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Frank W. Putnam

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1–13

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Frank W. Putnam, MD^{1,2}

Abstract

Historically, clinical case reports have played an essential role in the professional communication of medical and psychiatric knowledge. Case reports continue to play important roles in the initial identification of new syndromes or unusual variants of established conditions. Case reports and case series also serve to alert clinicians to preliminary evidence of the efficacy of novel treatments or adaptations to new populations. The Jane Doe Case provides a seminal example of the ethical/medico-legal dilemma arising from a patient's right to confidentiality versus the principle of independent review/replication as a necessary requirement for scientific credibility. As a result of being the subject of dueling case reports concerning the validity of her delayed recall of childhood sexual abuse, Jane Doe's identity was revealed. Consequently, she suffered significant emotional distress, bankruptcy, and the end of her career as a naval officer and aviator. Current medical journal guidelines call for protection of confidentiality of the patient's identity; yet, scientific credibility requires the possibility of an independent outside review if there are legitimate reasons to question facts or claims advanced in a case report. A potential solution is proposed as a starting point for resolving the dilemma posed for case study subjects and authors by the conflicting requirements of patient confidentiality and, if warranted, the possibility of an independent scientific review.

Keywords

Taus v. Loftus, case studies, ethics, confidentiality, privacy

¹Cincinnati Children's Hospital Medical Center, OH, USA

²University of North Carolina, Chapel Hill, USA

Corresponding Author:

Frank W. Putnam, Department of Psychiatry, 387 Medical School, Wing D, Campus Box 7160, Chapel Hill, NC 27599-7160

Email: frank_putnam@med.unc.edu

Case studies are historically the oldest form of medical reporting and are still valued by leading medical journals. For example, both the *New England Journal of Medicine* and the *Journal of the American Medical Society*, two top-ranked medical journals, continue to regularly publish case reports.

For generations, the *Case Records of the Massachusetts General Hospital* have helped physicians hone their clinical acumen. These articles focus on a single case, offering insights into the treating physicians' medical decision-making, differential diagnosis, progressive workup of symptoms, and, when appropriate, treatment options and outcomes. (New England Journal of Medicine, 2011)

The basic case report format was established by the late 18th century, and by 1830 there were more than 30 English language medical journals publishing case reports. Freud is given credit for introducing a clinical immediacy to the genre by including the patient's dialogue and seeking to provide the reader with a sense of "being in the room" with the patient. He was also an early advocate of disguising the patient's identity in an effort to protect anonymity (Levine & Stagno, 2001). Until the 1930's a major educational exercise for medical students involved writing case reports.

Although modern peer-reviewed medical and psychology journals primarily publish controlled clinical trials, case reports are still valued because they provide information on underrepresented areas. Drotar (2009) notes that these include (1) new clinical populations, needs, and challenges; (2) development of new intervention models and frameworks; (3) feasibility and preliminary efficacy of interventions; (4) clinical effectiveness of new interventions delivered in practice settings; (5) generalizability of empirically supported interventions to clinical practice; and (6) the clinical utility of evidence-based assessments (Drotar, 2009). Case reports and case series will likely remain an important mode of clinical communication and education in medicine and psychology for the foreseeable future.

The Jane Doe Case

The Jane Doe case occupies a flashpoint in a long running, acrimonious debate about the veracity of the delayed recall of traumatic memories (Corwin & Olafson, 1997). Corwin and Olafson originally described the case of Jane Doe in a professional journal article accompanied by five commentaries in the same issue—including one by myself (Putnam, 1997)—and a sixth in the following issue (Lindsay, 1997). Their report documented the sudden recall of a previously unavailable memory of sexual abuse recorded on videotape that was compared with a previously videotaped interview of

Jane Doe 11 years earlier. The case report included transcripts from a videotaped forensic interview conducted by Corwin at the request of the court when Jane was aged 6 years and from a videotaped informed consent discussion at age 17 years.

