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THE PRACTICES OF DO-IT-YOURSELF BRAIN STIMULATION: IMPLICATIONS FOR ETHICAL CONSIDERATIONS AND REGULATORY PROPOSALS

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Introduction

Scientists and neuroethicists have recently drawn attention to the ethical and regulatory issues surrounding the do-it-yourself (DIY) brain stimulation community, which is comprised of individuals stimulating their own brains with transcranial direct current stimulation (tDCS) for self-improvement.[1-3] Because DIY tDCS takes place outside research labs and medical settings, concerns have been raised about potential safety risks.[4-5] However, to date, existing regulatory proposals and ethical discussions have been put forth without engaging those involved in the DIY tDCS community or attempting to understand the nature of their practices.[i]

I argue that to better contend with the growing ethical and safety concerns surrounding DIY tDCS, we need to understand the practices of the community. Who are these people, what are their motivations for using tDCS, and what are their processes of stimulation? When and how do they draw upon published scientific literature? This study presents the results of a preliminary inquiry into the DIY tDCS community, with a focus on the kinds of knowledge that are formed, shared and appropriated within it. Analyses are based on open-ended, in-depth interviews with DIYers (as some members call themselves), extensive observations of the main online forum where members communicate, and analyses of videos, websites, and blogs related to DIY tDCS. Ethics approval for the interview component of the study was obtained from the Massachusetts Institute of Technology's Committee on the Use of Humans as Experimental Subjects (COUHES). Content was reviewed for two main themes: (a) interaction with scientists, as well as references to scientific literature and/or scientific precedents; and (b) individuals'

[i] I use the term "DIY tDCS" here to refer to the use of tDCS outside of professional academic or medical settings. Although the movement began with individuals building their own stimulation devices—in the true sense of the "do-it-yourself"—today many users purchase stimulation devices. Still, as the term DIY tDCS is most frequently used by this group to describe their own practices, I have adopted it here as well.

attempts to assess the effects of tDCS. The overall conclusions of this paper are based on patterns that emerged from this review.

I begin by providing a brief introduction to the DIY tDCS community. Next, I discuss the kinds of knowledge that users draw upon at various stages, such as making/acquiring a device, applying stimulation, and measuring the effects of tDCS. I conclude by discussing why it is crucial for researchers to understand how their unintended "second audience" utilizes their research.

The rise of DIY tDCS

In 2000, two German neurophysiologists, Michael Nitsche and Walter Paulus, published a paper showing that passing a weak electrical current (.2 to 1 milliamps) through the motor cortex caused human subjects to perform significantly better on motor tasks[6]. Their paper spearheaded a revival in the use of direct current on the brain: in the years since its publication, approximately 1,000 articles about what has come to be known as transcranial direct current stimulation (tDCS) have been published in academic journals (figure 1). There are two main lines of tDCS research: studies that explore the effects of tDCS in clinical populations, and studies that examine its effects in healthy individuals. The first line includes research that has shown the beneficial effects of tDCS for pain as well as various psychiatric disorders, such as schizophrenia and depression.[7] The second line is comprised of studies showing that tDCS can enhance learning and cognition and improve performance on tasks requiring working memory, attention, and perception.[8]

Although isolated mentions of non-professional use of tDCS come as early as 2007[9], the movement gained steam in the second half of 2011 and early 2012, when blogs and websites began appearing dedicated exclusively to the topic. Broadly speaking, DIYers can be divided into two camps: those interested in enhancing cognition and learning, and those interested in ameliorating psychiatric disorders such as depression. As of the time of writing, the most active tDCS forum on Reddit.com (www.reddit.com/r/tdcs) averages several posts per day, and the two most popular tDCS tutorial videos on YouTube have garnered tens of thousands of views each. The start of

the DIY tDCS movement roughly correlates with the concurrent rise in popularity of tDCS in scientific articles: as can be seen in figure 1, there were 135 publications about tDCS in 2011, more than double that of the previous year.

Who are the people known as DIYers? To-date there has yet to be a large-scale demographic study, although one survey from Stanford University is in progress. Indeed, the question is not a simple one to answer, as the main nexus of communication—the Reddit forum—is largely anonymous. On the forum, individuals are identified by self-created usernames (known as "flairs"), which most often do not contain an individual's actual name. Clicking on an individual's flair yields a detailed history of postings to all Reddit forums, but there is no profile page displaying a self-description or demographic information. To the best of my knowledge, DIYer have yet to convene in a non-virtual arena (though there have been at least several instances of local members of "hackerspaces" meeting to experiment with tDCS). Indeed, most DIYers I interviewed said that they had not met another DIYer in person. Thus, being an active member of the DIY tDCS community is simultaneously private, as stimulation is most often done in the seclusion of one's home, and public, as an individual's forum posts are visible to any casual internet user.

