Provoking Pseudo-Seizures: Provocative Placebo Practices

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Conversion disorders are ubiquitous throughout all fields of medicine. Hysterical blindness, globus hystericus, and “noncardiac chest pain” are psychogenic entities with symptoms that respectively mimic true visual loss, difficulty swallowing, and heart attacks. The most striking diagnoses tend to mimic neurologic disorders, such as pseudoparalysis, pseudo-tremor, and pseudo-seizure.

Recently, a remarkable public case involved conversion disorders. In 2012, 18 teenagers were diagnosed with uncontrollable twitches, tremors, and seizures in a small town in upstate New York (Dominius 2012). This situation began when one popular high school cheerleader and her best friend started suffering similar symptoms, followed by other individuals in the same town. All individuals underwent repeated and expensive medical testing, and fear gripped the community about environmental poisoning factors. However, none of the tests could confirm that any somatic or environmental factors were to blame. A diagnosis of mass hysteria and conversion disorders seemed reasonably possible.

Of all conversion disorders, pseudo-seizures are perhaps the best studied because, unlike the others, they can be tested. Pseudo-seizures can be identified by video/electroencephalogram (EEG), while diagnosis of the other disorders typically depends on exclusion, reached in part by the underlying history and exam, but mostly by the negative testing in their evaluation. Unfortunately, pseudo-seizures are intermittent. As such, the evaluation can take days or even more than a week. In Rommelfanger’s article “Attitudes on Mind Over Matter” (2013), she addresses psychogenic movement disorders (PMDs) and asks whether withholding placebos can harm patients. She describes placebos for diagnosis and therapy, and discusses providing patients with placebos to stop a psychogenic illness for the sake of treatment. We turn this question around and ask: Can provocation maneuvers be an acceptable tool to elicit pseudo-seizures, strictly for the sake of reaching a diagnosis?

We propose that verbally provoking pseudo-seizures (VPPS) can be an ethically acceptable practice, and that it can be used in the scenario just described. We suggest that the specifics of pseudo-seizures, combined with the nature of this non-substance-based intervention, provide a context that legitimizes its use. Although VPPS is not a placebo in a strict sense of the word, the underlying mechanisms and concerns are the same, and allow us to consider them under the same heading. VPPS involves a clinician, technician, or other medical practitioner who, during his or her monitoring of the EEG process, provokes the patient through verbal suggestion that a seizure may be starting (e.g., “Did your hand just twitch; is that your seizure starting?”) to entice the patient to then go on and perform their event. In turn, this suggestion can provoke the patient into having their psychogenic event. But as the EEG does not register any irregular brain activity, the seizure’s psychogenic character is confirmed. If a witness subsequently affirms or denies that the seizure followed its regular pattern, the clinician can diagnose accordingly, and can decide whether or not there are other types of seizures to be worried about. Additionally, epileptic seizures that are scalp EEG negative (such as simple partial seizures or some frontal lobe seizures) can be difficult to diagnose, but the elicitation with suggestion alone would help confirm a diagnosis of non-epileptic seizures.

We maintain that use of placebo interventions like VPPS is common practice for these types of conversion disorders, even by those who argue against it. The real question about these types of interventions is simply a matter of degree, and a matter of where we can draw the line.

Rommelfanger discusses physicians’ views on the role of placebos, and questions how we should use them. She provides a general framework of thinking about these interventions, but refrains from making a persuasive argument in favor of them or to give concrete examples. She describes that physicians perceive these practices as unethical but necessary. In response, we propose that this dichotomous discourse is not necessary, and deem that pseudo-seizures are concrete examples where VPPS can be acceptable and even ethical. Proceeding from a pragmatic framework, rather than a categorical one, in which deception is always wrong, a plethora of arguments justifies the use of VPPS.

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A slight modification and complementation of Rommelfanger’s framework allows us to make the case for VPPS interventions. Concerns about harms through deception, harm to the patient’s autonomy or to the patient–physician relationship, are outweighed by the benefits. As VPPS interventions are short in time, happen relatively early in the treatment relation, and are executed for prognostic reasons, they open a route to a sincere and open relationship between the doctor and patient, and fit into an ethical practice.

VPPS interventions are a special category in the placebo controversy as their potential harms are limited. VPPS, arguably, involves harms to the physician–patient trust relationship and informed consent. Yet these need to be considered in light of the reasons for VPPS use and its diagnostic character, which mitigates the typical concerns about placebo use. Trust means “reliance on the character, ability, strength or truth of someone or something” (www.merriamwebster.com). Particularly in diagnostic situations, the patient relies on the physician’s ability to detect the cause of the seizures. VPPS interventions should therefore enhance trust; they allow social methods, such as observations, to be combined with scientific methods, such as EEG, to confirm the absence of underlying somatic causes in the brain and to diagnose the disorder. Furthermore, these interventions allow for early detection, which is essential to prevent development of further behavioral patterns: patients falling into the habit of seizing, medication taking, checkups and hospitalizations, or enlarging the gap between normality and chronic illness (Wilson, Bladin, and Saling 2004). VPPS appeases concerns around informed consent in a long-term treatment relationship. Deception is only used for instant diagnostic purposes and does not involve a continuous mismatch between the consent and the information (Kanner 2003). The early detection quality of VPPS, similarly, alleviates concerns around the typical vulnerability of the patients with pseudo-seizures. These patients are often women who were victims of abuse in their early years (Bernat 2011), and for whom trust is particularly important. As the deception is brief and allows treatment of the “real problem,” it contrasts with placebo in used in the therapeutic relation, where trust violations persist.

