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### The Efficacy of Electroconvulsive Therapy in Managing Self-Injurious Behaviors Among Youth with Autism Spectrum Disorder: A Review

#### **Cover Page Footnote**

This research paper was made possible due to the support of certain individuals. I would especially like to thank Dr. Esteban Cardemil and Jessica Armstrong, who provided invaluable assistance in conceptualizing and organizing this effort.

## The Efficacy of Electroconvulsive Therapy in Managing Self-Injurious Behaviors Among Youth with Autism Spectrum Disorder: A Review Themal Ellawala



Themal Ellawala is a Psychology major with a special interest in the intersection of Clinical Psychology and social justice. He is particularly interested in the prevalence of mental health issues in racial and sexual minorities, and how stigma and discrimination leads to poorer outcomes among such demographics. He is currently involved in studies in Clark's Hyatt School of Psychology examining internalized psychopathology, effective interventions to mediate relationship stress, and volunteers in Clark's CAVE program. He hails from Colombo, Sri Lanka, and hopes to use his research to create greater awareness of sexual minorities who live in the shadows of his country.

#### **Abstract**

Self-Injurious Behaviors (SIB) in Autism Spectrum Disorder (ASD) form a constellation of particularly pervasive and harmful symptoms signifying high morbidity for children and adolescents. Electroconvulsive Therapy (ECT) has been proposed as a last resort for particularly severe and treatment-resistant forms of SIB, yet has received little acceptance in mainstream clinical psychology. This paper summarizes findings of four studies investigating the efficacy of ECT in treating SIB in ASD inflicted youth. This paper also evaluates the research on potential side-effects and ethical implications of ECT use. I conclude that while extensive further research is required to understand the implications of usage, that ECT may bear the potential to benefit an erstwhile untreated population.

#### Introduction

Children with Autism Spectrum Disorder (ASD) present a distinctive set of symptoms which affect areas of socialization, communication, and volition (American Psychiatric Association, 2013). Of these, Self-Injurious Behaviors (SIB) may be one of the most grave. Self-Injurious Behaviors are defined as, "a class of behaviors, often highly repetitive and rhythmic, that result in physical harm to the individual displaying the behavior" (Fee & Matson, 1992, 4). These repetitive behaviors include pulling hair or skin, picking skin, biting self, inserting fingers or objects into bodily orifices, and other hand-to-head and hand-tobody injuries (Lam & Aman, 2007). Researchers have concluded that

of a variety of consequences from SIB, the most detrimental are tissue damage, disfigurement, health risks due to infection, and stigmatizing consequences (Humenik, Curran, Luiselli, & Child, 2008). There exists considerable debate on the prevalence of SIB in ASD. The research of Janicki and Jacobson (1983) posited that 20% of children diagnosed with autism display some form of SIB. In contrast, the more recent findings of Baghdadli, Pascal, Grisi, and Aussilloux (2003) indicated that SIB is prevalent in 50% of children with ASD, with 14.6% demonstrating SIB at severe levels.

A number of hypotheses attempt to illustrate the etiology of SIB while little consensus exists within the clinical ranks on treatment. This is indicated by the controversy that surrounds the use of Electroconvulsive Therapy (ECT) in treating severe forms of this condition. A negative view of the therapy, reinforced by representations in popular culture, has been enshrined in the laws of states such as California, Colorado, Tennessee, and Texas, to name a few (Consoli, et al., 2012). Meanwhile, some authors have augmented these concerns by stating their opposition to the practice for ethical reasons and the risk of various secondary cognitive side effects (Baker, 1995). Nonetheless, experts have concluded that alternative therapies, such as psychotropic medication and behavioral therapy do not succeed in treating all patients (Food and Drugs Administration, 2014). The severity of SIB and its consequences heightens the need to determine the effectiveness of ECT. The focus of this paper is to evaluate existing literature on the use of ECT to treat SIB, ASD youths. This review of material will be used in an attempt to assess and draw conclusions on the efficacy and ethical considerations of this practice while taking into account the unique population in question.