The vast majority of tDCS websites, blogs and videos are created by males, and I have watched videos from, or have interviewed, those ranging in age from late teens to early 60s. The DIY brain stimulation phenomenon seems to be global: on the DIY tDCS Facebook group and other websites where users list their location, there are individuals from over three dozen countries around the world. There are at least a handful of members of the Reddit forum whose posts have made it clear that they are involved in neuroscience research at a graduate or post-doc level, and there are other users who have a good deal of electrical engineering expertise. However, a large number of posts seem to come from those without engineering or neuroscience backgrounds. Indeed, a recent survey of neuroscientists provides initial validation that professional researchers are, for the most part, not involved in using tDCS on themselves.[10]

Making/Acquiring a tDCS device

When it comes to acquiring or making a tDCS device, DIYers are largely disconnected from the world of researchers, who can purchase a device from one of several medical device companies. In the United States, two companies have an "investigational device exemption" (IDE) from the Food and Drug Administration (FDA) for their tDCS devices,[11] and per FDA regulations may only sell the device to qualified investigators for research purposes.[12] Some researchers, unable or unwilling to pay thousands of dollars for one of these tDCS devices, repurpose iontophoresis devices (current-providing machines used to treat various conditions, such as excessive sweating) for tDCS use.

Since DIYers lack the research credentials to purchase a device from a medical company (and given the price of such devices it is not clear that they would want to), they invest a significant amount of energy in figuring out how to obtain a device. Thus, one of the primary topics of conversation on the forum is the construction, modification, or acquisition of a tDCS device. At the most basic end of the spectrum, users can build the device themselves. Since a tDCS device is essentially a 9V battery with two wires that rest atop the head, a crude, but functional, device can be soldered together with parts from a hardware store and a bit of electrical know-how. On forums, blogs and websites, users post descriptions and diagrams of their self-built devices. There are frequent discussions about fuses, voltages, electrodes, resistors, diodes, transistors and regulators.

Individuals who want to purchase consumer tDCS devices, which are not regulated as medical or investigational devices, and therefore available to the general public, have a number of options: some choose device "kits" whereas others choose direct-to-consumer products. Others users opt to buy and modify iontophoresis devices, which are available online without a prescription. On the forum, users who purchase devices share reviews of their purchased devices and discuss safety issues.

Thus, when making or acquiring a device, knowledge produced by the DIY tDCS community is completely separate from that of the scientific community, for whom the acquisition of a device does not present a major barrier. Figure 2 outlines the device options available to a DIYer.

Applying tDCS

When using the device—in contrast to acquiring/making it—DIYers draw heavily upon scientific publications, especially when discovering whether a 'montage' (i.e., a specific orientation of electrodes) exists for their specific disorder or enhancement goal. On the Reddit forum, members link to scientific journal articles as well as popular news reports. When an academic article is behind a pay-wall, users sometimes post an unrestricted copy of it. DIYers also make use of other resources geared toward professionals, such as a video tutorial on electrode positioning created by several tDCS researchers. Scientific review articles are particularly appealing to DIYers as they provide broad overviews of the medical conditions that have been successfully treated by tDCS as well as the cognitive functions that have been enhanced by it. DIYers have largely adopted the standardized 10-20 electrode placement system used by neuroscientists, and seem to adhere to the conventional maximum of 2 milliamps of current used in scientific studies.

Sometimes DIYers co-opt and appropriate scientific knowledge, producing their own derivative work. For example, one DIYer compiled a document containing over 400 abstracts about tDCS, and another, frustrated that information about montage placements was scattered across the Internet, created a website (tdcsplacements.com) that featured stimulation diagrams in a clean, easy-to-browse format. Thus, DIYers transform existing scientific knowledge and diagrams into user-friendly indexes and guides geared toward their needs.

