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Contingent Electric Shock as a Treatment for Challenging Behavior for People With Intellectual and Developmental Disabilities: Support for the IASSIDD Policy Statement Opposing Its Use

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Abstract

Issues: The International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) is an international group of researchers, clinicians, students, parents, and self-advocates that promotes worldwide research and exchange of information on intellectual and developmental disabilities. IASSIDD recently developed a policy statement regarding their opposition to the use of contingent electric skin shock (CESS) with individuals with challenging behavior and intellectual and developmental disabilities. To support the policy, the available literature was reviewed to evaluate the efficacy, side effects, generalization, and long-term effectiveness of the procedure as an intervention for challenging behavior.

Findings: The review provides a history that demonstrates that, although CESS can decrease the frequency of challenging behavior, it comes at a cost in terms of physical and emotional side effects, and questions remain regarding the long-term effectiveness of the procedure. In addition, we raise several ethical and methodological issues that make the research on the use of CESS even more concerning.

Conclusions: Although research continues in some countries, these studies are now rare. In fact, in the United States, the Food and Drug Administration has just banned the use of such devices with individuals with self-injury and aggression. It is hoped that, because there are many other forms of treatment that have shown to be effective for severe challenging behavior, we can completely avoid the use of CESS.

Keywords: challenging behavior, contingent electric skin shock, treatment; intellectual disability

Contingent electric skin shock (CESS) has for several decades been a highly controversial form of treatment for severe challenging behavior in people with intellectual and developmental disabilities. Currently, it is seldom used, and usually only after other options has been deemed unsuccessful or impractical. Thus, the use of CESS led the Challenging Behavior and Mental Health Special Interest Research Group (SIRG) of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) to develop a policy position statement opposing its use. Wide consultation on the matter occurred and, on October 1, 2018, the Executive Committee of IASSIDD approved the following policy statement, under the heading "IASSIDD Opposes Electric Skin Shock as Treatment" (IASSIDD, 2018; see Figure 1). The purpose of this

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paper is to provide IASSIDD's rationale, based on published research, for developing and promoting this policy statement.

Review of Contingent Electric Shock as Treatment

The general finding of the United States' Food and Drug Administration (2014) was that CESS, while effective at reducing severe challenging behavior for individuals with intellectual and developmental disabilities, is associated with limitations, ethical concerns, and side effects that draw the validity of the treatment into question. Thus, they recently made the rare decision to ban the use of the device completely on March 5, 2020 (Federal Register, 2020).

The FDA and others have noted some successes of CESS. Across the 41 studies published within the 30 years prior to the FDA report in 2014, researchers reported at least an 80% reduction in target challenging behavior in 100% of participants (n = 80). Additionally, in a study not reviewed by the FDA, ter Mors, van Heugten, and van Harten (2012) reported that CESS was effective at reducing the occurrence of inappropriate sexual

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IASSIDD Policy Position Statement IASSIDD Opposes Contingent Electric Shock



The International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) strongly opposes administering electric skin shock to individuals with intellectual and developmental disabilities who have challenging behaviour.

The Issue:

In some parts of the world, electric shock is still being administered to the skin of people with intellectual and developmental disabilities in an attempt to correct their challenging behaviour. This intervention has been widely discredited by scientific research, especially in the disciplines of disability studies, psychology, medicine, and education. Electric skin shock is not effective in reducing self-injurious and aggressive behaviours in the long term and may actually increase them.

Instead, there is increasing evidence that interventions based on applied behaviour analysis and positive behaviour support, including the use of medication, can be effective in addressing challenging behaviour.

The practice of electric skin shock violates the human and civil rights of people with intellectual and developmental disabilities, as set out in numerous country-specific and international documents. For example, the United Nations' Convention on the Rights of Persons with Disabilities clearly sets out a comprehensive set of rights, including the necessity to provide habilitation (Article 26) in ways that are humane, and free from degrading treatment, violence, and abuse (Articles 15 and 16). Such rights must be protected and enforced.

What should be done:

IASSIDD calls on all countries around the world to immediately ban the use of electric skin shock as an inhumane and ineffective method of correcting challenging behaviour. Further, we invite all other organizations and stakeholders involved in the lives of people with intellectual and developmental disabilities to publicly support our position.

IASSIDD Challenging Behaviour / Mental Health Special Interest Research Group Dr Jennifer Zarcone and Professor Peter Langdon August 31, 2018.

Approved by:

IASSIDD Executive Committee

October 1, 2018

FIGURE 1 IASSIDD policy position statement pertaining to the use of contingent electric skin shock.

behavior in a 40-year-old man with traumatic brain injury. Despite this reported effectiveness, there are (1) methodological concerns with the literature, (2) difficulties with determining

long-term effectiveness, (3) ethical concerns about the use of CESS, and (4) adverse and unwanted side effects. Each of these is further described below.

