Why caregivers discontinue applied behavior analysis (ABA) and choose communication-based autism interventions

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Abstract

Purpose – The purpose of this paper is to explore why autistic people and their caregivers choose interventions other than applied behavior analysis (ABA), and how their decision impacts them over their lifespan. The focus group was divided into those who pursued augmentative and alternative communication (AAC)-based supports, received ABA, selected other interventions or received no intervention at all. The reported posttraumatic stress symptoms (PTSS) of ABA recipients were compared to non-ABA recipients in order to evaluate the long-term impacts of all intervention types. Using a mixed-method thematic analysis, optional comments submitted alongside a quantitative online survey were reviewed for emergent themes. These comments augmented the survey Likert scores with a qualitative impression of the diverse intervention-related attitudes among participants. Investigating the lived experiences of autism intervention recipients illuminated the scope of the long-term impacts of each intervention that was chosen. Overall, autistics who received no intervention fared best, based on the lowest reported PTSS. These findings may inform the potential redesign of autism interventions based on the firsthand reported experiences and opinions of autistics.

Design/methodology/approach – The aim of this study was to conduct research that is both question-driven and data-driven to aid in the analysis of existing data (Van Helden, 2013). In the research question-driven approach, the independent variables were the intervention type and duration of exposure relative to lifespan; the dependent variables were the PTSS severity score and binary indicator of meeting PTSS criteria. The analyses that were conducted included linear regression analyses of severity score on intervention type and duration, and χ^2 tests for independence of the probabilities of PTSS criterion satisfaction and intervention type. This experiment was designed to test the data-driven hypothesis that the prevalence and severity of PTSS are dependent on the type of autism intervention and duration of exposure. After reviewing the primary data set, the data-driven inquiry determined that the sample for secondary analysis should be categorized by communication-based vs non-communication-based intervention type in order to best complement the limitations and strengths of the published findings from the primary analysis.

Findings – Autistics who received no intervention had a 59 percent lower likelihood of meeting the PTSS criteria when compared to their ABA peers, and they remained 99.6 percent stable in their reported symptoms throughout their lifespan ($R^2 = 0.004$). ABA recipients were 1.74 times more likely to meet the PTSS criteria when compared to their AAC peers. Within the 23 percent who selected an intervention other than ABA, consisting of psychotherapy, mental health, son-rise and other varying interventions, 63 percent were asymptomatic. This suggests that the combined benefits of communication-based interventions over behaviorism-influenced ABA practices may contribute to enhanced quality of life. Although not generalizable beyond the scope of this study, it is indicated from the data that autistics who received no intervention at all fared best over their lifetimes.

Research limitations/implications – The obvious advantage of a secondary analysis is to uncover key findings that may have been overlooked in the preliminary study. Omitted variables in the preliminary data leave the researcher naive to crucially significant findings, which may be mitigated by subsequent testing in follow-up studies (Cheng and Phillips, 2014, p. 374). Frequency tables and cross-tabulations of all variables included in the primary analysis were reproduced. The secondary analysis of existing data was conducted from the design variables used in the original study and applied in the secondary analyses to generate less biased estimates (Lohr, 2010; Graubard and Korn, 1996). Inclusion criteria for each intervention group, PTSS scores and exposure duration, were inherited from the primary analysis, to allow for strategic judgment about the coding of the core variables pertaining to AAC and PTSS. The data sample from 460 respondents was reduced to a non-ABA group of $n = 330$. An external statistician scored each respondent, and interrater reliability was assessed using Cohen's κ coefficient ($\kappa = 1$).

