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COMMENTARY

The Tangle of Autonomy, Beneficence, Liberty, and Consent in the CESS Debate

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Abstract

This commentary on the task force report addresses the complex issues involved in autonomy, beneficence, liberty, and consent, which are often in competition in this and many other treatment issues for individuals with intellectual and developmental disabilities, especially those with limited vocal/verbal repertoires. The issues at hand are multifaceted, and behavior analysts should be aware there is much we do not know enough about. As good scientists, it is important to maintain an attitude of philosophic doubt and endeavor to deepen understanding.

Keywords Contingent electric skin shock · Bioethics · Autonomy · Beneficence · Intellectual and developmental disabilities · Choice

When I attended the Association for Behavior Analysis, International's conference in Boston last year (2022), a senior member of the field approached me and asked me why on Earth I agreed to serve on the Contingent Electric Skin Shock (CESS) Task Force. I replied that I had been wrestling personally with the issue of the use of CESS for a couple of years prior to it becoming a central topic of debate in the field. A couple of years earlier, I had taken it upon myself to travel to Boston and visit the Judge Rotenberg Center (JRC) as part of my effort to educate myself and form an opinion. I spent the better part of a day touring the facility and meeting with the leadership to get my questions answered. I had been doing some reading. I had been considering many facets of this issue—for 2 years—and I still did not know where I stood on the issue. It is such a complex issue. I told my senior colleague that I said yes to serving on the task force because I thought doing so would help me dig into the issue further, to learn more, and to really decide where I stood on the issue once and for all. Now, after months of continued study on the issue; a second, longer and deeper visit to JRC; conferring with many colleagues; listening carefully to people

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on both sides of the issue; conferring with medical ethicists outside our field; interviewing parents and clients who have received CESS treatment; lying awake at night trying to sort it out; and examining my own moral and ethical code, I have come to only one conclusion: anyone who thinks the answer to this issue is easy or clear is misguided and has not fully considered all the nuances involved.

Some will disagree with me. They will argue that the answer is simple and clear—our field should not tolerate the use of CESS because it is torture, inhumane, and painful. Such people would argue that these so-called facts[1] trump any other context surrounding an individual case of severe problem behavior. I disagree. There are many complexities involved that need to be considered. To ignore them is shortsighted. I could raise many of these considerations here. However, with the page limits imposed on our commentaries, there is not enough space for me to adequately do so. Further, the reader could dispute any arguments I might raise—and they would do so rightfully. The reader might be surprised to learn I would likely agree with the contradictions the reader might raise. Many of the dissenting opinions have merit. In many cases, the opposing viewpoints are both correct. I could suggest that individuals have the right to choose a treatment they think is most appropriate for them, even if their health-care provider disagrees with that course of action. For example, an individual with a strong family history of breast cancer might choose a preventative double mastectomy to avoid getting breast cancer, even if their physician believes this is a radical and unnecessary solution. The reader might counter my example by suggesting that situation is not comparable to the CESS issue because in my example the individual is making a choice for themself and about their own body. And the reader would be making a fair counterargument. The examples are not exactly the same. I will come back to this distinction later. Another reason it is unwise for me to attempt a discussion of all the facets of this issue; surely, I would omit one. The reader would call me out on that. Though I will not discuss all the nuances here, rest assured, the members of the task force had numerous conversations about every issue the reader could raise, and we debated each issue in detail somewhere along the way in the process of our work.

In my case, the major issues that came into play when sorting through the problems involved in the use of CESS were the conflicting principles of autonomy and beneficence. Respect for autonomy is one of four principles relevant to bioethics in clinical practice. Beauchamp and Childress (2019) discuss "autonomous choice" and suggest that "choosers . . . act (1) intentionally, (2) with understanding, and (3) without controlling influences that determine their action" (p. 102). Autonomy is defined at the level of the individual decision making (Beauchamp & Childress, 2019). In fact, Beauchamp and Childress focus primarily on autonomous choices rather than autonomous persons. (An autonomous person may make a nonautonomous choice; a person deemed incompetent may still make an autonomous choice.) Beneficence is

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[1] I use the phrase "so-called facts" only to suggest that some people view the preceding information as facts and others (including me) do not. I am not using this phrase in a judgmental or derogatory way. I ask the reader to refrain from reading into my usage of this phrase as anything other than my own way of suggesting there is not agreement that these are, indeed, facts.