But there are several points where the existing scientific literature does not extend far enough to cover the knowledge desired by the DIY tDCS community, and in these areas of uncertainty, or 'unknowns', DIYers experiment, extrapolate, and share their results. One such 'unknown' concerns session duration and frequency: there is currently no standard stimulation protocol in tDCS research, though the majority of studies utilize a session length of 20 minutes (some go up to 60 minutes). Session frequency also varies greatly: while most studies utilize several sessions of tDCS spread across days or weeks, experimental designs have ranged from a single session of tDCS to twice-daily applications.[13] There is no published research on the long-term use of tDCS over periods of months and years (with the exception of a single case report of a schizophrenic patient).[11] One frustrated DIYer wrote on the Reddit forum that "most studies never

measured 'the point at which it [tDCS] stops working.'" [14]His (or her) comment cuts to the heart of the issue for many DIYers: why limit tDCS? Wouldn't an hour (or more) of stimulation each day provide better cognitive enhancement or medical treatment? Indeed, users want to push the limits—to learn the fastest, to self-treat in the most effective way possible—and so they experiment with longer and more frequent sessions. One DIYer used tDCS for one hour each day as he tried to learn German; another user reported doing 90 minutes of stimulation, five days a week, for cognitive training purposes.[15]

A second unknown in scientific knowledge from the point of view of DIYers concerns the lack of research on particular disorders. From a scientific standpoint, the field and rate of publication of tDCS studies has grown exponentially. But to those outside the academic community, and especially to individuals suffering from a debilitating disorder, the progress can seem glacial. Thus, where they perceive scientific literature to be lacking, DIYers sometimes take matters into their own hands: they experiment, try different montages, and document the results. For instance, one user posted on the Reddit forum that he 'extrapolated' from a scientific finding about tDCS on depression to self-treat his bipolar disorder.[16] Another self-treated for seasonal affective disorder and generalized anxiety disorder, for which tDCS has not been shown to be effective.[17]

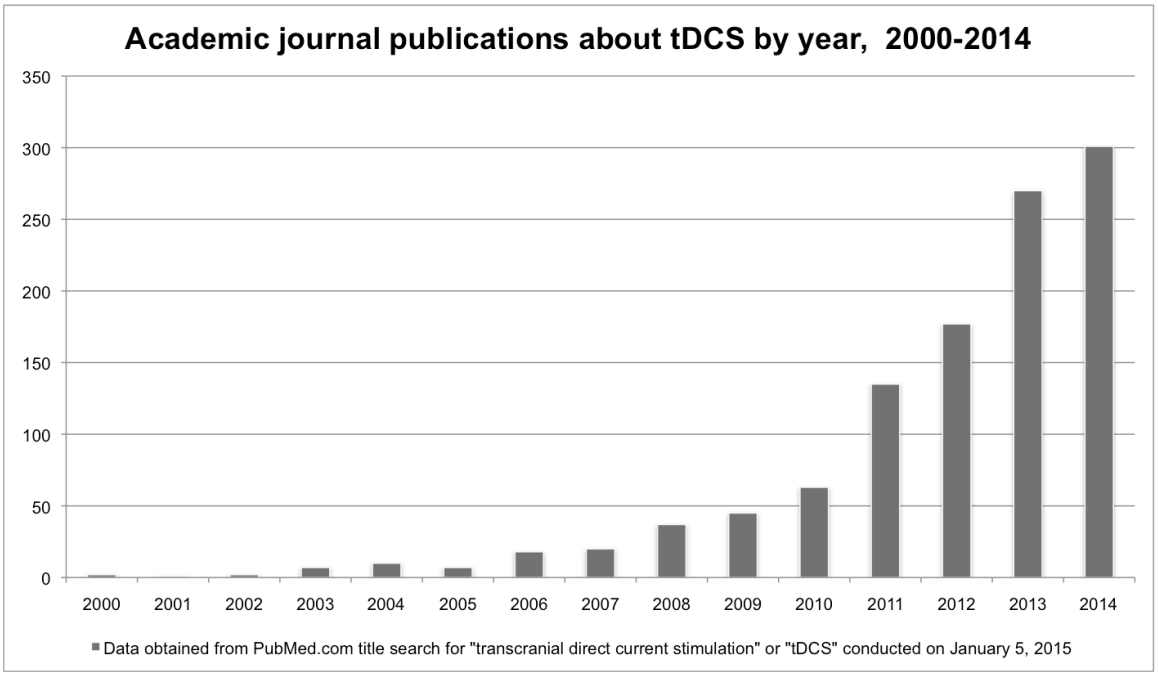

Figure 1. Number of academic journal publications about tDCS by year, 2000-2014.