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Methodological Concerns

The results and implications of CESS research are attenuated by several critical methodological limitations. Take, for example, the authors of one small study that included a comparison group and that reported positive results (i.e., Duker & Seys, 2000). That study implemented CESS with only eight participants and the participants were not randomly assigned to the CESS or comparison group. Researchers assessed the effectiveness of CESS not by reporting data on challenging behavior, but rather by reporting changes in participants' scores on a rating scale (i.e., The Imposed Mechanical Restraint Inventory; Duker & Seys, 1997) that measured the degree and duration of mechanical restraint implementation related to challenging behavior. Because it is unclear whether researchers controlled the decision-making process related to the implementation and subsequent fading of mechanical restraint, it was unclear whether there was a one-to-one relationship between challenging behavior and mechanical restraint and how it was related to CESS implementation. Furthermore, although the study included a comparison group, the researchers did not control for any other interventions that were implemented during the CESS trial. This makes it difficult to determine the efficacy of CESS alone and whether it was adequately measured.

Another methodological concern that arose from the review was that several of the CESS studies utilized single-case experimental designs that did not demonstrate sufficient experimental control, making it difficult to determine a functional relationship between the treatment and its effects on behavior (e.g., Israel, Blenkush, von Heyn, & Rivera, 2008; Israel, Blenkush, Von Heyn, & Sands, 2010; Williams, Kirkpatrick-Sanchez, & Crocker, 1994). Israel et al. (2008, 2010) examined the effectiveness of CESS by reporting levels of challenging behavior prior to and following CESS implementation using a simple AB design with 60 individuals where the start of treatment was staggered. Unfortunately, this design does not provide repeated demonstration of the effects of the treatment with the individual, and thus does not provide evidence for experimental control (Horner et al., 2005; Johnston, Pennypacker, & Green, 1993). Although six studies demonstrated the effectiveness of CESS utilizing a design that provided repeated demonstrations of the effectiveness of CESS, the total number of participants was only 12. Moreover, neither of the Israel et al. studies reported data regarding inter-rater agreement nor procedural integrity, which is necessary to evaluate validity and reliability effects of the treatment. In addition, very few studies collected information on whether CESS was acceptable to those implementing or overseeing the treatment (e.g., families, staff). Finally, as with Duker et al. (2002), several studies included other treatments in combination with CESS (e.g., differential reinforcement of other behavior, physical guidance, verbal reprimands, functional communication training), making it difficult to evaluate the isolated effects of CESS on behavior change (e.g., Israel et al., 2008, 2010; Williams et al., 1994; Williams, Kirkpatrick-Sanchez, & Iwata, 1993).

In all, the CESS research over the past 30 years reflects a series of studies whose internal validity might be open to questions due to their methodological limitations or whose generalizability might be debated due to small sample sizes and a

limited number of studies. From these limitations alone, a clinician would be justified in approaching the use of CESS with a high degree of caution.

Difficulties With Long-Term Effectiveness

The extant CESS literature provides inconsistent information regarding the immediate and long-term effectiveness of CESS, as well as whether treatment gains were maintained once CESS was removed. Regarding the immediacy of effectiveness, several studies (e.g., Linscheid, Iwata, Ricketts, Williams, & Griffin, 1990; Salvy, Mulick, Butter, Bartlett, & Linscheid, 2004) demonstrated that CESS significantly reduced challenging behavior in only a few brief sessions (e.g., 10 min), whereas other studies demonstrated that CESS was only effective after numerous months of all-day implementation (e.g., Israel et al., 2008, 2010). Regarding long-term efficacy, some studies showed that CESS remained effective for many months (e.g., Mudford, Boundy, & Murray, 1995; Williams et al., 1993), while other studies showed that CESS lost its effectiveness over longer periods of time (e.g., Ricketts, Goza, & Matese, 1993). Last, research has yielded different results regarding whether CESS can be successfully faded. Williams et al. (1993) were able to maintain treatment gains after fading CESS and, similarly, Salvy et al. (2004) reported a single 10-min session in which low levels of target challenging behavior were maintained without the repeated use of CESS. However, several studies either did not attempt to fade CESS (e.g., Mudford et al., 1995) or demonstrated that withdrawing CESS resulted in an immediate increase in challenging behavior (e.g., Israel et al., 2010; Linscheid et al., 1990). Overall, the type and number of treatments for long-term effectiveness, and the length of time treatments remain effective either with CESS in place or after it has been withdrawn, are not well demonstrated, and indeed are sometimes contradictory, in the available literature.