Although Jane Doe knew that she had made allegations of sexual abuse against her mother at ages 5 to 6 years, she requested an opportunity to view the videotape of her forensic interview by Corwin because she told Corwin that she could not recall the abuse *per se* (Taus, *in press*). During the informed consent discussion, but prior to viewing the tape of herself at age 6, Jane Doe suddenly recalled an episode of sexual abuse by her mother. At the moment of recall, Jane Doe has an abrupt shift in affect, becoming tearful, and makes a statement about the incident that is similar to her original disclosure at age 6. With Jane Doe's informed consent, Corwin made the relevant segments of both videotapes available to experts in the forensic evaluation of child sexual abuse, to experts on memory, and to an expert in the detection of lying, who wrote commentaries included in the same journal issue (Armstrong, 1997; Ekman, 1997; Neisser, 1997; Putnam, 1997; Schooler, 1997) and the next issue (Lindsay, 1997). All of these articles are available on the American Professional Society on the Abuse of Children (APSAC) publications web page at <http://www.apsac.org/apsac-publications>.

The Jane Doe case was subsequently revisited by Elizabeth Loftus and Melvin Guyer in a two-part newsstand magazine article (Loftus & Guyer, 2002a, 2002b). They did not re-analyze the videotapes nor interview Jane Doe, but relied on uncovering Jane Doe's real identity (Nicole Taus) through the use of a private investigator and allegedly through unauthorized access to sealed court records (Taus, *in press*). Once they learned her identity, the private investigator questioned Jane Doe's friends and Loftus interviewed her biological mother, her stepmother, and her foster mother. In their version of the Jane Doe Case, Loftus and Guyer dispute the veracity of Jane Doe's delayed recall of sexual abuse by her biological mother implying that it is a "false memory." Distressed by the invasion of her privacy, Jane Doe contacted Loftus and requested that she cease investigating her personal life (Taus, *in press*). When Loftus continued, Jane Doe filed an ethics complaint against Loftus with the University of Washington, where Loftus was on the faculty in the Department of Psychology.

This was the third ethics complaint filed against Elizabeth Loftus associated with her re-analysis of cases of women reporting childhood sexual abuse. Jennifer Hoult and Lynn Crook filed separate ethics complaints with the American Psychological Association (APA) in December 1995. Both women had won civil suits against their fathers (and mother in Crook's case) for sexually abusing them in childhood. Both ethics complaints alleged that

Loftus misrepresented pertinent facts of their cases. Hoult alleging misrepresentation of facts in an article in the *Skeptical Inquirer* (Loftus, 1995) and Crook alleging misrepresentation of the facts of her case in an interview that Loftus gave to Jill Neimark for *Psychology Today* (Neimark, 1995).

These ethics complaints were never investigated because Loftus resigned from the APA after they were received but before the Chair of the Ethics Committee, Jeffery N. Younggren, PhD, officially accepted them. It was noted that at the time Younggren and Loftus were serving as expert witnesses on the same legal case. Younggren has served as an expert witness on “false memory syndrome” usually for the accused or against therapists being sued for “implanting false memories.” In her letter of resignation, Loftus states that the APA had “moved away from scientific and scholarly thinking” and that she wished “to devote her energies to the numerous other professional organizations that value science more highly and consistently” (Constantine, 1995-1996).

The University of Washington took almost 2 years (22 months) to investigate Jane Doe’s ethics complaint, finally recommending that Loftus take an ethics course. Within a year, Loftus left the University of Washington for the University of California at Irvine and published the two-part article in the *Skeptical Inquirer*, a newsstand magazine, in 2002 (Loftus & Guyer, 2002a, 2002b). In the Loftus and Guyer article, Jane Doe is portrayed in unflattering terms. An accompanying commentary by Carol Tavis, who also never interviewed Jane Doe, describes her as “. . . an unhappy young woman whose life has been filled with conflict and loss . . .” (Tavis, 2002, p. 43). These statements, coupled with the negative statements about her deceased father in the Loftus and Guyer articles, greatly distressed Jane Doe, who described herself as “appalled, disgusted, heartsick and completely overwhelmed” (Taus, in press).