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Practical implications – *Including the autistic voice in the long-term planning of childhood interventions is essential to those attempting to meet the needs of the individuals, their families and communities. Both parents and autistic participant quotes were obtained directly from the optional comments to reveal why parents quit or persisted with an autism intervention.*

Social implications – *Practitioners and intervention service providers must consider this feedback from those who are directly impacted by the intervention style, frequency or intensity. The need for such work is confirmed in the recent literature as well, such as community-based participatory research (Raymaker, 2016). Autistics should be recognized as experts in their own experience (Milton, 2014). Community–academic partnerships are necessary to investigate the needs of the autistic population (Meza et al., 2016).*

Originality/value – *Most autistic people do not consider autism to be a mental illness nor a behavior disorder. It is imperative to recognize that when injurious behavior persists, and disturbance in mood, cognition, sleep pattern and focus are exacerbated, the symptoms are unrelated to autism and closely align to the diagnostic criteria for posttraumatic stress disorder (PTSD). When PTSD is underdiagnosed and untreated, the autistic individual may experience hyperarousal and become triggered by otherwise agreeable stimuli. Since autism interventions are typically structured around high contact, prolonged hours and 1:1 engagement, the nature of the intervention must be re-evaluated as a potentially traumatic event for an autistic person in the hyperarousal state. Any interventions which trigger more than it helps should be avoided and discontinued when PTSS emerge.*

Keywords *Autism, Communication, Support, Intervention, Narrative, Applied behaviour analysis*

Paper type *Research paper*

The purpose of this study was to investigate the reasons for decisions made by both autistic adults and parents of autistic children, regarding their selection of interventions other than applied behavior analysis (ABA). A previous quantitative study surveyed 460 autistic adults and caregivers of autistics, and found that among the 116 participants exposed to ABA, nearly half (46 percent) indicated posttraumatic stress symptoms (PTSS), with an 86 percent chance of trauma symptoms after initial exposure to ABA (Kupferstein, 2018).

This initial analysis of the primary data set incidentally produced an additional finding, concerning a comments box which had been provided for optional use. Most participants who specified that they had terminated ABA entered comments to explain why they did so, and likewise, those who persisted with ABA justified their choice in the optional comments box. This unexpectedly rich source of supplementary data became the impetus for this study. Upon cursory review of the optional comments, one particular thematic correlation was prominent. The people who discontinued ABA had a tendency to use language indicative of an autonomy-based attitude, whereas those who persisted with ABA had a tendency to use pathology-based language. The question raised at this stage of analysis was why autistics or their caregivers chose one intervention over another, based on their justification narratives from the optional comments entered.

For this study, the primary data were analyzed to generate operational definitions of the exposure variable(s), outcome variable(s) and covariates to be considered in the analysis. According to the National Institutes of Health (NIH), the use of primary data analysis is limited to data that were collected to answer the original hypotheses proposed in the study (NIH, n.d.). All other analyses of the same data set are considered secondary analyses of existing data, whether or not the persons conducting the analyses participated in the collection of the data. A secondary analysis of existing data categorizes the secondary findings as distinctly attributable to the primary data employed. A secondary analysis does not allude to a second analysis being performed on an entirely new data set. The obvious advantage of a secondary analysis is to uncover key findings that may have been overlooked in the preliminary study. Omitted variables in the preliminary data leave the researcher naive to crucially significant findings, which may be mitigated by subsequent testing in follow-up studies (Cheng and Phillips, 2014, p. 374).

This study was designed to conduct research that is both question-driven and data-driven to aid in the analysis of existing data (Van Helden, 2013). The independent variables in this question-driven approach were the intervention type and duration of exposure as a percentage of daytime lifespan – the amount of time spent with the intervention during the waking hours of each year in the life continuum. The dependent variables were the PTSS severity scores, and binary indicator of meeting PTSS criteria. As the comments were submitted voluntarily, the findings

cannot be generalized to the extent of being representative of the study population and their choices for interventions. The justification narratives were significantly higher in one intervention type over all others, which provide a conceptual framework to take into account the perspectives of those who feel compelled to submit a justification.

