

Sonic bombardment, noise hypersensitivity and ethics: A response to Fodstad and colleagues: ‘Assessment and treatment of noise hypersensitivity in a teenager with autism Spectrum Disorder’

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Abstract

This commentary – provided by a group of Autistic researchers – reflects on a case study trialling a ‘modified Cognitive Behavioural Therapy intervention’ to address the ‘noise hypersensitivity’ and associated behaviours of an Autistic teenager, ‘Aaron’. We identify serious flaws in the evidence base behind the ‘therapy’: including failing to account for divergent Autistic sensory reactivity, aiming to remove ‘stimming’ behaviours and promoting masking. We challenge the lack of informed consent reported as given by either Aaron or a proxy and the absence of any reported ethical approval for this case study. We also strongly condemn the methods of sonic bombardment delivered upon Aaron under the guise of ‘therapy’. We conclude with three questions around the processes that led to the original article’s publication.

Introduction

In an article published earlier this year in the *Journal of Autism and Developmental Disorders*, Fodstad, Kerswill, Kirsch, Lagges and Schmidt (2021) report on a single patient case study which aimed to assess whether distress responses to noise sensitivity in an Autistic adolescent could be reduced using what they referred to as a ‘modified Cognitive Behavioural Therapy (CBT)’ intervention. The data reported was taken from a 16-year-old Autistic young person with mild intellectual disability (‘Aaron’), who had been admitted for outpatient clinical assessment and treatment of what the authors termed ‘severe problem behaviour’. This behaviour, demonstrated in the presence of loud or unexpected noise, reportedly manifested in self-injury, aggression towards other people/items, and attempts to escape. The authors report on their initial assessment of noise avoidance (which they label as ‘phobic’), functional analysis to assess links between noise and behaviours, assessment of coping mechanisms, and final treatment evaluation.

As a group of Autistic researchers, we hold a number of grave concerns around the ethical basis of the study itself, its methodology, and its publication in its present form within the *Journal of Autism and Developmental Disorders*. We reported these concerns to the publishing journal in June 2021. The (single) peer reviewer and the journal's editor refuted the merits of our concerns, but failed to satisfy them, allowing us no right to revise and resubmit our commentary. For this reason, and because we still have serious concerns about the ethics of Fodstad et al's case report, we present the substantive points here for consideration by the wider community of Autism researchers. We hope that this will stimulate conversation leading to more ethical treatment for Autistic inpatients in the future.

In this article we thoroughly consider the paper by Fodstad et al. (2021) and provide an ethics-based critique founded on three substantive points: potential harm to the participant,

lack of informed consent, and poor scholarship. First, the premise and method of intervention itself was highly unethical in relation to the potential to harm the patient. There was no solid evidence to suggest that this experimental intervention was the best available approach, and a core principle of ethical intervention-based research is making participants aware of alternatives. This harm occurred in two ways: the first by means of exposing the patient to painful sonic bombardment methods which have the potential to harm recipients psychologically and physically; and the second by means of dehumanising practices.

Second, we have serious concerns in relation to the apparent absence of any attempt to obtain informed consent from the subject in this case study or discuss the intervention with them in advance. Failure to note whether the patient attended for therapy on a voluntary or mandatory basis is also important and missing. As such, the publication does not meet best practice in ethical reporting as identified by Committee on Publication Ethics (COPE): a body to which the Journal of Autism and Developmental Disorders is subscribed. COPE (2008) state in relation to medical case studies that ‘consent should be sought and a disclaimer added to the effect that patients should accept that no-one but themselves would be able to recognise them and that patients need to understand that, although each is unique, there are many like them who share similar problems’.

Third, the premise of the treatment was based on outdated research, given that the majority of cited papers are over five years old and also centred around contested theory which was used to justify the allegedly therapeutic intervention. This includes failure to consider relevant research in relation to sensory profiles and overwhelm within Autistic individuals; and aiming for the 'therapy' to produce masking, which is known to be harmful for Autistic people (Mandy, 2019).

We conclude with three questions relating to the processes that led to the original article's publication in the Journal of Autism and Developmental Disorders.

Autistic sensory profiles and sensory overwhelm

The 'atypical sensory reactivity' (Hannant, Tavassoli and Cassidy, 2016: 2) of Autistic individuals has been observed and reported from as far back as the early descriptions by Kanner (1943), although it has only recently appeared in the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychiatric Association, 2013) and the forthcoming 11th edition of the International Classification of Diseases (ICD-11, World Health Organization, 2018).

