Reconsidering the Pseudo-Patient Study

C. D. HERRERA

Overview

In pseudo-patient study (PPS), fieldworkers cloak their identities and intentions and pose as “patients.” This enables them to observe the practice of healthcare from within a naturalistic, nonreactive research setting. Rosenhan and his assistants conducted the most famous PPS, where they faked symptoms of schizophrenia so that they could gain admittance to a mental-health facility and observe the treatment that genuine patients were receiving. More subtle pseudo-patients might arrange “appointments” over the phone, after reporting varying levels of health insurance. Others might provide dummy lab specimens or test a physician’s response to technical questions. A few genuine patients have transformed their legitimate stays in the hospital into fieldwork, transforming themselves into disguised participant-observers.

For a number of reasons, however, the PPS remains on the fringes of the literature on human-subject research, often regarded as a curious hybrid of social science and medicine. On one hand, this is somewhat surprising, given the growing popularity of fieldwork approaches in medicine. On the other hand, not the least of the drawbacks to the PPS is that the healthcare workers become unwitting subjects, swept up in studies that they may know nothing about and that may run counter to their interests. To readers accustomed to thinking in terms of nonmaleficence and autonomy, the PPS may appear to commit bioethics sacrilege: To succeed, the PPS has to deliberately ignore informed consent in the clinical setting, where strict prohibitions against deception and involuntary participation in research are the norm. Still, one can make a qualified case for the PPS, and conventional wisdom in research ethics actually offers insight developing that case.

The Case of the PPS

To understand the advantages that the PPS offers, it is helpful to consider the use that instructors in medical school make of simulated patients. With these stand-ins, whom the students may not recognize as such, instructors can test understanding of comparatively basic areas of practice in ways that they probably could not by openly quizzing the students. The rationale behind the simulated patient holds that “although students are being taught proper physical examination technique in the early years of medical school, numerous errors . . . have become habitual by the fourth year. These include examination through gowns, improper patient or examiner positioning, and neglecting to
wash hands” (p. 626). And as another instructor explains, simulated patients can help test complex skills, including the student’s clinical communication. Methodologically, the simulated patient offers a unique opportunity to witness the medical student’s interaction with a person who is to the students a genuine patient.

The case for a PPS would draw on a similar rationale. Medical education does not end with the diploma, so why not look on the PPS as a way to observe practice from the vantage point of a “pseudo” patient? The research would have healthcare workers believing that they are treating genuine patients, and would aim to gather information that is otherwise unobtainable. In one open, nondeceptive survey of physician-patient dyads, fieldworkers sought individual accounts of each member’s office encounter. They found “very low rates of agreement between patients and physicians on what happened during the medical visit.” At times, the fieldworkers noted enough divergence between the two accounts that “it hardly seems as if the doctor and patient [had been] in the same room” (p. 35). A PPS could in a scenario like this compensate for honest lapses in memory or unintended bias in reporting. A PPS could also wade through the anecdote, hearsay, and outright silence that conventional fieldworkers sometimes encounter. From nondeceptive studies, we know that physicians occasionally try to identify “problem patients” who they suspect might sue for malpractice. Nondeceptive fieldworkers could test such findings by openly asking healthcare workers how they feel about patients with different attitudes and professional backgrounds. But if that information is worth having, why not try to confirm the responses with observation of physicians who are unaware that they are under study, especially when existing evidence raises doubts about self-reported data?

In any attempt to balance the allocation of power between patients and doctors, information will play a key role. Information derived from the PPS could increase the control that genuine patients have over their healthcare, inasmuch as this type of research might provide better information about the practice of medicine. The PPS might supplement and verify a wealth of information on high-profile issues, ranging from physician-patient interaction to treatment patterns. But it is important not to portray the strengths of the PPS too narrowly. The PPS could also investigate issues that do not attract headlines. A PPS could help clarify discrepancies in the amount of money spent on healthcare and the perceived quality of service that patients receive, the different criteria used to define “futile” treatment, and the variation in diagnoses among specialists at the same facility. It is thus short-sighted to think of the PPS solely in terms of power and confrontation, whether between the research community and healthcare workers, or between those workers and their patients. Rather, the PPS holds the promise of delivering information that would serve anyone who could benefit from more accurate information about healthcare practice, which is to say it could help inform all patients, healthcare workers, and policymakers.