a principle that requires health-care providers to be of benefit to the patient, promote well-being, and remove harm from the patient. Other principles are nonmaleficence and justice, both of which also have relevance, but those are beyond the scope of my comments. There is no one supreme principle; rather a plurality exists and all principles must be considered simultaneously. Nonabsolutism suggests that one principle may be overridden by a weightier principle in specific circumstances. One must balance each principle against the others when making ethical and moral judgments. Balancing is a process that involves consideration and examination of "the relative weights and strengths of different moral norms" (p. 17) to reach a conclusion regarding which principle should be followed (Beauchamp & Childress, 2013).

Katz (1994) argued the principles of autonomy and beneficence are often at odds and that autonomy is too often sacrificed for beneficence:

> (1) Autonomy assures that ultimate authority about treatment decisions resides with patients including the decision to authorize doctors to decide for them. Since it is their bodily integrity that is at stake, no one but they can decide what should be done for them. (2) In the past, beneficence has served too unquestionably as justification for the unilateral exercise of physicians' authority to make decisions on behalf of patients. (p. 86)

How do we balance beneficence and autonomy in the case of CESS? For some, beneficence might outweigh autonomy because they believe CESS harms the client. A ban on CESS is justified in the spirit of *beneficence* because it spares clients from experiencing a painful stimulus. However, we must be aware that such a "unilateral exercise of authority" also strips the individual of *autonomy* and the authority to make a decision regarding their own "bodily integrity." Benefits, harms, and physical integrity are all abstract, nuanced constructs. Katz suggests that autonomy should rarely be sacrificed for beneficence (or any other principle).

Autonomy is further complicated in the case of CESS because the clients who receive CESS tend to be clients with intellectual and developmental disabilities (IDD), who are often judged as "incompetent" to make decisions for themselves. Thus, parents or family members frequently make decisions for individuals with IDD—as their legal guardians. In these cases, the legal guardian serves as a proxy for the client and participates in substitute decision making for the client. In an ideal situation, a proxy would make treatment decisions that are consistent with the wishes expressed by the client when they were competent to make a decision, if there was a time when competency existed and wishes were effectively expressed. However, in the case of individuals with IDD,[2] there may not have been a time when "competency" existed and wishes were effectively expressed (as a result of a limited communication repertoire). Thus, it may be impossible to ascertain what the client would have wanted under the current circumstances. In these cases, the proxy

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[2] I am using the example of IDD here because it is relevant to the context. This is not to say that *only* individuals with IDD experience periods of incompetency. In fact, any one of us may have time periods where we are incompetent, for example, one is in a coma and decisions may need to be made regarding medical treatment.

is challenged to make a decision using the best interest standard, which typically means choosing the treatment with the best prognosis and that is also congruent with the client's values and well-being (Scholten & Gather, 2018).

To further complicate matters even further, in 2006, the UN Convention on the Rights of Persons with Disabilities rejected the "competency model" and issued a determination that it is not permissible to deny a person the right to make their own treatment decisions because others have judged them as having diminished decision-making capacity (United Nations, n.d.). They suggested that a more appropriate model for decision making is "supported decision making," in which the supported client retains legal capacity to consent to treatment. However, it must be noted that the person providing decision-making support remains in the position of interpreting the wishes and preferences of the client when expressing the client's preferred treatment (Scholten & Gather, 2018). Shalowitz et al. (2006) found that substitute decision-makers accurately predicted the treatment preferences of patients only 68% of the time, suggesting care providers who assist in decision making may not accurately understand the wishes of their wards. It is notable, however, that Owen et al. (2009) found 83% of patients deemed as incompetent, whose treatment preferences were overridden by decision makers, later approved of the received treatment in retrospect, suggesting that nonpreferred treatments may be the desired treatment in the long run.