Ethical Concerns

Ethical decision-making during intervention for challenging behavior is widely understood to involve choosing the course of action that is deemed to be the least intrusive and the most contextually driven. It is also understood that ethical decisions should be made following a careful weighing of alternatives against the possible benefits and risks that could result from any treatment, whether it is medical, psychiatric, psychological, or behavioral. Because CESS is assumed to involve inherent physical pain, extra caution in selecting it as the best course of action in any situation is warranted.

At first glance, many of the published studies involving CESS have been justified by arguing that previously used treatments that have a low risk of harm (e.g., differential reinforcement procedures) were ineffective. Across the 101 participants with whom CESS had been examined in the scientific literature in the last 30 years, researchers reported that previous treatments had failed for 75% of people. But for 42% of these participants, no data from previous failed treatments were reported, and of the two studies that did report data on previous failed

treatments (i.e., Israel et al., 2008, 2010) neither reported baseline levels of challenging behavior prior to the failed treatment nor provided technical information regarding the failed treatment(s) beyond general terms (e.g., describing it as differential reinforcement). These reports do not make us confident that alternative treatments had been adequately considered.

In evaluating the rationale for relying on failed treatments to justify the use of a more restrictive treatment with a higher risk of harm (e.g., CESS), we must take into consideration not only the quality of the failed treatments but also the quality of the assessment used to design those treatments. Our field has come a long way in developing function-based assessment procedures (e.g., Beavers, Iwata, & Lerman, 2013) that have significantly expanded our ability to design and implement effective treatment (e.g., Filter & Horner, 2009; Miller & Lee, 2013) that do not rely on overly restrictive or aversive techniques (e.g., CESS). There might be justification to move to more restrictive treatment when previous treatments based on functional assessment have proved ineffective. Unfortunately, it appears that the degree to which a functional assessment was implemented prior to the use of CESS is unclear. Based on this review, researchers reported conducting a functional assessment to inform treatment with 66.3% of participants but provided detailed information on the assessments for only 13.4% of participants and reported actual data from these functional assessments with only 1.5% of participants. From the information provided, it is difficult to determine whether previous failed treatments were based on functional assessment which in turn detracts from our ability to assess the quality of failed treatment. Thus, whether the use of CESS was justified over alternative treatments was difficult to determine.

As an example of the lack of justification for the use of CESS, Salvy et al. (2004) implemented CESS to reduce selfinjurious behavior (SIB) in a 3-year-old child. The authors reported that the only other failed treatments were implemented by family members prior to admission to their programme. The authors did not conduct any type of functional assessment to inform treatment, only reporting that SIB "occurred across all settings." The authors also cited a decision-making model (Meinhold & Mulick, 1992) to explain how they arrived at the decision to use CESS without first trying any other procedures. Although discussing the various claims made by Meinhold and Mulik is beyond the scope of this paper, the use of this model by Salvy et al. is problematic because the technological advances in the field since the publication of this decision-making model make it obsolete. At the time of the Salvy et al. study, there had been more than 300 published articles examining the use of functional analysis in developing effective treatments based on modifying the reinforcers associated with the behavior (Beavers et al., 2013; Iwata et al., 1994). Thus, there appeared to be little justification in moving toward such a high-risk treatment with

There are also examples of researchers implementing CESS without there being a pressing need for treatment. Of the 60 individuals with whom Israel et al. (2008) implemented CESS, 11 had not engaged in challenging behavior for the prior two weeks, six of whom had not engaged in challenging behavior for at least one month prior to starting CESS. It remains unclear why the treatment was even implemented, as there may

not have been a need for any treatment for some of their participants.

Israel et al. (2008) also reported that they implemented CESS not only for severe challenging behavior (e.g., aggression), but also for nondangerous forms of challenging behavior (e.g., noncompliance, yelling) that they believed were precursors to severe challenging behavior. The authors did not provide any evidence that these nondangerous behaviors were related to these individuals' severe challenging behavior. From the procedures reported, it seems quite possible that CESS was used with some individuals simply because they had yelled or did not follow instructions. Even if these nondangerous behaviors were occurring frequently, there are many reinforcement-based treatments that do not use physical pain that are highly effective for reducing them (see Iwata et al., 1994 for a review of function-based treatment outcomes, and Marquis et al., 2000).