In a mixed-method approach, the constructivist deliberately includes participant narrative to bring in the social reality of the participants as a truth to the data. Lincoln and Guba (1985) stated that extraordinary experiences cannot be generalized; therefore, from a social-constructivist view, phenomena can only be understood within their context (p. 110). This approach contrasts the standard practice in autism research today which is primarily fixated on interviewing caregivers about their autistic child's experience. Instead of obtaining secondary data, the direct experience of autistic individuals was gathered by interviewing autistic adults with the particular aim of circumventing second-hand experience (Birks and Mills, 2015):

> To this day, the language of the early philosophers, spoken through modern-day categorization systems, continues to serve as the foundation for the majority of inquiries in the field of human development. (Thurman, 2016, p. 13)

Gergen (1985) called for the social constructivist to "enter into the creation of new forms of cultural life." Charmaz (2006) proposed a constructivist form for grounded theory where the researcher's immersion into the data honors and maintains the individual voice of the participants. Only then can the narrative be both analytical and literary in ways that evoke the life of the participants. In this social-constructivist approach, all knowledge is constructed with input directly from the people impacted by these interventions, and their narrative shared through communication, verbal or typed. This study welcomed and accommodated all communication styles utilized by the participants.

The capacity of the autistic participants to relay an accurate life experience was implied when informed consent was provided. As such, the online survey was not used as an evaluation of competency in areas that are outside the scope of the study task. Therefore, nonspeaking and supported typists were considered informed respondents, and in that respect, no identifying data were collected on communication style used for completing the survey. At least 63 percent of autistics have neurological motor movement disorders such as apraxia of speech; the dyspraxia persists even after speech emerges (Tierney et al., 2015). Limiting the inclusion criteria to only those who use speech to communicate would essentially skew the sample on the basis of comorbid disorders and limits input from those with firsthand experience. In this paper, nonverbal autistic people are referred to as nonspeaking because they generally see themselves as perfectly capable of communicating, albeit without the use of speech (ASAN, n.d.).

Methods

In a previous study by Kupferstein (2018), an online survey was used to obtain data from autistic adults and caregivers of autistic children. Responses were automatically recorded and transcribed as Likert-scale binary data with an optional comments entry box. Coding and first level analysis were performed from participant data. The binary data were statistically analyzed and tested for correlations between intervention type and the prevalence and severity of the PTSS for each group. Frequency tables and cross-tabulations of all variables included in the primary analysis were reproduced. For the present study, a set of procedures was applied to classify and organize the narratives within the comments to prepare for a content analysis (Elo and Kyngäs, 2008). The first-cycle coding method was used to explore categories as described by Miles et al. (2013). A thematic analysis (TA) was then applied using the Braun and Clarke (2006) linear method for reviewing, naming and writing of the findings of themes. Similar analyses were used in autism studies where firsthand accounts of participants exhibited themes of isolation and frustration in the recorded narratives (Jones et al., 2001).

The secondary analysis of existing data was conducted from the design variables used in the original study and applied in the secondary analyses to generate less biased estimates (Graubard and Korn, 1996; Lohr, 2010). Inclusion criteria for each intervention group, PTSS scores and

exposure duration were inherited from the primary analysis, to allow for strategic judgment about the coding of the core variables pertaining to AAC and PTSS. The data sample from 460 respondents was reduced to a non-ABA group of $n = 330$. An external statistician scored each respondent, and interrater reliability was assessed using Cohen's κ coefficient ($\kappa = 1$).

The analyses that were conducted included linear regression analyses of severity score on intervention type and duration to determine if there was a correlation between the length of time exposed and the severity of the PTSS. The χ^2 test for independence was used to find if all intervention groups had equal probabilities for satisfying the PTSS criteria. Thus, the data-driven analysis investigated whether the prevalence and severity of PTSS are contingent on the reasons for terminating ABA. After reviewing the primary data set, the data-driven inquiry determined that the sample for secondary analysis should be categorized by communication-based vs non-communication-based intervention types in order to best complement the limitations and strengths of the published findings from the primary analysis (Kupferstein, 2018).