It would be ideal if individuals in need of treatment for their problem behavior have the opportunity to express what they want for treatment. We attempted to gain an understanding of client preferences for treatment of their severe problem behavior when we interviewed JRC clients regarding their perceptions of CESS treatment. As was described in our report, we talked to four individuals at JRC who had received CESS treatment. We reported that three of the four individuals stated they did not prefer CESS treatment. All three of these individuals had developmental disabilities, and two of them had very limited vocal verbal repertoires. The fourth individual did not have intellectual disabilities and had an extensive vocal verbal repertoire. This individual stated emphatically that CESS had saved their life and had allowed them to live outside a psychiatric hospital, which this individual tearfully described as a traumatizing residential placement. This individual seemed proud of themself for doing so well with the CESS treatment and even initiated a request that it be reinstated for a short period of time when they experienced behavioral regression. We read comments submitted to the ABAI portal that criticized us for more heavily considering this individual's comments than the others. These critics suggested we weighed this individual's comments more heavily because they did not have IDD. This is not true. This individual had the most well-developed vocal-verbal repertoire and could share more detailed information about the effects of alternative treatment on their behavior, as well as more detailed perceptions of CESS. Thus, these comments provided insight that comments from the other clients did not. Another criticism levied in the comments submitted through the portal was that we did not make a recommendation that was consistent with the majority viewpoint expressed by the clients we interviewed. Several commenters noted that three of the four individuals we interviewed stated they did not like CESS treatment. These commenters suggested that because the majority of individuals did not prefer the treatment, banning CESS was justified. I was not swayed by this argument.

The fact that *even one* person found CESS life-saving and necessary was compelling. A 1986 Supreme Court ruling upheld an injunction against the Pennsylvania Abortion Control Act of 1982 because it violated the U.S. Constitution by imposing abortion restraints (*Thornburgh* v. *American College of Obstetricians & Gynecologists*, 1986). Justice Stevens wrote a concurring opinion that was appended to the decision, in which he stated ". . . it is far better to permit some individuals to make incorrect decisions than to deny all individuals the right to make decisions that have a profound effect upon their destiny." Justice Stevens further opined, ". . . no individual should be compelled to surrender the freedom to make a decision for herself simply because her 'value preferences' are not shared by the majority." These arguments *are* compelling, and I found myself deeply considering issues of liberty, self-determination, and how these interact with decision making, whether for self or via a proxy. Even if most people do not prefer CESS as treatment for decreasing severe problem behavior, should any single person be denied access to that treatment if that person wants the treatment and the treatment could potentially improve the quality of their life?

As stated earlier, autonomy does not automatically trump the other principles. We must also consider beneficence (and nonmaleficence and justice). From our review, CESS cannot be considered best practice, because there are many alternative treatments available (see our report for a summary of these). These more positive alternative treatments have efficacy in the vast majority of cases and are generally accepted as best practice in the field. Given evidence that at least in some cases, CESS has proven successful and to have few documented negative side effects, it could be considered at best an *emerging practice*—using the National Autism Center's Intervention Effects Rating Scale (National Autism Center, 2015).[3] Are there situations where a client might benefit from a procedure that is aversive and/or restrictive, such as CESS, that is implemented within an overall behavior support plan that includes positive reinforcement? In some cases (e.g., life-threatening situations), one might be able to convince me that the client is best served with the inclusion of such techniques, at least for a short period of time. Treatment decisions for any individual client require several considerations, and those considerations must be analyzed and evaluated by multiple professionals, care providers, and the individual themselves. Thus, to make a blanket claim that a specific emerging practice should never be implemented for any client at any time feels like an overreach.

In the above paragraphs, I have cited literature from the field of bioethics, UN resolutions, and Supreme Court decisions. I feel it important to state the obvious. I am not an expert in bioethics. I am not a disability advocacy expert. I am not an attorney. My knowledge of the literature in all these fields is limited. I do consider myself an expert in functional analysis of severe problem behavior, as well as reinforcement-based treatment of severe problem behavior, among other things (e.g., special education). Other members of the task force also have expertise in these

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[3] At worst, CESS might be considered unestablished/harmful, given that the procedure is painful.

areas, as well as expertise in punishment contingencies. Still others have expertise in the effects of electric shock in nonhuman animals, which also had relevance to our work. As a result of our combined expertise, we were in a good position to evaluate the research on CESS, as well as alternative treatments. However, I admit that frequently, as we completed our tasks, I found myself wishing we had at least one expert on bioethics on the team. As noted by several people who commented on our report, not having a bioethics expert on the team was a limitation. I tried to compensate for this by consulting with peers at Western Michigan University who are experts in philosophy and bioethics, consulting with medical professionals who had been faced with challenging situations that were unrelated but similar, and even consulting with professionals in unrelated fields who had histories of making complex decisions. Our work would have been strengthened by having one or more experts in bioethics on our team. Such experts would not need to have been behavior analysts. In fact, the team may have been strengthened most by bioethicists who were *not* behavior analysts. Perhaps issuing a position statement in the absence of such expertise was premature.