Type of device	**SELF-BUILT** *($30-50)*	**TDCS DEVICE "KIT"** *($40-180)*	**IONTOPHORESIS DEVICE** *($300-400)*	**DEVICE DESIGNED FOR TDCS** *($379)*	**DIRECT-TO-CONSUMER HEADSET** *($249)*
Description	Diagrams and how-to videos are available online; schematics vary. Construction requires some amount of electrical knowledge	Often made by people involved in DIY tDCS community; some kits require more assembly than others	Can be purchased without prescription but requires slight modification for tDCS use	One of earliest and most expensive models. Marketed directly for tDCS; requires no modification	Currently, only available model is the foc.us. Headset has fixed electrode design, but extras pack allows for placement variation
Marketed for	N/A	Varies; website often explicitly says kit is "not a medical device"	Hyperhydrosis (excessive sweating)	Website notes that research has found benefits of tDCS for treating disease and enhancing cognition	Website states that it is marketed for gamers
Manufacturer	Oneself	Constantly in flux. As of April 2014, models available from thebrainstimulator.net and tdcs-kit.com	ActivaTek (Activa Dose II), Chattanooga Medical Supply, Inc. (Chattanooga Iontophoresis System)	TCT Technologies; registered in Hong Kong but ships worldwide	Foc.us, based in UK but ships worldwide

Figure 2. Types of tDCS devices that DIYers can make or acquire.

Measuring the effects of tDCS

When testing the results of tDCS, that is, assessing whether or not tDCS is effective, some DIYers attempt to mimic the experimental tests used in scientific studies, whereas others do not. In professional tDCS studies, scientists experiment on multiple subjects to ensure a constant result across a varied population. Such studies also employ a wide range of measures to control for potentially confounding effects and ensure experimental validity. For example, researchers utilize blind or double-blind

experimental designs, counterbalance the order of conditions, use well-validated scientific tasks, and make use of 'sham' stimulation, which is the tDCS equivalent of a placebo, wherein a subject is a set up for a regular tDCS session, but no current is passed through the device (except for up to a minute at the beginning of the session to mimic the sensation of a real session).

Those interested in tDCS for self-treating a mental disorder largely eschew scientific tests of validity; for them, a subjective feeling of improvement is often sufficient evidence of the effectiveness of tDCS. "I have found a montage that seems to alleviate some of the effects of bipolar disorder," wrote the user mentioned above who self-treated for bipolar disorder, "I use the CATHODE on r4 and the anode over the motor cortex. This one basically stopped my mood swings."[16] While relying on subjective feelings of self-improvement is most common for those who use tDCS to treat a medical condition, some who use tDCS for cognitive enhancement accept this same criterion. For example, one user wrote: "… if I use this stuff to help learn how to juggle and I'm juggling like a pro in a week, I don't care if it's actually doing anything or not."[18]

Other DIYers, particularly those interested in cognitive enhancement, strive for some kind of validation of tDCS, and attempt to quantify their performance on cognitive tests. Some track their scores on open-source versions of dual n-back tests, which are performance measures often used in scientific studies that assess working memory. Others use cognitive tests those are freely available online, such as the ones from Quantified Mind and Cambridge Brain Sciences.[19]

Some, but not all, DIYers attempt to control for potential confounding factors. For example, one user began by assessing his improvement on cognitive tests on a website called Lumosity, until someone on the forum pointed out the problem of the practice effect, that is, his experience taking the tests could have influenced his performance on the same (or similar) future tests. In response to the critique, the user posted a video describing how he controlled for the practice effect, which he referred to as 'test-wiseness': he *first* takes a set of tests with stimulation, then takes a second set without stimulation.[20] After relating how he did worse on the second set of tests (unstimulated), he concluded that tDCS was effective. Another user attempted to circumvent the practice effect by taking two IQ tests, conducting regular 15-minute tDCS sessions for two years,

and then taking the same IQ tests again. On the forum, the user rationalized the 2-year gap as being advantageous for the validity of his results: if he was not taking the IQ test, then he was not 'practicing' it, and therefore his improvement could not be due to a practice effect.[21] Yet another user I interviewed described an entirely different strategy. His test of validity involved reaching a limit—'a wall', as he put it—on an open-source dual-n-back test, and only then using tDCS.

Interestingly, DIYers frequently discuss the placebo effect but invest little effort in controlling for it. To circumvent the placebo effect, a user would have to receive several sessions of real and placebo (sham) tDCS, but be unaware of what kind of stimulation he or she was receiving. Some tDCS devices available to the DIY community do come with a sham setting, but using it is not straightforward: first, unlike inexperienced subjects, it is likely that frequent tDCS users could tell the difference between sham and real settings. Second, there is currently no built-in way to randomize the sham and real settings on DIY devices, so barring a more creative solution, a second individual would have to be present to covertly select a 'sham' or 'real' stimulation session. While such a scenario is possible, and seems to have taken place on at least one occasion,[22] I have not come across an instance of a solo user employing such a technique. This is probably due to both practical issues (most DIY tDCS is done privately, in the comfort of one's home) and motivational ones (the primary goal of DIY tDCS practitioners is self-improvement, not discovering a scientifically reliable effect). Circumstances could easily change, however, if there was a commercial device that facilitated the randomization of the sham setting.

