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Public Health Research, Deception, and Distrust

Andrew D. Plunk and

Washington University School of Medicine

Richard A. Grucza

Washington University School of Medicine

We share McCambridge and colleagues' (2013) view that substantive ethical guidance is lacking for public health research, especially in applied settings like substance abuse epidemiology. Further, the case-based approach that they describe is especially appropriate for a field like public health, where the particular factors that influence our decision making, both ethically and methodologically, often vary considerably from one context to another. We thus appreciate their contribution and view it as an important starting point for further discussion, especially insofar as it highlights an unmet need for developing cases that are broadly relevant to applied public health researchers. Unfortunately, while their approach has merit, we remain unconvinced that deception was justified in the authors' research, in large part because they are likely underestimating the harm that it creates, both to participants and to researchers, who have a harder time recruiting people who do not trust them. More importantly, even if deception was warranted in the context of their specific research, the authors have described a series of very particular cases that do not justify the practice in other settings.

Case-based reasoning is most useful when we have established, relatively uncontested paradigm cases that outline when certain actions are ethically appropriate, given the contextual constraints of each specific case (Jonsen 2001). New cases can then be compared to the paradigm case to determine whether the context of the new case would impact how we deliberate about the morality of the action in question. That said, McCambridge and colleagues would likely maintain that their cases are nonparadigmatic by their very nature; they seem to expect that their conclusions will generate disagreement. However, it is a useful starting point to more fully explore how their cases are not appropriate for other contexts. That is, examining when these cases fail to generalize to other settings, or pointing out when we do not have enough information to decide whether these cases generalize, can help us determine what features paradigmatic public health research ethics cases should have, which we hope contributes to further discussion of these important topics.

To start, while the authors listed many contextual features of their studies, they gave little insight on the relative significance of each, which might change as the features themselves change. The authors also did not often explore *how* a given contextual constraint might differ and, more importantly, how such a change would directly impact the decision to use deception. In short, the authors listed many of the things that influenced their decision making, but did not describe the relevant process by which they deliberated about and weighed each issue.

These are important omissions, as they make it difficult to apply these cases to other settings. For example, McCambridge and colleagues imply that members of their study

population are less likely to be harmed by deception because they are not vulnerable. Even if this is true in the specific context of their research, most substance-abusing populations are almost by definition vulnerable in some way. McCambridge and colleagues do at one point note that researchers know little about the potential harm caused by deception outside of college student populations, but do not offer other guidance. How then should the vulnerability or stigma associated with alcohol or even another drug, which can be quite significant for some users or for other substances, affect a researcher's decision to deceive his or her participants? On a related note, how should vulnerability associated with race or ethnicity be treated, even for normative alcohol use, which itself is not stigmatizing?

The interplay between vulnerability and deception also raises questions about another contextual constraint that McCambridge and colleagues only briefly touched upon: public trust in research. This is especially important when working with populations that are vulnerable or stigmatized irrespective of their drug use and that are already distrustful of research. For example, many African Americans distrust researchers, which has had a long-standing impact on their participation in research (Gamble 1993). This distrust is perpetuated by a range of factors, including a shared folk history that features "body snatchers" and "night doctors" who robbed graves for bodies upon which to experiment (Fry 1975; Savitt 1982; Waite 1945), the lingering impact of the Tuskegee syphilis experiments (Jones 1993), and, more recently, through mainstream media coverage about the development of the HeLa cell line (Skloot 2010).

However, focus-group feedback cited by the authors suggests that distrust was an issue for their study populations, as well:

The other main finding concerned heightened distrust of research invitations, and although this was interwoven with confidentiality and privacy concerns about Internet use in general, it suggested a paradoxical harm arising from, or accentuated by, debriefing itself. (McCambridge et al. 2013, 45)

The authors state that this feedback led them to rethink debriefing following deception and that they are "considering not doing so" (45). We are inclined to assign this harm not to the debriefing per se, as a reaction to the deception itself. This feedback was also from participants whom the authors describe as nonvulnerable college students; it is reasonable to assume that individuals from more vulnerable populations would react with even greater distrust, especially if it came to light that there had been a series of deceptive studies, for example, by featuring nonefficacious treatment, which only became known after the fact because debriefing was not performed.

Along similar lines, even if one accepts deception generally, we also wonder whether basing the decision to deceive on the likelihood of causing harm has the potential to increase bias and reduce generalizability. In effect, conditioning on the likelihood of promoting harm would mean conditioning on vulnerability, which implies that college students would likely be the population of choice when deception is used in alcohol research. While college students do exhibit high rates of problematic drinking, research that focuses on them is not always applicable to other populations, since college education itself is associated with lower risk overall. For example, low education is associated both with earlier substance abuse (Johnson et al. 1999) and with decreased health more generally (Walsemann, Bell, and Hummer 2012).

In summary, McCambridge and colleagues' cases do seem limited and are likely not broadly applicable to other contexts. Even if one assumes that their use of deception was acceptable, it is not clear what this would imply for other researchers, or whether choosing study populations based on the likelihood of deception causing harm might itself be

methodologically limiting. Despite these concerns, we appreciate their work on this topic and hope that the discussion that it starts leads to further work to develop a robust case-based framework that will help applied public health researchers better understand how context affects their ethical considerations.

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