. Nonetheless, improvement of mental health pathology in parents of children with ASD is both significant and timely.

Some research has indicated positive results associated with parenting a child with autism spectrum disorders (ASD), such as increased spirituality (Ekas, Whitman, & Shivers, 2009), acceptance of differences, and heightened compassion (Pakenham, Sofronoff, & Samios, 2004). However, accumulating evidence maintains that a large majority of parents caring for a child with ASD experiences deleterious mental and physical health consequences. Studies have reported unfavorable parent outcomes such as elevated anxiety (Lecavalier, 2004), poor health-related quality of life (Allik, Larsson, & Smedje, 2006; Khanna et al., 2011), irregularities in cortisol production and immune system dysfunction (De Andrés-García, Moya-Albiol, & González-Bono, 2012; Lovell, Moss, & Wetherell, 2012), and heightened parental stress (Barroso et al., 2017; Dunn et al., 2001). Moreover, parents or caregivers of...
children with ASD sustain a greater incidence of parenting stress, depression, and psychological distress compared to parents of children with other developmental disabilities such as Down’s syndrome, cerebral palsy, or fragile X syndrome (Abbeduto et al., 2004; Estes et al., 2009; Hayes & Watson, 2013; Mugno et al., 2007; Smith et al., 2008; Weiss, 2002).

With the high prevalence of children diagnosed with ASD (Wingate et al., 2014) and the many challenges that parents may face, it is imperative to identify effective methods that target improvement to caregiver mental health. Previous research offering “treatment” for caregivers of children with ASD focused on improving the child’s behavior or providing parent education to increase parental understanding of autism (Da Paz & Wallander, 2017). Rather than targeting parent health, researchers evaluated the effectiveness of these programs on outcomes specific to children with ASD, such as behavior management or improvement in language and social skills (McConachie & Diggle, 2007). While these approaches are commendable, subsequent investigations have recognized the need to target parent mental health and evaluate treatments that improve well-being (Dababnah & Parish, 2016). Interventions such as mindfulness-based stress reduction (Dyken et al., 2014; Ferraioli & Harris, 2013; Neece, 2014), relaxation therapy (Gika et al., 2012), and cognitive behavioral therapy (Feinberg et al., 2014; Lunsky et al., 2017) have shown promise in the attenuation of psychological pathology for parents of children with ASD. However, work still remains to expand intervention variety and improve methodological limitations such as, few randomized controlled trials, small sample size, and inconsistent measurement of parent outcomes (Dababnah & Parish, 2016). Moreover, poor parent mental health not only affects the parent, it has also been linked to unfavorable outcomes for the child, such as, reduced effectiveness of child gains acquired through early intervention (Osborne et al., 2008) and increased child behavioral problems (Barroso et al., 2017; Tomanik, Harris, & Hawkins, 2004).

In addition, a parent’s ability to access to their own treatment might be hindered due to time constraints caused by their child’s behavior intervention sessions which typically occur three to five days per week at an average of two to six hours per day (Granpeesheh et al., 2009). The prohibitive costs typically associated with many psychological interventions might also serve as a deterrent or barrier to treatment for most parents (Wallander, Madan-Swain, Klapow, & Saeed, 2011). To address these barriers and expand evidence-based interventions targeting parent mental health, this study evaluated written disclosure (WD), a treatment that is efficient with both, cost and time.

Developed by Pennebaker and colleagues, WD provides an outlet for the private expression of traumatic events yielding health benefits over time. Pennebaker and Beall (1986) operationally define trauma as a “personally upsetting experience.” Henceforth, references to trauma within this manuscript will be synonymous to Pennebaker’s definition. Standard writing protocol proposes three consecutive days of writing about the same topic or different topics across writing sessions. Several “doses” of writing have been examined (ranging from one to five days) and found to be unrelated to treatment effect size (Frattaroli, 2006; Sloan & Marx, 2004; Smyth, 1998). Health improvements are usually observed 3–6 months later and typically not immediately post-treatment, despite only requiring three 20-min sessions of uninterrupted writing, making it extremely economical and convenient.