Ideally, the PPS would be part of an integrated research agenda, used in “multiple triangulation” with less controversial, quantified methods. These methods include confidential surveys and voluntary reports. As the simulated patient in medical school does not eliminate the need for other testing methods, the PPS needn’t displace non-deceptive forms of research, and even armchair analyses of medical practice. The key is that information on healthcare practice
Reconsidering the Pseudo-Patient Study

now passes through the subjective filter of confidential surveys and voluntary reports. The PPS could supplement these valuable sources, by providing first-hand, verifiable data that remains unobtainable for most fieldworkers who would simply ask for it.

Autonomy and Deception

Critics might worry that valuable information on human behavior in and around healthcare is beside the point if researchers obtain it through deceptive means. According to this view, the costs of the PPS are simply too high. As one critic warns, “deceptive research practices virtually always present risks not only to the subjects but also to the scientific community and to the general public” (p. 8). But although no one should take research deception lightly, simplistic or negative generalizations do nothing to advance the moral debate. Research scenarios rarely present only one risk to consider, and critics who talk of risks to the “general public” tend to provide little substantial evidence. When evaluating a PPS, we must specify which risks are at issue, including the risk of not conducting the study and the risk of relying on incomplete data. Commentary that lacks this level of detail trades argument for alarmism, as when one critic of the PPS warns that

any case of unlimited deception, deception not limited by a publicly approved public practice or by the consent of the individual subject, is exploitative. The liars assume a position of superiority, free to choose the conditions of the relationship, which is thereby forced on the subjects regardless of the subjects’ probable perceptions and preferences in the matter. The immorality of this relationship of the deceiver to deceived is its injustice; the deceiver perceives reality correctly, and is able to make rational decisions with regard to it, but choose to entangle the deceived in a false reality, rendering all choices objectively irrational. (p. 7)

Obscured amid this hyperbole is the fact that the PPS in question involved only phone calls by pseudo-patients, who sought to measure the healthcare worker’s willingness to prescribe X rays. And although deception is a central feature in studies like this, this alone does not make all PPS “exploitative” or unjust.

The task of assessing the deception in a PPS is not terribly complicated. More useful than generalities is a careful consideration of what could go wrong and, equally important, what researchers might gain in a PPS. Certainly, many of the qualifications that ordinarily apply to nondeceptive fieldwork would have to apply to the PPS. Fieldworkers should resort to deception only when obtaining consent would likely cause reactions in the very behavior that is under study. When deception seems warranted, the goal would never be to entangle the healthcare worker “in a false reality” or render “all choices objectively irrational.” That outcome would be immoral, and a situation where the pseudo-patient encouraged irrational or unnatural behavior would lead to findings of questionable validity anyway. The PPS would aim to leave the healthcare worker for the most part able to make the same decisions when treating the pseudo-patient as would be made with a genuine patient.
It is true that a pseudo-patient would take advantage of the habit that we all have of revealing more than we realize in our casual talk.\textsuperscript{19} Words that healthcare workers intend as mere “conversational lubrication” would probably take on unexpected significance in the overall study.\textsuperscript{20} Yet risks like this are common in qualitative research, and not a necessary byproduct of the deception. The risk of saying or doing something that might become relevant as “data” exists in any noncovert field study, and it arises in all human communication, even when we trade in cues and impressions instead of “data.” If there is no way to completely avoid this risk, the goal should be to keep the risk consistent with the risk of saying “too much” in a nonresearch, clinical setting.

In other words, there are ways to make the most of unintentional behaviors without exploiting the subjects. And because unwanted dissemination of information can violate the subject’s sense of personal control, researchers would simply need to remove any identifying features from their descriptions of the subjects and the setting.\textsuperscript{21} This too would keep the risks associated with a PPS commensurate with what the healthcare workers face in openly announced research and when treating genuine patients. Indeed, unlike the genuine patient, the pseudo-patient would have to protect the healthcare workers from recognition or reprisal when describing them and their behavior (American Sociological Association, 1997).

A Variable Standard of Autonomy

Informed-consent doctrine enjoys a status in commentary on clinical and some areas of psychological research that it has never really attained in commentary on fieldwork methods.\textsuperscript{22} Traditionally, one of the reasons offered for this is that biomedical research is supposed to pose greater risks to human subjects than other forms of research. Hence, it would seem that ethnographers, sociologists, and anthropologists have less to protect their subjects from. This thinking is probably misguided on several points, but it is particularly mistaken inasmuch as it casts informed consent as a mere protective device.