This inclusion of sensory hyper- and/or hyposensitivities in the diagnostic criteria for autism is based on persuasive modern research recognising the neurological basis of autistic differences in sensory processing across auditory, visual, tactile, olfactory, gustatory, and interoceptive domains (see Proff et al., 2021, for recent systematic review). Consensus is also building around the understanding that these neurological differences may cascade towards some of the 'autistic particularities of moving, perceiving, and emoting' (de Jaegher, 2013: 1), as well as behavioural characteristics and cross-neurotype social difficulties (see for example: Belek, 2019; Beardon 2017; Bogdashina, 2010, 2016; Constant et al., 2020; de Jaegher, 2013; Donnellan, Hill, and Leary, 2013; Garfinkel et al. 2016; Hannant, Tavassoli and Cassidy, 2016; Jackson-Perry et al., 2020; Marsh et al., 2013; Milton, 2012; Milton, Heasman and Shepard, 2018; Nicotera et al 2019; Proff et al., 2021; Smith and Sharp, 2013; Tomchek and Dunn, 2007; Williams, 2020).

Autistic auditory processing differences include, in addition to a typically reduced automatic filtering of concurrent sound streams (Lepistö et al, 2009), an increased tendency to extract

local rather than global features from melodies (Bouvet et al., 2014; Mottron et al., 2000) and a tendency towards a reliance on incoming auditory data over habituated sensory predictions (Goris et al., 2018; Hudac et al., 2018). These are potential factors in the distress caused by continued exposure to problematic or loud sounds. Aside from this, two additional co-occurring conditions are common among Autistic individuals: *hyperacusis* and *misophonia* (Williams, He, et al., 2021; Williams, Suzman et al., 2021). These factors and co-occurring conditions are both legitimate functional impairments at the level of sensory processing that can cause extreme levels of distress or physical pain when exposed to loud, or repetitive noises.

Hyperacusis is defined as a hearing disorder characterised by an increased sensitivity or reduced tolerance of sound at levels that do not typically cause distress to others (Fackrell et al. 2019; Williams, Suzman et al., 2021). Importantly, hyperacusis is distinct from *phonophobia* – a phobic response to specific sounds or categories of sounds (Fackrell et al. 2019; Williams, Suzman et al., 2021). In a recent systematic review (Williams, Suzman et al., 2021), hyperacusis was found to be highly prevalent among Autistic individuals, and crucially: across the lifespan. Misophonia, on the other hand, is a ‘chronic condition in which a person experiences autonomic arousal (analogous to an involuntary “fight-or-flight” response) to certain innocuous or repetitive sounds such as chewing, pen clicking, and lip smacking’ that triggers a high arousal response of the sympathetic nervous system (Edelstein et al., 2013). Both of these conditions ought to be thought of more like the potential analogues of *stereoblindness* (a cognitive inability to merge incoming binocular data to generate depth perception) in the visual domain, or *synaesthesia* (an atypical fusion of cross-modal sensory experiences, Ward, 2013): not as behaviours that an individual can be trained out of.

‘Challenging’ or ‘problem’ behaviours (Fodstad et al., 2021) arising when an Autistic individual with auditory hyper-sensitivity, hyperacusis or misophonia is exposed to auditory stimuli that provoke a distress response should be understood in terms of biophysical overwhelm or – in other words – *sensory overload*: in which a person loses some or all of their normal functioning (Bogdashina, 2016: 103). As Proff and colleagues have argued (2021: 31), ‘instead of impaired perception, we need to understand sensory differences as individual facets of a highly diverse and heterogeneous phenotype with equally varying emotional, social, and behavioral implications’. Given the biological underpinning for divergent sensory profiles described above, the utility of any intervention which fails to address the body should be called into question.

Sonic bombardment and dangerous volumes

Furthermore, there are ethical and safeguarding issues surrounding bombardment with constant sound over extended periods of time – as Aaron experienced. In the first case, such techniques are a common to the methods of sonic bombardment, as used by the US military against prisoners in Abu Ghraib, Camp Nama, Guantanamo Bay, Mosul Air Force Base and beyond (Hill, 2012) and by the British army against the ‘Hooded Men’ in Northern Ireland (Newbery, 2009). Continuous white noise, music, or distressing sounds are played in these instances so as to ‘coerce compliance’ (Hill, 2012: 218), and to induce ‘sonic dominance’ (Henriques, 2003; Hill, 2012) over the prisoners’ bodies and bodily responses by virtue of its all-pervasive nature. While the noise was not continuous over many hours, we note that Aaron experienced a form sonic dominance, in a small (4.4m x 4.8m – Fodstad et al., 2021: 1813) padded room where sound (specifically those sounds identified to be most distressing to Aaron – Fodstad et al., 2021: 1814) was used to coerce researcher-intended behaviours. This, when compounded with potential underlying biological mechanisms which generate

sensory sensitivity in Autistic people (as described above), create a situation which undoubtedly can cause overwhelming distress.

