Response to Open Peer Commentaries on "Placebo Effects and Informed Consent"

Alfano, Mark

Response to critics
Mark Alfano
Delft University of Technology

I am grateful to the critics of "Placebo Effects and Informed Consent" for their thoughtful and constructive responses.[1] In this brief reply, I try to organize and respond to the main concerns they raise.

The bulk of the critics' attention is on the second half of the target article, where I explored the implications for informed consent of the conceptual and empirical discussion in the first half of the article. However, Sabine Roeser questions whether the negative definition of placebos and placebo effects I there decried is a serious problem, and Azgad Gold & Pesach Lichtenberg argue that positive definitions of these phenomena have already been provided. Roeser pragmatically suggests that "people understand each other" already despite popular negative definitions of placebos and placebo effects. This is far from clear; think about foot reflexology, acupuncture, vertebroplasty, arthroscopic knee surgery, etc. Indeed, if the positive definition furnished by Gold & Lichtenberg (2014) is correct, then, as they themselves point out, all top-down psychotherapeutic interventions (including everything from cognitive-behavioral therapy to psychodynamic therapy) are placebos. I doubt that Roeser's pragmatism extends this far. I also worry that their definition captures both too little and too much. It's not clear that the classical conditioning I mention (and Luana Colloca explains at greater length) involves top-down mechanisms. Furthermore, according to the Gold & Lichtenberg (2014) definition, all advice counts as placebo. This seems more than a little overbroa. Colloca's Integrative Frame Theory (Colloca & Miller 2011), while consistent with Gold & Lichtenberg's definition, does not specify necessary and sufficient conditions for something's being a placebo or placebo effect; indeed, I take this learning framework to further support my arguments because there are many instances of health-related learning that have nothing to do with placebos or placebo effects.

This raises the fraught question whether definitions, in the philosophical sense, are needed in medicine or medical ethics. Is it possible to truly and informatively fill in the ellipsis in "X is a placebo if and only if …"? Is it a problem if not? My own inclination is to treat 'placebo' (and 'placebo effect') as philosophers of language have treated 'jade': it's a term that was presumed to designate a single natural kind but turns out instead to designate a disjunction of kinds, in the same way that 'jade' refers to either jadeite or nephrite (LaPorte 2004, pp. 94-100). Just as natural scientists study jadeite and nephrite but not jade as such, so medical researchers and medical ethicists can study various mechanisms that tend to produce what have been called placebo effects but not the placebo effect as such.

Regardless of how this issue is resolved, the problems for informed consent are likely to remain. Most of the critics rightly point out that I wrongly assumed that the physician is the patient's primary or even sole source of information about diseases, potential treatments, and prospects. This assumption is untenable in the age of www.uptodate.com, Google, www.webmd.com, and the informational cesspools where anti-vaccination sentiment festers. This raises questions about the practical feasibility of authorized concealment and authorized deception. Even if the patient agrees with the physician to have certain potential side-effects of

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treatment concealed or lied about, that's no guarantee that the patient will remain uninformed or misinformed. Many patients will be tempted to search high and low for the information that was withheld from them. Indeed, if Charlotte Blease is right, patients will be more tempted to search for every possible negative side-effect of their treatment when concealment is dramatically emphasized than when it is done surreptitiously. Like the youth in Schiller's "Veiled Image of Sais," the patient to whom knowledge is forbidden might return home but then be "robbed of sleep" by the "fierce fever of the wish to know." In this vein, Roeser wonders whether "the uncertainty created by lack of information itself creates even worse side-effects," and FIRSTNAME Schwartz suggests that authorized concealment "may confuse or concern individuals, causing anxiety or even raising the chance of developing other symptoms."

Thus, the uncertainty and curiosity induced by requesting permission to conceal information from the patient or outright deceive the patient may cause nocebo effects despite the doctor's attempt to avert them. This concern remains despite the empirical literature I cited in the target article. In that work (e.g., Mondaini et al. 2007), the contrast is between unauthorized concealment and full information. Patients who receive full information tend to fare worse in terms of nocebogenic side effects than patients in the unauthorized concealment condition. I used this evidence to argue for authorized concealment. But outcomes may differ between unauthorized and authorized concealment. To my knowledge, the effects of authorized concealment have not been studied in laboratory or clinical trials. I agree, then, with Gerben Meynen & Guy Widdershoven that further empirical research on authorized concealment and authorized deception is called for.

Meynen & Widdershoven, along with Roeser, also point out that the request for permission to conceal or deceive may have knock-on effects on patient compliance and trust in the physician. Patients may ask themselves, "What kind of doctor intentionally keeps things from their patient?" or, "What kind of doctor intentionally lies to their patient?" The destruction of trust may in turn undermine the doctor's attempts to achieve benevolent and non-maleficent outcomes, as well as the patient's autonomy (since loss of trust in the informant/doctor makes it harder for the patient to reach an epistemically advantageous perspective). Meynen & Widdserhoven say that the "fact that a doctor would be planning or willing to deceive you as a patient may be alarming" and lead to distrust. I myself would find it reassuring to be asked for permission to engage in deceit, since that would indicate to me that my doctor only deceived me after seeking such permission. Along this line, Arnold et al. claim that it is "difficult to imagine how a patient would find objectionable a preamble to advice-giving which indicated that [giving the patient] information in a certain way could increase their benefits and reduce their potential for harms." But the plural of 'anecdote' is not 'data'; further research on this question is also called for.