# Positive-only Treatment of Self-Injurious Behaviors

First line interventions for SIB in ASD consists of a combination of behavioral and psychopharmacological treatments (Weiss, 2002). These first line interventions have proven to be effective when observable environmental circumstances appear to be maintaining the behaviors, or if an underlying psychotropic condition is present (Weiss, 2002). However, several clinical phenomena challenge the therapeutic primacy of first line interventions. Efficacy of these therapies differ from one clinical case to another due to the highly individualized nature of SIB in ASD (McCorkle, 2011). An added complication is that only two antipsychotics, aripiprazole and risperidone, have been approved by the FDA for use in treating behavioral impairments associated with autism and/or intellectual disabilities in children and adolescents (Consoli, et al., 2012). This is due, in part, to the significant side effects associated with antipsychotic use. Indeed, two meta-analyses of randomized, placebo-controlled trials of antipsychotics among children (Cohen, Bonnot, Bodeau, Consoli, & Laurent, 2012; De Hert, Dobbelaere, Sheridan, Cohen, & Correll, 2011), including aripiprazole and risperidone, have

demonstrated that antipsychotic usage is linked to short term extrapyramidal symptoms (movement disorders such as restlessness, involuntary muscle contractions, pseudo-parkinsonism), cardio-metabolic and endocrine side-effects, hyperprolactinaemia (elevated levels of the hormone prolactin), and weight gain (Cohen, Bonnot, Bodeau, Consoli, & Laurent, 2012). Lastly some patients display particularly severe forms of first line treatment-resistant SIB (Consoli, et al., 2012). It is this population that researchers look to in the debate on ECT.

# The Efficacy of Electroconvulsive Therapy

Despite the controversy that surrounds the use of ECT, a number of studies have demonstrated significant treatment effects in cases of severe and treatment-resistant mood disorders (Ghaziuddin, Dumas & Hodges, 2011; Kessler, 2004; Ligas, Petrides, Istafanous & Kellner, 2009; Reinblatt, Rifkin & Freeman, 2004). The literature on clinical benefits of ECT use in cases of maladaptive behavioral conditions, especially in ASD, is considerably more sparse but warrants assessment. What follows is a summary of four studies - all of which involve small sample sizes – that demonstrate significant treatment benefits of ECT in cases of severe SIB.

The case of a sixteen year old male diagnosed with autism, catatonic symptoms, and severe SIB demonstrates the dramatic treatment effects of ECT (Haq & Ghaziuddin, 2014). The patient had been hospitalized due to an acute increase in SIB, such as biting himself, throwing himself against walls, and banging his head. After over a month of admission and the failure of pharmacological and behavioral management

therapies, the patient was referred to ECT treatment. This resulted in gradual but dramatic improvement with aggressive episodes declining enough by the 16th session to allow for hospital discharge, school attendance, and out-patient treatment. The tapering of treatment occurred over the next four months and ended with termination upon which the patient experienced a gradual decline in functioning and an increase in SIB. This development necessitated the reinstatement of ECT, which resulted in an immediate decrease in problematic behaviors and an increase in functioning. The tapering of the second treatment course resulted in the same pattern of regression, which could not be mediated by antiepileptics. Electroconvulsive therapy was restarted again, leading to an immediate cessation of SIB, and a more effective tapering schedule was identified. This case highlights the efficacy of ECT in managing SIB and identifies the need for additional research into effective maintenance schedules and tapering trajectories for this particular treatment method.

The clinical case of an eight year old boy with autism, who presented a five-year history of extreme self-injury supports the findings of the previous research (Wachtel, et al., 2009). The patient's SIB included slapping and punching his head, as well as banging his head on his knees and shoulders, with the frequency averaging 109.3 attempts hourly. Despite undergoing extensive applied behavioral assessments, medication, and behavioral trials for three years, the patient showed little to no decrease in SIB. He also displayed significant mood instability, with negative affect correlated to increase in SIB. Fifteen ECT treatments were administered over a

period of five weeks, three times per week with tapering towards the end. Significant improvement was noted after the first session alone. Overall, the rate of self-injury was reduced to 6.5 attempts hourly with restraints and 19.4 without restraints. The restraints required were canvas sleeves and not the bilateral arm restraints and cervical immobilizer that were worn before treatment.