Moreover, it is important to highlight that the upper volume of the distressing sounds played from five ceiling-mounted speakers (thus increasing the oppressive effect) was set at 85dBs. In the USA (where the study is assumed to have taken place: due to the authors' affiliations), in recognition of the fact that 85dBs is the threshold level at which hearing can become damaged over time (Royal National Institute for Deaf People – UK, 2021) the federal Occupational Safety and Health Administration Standards (US Department of Labour, 2000) require employers to implement a hearing conservation program when noise exposure reaches 85 dBs averaged over a working day. For an individual with evident auditory sensitivities, this volume may have been experienced as even louder, more dominant and more painful.

Self-Determination

Fodstad and colleagues (2021) report that the aim of their intervention was to increase self-determination through teaching independent coping strategies, aligning their aims with the values suggested in Cheak-Zemora et al. (2019) for increasing self-determination in Autistic young adults. Cheak-Zemora et al. (2019) used caregiver report to assess self-determination in Autistic young people. They found that caregivers rated their young adult's capacity to engage in self-determination as low in comparison to how they rated the opportunities provided to engage in self-determination in the home. The authors stressed the importance of increasing a young person's understanding of self, self-advocacy, and self-regulation, and noted the limitations of using parent reports to measure self-determination. Arguably a focus on trying to reduce an external response to sensory distress, and encouraging non-native coping strategies as opposed to providing the opportunity to self-regulate through stimming

or the use of assistive technologies (i.e. noise cancelling headphones) is not aligned with increasing self-understanding or advocacy, nor is it conducive with generating agency. Despite Fodstad and colleague's (2021) assertions that there is little known about how to assess and treat noise sensitivity, Fodstad et al. acknowledge themselves that they did not use a (validated) sensory questionnaire. There is a body of literature on the assessment (i.e. Tavassoli et al. 2014) and treatment (Pfeiffer, Duker, Murphy and Shui, 2019; Pfeiffer, Erb and Slugg, 2019) of noise sensitivities in Autistic people. This research stresses the importance of sensory validation (Landon, Shepherd, and Lodhia, 2016), environmental adjustments, and helping a young person to recognise their sensory stressors so that they can identify and implement coping strategies that allow them to flourish; such an approach is in line with a stress management plan outlook to reducing distress behaviour, as advocated by a person centered Low Arousal Approach (McDonnell, 2019).

Masking

The 'success' of the methods reported in Fodstad (2021) are predicated on the basis of a reduction in distress behaviour displayed by Aaron in response to aversive sounds, including a small reduction in heart rate elevation, and independent use of the 'coping strategies' taught during the intervention. The training of the researcher-approved 'coping strategies' occurred during sessions in which Aaron was prompted to choose a response in order to elicit praise from the researcher, as the aversive sound was systematically increased. The suppression of a native response in favour of a non-native response is known as masking (Milton and Sims, 2016; Holliday-Willey, 2014; Pearson and Rose, 2021), camouflaging (Hull et al. 2017), compensation (Livingston and Happé, 2017), concealment (Botha & Frost, 2020), and adaptive morphing (Lawson, 2020). Autistic people have reported that masking of a distress response to aversive sensory stimuli, and suppressing associated coping mechanisms such as stimming, have a negative impact (Kapp et al., 2019; Miller, Rees and Pearson, 2021). This is

only one aspect of the broader deleterious effects masking has upon Autistic wellbeing (Mandy, 2019). The act of concealing behaviours (including coping strategies relating to sensory sensitivities) is itself a form of minority stress which predicts significantly worse wellbeing for Autistic people (Botha & Frost, 2020).

Behavioural interventions that focus on removing innocuous native coping mechanisms like stimming, and replacing them with strategies that clinicians view as more palatable invalidate Autistic methods of self-regulation. Furthermore, it prioritises the ‘gaze’ of non-Autistic people over the comfort of Autistic people. This comes across as particularly disingenuous when Autistic coping mechanisms (i.e. stimming and covering ears as a response to aversive noise) are labelled as ‘stereotypy’, in comparison to behaviour such as ‘singing to self’ and ‘self-hugging’, which were the clinically ‘functional’ alternative coping mechanisms Aaron was trained to use in Fodstad et al. (2021). We must stress there is no evidence to suggest that non-Autistic ways of being are superior to Autistic ways of being, and vice versa (Beardon, 2007). Moreover, a majority of Autistic persons desire more research into better support and services (Pellicano, Dinsmore, and Charman, 2014). Many neurodiversity supporters advocate depathologising autism, removing it from the diagnostic manuals (Chown and Leatherland, 2018). This begs the question as to why Fodstad et al (2021) replaced Aaron’s natural coping strategies with ones of their own preference.