Participants are randomly assigned to one of two conditions, the WD condition (treatment) where they are instructed to write about the most traumatic experience of their lives, preferably not shared with anyone, or control condition where they write about a neutral topic, one that does not elicit distressing emotions. Although this study focuses on parents of children with ASD, we purposely chose not to instruct them to write specifically about traumatic parenting experiences concerning autism. Research has shown that intervention effects are less successful when participants are given more constrained or focused writing topics (Sloan & Marx, 2004; Smyth & Pennebaker, 2008). Rather, they need to be able to bring forth the area of most concern for themselves. Thus, this study maintained standard protocol and encouraged treatment participants to choose their own experience of trauma as their writing topic.

For over three decades of written disclosure research, scientists (including founder Pennebaker) have been unable to pinpoint one single mechanism that can account for effects experienced by all participants (Pennebaker & Chung, 2007; Sloan & Marx, 2004). In their seminal study, Pennebaker and Beall (1986) posited that the expression of undisclosed trauma maintained by inhibition might be associated with health benefits over time. For example, healthy college students reported improved mood and reductions in blood pressure, six months after completing four consecutive days of writing about a traumatic event (Pennebaker & Beall, 1986). In a similar study, after three consecutive days of writing about their trauma, adolescents experiencing chronic abdominal pain reported fewer pain experiences and fewer health care visits compared to controls who wrote about a neutral topic describing activities in their daily life (Wallander et al., 2011). Subsequent studies have compared written disclosure to exposure therapy, due to the similarities of repeated exposure or repetitive confrontation of painful memories at each writing session (Sloan, Marx, & Epstein, 2005). However, findings have been inconsistent, with some studies indicating improvement in self-reported psychological distress (Stanton et al., 2002) and some finding no physiological benefit due to the effects of repeated exposure (Kloss & Lisman, 2002).

Hence, converging evidence suggests no single mechanism or all-encompassing theory that explains the treatment effect of the writing paradigm. Overlapping explanations with multi-leveled factors interact to evoke healthy adaptation, with each level governed by the focus of analysis, whether physiological (e.g., optimal functioning of the HPA axis or other autonomic health indices) or psychological (e.g., reductions in mental pathology or improved well-being). Pennebaker posits that the actual mechanisms influencing health outcomes are multi-leveled with numerous interacting components (Pennebaker & Chung, 2007). Regardless of lacking a definitive process catalyst, WD has resulted in significant psychophysiological improvements across numerous populations (Lepore & Smyth, 2002; Smyth & Pennebaker, 2008).

We conduct here a pilot study, using a randomized controlled design, to evaluate the effects of WD on caregiver psychophysiological stress. We hypothesize that parents who write about traumatic events in the treatment condition would display at 6-month follow-up: (1) improved physiological stress as indicated by salivary cortisol reactivity; and (2) reduced subjective stress as measured by global stress and caregiver-specific stress (parenting stress and caregiver strain), compared to parent controls who write about a neutral topic.
1. Methods

1.1. Recruitment

Participants were recruited via agencies that serve children with ASD, including regional centers, in-home behavioral support agencies, and local school districts. Over a period of 18 months, five waves of recruitment flyers were provided for agency distribution via mail or school distribution via classrooms. Interested parents called or emailed the research lab, yielding 121 screened participants.

1.2. Eligibility and enrollment

Eligibility criteria stipulated that a participant: (1) was the primary caregiver of a child diagnosed with ASD; (2) would provide documentation (i.e., psychologist report from school, pediatrician, or regional center) of the child’s ASD diagnosis for verification purposes; and (3) the child with ASD was between the ages of 3 and 18 years. As shown in the CONSORT Flowchart in Fig. 1, only three parents were ineligible for not having a qualifying child with ASD. A further 16 declined participation, citing issues with family, time conflicts, transportation, or wanting parenting classes on stress and autism. The remaining 102 were scheduled for assessment, but 31 did not show up for their appointment and efforts to reschedule were unsuccessful. In total, the study enrolled 71 parents.

Fig. 1. CONSORT flowchart for recruitment and study enrollment. CAR = cortisol awakening response.
1.3. Procedures

All study procedures were approved and in accordance with the ethical standards of the University Institutional Review Board (IRB). Participants were screened via phone to determine eligibility prior to scheduling an assessment appointment. Informed consent was obtained from all participants included in the study. The standard informed consent process was supplemented with a verbal explanation of the consent form and a copy was provided to each participant. Research appointments were held in the University lab or in private rooms within community agencies serving clients with ASD.