Informed-consent doctrine preserves a degree of autonomy or personal control for research participants, and it is only where autonomy is protected that risk control becomes meaningful. This explains why a pervasive belief in research ethics holds that informed consent makes the “principle of the advancement of science bow to a higher principle: protection of individual inviolability . . .” (p. 236).\textsuperscript{23} Regardless of its disciplinary origins, research like the PPS, which would involve subjects in something that they may not understand or agree with, demands justification.\textsuperscript{24}

I suggest that for the PPS this justification draws on an argument from analogy. Society allows for varying standards of autonomy based on workplace roles. The worker who scans luggage at the airport exemplifies this qualified right to autonomy. This right allows for an attempt to smuggle a mock explosive aboard an aircraft by someone whose role includes that prerogative. Workers in public transportation or security are subject to a moral amendment that sanctions occasional, no-notice inspections. This interference, and the accompanying right, is consistent with the social “location” of this type of work. Restaurant workers too have rights to noninterference, but society grants the need for unannounced, periodic checks by the public sanitation inspectors.
The guiding idea is that in a few clearly defined, public roles, trust is contingent on verification and incompatible with a strict right to autonomy, if this is construed as a right to noninterference. Covert observation of healthcare workers would certainly constitute interference. But interference with workers in other select occupations is no denigration of personhood, and it can also be kept within parameters of minimal risk. Were this strategy applied to the covert observation of healthcare workers, autonomy would manifest as a defeasible, variable right to noninterference, not an absolute entitlement. There are morally relevant similarities between the clinic and the airport, of course. Yet in both areas the cost of misplaced trust in the worker is very high. This cost is exceptional in terms of risk to those whom the workers must interact with, whether customers or patients. The cost of misplaced trust is also unacceptably high in terms of the money and resources that are at stake in the healthcare work environment. In general, the goal of acquiring information is consistent in both cases with the public dependence on that profession, and the relative power imbalance that a lack of information can produce. From the scheduling of an appointment, to the physical examination, to the filling of the prescription, healthcare is useful only to the extent that patients find it safe and responsive to their needs.

A trust also links healthcare workers to each other. They have to be able to make reliable recommendations, as when one physician refers a patient to a specialist, and they must be aware of information concerning the trends in the practices at their own institutions. This reliance on information puts healthcare, along with the air-travel and food-production industries, at a convergence of public service and safety. And the need for reliable information, combined with the impracticality of collecting it outright, helps once more to justify certain limitations on the healthcare worker’s autonomy.

Sanctioning Qualified Use of the PPS

Having established that there are in some instances good reasons to limit the healthcare worker’s entitlement to on-the-job autonomy, the challenge in practical terms is still to ensure that any interference in the guise of research poses only minimal risks. To appreciate the nature of the risks, we only have to remember that the justified entry into the research setting is premised on two elements. First, we are assuming that the healthcare worker holds a variable right to workplace autonomy. Second, we assume that entry into that workplace follows a demonstrated need for information. This means that the justification sharply limits the acceptable range of pseudo-patient observations. For example, once on “the inside,” the justification for the PPS would extend only to the observation to job-related behavior of the healthcare workers. Details about the physician’s private life would remain off-limits in the research and the reporting. Nor should there be any snooping through medical records, or entry into areas of the workplace that genuine patients do not ordinarily observe. So long as this range of observation is kept as narrow as possible, risks will be easy to control.

There is one important dissimilarity in the analogy that I made earlier between the various forms of workplace autonomy. The prospect of immediate danger to genuine patients or the possibility of uncovering blatant misbehavior should not justify the deception in a PPS. Here the risk in converting the PPS
into a secret-police apparatus is just too great. The proper course where one suspects malpractice is to alert authorities, not conduct research. The PPS might, like any form of research, uncover evidence of mistreatment as easily as it might show healthcare workers in their best light. And the separation between research, quality control, and undercover investigation is tenuous at best. Nevertheless, there is no point in having the pseudo-patient enter the hospital thinking that some workers “have it coming.” Neither perceived wrongdoing nor power imbalance, by themselves, justify the PPS. This type of study should proceed only when risks to subjects are likely to be minimal, nondeceptive methods appear inferior, and the observation can focus on what is at least perceived as routine, working behavior.26

In one sense, the PPS has been relegated to the hall of bioethics curiosities on good grounds. Rosenhan’s account of “being sane in insane places” tells how some of the pseudo-patient researchers dropped out of the project, while healthcare workers naively administered real treatment to a few pseudo-patients who continued on.27 Rosenhan’s PPS dragged over weeks, without any clear research objectives, and more healthcare workers and real patients were drawn into the ploy. This PPS came to resemble a slumber party more than rigorous fieldwork.28 Almost from the start, a few of the genuine patients saw through the pseudo-patients’ “cover.” Yet the PPS continued, with some of the pseudo-patients writing up their fieldnotes in view of the genuine patients.