Dehumanisation

We have concerns over the potential dehumanisation and objectification that Aaron experienced, and which this alleged treatment facilitated. Dehumanisation includes the denial of human nature (emotional responsiveness, agency, and individuality), and human uniqueness (rationality, logic, and maturity) to people, or groups of people (Haslam, 2006),

while objectification includes the denial of subjectivity and personhood (LaCroix and Pratto, 2015). Of concern is the categorisation of acts of agency, emotional responsiveness, and rationality from Aaron as evidence of pathology. For example, on exposing Aaron to sounds specifically designed to cause emotional distress, the authors then describe the following behaviours as 'phobic avoidance':

'facial grimacing, crying for 3 [seconds] or more (with tears), yelling/screaming for 3 [seconds] or more, nail-biting, covering ear(s) for 3 [seconds] or more, arm/body stereotypy, and trunk contortions.' (Fodstad et al, 2021; 1814).

Facial grimacing is an emotional responsiveness to an experience of discomfort, as is crying, nail-biting, covering ears, moving the body and arms, and yelling or screaming. In particular, it is noted that none of these behaviours are channelled towards bystanders; they are individual acts of agency, which express subjective discomfort from Aaron involving his own body. Despite covering one's ears when being exposed to overwhelmingly loud noises (55-85 dBs) being a completely rational act to protect oneself, and one's hearing, Aaron is ascribed an irrationality and childlikeness, and denied the agency to respond in ways which come naturally to him. The volume range at which Aaron experiences said discomfort should not actually matter, because acknowledging personhood, and a person's right to subjectivity, means acknowledging the individual range of a person to withstand a certain discomfort - a level which may be lower given there are biophysical underpinnings to sensory sensitivity in Autistic people. To claim that Aaron (or anyone) should be able to withstand certain sounds, at certain frequencies, in ways which hide all emotional responsiveness is inherently dehumanizing and objectifying, *by definition*. This is of key importance because objectification and dehumanisation facilitate moral disengagement from, and permissible violence against, dehumanised people (Haslam and Loughnan, 2014; LaCroix and Pratto, 2015).

Consent

The Journal of Autism and Developmental Disorders is a member of the Committee on Publication Ethics (COPE), and as such it is expected that papers published in this journal will (1) display high ethical integrity, and (2) provide detail about the ethical guidelines and procedures used to conduct research. The World Medical Association (WMA) Declaration of Helsinki (WMA, 2013) outlines ethical principles for conducting medical research with human subjects, including the need for ethical approval prior to data collection, the importance of informed consent, and the consideration that 'vulnerable individuals or groups of individuals' may have an increased likelihood of being harmed. The WMA definition of a 'vulnerable person' in medical research is unfortunately vague, but is generally argued to include those who may be unable to make autonomous decisions (such as children) or who lack basic rights and freedoms (Zion, Gilliam, and Loff, 2000). Although Fodstad et al. report on a single case where the requirements for ethical approval are less clearly stated, we would expect them to follow best practice guidance. Both COPE (2008) and the BMJ (2021) – formerly known as *British Medical Journal*: a leading medical journal which publishes case studies – recommend obtaining consent prior to publication.

The 'Compliance with Ethical Standards' statement has not been completed in Fodstad et al. (2021), thus it is not clear whether institutional or clinical ethics were sought prior to the commencement of the experimental intervention or publication of this case study, as neither are explicitly reported in the manuscript. The authors also neglected to report on procedures (if any) that were used to gain informed consent, either from Aaron or his guardian and it is unclear as to whether Aaron was provided with the opportunity to withdraw from the intervention. This is particularly concerning given that Aaron's age, and intellectual disability, would certainly place him under the WMA definition of 'vulnerable'. Fodstad and colleagues (2021) do not specify any steps taken to minimise any harm that might have come

to Aaron during the intervention. Additionally, they do not report on the long term impact of the intervention: a shortcoming that is common in behavioural interventions (Bottema-Beutel, Crowley, Sandbank and Woynaroski, 2021).