Several critics take issue with my 'bad fortune cookie' and 'agony aunt' suggestions. It might be asking too much of patients in terms of self-control to request that they not open their bad fortune cookie; likewise, it might be asking too much of both the patient and the agony aunt in terms of self control to request that the agony aunt not unnecessarily disclose potential side effects to the patient. Moreover, one might reasonably worry that opening the bad fortune cookie while alone or hearing about side effects from a medically untrained agony aunt is an epistemically worse context for the patient. To get around these problems, Roeser suggests the development of moral technologies such as apps for disclosing information "in a dosed way, adjusted to the physiological and psychological profile and preferences of the patient." Blease claims that "even if medical apps were designed in order to substitute for (real, off-line) agony

aunts," the theatrical secrecy involved would likely pique the patient's interest in potential side effects, leading to worse nocebogenic outcomes. It is an empirical question – and one that depends on thoughtful, psychologically and technologically informed design of the apps in question – whether this is so; so once again, further research is called for.

If Blease is right, and even if she isn't, I heartily endorse her suggestion to take better advantage of the linguistic context of the doctor-patient relationship. For instance, she argues that, instead of seeking authorization to conceal or merely framing things positively, the doctor should actively seek to divert the patient's attention from negative side effects. The doctor could say, "If you take this drug you have a 70 percent chance of feeling better. We can talk about the low risk of side effects if you like, but research shows that if we don't dwell on these things, you will have an 80 percent chance of avoiding any unnecessary and unpleasant symptoms." Schwartz, who claims that priming "raises more ethical questions than authorized concealment," would evidently disagree. I find myself allied with Blease and other respondents, then, in finding little to worry about in strategically framing the informed consent process in such a way that the same propositions are presented as positively as possible.

By way of conclusion, I want to introduce a novel suggestion that may help to allay autonomy-related concerns about framing, authorized concealment and deception, and the bad fortune cookie and agony aunt solutions I initially suggested. As I mentioned at the end of the the target article, autonomy needn't be pitted against benevolence or non-maleficence. Sometimes, enhancing a patient's autonomy also causes benefit or prevents harm. Inspired by Veatch (1991) and Roeser, I want to suggest that autonomous decision-making and better health can both be encouraged by the development of *deep value-matching health apps*. As Veatch has pointed out, one key source of rational trust in the doctor-patient relationship is the sharing of values by doctor and patient. If your doctor cares about what you care about and is indifferent to what you're indifferent to, she will be better able to empathize with the choices you face and you will probably trust her judgment more. Over two decades ago, Veatch made the practically unfeasible suggestion to match patients with doctors who share their values on multiple dimensions, including not just medicine and health but also "religion, social philosophy, socioeconomic and political persuasion, [and] moral instinct" (1991, p. 4).

Given how mobile patients are and how difficult it can be to find a local doctor who matches you this well, this suggestion seems a bit quixotic. However, it's not hard to imagine an app that simulates this kind of value matching. Both patients and doctors could take a values questionnaire (initially, e.g., the Schwartz (2012) values questionnaire, but eventually something bespoke) that would identify their values signature. Physicians would also answer a battery of hypothetical questions about both what they, in the role of patient, would want to know (or not) about various treatments in their field of expertise and what they, in the role of patient, would choose to do when faced with various common (and, eventually, not-so-common) treatment options. These data could then be used to generate suggestions for patients both during the informing stage and during the decision stage. For instance, their local doctor could show them that their deep value match would want high, medium, or low levels information about a particular outcome; this would function as the default unless the patient opted to switch. Then, when it actually came time to consent or not, and to which potential treatment, again the local doctor could show them that their deep value match would prefer X, Y, or Z; this would function as the default unless the patient opted to switch. Such a deep value-matching app fits into the libertarian paternalistic framework of the target article but would, I contend, both enhance patient autonomy and lead to better health outcomes.

References

Colloca, L. & Miller, F. (2011). How placebo responses are formed: A learning perspective. *Philosophical Transactions of the Royal Society*, 366(1572): 1859-69.

Gold, A. & Lichtenberg, P. (2014). The moral case for the clinical placebo. *Journal of Medical Ethics*, 40(4): 219-24.

LaPorte, J. (2004). *Natural Kinds and Conceptual Change*. Cambridge University Press.

Schwartz, S. (2012). An overview of the Schwartz theory of basic values. *Online Readings in Psychology and Culture*, 2:1. Available at: http://dx.doi.org/10.9707/2307-0919.1116.

Veatch, R. (1991). *The Patient-Physician Relation: The Patient as Partner, part 2*. Indiana University Press.