Similarly, the case of an eleven year old boy diagnosed with autism and concomitant psychotropic-resistant bipolar affective disorder demonstrates the efficacy of ECT in reducing severe SIB (Wachtel, Jaffe, & Kellner, 2011). Self-Injurious Behaviors consisted of a several-year history of hand-to-head injury, resulting in bleeding, a broken arm, and repeated hand-biting. Several years of extensive psychopharmacological interventions had failed to produce any lasting results so an acute ECT treatment was initiated, consisting of eight sessions over a course of 2.5 weeks. After the end of the acute treatment, clinical and parent observations recorded near extinction of SIB. Maintenance therapy of once weekly sessions led to an intense violent outburst on Day 6 post-acute treatment. The frequency of maintenance therapy was then increased leading to previously noted behavioral and affective stabilization and a return to normal, educational, and social activities.

The efficacy of ECT was demonstrated in the final case, to treat the catatonic symptoms of a teenage girl diagnosed with autism, who developed severe SIB at an early age (Wachtel, Kahng, Dhossche, Cascella, & Reti, 2008). Handto-head, knee-to-head, and handto-body self-injury were the most prevalent behaviors observed, intensifying in frequency to hundreds

of times hourly. The failure of multiple psychopharmacological therapies led to the use of ECT with 25 treatments administered three times per week, and tapering to maintenance levels. Self-Injurious Behaviors was reported to have markedly decreased by the ninth treatment and neared extinction towards the end of the therapy. Clinicians experimented with the placement of the leads, and discovered that bilateral placement delivered the best results. This highlights the need for further research in the clinical benefits of bilateral lead placement in ECT.

In addition to these studies, a number of other clinical cases have revealed the significant treatment effects of ECT in managing severe psychological disorders with concomitant SIB (Black, Wilcox, & Stewart, 1985; Carr, Dorrington, Schrader, & Wale, 1983; Chung & Varghese, 2008; Cizadlo & Wheaton, 1995; Fink, 1999; Thuppal & Fink, 1999). Of these, the most relevant to this review are studies examining SIB and concomitant intellectual disabilities (ID). A wealth of knowledge exists to demonstrate the overlap and similarities between ID and ASD as risk factors for predicting SIB (Bartak, Rutter, & Michael, 1976; McClintock, Hall, & Oliver, 2003). A retrospective study of the efficacy of ECT in treating severe and treatment- resistant SIB among a small sample of adolescents with ID (n=4) showed promising results (Consoli, et al., 2012). The SIB reported was severe in scale and included repeated attempts of suicide, repeated head banging, attempts to remove an eye with a fork, and daily ingestion of objects. When comparing the efficacy of ECT, mean SIB scores post-ECT were shown to be half of pre-ECT values. Three of the four patients transitioned to fewer

restrictive environments, indicating the success of ECT in treating SIB in conditions highly related to ASD.

Despite the relative success of ECT in treating SIB, little knowledge exists on the underlying reasons of its efficacy. Researchers have presented several neurobiological hypotheses, one being that SIB in some cases can be explained by monoamine dysfunction, which could potentially be reversed by ECT (Sanacora, et al., 2003). This theory posits that the treatment has been shown to increase GABA-ergic transmission, which other research indicates may correct the lack of GABA-led inhibition displayed in SIB (Schroeder, et al., 2001). Furthermore, decreased dopamine and serotonin activity in SIB (Schroeder, et al., 2001) could be ameliorated by ECT (Yoshida, et al., 1998). Lastly, researchers have suggested that ECT achieves the normalization of HPA axis activity in SIB (Fink, 1999). Thus, evidence exists to support the theoretical conceptualization of the treatment efficacy of ECT in severe SIB.