In this present study, intervention focus groups were established to represent participants who received none or other interventions in lieu of ABA, which included psychotherapy, psychiatry, physical therapy, occupational therapy and speech and language pathology (SLP). Interventions were classified as communication-based if they included facilitated communication, rapid prompting method, SLP, or augmentative and alternative communication (AAC) supports. The participants not exposed to ABA were assigned to either an AAC or non-AAC focus group based on intervention type indicated. These groups were formed to evaluate the source of the attitudes driving the choice of autism interventions in comparison to the intervention specified and commented about.

Participants

A total of 460 respondents consisting of autistic adults and caregivers of autistic children completed an online survey. Almost half (47 percent) of the 218 caregivers specified that their children were exposed to an ABA autism intervention. More than half (57 percent) of the 242 adults indicated that they received no intervention at all, while 31 percent referenced varying interventions other than ABA, such as AAC, sensorimotor or mental health. The majority of participants were recruited via e-mail through the Interactive Autism Network (IAN) research database and research registry. The IAN database is populated with probands who have a verified and formal diagnosis of autism (Lee *et al*., 2010). The remaining participants were included based on self-report.

Instrument

The primary data set was composed of responses to a 26-question survey. The survey questions were modeled after the PTSD Checklist for DSM-5 (PCL-5) instrument, which is the current gold standard for diagnosing posttraumatic stress disorder (PTSD) by scoring the degree of responses to traumatic experiences (Blevins *et al*., 2015). Weathers *et al*. (1991) also designed a PCL-M (military) checklist to assess the degree in which veterans are bothered by war related stressors, with questions such as "Repeated, disturbing memories, thoughts, or images of a stressful military experience" or "Trouble remembering important parts of a stressful military experience." The PCL remains the most psychometrically validated instrument for scoring self-report measures related to a traumatic response (Weathers *et al*., 2013). As such, the PCL was utilized to construct a temporary instrument with self-reported measures for evaluating PTSS in autistics; war-time references were replaced by autism intervention exposure to score an associated stress response in this demographic. Clinical PTSD was differentiated from intervention PTSS by grouping the symptom questions within the context of specific interventions. Severity of symptoms was scored by individual symptom clusters, and classified by thresholds of moderate, severe or extreme.

Measures and scoring

The DSM-5 requirements for evaluating PTSD include exposure to a potentially traumatic event (PTE) preceding the symptoms' assessment. The primary data set accepted the intervention selection as meeting one of four exposure types per this criterion. The three exposure metrics of intervention selection, hours per week and relative to daytime hours of lifespan, fulfilled the criterion for children aged six and younger. In the primary data set, the PTSS criterion was marked as true, for having fulfilled the overall criteria; or false, for not having met the threshold. Participants symptom frequency was measured on a five-point Likert scale. PTSS determination was made by a cumulative sum of individual subscales within each of the DSM symptom clusters. Those cumulative scores that exceeded a PTSD diagnostic threshold of moderate were further divided into a severity spectrum of moderate, severe or extreme.

A thematic analysis (TA) was conducted on the optional comments submitted ($n = 131$), to explore the depth and breadth of the interventions chosen and their subsequent impact. As the quantitative findings were already correlated to intervention type with PTSS prevalence, the optional comments were now contextually evaluated to investigate the underlying causal reasoning for why these rates exist. First, all the comments were extracted from their data record, and recreated into a new datasheet. Each row contained each participant's comment, a true/false flag for PTSS severity, the intervention specified and relative treatment duration by percentage of their lifetime. A word-find search was conducted to find every comment which contained the word "ABA," and verify that it was in context with having "quit" the intervention. Those who quit were marked to include another variable for all those who experienced ABA in their lifetime.

Of the 40 participants who indicated AAC, 70 percent were asymptomatic. The most prevalent finding was that of the remaining 30 percent of the AAC group, consisting of those who did meet the PTSS criteria, almost all (83 percent) indicated a past history of ABA exposure. At this stage, it became apparent that an in-depth analysis of their comments might explain why they quit ABA even if the symptoms persisted. Comparatively, all those who mentioned ABA in their comments had cumulatively met the severity threshold, and that severity exceeded all the other groups combined. The vocabulary content for each comment was compared to the PTSS status by participant, and the tendency to abandon the survey by intervention, to provide context to their justification.