We can learn from Rosenhan’s example. It seems best to avoid carrying the PPS beyond a short-term intrusion into the workplace and to reduce the number of people who must be deceived, regardless of the risks involved. Furthermore, researchers might enter the setting with explicit objectives in mind; this would prevent the pseudo-patient from merely “wandering around” in search of data. Institutional review boards might take an active role in guiding this aspect of the PPS. And perhaps most significant, why not inform as many people as possible in or close to the research setting? Patients in a clinical trial often consent with the knowledge that they stand to receive either an experimental treatment or a placebo. Healthcare workers could in the same way learn their facility is on a list that the pseudo-patient might visit. This would not be a direct method of informing potential subjects, but it would put the greatest number on notice of their possible inclusion in the study. The advance notice might stop just short of the point where this information would undermine the deceptive methodology.

Admittedly, these are compromises, not moral resolutions. Informing healthcare workers would not be the same as obtaining consent from them. Patients who consent to a placebo-controlled trial at least know that they are subjects and that they can stop being subjects at any time. Subjects who volunteer for deceptive psychology experiments usually understand (or anticipate) that they may not know the true objectives until much later.29 But the requirement that the pseudo-patient inform at least some potential subjects would signal good faith and help minimize risk. And by providing for greater participation and oversight from outside review agencies, the use of PPS might accommodate concerns about exploitation and deception. To this end, conventional, non-deceptive research should be used to collect data on the possible effects of using the PPS, and on ways to lower risks associated with it.

These final recommendations should not be read as equivocation. All deceptive methods only appear necessary, usually because conventional methods
Reconsidering the Pseudo-Patient Study

have so far proven unsatisfactory at gathering data. Because subjects pay the price of methodological shortcomings, we must look on the PPS as an interim method. One can have as an ultimate goal the elimination of deception in human studies at the same time that one grants that something like a PPS can improve our knowledge of healthcare for the time being.

Notes

12. This is just a sample of issues that pseudo-patient study might illuminate. See also Rays NP. Hospitalization style of physicians in Manitoba: the disturbing lack of logic in medical practice. Health Services Research 1992;27(3):361–84.
18. I leave aside the question of whether this “ordinary risk” criterion would qualify the PPS for expedited review by oversight committees.
Commentary

Charles MacKay

The methodological device of “deception,” or, as sometimes euphemistically labeled, “less than full disclosure,” does not enjoy much support among institutional review boards (IRBs) and a large portion of scholars in bioethics. The reasons for this have been documented sufficiently, beginning with the now-paradigmatic attack on the well-known study by Milgram and the unsavory study of Laud Humphries on male homosexual activities in public restrooms. But are the current attitudes interfering with some worthwhile approaches to data gathering that seem to have no other methodology of equal effectiveness?

A recent example from one IRB involved a device of two “pseudo-patients” requesting a breast exam from physicians as a way to evaluate whether or not the examination met the current practice standard. The first pseudo-patient, a health professional skilled and certified in the proper breast examination technique, would present for a routine breast exam. She would take note of whether or not the best procedures were followed; for example, directly palpating the breast, rather than through the underclothing or gown, as well as probing and carefully examining all areas of the breast for any trace of a lump. Subsequently, a second “confederate” would request a breast exam. On completion, she would identify herself as a skilled practitioner and critique the performance of the physician and provide instruction on the proper method.

The aim was not to collect information so much as to ensure that physicians were actually meeting the standard of care and offering them immediate assistance in a discreet way about how to improve or correct their technique. Naturally, as most activities within an academic medical setting, the opportunity
Commentary

to gather some data about how many physicians were employing the most effective techniques and what results were achieved by this intervention provided the grist for a publication. One can see some parallels to the situations that Herrera lists as ways to maintain or measure quality of services that the public depends on and to ensure that physicians acquire and use the skills needed to meet the best standard of care.