1.4. Data collection/intervention timeline

Parents who provided informed consent to participate in the study were mailed saliva collection instructions and four saliva tubes for in-home sample collection (see below for detailed saliva collection procedures). After collecting two days of saliva, parents brought the samples to their baseline assessment appointment that was conducted in the University lab or community location. At the baseline appointment, participants (1) completed all psychosocial questionnaires; (2) were randomized into treatment conditions (see below for randomization procedures) and (3) completed their first day of writing. Participants then received writing instructions and paper to complete the remaining two days of writing at home.

1.5. Follow-up assessments and participation incentives

Follow-up assessments included the collection of saliva samples and the completion of psychosocial questionnaires. Saliva samples were collected in-home using the identical collection protocol as baseline. Follow-up appointments were conducted in the University lab or community location six months (range 24–28 weeks) after the baseline assessment was completed. Participants received a $25 gift card after completing both assessment appointments.

1.6. Randomization, allocation concealment, and blinding

Using a block randomization technique of varying block sizes (4 to 6), research staff not involved in conducting assessments placed individual treatment assignments and writing instructions in a set of opaque envelopes and sealed them to prevent knowledge of the treatment group contained within. Sealed envelopes were thoroughly shuffled by a different staff member, sequentially numbered, and placed in a locked file cabinet. After completing baseline assessments, the experimenter gave participants the next unopened envelope in the predetermined sequence. Participants were told that they would write about various topics. Unaware of the specific writing conditions (traumatic or neutral), participants were blinded to treatment allocation.

1.7. Intervention conditions

Participants were given a 20-min writing task to be completed on each of three days. Standard writing task instructions were replicated from WD research by Pennebaker (see Schwartz & Drotar, 2004 for exact script). The first writing session was conducted at the baseline appointment after participants were randomly assigned to one of two conditions: (1) WD treatment condition where participants wrote about the most traumatic experience in their lives (see Schwartz & Drotar, 2004 for exact script), or (2) control condition, where they were instructed to write about what they did last summer (neutral topic). The participant completed the two remaining writing sessions according to the same instructions within the next five days in their homes or a location of their choosing. To maintain intervention adherence, the participant was phoned at an agreed upon time and reminded to complete their next writing session. They were provided with self-addressed stamped envelopes to return their completed writing. Participants also received a reminder call to mail their writing, if it had not been received within a week after their last scheduled writing task.

1.8. Manipulation checks and intervention adherence

In consideration of WD meta-analysis findings that number of writing sessions were unrelated to effect size (Smyth, 1998), we determined intervention adherence as participant completion of at least two of the three days of writing samples. All 71 participants met intervention adherence criteria. Prior to text analysis, two independent coders blinded to the intervention read each narrative and coded whether the events described were traumatic (i.e. a personally upsetting experience) or not. Inter-rater reliability was examined by calculating total agreement between the two coders divided by the total number of narratives read. Percent agreement between the observers was 90%. For descriptive purposes, we also examined each narrative for writing topics using the Linguistic Inquiry and Word Count (LIWC) text analysis program (Pennebaker et al., 2015). The LIWC program employs an extensive algorithm that analyses text and classifies words according to a comprehensive list of word categories that capture multiple constructs (Pennebaker, Boyd, & Blackburn, 2015; Tausczik & Pennebaker, 2010). The software evaluates each word within the text file and matches it to a particular domain. For example, words like “I, me, mine,” contained within the text would be categorized and counted as personal pronouns. In these cases, assignment to categories was done by a software program and not by an independent coder. The LIWC procedure of categorization has demonstrated strong internal consistency reliability across several psychological domains.

To determine adherence to writing instructions and condition assignment, essay content was examined using the LIWC psychological processes category (e.g., positive emotion and negative emotion) was targeted for analysis. We tested intervention fidelity by
comparing treatment and control group writing for words conveying positive emotion (e.g. fun, happy, likes, etc.) and negative emotion (e.g. bad, miserable, fight, etc.). We hypothesized that writing about traumatic events would include a greater number of negative emotion words compared to neutral writing. We further tested indications of writing about traumatic experiences by examining both conditions for words contained within the anxiety, anger, and sadness categories (e.g. worry, stress, crying, depressing, etc.).