In response, Jane Doe filed a civil suit (February 2003) for invasion of privacy and slander against Loftus, Guyer, Tavis, Shapiro Investigations (the private investigator), The Committee for the Scientific Investigation of Claims of the Paranormal (publisher of the *Skeptical Inquirer*), the *Skeptical Inquirer*, and the University of Washington. The eventual outcome of the protracted legal process, which was appealed by Loftus et al., all the way to the Supreme Court of California, ended Jane Doe’s career as a naval officer, as well as forced her to declare bankruptcy with the loss of two homes and the repossession of her vehicle in front of friends and neighbors (Taus, in press). Thus, there were devastating emotional, career, and financial consequences for Jane Doe as a result of being the subject of a pair of point-counterpoint case studies that were focused on the nature of delayed recall of childhood

sexual abuse. See Taus (Jane Doe) in press for a personal account (Taus, in press).

The Jane Doe Case attracts such intense interest from both sides of the traumatic memory debate because it serves as a “black swan” example for the existence of delayed recall of traumatic memories of child abuse. As John Stuart Mill observed, the existence of a single black swan is sufficient to refute the inference that all swans are white. (While exploring the coast of Australia in 1697, Willem de Vlamingh was the first European to see a black swan.) If the delayed recall event recorded on Corwin’s videotape is real, then the entire traumatic memory debate shifts from the question of whether it ever happens to the question of how often and under what circumstances does it occur? (It should be noted that early in her career Loftus was on the other side of this debate publishing several research articles and book chapters supporting the existence of amnesia for traumatic experiences (e.g., Christianson & Loftus, 1987; Loftus & Burns, 1982).

The larger focus of this article is on the ethical and informed consent implications of the Jane Doe case for future case reports, especially for case studies that involve controversial topics such as the validity of recall of child maltreatment, use of illegal substances, or therapeutic claims for unconventional treatments. In some instances, there may well be entirely legitimate scientific reasons for independent parties to seek to verify the accuracy of details in the case report, which could potentially expose the subject’s identity with serious negative consequences for individuals involved. The outline of a possible solution to this dilemma is proposed.

Case Reports and Patient Confidentiality

Discussions of ethical concerns raised by case reports tend to converge around the intertwined issues of informed consent and the protection of confidentiality. In 1995, an international committee composed of editors from top-ranked biomedical journals issued guidelines for case reports (International Committee of Medical Journal Editors, 1995). While not mandatory, these highly respected journals have considerable influence on medical publication practices. The guidelines (1995) include the following statement:

Patients have a right to privacy that should not be infringed without informed consent. Identifying information should not be published in written descriptions, photographs, and pedigrees unless the information is essential for scientific purposes and the patient (or parent or guardian) gives written informed consent for publication. Informed consent for this purpose requires that the patient be

shown the manuscript to be published. Identifying details should be omitted if they are not essential, but patient data should never be altered or falsified in an attempt to attain anonymity. Complete anonymity is difficult to achieve, and informed consent should be obtained if there is any doubt. (International Committee of Medical Journal Editors, 1995, p. 3)

The publication of these guidelines resulted in several critiques, primarily from psychiatrists but also from ethicists, arguing that a requirement for written informed consent could actually be harmful to some patients and would greatly discourage clinicians from publishing valuable information (e.g., Gabbard, 2000; Levine & Stagno, 2001; Rogers & Draper, 2003; Wilkinson et al., 1995). In general, these critiques identified an ethical dilemma inherent in a clinician's obligation to respect a patient's right to privacy and his or her obligation to make known potentially valuable information that may advance the field and improve the care of others. Freud (1905/1953) articulated this dilemma in the forward to his case of Dora—whose real identity, like that of Anna O and several of Freud's other cases, was eventually unmasked:

[T]he physician has taken upon himself duties not only towards the individual patient but towards science as well; and his duties towards science mean ultimately nothing else than his duties towards many other patients who are suffering or will some day suffer from the disorder. Thus, it becomes the physician's duty to publish what he believes he knows of the causes . . . and it becomes a disgraceful piece of cowardice . . . to neglect doing so, as long as he can avoid causing direct personal injury to the single patient concerned. (Freud, 1905/1953, p. 8)

Several of the critiques of the biomedical journal editors' guidelines suggest that the requirement that the patient must read and approve the case report as part of the informed consent process could prove psychologically injurious to certain patients (Gabbard, 2000; Levine & Stagno, 2001; Wilkinson et al., 1995). Moreover, it would be difficult to predict which patients might be most negatively affected. Some conditions (e.g., psychosis or dementia) may impair a patient's capacity to give an informed consent. Psychotherapists also worry that if the patient becomes aware of the therapist's clinical formulation or fascination with some aspect of the case, it could distort the focus and course of treatment. Finally, most journal submissions commonly require revisions following each set of peer-reviews and it may be difficult to re-consent multiple revisions and resubmissions (perhaps to several journals before acceptance) with the case study subject(s).

On the other hand, should a patient suddenly discover himself or herself to be the subject of a case history published or presented by their physician or

therapist, they may also be harmed. The most famous example is the novelist Philip Roth's literary revenge after he discovered that his psychoanalyst had published an article on the role of anger in creativity using material traceable to Roth's own analysis (Berman, 1985; Gabbard, 2000). In his novel, *My Life as a Man*, Roth metaphorically skewers his therapist by creating a similar fictional patient–therapist situation and then quoting from his therapist's actual article (Roth, 1974). Most patients, however, will not be as able to creatively sublimate their impulses and may be driven to more concrete action. Indeed, Jane Doe's discovery of herself as the subject of the Loftus and Guyer articles ultimately led to a lawsuit.

A number of potential solutions to this dilemma have been offered ranging from calls for the elimination of all unauthorized case studies in education and research to the use of “thick disguise” to hide a patient's identity (Gabbard, 2000). Just how thick is “thick,” of course, is a judgment call. What virtually all parties agree on is that a disguise cannot be so thick as to alter essential clinical details, for example, describing a man as a woman. But the permissible degree of alteration for many other personal details, (e.g., age, race or ethnicity, marital status) is less clear-cut. Gabbard notes that the act of disguising a patient's identity forces the author “. . . to be deliberately deceptive and misleading in the service of a higher ethical standard, namely protection of the patient's identity” (Gabbard, 2000, p. 1074).

Informed Consent in the Jane Doe Case

Corwin sought and received informed consent for using the Jane Doe materials at several points in the history of the case (Corwin & Olafson, 1997). He initially obtained consent from Jane Doe's father, who had legal custody, and assent from Jane Doe for using the videotape of the initial interview for educational purposes. He obtained consent and assent again when Jane Doe was 12 years old. When Jane Doe was 16, Corwin re-contacted her father, now in a convalescent home, who gave his consent and provided contact information for Jane Doe who was living in a foster home. Corwin obtained her assent by phone and about a year later (when he was attending a meeting near her home) he conducted the videotaped informed consent per her request to view the tape of herself at age 6 years.

Indeed, it was in the process of obtaining Jane Doe's informed consent before viewing the original tape, that Jane Doe recalled the episode of sexual abuse that she had disclosed at age 6 years. Corwin then obtained informed consent for publication of the transcripts of the two videotapes (Corwin & Olafson, 1997). He also obtained informed consent for presenting excerpts of the two tapes at professional meetings for educational purposes, often with a

panel of discussants (including myself at the annual meeting of the International Society for the Study of Traumatic Stress, Montreal, November, 1997).

Loftus and Guyer (2002a) describes how information from Corwin during these presentations allowed her to uncover Jane Doe's identity.