Recent concern has been raised around the lack of conflict of interest (COI) reporting in behavioural intervention research: as a general, more systemic issue (Bottema-Beutel and Crowley, 2021) and more recently, specifically within the Journal of Autism and Developmental Disorders (Luterman, 2021). Fodstad et al. (2021) declare that they have no conflicts of interest, however multiple authors meet the standards for a COI as specified in Bottema-Beutel, et al. (2021) for example affiliation with, or employment by, a clinical provider. There is a lack of transparency about where the data reported in the paper was collected, the connection of the authors to the clinic in which Aaron received treatment, and any gain that might come from publication of this study, financial or otherwise. Multiple researchers have criticised the lack of quality control in autism intervention research, and the relationship that this has with poor quality ethics (Waltz, 2007; Bottema-Beutel, et al., 2021). Furthermore, we have concerns because while it is not unheard of that authors and researchers publish in journals for which they are on the editorial board, this conflict of interest is compounded with the other conflicts of interest, the lack of transparency, and the failure to disclose key consent information to meet the COPE requirements for the journal.

Consulting with Autistic expertise

Given the often markedly divergent dispositions of Autistic and non-Autistic people and the difficulty in mutual understanding that can occur across these dispositional differences (e.g. Brewer et al., 2016; Edey et al., 2016; Heasman and Gillespie, 2018; Hubbard et al., 2017; Milton, 2012; Sheppard et al., 2016), we feel strongly that guidance by ‘Autistic expertise’ (Gillespie-Lynch et al., 2017; Milton, 2014; Woods and Waltz, 2019) is an essential

component of any ethical autism research. We strongly believe that for all autism research – but particularly so in the instance of research and case studies trialling new interventions – Autistic consultation should be an integral part of the process: across all stages. This position is in line with the drive in the past decade to move towards meaningful participatory research (e.g. see: Aspis, 2021; Chown et al., 2017; Fletcher-Watson et al., 2019; Gillespie-Lynch et al., 2017; Happé and Frith, 2020; Milton and Bracher, 2013; Nicolaidis, 2012; Pellicano, 2014; Pellicano and Stears, 2011; Woods and Waltz, 2019) and is founded on the ethical principle of ‘*nothing about us without us*’ (Charlton, 2004).

There are many different ways of engaging with Autistic expertise: some more meaningful than others (see Fletcher-Watson et al., 2019). We would like to argue, however, that any (even tokenistic) engagement with Autistic expertise would likely have highlighted grave concerns around this approach. For example, [in an informal poll – conducted over Twitter and carried out in a personal capacity by a trusted autistic advocate](#) – respondents were asked ‘whether they believe autistic people should be trained to cope with noise instead of wearing noise cancelling headphones’ with the option to answer ‘yes’, ‘no’ or ‘not sure /maybe’ (Memcott, 2021). Of over 4500 responses, 93.3% answered ‘no’. While informal polls do not share the same rigour as formal academic research, and are limited by potential bias of sampling, at over 4500 responses we believe this lends a good indication of whether the researchers were engaging in actions that would be supported by many in the autistic communities. We firmly believe that all autism research should involve meaningful engagement with Autistic expertise in the form of genuine co-productive methodologies. However, where this is neglected, a simple litmus test like this online survey could save a lot of difficulties for researchers, and potentially a lot of distress for autistic individuals.

Conclusion

In the above we have outlined some of what we consider to be extremely serious ethical and methodological concerns surrounding the case study reported on by Fodstad and colleagues (2021). We have addressed three substantial issues: (1) potential harm to the participant (by means of sonic bombardment, the enforced suppression of native coping mechanisms such as stimming, and the promotion of masking behaviours); (2) apparent lack of informed consent; and (3) poor scholarship.

While the focus of this response paper is directly levied at this specific case study report and the processes within the Journal of Autism and Developmental Disorders that led to its publication, our essential message is universal. Research – including case studies – involving Autistic participants *must* be undertaken in a humane, ethical manner, respecting individual needs and ways of being and informed by the expert guidance of Autistic stakeholders.

Academic journals whose remit it is to publish autism-related research (or case study) findings must rigorously uphold the ethical standards of the papers they select to bring to the attention of a wider audience.

Finally then, we consider the following questions to be of great importance and would appreciate hearing the Journal of Autism and Developmental Disorder's response:

1. Why have no details been published regarding the ethical guidelines and procedures surrounding this case study, as per COPE standards (to which this journal subscribes) and the WMA Declaration of Helsinki (2013)?
2. How has this paper progressed through peer and editorial review without identification of the clear (yet unstated) conflicts of interest (COIs)?

3. As a reputable journal and a community of peers, we have a joint responsibility to ensure that research is not endorsed (by its publication) which (a) does not meet ethical standards; (b) presents a serious risk of harm to participants; and (c) is inherently dehumanising. How will the Journal of Autism and Developmental Disorders remedy this present shortcoming and prevent future reoccurrences?

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