1.9. Outcome measures

1.9.1. Perceived stress

The participant’s perception of global stress was evaluated with the 10-item self-report Perceived Stress Scale (PSS) (Cohen & Williamson, 1988), which uses a 5-point response scale ranging from 0 (never) to 4 (very often). Participants were asked how often they have felt a certain way in the last month (e.g., “How often have you felt nervous or stressed?” and “How often have you felt that you were on top of things?”). PSS scores are obtained by reverse coding the four positively stated items (items 4, 5, 7, & 8) and then summing across all scale items, with a higher score indicating greater perceived stress (Cohen, Kamarck, & Mermelstein, 1983). Within the current sample, the PSS demonstrated high internal-consistency reliability with a Cronbach’s alpha of .85.

1.9.2. Caregiver strain

The burden of caring for the child with ASD was assessed with the Caregiver Strain Questionnaire (CGSQ), a 21-item self-report scale (Brannan, Heflinger, & Bickman, 1997) that measures strain associated with caregiving. The caregiver is asked, “How much of a problem each occurrence or feeling was in the past 6 months as a result of your child’s problems?” Responses are provided on a 5-point scale ranging from 1 (not at all a problem) to 5 (very much a problem). The CGSQ demonstrated high internal-consistency reliability (α = .93) for the current sample. Global caregiver strain is calculated as the mean of all 21 items. A higher score indicates higher perception of strain associated with caregiving.

1.9.3. Parenting stress

The 36-item self-report Parenting Stress Index-Short Form (PSI-SF) assessed stress associated with parenting (Abidin, 1990). Derived from the full 120-item PSI, the PSI-SF contains three subscales: (1) difficult child, (2) parental distress, and (3) parent-child dysfunctional interaction. Each subscale contains 12 items measured on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). A total PSI score is calculated by summing each subscale total, with higher scores indicating greater perceived parenting stress. Within the current sample, the PSI demonstrated high internal-consistency reliability, α = .92.

1.9.4. Salivary cortisol

The cortisol awakening response (CAR) was assessed as an objective biomarker of stress across two days, separately at baseline and six-month follow-up. Caregiver salivary cortisol was collected at waking and 30 min post-waking with CAR calculated as the average change in cortisol concentrations from waking to post-waking (Stalder et al., 2016; Wüst et al., 2000). CAR was assessed across two consecutive weekdays, given that perceived workload or anticipated challenges of the day are typically predictive of greater CAR during weekdays versus weekends (Kunz-Ebrecht et al., 2004; Schlotz et al., 2004).

Saliva samples were collected using Salivette collection tubes (Sarstedt Co. Ltd., Nümbrecht, Germany). After obtaining informed consent, participants were mailed collection kits that included: four collection tubes labeled with participant ID and collection number; a plastic bag labeled with participant ID for storing collected samples; and both written and pictorial collection instructions. For quality assurance, the instructions also informed participants to refrain from foods with high sugar, acidity (e.g., orange juice), and high caffeine content (e.g., coffee or energy drinks) for 12 h preceding sample collection. In addition, participants were instructed to refrain from eating, drinking, or brushing their teeth 12 h before sample collection.

To ensure collection fidelity, research staff called participants in the morning at an agreed upon time when the participant expected to wake up and followed a protocol script to guide participants through the collection process. This included timing the participant for two minutes with the salivette under their tongue and calling back 30 min later for the second collection. At each saliva collection, research staff assessed medication intake and strenuous physical activity within the past 12 h. Other than over-the-counter aspirin or acetaminophen, there were no reports of contraindicating medications (Granger et al., 2009). After two days of saliva collection, participants brought their frozen samples to their assessment appointment. All samples were stored in a −20°C freezer until assay procedures were performed. thawed samples were centrifuged and assayed in duplicate with a test volume of 25 μL. A commercially available enzyme immunoassay kit was used, without modifications to the manufacturer’s recommended protocol (Salimetrics, State College, PA). The range of sensitivity was from 0.007 to 3.0 μg/dL. Intra-assay and inter-assay coefficients of variation were below 15%.

1.10. Statistical analysis

Analyses were conducted using SPSS, Version 23 (SPSS Inc., 2016). Independent samples t tests and χ² analyses, where applicable, were performed to test for baseline group differences in demographics and outcome measures. A univariate analysis of variance (ANOVA) was conducted to assess whether there were any significant baseline differences between parents who completed follow-up assessments and those who did not. Using a one-tailed test of significance controlling for baseline scores, we performed a univariate analysis of covariance (ANCOVA) to test our directional hypotheses that expected improvements in psychophysiological stress over
time for treatment parents. In the case of significant results, at one-tailed $p < 0.05$, effect sizes using Cohen’s $d$ (Cohen, 1990) were computed. Cortisol data was positively skewed, requiring a logarithmic transformation to normalize the distribution.