Finally, it should be noted that the main limitation facing DIYers is that there is a sample size of one. Indeed, a small number of users seem to be concerned about this limitation and have urged their peers to start gathering or aggregating data as a way of overcoming the sample-of-one constraints. However, as of yet, there has been no formal data aggregation initiative.

Discussion

This paper presented a preliminary description of the practices of the DIY

community, with a focus on when and how DIYers draw upon scientific literature and established scientific standards. When making or acquiring a device, DIYers largely produce, document, and share their own body of knowledge. In contrast, when using the device, DIYers seem to draw heavily on scientific precedents; where scientific literature is lacking, DIYers frequently experiment and extrapolate. When testing the efficacy of tDCS, DIYers using tDCS for therapy largely rely on subjective feelings, whereas those interested in cognitive enhancement often attempt to mimic the quantification used in scientific studies.

It should be emphasized that the present study was exploratory in nature; future research should include formal analyses, as well as in-depth interviews with larger samples of the DIY tDCS community. Furthermore, since forum posts, interviews and websites were not systematically coded, the results presented here should be viewed as an impressionistic sketch of the DIY community, one that should be examined by future empirical scholarship.

Despite the above-mentioned limitations, the present analysis of the practices DIY tDCS community can serve a number of functions. First, it can inform regulatory guidelines. One regulatory proposal that has been suggested involves extend current medical device legislation to cover cognitive enhancement devices such as tDCS devices.[23] While this represents a promising approach, a deeper understanding of which devices members use (and why) should be taken into account when evaluating the potential effectiveness of such a proposal. For example, while the proposed extension of medical device legislation would cover direct-to-consumer headsets (figure 2, right column) it would not cover iontophoresis devices; it is unclear whether it would encompass 'kits'. If enacted, such legislation may not even address the bulk of the concerns put forth by researchers, who are worried about usage practices in addition to the safety of the devices.

Some neuroethicists have advocated an 'open communication and education' approach such as the one taken by the US government to DIY biologists.[24] This approach seems to be more on-point: given that the DIY brain stimulation community (along with other DIY and citizen science movements) has arisen largely in reaction to the seclusion of science in the 'ivory tower', instituting regulations from this same place is likely to be

less successful than directly engaging with the community. In moving forward, however, a deeper understanding of the practices of the DIY tDCS community will be crucial. For example, while there may be surface similarities between the DIY biology community and the DIY tDCS community—they both use online forums as a main nexus of communication, and much of the conversation is about sourcing and building scientific instruments outside of academic settings—the underlying goal of DIY tDCS is self-improvement, whereas the underlying goal of DIY biology is a mixture of experimentation, tinkering and political speech.[25-26] Furthermore, there seem to be at least two distinct subgroups among DIYers: those who are interested in self-treating a mental disorder and those interested in using tDCS for enhancement. Such groups may react differently to regulatory guidelines. At the very least, a comprehensive regulatory model should take into account the variations in goals and practices within the DIY community.

Second, an analysis of how the DIY tDCS community draws on published scientific literature and construes validity may be important, as it can lead to greater awareness among neuroscientists of how their unintended 'second audience' uses their research. Knowledge that DIYers will likely use scientific papers to conduct self-experiments may be something for neuroscientists to keep in mind when reporting the results, if not in designing the experiments themselves. For example, researchers could address the unknowns with regard to dosage level: establishing the levels of current, session duration and session frequency that lead to adverse effects would be useful for both scientists and for the DIY community. In addition, while neuroscientists may be tempted to quickly reject the self-experimentation practices of this community, it should be kept in mind that until relatively recently, experimentation on the self was viewed as a valid method of producing scientific and medical knowledge. Thus, rather than dismissing the whole DIY tDCS endeavor, researchers working on tDCS with the ultimate aim of developing a medical treatment may find small kernels of value in the content of users' self-reports. For such researchers, particularly those interested in developing tDCS for home-use applications under the guidance of a physician, it might be useful to understand how DIYers use tDCS and what obstacles they encounter.

Looking closely at the unanticipated audience of scientific publications might affect both the way science is conducted as well as the way it is reported. As such,

additional efforts should be made to understand and engage with the DIY tDCS community, as a greater knowledge of its practices can better inform regulatory proposals and ethical considerations.

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