Corwin disguised the case - using names like Jane Doe and John Doe, Momstown, Dadstown. But he showed the tapes at a number of professional meetings, and the tapes mention Jane's real first name and the city where some of her childhood activities took place. We searched legal databases with a handful of key words, and found an appellate court case involving Jane.

From this appellate court case we now knew Dad's first name and the first letter of his last name, but the rest of his identity was not revealed. We know only, from Corwin's article, that he died in November 1994. After a long and tedious search of the social security death records and newspaper obituaries, we found out who he was, and from there we uncovered the full history of the custody dispute and the abuse allegations. (Loftus & Guyer, 2002a, p. 29)

Corwin's article, however, does not give a date of death for the father stating only, "Upon recontact, Jane informed Corwin that her father had died the previous year and that she continued to live with the foster family, although she technically had no legal guardian" (Corwin & Olafson, 1997, p. 98). Thus, it is not clear how Loftus obtained the date of her father's death. Loftus also omits the details of how she was able to use the father's name to uncover ". . . the full history of the custody dispute and the abuse allegations," which were sealed court documents (Loftus & Guyer, 2002a, p. 29).

This story encapsulates a number of emerging issues. First is the relative ease with which one can now search public databases using only a few keywords and how information gleaned in one database can be used to search other databases. Searching is becoming ever easier and more powerful as key information is shared across systems and indexed by common identifiers. Second, how might protected information be unwittingly revealed on video and audio recordings made in a clinical context, when the intention is to gather and document pertinent facts. Later, when these recordings are used for educational purposes, it may be difficult to edit out this information.

Finally, from an informed consent perspective, case presentations are far less controllable than a published case report. No two presentations of a case will ever be the same. The presenter may tailor aspects to the make-up of the audience or the focus of the conference. Questions from the audience may require responses that the presenter had not considered in an informed consent discussion with the subject. And, time and memory fallibility may blur the presenter's recall of what exactly the subject had consented to years earlier.

Could Corwin have foreseen the consequences to Jane Doe of his publication of her case a decade earlier? Certainly, no one could have predicted the twists and turns that this case has taken over the course of many years. However, in light of what has happened to Jane Doe, authors of future case reports and presentations need to consider the possibility that others may seek to aggressively unmask the identity of individuals (patients or significant others) included in their cases. Gabbard notes this possibility:

In today's climate we cannot ignore the fact that there is a cadre of critics who are intensely hostile to psychoanalysis and are eager to track down the identity of analysts and pursue details of published cases that might disparage psychoanalytic treatment. (Gabbard, 2000, p. 1075)

Independent Review of Case Report Materials

One of the fundamental principles of science is that authors of peer-reviewed publications are expected to make available to qualified professionals data and materials necessary to repeat the experiment or verify the accuracy of findings. Most funders and academic institutions require that these data be retained for specified lengths of time should any questions arise. Case reports, if they are intended as contributions to a scientific literature, should be held to the same standard. In this vein, Corwin and Olafson (1997) provided the videotapes to a number of experts, who offer differing opinions.

Release of case report materials—and any type of clinical information that can be linked back to individuals—always runs a risk of breaching confidentiality. Nonetheless, there are valid reasons for professionals to request access to such information. Numerous instances of scientific misconduct have been discovered in recent years attesting to the need for an independent review of experimental and clinical data when circumstances warrant it. One of the most common forms of scientific misconduct is the “phantom patient or subject,” in which research subjects and their accompanying data are fabricated out of thin air. In such cases, outside investigators will need to know the identity of all subjects in a study to verify their participation. In other cases, extraordinary claims of efficacy may be made for unusual or exotic treatments on the basis of a case report or case series. Investigators may need to contact treated individuals to determine if the claims are true.

Key questions in the independent evaluation of case report material is what constitutes a legitimate reason to risk a breach of confidentiality and who is qualified to conduct such an investigation? All institutions receiving U.S. Public Health Service funding must have a designated Research Integrity Officer (RIO), who is empowered to convene an inquiry and, if warranted, an

investigation of allegations of scientific misconduct. One of the important tasks of the RIO is to ensure that any inquiry or investigation is objective and is conducted by a committee qualified to evaluate the material in question and without conflicts of interest in the matter.