1.11. Intent-to-Treat analysis

A missing values analysis of 6-month follow-up data indicated that 12 cases (23%) had missing data. We performed Little’s MCAR test (Little, 1988) and determined that data were missing completely at random ($X^2 = 10.77; df = 11; p = 0.46$). To avoid a reduction in sample size and loss of statistical power, we conducted an intent-to-treat analysis (ITT) by imputing missing values on all outcome variables using the expectation-maximization algorithm (EM). This yielded data for a complete sample size of 71 participants at 6-month follow-up.

1.12. Sample size summary

An a priori power analysis indicated a sample size of 102 (at least 51 subjects in each of the two groups) was required to have 0.8 power for detecting a medium effect size ($d = 0.50$) on the primary outcome of psychological stress.

2. Compliance with ethical standards

2.1. Ethical approval

All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. All participants provided written, informed consent using IRB approved procedures.

3. Results

3.1. Participant characteristics

This study provided a diverse and representative sample of participants based on the population area. For example, Table 1 shows that caregivers were Hispanic (48%) and Caucasian (33%) women, with a mean age of 39 years. A majority were married or

<table>
<thead>
<tr>
<th>Table 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant Descriptive Statistics by Treatment at Baseline.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>WD (n = 36)</th>
<th></th>
<th>Control (n = 35)</th>
<th></th>
<th>Total (n = 71)</th>
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</thead>
<tbody>
<tr>
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<td>%</td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Parent Age, mean (SD)</td>
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<td>39.89 (10.06)</td>
<td>39.66 (10.11)</td>
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<td></td>
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<tr>
<td>Child with ASD Age, mean (SD)</td>
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<td>8.34 (4.62)</td>
<td>8.17 (4.49)</td>
<td></td>
<td></td>
</tr>
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<td>Education</td>
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<td>High School or less</td>
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<td>5</td>
<td>14</td>
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<td>Marital status</td>
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<td>Divorced/separated</td>
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<td>28</td>
<td>4</td>
<td>11</td>
<td>14</td>
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<td>Married/cohabitate</td>
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<td>3</td>
<td>9</td>
<td>5</td>
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<tr>
<td>Race</td>
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<td>53</td>
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<td>16</td>
<td>46</td>
<td>25</td>
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<tr>
<td>African American</td>
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<td>2</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Asian</td>
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<td>3</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>11</td>
<td>2</td>
<td>6</td>
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<td>&gt; $10,000</td>
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<td>6</td>
<td>6</td>
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<td>3</td>
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<tr>
<td>&lt; $100,000</td>
<td>4</td>
<td>11</td>
<td>6</td>
<td>17</td>
<td>10</td>
</tr>
</tbody>
</table>

Note. WD = written disclosure. WD and Control conditions did not differ significantly ($p < 0.05$) on any of these characteristics.
cohabitating (73%) and college educated (54%), caring for a male child with ASD (97%) with a mean age of 8 years.

3.2. Analyses of randomization and attrition

Conditions did not significantly differ on demographic and child-related variables (see Table 1) or treatment outcomes at baseline (see Table 2). Compared to parents who completed all assessments, parents lost to follow-up reported higher caregiver strain at baseline, $M = 3.20$ vs. $2.47; F(1,69) = 7.81; p < .001$. There were no other differences related to loss at follow-up.

3.3. Manipulation checks and intervention adherence

We examined the content of each group’s writing to calculate descriptive statistics for each writing topic by condition. We also examined each written narrative to determine (1) whether participants adhered to writing instructions and (2) whether there were significant group differences in writing content. An independent coder identified all treatment group content as traumatic (i.e. describing a personally upsetting experience). As shown in Table 3, treatment group participants wrote about a variety of traumatic experiences. A majority (25%) wrote about negative experiences associated with autism (e.g. “By far the most traumatic experience for me was the diagnosis of autism.”). Death of a loved one and divorce or breakups were the second largest treatment group writing topics (19%; e.g. “It was a very traumatic time in my life, after she passed away.” and “The most traumatic and upsetting thing to me was finding out the man I thought I would spend the rest of my life with was a liar.”). When combined, topics that disclosed abuse or violence against the participant accounted for almost one third of treatment writing topics (e.g. rape (16%), child abuse/sexual molestation (9%), and domestic violence (6%)). Control group writing included three topics, vacations (52%), summer fun activities (44%), and positive experiences with autism (4%).