#### Risks and Ethical Implications of ECT Treatment

Proponents of the use of ECT claim that misperceptions regarding the treatment have biased mainstream clinical thought, leading to the underutilization of a purportedly effective therapy. The American Psychiatric Association (APA) and the American Academy of Child and Adolescent Psychiatry (AACAP) consider ECT to be a viable option for children with certain affective, psychotic, and catatonic disorders (Consoli, et al., 2012). In 2004, the AACAP issued practice parameters on ECT in adolescence (AACAP Of-

ficial, 2004). Nonetheless, a review of the literature concerning potential side-effects of ECT has been incorporated in this paper. Here I wish to note the paucity of literature exploring the side-effects of ECT when applied to youth with ASD and SIB. Many of the studies reviewed in this section consider the risks posed to all populations undergoing treatment, even adults and those with other conditions. However, it may be possible to draw inferences for the specific population in question through this analysis.

The potential risks that ECT poses to any population can be divided into three broad categories according to the review of literature presented by Lawrence Park before the FDA Neurological Devices Panel in a deliberation of the reclassification of ECT (Food and Drugs Administration, 2011). Of these, the third category, one dealing with device malfunction, has been omitted from this review in the interest of brevity. According to Park, the medical and physical risks of ECT include adverse reactions to anesthesia, cardiovascular complications, dental and oral trauma, physical trauma, pulmonary complications, skin burns, and strokes. These are classified as uncommon side effects and the risks of occurrence can be minimized by pre-ECT medical tests, assessments, gaining a detailed medical, surgical, and family history, and post-ECT monitoring and clinical management. Alterations in blood pressure pain, and discomfort are the two most common physical side effects - both reported to be benign and transient in nature - which clinicians have to account for (Food and Drugs Administration, 2011). With regard to certain side effects such as cardiovascular complications, other research suggests that children

may be at lesser risk than adults, who may have pre-existing medical conditions or risk factors (Wachtel, Dhosscheb, & Kellner, 2011). Most importantly, no pediatric deaths have been reported due to ECT (Rey & Walter, 1997). This suggests that while concerns of mild medical and physical risks exist, that they can be effectively managed by clinicians.

The second category of risks deals with cognitive and memory impairment. Park's review of literature demonstrates that immediate cognitive dysfunction, in the form of disorientation, may occur. This effect is observed to be transient and is expected to cease within minutes after treatment. Memory dysfunction is a more significant risk and deserves greater exploration. The research of Krulewitch and Como (2011) that was presented before the same FDA panel suggests that anterograde verbal memory deficits may result through ECT, which generally resolves within a few weeks post-treatment. Of greater concern, according to Krulewitch and Como, is the risk of autobiographical memory deficits, with evidence suggesting that autobiographical memory performance is approximately 76-77% of baseline performance for right unilateral treatment and 58-67% for bilateral treatment. This is particularly significant as Wachtel and colleagues suggested the potential efficacy of bilateral lead placement in ECT (Wachtel, Kahng, Dhossche, Cascella, & Reti, 2008). Conflicting with this finding, two separate studies (Wachtel, Hermida, A, & Dhossche, 2010; Wachtel, Reti, Dhossche, Slomine, & Sanz, 2011) maintain that bilateral placement, even when continued over several years, did not lead to cognitive impairments. This highlights the need for additional research to

resolve this point of contention. Several factors may mitigate this particular risk, such as the use of certain types of currents (Food and Drugs Administration, 2011).

Research into risk of retrograde amnesia post-ECT have concluded that while a loss of memory is observed immediately after treatment, by 3 months, retrograde memory had reached baseline levels and that anterograde memory appeared to be unaffected (Meeter, Murreb, Janssen, Birkenhager, & van den Broek, 2011). A study assessing learning and memory impairment among adult patients undergoing ECT for Bipolar Disorder shows that, even after adjusting for the inherent memory and learning dysfunction associated with the disorder, patients reported lower performance (MacQueen, Parkin, & Marriott, 2007). While the researchers have stated that this finding is unlikely to alter the risk-benefit ratio of the treatment significantly, it does highlight the importance of attending to the cognitive factors of patients before and following treatment. One significant finding from this research is that patients receiving ECT are more likely to self-report memory impairment, which speaks for expectations which could affect their performance in tests in a self-fulfilling prophecy effect. If this hypothesis is likely to be true, managing patient expectations regarding ECT treatment could mitigate risks of memory impairment significantly. A study assessing cognitive functioning of adolescents with severe treatment-resistant depression arrived at a contradictory result, indicating evidence of improved short-term memory and verbal learning as well as a statistically significant improvement in long-term delayed memory recall (Ghaziuddin, Dumas, &