Furthermore, VPPS is a special category of placebos, as there are no adequate alternatives for diagnosis, while it is a simple, cost-effective tool that carries more benefits than harms. Nonresponsiveness to seizure medicine is in itself insufficient to establish a diagnosis. EEG results, however, provide a tool beyond observations alone, and have diagnostic validity. They provide a truth claim in today’s society of neuro-realism (Racine, Bar-Illan, and Illes, 2005), where people identify results generated by scientific methods as objective truths that are hardly questionable. VPPS is preferable over the use of saline, as an alternative diagnostic tool. Saline use may generate problems of false positives/negatives and entails certain—though limited—physical risks (Bernat 2011). VPPS is also favorable over institutionalization in a long-term observation unit. Immediate diagnosis means less financial costs, involves less people, and reduces manpower or health care burdens.

As long as a witness can confirm that the seizure in the monitoring unit conforms to the patient’s regular seizures, and other types of seizures can be ruled out, this can confirm the pseudo-character and help to determine that no further research is necessary. Finally, early detection reduces the use of seizure medications with all of their side effects, risks, and costs (Wilner, Keezer, and Andermann 2010), and reduces the risks of misdiagnosis (Kirschner 2012).

VPPS may still prompt particular concerns about specific harms related to the underlying condition and to the method of the intervention. This may lead some people to object to the practice. However, we maintain that none of these claims is persuasive, given the totality of arguments in favor of its use. For example, concerns could arise around dignitarian harms, here synonymous with harms that could be caused by shame connected to suffering of the seizure, concerns about going through a seizure as an “undignifying event”, or the fact that someone is “robbed of the dignity of his own narrative” (Hustvedt 2013). Yet, we hold that such concerns are lessened through effective diagnosis. This diagnosis is that the seizures are real, but that they cannot be confirmed in somatic terms. Furthermore, the method of verbal provocations could be seen as problematic. VPPS reveals “suggestibility” and could, arguably, harm the patient’s psychological integrity. In comparison to saline as a diagnostic tool, VPPS may even be exacerbating this concern; saline use leaves the mystery of the substance intact. In response, we see the benefit of diagnosis as the key consideration. Compared to other placebos for this context, such as saline interventions, VPPS is still preferable. Saline interventions directly invade the patient’s bodily integrity, while VPPS does not involve such concerns.

Rommelfanger’s quotes suggest that physicians label the use of most placebos as unethical but sometimes necessary, and the American Medical Association (AMA) guidelines confirm this idea (American Medical Association 2010). We do not agree with this position, and do not perceive VPPS as an unethical practice, regardless of its necessity. The use of such practices can be ethical, depending on the framework of reasoning. A pragmatic rather than categorical framework allows us to consider the total sum of arguments to support VPPS interventions. This is not to say that all placebos are ethical, but that at least VPPS is one of the exceptions. None of the concerns about trust, autonomy, respect, and deception is persuasive against this simple, short-term, and cost-effective diagnostic intervention.

REFERENCES
Do Placebos Cause Their Effects and Does It Matter?

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In the target article, Karen Rommelfanger (2013) reports on physicians’ views on the role of placebos in psychogenic disorders, and finding them broadly supportive of their use, she argues that the primary ethical considerations against their use can be significantly overcome. Her argument hinges largely on the questions of whether placebos are inert and whether doctors are (consequently) deceptive when prescribing them. She references a body of research demonstrating placebo effects to argue that (a) placebos are not inert after all, and (b) since doctors believe this, they are not being deceptive in placebo use, and (c) where there is no deception there is no deceptive harm. I argue that (a) is false—that placebos really are inert—but that may not matter, as (b) and (c) may still be true. I give further reasons, however, why placebo prescription should be avoided.

Rommelfanger reports clinical research showing that placebo effects can be profound even in conditions with established pathology, such as Parkinson’s disease, and neuroscience research revealing neural correlates of the placebo effect, and takes these as evidence that the placebo effect is very real. She writes, “If placebos are inert, then they cannot cause effects. If placebo effects occur, then placebos cannot be inert” (12). She then cites this “growing body of research” showing a placebo effect and its correlates, and claims hence that placebos are not inert. There is a problem with this argument. The first sentence quoted above is true; the second is not. Though the second may seem like a restatement of the first, to be logically equivalent (a proposition and its contrapositive), it isn’t, for the first speaks of causation, the second only of occurrence. That placebo effects occur is indisputable, but that does not mean they are caused by placebos (paradoxical as that may sound). Rather, we think placebo effects are caused by beliefs.

Causation is immensely complex, both conceptually and practically, but I hope a few examples will illustrate this. A doctor says he’s going to give a patient one of these [placebo] tablets dissolved in this water. In fact, the doctor palms the tablet and just gives the patient the water. The placebo effect would be undiminished, we would expect. If one argued that the glass of water becomes the placebo, we could change the example to a patient who wakes from an operation to be told he’d just been given a powerful drug while asleep. We would again expect a substantial placebo effect, showing that the placebo itself is not necessary, it’s only the belief in the drug that has given rise to the effects in this case. But what of the more common case, when the placebo is actually given? The placebo may well have a causal role there, but not a sufficient one. No placebo effect would be found were the patient simply to have taken the sugar pill by chance (eaten unknowingly, say, from a packet of candy), without some expectation of its effect. The belief and expectation are doing all the work in these examples; in the normal case the work is done by the doctor’s explanation, the confidence and trust of the patient, the patient’s beliefs about medication, and so on, as well as all the “theatre” of the administration itself. Which is of course to acknowledge that the placebo may well contribute to its effects—its color, shape, size, as well as any drug effects (in the case of active placebo), may all enhance expectation or provoke conditioned effects. Placebos may well be causally relevant, but this is true only under certain descriptions.

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