Independent t-tests were performed to examine group differences between written content that conveyed positive emotion versus

Table 2
Results for Intent-to-Treat Analysis of Treatment Outcomes.

<table>
<thead>
<tr>
<th>Outcome (Measure)</th>
<th>Observed Means (SD)</th>
<th>Intent-to-Treat Analysisa</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>6-month Follow-up</td>
</tr>
<tr>
<td></td>
<td>WD (n = 36)</td>
<td>Control (n = 35)</td>
</tr>
<tr>
<td>Perceived stress (PSS)</td>
<td>22.69 (6.14)</td>
<td>19.63 (7.15)</td>
</tr>
<tr>
<td>Caregiver strain (CGSQ)</td>
<td>2.64 (0.95)</td>
<td>2.56 (0.84)</td>
</tr>
<tr>
<td>Parenting stress (PSI)</td>
<td>129.08 (26.89)</td>
<td>133.06 (25.03)</td>
</tr>
<tr>
<td>CAR</td>
<td>2.77 (2.41)</td>
<td>4.14 (3.21)</td>
</tr>
</tbody>
</table>

Note. WD = written disclosure; PSS = Perceived Stress Scale; CGSQ = Caregiver Strain Questionnaire; PSI = Parenting Stress Index; CAR = Cortisol Awakening Response.

** Data imputed using expectation-maximization (EM).

b Follow-up outcomes analyzed with ANCOVA using baseline values as covariates.

*** p < 0.001.

* p < 0.05.

Table 3
Caregiver Writing Topics by Condition.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Writing Topic</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment</td>
<td>Autism (negative experiences; e.g. receiving diagnosis)</td>
<td>25%</td>
</tr>
<tr>
<td></td>
<td>Death of a loved one</td>
<td>19%</td>
</tr>
<tr>
<td></td>
<td>Relationship difficulties (e.g. divorce or breakups)</td>
<td>19%</td>
</tr>
<tr>
<td></td>
<td>Rape and/or Assault (e.g. animal attack or robbery)</td>
<td>16%</td>
</tr>
<tr>
<td></td>
<td>Child abuse/sexual molestation</td>
<td>9%</td>
</tr>
<tr>
<td></td>
<td>Domestic violence</td>
<td>6%</td>
</tr>
<tr>
<td></td>
<td>Serious accidents/injuries</td>
<td>6%</td>
</tr>
<tr>
<td>Control</td>
<td>Vacation or trips</td>
<td>52%</td>
</tr>
<tr>
<td></td>
<td>Summer fun activities (e.g. swimming or amusement parks)</td>
<td>44%</td>
</tr>
<tr>
<td></td>
<td>Autism (positive experiences; e.g. personal growth)</td>
<td>4%</td>
</tr>
</tbody>
</table>
negative emotion (see Table 4). Treatment group participants significantly differed in writing words expressing negative emotion compared to controls ($M = 2.97$ vs. $0.97$; $p < .0001$). On the contrary, control group participants wrote significantly more words denoting positive emotions compared to the treatment group ($M = 3.76$ vs. $2.48$; $p < .001$). Moreover, in describing their experiences, treatment participants wrote significantly more words that contained feelings of anxiety, anger, and sadness ($p < 0.001$ for each category).

### 3.4. Treatment outcome analysis

#### 3.4.1. Perceived stress

Parents in the treatment group reported less perceived stress at 6-month follow-up compared to parents who wrote about a neutral topic. As shown in Table 2, results of ITT analyses yielded a significant treatment effect, $F(1,69) = 10.60; p < .001$. The model predicted 14% variation in parents’ report of perceived stress with a small effect size of $d = .18$. These results are similar to analyses that did not apply ITT, $F(1,56) = 9.14; p < .001$; $d = .19$.

#### 3.4.2. Caregiver strain

There was a significant effect of time on caregiver strain, for both observed and imputed values, $F(1,55) = 5.52; p = 0.01$; $F(1,69) = 12.41; p < 0.001$, respectively, but there was no effect due to treatment condition. These results remained non-significant also for the ITT.