Hodges, 2011). These findings could perhaps be attributed to symptom relief, positive effect, greater motivation and increased psychomotor control that results through high treatment efficacy. Despite contradictory findings, proponents of ECT argue that enough research has been conducted to dismiss the more serious claims of long term cognitive and memory impairment among youth (Cohen, et al., 2000; Ghaziuddin, et al., 1996; Walter, Koster, & Rey, 1999).

With regard to the ethical implications of ECT use, guidelines such as those put forth by the AACAP confirm the importance of gaining the consent of parents/legal guardians and the patients. Emphasis is placed on educating both the patient and the parents/guardians on the benefits and risks of the treatment and granting both parties the right to reject treatment at any time once therapy has commenced. The consulting of an independent psychiatrist is another safeguard that has been instated, along with a seventy-two hour waiting period before treatment begins, allowing the patient and parents/guardians time to reflect on their choice. A potential ethical dilemma – one faced by all child mental health practitioners – arises if the patient and the parents disagree. If the use of ECT was to become more accepted, a question that requires consensus is at what point SIB is declared to be treatment-resistant and is referred to ECT. As the focus on early interventions in SIB in ASD grows, it must be decided if there is any age that is considered too young for receiving ECT. Lastly, although clinicians are quick to declare pain experiences to be mild to moderate (Food and Drugs Administration, 2011) any potential significant pain occurring

through ECT warrants attention given the ethical implications of subjecting children to treatment that is potentially painful. A growing body of research is challenging the misconception that ASD is associated with higher pain thresholds or pain insensitivity (Allely, 2013). This research suggests that children with ASD may express pain in ways different to neurotypical children, which may lead to an underestimation of pain experience. This is particularly relevant to the sub-population of patients with severe intellectual disabilities. Thus, further research is required to accurately gauge pain experience. While it is important to bear in

while it is important to bear in mind the potential physical and cognitive impairments that may occur as a result of ECT usage, active management of such situations, and adherence to clinically tested guidelines may offer clinician the opportunity to minimize potential hazards.

#### Discussion

A summary of the literature that exists on the subject of managing and treating SIB of children and adolescents with ASD, demonstrates that there is some evidence for the efficacy of ECT as a last-resort intervention for particularly severe and treatment-resistant cases. However, there are limitations to this review that must be taken into account when interpreting the results. First, there is the possibility of certain relevant research being overlooked in the review process. It is of particular significance that no research was found to reveal the ineffectiveness or substantial risks of ECT in treating SIB in ASD. This may be explained by the limitation elucidated earlier. but it is notable that there is no easily available wealth of knowledge supporting this position. Given

the dearth of research examining the unique side-effects that youth with ASD and SIB experience when undergoing ECT, another limitation imposed upon this review was having to generalize side-effects of ECT use in other conditions to this particular context. Additionally, the studies that were reviewed were conducted over the past five decades, and thus there may exist varying standards in the quality of research and analysis, with a general trend of improvement over time. While every effort was made to use more recent materials, this limitation cannot be discounted. Related to this is an additional concern of varying diagnostic definitions and criteria as well as assessment tools being used across studies, potentially contributing to low reliability, validity and comparability. Lastly, all of the research on efficacy and complications of ECT are single subject designs with no controlled trials, which may affect the generalizability of findings.

It is, therefore, imperative that more research involving larger samples is conducted on the efficacy of ECT (e.g. unilateral vs. bilateral placement, tapering trajectories) and potential side effects (e.g. pain experience, mitigating effects on autobiographical memory among others). It is of utmost importance that future research study populations of youth with ASD and symptoms of SIB specifically. While further research along streamlined, uniform, and universal standards is required to conclude authoritatively on the question of ECT use, the research exhibiting the treatment gains and risk-management capabilities of ECT cannot be denied. Therefore, this treatment carries significant potential to offer relief to those who do not respond to first-line interventions and have little hope.

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