At the crux of this problem is that only one facility in the world is currently using CESS—JRC. It appeared that some people in our field viewed the function of the task force to be evaluative in nature—that we should evaluate JRC, condemn them for using CESS, and maybe even be responsible for closing down JRC. However, this was not our task. Our charges were to describe the contemporary use of CESS, for what behaviors it is used, how effective CESS is as well as alternatives to CESS, ethical issues raised by the use of CESS and any alternatives, and the like. If a position statement was issued that allowed for *some* use of CESS, then it seemed reasonable and prudent to define parameters and requirements for safety, oversight, expert opinions, and the like. Having such parameters in place would provide the greatest protections for clients, should they choose this treatment. Throughout this project, I found myself motivated to recommend that a ban be placed on the use of CESS. In my view, doing so was the easiest path forward and felt the most comfortable. However, for a number of reasons, I could not support a position that banned CESS (Position B). First, the issues involved with CESS are not unique. Parallel discussions could be taking place for other reductive procedures, such as other punishment techniques (e.g., time out) and restraint, to name two. A ban on CESS represents a slippery slope in the field. Second, when all else was considered, client autonomy (whether for self or by proxy) rose to the top as the most critical variable when I attempted to balance ethical decision-making principles. I supported Position A because it provided for client autonomy. Likewise, I then supported limits on and oversight of CESS's use.

There are many facets to the issues involved with the use of CESS. I have briefly touched on a few key issues, including the principles of beneficence and autonomy. The reader may easily identify many other issues and would be right to do so. The reader may have different perspectives than I on both beneficence and autonomy, as well as other issues. My guess is that if the reader and I debated these issues, we would agree on most things (even on both sides of the issue); but the few disagreements we might have could cause us to ultimately land on one side or the other of this issue. My esteemed colleagues have discussed important considerations in their own commentaries to our recommendations. I had the opportunity to read Lerman's excellent article as I was working on my own commentary. I agree with almost everything she wrote, but we landed in different places in terms of our ultimate conclusions. We still get along, we still respect each other, and we both readily admit we agree on most things. It is my hope the rest of the members of our field can have meaningful discussions about this issue, focus on areas of convergence, and seek to better understand points of divergence. Participating on this task force was truly a humbling experience. As we looked to the literature and studied the various issues involved, it became clear to all of us that there is much we do not know. The research on CESS is relatively sparse. Our understanding of the effectiveness of reinforcement-based interventions with and without the concurrent use of psychotropic medications is incomplete. The positive and negative side effects of CESS, other reductive procedures, and even reinforcement-based interventions are not well documented. As a scientist, I found myself frequently faced with philosophic doubt (as a scientist should) as we worked our way through this problem. To my chagrin, I was often reminded that we do not know as much as we think we do, which led me to believe we should tread lightly and approach our conclusions with a healthy dose of skepticism. After all, no matter on which side of this issue you find yourself, it is important to recognize you could be wrong. As more research is conducted and our understanding of various facets of this problem increases, some or all of us (including me) may change our minds. Hindsight may cause us to cringe when we consider our current stance on this issue, whatever it is. I will always be proud of the work we did on this task force. The work was really hard—sometimes gut wrenching—but I think we fairly and deeply considered all perspectives on the issue to the best of our collective abilities. At the same time, I repeatedly asked myself (and still do) whether I will be proud of myself 10 years from now when I reflect on the conclusions I drew and the recommendations I made.

Data Availability Data sharing is not applicable to this article as no datasets were generated or analyzed during the current study.

Compliance with Ethical Standards

Conflict of Interest The author declares no conflicts of interest or competing interests relative to the work presented in this commentary. The author has no financial or professional relationship with an organization that uses contingent electric skin shock. The author is the director of the Autism Center of Excellence at Western Michigan University, which consists of multiple entities that provide therapeutic services to individuals with intellectual and developmental disabilities, including behavioral support. In addition, the author holds a faculty appointment in the Behavior Analysis Program in the Department of Psychology at Western Michigan University and mentors graduate students in behavior analysis.

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