#### 3.4.3. Parenting stress

Whereas there was no significant treatment effect, parenting stress was reported significantly better for all participants over time, $F(1,56) = 7.64; p < .001$. These results are similar to analyses that did not apply ITT, $F(1,69) = 14.05; p < .001$.

#### 3.4.4. Salivary cortisol

As shown in Table 2, results indicated a significant treatment effect for CAR at 6-month follow-up, $F(1,39) = 5.07; p = 0.01$. The model predicted 12% variability in CAR with a medium effect size of $d = 0.74$. This treatment effect was also significant prior to the performance of an ITT, $p = 0.01$.

### 4. Discussion

It is well documented that parents of children with ASD experience chronic stress associated with caring for a child with ASD (Abbeduto et al., 2004; Miodrag & Hodapp, 2010). Research has shown significant associations between chronic stress and poor health in both, clinical and nonclinical populations (Barroso et al., 2017; Miller, Chen, & Zhou, 2007). This study hypothesized that providing a written outlet for parents to express their emotional difficulties might therapeutically attenuate reports of psychological distress (i.e. caregiving strain, perceived stress, and parenting stress) and improve physiological stress (i.e. cortisol reactivity). Study results indicated that the cortisol awakening response was significantly lower in the treatment group compared to controls at six month follow-up. In addition, parents who wrote about personally upsetting incidents (traumatic events) at baseline reported lower perceived stress compared to controls at the six month evaluation. These findings are consistent with previous WD studies that demonstrated salutary effects occurring over time. In addition, the inclusion of an objective biomarker of stress tested within the framework of a randomized controlled-trial offered a robust method of investigation, particularly since effect sizes have commonly shown greater magnitudes in physiological outcomes evaluated within the WD literature (Smyth, 1998). Likewise, the current study results showed stronger physiological effects of cortisol reactivity compared to perceived stress evaluated subjectively. Thus, the inclusion of objective biomarkers might be essential in future examinations of treatments previously overlooked due to insignificant self-reported outcomes.

Pennebaker’s initial theory posited that written disclosure was effective due to the expression of thoughts and feelings about a previously undisclosed trauma. In this study, participant reports of rape, childhood molestation, domestic violence, and being physically abused by your child with ASD, might not have been disclosed out of fear of judgement, shame, or stigmatization delivered
by others. Studies have shown that efforts to maintain concealable stigmas have led to a host of negative psychological consequences (Pachankis, 2007). Favorably, WD allows for confidential self-disclosure without the associated anxiety or threat of discovery. For example, when describing traumatic experiences, some study participants specifically indicated that they had not shared their feelings with others:

“I told no one and carried my shame alone.”
“I was alone and secluded myself from everyone. No one knew.”
“I still think about it, but… I never talk about it.”
“Someday, I hope I will be able to talk about it more openly.”
“We have a big beautiful home and no one knows from the outside the tears shed by the minute.”
“No one was told in my family.”

Although Pennebaker writing protocol instructed treatment participants to write about experiences not shared with others, nondisclosure was not consistently noted. Considering this question was not asked post-writing sessions, other participants may have written about experiences they had not revealed to anyone. Hence, adding a question of disclosure history might be useful in future studies to determine whether differential effects exist between previously disclosed versus undisclosed trauma.

### 4.1. Treatment to benefit parents directly

Researchers have administered and evaluated the effects of two treatment modalities for parents of children with ASD: (1) parent training, improving parenting skill and (2) parent education, increasing parent knowledge. However, a growing number of studies have targeted parent-focused outcomes such as maternal depression and stress management with methods ranging from mindfulness interventions and parent-clinician partnerships to relaxation training and manual-based stress reduction practices (Da Paz & Wallander, 2017). The current research joins this emerging trend by directly targeting improvement in parent outcomes, rather than relying on indirect collateral effects of child-focused treatment. Compared to the normed average of psychological stress for similar aged women (Cohen & Janicki-Deverts, 2012), study parents’ report of perceived stress at follow-up exceeded the national norm (M = 19.80 vs. 16.94), even after treatment. Moreover, parents lost to follow-up reported greater caregiver strain at baseline compared to those who completed all assessments. This is just another example of the importance of addressing caregiver health. Parents reporting more distress are the same parents who are most at risk of treatment dropout, thereby, failing to receive treatment and potentially exacerbating their circumstances.