To saturate these initial findings of PTSS in those who quit ABA, a more extensive analysis of the vocabulary sets for each group was performed. To draw attention to the entries which contained specific words, a boolean search was conducted to return results for comments containing the words "ABA," "behav*," "intens*," "reduced*," "received," "no longer" and "happ*." After the initial search, each record was reconfirmed to validate the initial return of each phrase. For example, "happ*" returned 15 hits. The comment "Therapy did not help. I participated to keep everyone else happy" was made by an adult who received psychotherapy for 10 years, and met the criteria for PTSS. A caregiver of a nine-year-old child exposed to 20 h of ABA for three years, who then quit ABA, wrote, "She has learned and matured way faster after therapy ended and is now a happy child with no meltdowns."

The dominant results that emerged were: those who justified persisting with ABA had the highest tendency for pathological scoring of sensitive behaviors using behaviorism metrics, and those who justified the child's express wishes tended to contain neurodiversity-accepting language styles using autonomous metrics in their vocabulary sets.
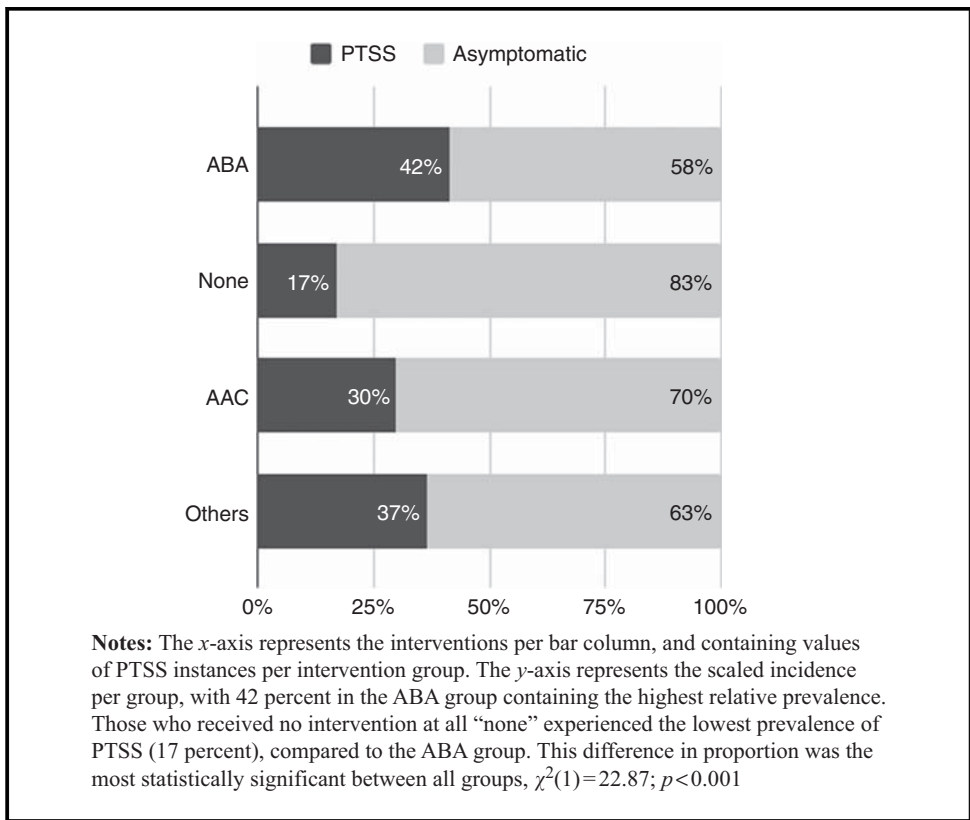
Findings

A total of 460 participants completed a survey about autism interventions and related PTSS. More than a quarter, or 28 percent of respondents ($n = 130$) indicated having been exposed to ABA interventions. The largest group of participants ($n = 186$) reported having received no intervention at all, while 40 participants indicated having received a communication-based intervention (AAC). Within that primary data set, nearly half (46 percent) of autistics exposed to ABA met the PTSS criteria while their non-exposed peers had a 72 percent chance of being asymptomatic (Kupferstein, 2018).