Adverse and Unwanted Side-Effects

As noted above, several studies demonstrated an immediate and significant reduction in challenging behavior and a reduction in the use of restraint and fewer staff injuries (e.g., Israel et al., 2008). However, there have been several negative side effects indicated as well. Early studies identified adverse behavioral effects such as symptom substitution (e.g., incontinence; Birnbrauer, 1968), hostility and retaliation (Brandsma & Stein, 1973), anticipatory fear and avoidance of experimenter (Bucher & King, 1971), panic, extreme anxiety, and "freezing" or suppression of all behavior (Duker & Seys, 1996). More recent studies indicated that participants attempted to remove the device (Israel et al., 2008), and were crying and made other negative vocalizations when CESS was implemented (Israel et al., 2008; Linscheid, Pejeau, Cohen, & Footo-Lenz, 1994; van Oorsouw, Israel, Von Heyn, & Duker, 2008). In addition, the FDA report provided a table that listed adverse events associated with the use of CESS that were reported in the research they reviewed (Food and Drug Administration, 2014). Adverse events were categorized as:

- Anxiety (6 reports),
- Fear and aversion/avoidance (6 reports),
- Substitution of other negative behaviors (5 reports),
- Burns and other tissue damage (4 reports),
- Depression/crying (4 reports),
- Pain/discomfort (3 reports),
- Neurological symptoms (1 report), and,
- Other negative emotional reactions or behaviors (11 reports).

It should be noted that most of these reports were made anecdotally in the research and were not based on systematic data collected for the purpose of evaluating the frequency or duration of adverse events. In fact, there may have been an inherent bias on the part of the researchers not to report any adverse events or possible side effects. Given that it was not systematically evaluated and, as anecdotal information, it may have been discouraged as part of the research publication process (Carr & Lovaas, 1983). In addition, there was no attempt to evaluate any short- or long-term psychological effects (e.g., anxiety disorders) with the study participants, nor whether

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there were long-lasting traumatic effects. Thus, this list of negative side effects may be incomplete.

Finally, when the Federal Register (2020) summarised the Food and Drug Administration ban on the use of such devices with individuals with self-injury and aggression, they provided information from the consent form used by Judge Rotenberg Center (JRC), the only programme currently using CESS and stated:

"The potential physical risks associated with the graduated electronic decelerator (GED) may include temporary skin redness, which clears up within a few minutes or a few days at most, and there is a possibility that a small blister may appear. JRC rotates the placement of the electrodes to avoid superficial red marks or scaling of the skin. The psychological/behavioral risks that might be associated with the GED include anxiety (nervousness, tensing muscles) during the period between the occurrence of the behavior and the occurrence of the programmed consequence, escape responses and short-term or long-term collateral effects including: nightmares; intrusive thoughts; avoidance behaviors; marked startle responses; mistrust; depression; flashbacks of panic and rage; anger; hyper-vigilance; and insensitivity to fatigue or pain" (Federal Register, 2020, p. 13321).

Conclusion From the Review

Research on CESS has shown a steady decline over the past 10 years with the last identified study published in 2012. This may be due to the further refinements in reinforcement-based treatments as well as cultural and legislative changes related to how we support people with intellectual and developmental disabilities. When CESS is implemented, clinicians, in accordance with their professional codes of conduct within their associated jurisdictions (e.g., American Psychological Association, 2017; Australian Psychological Society, 2010; British Psychological Society, 2018), should weigh the risks and benefits of various treatment options and select one that they determine would benefit the individual while also minimizing potential harm (i.e., beneficence and nonmaleficence). Working within this framework, clinicians opting to choose CESS as a treatment do so only because they believe that CESS would result in the most benefit and the least harm to the client relative to the other treatments available.

From our analysis of the literature, we do not support the use of CESS for several important reasons. First, the lack of justification for using CESS as a treatment for challenging behavior in several of the studies reviewed makes it difficult to justify that the physical and emotional costs associated with using CESS outweigh the clinical benefits. Second, many CESS studies did not provide information on whether or what type of functional assessment was conducted, or whether less restrictive treatments were properly evaluated prior to using shock. Third, there is strong evidence to suggest there are adverse side effects associated with the procedure. Overall, methodological limitations, difficulties with determining long-term effects, ethical concerns, and reported adverse side effects of CESS lead us to recommend against the use of CESS.

In the United States, the FDA has just recently implemented a ban on all electrical stimulation devices for the treatment of SIB and aggressive behavior in individuals with intellectual and developmental disabilities (Federal Register, 2020). Criticism of CESS stretches beyond the United States. It will also most likely violate Article 15 of the United Nations (2006) *Convention on the Rights of Persons with Disabilities* (CRPD) regarding freedom from torture or cruel, inhuman or degrading treatment. The CRPD has been ratified by 180 countries. Although research continues in some countries, these studies are now rare. It is hoped that, today and into the future, the principal forms of treatment for individuals with severe challenging behavior are function-based treatments that have been shown to be effective. Such treatments should replace the need for CESS.

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