### 4.2. Limitations

Treatment group parents showed improvement in global stress outcomes of perceived stress (PSS) and cortisol reactivity (CAR). However, there was no significant treatment effect for caregiver strain (CGSQ) and parenting stress (PSI). Quite possibly, caregiving-specific subjective stress was not attenuated due to the parent’s chosen writing topic of trauma. When presenting the writing instructions, we did not instruct parents to write specifically about parenting a child with ASD. Rather, we elected to provide them the freedom to access their most traumatic experiences, which may or may not be ASD-related. Given this choice, 75% percent of parents described personal issues other than negative experiences associated with parenting, such as childhood trauma, sexual assault, and emotional upheavals because of relationship difficulties. Only 25% of parents wrote about experiences related to ASD. Common themes depicting ASD and parenting trauma included: (a) receiving the ASD diagnosis, e.g. “I felt like I was hit by a BUS!!”; (b) experiencing intense child tantrums, e.g. “I endured (my son) kicking, hitting, punching, and yelling at me…”; and (c) losing a spouse due to the child’s disability, e.g. “Their dad eventually moved out in the next few months (after the ASD diagnosis) and left me to deal with it all alone.” Future studies might explore differences in treatment effects between the traditional WD intervention conditions (self-chosen trauma vs. neutral topic) and parent groups specifically writing about their parenting experiences with ASD, both positive and negative.

To protect parents’ right to confidentiality, recruitment sources could not provide any parent names or contact information for research staff to recruit directly. Consequently, parents had to initiate the screening process, which limited study enrollment and resulted in a relatively small sample size. As such, this pilot study may not claim high external generalizability. In addition, the small sample size underpowered the study, which further challenged our ability to detect meaningful treatment effects for caregiving-related stress outcomes. Recruitment and retention is a common problem in studies with parents experiencing chronic stress combined with caring for a child with a behavior disorder such as ASD (Kazdin, 1990). Future studies might consider a more personal and direct recruitment strategy, such as sending research staff to screen and recruit potential participants from community locations where parents might gather (e.g. pediatrician’s office or autism treatment centers). However, such an endeavor might require substantial funding or other mechanisms to compensate research staff. This pilot study had limited financial resources, another factor that might be considered as a limitation.

Finally, this pilot sought to evaluate the feasibility of implementing a purported time-efficient and cost-effective intervention to caregivers of children with ASD. Whereas, the WD intervention delivery protocol might be a simple one, certain logistics employed to evaluate this intervention among caregivers was challenging. Numerous research staff was essential for calling parents to aid in
cortisol collection and delivering reminders for intervention adherence. Even with this support, the study still experienced an 18% rate of attrition. Future investigations might employ technological platforms to simplify the intervention delivery method such as completing writing online with electronic reminders sent automatically (e.g. via email or text message). In addition, given the arduous research effort and time-sensitivity of the cortisol awakening response, future examinations might evaluate a different stress biomarker requiring less time and exertion, such as hair cortisol or a serum cortisol blood test.

5. Implications

Exorbitant costs and obligatory time constraints of autism therapeutic intervention may create barriers preventing parent access to appropriate resources for their own health. WD is a portable and cost-effective treatment with demonstrated benefit on stress-related consequences across various populations. This investigation found significant reductions in perceived stress and improvement in cortisol reactivity after treatment parents wrote for only 20 min per day for three days. With the daily challenges of disruptive child behavior and the social isolation that parents might face, simply writing for a brief time with the likelihood of meaningful improvement months later is a promising finding. Nonetheless, further investigation is needed with larger sample sizes before achieving external generalization.

Documented in the ASD literature are numerous challenges that a parent might face when caring for their child with ASD. These include disruptive child behavior, parental emotional distress, limited social interaction, and the financial burden of costly therapy for either the child or the parent. Individually, each of these concerns might have a negative impact on a parent’s mental and physical well-being. Combined and experienced chronically over the course of several years, these issues have the potential to evoke extensive harm to the caregiver. With the continual upsurge in the prevalence of ASD diagnoses, more parents may require relief of negative effects associated with their caregiving experiences. As such, it is important to identify effective evidenced-based treatments to ameliorate the deleterious consequences that might result. The improvement of mental health pathology in parents of children with ASD is both significant and timely. Markedly, further research into effective treatments is warranted.

Conflict of interest

All authors declare that there is no conflict of interest.

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References