The reactions of the IRB members was uniformly negative to the proposed study. The word “deception” was the epithet of choice in the discussion and, as one might predict, the connotations of the word itself determined the outcome. How could the IRB, with its ethical mission, condone something clearly immoral, like “lying” and “deception”? The discussion quickly broadened to denunciation of the proposed activity as corrosive of the fundamental trust relationship that was the heart of the physician-patient interaction. Some speculated that the weakening of trust would be a lasting taint and conceivably leave physicians uncomfortable in the presence of new or unfamiliar patients. Other physician members of the IRB were less catastrophic in their reservations. But they were of the view that the so-called deception could not be justified by the importance of the knowledge: it was widely known that physicians are deficient in breast examination techniques and seldom devote the time and attention they should to carrying it out properly. Thus, there were no “scientific results” to offset the device of deliberately deceiving the physician. The researchers were allowed to withdraw the proposed study and to redesign it so that proper informed consent was obtained. Or, to propose the approach straightforwardly as a “quality assurance” approach that might be reported afterward in a publication, but without the artifice of a research design, which, in fact, was not contributing to more reliable findings and had its own disadvantages in risking the alienation of some of the physicians.

In this era of emphasis on autonomy and ensuring that adequate information is communicated to patients and to subjects in the research setting, it is difficult to argue that a less-than-candid approach to obtaining information is justified. Covert activities may be justified in infiltration of illegal groups or to prevent crimes or calamities. But it is hard to persuade IRBs and others that some information to be learned in a routine healthcare setting is of such importance that the physician must be left in a naive state by a disingenuous investigator. Instinctively, the prospect runs counter to our sensibilities.

Of course, there are often alternative ways of obtaining information, for example, about physicians’ behaviors, skills, procedures, billing, attitudes, and so forth, even if it may not meet the highest standards of evidence. Thus, the oft-cited justification for “less than full disclosure,” to ensure a naive subject, cannot be invoked as an indispensable method. But might it not serve a “part of an integrated research agenda, used in ‘multiple triangulation’ with less controversial, quantified methods”?

It would seem not. The integrated research agenda cannot lessen the wrong of failure to make full disclosure in the situation in which the physician has no reason to suspect that he/she is an unwitting research subject. What might be justifiable in terms of public safety for airport workers and food service personnel enjoys the backing of laws to ensure and protect the well-being of the public and is an explicit condition of employment. What may be justified by enactment of laws and procedures to protect the public
provides an inexact analogy to the discretionary and perhaps purely idiosyncratic interests of the researcher desiring to know something about how physicians carry out their profession. Not even the mitigating element of the desire to “help improve breast examination techniques and proficiency,” as in the IRB example described earlier, is present to offer a socially redeeming motive.

Nonetheless, the information that could result from this research is potentially valuable. How then could we try to obtain it?

I would propose a variant on the methodology suggested by Herrera. Suppose we were to propose a larger-scale research effort. Let’s say, regions or sections of a major city were chosen and the physicians in these areas were told that they would be “single-blinded, randomized subjects” in a study, in which trained observers would present themselves as office or clinic patients. To remedy interrater variation, one might send teams of trained observers as pseudo-patients to each of the selected physicians. Some physicians might not ever be visited by pseudo-patients. One might also interview authentic patients of all physicians as a way of “triangulation” to correct for possible bias from the observers. These mechanisms might reduce potentially spurious findings. Physicians would all be informed in advance of the general nature of the study and agree to it, as, for example, to rule out research that they might find objectionable or compromising, such as observers who were testing the physicians’ virtue by attempting to seduce them.

An approach along these lines would, in my view, more successfully meet the tests that Herrera proposes: (a) a variable right to workplace autonomy, and (b) a demonstrated need for information. The licensure and professional self-regulation of physicians, although imperfect in many ways, does not seem to me to brook a unilateral disregard for their autonomy by a researcher. No IRB would think it had the authority to approve this type of “deception.” The participation of physicians in agreeing to the general purpose and nature of the research accomplishes the purpose of the second test: demonstrated need for the information. Once again, any IRB or scientific review board would find itself hard pressed to determine that the knowledge to be gained was of such great importance as to warrant withholding information from the research subjects.

We have come to accept “blinding” as permissible in research to eliminate or offset bias, whether of researcher or subject. It is, of course, a benign form of deception, but one voluntarily accepted. It needs to be more fully explored within the type of observer and participant-observer research described in Herrera’s proposal. There are important areas for study that oblige us to become more imaginative and adventurous in research methodology.