A Possible Solution

The question of whether or not every case report requires a signed informed consent from a subject who has read the draft is beyond the scope of this article. However, if a case study author or presenter does choose to engage in an informed consent discussion with his or her subject(s), the possibility of a hostile breach of confidentiality should be included as one of the risks. This breach of confidentiality could take a variety of forms, including a rebuttal case report that impugns the character or competence of the case study subject or the author.

The Jane Doe case has made it clear that there can be devastating personal, emotional, financial, and professional consequences for case study subjects whose identities are revealed. A process is needed that can provide a reasonable (albeit never perfect) degree of protection of privacy, while still permitting legitimate outside scientific review. In the spirit of scientific and ethical debate, the following proposal is intended as a suggestion to stimulate thinking about possible solutions that protect all parties while permitting an objective investigation and verification of the facts by qualified professionals.

Case study authors would be required to identify, enumerate, and sequester materials that are central to the facts and claims advanced in the case study. They would list and describe these materials in a document accompanying submission of the case study to a journal. If the case study were accepted for publication, they would be required to retain these identified materials for a specified period of time—similar to requirements to retain raw data from clinical trials or laboratory experiments. Editors (and reviewers?) would have the prerogative of requesting that additional materials be retained if they considered them critical to the credibility of the case study.

If significant concerns (e.g., clinical, ethical, legal) are raised about a case study, the editor (or proxy) would make a determination as to whether they justified requiring the case study author to submit the sequestered materials to outside parties for independent review. The editor would also make a determination as to whether the outside party requesting access to these materials was professionally qualified and without disqualifying conflicts of interest. If there were questions about qualifications or conflicts of interest, the editor could invite a third party to conduct an independent review of the facts while protecting identifying details from the requesting party. In institutions

receiving funds from the U.S. Public Health Service, the RIO is the authority best qualified to oversee this process.

Whoever conducts the outside review is required to maintain confidentiality and to protect subject privacy, and would be held accountable if protected information is publicly released. If, for some reason, public release of case study information were deemed necessary (e.g., to protect the safety of other patients receiving a potentially harmful intervention), the editor or RIO could make that decision in consultation with appropriate others (e.g., the journal's editorial board, an independent ethicist, National Institutes of Health Office of Research Integrity). This process would protect the privacy of case study subjects to the extent that is possible, while permitting legitimate scientific scrutiny of disputed facts or claims. The requirement to enumerate and retain supporting materials prior to publication reminds both author and editor that there is always a great deal at stake for the individuals involved and for science as a whole.

The Jane Doe case may be a watershed moment in the long history of clinical case reports. Total abandonment of this genre would be an enormous loss for clinical and ethical education at every level of training and practice, particularly in terms of conveying the look, feel, and circumstances of unique clinical presentations or ethical dilemmas. It would stifle efforts to bring unusual or rare clinical phenomena to the attention of practitioners, and eliminate the major format for preliminary reports of the effectiveness of new or adapted treatments. We need case reports. But we need to hold them to the same standards of independent corroboration/replication that we require of other reports of medical and psychological science. Yet, we also must respect and protect to the fullest extent possible the privacy and confidentiality of the subject(s). This is the dilemma manifest in the cautionary tale of the case of Jane Doe.

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Author Biography

Frank W. Putnam, MD, is a professor of psychiatry at the University of North Carolina at Chapel Hill. From 1999 to 2011, he was a professor of pediatrics and director of the Center for Safe and Healthy Children at Cincinnati Children's Hospital Medical Center, University of Cincinnati College of Medicine. Prior to that, he directed a research program on the psychobiological effects of maltreatment at the National Institutes of Health for 20 years. His current research interests include the dissemination of interventions for the prevention and treatment of child abuse.