For the purpose of this secondary analysis of the primary data set, a sample size of 330 respondents, or (71 percent) of the total, were reviewed by exposure to non-behavior-based interventions, or communication-based interventions (AAC). The AAC group experienced less PTSS (30 percent) than their ABA-exposed peers (42 percent), but this difference was not statistically significant. Surprisingly, the group with the lowest likelihood of meeting the criteria for PTSS (17 percent) consisted of those who received no intervention at all. Those who received ABA had a 170 percent higher incidence of PTSS, compared to those who received no intervention at all; this proportion was the most statistically significant in pairwise difference between all groups, $\chi^2(1) = 22.87$, $p < 0.001$.

Participants exposed to ABA indicated the highest rate of PTSS (see Figure 1). Among all autism interventions selected, 57 percent of respondents indicated that they received no intervention at all, and they had the lowest incidence of PTSS, at only 17 percent. Although 30 percent of AAC exposed individuals met the criteria, at least one-fourth of the AAC group total specified that they had terminated other behavior-based interventions to pursue AAC. Those who indicated participation in interventions other than ABA or AAC were exposed to psychotherapy, sensorimotor supports or mental health interventions. Exposure to such other interventions was a strong indicator of PTSS by as much as 38 percent. Based on the findings, we predict that 83 percent of autistic adults who received no intervention at all will remain asymptomatic, and that those who meet the PTSS criteria will not experience an increase in severity of PTSS throughout their lifespan.

Autistics who received no intervention had a 59 percent lower likelihood of meeting the PTSS criteria when compared to their ABA peers, and they remained 99.6 percent stable in their reported symptoms throughout their lifespan ($R^2 = 0.004$). ABA recipients were 1.74 times more likely to meet the PTSS criteria when compared to their AAC peers. Within the 23 percent who selected an intervention other than ABA, consisting of psychotherapy, mental health, son-rise and other varying interventions, 63 percent were asymptomatic.

| Figure 1 | Percentage of PTSS by autism intervention |

Notes: The x-axis represents the interventions per bar column, and containing values of PTSS instances per intervention group. The y-axis represents the scaled incidence per group, with 42 percent in the ABA group containing the highest relative prevalence. Those who received no intervention at all "none" experienced the lowest prevalence of PTSS (17 percent), compared to the ABA group. This difference in proportion was the most statistically significant between all groups, $\chi^2(1) = 22.87$; $p < 0.001$

The qualitative analysis of the optional comments generated several causal themes by intervention type. Participants who were exposed to ABA had the highest frequency of pathologized language terms that were indicative of desensitization to chronic observation and scoring of sensitive behaviors. Those who opted out of the survey did so around the questions pertaining to self-harm and injurious behavior. Those who abandoned the survey were also least likely to have been exposed to ABA or any other intervention at all. Overall, the language for pathological scoring of sensitive behaviors was remarkably highest in those who justified persisting with ABA. The language tendency to score the autonomy of the autistic individual correlated with the tendency to justify quitting due to the child's express wishes. Themes about informed choice and external pressures to pursue an intervention emerged from this data set. The intervention exposure became a predictor for accurate PTSS reporting for those who received ABA.

Discussion

Recurring themes derived from the comment language indicated a generalizable representation of the wider sample of narratives. The ABA parents employed language of conformity and enforced compliance, such as "eliminated," and behaviors that were normalized with the ABA intervention, such as "hitting," "scratching" and other activities that are typically included in a behavioral intervention plan because they are deemed aberrant. The non-ABA parents or autistic adults used terms of individual-focused development, where self-esteem and emotional regulation were at the core of the treatments pursued. Specifically, "he is happier" or "did not receive therapy, am currently a pretty happy doctoral student" is highlighted to compare with the second-hand reports of behavioral changes by therapists and caregivers.

Communication-based interventions, especially AAC, focus on instilling tools for the individuals to shape their behaviors as they choose to, or see fit within their environment. ABA-exposed peers had no qualms about scoring themselves on sensitive topics using behaviorism metrics. It is conjectured that ABA solicited an unexpected susceptibility to report explicitly on sensitive behavioral criterion. Those who received no intervention at all were most likely to abandon sensitive scoring in the survey, which exemplified the need for an adaptive self-report instrument to adequately evaluate PTSS in autistics. This suggests that the combined benefits of communication-based interventions over behaviorism-influenced ABA practices may contribute to enhanced quality of life. Although not generalizable beyond the scope of this study, it is indicated from the data that autistics who received no intervention at all fared best over their lifetimes, based on their self-reports.

The emerging theory grounded in the participatory narrative contributed to the overall insights on why people quit or avoided ABA, and at what point their attitude shifted to accept and support a unique neurotype. The emergent theory also calls attention to the authentic autistic voice within the narrative (Thurman, 2016). The study was conducted as rationale for a holistic and integrative approach to evaluation and care. The results of this study suggest that the best care for autistic people is care designed by an autistic health professional in conjunction with the client and autistic researchers. These themes may inform parents of newly diagnosed children in choosing one intervention over another, and to explore the lifespan experience of autistic adults based on firsthand reports. Comparing communication-based interventions with trauma-correlating treatments revealed the iatrogenic effects of ABA based on adverse outcomes.

Implications

Including the autistic voice in the long-term planning of childhood interventions is essential to those attempting to meet the needs of autistic individuals, their families and communities. Both parents and autistic participant quotes were obtained directly from the optional comments to reveal why parents quit or persisted with an autism intervention. The autistics who did not provide optional comments still contributed data pertaining to PTSS prevalence by completing the survey. Most autistic adults indicated that their parents persisted with the intervention without considering the autistic recipient's preference.

Practitioners and intervention service providers must consider this feedback from those who are directly impacted by the intervention style, frequency or intensity. The need for such work is confirmed in the recent literature as well, such as community-based participatory research (Raymaker, 2016). Autistics should be recognized as experts in their own experience (Milton, 2014). Community–academic partnerships are necessary to investigate the needs of the autistic population (Meza *et al*., 2016).

Most autistic people do not consider autism to be a mental illness nor a behavior disorder. It is imperative to recognize that when injurious behavior persists, and disturbance in mood, cognition, sleep patterns and focus are exacerbated, the symptoms are unrelated to autism and closely align to the diagnostic criteria for PTSD. When PTSD is underdiagnosed and untreated, the autistic individual may experience hyperarousal and become triggered by otherwise agreeable stimuli. Since autism interventions are typically structured around high contact, prolonged hours and 1:1 engagement, the nature of the intervention must be re-evaluated as a PTE for an autistic person in the hyperarousal state. Any intervention that triggers more than it helps should be avoided and discontinued if and when PTSS emerge.

Conclusion

This study was performed to investigate why some caregivers of autistics choose an intervention other than ABA. The TA revealed that these parents quit ABA because of their observation of trauma symptoms coinciding with the intervention.

Overall, the longitudinal data provided a closer look into how the caregiver's choice may impact the emotional wellbeing of the autistic child into adulthood. Autistics who received no intervention ("none") in their lifetime, experienced the lowest rates of PTSS. Autistics who were not exposed to ABA were also accustomed to scoring sensitive behaviors pertaining to self-harm. They avoided the behaviorism-based self-report by abandoning the survey, and/or commenting about their aversion to these metrics. Parents may consider these findings to make an informed decision about pursuing an autism intervention that is least likely to correlate with traumatic stress, while optimizing the long-term outcomes. It is recommended that future researchers should develop inclusive self-report instruments to clinically evaluate PTSD in autistics by adapting to known stressors for this demographic.

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